Pulled through a hedge backwards: Improving the Quality of Life of People with Dementia through Dramatherapy

Esme Joanna Jaaniste, BA (Hons.), Dip. Ed., Dip Dramatherapy, AthR (Drama)

School of Social Sciences and Psychology

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy at the University of Western Sydney

June, 2013
Statement of Authentication

The work presented in this thesis, entitled *Pulled through a hedge backwards: improving the quality of life of people with dementia through dramatherapy*, is to the best of my knowledge and belief, original except as I have indicated in the text.

I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

……………………………………………

(Signature)
Dedication

Our approach derives from a phenomenology that restores the sense of the experienced world, and from an archetypal psychology that restores the autonomy of the imagination as the place between the empirics of the material world and the literalisms of the world of spirit.

Robert Sardello

Thank you to all those teachers, students, colleagues and the inspiring fieldwork participants who have shared their ideas and themselves in the coming together of this thesis.
Acknowledgements

Without the help and support of many people, it would not have been possible for the journey of this work to have been undertaken.

Firstly, I wish to thank my supervisors. Professor Gerald Muench gave advice early on in the areas of pharmacology and dementia and provided feedback and guidance at key moments of the project. Dr. Shameran Slewa-Younan inspired and encouraged me to see among other things that I could navigate the world of statistics. With her help, and that of A/Professor Richard Ollerton of the School of Computing, Engineering and Mathematics to whom she sent me for additional understanding, I was able to gain the confidence to manage the analysis needed for the work. Dr. Sheridan Linnell, my primary supervisor, was consistently an amazing, inspiring, judicious and generous mentor and colleague.

In 2008, Professor Richard Fleming asked me to give a speech at a conference on dementia. This speech, together with the brief performance I co-directed there with Dr. Jill Westwood, brought me together with colleagues from Dementia Care Australia, who introduced me to the area of the arts in dementia care.

Thanks are also due to my business partner and colleague, Adrian Lania, Dr. Elvira Zilliacus (also my long-suffering transcriber) and Dr. Tiina Jaaniste, who all gave me help and understanding in making sense of the statistics.

I am indebted to Dr. Christina Virago, who read some of my work and made helpful suggestions and encouraged me early on in the process when I wondered whether I had taken on something I could not finish. Thank you, too, to Dr. Constance Ellwood for her excellent editing.

Thanks go to the staff at Alzheimer's Australia (NSW) in Sydney and Newcastle who gave me valuable assistance in setting up and facilitating sixteen sessions of the dramatherapy and film groups. I am grateful also to the three wonderful art therapy students, two of whom filmed and photographed work from the dramatherapy sessions which they also took
part in, and the third who ran the film group single-handedly in Newcastle. Their quick-thinking ability to grasp the requirements of a dramatherapy group and a two-arm study enriched the quality of the fieldwork.

An audio recording of the ethnographic drama For love of the world, which accompanies this thesis, was produced and edited by Buzz Pringle for a fraction of the normal cost in his professional studio. My thanks to him and to the actors: Amanda and Steve Vella, Joanne Strauss and Bruce Disney for their able and generous input into their roles.

My clinical supervisor, Dr. Rosemary Faire, assisted me at every step of the preparation, duration and reflection on the fieldwork using drama, visual art, song, embodiment and poetry.

I offer thanks to my friends and colleagues in Australia and overseas who have asked me curly questions about the thesis topic, enabling me to go deeper, and have supported me through more than three years of otherwise solitary engagement with my computer. Also to the members of my Sardello study group.

To my family: to the spirits of my parents, David and Daphne and sister Bryony who have inspired me, and to my godmother, children and siblings on both sides of the world who have supported me in this endeavour, I thank you. Special thanks go to my husband, Rein, who has been long-suffering and uncomplaining in his moral and physical support of me in this process.

My heartfelt thanks go to the courageous and open people who gave of themselves so that this research could be undertaken: the seventeen people with dementia and their carers who offered their trust and goodwill so that the research could be carried out. I offer thanks to the participants for their engagement and cooperation. The legacy of this work rests in their willingness and enthusiastic support of the project.
Table of contents

Dedication .......................................................................................................................... ii
Acknowledgements........................................................................................................ iii
Abstract ............................................................................................................................. xii
List of Acronyms................................................................................................................ xiv
List of Illustrations........................................................................................................... xvi
List of Tables.................................................................................................................... xvii
List of Figures................................................................................................................... xvii

Prologue ............................................................................................................................. 1

Chapter 1: Introduction ........................................................................................................ 5
  Why I have chosen to use a mixed methods approach to this question .................. 6
  How will I be dealing with and triangulating the research method? ................. 8
  Pragmatism – a practical approach to the project .......................................... 11
  Introduction to dementia, and in particular to Alzheimer’s Disease (AD) ....... 12
    Global spread of AD and its consequences ...................................................... 13
    Alternatives to the “disease narrative” ............................................................ 15
    Feeling intelligence as part of the dementia picture ........................................ 16
  Alzheimer’s Disease (AD) .................................................................................... 19
    Diagnostic criteria for 294.1 x dementia of the Alzheimer’s type .................. 19
    Vascular Dementia (VD) .................................................................................. 21
    Lewy Bodies Dementia (LBD) ......................................................................... 22
  Grief and loss ............................................................................................................ 22
  Post-traumatic stress disorder (PTSD) ................................................................. 25
  Dementia and spirituality ....................................................................................... 27
  Dementia, quality of life and spirituality ............................................................. 29
  End of life for people with dementia ................................................................. 30
  The question of soul and its impact in ageing and dementia ......................... 32
  The structure of this thesis ..................................................................................... 33

Chapter 2: Situating this research in relation to the literature relevant to
  dramatherapy with people who have dementia ..................................................... 41
  What is dramatherapy? ......................................................................................... 45
Supervision for dramatherapists ................................................................................................................. 46
Four models of dramatherapy ....................................................................................................................... 47
The anthropological model and shape-shifting ............................................................................................ 49
Distancing and developmental models ........................................................................................................ 51
Embodiment, Projection and Role (EPR) ...................................................................................................... 52
Kitwood’s Malignant Social Psychology and the EPR/RPE paradigms ....................................................... 54
Developmental Transformations (DvT) .......................................................................................................... 56
Concepts, practices and evidence ................................................................................................................ 57
Session structure ........................................................................................................................................ 57
Qualitative and mixed methods evidence .................................................................................................... 57
Qualitative practices ................................................................................................................................... 58

Chapter 3: Polarities of thinking, and how the tension between them informs the thesis ................................................................. 62

The contribution of person-centred therapy to the treatment of people with dementia ..................................... 65
Carl Rogers and person-centred therapy ...................................................................................................... 66
Abraham Maslow and the transpersonal ..................................................................................................... 67
Transpersonal psychology’s links with quantum physics ........................................................................... 69
Difficulties for a wholistic interpretation of phenomena when "evidence-based theory" is allowed to take over ........................................................................................................................................ 70
Towards wholism ....................................................................................................................................... 72
From wholism to spirituality ......................................................................................................................... 73
My understanding of phenomenology for the purposes of my research question ....................................... 78
Phenomenological considerations ................................................................................................................ 78
Husserl and his followers ............................................................................................................................. 79
Heidegger and Dasein .................................................................................................................................. 80
Towards a phenomenology of the body ......................................................................................................... 83
Implications of the "embodied language" concept for work with people with dementia .... 85
What would a phenomenological methodology elicit which could not be demonstrated by, say, biophysical evidence? ........................................................................................................................................... 89
Conclusion .................................................................................................................................................... 90

Chapter 4: Mixed methods .......................................................................................................................... 92
Supplementary research questions ............................................................................................................... 93
Value of the study ......................................................................................................................................... 94
Why am I using mixed methods in this thesis? .......................................................................................... 95
The emphasis on the carer perspective in dementia research ........................................ 95
Mixed methods and integration ......................................................................................... 96
Phenomenological considerations ...................................................................................... 97
Triangulation ..................................................................................................................... 98
The pragmatic approach ................................................................................................... 100
Quantitative research for this thesis ............................................................................... 101
Exploration of the preferred method of quantitative assessment ..................................... 102
Quantitative research and its critics ................................................................................ 103
The case for a randomised control approach and the art therapy experience .................. 104
The case for and against the use of biomarkers in this research ...................................... 107
Literature search for scales and measures ......................................................................... 110
Mood .................................................................................................................................. 111
Language retrieval and cognition .................................................................................... 114
Quality of Life ................................................................................................................ 116
Protocol and Design .......................................................................................................... 118
Participants ....................................................................................................................... 119
My chosen qualitative methods ....................................................................................... 120
Ethnographic drama ......................................................................................................... 122
Narrative .......................................................................................................................... 127
Performance ethnography - The Dementia Drama of Chapter 8 ....................................... 128
Metaphor ............................................................................................................................ 129
Ethics ................................................................................................................................. 131
Research bias .................................................................................................................... 132
Conclusion ......................................................................................................................... 132

Chapter 5: Quantitative analysis and findings ................................................................. 133
Assessments and measures ............................................................................................... 133
Quality of Life Alzheimer's Disease (QoL-AD) ................................................................. 133
Mood: Geriatric Depression Scale (GDS) ......................................................................... 134
Language and cognition: Boston Naming Test (SBV-15) ................................................. 134
Procedure .......................................................................................................................... 135
Statistical analyses ............................................................................................................ 137
Quantitative results .......................................................................................................... 137
Quality of Life Alzheimer's Disease (QoL-AD) ................................................................. 138
Geriatric Depression Scale (GDS)..................................................................................... 139
Boston Naming Test - Short Boston Version (SBV-15) ..................................................... 140
Chapter 9: Qualitative analysis and findings ........................................ 255

Analysis ................................................................. 255
Ethics of analysis .................................................. 258
Phases of the analysis ............................................. 258
  Watching the video .................................................. 258
  Deep dive into the transcript ....................................... 259
  The art works ..................................................... 260
The drama ................................................................. 261
  Developmental Transformations .................................. 261
  Embodiment .......................................................... 264
  Projection ............................................................... 265
  Roleplay ................................................................. 266
  Trust and disinhibition .............................................. 267
Reflection on the qualitative methods analysis ......................... 267
  David ................................................................. 268
  Ben ................................................................. 271
Themes emerging in the dramatherapy ........................................ 275
  Choice of session themes ......................................... 275
  Anger and frustration ............................................... 275
  Family ................................................................. 276
  Grief and loss .......................................................... 278
  Memory ................................................................. 279
Qualitative/mixed method findings ........................................ 281
  Individual change scores: triangulation with qualitative data .......... 281
Conclusion ................................................................. 287

Chapter 10: Quantifying Quality of Life ........................................ 288

Creative Expressive Abilities Assessment (CEAA) .......................... 288
  Memory ................................................................. 290
  Attention ................................................................. 291
  Language ................................................................. 293
Abstract

This thesis links my interest in the area of dramatherapy with existing and new research in the fields of dramatherapy and dementia. It has been written as a result of invitations by individuals and organisations interested in Kitwood's (1997) person-centred approach, to work with and write about people with dementia and the effects of dramatherapy upon them. In the light of public awareness of the ageing of our population and since, in the area of dramatherapy for people with dementia, the body of published research is small, I wanted to use a mixed method approach to find out if a small study of sessional work would improve their quality of life (QoL).

Qualitatively, the ontological concepts of being-in-the-world put forward by the phenomenologists, held in tension with Steiner's understanding of consciousness, underpin this study. It was important to hear the stories of people with dementia, help them connect consciously with end of life issues, and to respond to existential difficulties with dementia which might impede their QoL.

A literature search was conducted for neuropsychological scales and measures which would effectively assess certain areas of QoL: namely, mood, cognition, language and QoL itself. These measures were selected to access levels of potential improvement in these four areas. In order that research findings could be compared, a two-arm study was set up. Volunteers with dementia diagnoses were invited to participate in sixteen sessions of dramatherapy in Sydney, Australia or film-watching as a diversional activity in Newcastle, New South Wales. The two venues for the research were located at branches of Alzheimer's Australia, NSW.

The main qualitative epistemological method of inquiry chosen was a phenomenological approach, including an investigation of embodiment phenomena. Qualitative methods also applied to the investigation were narrative, metaphor and ethnographic procedures. Rather than looking for a
"heat solution", a meta-analysis of reflexive inquiry was conducted and findings of the mixed methods of exploration were triangulated using pragmatic abductive means.

Statistical change score data for individuals were also examined, triangulating findings with the heuristic research. Narrative descriptions of dramatherapy sessions were completed in the form of a playscript. Individual narratives of four of the dramatherapy participants were written for the thesis. An ethnographic drama dealing with tensions in the mixed method approach I had taken was also prepared.

Results of the quantitative research were not found to be statistically significant, possibly because of low numbers or the lack of ability to match variables of gender, diagnosis, educational level and age between the two groups at baseline. Bearing this in mind however, the QoL-AD measure (Logsdon, Gibbons, McCurry & Teri, 1996) did show an improvement in the dramatherapy group.

The qualitative research demonstrated a robust ability on the part of participants to engage with group activities, psychotherapeutic intervention and reflective practices. QoL levels were observed to improve substantially and higher levels of body awareness and interaction were indicated.

The enquiry suggests that dramatherapy is indeed a promising modality for people with dementia and can and does improve their QoL. It indicates that dramatherapy, with its person-centred approach and engagement of creativity can reveal consciousness and inspiring soul qualities that are often missed by the biomedical model. It has shown that personal issues from childhood can be healed through drama psychotherapy. Recommendations for its cost-effective introduction into facilities for the elderly are identified in the thesis, as well as further research in this important area.
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>Alzheimer's Disease</td>
</tr>
<tr>
<td>AlzA</td>
<td>Alzheimer's Australia (NSW)</td>
</tr>
<tr>
<td>ASIO</td>
<td>Australian Security Intelligence Organisation</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>BFT</td>
<td>Benson Fluency Test</td>
</tr>
<tr>
<td>B-LMS</td>
<td>Bond-Lader Mood Scale</td>
</tr>
<tr>
<td>BNT</td>
<td>Boston Naming Test</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and psychological symptoms of dementia</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and language diverse</td>
</tr>
<tr>
<td>CgA</td>
<td>Chromogranin</td>
</tr>
<tr>
<td>CSDD</td>
<td>Cornell Scale for Depression</td>
</tr>
<tr>
<td>CT</td>
<td>Computerised tomography</td>
</tr>
<tr>
<td>dAD</td>
<td>Depression in Alzheimer's Disease</td>
</tr>
<tr>
<td>DASS</td>
<td>Depression Anxiety Stress Scale</td>
</tr>
<tr>
<td>DMAS</td>
<td>Dementia Mood Assessment Scale</td>
</tr>
<tr>
<td>DQoL</td>
<td>Dementia Quality of Life Questionnaire</td>
</tr>
<tr>
<td>DSM-IV-TR</td>
<td>Diagnostic &amp; Statistical Manual of Mental Disorders (4th edition, text revision)</td>
</tr>
<tr>
<td>DvT</td>
<td>Developmental Transformations</td>
</tr>
<tr>
<td>EBP</td>
<td>Evidence Based Practice</td>
</tr>
<tr>
<td>EOD</td>
<td>Early onset dementia</td>
</tr>
<tr>
<td>EPR</td>
<td>Embodiment Projection Role</td>
</tr>
<tr>
<td>F3</td>
<td>Freeway 3, New South Wales</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>GDS</td>
<td>Geriatric Depression Scale</td>
</tr>
<tr>
<td>IBS</td>
<td>Irritable bowel syndrome</td>
</tr>
<tr>
<td>JASDI</td>
<td>Jones' Adaptation of Smith-Lazier Dramatic Involvement</td>
</tr>
<tr>
<td>LBD</td>
<td>Lewy Bodies Dementia</td>
</tr>
<tr>
<td>MCI</td>
<td>Moderate cognitive impairment</td>
</tr>
<tr>
<td>MDD</td>
<td>Major depressive disorder</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental State Evaluation</td>
</tr>
<tr>
<td>MOS</td>
<td>Medical Outcomes Study</td>
</tr>
<tr>
<td>MOSES</td>
<td>Multi-Observational Scale for the Elderly</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>MS-E</td>
<td>Mood Scales-Elderly</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health &amp; Medical Research Council</td>
</tr>
<tr>
<td>OAM</td>
<td>Medal of the Order of Australia</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Co-operation and Development</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PET</td>
<td>Positron Emission Topography</td>
</tr>
<tr>
<td>PTSD</td>
<td>Post-Traumatic Stress Disorder</td>
</tr>
<tr>
<td>PWD</td>
<td>Person with dementia</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>QoL-AD</td>
<td>Quality of Life Alzheimer's Disease</td>
</tr>
<tr>
<td>RAID</td>
<td>Rating for Anxiety in Dementia</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>RPE</td>
<td>Role Projection Embodiment</td>
</tr>
<tr>
<td>SBV-15</td>
<td>Short Boston Version 15</td>
</tr>
<tr>
<td>T1</td>
<td>Time 1</td>
</tr>
<tr>
<td>T2</td>
<td>Time 2</td>
</tr>
<tr>
<td>TEA</td>
<td>Tests of Everyday Attention</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>VD</td>
<td>Vascular Dementia</td>
</tr>
<tr>
<td>WW1</td>
<td>World War 1</td>
</tr>
<tr>
<td>WW2</td>
<td>World War 2</td>
</tr>
</tbody>
</table>
List of Illustrations

Red Dragon by William Blake ........................................................................................................ 147
Baboushka Doll .......................................................................................................................... 169
Socialist Party flag, Vienna by Tanya ........................................................................................ 172
New Australian flag by Neil ..................................................................................................... 173
Monkey by Neil ......................................................................................................................... 184
Bulldog by David ...................................................................................................................... 184
No Escape by Leanne ............................................................................................................... 199
In the Vienna Woods by Tanya ................................................................................................ 209
A semi-written Picasso by Paul ................................................................................................ 216
Clay animal by Paul ................................................................................................................ 223
Reminder of the natural world by Leanne ............................................................................... 225
The fizzy drink by Leanne ...................................................................................................... 226
I thought I would have you for ever by Neil ........................................................................ 245
A fish out of water by Joanna .................................................................................................. 252
Notes on A fish out of water by Joanna .................................................................................. 253
Projection objects .................................................................................................................. 266
Swim between the flags by David ......................................................................................... 268
Torch ...................................................................................................................................... 269
Ben's clay work ....................................................................................................................... 271
List of Tables

Table 1: The Two-Arm Study - Quantitative and Qualitative Assessment ................................................................. 5
Table 2: The characteristics of the dramatherapy and filmwatching groups .............................................................. 137
Table 3: Difference in the change scores between the groups ..................................................................................... 138
Table 4: Change Scores for QoL-AD ......................................................................................................................... 282
Table 5: Change Scores for GDS ............................................................................................................................ 284
Table 6: Change Scores for SBV-15 ......................................................................................................................... 286
Table 7: Client Assessment using Jones's Adaptation of Sutton-Smith, Lazier Scale of Dramatic Involvement (next page) .......................................................................................................................... 303

List of Figures

Figure 1: Maslow’s Hierarchy of Needs .................................................................................................................. 68
Figure 2: Quality of Life Scores over Time by Group ............................................................................................ 138
Figure 3: Geriatric Depression Scores over Time by Group ................................................................................. 139
Figure 4: Boston Naming Test (SBV-15) Scores over Time by Group ................................................................. 140
Figure 5. 'Forming, storming, norming and performing' Yalom ........................................................................ 236
Figure 6: Average Memory Score over time ......................................................................................................... 291
Figure 7: Average Attention score over time ......................................................................................................... 292
Figure 9: Average psychosocial score over time .................................................................................................. 295
Figure 10: Average reasoning/problem solving scores over time ...................................................................... 296
Figure 11: Ben’s R19 (Insight) scores over time .................................................................................................... 297
Figure 12: Ben’s R20 (Decision-making) scores over time ..................................................................................... 297
Figure 13: Average emotion scores over time ....................................................................................................... 299
Figure 14: Average culture score over time ........................................................................................................... 301
Prologue

Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything.
(William Shakespeare, As you like it. II, 7, p. 497)

The rather macabre view of old age presented by Shakespeare has nevertheless seeds of truth in it; a naive simplicity about the "childishness" and the "oblivion" reveals a link between the state of mind of elders 400 years ago and the dementia of our era. In 2013 however, our elderly people and especially those with dementia, enjoy fewer intergenerational connections than in Shakespeare's time. Extended families are collapsed into ever smaller compartments as increasingly globalised communication sends working people in all directions and communities of mixed age groups are more difficult for the elderly to find. From the perspective of our time, when the depression that is sometimes connected with dementia can be a byword for sadness, grief, or just being alone, there is a personal question for me: could dramatherapy make a difference to this "mere oblivion" for people with dementia? In other words, could it improve their Quality of Life (QoL)?

Since 2007 I have enjoyed working with people with dementia and I wanted to address this question once I made the decision to propose a thesis topic for higher degree research. My interest in the area had been sparked in an unusual way. I had been guest lecturing for some years on the Postgraduate Diploma in Expressive Arts Therapies at the University of Western Sydney, Australia when I was asked to direct a play for the students by the Course Coordinator, Jill Westwood, to be performed for 300 aged care professionals at their conference. The Successful Ageing Conference 2007 was sponsored by the Australian Government Department of Health & Ageing, and was held at the Powerhouse Museum in Sydney on 28 June 2007 and included an arts therapies presentation and performance.
The performance, entitled *Soul Journey – Looking Forward, Looking Back*, showed the delegates how each of the arts therapies could assist the elderly to cope with the ageing process (Westwood, 2007), allowing me at the same time to meet new colleagues in the dementia area. The students did a valiant job in their roles, and this led to networking with the colleagues from Dementia Australia, WA who came backstage to congratulate them.

These contacts opened the door for me to an interest in working with people with dementia in an old age hostel at a retirement village where I had been on the Board of Directors for three years. My experience working with depression in the mental health system was useful, but my main inspirations for this thesis were the elderly in their last and crucial lifestage. (I am also nearing this lifestage, and beginning research beyond retirement age is personally challenging as the years collapse together with ever greater rapidity in the face of unfulfilled aspirations.)

At the *Successful Ageing Conference*, I met Hilary Lee and Jane Verity, President and Founder of the Spark of Life Programme which is associated with the work of the Dementia Foundation of Western Australia. Their programme delivers multi-modal creativity for people with dementia. Their training schedule aims to have all staff on board in the area of the arts and activities to improve the quality of life (QoL) of participants in care facilities.

Through these two women I learned about Tom Kitwood and the Bradford Dementia Group, although not for the first time. I realised that Kitwood’s book, *Dementia Reconsidered* (1997) was already on my bookshelves at home, and that my sister Jane had sent it to me some years earlier when my mother had a form of dementia. Although he does not directly refer to the arts therapies, Kitwood's work is referred to often in this thesis as a human and inspiring way of working with people with dementia.

Julie Gross Macadam, an art therapist whose thesis deals with the relationship between art therapy and wellbeing in people with dementia, describes the Bradford Group, founded in 1992, as follows:

*The group is a multi-disciplinary, multi-professional group committed to excellence in research and education, and the delivery of training to*
create an informed and effective workforce in line with the British National Dementia Strategy (Department of Health, 2009). Although, strictly speaking the group’s work does not focus on the creative arts, in the Kitwoodian tradition, the group’s mission is to make “a difference to policy and practice in dementia care” by working with practitioners and healthcare professionals to improve the wellbeing and quality of life for individuals living with dementia and their families (McAdam, 2012, p.133).

A much greater respect for the dignity of elderly people with dementia has resulted from the work of the Bradford Group, and many of its followers, including Dahlia Gottlieb-Tanaka whose Creative-Expressive Abilities Assessment (Gottlieb-Tanaka, Lee, & Graf, 2008) will be used for the fieldwork in this project.

A childhood recognition of this dignity was fostered early whenever I accompanied my doctor father on his rounds at a home for the elderly. His mother, my Australian grandmother (“Granny”), was a wonderful role model, loving and humouring her much older, British Raj Victorian husband with dignity (he was born in 1870!). She always found creative ways to interest her grandchildren, making apple pies, knitting and absorbing us in craft work.

I seem to have become a well-loved storyteller for my own grandchildren and they call me by her namesake - "Granny". A colleague within mental health care once said that client rehabilitation "has Harry Potter’s cloak of invisibility thrown over it" (Rowling, 1997, cited by Still, 2007, personal communication). This is an apt metaphor also for certain facilities for the elderly, which appear to have little to do with the respect for elders which lived in me as a child when I visited the old folks’ home. Lev-Aladgem (1999), dramatherapist, describes an Israeli care home where nearby suburban residents “ignored it as if the place and its elderly inhabitants were completely invisible” (p. 3). Often the physical needs of older people are looked after, but their spiritual, mental and emotional needs are neglected.

In a chapter I wrote for a collection of essays (Jaaniste, 2011a), I contributed the following anecdotal material from an early experience of working with the elderly, in which my belief in the dignity and imaginative capacity of people with dementia shaped my response:
My first experience of improvisation and dementia came as a young mother in her early thirties, working night shifts, with no knowledge of dramatherapy, as a nursing assistant in a home for elderly people. Mavis, who had dementia, would come downstairs in the middle of the night, informing her care worker that she could not return to bed, because her husband was still away and the roast dinner was ready. Up to the bedroom we would go, and I would ask Mavis to look out of the window for her husband Bob while I helped to "prod the roast", and then got her to "help set the table". When everything was ready, and she was sure she could hear Bob's footsteps on the stairs, she would get back into bed. Improvisation had solved the midnight wandering (Jaaniste, 2011a, p. 61).

I learned from Mavis that if I respected the world of memory that she inhabited as if it were the present, we could find a way to resolve her immediate pain, which poignantly re-enacts an ongoing sense of loss. My clients in acute and community mental health over the past eighteen years have also taught me a great deal – they have trained me, showing me the way to empathise with their deep suffering and revealing the "mad person" inside me. I have no experience of the depths of severe depression, but have come from a family where there is an over-supply of mental illness and have lost a sister through suicide. Grief has taught me many lessons which lead me joyfully into the therapeutic work with people who are elderly, whose bodies are failing them and whose friends have died.

It may seem paradoxical, but the awareness that the lessons of grief in its many forms (Kübler-Ross, 1969) have taught me has actually brought me closer to a kind of joy in assisting others with their grief. The following quotation in the frontispiece to Laurens van der Post's book on his experiences in a Japanese prisoner of war camp in World War II helps explain this, albeit that his experiences of grief, loss and abuse were far more severe than most:

*The depths of darkness into which you can descend, and still live, is an exact measure, I believe, of the height to which you can aspire to reach.*

(McGlashan, quoted by Van der Post, 1975, frontispiece).

It is as though, as I approach their life stage, the clients have chosen me for this work, instead of the reverse.
Chapter 1: Introduction

This thesis is a mixed methods inquiry exploring whether dramatherapy can improve the quality of life (QoL) of people with dementia. The research was conducted with the help of seventeen volunteers at two locations run by Alzheimer's Australia, NSW (AlzA). Most participants had Alzheimer's Disease (AD), a type of dementia, and were living in the community. They participated in a two-arm study in the two venues that were 120 kilometres apart, in Newcastle and Sydney, NSW. The Newcastle cohort of ten completed Time 1 (T1) of the quantitative assessment before joining a group who watched movies and the seven Sydney volunteers were assessed at T1 prior to participating in group dramatherapy. Sixteen sessions of each activity were completed over a four month period, with a three week median break. Thirteen participants completed at Time 2 (T2) of the quantitative assessment. Qualitative assessment involved the dramatherapy participants only, totalling six individuals including two who were not assessed at T2.

Table 1: The Two-Arm Study - Quantitative and Qualitative Assessment

Mixed methods studies of this population have been carried out in the past employing other arts therapies (principally art therapy and music therapy),
but I have found little in the way of research support for mixed method work in the area of dramatherapy. Thus, because of a perceived gap in the literature and also for the reasons that follow below, I wish to position my choice of this method as clearly as possible. The following two sections of this introduction will set out my reasons for choosing a mixed methods approach, and the triangulation of the two main methods in the enquiry.

Why I have chosen to use a mixed methods approach to this question

Analysis on both sides of the methodological – qualitative-quantitative – divide is very significant for me, as is the later triangulation to elucidate findings. The biomedical model often looks for a standardised form of Evidence Based Practice (EBP) which quantitative research can provide. The search for EBP in dementia has in the past provided pathways to the goal of accurately diagnosing the condition before death. Not long ago, people had to die before having their brains autopsied to show beyond any doubt that amyloid plaque and other brain changes cause dementia. This process ensured more exact post-mortem diagnosis, or detected a misdiagnosis (Kolata, 2010). More recent research has led to the discovery of shrinkage in the brain through MRI scans and uptake of glucose to show brain activity through PET scans. These innovations have been reached through rigorous research culminating in EBP for diagnosing dementia.

Quantitative research and its deductive methods of identifying patterns in the data is regarded as best practice in the biomedical domain. Even though there is evidence, now provided by quantum physicists, that such patterns may be subjectively influenced and therefore scientifically unreliable (Schwarz and Begley, 2003), the capture and re-use of information is the preferred method of analysis for the medical model. Having spent many years working in this domain, I wish to be able to show quantitative researchers, professionals and of course to find out for myself, whether or not dramatherapists are able to speak their language modestly, yet successfully, even in a small study like this one. The gesture is a significant
one, even though there are difficulties associated with quantifying the arts therapies: "Dramatherapy...sometimes appears to shy away from both things - interpretation and measurement!" (Grainger, 1999, p. 15).

Quantitative and qualitative approaches have their own characteristics for practice. Grainger also quotes James Maxwell (1996): "Quantitative approaches are powerful ways of determining whether a particular result was causally related to one or another variable, and to what extent these are related" (Maxwell, p. 9). He goes on to say that qualitative research is often better at demonstrating how this change happened. In other words, for those who are interested in the amount of change dramatherapy produces by way of outcomes, in their own positivist terms, quantitative approaches are best. For those who want to know how these outcomes are produced so that aims for healing can be achieved more cogently, qualitative assessment works best (Grainger, 1999).

This dual role of qualitative and quantitative investigation can demonstrate to the sceptical within the biomedical system that quantitative research does not present the whole picture. In this thesis, the how of the research can be found in the phenomenological inquiry. The acts and voices of the participants as well as the intersubjectivity of the dramatherapist and group members can be found there. The phenomenological, metaphorical, ethnographic and narrative analyses I am using are positioned to lift the veil from the invisibility of people with dementia. These methods of analysis aim to demonstrate the existence of conscious wisdom in elders, despite (and perhaps because of!) their disabilities. Qualitative enquiry "knows how" to do this, whereas quantitative research displays a certain rigour in juggling with variables that may be absent from the former method. Rigour is also needed in vigorous qualitative enquiry of course; however this qualitative order of rigour may not be recognised by scientifically trained people who are unaware of phenomenological ontology or do not take it seriously. Thus re-
cognition of phenomenological methods for researching dementia is principally sought from two directions: by the biomedical fraternity and by the aged care research affiliation.

**How will I be dealing with and triangulating the research method?**

It must be stated at the outset that it is not easy to conduct research with people with dementia, due partly to some of the reductionist attitudes of decision-makers in the area of aged care, influenced to some degree by the biomedical approach described in previous paragraphs. Power (2010, 2011) describes a traditional view of dementia as one that emphasises *loss* (of executive brain function and memory, for example). Referring to the assessment of people with dementia by their inabilities, rather than their abilities, he cites the widely-used Mini-Mental Status Examination (Folstein, Folstein & McHugh, 1975) where there is:

...a litany of discrete tasks to be performed: Can you spell "world" backwards? Can you remember three objects after five minutes? Can you copy a figure of two intersecting pentagrams? (2011, p. x).

There are similarly complex tasks involved in other neuropsychological tests which could appear just as confronting to those actually making the assessment and/or fulfilling the caring roles as can be the case for people who have dementia!

Power goes on to describe how the "biomedical approach to dementia" (2011, p.x) has encouraged us to set up environments (and, I would add, form attitudes) which are more appropriate to the needs of the care force or family carers than to individuals living with the diagnosis. He recommends instead that a new experiential attitude to dementia would free individuals to grow and develop, seeing the diagnosis as a change or variation in a person's way of seeing the world. If we, the carers, researchers and family

---

1 By "re-cognition" I mean that research into dementia needs to be thought through by researchers for some of the reasons I have mentioned here.
members, can alter our focus to this paradigm shift, we are more likely to perceive the person wholistically (Power, 2011, 2010).

As a result of this necessary shift in focus from mainstream thinking – to a position which aligns with my own view of dementia – it has been essential that the design of this research has included a careful and thorough review of the literature seeking the appropriate neuropsychological scales for the project. Through this review, suitable scales for assessment have been selected which are straightforward and clear in their requirements of the participants with dementia. This literature review for scales and measures can be found in Chapter 4.

The measures were chosen also with the research question in mind. I therefore selected scales which appeared to suit the assessment of cognition, language, mood and quality of life (QoL) in people with dementia. The rationale for this choice is described in detail in Chapter 4. Suffice it to say here that these dispositions and abilities were considered necessary for an acceptable level of QoL for such people. I have since discovered qualities, different from the three mentioned above (cognition, language and mood), which were identified by people with dementia who were actually involved in a project during which, with the help of picture cards, they decided upon the attributes necessary for their own QoL:

- Family
- Physical health
- Independence
- Relationships
- Communication
- Who I am (Alzheimer’s Society, 2010, p. 27).

Had I discovered these participant-based choices earlier, the quantitative arm of this research might have looked somewhat different, although these attributes do appear in the qualitatively assessed data and are partially covered in two of the scales: Quality of Life Alzheimer's Disease (QoL-AD), (Logsdon, Gibbons, McCurry, & Teri, 1999) and the Geriatric Depression Scale (GDS), (Brink et al., 1982; Yesavage & Brink, 1983). Arguably, since there are other ways of communicating besides speech, the third measure for
language and cognition (Short Boston Version [SBV-15] of the Boston Naming Test [BNT], Kaplan, Goodglass & Weintraub, 1978) might only have been indirectly relevant.

It is in the qualitatively evaluated arm of the research; that is, in the phenomenologically rich descriptions and analysis provided by this thesis, that all of the above attributes of QoL, self-selected by people with the diagnosis in the British report, shine out. Phenomenology describes consciousness, subjectively experienced, as I have said. Wilson (2002) sees it in the following light:

*The aim is to study how human phenomena are experienced in consciousness, in cognitive and perceptual acts, as well as how they may be valued or appreciated aesthetically. Phenomenology seeks to understand how persons construct meaning and a key concept is intersubjectivity. Our experience of our world, upon which our thoughts about the world are based, is intersubjective because we experience the world through others. Whatever meaning we create has its roots in human actions and the totality of social artefacts and cultural objects grounded in human activity* (Wilson, 2002, p. 1).

The generous self-revelation by the research participants has been a key factor enabling me as the researcher to work phenomenologically. The intersubjective experience of the whole group enabled me to recognise, upon reading the transcript of videoed material, the essential nature of the group experience as well as the significance of the metaphors which occurred and segued into themes. *The Dementia Drama* in Chapter 7, describing highlights of each of the sixteen sessions, together with the narratives which document the participants’ conscious self-revelations through the drama, have enabled participants to be individually and collectively re-cognised.

Denzin and Lincoln (2008, p. 22) advise that all research involves interpretation: "it is guided by the researcher’s set of beliefs and feelings about the world and how it should be understood and studied". Triangulation of the two forms of data – quantitative and qualitative – allow me the opportunity as a researcher to "give a more detailed and balanced picture of the situation" (Cohen and Manion, 2000, p. 254). Triangulation affords me the opportunity at the same time to examine my assumptions and prejudices.
I do acknowledge researcher bias in this thesis; it is important to do so, as I wear the two hats of both therapist and researcher and believe strongly in the power of dramatherapy to heal. Thus, the triangulation of a mixed methods approach is expected to act as a brake on any preconceptions, minimising the impact of bias upon the project.

**Pragmatism – a practical approach to the project**

The philosophical foundation for my research has been taken care of partly by my "belief system", as quoted in the section above on interpretation from Denzin and Lincoln (2008, p. 22). In the Prologue to this thesis I have pointed out certain elements of my personal philosophical stance and more will be said later in this introduction and in Chapter 3 about the questions of spirituality and consciousness. Biesta (2010) believes that pragmatism encourages researchers to ask cogent questions about their philosophical approach and their research design. These are actually also the kinds of questions I have asked in order to establish my pragmatic position. Bearing in mind the intended purpose of writing a thesis on this topic of dementia, pragmatism is the approach which suits me best.

In Chapter 4, where I discuss the methodological thrust of the thesis, and especially in Chapter 9 where findings are discussed, it will be pointed out that my research tells a story which needs to be heard in the aged care sector. One of the characters asks a question regarding this thesis' future in the ethnodrama *For Love of the World* (Chapter 6), which can be seen as a commentary on the methodological decision-making process,

> Will it, when bound, stay on the shelves of dark and dusty libraries,  
> Or will it be a guiding help for good dementian souls?

**Pragmatism** is one of the Five P’s framework in Roslyn Cameron’s analysis of mixed method research. Another is **Praxis**, which concerns the integration of data and modes of analysis. She quotes Bazeley (2010) who says this integration should be done

> throughout the study in such a way as to become interdependent in reaching a common theoretical or research goal, thereby producing findings that are greater than the sum of its parts (p. 432).
At this point, it is important to give an explanation of dementia in some of its forms, in particular the types of dementia which affected the participants in this project. The following section gives an account of the diagnosis of dementia and its ramifications, and pays some attention to the area of Alzheimer's Disease.

**Introduction to dementia, and in particular to Alzheimer’s Disease (AD)**

The sections that follow describe general as well as specific types of dementia such as Alzheimer's Disease (AD) which were experienced by most of the project participants. Each diagnosis is defined and explored, so that the reader of this thesis can more readily comprehend the methodological choices made for this project. At the same time, some of the deficits of the mainstream medical descriptions of people with dementia are critiqued.

Dementia, rather than an actual disease, can be seen as a group of symptoms that affect the brain. An inability to carry out normal activities like getting dressed in the morning, having regular meals or looking at the calendar to see what day it is are some of the disruptions to their everyday thought patterns that are faced by people with dementia. Face recognition, communication and decision-making can become more difficult.

Loved ones and familiar people may see personality traits they do not recognise as belonging to their friend or family member. If others are unable to enter their world, those with dementia may become irritable or even aggressive.

This section of the Introduction begins by giving an overview of dementia globally. It then draws attention to an alternative way of thinking about dementia.

---

2 See Appendix 17 for full DSM-IV-TR characteristics of other diagnoses mentioned in this chapter. Generalised features of dementia are recorded in the body of this chapter.
dementia which exists alongside the dominant positivist view held by most members of the medical fraternity. The section then details several reasons why dramatherapy, when considered in the light of an alternative view, offers benefits to elders with dementia. In general, the chapter focuses on Alzheimer's Disease (AD), but it also briefly describes the two other diagnoses given to participants in the research: Vascular Dementia (VD) and Lewy Bodies Dementia (LBD).

Since most of the tools for making these diagnoses are within a positivist paradigm and focus solely on the cognitive function of individuals, much of the literature on diagnosis ignores the "windows of clarity" experienced by many people with dementia. Yet there is an alternative discourse to this "disease narrative". It argues that "feeling intelligence" as opposed to "emotional reaction" (Jaaniste, 2013, in press) is present in elders, even when they have a diagnosis of dementia. Feeling and emotion are differentiated here – emotion being a raw, reactive physical state and feeling referring to the involvement of memory and consciousness. This alternative wholistic discourse of the healthy mental, physical and spiritual development of the ageing individual will be discussed again in detail in Chapter 3.

**Global spread of AD and its consequences**

Around the world, there is considerable concern, especially in western countries, about the burgeoning numbers of people suffering from dementia. The number of diagnoses of neurodegenerative dementia has risen in countries where the population’s average age has increased (Goto, Ishii, Uemura, Miyamoto, Yoshikawa, Shimada, et al., 2010). AD, which may strike earlier as Early Onset Dementia (EOD) has been predicted to debilitate approximately 1 in 85 persons worldwide by 2050 (Brookmeyer, 2007). After the age of 60, prevalence of this disease doubles; it increases from 1% to 25% in those aged 85 years or more (Jorm, Korten, & Henderson, 1987). If dementia were a country, Alzheimer’s Disease International (ADI) has calculated that on a worldwide basis, it would be the 18th largest economy in the world, ranking between Turkey and Indonesia.
This predicted rise in dementia diagnoses means that the cost to governments and the community will also increase because of the associated extra care needed as people age. Dementia brings with it memory impairment and deterioration of other higher cortical functions of the brain (Coulson, Fenner, & Almeida, 2002), adding to people's care needs and leading to consequences for funding bodies. Alzheimer's Disease International, in their 2010 Report, has called on governments to prioritise dementia, tentatively estimating that costs will soar internationally by about 85% before 2030.

Only by investing now in research and cost-effective approaches to care can future societal costs be anticipated and managed. Governments and health and social care systems need to be adequately prepared for the future, and must seek ways now to improve the lives of people with dementia and their caregivers. (Alzheimer's Disease International World Alzheimer Report, 2010).

The projected future of ageing people is also a concern in Australia. The number of Australians living with dementia in 2013 has been predicted to rise considerably over the next 30 years, concomitant with global expectations. It has been estimated that there were 266,574 people with dementia in Australia in 2011. This number is expected to increase to 553,285 by 2030 and 942,624 by 2050 (Alzheimer's Australia Report, 2011).

Since there is a substantial growth in the numbers of older people, the totality of those with EOD (less than 65 years) is predicted to decrease from approximately 6.1% in 2011 to 2.9% in 2050 (Alzheimer's Australia Report, 2011), although this reduction is outweighed by the predicted overall increase in dementia diagnoses. The reason for the EOD decrease is the slowing of population growth in Australia since 1961. The replacement rate of children born is not keeping pace with this decrease, at 1.89 births per woman, to replace herself and her partner in 2010 (Australian Bureau of Statistics, 2012).

Dementia funding in Australia, in comparison to other OECD countries, has in past years been low to average (Report for Alzheimer's Australia, 2003); however government funding to such institutes as the Centre for Research
on Ageing at Curtin University in Perth, Western Australia may serve to improve these statistics. The Australian national funding arrangements still need to improve in comparison with those of the USA, where the total percentage of GDP spent on research is .025 as compared with Australia’s .0015 (Report for Alzheimer’s Australia, 2008). However, in April 2012 the *Living Longer Better Aged Care Reform* package of $3.7 billion was announced by the Australian Government, which will partially assist dementia care over the next five years (Australian Government Department of Health & Ageing website, retrieved May 31, 2013).

Alzheimer’s Australia has asked government for a total of $200 million over the next five years, starting with $16.5 million in 2013-14, to build the potential of the dementia research sector, especially in the area that is relevant to best practice. This research-based capacity building is targeted to improve service delivery and infrastructure for people with dementia (*Alzheimer’s Attacks - Australia Acts* Budget Submission 2013-14, 31 January 2013). The report points out that the National Health and Medical Research Council (NHMRC) released only $21.5 million for dementia research in 2012-13 in comparison for much larger sums for cancer, cardio-vascular disease and diabetes; dementia is, however, the second most costly health system area behind cardio-vascular disease in terms of expenditure (NHRMC Summary Funding Data, Retrieved March 14, 2013).

**Alternatives to the "disease narrative"**

This research embraces alternatives to a dominant “disease narrative”, and from that standpoint is concerned for the cultural and spiritual life of elders in care who have been removed from substantial interaction with people of various lifestages (O’Neil and O’Neil, 1990, p.224; Kitwood, 1997). It is of concern that in the late stages of life, existential issues are not being addressed in a healthy way (Shamy, 1997). This problem might be a cultural response, denoting our society’s disregard for advanced age as a life stage to be honoured for elders’ reservoirs of wisdom, experience and knowledge.
There is a significant question to be asked in connection with this issue of alternatives to the "disease narrative": is there a belief that quality of existence for people with dementia later in life should be available? Malone and Camp (2007, p.151) found that "the single greatest barrier to the provision of high quality care for persons with dementia is not a lack of resources, but a belief". Their statement points to a widespread lack of faith in the ability of people with dementia to engage with high quality experiences. These authors expose a nihilistic approach to the care of the elderly, where learned helplessness results from "an over-emphasis on the deficits associated with dementia" (p. 151) and a lack of acknowledgement of the resilience of those who suffer from the disease. It is possible that there are difficulties associated with documenting the positive cultural and spiritual qualities of old age in the diagnostic dementia literature, or perhaps there is an apparent blind spot in most discussion of treatments where only the deficits of ageing are discussed (Jaaniste, 2011b).

**Feeling intelligence as part of the dementia picture**

The "intelligence of feeling" (Jaaniste, 2013a) that can emanate from people with dementia is a highly refined ability, involving memory and consciousness in contrast to common deterioration in the frontal cortex of such people (Gerhardt, 2002). Labar, Mesulem, Gitelman, and Weintraub, (2000) report that the neural systems responsible for feeling-attention interactions are generated in the amygdala, deeper in the brain than the frontal cortex. This is an area which may have been passed over by researchers in the past because of an inappropriate emphasis on the higher cortex, thus neglecting cortex and subcortex.

May, Rahhal, Berry, and Leighton, (2005) found that although general recall declines with age, memory for "emotionally meaningful material" (p. 577) is relatively undamaged, referring to research that suggests there are only moderate age-related changes in the amygdala compared with other brain areas (Smith, Malcein, Meurer, Schmitt, Markesberry, & Pettigrew, 1999). Sattler, Garrido, Sarmiento, Leme, Conde, and Thomaz (2007) found that in
20 subjects with AD, recall was more evident when hearing an arousing story than in the control group of elders with no dementia.

Zeisel and Raia (2000) were among the first to see the link between the amygdala and AD. They found evidence to suggest that this area of the brain is one of the last to be affected by AD, remaining "readily accessible until very late in the disease" (Raia & Koenig-Coste, 1996; Zeisel & Raia, 2000, p. 7). Thomaz, Duran, Busatto, Gillies, and Rueckert (2007) found that in 20 subjects with AD, recall was more evident when hearing a story with feeling content than in the control group of elders with no dementia. This finding indicated to the authors that "the enhancing effect of emotional arousal on declarative memory is preserved in patients with AD" (p. 355).

Thomaz's “enhancing effect of emotional arousal” can be related to the concept of “the intelligence of feeling” (Jaaniste, 2013a). Old age is the phase of life when healthy human beings can experience "a second wind" and a renewal of inner life forces’ (O’Neill & O’Neill, 1996, p. 226). This renewal is capable of bringing about inner transformation and requires a capacity for conscious feeling. Steiner (1926) refers to the figure of Goethe’s Faust as an example of Everyman in terms of life fulfilment. Faust goes from hedonistic wish to pleasure and from pleasure to self indulgence, finally transforming all his passions at the end of his life through his own higher self.

Dr. Basil Williams, a physician in internal medicine from Los Angeles, describes the possibilities of the later years in healthy adults in the following way:

As we grow into our elder years we can transform the forces of our youth. During the second half of our life we can change the will forces of youth into a disposition filled with love, goodness and wisdom. If we have formed a harsh judgment in our youth, we can change our soul forces to forgiveness and understanding. If we had anger in our youth, we can develop gentleness and patience in our old age. If we were materialistic in our youth we can still open ourselves to experience revelations from the spiritual world. Throughout our lives we can undergo an evolution of love. Younger love with basic desires can evolve into a higher form of spiritual love. (B. Williams, personal communication, September 20, 2011).
Elderly people with dementia have a capacity for, and, I would argue, a right to such inner change and fulfilment, but these possibilities are very often forgotten when elders are diagnosed with one of the dementia-type diseases.

Apart from the possibilities of inner change and development, there is evidence that social, physical and mentally stimulating activities, such as those associated with dramatherapy, can be helpful in maintaining cognitive abilities and may delay the onset of AD. Cognitive activity (Wilson, Mendes de Leon, Barnes, Schneider, Bienias, Evans, et al., 2002), exercise (Larson, Wang, Bowen, McCormick, Teri, Crane, et al., 2006) and social leisure activity (Purandare, Ballard, & Burns, 2005) are believed to act as protective factors (Moniz-Cook & Vernooij-Dassen, 2006). Not all activities are of equal value: learning something new is more successful than repeating well-known activities such as crosswords. For instance studying a musical instrument, playing board games, reading and dancing are associated with a lower risk of cognitive deterioration (Doidge, 2007). Roleplaying and improvisational activities associated with dramatherapy also fit with Doidge's example of new neuronal pathway formation. Sally Bailey, dramatherapy lecturer at Kansas State University attests to the value of dramatherapy for improved orientation to place and time:

What we now believe is important in long-term care is improving the patient's quality of life," she said. "If, for 30 minutes twice a week during drama group, a patient is re-oriented to person, place and time, that is a big improvement of their quality of life (Garrett, 2006. Retrieved February 6, 2012).

Dramatherapy can also assist participants with anxieties, especially those they are faced with as they age. Fear of dementia onset, often exaggerated in the media, can affect carers and professionals, as well as members of the community. In her heuristic exploration of her experience of working with a group of older adults with dementia, dramatherapist Nicky Morris expresses the fear associated with the disease and its diagnosis, for herself as well as the clients, as well as the positive ways in which she deals with it:

Dementia gradually takes hold of people, suffocating their abilities, personality and memories. This is a terrifying concept and fear itself has become an essential component of my research.
Then, a personal note from her research log:

* I am now in touch with the fear attached to the diagnosis of dementia. It seems to exist on a cultural and personal level... stirred even by close friends and family. Dramatherapy can perhaps work with this often unconscious fear, by offering unconditional positive regard, respect, acceptance and encouragement. (Log, August 2010) (Morris, 2011, pp. 148-149).

**Alzheimer’s Disease (AD)**

The main symptoms of AD, as recognised by the DSM-IV-TR (American Psychiatric Association, 2000), are as follows:

**Diagnostic criteria for 294.1x dementia of the Alzheimer’s type**

A. The development of multiple cognitive deficits manifested by both:

   1) Memory impairment (impaired ability to learn new information or to recall previously learned information)

   2) One or more of the following disorders:

      (a) aphasia (language disturbance)

      (b) apraxia (impaired ability to carry out motor activities despite intact motor function)

      (c) agnosia (failure to recognize or identify objects despite intact sensory function)

      (d) disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning

C. The course is characterized by gradual onset and continuing cognitive decline

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:

   (i) other central nervous system conditions that cause progressive deficits in memory and cognition

   (ii) systemic conditions that are known to cause dementia

---

3 The diagnostic criteria of AD have been reproduced in full here, since most of the participants in the research had been diagnosed with this illness. Additional information on the other diagnoses represented in this chapter, including subtypes of AD, may be found in Appendix 17.
(iii) substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis 1 disorder (e.g., Major Depressive Disorder, Schizophrenia) (DSM-IV-TR American Psychiatric Association, 2000, 294.1).

The medical cause of AD is as yet unknown, although it is hypothesised that the presence of amyloid plaques is generally a sign of the disease. Amyloid is the term that describes tiny protein fragments located in the brain. These fragments eventually cause over-expansion of whole sections of cerebral tissue. In a brain that is healthy, these flecks of protein are eliminated from the body as a normal process. In AD, they are responsible for the invasion of the neuronal sheath, deposition of plaque, degradation and tangling of neuronal networks.

In mainstream medicine, commonly recognised features of AD are an inability of recall (Greene et al., 1997; Pillon, Deweer, Agid, & Dubois, 1993) and deterioration of language (Brotons & Koger, 2000). Assessment leading to confirmation of these symptoms can be made by means of a brain scan. The following information from Alzheimer’s Australia delineates the types of brain scan commonly used:

*Brain scans are sometimes used in the diagnosis of dementia. The most common types of brain scans are called Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) scans, which both generate excellent images of the brain. Positron Emission Tomography (PET) scans can also be used to monitor brain activity but are not typically used in diagnosis.* (Alzheimer’s Australia Website, retrieved 18.07.10).

Short term memory loss is a defining feature of this condition and difficulties with expression can occur (DSM-IV-TR 15:9: American Psychiatric Association, 2000) due to damage to the frontal cortex (DSM-IV-TR 15.32: American Psychiatric Association, 2000). Self and body awareness, gait problems and seizures can also occur in the later stages of the disease (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984). Loss of cognitive and functional deficits leaves the individual at risk of being locked up in their emotions and thoughts, relying on others to understand or
misunderstand feelings and opinions which are hard to express (Edberg, 2000). Neurofunctional disturbances are thought to be present in 80-90% of people with dementia (Drevets & Rubin, 1989; Burns, Jacoby, & Levy, 1990). Many are required to live in specialised facilities for the aged, hostels for the elderly and nursing homes (Johns, 2010).

Neuropsychological testing is usually a necessary part of assessing whether houses should be put on the market, driving should cease, financial strategies be revised, family members move in, or the elderly relative be relocated to an old age facility (Baird, 2006). Due to the presence of cognitive and behavioural problems, there is difficulty with diagnosis when the person is depressed. Symptoms of depression tend to be masked by the associated agitation, aggression, restlessness and withdrawal accompanying neuronal impairment and can be difficult to diagnose (Zarros, Kalopita, & Tsakiris, 2005).

Neuroscientists are now able to track the course of the disease and advise on prevention in a way that was not possible twenty years ago. In the case of AD, when memory can be fragmented and impaired leading to difficulty in meaning-making, the mind can begin to try to make new pathways, attempting to find other channels of improving memory (Doidge, 2007). Many studies confirm that older people leading mentally active lives have better brain function than those who do not undertake mentally protective activities.

**Vascular Dementia (VD)**

VD usually occurs after a stroke or a series of strokes, as it is caused by a poor supply of blood to the brain, causing hypertension, predisposing elders to this form of dementia (Sadock & Sadock, 2008). Onset of dementia as a result of several small strokes is known as "multi-infarct dementia". There appears to be a rise in the prevalence of VD, although this may be because victims of stroke now live longer in Western countries than in the past (Skoog, Nilsson, Palmertz, Andreasson, & Svanborg, 1993). In some cases people may develop dementia between 5 and 10 years after experiencing a stroke. VD onset can also occur through aneurysm (a place on an artery wall
which has become worn or weakened). If the aneurysm bursts, oxygen can no longer reach the brain cells.

One participant in the programme who had a diagnosis of VD appears to have experienced none of the following possible recognisable symptoms as referenced by the DSM-IV-TR 290.40, (2000) (uncomplicated) with the notable exceptions of 1 and 2 as follows:

1. Memory impairment (impaired ability to learn new information or to recall previously learned information)

2. d) Disturbance in executive functioning (i.e. planning, organising, sequencing, abstracting) (DSM-IV-TR 290.40, 2000.).

However, this participant had the addition to the diagnosis made by her doctor: "with behavioural disturbance, i.e. wandering" 294.11x Dementia of the Alzheimer's Type (DSM-IV-TR 294.11, 2000).

**Lewy Bodies Dementia (LBD)**

Autopsy research has found that 10-15% of people with dementia had the LBD variety (Walker, McKeith, Rodda, Qassem, Tatsch, Booij, et al., 20012) and it has been reported to occur in approximately 20-60% of individuals with Parkinson’s Disease (DSM-IV-TR, 2000, 294.11). However, even with imaging, it is difficult to diagnose LBD effectively unless at autopsy. Research is presently being conducted using single-photon emission tomography to more specifically distinguish LBD from AD by ascertaining the level of dopamine and flow of blood (Goto et al., 2010).

**Grief and loss**

I move now from these bald, if chilling, diagnostic criteria, to the emotional and existential implications of receiving and living with a diagnosis of dementia. Concerns about the prognosis, the loss of friends and opportunities and fear about the future are cruelly absent from the diagnostic manual's clinical description of the disease.
In her novel about an old man with creeping dementia who has led an
amazingly adventurous, although sometimes violent young life as a circus
veterinary surgeon and then a more settled one in a suburban veterinary
practice; also by then a husband, father and grandfather, Sara Gruen (2006)
writes of the grief of memory loss in the nursing home:

_If I’m completely honest with myself, there have been hints I was
slipping...I close my eyes and reach for the far corners of my mind.
They’re no longer clearly defined. My brain is like a universe whose
gases get thinner and thinner at the edges. But it doesn’t dissolve into
nothingness. I can sense something out there, just beyond my grasp,
hovering, waiting – and God help me if I’m not skidding toward it again,

Such honesty is as admirable as it is rare.

The existential fears and potential crises faced by people who are nearing
their own deaths, and yet have a sense that their faculties are failing them,
inform this thesis. It is difficult enough for people who have not received this
diagnosis to make sense of their old age and impending demise, but when
the cognitive faculties are failing, it seems doubly hard. Johnson, Smith and
James (2003) refer to the stereotypes of elderly people: the rigid, unbending
and often curmudgeonly person who finds it difficult to be flexible and may
criticise the young, on the one hand. On the other hand, the young-at-heart
person, full of fun and enthusiasm who encourages the youthful to take risks
and enjoy life. Many people in between these two stereotypes still receive
these projections, and if they have the additional burden of recognising that
their cognitive skills are disappearing quickly, grief can soon follow.

Working in mental health over the last years, I have been inspired by John
Bowlby’s (1980) work on grief and loss in mental health. Bowlby writes about
the "prolonged absence of conscious grieving" (p.138) which can take place
in mental illness. Bowlby (1980) mentions that during psychotherapy, ill-
defined symptoms which occur, occasionally after breakdown, are found to
derive from normal mourning, although they are oddly disconnected from the
original loss which led to them. It has been very important to revisit Bowlby’s
(1980) work in connection with people with dementia. He considers that a
delayed reaction to the grief which the person experiences at the time of loss
can be repeated and displaced to an unresolved additional loss such as moving house or receiving a diagnosis of dementia. Thus, if the first loss is not dealt with in some way, the second loss is exacerbated. There can be a masked grief reaction where patients experience symptoms and behaviours which cause them difficulty, but they do not recognise the fact that these are related to the hidden grief of the first loss. What then of the grief involved in losing aspects of the memory or parts of the mind and how might this be complicated by past unresolved grief?

Alida Gersie (1991) recognises how storytelling and creative-expressive activities can elicit narratives of mourning and hidden grief and her words are particularly relevant here. For the elderly people she describes below, whose carers are sometimes so focused on the practical solutions for memory loss, depression and failing capability of their person with dementia, conversations surrounding the real and sometimes heartbreaking issues of grief and loss do not happen.

Numerous reasons may have led us to keep our grief under tight control and therefore to wait incessantly, or we may have been forced to run away from our mourning and thereby never rest again. When we are thus knotted up inside ourselves, preoccupied with words spoken and deeds done or words unspoken and deeds undone, we may at last seek help, or help may be offered (Gersie, 1991, p. 232).

This "grief (kept) under tight control" can be an unwelcome stress and even a kind of inner paralysis for people who have received a dementia diagnosis. Elsewhere I have written about the importance of closure in a dramatherapy group, which has particular significance for people with dementia. The reference is also relevant for Bowlby’s model of grief reaction delay:

From the first day onward there should be some kind of ritual ending for the session. This could be a song, a verse, a gesture – the group may find a way of providing this if the therapist does not. These people are living the last years of their lives, and endings are important; marking them will help with their grief process, as noted with the ‘funeral table’ example (Chin, 1996). "A period of reflection, as shown in previous examples, can connect imaginary scenes with participants’ lives and is existentially important". (Jaaniste, 2011a, p. 66).
Time needs to be dedicated to the participants at the end of a group, so that all can reflect on any uncomfortable feelings that need to be discussed (Andersen-Warren, 1996). Closure and ritual endings are symbolic reminders of our losses and our own physical demises as human beings, and if these are not ritually marked, we are liable to blunder in and out of social and other engagement without a sense of our own mortality.

An example of what I would call "paralysis of the soul" is brought to us with sardonic emphasis by Beckett in his play, *Waiting for Godot* (2006), where the long-awaited Godot never comes to meet with the two tramps in their barren landscape (Jenkyns, 1996). Each of the play’s two acts ends with Vladimir’s question “Well, shall we go?” followed by Estragon’s "Yes, let’s go", followed by the stage direction "They do not move" (Beckett, 2006).

The tramps are paralysed; however, existential anxiety can actually be softened and assisted by recognising a series of "little deaths": not necessarily orgasmic in the sense of "la petite mort", or literary as presented by Barthes (1973). In the form of reminders, however, like Beckett’s small stage directions, we as audience members realise somewhat reluctantly that we will all die one day.

When conversations surrounding death and dying do not take place in families, there can be ill-feeling when a partner decides not to allow medical interventions for the frail patient suffering a heart attack or stroke. Life is so busy for the children of the elderly person, and when that person puts on a cheerful front for their child, or the presence of grandchildren encourages them to do so, often the children no longer have a realistic idea of the parent’s state of health or quality of life (Hillyard & Dombrink, 2001).

**Post-traumatic stress disorder (PTSD)**

Over the past three decades, there has been some work done on the connection of PTSD and dementia, two conditions which share several risk factors and neuroanatomical preconditions (Qureshi, Long, Bradshaw, Pyne, Magruder, & Kimbrell, 2011). Cognitive deficit (Kremen, Koanen, Boake,
Purcell, Eisen, Franz, et al., 2007; Schmand, Smit, Geerlings, & Lindeboom, 1997); lower educational level (Stern, Gurland, Tatemichi, Tang, Wilder, & Mayeux, 1994); smaller hippocampal volume (Small, Pereira, DeLapaz, Mayeux, & Stern, 1999; Ball, 1977) and dysfunction of frontal and parietal cortical regions (Shin, Wright, Cannistraro, Wedig, McMullin, Martis, et al., 2005) are associated with PTSD and dementing illnesses.

There is also some evidence of a relationship between the restraint of dementia patients and re-traumatising where restraint, even with the best of intentions – i.e. safety – exacerbates symptoms such as flashbacks and anxiety (Flannery, 2003).

Flashbacks are associated with PTSD for war veterans, and Kristine Yaffe has done some leading-edge work with soldiers returning from the Iraq and Afghanistan wars uncovering evidence to suggest that PTSD amongst veterans of these conflicts increases the risk of developing dementia (Yaffe, Vittinghoff, Lindquist, Barnes, Kovinsky, Neylan, et al., 2010). She and her colleagues anticipate that, given that PTSD symptoms regularly continue until late stages of life and that changes in the hypothalamic-pituitary-adrenal axis frequently accompany PTSD (Yehuda, 2002), such symptoms could be associated with an increased risk of being diagnosed with dementia. They found that veterans diagnosed as having PTSD had a nearly two-fold increased risk of dementia compared with those veterans with no PTSD.

Yaffe et al. (2010) reached this conclusion after carefully attempting to adjust for possible confounding due to medical and neuropsychiatric comorbidities. I find these latter findings significant, as they have excluded veterans who may have received blows to the head resulting in neuronal damage and memory loss as a consequence, thus hastening onset of dementia. These findings do not necessarily generalise to women and to those patients not cared for at Veterans Affairs medical centres. It is interesting however, to hypothesise whether in the future work will be done to investigate non-combatant individuals who have experienced earlier trauma of a severe nature.

In the past and even today many elderly clients with diagnoses of dementia are not asked about traumatic events in their childhoods which could cause
PTSD and it would be advantageous to them if this omission could be reversed. Today, PTSD is treatable, especially if correctly diagnosed and/or reported. Many children are not routinely screened for PTSD; however the consequences of this untreated disorder in children are serious. The costs to the community of children’s undiagnosed mental health problems are high, both from humanitarian and fiscal standpoints (Geller & Biebel, 2006).

When these untreated children reach adulthood it is still not too late to seek professional help for the painful memories which occur, sometimes when they have been blocked by the memory, resulting in deep feelings of misplaced guilt or inadequacy. This realisation does not always take place, sometimes leaving the person in later life stages searching for reasons for their depression or needless guilt. If dementia then follows, there could be cogent reasons for still further fracturing or numbness of feeling life.

**Dementia and spirituality**

Another preoccupation of this thesis is the matter of spiritual needs in this population and life stage. Elsewhere I have explored this area in detail (Jaaniste, 2011b; Jaaniste, 2013a) and drawn attention to the meaning of spirituality for elders with or without dementia, and its association with QoL. Roger Grainger, a theologian, psychologist and dramatherapist, believes that dramatherapy "not only lives spirituality in the moment of encounter, it speaks spirituality" (Grainger, 1995, p. 2). Dramatherapy does this kind of living and speaking, as I have shown elsewhere (Jaaniste, 2011b). At the exact moment in the drama when the therapist and the client are interactively revealing a truth in the "as if", authentic meaning can be brought to the client’s own story.

Jung called these salient moments "numinous". They are sacred time points in a turbulent or chaotic world where "spiritual sense" occurs. Jung said of the spiritual confusion of the world:

---

The modern world is desacralised, that is why it is in crisis. The modern person must rediscover a deeper source of his [or her] own spiritual life (Eliade, M. [Interviewer] with C. G. Jung [1952], in McGuire & Hull, [1977], p. 26).

As discussed earlier, it is difficult to find reference to the positive qualities of old age or spirituality in the dementia literature, perhaps because of the focus on medicalised care in a society which lauds youth. Advertising and celebrity reporting in the media rarely depict people in later lifestages, and discussions of longevity often emphasise the question of how to stay young. There is an apparent blind spot in most discussions of treatments where only the deficits of ageing are discussed. Aricept and other similar medications can be administered to increase the amount of acetylcholine\(^5\) in the brain (Ganzer, 2007) and anti-psychotic medication can be given because of aggressive behaviour towards others; however no drug holds the secret of increasing QoL for someone with dementia. In searching literature on QoL, I found that much of the research is actually applied to carers and relatives, rather than people with dementia (Brodaty & Donkin, 2009; Schölzel-Dorenbos, Draskovic, Vernooij-Dassen, & Olde Rikkert, 2009).

The stress levels in carers undeniably constitute a significant area of discourse, and research should embrace their inclusion; however, there has been a gap in the literature, now filling, when those who suffer from dementia are not the main subject of investigation. This situation has been to some degree mitigated, as previously mentioned, by Kitwood and the Bradford Group in their research of person-centred therapy (Kitwood, 1997, pp. 55, 69). Wendy Moyle (2007) and others in Australia, including Lee (2011) and Verity (Kuhn and Verity, 2008) have also taken this work forward.

In the Australian context, and as a different way of engaging with the process of ageing, spirituality and dementia, it is worth noting that Indigenous Australian elders are treasured within the Indigenous community as well as in

\(^{5}\) One of the many neurotransmitters in the autonomic nervous system and the only one in the somatic nervous system. All of these drugs inhibit acetylcholinesterase which degrades the acetylcholine; thus the medications increase levels of the latter substance.
other culturally and language diverse (CALD) populations, and are often central to spiritual practices and knowledge transfer. Issues such as depression are not pathologised, but rather accepted as existential actualities and needful of accommodation. There is a practice at conferences of respectfully addressing Indigenous elders as "Uncle" and "Auntie" for example, thereby acknowledging their status, often transferring into the wider society and recognising the wisdom they have gained through experience.

**Dementia, quality of life and spirituality**

Towako Katsumo (2003, pp. 332-333) specifically addresses spirituality and remarks that healthcare professionals should try to fulfil three main requirements:

- *To understand and respect a person’s spiritual beliefs*
- *To provide spiritual care for people with dementing illnesses in educational programmes*
- *To include standardised questionnaires for assessing the personal spirituality of people with dementia*

As stated earlier, all three of these conditions are or can be met by the dramatherapist. For me, quality of life which includes spiritual care and a respect for the spiritual beliefs of people with dementia can be termed "experiential wellbeing" which is at the heart of this thesis.

Krieger and Hanson (1999) argue for the importance of the spiritual element, by opining that:

*One meaning of "to be healthy" is "to be whole"; and to experience wholeness is the very essence of what it is to be spiritual* (Krieger & Hanson, 1999, p. 305).

Margaret Goodall (2009, p.167) believes that "all good care should have a strong spiritual dimension at its heart", and the UN sponsored World Assembly on Ageing (1971) states that:

*Neglect of the spiritual dimension of care seriously impoverishes the QoL of people just as surely as the physical dimension – though the latter may be more apparent.* (Quoted by Shamy, 1997, p. 60).
End of life for people with dementia

Erikson considers the end stages of life as “Ego Integrity Versus Despair” (Erikson, 1963), stating that "the possessor of integrity is ready to defend the dignity of his own lifestyle against all physical and economic threats" and in the "healthy" person: "in such final consolidation, death loses its sting" (p. 268). Since Erikson sees the alternative to what he calls integrity as despair, it is uncertain that death in fact loses its sting, especially for those with dementia. Erikson's idea of integrity assumes that someone has the autonomy and cognitive ability to defend their lifestyle and his definition excludes people with dementia, apparently condemning them to despair, as well as death!

In dementia, it ought to be a given, surely, that treatment addresses the whole person. The resilient aspects of the person respond with creativity in dramatherapy, and this may ease the difficulty and discomfort which could stem from being elderly as well as having dementia (Jaaniste, 2011b, p. 19).

Developmental and life-stage models such as Erikson's are useful tools up to a point. There is no doubt, however, that such models should be treated with care, since the majority imply that autonomy and self-responsibility are the highest stage of development. All of us, with very few exceptions, are deeply intertwined with and dependent upon others. This is especially true of ageing people. In this case I prefer Lievegoed's (1997) more modest developmental comment on old age. A psychologist and follower of Rudolf Steiner, he admits that with "declining powers and physical infirmities" people become more dependent (p. 81). He then asks the following question, saying he cannot speak of the final stage of life:

Who can speak with authority about a phase of life through which he has not yet passed and been able to compare his own experiences with the experiences of others, acquired in friendly or therapeutic discussion? (Lievegoed, 1997, p. 81).

Other less severe developmental paradigms specific to the age group covered by my fieldwork include O'Neil and O'Neil (1990) who see 63 to 84 years as mirroring the middle life stages from 21 to 42 years. Thus, for the
elderly person the first seven years of “elderhood” up to the age of 70 is a period of adventure and discovering the world of retirement; the next years to 77 can be a time of "dying and becoming", and the third period to the age of 84 represents a renewal and resurgence of creative forces (pp. 226-227).

These positively characterised life stages should also be borne in mind for the person with dementia, rather than labels such as "end-stage dementia" (Morrison & Siu, 2000, p. 47) or "moderate decline" (Alzheimer’s Association website. Retrieved December 1, 2010) which although useful, are dominated by the negative symptoms of dementia’s various forms. Instead, more positive labels could identify the fact that well-entrenched memories laid down during childhood are the last memories to be lost in dementia. This situation occurs because children’s memories are not subject to the short-term or middle-term memory loss, characteristic of the process of cognitive disintegration associated with the disease (Weisberg & Wilder, 2001).

Lievegoed (1997) once again describes the last phases of life for healthy elders more positively than Erikson. He notes that those involved in creativity can live and express themselves through the arts until their eighties and even nineties. He cites Grandma Moses, Goethe, Richard Strauss, Verdi, Schuetz and Sibelius as practising their arts until the end (1997, p. 81).

Also interested in creativity, neuroscientist Norman Doidge (2007) cites Frank Lloyd-Wright as designing the Guggenheim Museum in his nineties, and Benjamin Franklin inventing bi-focal spectacles at seventy-eight. He tells us:

When Pablo Casals, the cellist, was ninety-one years old, he was approached by a student who asked, "Master, why do you continue to practice?" Casals replied, "Because I am making progress". (Doidge, 2007, p. 258).

John Zeisel, President and co-founder of Hearthstone Alzheimer Care and Hearthstone Alzheimer’s Foundation, USA (2009) is also passionate about artistic and non-pharmacologic ways of treating Alzheimer’s disease (AD). He believes that by understanding music and art, through touch and facial expressions, people with severe dementia show that they are highly creative and emotionally intelligent. By harnessing these qualities and using
techniques such as gallery visiting to view well-known and easily recognisable paintings, he believes it is possible to increase people's QoL, as well as their connection to others and to the world (Zeisel, personal communication, June 15, 2010).

The question of soul and its impact in ageing and dementia

By the soul is signified that (through) which we link the things to our own being, through which we experience pleasure and displeasure, desire and aversion, joy and sorrow, in relation to them (Steiner, 1993, p. 18).

Rudolf Steiner writes of denial of the soul as trying to run away from it: "a desire to run away from one's own soul. This, however, represents an impossibility. One must remain with oneself" (Steiner, 1985a, p. 29).

The concept of soul, although presently unfashionable, is in fact extremely helpful in alerting people to their own presence. Auguste D., the very first patient with dementia of Dr. Alois Alzheimer, after whom AD is named, said in 1901, "Ich habe, sozusagen, mich verloren" ("I have, so to speak, lost myself" Naue, 2008, p. 315). I agree with Naue that this statement seems to be a sign that she knows she has a self to lose. Sadly, it appears to have resulted in encouraging a view of dementia as a "loss of self and a changing identity" and people with the diagnosis as "the other" (Naue & Kroll, 2009, p. 26).

One important way of developing an understanding of identity is to practise a sense of soul in the feeling life. Throughout this thesis, the "intelligence of feeling", rather than "emotion", has been put forward as a preferable way to describe many of the communications of people with dementia. Witkin (1974) believes it is "the inner act of reciprocation that lies at the heart of the creative movement" (p. 188). Robert Sardello believes that individuality is actually present in the feeling life. "Feeling is that soul region where life first crosses over into experience" (Sardello, 2008, p. 55). This project tries to show how this occurs when people with dementia feel safe and valued in a
contained group, and are allowed to express these feelings through drama and reflection.

In the section that follows, the structure of the thesis will be previewed, allowing the reader to anticipate the story and stages in the research journey.

**The structure of this thesis**

**Prologue**

In the prologue, I have chosen to describe my personal background in relation to the elderly and the choice of my research topic for this thesis. Early experiences with family members and the ageing process, as well as in the area of mental health and dementia, are recounted. These experiences have influenced my choice of thesis topic, after gaining some dramatherapy experience with elderly people with dementia.

A personal introduction to person-centred therapy, sometimes overlapping with the field of mental illness in general and depression in particular, led me to this work experience. Particular personal aspects of ageing, such as grief and loss and the connection between spirituality and quality of life are touched on in this prologue.

The thesis is divided into a prologue and eleven chapters.

**Chapter 1: Introduction**

This introduction begins with the choice of my research topic for this thesis and its description, as well as the two arm-study and the mixed methods approach I have taken. It includes my rationale for taking such an approach, and the intention to use triangulation. It further describes the design strategy for the employment of a pragmatic, abductive focus for the research enquiry. Following this introduction, Chapter 2 will explain some of the history, key pioneers, concepts and practices of dramatherapy, presenting a literature search and chosen interventions used in the fieldwork.
Chapter 2: Situating this research in relation to the literature relevant to dramatherapy with participants who have dementia

The history of dramatherapy is firstly considered here, together with key pioneers in the UK and to a lesser extent in the USA. As described by the title, this chapter positions this enquiry relative to the literature for people with dementia. Explanations of dramatherapy concepts are described, identifying the major streams of practice in dramatherapy – an arts therapy which is very eclectic in nature. The modes of practice preferred by the author (as therapist) are compared and examples given.

Aims and objectives of dramatherapy for participating client groups are considered and described. Concepts and practices of dramatherapy are presented, with emphasis in the literature search on interventions and techniques which have been chosen for their suitability for people who have dementia. Concepts and developmental paradigms used in the fieldwork are explained and discussed.

Comparisons are made with studies in the other arts therapies, and the gap is identified in the research literature on dramatherapy and dementia using a mixed methods approach. Qualitative evidence is considered, together with successful qualitative practices which have encouraging outcomes for dramatherapy.

Chapter 3: Polarities of thinking, and how the tension between them informs the thesis

This chapter begins with an introduction which explains some of the general reasons for choosing a mixed methods approach, while at the same time positioning the author as someone who will be approaching her hypothesis with a metalevel of reflexive inquiry, triangulating her quantitative and qualitative findings. The chapter will bring together somewhat opposing views of consciousness and self, since spirituality will to some extent be held in tension with certain phenomenologists' views of "being-in-the-world".

The chapter begins with an overview of the humanist psychotherapists since Freud and Jung, and their relationship to the person-centred approach to
treatment of people with dementia. This approach pervades this thesis, and is mainly attributable to the work of Kitwood (1997). Carl Rogers, and others who built upon the foundation of his work, extending it into transpersonal psychotherapy, are discussed.

A discussion of wholistic transpersonal thinkers and their views leads into a consideration of Steiner's work, encompassing his understanding of the fourfold human being, and his views on consciousness. My own view of consciousness is also made clear, as a prelude to an exploration of Husserl and those phenomenologists influenced by him. Heidegger's understanding of Dasein and being-in-the-world and Gadamer's view of hermeneutics are also considered.

As a result of the theme of embodiment taking a substantial role in this thesis, partly as a vehicle for performance and partly in its capacity for everyday communication, the ontology of Merleau-Ponty is emphasised. Not only does he take the idea of Dasein a step further, he also gives the dramatherapist significant information about the body-consciousness of people with dementia when they have lost the means of communicating verbally.

The chapter ends with a discussion of phenomenology as a methodology and a consideration of where it might be able to shed light that could not be revealed or shown by biophysical evidence.

Chapter 4: Methodology

In this chapter, mixed methods are defined and the reader is reminded of the hypothesis which is the title of this thesis. Supplementary questions are posed, together with a discussion of the study's value to other researchers in the areas of dramatherapy and dementia.

My reasons for the choice of a mixed methods approach are given in this chapter, assisted through a brief overview of the literature which demonstrates the deficits of some carer-driven qualitative research and notes the regrettably small number of quantitative arts therapy studies in the topic.
area. The strengths of a phenomenological perspective are considered in relation to the study.

Following this consideration of strengths and weaknesses of the available research, the benefits of triangulation are discussed, bringing together subjective and objective perspectives. Additional challenges of the integration of methods are also included here, such as responses to the problems of integrating diverse approaches and the language used to express them. Pragmatism is considered as a helpful outcome-oriented way of coordinating data and drawing inferences.

Empirical research is introduced and a successful RCT study measuring art therapy and dementia is described. An early enquiry is made into measurement using biomarkers for the present project; however this is abandoned in favour of assessment using neuropsychological scales. The case is also made for a randomised control trial (RCT); however, this strategy is also rejected and replaced by a two-arm study. A literature search is presented to find the best scales to use, measuring mood, language and cognition, since they are considered to be integral to good QoL, together with an additional QoL-specific scale. The participants and their selection and enrolment methods are discussed, as well as the design of the two-arm study in Sydney and Newcastle, NSW. Some of the difficulties of obtaining the desired number of volunteers are considered.

An overview of my chosen qualitative research methods is presented, including the writing of an ethnographic drama portraying the tensions in bringing together the quantitative and qualitative types of enquiry. Other ways of bringing the phenomenological observations to the reader are explained. *The Dementia Drama* is described, portraying the highlights of each of sixteen sessions of dramatherapy, as well as four narratives of individual participants. Metaphor is also employed as a method of analysis, theme-gathering, and the "making visible" of aspects of the participants and their lives through this medium.
Chapter 5: Quantitative Analysis and Findings
This chapter aims to evaluate the data elicited from the pre- and post-group measurements of the groups in the two-arm study in order to appraise the effectiveness of dramatherapy for people with dementia. Each of the three measures are briefly described as is the procedure for setting up the two groups for assessment. The description includes volunteer numbers at baseline and Time 2 (T2) and explanations for those who discontinued.

Rationale and method for the analysis is then discussed, and tables are presented, showing numbers, age, gender, levels of education and diagnoses of the participants. A second table is shown, giving scores for each of the two groups in the two-arm study at Time 1 (T1) and Time 2 (T2). These statistics are then shown separately in three figures displaying graphs of the findings for each measure.

A discussion of the findings from each of the measures then takes place, and the chapter concludes by asserting that in the case of the QoL-AD it has been shown that dramatherapy has a small although not a statistically significant effect on the QoL of people with dementia.

Chapter 6: Ethnographic drama: For Love of the World
This playscript of the ethnographic drama portrays some of the the tensions which occur for the researcher when faced with mixed methods research, and in particular acknowledges her diffidence in the face of the challenge of eliciting data through statistical measurement.

I was prompted to place this chapter and the one that follows at the centre of the thesis. Encouraged by eminent theatre activist Augusto Boal's (1979) view of theatre's role as a driver of valid forms of social change and liberation, I chose to write a play which encapsulates some of the spoken and unspoken social justice views of participants with dementia and their advocates. It also included my own struggle with the mixed method approach selected. The process of creating a drama and having it recorded as a radio play allowed me as researcher to be "steeped in the data in a way the
previous rounds of coding and categorising hadn't allowed" (Cannon, 2012, p.590). It enabled me to come to terms with the triangulation of qualitative and quantitative investigation, along with its frustrations, at a poetic and often lyrical level and more readily to understand its tensions.

A compact disc of the play, produced as a radio production, is included at the back of the thesis.

**Chapter 7: The Dementia Drama**

The Dementia Drama also takes the form of an ethnographic drama. Its purpose, however, is different from the play in Chapter 6. As fieldworker, researcher and dramatherapist I hoped to engage the reader in the dramatic work of group sessions. By framing the sessions as a playscript with scene titles rather than themes, dividing the scenes into acts and adding a cast list and audition information, I wanted to give the reader an imagination of the drama that took place each week. This kind of ethnography allows a thematic narrative (Emerson, Fretz & Shaw, 1995) to be more accessible to the reader. My method aligns with the advice on performance ethnography given by these three authors on script-writing:

> ...the writer organises some of these themes into a coherent "story" about life and events in the setting studied. Such a narrative requires selecting only a small portion of the total set of field notes and then linking them into a coherent text representing some aspect or slice of the world studied (p. 427).

At "intermission" the progress of the "drama" is briefly assessed, and at the end of the "play" it is reviewed.

**Chapter 8: Narratives**

This chapter comprises narratives of four of the six members of the dramatherapy group as well as myself, indicating steps along the way in their engagement with the work. My own narrative includes a brief description of my clinical supervision process. The narratives augment individual stories, and build on a reading of *The Dementia Drama*. The selection of the stories of four individuals rather than all six was made with the length of the thesis in
mind. I also wrote a narrative of my own story within the frame of this research, as I wanted to show aspects of us all that might otherwise have been invisible. I had no interest in a glib "master story" that could end up with an impermeable surface narrative told from an elevated position as the researcher, where participants could be portrayed as "other". The two individuals whose narratives do not appear in this chapter are given space in the analysis section of the following chapter.

Chapter 9: Qualitative Analysis and Findings
This chapter sets out the various stages of analysis and interpretation of the mixed methods data. Phenomenological research methodology is discussed, clarifying distinctions between description and interpretation. The ethics of analysis are discussed, followed by a section on each form of analysis used: video watching, mining the transcript, the art works. Interventions as Developmental Transformations (DvT), embodiment and the Jones (1996) Adaptation of the Scale of Dramatic Involvement (JASDI), projection and roleplay are also considered as types of analysis.

A section on the qualitative method of analysis follows, including examples of reflective evaluation of the remaining two members of the dramatherapy group. Their narratives are not included in this thesis. Analyses also include information about the JASDI (Jones, 1996) and Creative-Expressive Abilities Assessment (CEAA) scores (Gottlieb-Tanaka, Lee, & Graf, 2008).

Themes emerging from the phenomenological observation and metaphor are recorded as follows: anger/frustration; family; grief and loss and memory.

The change scores from the quantitative measures of the Geriatric Depression Scale (GDS), Boston Language Test, Short Version (SBV-15) and QoL-AD are triangulated with qualitative information, to give an indication of the reasons behind some of the changes.

Chapter 10: Quantifying the Qualitative aspects of the research
The Creative-Expressive Abilities Assessment (CEAA) (Gottlieb-Tanaka et al., 2008) is described and its application for the purpose of this thesis is considered. Graphs are then presented which show the trajectory of group
progress through the sixteen sessions in each of the areas of ability: memory, attention, language, psychosocial, reasoning/problem solving, emotions and culture. The findings are discussed for the group, with particular attention to one client’s decision-making and problem-solving processes.

Jones' Adaptation of the Smith-Lazier Scale of Dramatic Involvement (JASDI) is presented and described, together with a chart describing the progress of two participants, according to the scale.

**Chapter 11: Further Discussion and Conclusion**

The early supplementary questions put forward in Chapter 4 are discussed and the advantages and disadvantages of the study design and methodology addressed. Recommendations are made for further research and limitations to this study are enumerated.

In conclusion, the QoL-AD and CEAA in particular are thought to be the appropriate scales to have used and the phenomenological methodology is recommended as a means to show that dramatherapy is a promising treatment to enhance the QoL of people with dementia. The study demonstrates very clearly that the otherwise invisible qualities of consciousness and intelligence of feeling can be revealed through research of this kind.
Chapter 2: Situating this research in relation to the literature relevant to dramatherapy with people who have dementia

I reflect on a journey of living positively with dementia, and of discovering a journey into the centre of self (Bryden, 2005, p. 10).

The healing power of drama has a long pedigree and many people have contributed to what we know as dramatherapy today. This chapter considers the history of dramatherapy as a foundation for the profession as it exists today, exploring its defining features. It employs a literature search which positions the present enquiry, as well as the researcher’s role as enquirer/practitioner, in relation to concepts and practices of dramatherapy with people who have dementia.

One of the earliest references dates back to Aristotle's definition of tragedy in the fourth century BC, where he cites catharsis, generally interpreted as pity and terror, vicariously experienced by audience members (Butcher, 2008). The possibility of some kind of personal change for the actors was also acknowledged. Early in the nineteenth century, Goethe’s doctor, J. R. Reil published Rhapsodies on the application of psychic cure method of mental disorders (1803). This treatise recommended the establishment of a therapeutic hospital theatre in which patients could take acting roles. At a hospital in Germany, Reil encouraged patients to play out scenes of "former life" by acting them. The therapeutic aspect of this activity is in doubt, especially as the enacted symptoms of patients were laughed at or ridiculed. During the remainder of the century theatres were built in some hospitals and asylums, for the benefit of the patients as actors (Jones, 1996; Casson, 1997).

Early in the twentieth century, experimental ideas in theatre emerged in the Soviet theatre. The work of Evreinov and Iljine, two contemporaries of the influential theatre director, Stanislavski, is dealt with at some length by Jones
Evreinov was a theatre director who explored "Theatrotherapy": the art of acting as a process of discovering meaning for the actors as well as the audience. He used Stanislavskian techniques of method acting to create his own techniques of "therapeutic theatre". He developed a means of playing out roles by tapping into two distinct realities: the person in everyday reality and their persona in an imagined reality (Evreinov, 1927). He believed the participant, through playing these roles, could overcome various physical as well as psychological issues. He called this experience "Monodrama", where the audience co-experiences with the hero of the play. As Jones (1996) suggests, Evreinov did not emphasise the trappings of theatre, but instead recommended the internal journey involved in acting a role. Golub (1984), in his biography of Evreinov, tells us:

Evreinov confronted life itself, which always moves too quickly and unexpectedly for man to fathom or properly inhabit. Evreinov actively sought a way for man to become absorbed back into life. In Evreinov we see the process whereby man reinvents himself through theatre and theatre reinvents itself through the basic masks, rituals, and archetypes that engendered it (Golub, 1984, p. 52).

It is this opportunity for actors to reflect upon their acting and to use theatrical skills to enter into their lives more fully and consciously that marks Evreinov out as a forerunner of the dramatherapy process. This concept has stayed with the profession until this day.

Also influenced by Stanislavski was Vladimir Iljine, who in the second decade of the twentieth century developed his Therapeutic Theatre in a psychiatric hospital in Kiev, Russia. His technique can be described by the following stages: theme identification and reflection, arrangement of scenarios and their realisation, and feedback (Blatner, 2007; Jones, 1996; Petzold, 1973). (Iljine’s work has not been published in an English translation.)

An important figure working in the early days of the twentieth century was Jacob Moreno. It is likely that he influenced dramatherapy; certainly, the discipline of psychodrama, which he developed, shares common elements with dramatherapy. He developed his "Theatre of Spontaneity", beginning as
early as 1909 in Vienna, when he became interested in treating Viennese schoolchildren by directing them to act short plays written for them about various problems in their behaviour. Soon the children were spontaneously presenting their own dramas in a manner which more directly represented their individual experiences (Starr, 1977). In 1924, Moreno published Das Stegreiftheater (The Theatre of Spontaneity). In 1947, this book was re-published; his ideas then covering three main areas: the spontaneous theatre, the living theatre and "the therapeutic theatre or theatre of catharsis" (Jones, 1996, p.62).

Moreno moved to the USA in 1925 where his work began to be explored further and built on by many practitioners and training institutes around the world. Moreno treated clients using individual and group psychotherapy combined with dramatic techniques such as the employment of an auxiliary ego (known as the protagonist) to assist the client with personal issues. He would direct the auxiliary ego to reverse role with the protagonist, in order to clarify difficulties between the client and his (possibly) problematic significant other in his life. Some interventions such as role reversal have been adopted by dramatherapy practitioners and the relationship between the two disciplines is still being explored (Jones, 1996; Landy, 1986; Langley, 1993; Chesner, 1994).

In the UK, one of the originators of dramatherapy was Billy Lindkvist. She had been training in voice, movement and performance at the City Literary Institute, London and visiting her autistic child in hospital between 1954 and 1964. Her visits brought her little joy. At this time she had a dream in which she saw everyone in the hospital coming together and sharing their skills and creativity (Jones, 1996). During hospital visits, she had been experiencing "the usual feeling of disintegration" (interview quoted in Jones, 1996, p. 87). When she awoke from the dream, she realised the nature of her task – to bring these skill-sharing ideas into hospitals, firstly addressing the occupational therapists and eventually to set up a training course in dramatherapy. There were many steps on the way, but the eventual result in
1974 was the foundation of the Sesame Course in Drama and Movement Therapy at the Central School of Speech and Drama in London.

A second pioneer in the U.K., Peter Slade, who was involved in theatre, observed children playing and realised that they had their own special form of drama (Slade, 1954). Brenda Meldrum calls him "a gentle man with a mind of flexible steel" who encouraged children to express themselves through drama (Meldrum, 1994, p. 12). He used his observations to assist people of all ages to gain confidence, and later worked closely with Kraemer, a Jungian psychotherapist at the Guild of Pastoral Psychology. Kraemer would work with the patient in analysis and Slade would follow up on the patient’s issues using drama. He was the first person to speak on Dramatherapy at the British Medical Association and to name what he was doing in one neologism: "Dramatherapy" (Jones, 1996, p. 84) as opposed to the American "Drama Therapy".

Dorothy Heathcote, although a "Drama in Education" pioneer, contributed her own brand of curative drama to this history. A television programme made in the seventies, *Three Looms Waiting*, documents her work, showing how her theories emphasise the encouragement of improvisational dramatic talent (Smedley, 1971). The programme uses interview and in-school episodes to demonstrate Heathcote's ideas, always emphasising children's choices in the roles they enacted. She used her considerable, and very individual, talents to take behaviourally difficult adolescents right back to the roots of their upbringing, encouraging each child to see that every person’s way of being is valuable in its own right. She asked British schoolgirls how their mothers made a cup of tea, showing them that "every mother brews their tea in a different way“ to illustrate human difference and help prevent the schoolgirls from forming cliques which can alienate the outsider (Heathcote, personal communication, April 29, 1997).

Sue Jennings, a prolific writer on the concepts and practices of dramatherapy, has exerted a continuous major influence on the profession in the UK for over fifty years. In the sixties she formed a Remedial Drama Group in London. This developed into the Dramatherapy Centre near the
London Hospital, offering training and group work for adults and children. Her own training was in drama, and during her drama training the supervisor at the local psychiatric hospital had asked her to dress up as a nurse and come and "do drama" with the patients, as "Nurse Jennings". At St. Albans in Hertfordshire, UK, Remedial Drama was re-named Dramatherapy following Slade's coining of the new compound title, and she established it there alongside the Art Therapy course (Jones, 1996).

Since then, Jennings helped to found the British Association of Dramatherapy in 1977 and has taken dramatherapy further afield into Europe, developing training programmes in Greece and Israel (Johnson, 2009). She has organised trainings and programmes in the arts therapies in Romania, and has written over 30 books on Dramatherapy, Playtherapy, Storytelling, Puppetry, Groupwork, Fertility, Ritual and Folklore which have been translated into several languages.

In America, Gertrude Schattner is recognised as a very early pioneer, using drama interventions with holocaust survivors. She taught drama for many years, training in psychotherapy and working with creative drama and movement exercises at the Turtle Bay Music School in the 1960s. Richard Courtney, a British Drama in Education practitioner, was passionately interested in her form of drama from a psychotherapeutic point of view. He assisted Schattner by helping to edit her two-volume book on drama therapy (two words), Drama in Therapy (Schattner & Courtney, 1981). The book comprised contributions by early American pioneers such as Eleanor Irwin, Judith Rubin, Barbara Sandberg, David Johnson and others. Some of those connections resulted in the formation of the American National Association for Drama Therapy (Johnson, 2009).  

What is dramatherapy?

Dramatherapy is a modality which helps people to experience themselves as embodied human beings within the full range of their feeling life. One of the

---

6 It is important to acknowledge here the substantial contribution of Lex Wils and Jan Boomsluiter as well as others in the Netherlands who recognised drama as a therapy as early as the 1950s (Jones, 1996). This chapter concentrates mainly on the birth of dramatherapy in the English-speaking world.
definitions of dramatherapy is my own and Adrian Lania’s, used by The Dramatherapy Centre, Sydney, as follows:-

Dramatherapy intentionally uses theatre and drama techniques to encourage the client’s creativity and expressive ability. It helps the clients to tell their story, express feelings, set goals, extend inner experience and try on new and more fulfilling roles, so far unexplored.

As dramatherapists, we are aiming to:

- Use the imagination to explore ideas, issues and memories
- Address real-life relationships and social situations through drama
- Play with your lifescript, telling your story in a new way
- Improve motivation, social skills, self-awareness and self-esteem
- Develop concepts of responsibility for the self and others in relationships


Dramatherapy is an involvement with drama practices with the intention of healing. It offers people techniques such as roleplay, improvisation, movement, voice work, puppetry and mask work for the purpose of expressing difficult as well as pleasant emotions and facing significant and sometimes confronting issues in their lives. It has been well-defined by registration bodies in several countries; however, I agree with Jones (2007, p.8) that local practitioners can offer a more defined sense of what dramatherapy aims to be in a particular context. A definition that aims to be a template for all is not always helpful to client groups with specific needs – people with dementia, for example.

**Supervision for dramatherapists**

The dramatherapist, after qualifying, is encouraged by all their registration associations to share their work experience with a professional supervisor; ideally an experienced person in the profession. This entails engagement in a peer exchange of ideas and strategies for work with clients. Supervision encompasses the resolution of significant dilemmas in the work, application
of theoretical concepts for particular client groups and adherence to codes of practice. It is not mandatory, but is extremely helpful for the dramatherapist to work out what belongs to her, and what belongs to the client within the compass of professional boundaries.

Four models of dramatherapy

Brenda Meldrum (1994, pp. 22-25) addresses disparities in this modality by dividing dramatherapy into four different theoretical models. She admits that it is not possible to do justice to the wide variety of eclectic approaches in existence, but describes the models as follows:-

a) **Theatre models of dramatherapy.** Here, the direct experience of theatrical work is offered to people who take on different characters and roles, often in a well-known play, while spectators suspend disbelief and accept that the actors are the characters they are playing, as if on stage, in imaginary time.

b) **Therapeutic drama and dramatherapy.** This model often makes use of the client’s own story, as well as using fairytale, myth and legend. Archetypes and metaphor are available for the client to project their own story onto this content, and to role-identify with story personae.

c) **Role theory models of dramatherapy.** In this model, which owes its origins to Moreno (Blatner, 1997), clients are assisted to increase the number of roles they see themselves playing and discouraged from getting stuck in only one or two (familiar) roles.

d) **Anthropological approach to dramatherapy.** Based on Grotowski’s work, the actor is seen as shaman. In some cases, the therapist plays the role of traditional healer, while the clients watch as audience. In other cases, she accompanies the client in diverse ways on their "shamanic journey".

My own view is that the **theatre model** has little to offer me and my clients, especially when working with people with dementia. We are not "doing a
play”; we are purely improvising situations that occur in a story they or I have told. However, there is an interesting combination between this model and the anthropological version of dramatherapy which will be discussed below.

The therapeutic model is much closer to the work I have done with all populations I have worked with, including my clinical research with the participants in this research project. For example, a client may come into the session having had the experience of a dream the night before. The therapist asks her if she wishes the group to improvise the dream (therapeutic model). She can choose a group member to play herself, and others to play various people or objects in the story. The dramatherapist as facilitator listens and watches for role identification and themes, incorporating them in the drama with an understanding of client situations and environments.

The role theory model has much to offer the elderly people who are at the centre of this study. This is a chance for them, in a safe space, to "try out" at least one role they have never played in their lives, which may help them cope with dementia. For example, they may wish to play a high status role such as a general practitioner, where they can identify not just the negative symptoms of dementia, but the positive attributes of ageing, or experiment with a gay role after a lifelong experience of heterosexuality.

The anthropological model has definite limitations and is only useful to me in the sense that I can help to shift scenes as a facilitator, or to demonstrate an improvisational technique or embodied movement which serves the clients. David Johnson’s Developmental Transformations technique is aligned to this model, since it is related to Grotowski’s Towards a Poor Theatre ethos (1968). Schechner (1997), sees Grotowski as "shape-shifter, shaman (and) trickster" (p. 458). I certainly have no interest in a fully shamanic role for myself as dramatherapist, as my main aim is to assist participants to perform. Improvisations arise from story work as already discussed, or from material that is contributed at any point during a session.
The anthropological model and shape-shifting

I have recently become interested in shape-shifting and scene-shifting and the role of the drama psychotherapist in assisting the participant to make a change from a position of hopelessness, for example, to a position of hope (Turner, 1974; McNiff, 1988; Levine, 2010). I facilitated a session at a residential facility before I began my fieldwork for this research and discussed it with another dramatherapist, Anna Seymour, the editor of the British journal, *Dramatherapy*. I realised then that I was using a form of my therapeutic style overlapped with the shamanic style of working. In the article I have argued that the history of theatre provides many examples of this, which can be accessed by the dramatherapist as useful templates for working with clients (Jaaniste, 2011b, 16). My description below of an intervention with a group of people with dementia, living in a retirement village, illustrates this point.

A client, Elspeth (not her real name), with mild dementia brought a dream to the dramatherapy group. Her memory of the dream was that she was floating above the earth, looking down upon her life, and unhappy about the course it was taking. She chose an elderly woman to play her "younger self" role. This participant also had mild dementia, but was able to move, whereas Elspeth was confined to a wheelchair.

One of the incidents portrayed concerned her teenage self travelling back to Australia with her mother, after a trip to Europe. Other group members played her mother and the captain of the ship. She told us during the improvisation that in real life her mother would leave her and play deck quoits or sit at the captain’s table on the voyage, and this made her feel sad. The two participants engaged with each other in improvised deck quoits. Perhaps for her (although she did not report this) some of the unhappiness was about omitting to tell her mother about how unfair this felt. Elspeth, as she watched the improvisation, admitted to feeling "hopeless".

Other events were portrayed, directed by her, where she did not feel "good enough" as a younger person. Elspeth in the wheelchair expressed how alone she had felt in the dream. As the therapist, I asked her to choose
someone to be with her, and she appointed the care worker, who took the role of an angel, at my request, and connected the young Elspeth with herself as dreamer as she looked on.

The scene-shift was made, connecting the client’s internal world and painful reminiscence of abandonment by her mother, continuing a theme of death anxiety which was being expressed in the dream and had also emerged in the group in earlier sessions. It enabled Elspeth simultaneously to be held by her younger self and an angel, observing her life, and provided an image for the group of a potentially smooth end-of-life transition. She accepted more positive aspects about her life in reflection, partly because of her own spiritual belief in angels (Jaaniste, 2011b, 21-22).

For Elspeth, it was a significant moment for her sense of self in a felt and imagined identity, and in owning her biography. Glaser (2004) points out that "good acting is a form of shape-shifting", and that "Developmental Transformations practitioners and clients are shape-shifting all the time". She also quotes Celtic practitioner Thomas Cowan, who states that:

In this dreamlike state, the imaginal realm reshapes itself, creating a placeless, timeless field in which (we) can participate in the consciousness of other creatures (Glaser, 2004, p. 81).

Many of Shakespeare's plays provide rich media for shape-shifting, and the following description provides a template for the dramatherapist interested in this way of working. In The Tempest, Prospero emerges from a dreamlike landscape and finds forgiveness for his enemies, just as Elspeth did. At one point in Act IV, still on his magic island, he says, "we are such stuff as dreams are made on" (IV, i, 156) and we believe him as we witness the magic he and his fairy, Ariel, have performed. At the end of the play (Act V sc. i, 55-62), he has a change of heart and promises to drown his great book of magic containing all he has learned on his dream island, and to break his magic staff for good. In the epilogue to the play (Act V sc. i, 356), he confirms he has done so. There is a poignant moment in the scene where his shape shifts; he steps out of his dream world and stands before his former enemies as a citizen of the world, rather than a magician. He faces them and then he
forgives them for the past wrongs they have done him (Act V, sc. i, 83), ready
to own his renewed and more authentic relationship to them in the "real
world" (Jaaniste, 2011b, 22).

It is important to emphasise, as Meldrum herself does, that the four
theoretical models of dramatherapy she has chosen are just some amongst
many possible others used by practitioners. Unlike some schools of
psychodrama and Gestalt practices upon which this modality sometimes
draws, dramatherapy does not claim one predominant set of clearly defined
structures underpinning training and practice, although the principles of
person-centred, Jungian, psychodynamic and other psychotherapies are
usually involved.

Meldrum sees a common thread in these diverse models, maintaining that
healing through drama allows the client, through the use of such structures,
to explore emotions in a special place in real and imaginary time, within a
social encounter (Meldrum, 1994, p. 15). Additional potential gains for people
with dementia are opportunities to deal with ageing and end of life issues
(Johnson, 1986), reality orientation (Langley, 2006), awakening memories,
and acquiring trust of others (Jaaniste, 2011a).

**Distancing and developmental models**

Safety can be maintained for clients through the use of distancing
techniques. Thomas Scheff, a sociologist, drew on the work of Stanislavski
and Brecht to create a method of practice that involved varying the emotional
distance at which the dramatherapist works with clients. Scheff maintains
that:

> Aesthetic distance is the point of reliving emotions without being
overwhelmed by them (quoted in Landy, 1983, p. 177).

In Scheff’s model, the participant or viewer experiences catharsis when he
relives emotions, but is not engulfed by them (Landy, 1983). The
dramatherapist assists the clients by moving them to a point of aesthetic
distance; in other words, by offering them concrete objects to work with as
projective devices, rather than taking on a role in a difficult situation.
Projective devices, such as dolls and puppets "allow most clients a safe margin of overdistance" (Landy, 1983, p. 180). Other distancing techniques I have used are: objects, de-roling techniques, metaphor in storytelling, drawing and videotape. Careful distancing techniques give clients a greater sense of their boundaries, indicating where they end and the drama begins; for example, the projective use of coloured cloths in the drama for waving or wearing.

Masks, on the other hand, can instil fear in emotionally disturbed clients, especially with people with dementia if they are losing aspects of their identity, such as professional status and social engagement. In such cases, their sense of identity may be fragile. I therefore decided not to use masks in the research project. Also, the participants would require extra preparation in understanding the archetypal power of ritual mysteries with which masks have been endowed over history. Jennings (1992) recommends that masks should be used cautiously and introduced gradually to participants in groups; Emunah writes that wearers may experience a sense of loss of self or alternatively: "..as audience, a loss of the person who has just put on the mask" (1994, p. 156).

**Embodiment, Projection and Role (EPR)**

Sue Jennings' developmental theory of EPR has informed my work with elderly people and offered me the opportunity to find ways to use it with them so that it fulfils the needs of their life stage. I have found it valuable to look at this paradigm, which she created in a phenomenological approach to working with prenatal mothers and observing children's play (Jennings, 1973; 1993; 1999, pp. 51-53).

**Embodiment**

Most of the young child's earliest experiences are expressed physically, through the senses and bodily stimulus. Facial muscles and limbs join in the act of exploring the outer world. The infant moves and plays along with the world physically, in order to experience it. This helps her to develop identity later on.
**Projection**

In projection, the child relates more to the outer world, beyond his body. There is a focus on the objects and toys belonging to his environment. During this stage, children explore the world through their own relationships to objects, and stories can be dramatised through toys or dolls. It is often easier for them to speak through their teddy bear or favourite doll, for example: "Teddy wants a drink".

**Role**

A significant change occurs at about three years old when the child identifies herself as "I". Dramatic play becomes a new way of playing, and she starts to distinguish between everyday and dramatic reality. The impulse to imitate is strong, and the role-modelling coming from parents and caregivers is played out. The child borrows the care-givers' clothes and goes into role.

An understanding of these stages of development is useful if working with dramatherapy participants of any age. Depending on their early experience, it can be helpful to reaffirm the stages in various ways to "en-role" them in therapy procedures. For example, a person who has autistic tendencies is likely to benefit from plenty of experiences of embodiment before taking part in projection or role, as a release from tension and an escape from "ritualistic thinking". Someone who is very nervous or has a fragile sense of identity may find satisfaction in projecting his thoughts and feelings onto an object or puppet. If the sense of self is robust, a participant is often ready for role earlier than others.

This paradigm is extremely useful for the dramatherapist in selecting interventions for all populations. The three different kinds of interventions can be used in individual or group dramatherapy, when it is possible that the person has had difficulties in early life. This knowledge may or may not be shared with the dramatherapist in the initial anamnesis, or during sessions. In my own experience, even if the history is not shared, it is sometimes possible to make an educated guess about what may have been the early circumstances of the client. Because of this flexibility of the paradigm for all
ages and stages, I have no difficulty in reversing it for old age and applying it in reverse as RPE is helpful. This is because, for people with dementia, taking a role is easier for those whose dementia is at a mild level, projection works best for a moderate state and embodiment works best where the person has a severe diagnosis of the disease. It may appear to the reader that this reversal could be interpreted as infantilisation; I believe however that this is very far from the truth. It is vital at the same time to note that treatment of elders as children is disrespectful and clearly to be avoided at all costs. This is a destructive infantilisation of older people, quoted by Kitwood as a "malignant social psychology" (Kitwood, 1997, p. 45).

**Kitwood’s Malignant Social Psychology and the EPR/RPE paradigms**

This expression of Kitwood's warrants a certain amount of unpacking, since any misunderstanding of what I am going to suggest next in the employment of RPE with participants nearing the end of their lives would be counter-productive to all of the work where this paradigm is used. Kitwood explains the invidious model of "encouraging disability" (my words) by listing seventeen elements which should not occur in relationships with people with dementia.

Among these malignant treatments of such people by caregivers, Kitwood mentions forced compliance (“treachery”), "stigmatisation", "intimidation", "labelling" and "infantilisation" (1997, p. 46). It is with this last element of damage that I am concerned here. Kitwood describes infantilisation as "...treating a person very patronisingly (or 'matronisingly'), as an insensitive parent might treat a very young child" (p. 46).

This kind of treatment of people with dementia is in no way to be confused with the reversal of this paradigm. I have always found it interesting, in the light of the very positive relationship that occurs between old people and children, that elderly people and those with dementia in particular seem to live their lives in reverse order of this developmental paradigm. The child has recently arrived on earth from a mysterious place, and the elderly adult is about to go to an equally mysterious one. Role, Projection and Embodiment
(RPE) can work as a safe structure for the elderly. A child comes into the world uncurling from its embryonic position to travel through the birth canal. A person who is close to death often curls up in bed to emulate the birth position. This is a movement we see in nature all the time: leaves on a tree, for example, unfurl in spring, then dry and curl up in autumn, ready for winter.

As an unapologetic comparison with the EPR reversal, it seems appropriate to cite McKenzie-Smith's (2009) application of an infant observation technique to her work with elderly people in the geriatric ward of a hospital. Her task was to observe what was happening between the residents and staff, with particular attention to the body language and voices of the former. She adopted Esther Bick's (1964) methodology of the observation of infants, and reports on her brief as follows:

By adopting this methodology and transferring it to the observation of elderly people in geriatric wards, I discovered that one could be in touch with the emotional needs of those people who have lost some or most of their capacity to communicate or verbalize clearly (McKenzie-Smith, 2009, p. 108).

Through her experience of watching the elderly people, who spoke very little, as closely as one might observe an infant, McKenzie-Smith was able to see, during sessions that the residents were communicated with "matronisingly" (Kitwood, 1997, p.46). They were "treated like a naughty child" (McKenzie-Smith, 2009, p. 111) by an occupational therapist and a care worker. This meant that they were going through emotional difficulties as a direct result of their treatment! She identified that, just as in a situation where infants were being cared for,

The observations enabled me to gain insights into the interactions and emotionality that would not have been possible through verbal communication, questionnaires or narrative texts (McKenzie-Smith, 2009, p. 108).

Her observation of bodily changes and nuances are very similar to those I try to watch for when working with people with dementia, especially those who have moderate to severe categories of the illness. This way of working is defined by a deep respect for people of all ages and should not be confused
with infantilisation; however it is to be hoped that McKenzie-Smith was in a position to make helpful suggestions about the culture of care also!

The reversal of the EPR model has been extremely helpful in identifying which interventions can be used for people with mild dementia (roleplay), moderate dementia (projection) and severe dementia (embodiment).

It is a simple matter to reverse the stages for old age (RPE) when considering interventions for elderly people with dementia. Such reversal of the paradigm has been discussed with Sue Jennings, the EPR model's author (Jaaniste, 2011b). Later in this thesis, it will be noted how and when projective interventions with a person who has moderate dementia, for example, can be more successful than roleplay techniques which would suit someone with the mild type.

**Developmental Transformations (DvT)**

I have also used the *developmental transformations* technique, a model created by David Johnson based on Erikson’s lifespan developmental paradigm (Erikson, 1963), where the playspace is clearly and safely defined by the therapist, and spontaneous interaction occurs within that area (Johnson, 1986, 1987, 1992, 2000). The basic goal of this form of dramatherapy is to build meaningful interpersonal relationships among group members (Johnson, 1986, 17). The dramatherapist aims to maintain a continuous "transformation of feelings, thoughts and group structures" (Johnson, 1986, 20).

This technique has several stages: *greeting*, or sharing important events, followed by warmup exercises: *defining*, as each person contributes words, sounds or movements which can develop into themes which can be picked up by the therapist, and *personification*, where these themes or images are crystallised into differentiated roles. This last phase may take the form of an "as if" Magic Box, usually stored in the ceiling, and participants can pull it down and take imaginary objects from the box. The therapist hypothesises to herself about current group issues, and can direct the drama accordingly, using the offerings of the group. Although Johnson does not provide a period
of reflection after this group intervention, I consider it important to do so, eliciting responses from participants once the box has been safely hauled back up to the ceiling. Alternatively, it can be changed into an *Emotional Soup*, where intense feelings can be dealt with and cast into the soup tureen by participants.

This developmental method is particularly effective in:

> improving relationships by ameliorating personal fears of being incompetent, stupid or awkward, feelings of humiliation and emptiness, and the projection of these feelings through antagonistic attitudes to others (“I’m not like those ugly old people”). (Johnson, 1987, p. 50).

### Concepts, practices and evidence

#### Session structure

A dramatherapy session for the purposes of this research always included the same structural elements, whichever techniques were being used. Each weekly session was loosely based on an overall theme, such as seasons, favourite animals, *Magic Box*, families, etc. The session began with warmup exercises using balls and cloths, to energise the body and bring energy and spontaneity to the participants. There was a warm-up period to facilitate connection between group members, some pair work, some group improvisation and then reflection, de-roling and closure. De-roling was of particular significance for this group. Over-stimulation of participants' imaginations was sometimes a difficulty for them if cognitive strengths and boundaries were weakened through the unwelcome persistence of a role which should have been left behind in the group space after a session.

#### Qualitative and mixed methods evidence

A literature search revealed various types of qualitative evidence for the efficacy of drama and dramatherapy with people with dementia. Schmitt and Froelich (2007) in a review of studies of creative therapies discussed one of the projects (Lepp, Ringsberg, & Holm, 2003). In this study, two weekly groups of randomly assigned elderly people with mild to moderate dementia were given an experience of dance, rhythm and songs using costumes
(Group A) and storytelling (Group B). Twelve elderly participants and seven nursing staff were enrolled in the groups (Lepp et al., 2003).

The main aim of the study was to find out the effect of the programme on the caregivers. However, this is not recorded by Schmitt and Froelich. A focus group was held with caregivers one month after the six week programme using phenomenography, finding that the people with dementia in both groups showed improved abilities in communication and confidence. It is not explained, either by Schmitt and Froelich or by Lepp et al. why two groups were used, and it has not been made clear why dramatherapists were not used: a drama teacher and a storyteller ran the groups. Schmitt & Froelich’s review of evidence in arts therapies inaccurately records this as dramatherapy, rather than therapeutic storytelling and drama. The study is valid as far as relationships between participants and staff are concerned, and one welcome outcome of the study is the improved interaction between them. Another research outcome is in the area of professional growth, as noted elsewhere (Jaaniste, 2011a).

A second study, examined in the Schmitt & Froelich review, assessed the combined use of dramatherapy and dance movement therapy with elderly people using a mixed methods approach (Wilkinson, 1998). This research was more accurately reported and involved dramatherapists. It found that members of the dramatherapy group had better cognitive function, better daily living skills and lower dependency than those not in the group. However, although none of the differences were statistically significant, the findings supported the idea that creative therapies may help people with dementia accept the disease and improve coping skills.

Further examination of evidence of the benefits of dramatherapy with this population will be discussed in Chapter 4.

**Qualitative practices**

The dramatherapist uses many strategies such as roleplay, improvisation and mime as well as the puppetry, storytelling, play and symbolic objects previously discussed. The question may be raised however: are these
strategies of the drama teacher, or of the recreational therapist? To answer this question, Joanne Hensman (2005) in her exploration of differences between drama and dramatherapy with older people, refers to the reintegration process that is necessary for safety and containment after improvisation. A qualified dramatherapist is trained to undertake this essential role. A range of interventions can facilitate this process in different ways. Hensman gives, for example, Sue Jennings’ previously mentioned Embodiment, Projection, Role (EPR) method (Jennings, 1999). Here, activities of embodying an emotion or feeling, projecting it onto an object or taking on a role synchronise with the early developmental processes of the human being. Awareness of the sequencing of interventions in this process is an essential tool for therapists, and can engage clients gradually and naturally into a trusting group experience.

I believe that, in order to work successfully with elders with dementia, it is essential for the therapist to enter the world of the participants as fully as possible. Casson (1994, pp. 3-4) shows us one way of achieving this goal in the dramatherapy context. He believes that the therapist’s direct entry into the client’s sometimes disturbed world is essential when working with people with dementia. He prepares for the work by practising a stream of consciousness delivery of apparently nonsensical words in private. He describes how he later attends to the client, listening on a symbolic level for emotional content, understanding that there might be feeling states the person is struggling to express that he could engage with. He documents his use of this technique with Laura, a client who was known to be violent, listening on a heart level for feeling, rhythm and symbolism. She appeared to enjoy receiving attention on this level, and took part in the playful communication. After their interaction, she chose a toy boat from a collection of playthings which she used as a shoe, whereupon he took on the role of a shoe salesman, massaging her foot. He describes her journey from a space of isolated hostility to one of warm human contact with him. Through his entry into her world, her need for compassionate and empathic contact was met. It is also of interest that the symbolic value of the boat, which became a "shoe"
was arguably what was needed for Laura to "bring her down to earth", and she chose it herself. Bion writes about the therapeutic effect of symbols, where two types of object (the boat and the shoe, for example) can be brought together - in this case, "held" by the therapist, so that they become meaningful in the situation.

The formation of symbols (which) depends for its therapeutic effect on the ability to bring together two objects so that their resemblance is made manifest, yet their difference is left unimpaired (Bion, 1957, p.269).

Although Casson does not refer to dramatic context in his article, there is a tradition in post-modern theatre of using displaced and "stream of consciousness" dialogue. For example, Pirandello (1995) in *Six Characters in search of an Author* has one of his characters declare early in the play:

What can I do if France can’t produce any good theatre, and we are reduced to putting on Pirandello plays which you have to be lucky to understand? (Pirandello, 1995, p. 6).

Beckett (2006), also, has his character, Lucky, in *Waiting for Godot*, utter a stream of abject nonsense in Act I, apparently to intensify the fragility of the human condition when waiting for something (perhaps death?) to happen:

...skating tennis of all kinds dying flying sports of all sorts autumn summer winter winter tennis of all kinds hockey of all sorts penicillin and succedanea in a word I resume flying... (Beckett, 1990, p. 36).

Dialogue or monologue that appears nonsensical is one matter; another more important issue is the language of respect. There are many publications based on person-centred therapy which give advice on the language we should use. The employment of invitations rather than imperatives or commands is suggested, and the tolerance by workers and carers of the need for repetition and general playfulness with ideas and language (Kuhn & Verity, 2007). In a dramatherapy session, this is validated and made easy by engagement in play.

The concepts and practices referred to above are just some of the methods dramatherapists have used in their work with people with dementia. Other techniques to assist such people are examined in greater detail elsewhere in
In the next chapter, the intellectual context and metaphysical aspects of this thesis will be explored and explained, leading to the phenomenological epistemology that informs the qualitative research.
Chapter 3: Polarities of thinking, and how the tension between them informs the thesis

Un-Cartesian terms force us to form the idea of an organic thought through which the relation of the "psychic" to the "physiological" become conceivable (Merleau-Ponty, 2002, p. 92).

Growing old is one of the ways the soul nudges itself into attention to the spiritual aspect of life. The body’s changes teach us about fate, time, nature, mortality and character. Aging forces us to decide what is important in life (Moore, 1992, p. 216).

This research enquiry has been conducted using a mixed methods approach; the main thrust of the qualitative exploration is phenomenological and the quantitative research aims to add to the small existing evidence base for dramatherapy used with dementia. On the one hand this thesis seeks to articulate the theoretical basis of dominant process-oriented and subjective approaches to dramatherapy and to research into dramatherapy, through reading and responding to the work of key phenomenologists. Within this paradigm, my own experience and that of participants is a legitimate form of evidence. On the other hand, the study seeks to explore how the evidence base for the effectiveness of dramatherapy can be expanded, through review and careful application of scientific methods.

I am interested in the usefulness and value of tensions which exist between the evidence based perspective (EBP) which relies substantially on the quantitative investigation, and the more practice-based qualitative inquiry. It is therefore my intention to undertake a metalevel of reflexive enquiry into the mixed method findings, using triangulation to arrive at an answer to my hypothetical question: Can dramatherapy improve the QoL of people with dementia through dramatherapy?

There is not an absolute binary between phenomenology-subjective experience, and positivist-objective scientific practice. These apparently opposite tendencies, the tensions between them, and the opportunities for partnership and synthesis have long accompanied me in my professional life.
I also have an interest in the latest research in quantum physics, which confirms the lack of a binary here, by questioning the objectivity of an empirical explanation of phenomena. In my role as an empirical researcher, I have no reason to believe that my findings will necessarily be entirely objective. Here, the role of the observer in an experiment is described:

*At its core, quantum physics challenges the ontology that permeated the scientific enterprise for centuries, the premise that the real world – independent of human choice and interference – is out there, uninfluenced by our observation of it. Quantum physics makes the seemingly preposterous claim (actually, more than a claim, since it has been upheld in countless experiments) that there is no "is" until an observer makes an observation. Quantum phenomena seem to be called into existence by the very questions we ask nature, existing until then in an undefined fuzzy state.* (Schwarz & Begley, 2003, p. 263)

This chapter will bring together some apparently conflicting views of consciousness and the self’s connection with the transpersonal. Spirituality as it is understood by psychotherapists such as Maslow and Wilber and by spiritual researchers such as Rudolf Steiner cannot necessarily be aligned with the perspectives of phenomenologists' views of "being-in-the-world", such as those of Heidegger and Merleau-Ponty. However, both these approaches inform this thesis.

The overriding rationale of this enquiry is based on my firm belief that, as humans, we all have an indestructible core to our being, even whilst that “being” is expressed in social and embodied ways. As a postgraduate student of dramatherapy at Hertfordshire University in the UK in the early nineties, many lively discussions held in our medical anthropology classes ended with this conclusion. Rudolf Steiner postulated the spiritual essence of humans as an essential element, impossible to destroy (Steiner, 1969).

Steiner's view of the human being and the interface between his philosophy and science will be important in establishing the rationale for this research. I hope to show that his theories of consciousness and Being offer a humanising possibility for people living with dementia, because people with this disability are not constituted as "conscious" by our society. Steiner's ontology demonstrates the profound respect he holds for the consciousness
of people with disabilities. He recognises that prejudices get in the way of some of the striking qualities of such individuals, so that they are identified by their deficits instead of their strengths.

...people have their ideas of what is to be considered reasonable or clever, and then everything that is not an expression of a “normal” life of soul (as they understand it) is for them an abnormality (Steiner, 1998. p. 17).

As mentioned in Chapter 1, there appears to be an obstacle to understanding the positive aspects of elderly people with dementia in most discussions of treatments where only the deficits of ageing are discussed (Jaaniste, 2011a). I have already referred to the transcendent, or spiritual “feeling” consciousness which is often missed, and is not affected by elderly people’s biological limitations. Studies show that older adults generally have memorial advantage for content that evokes strong feelings, relative to material that is socio-emotionally neutral (Carstensen et al., 1999; Fung & Carstensen, 2003). Their superior memory in the former case indicates that the neutral information is less important to them. Recall of selective socio-emotional information in a further study shows lack of impairment in elders when compared with content that is perceptual and cognitive in nature (May, Rahhal, Berry, & Leighton, 2005).

Empathic response is essential when dealing with people with dementia; “feeling with” another opens the heart centre and a feeling sense occurs there. Neurocardiologists tell us of the connection between brain and physical heart. Direct and indirect connections between these two organs have been researched and confirmed by Thayer and Lane (2009) through neuroimaging techniques.

In contrast to this feeling consciousness, one of the major figures of seventeenth century philosophy, René Descartes made a clear separation between the mind and the body. He argued that the mind, unlike the body, was not material. He believed that cognitive and physical phenomena are made up of distinctly different elements. Because of their diverse properties, they are, according to him, irreconcilable (Descartes, 1960). This split between mind and body has endured in many of its applications to this day.
I cannot in good faith reject the views of certain psychotherapists who are
known for basing their work on humanist ideas. In the history of
psychotherapy, humanism constituted a third force that went beyond the
psychoanalysis of Freud and its refutation by the positivists, by placing
human consciousness at the centre of the therapeutic process.

The next section will deal with my affiliation with significant practioner/authors
who have laid the foundations of person-centred therapy. These philosophers
and psychologists inspired Kitwood’s dedicated work, *Dementia
Reconsidered*, (1997). This book shows how a reversal of the disrespect
shown by personal carers and nursing home staff could improve the QoL of
people with dementia.

**The contribution of person-centred therapy to the
treatment of people with dementia**

The history of treatment of those unfortunate people with dementia leading
up to the mid twentieth century has been besmirched with ignorance and
disdain for those elderly who could no longer live their lives in the goal-
centred manner required of them by their carers. Part of the reason for such
attitudes can be traced back to the Freudian approach to human nature.
Although Freud wrote about "soul-making", his work was mainly focused on
the pathology of human nature (Cowley, 1993). The index to Freud’s
complete works contains no fewer than 400 references to neurosis, and none
to health (Walsh & Shapiro, 1983).

Jung (1933), a student of Freud's, nevertheless rejected his "pathologism"
and emphasised the importance to the individual of connecting the conscious
and unconscious processes and the relationship between the individual and
the higher self. He postulated that all mental disease after the age of 35 was
spiritual in character and said that individuation was an important task in mid-
life, connecting the ego and the self. Jung is seen by many as the father of
transpersonal psychology.
Carl Rogers and person-centred therapy

Initially known as nondirective therapy and later as client-centred therapy, person-centred therapy was originally the brainchild of Carl Rogers. Rogers believed that human behaviour was "exquisitely rational, moving with subtle and ordered complexity toward the goals his organisation is endeavouring to achieve" (Rogers, 1969, p. 29). He had faith in the power of individuals to help themselves and the ability to define themselves by observing and discerning the value of their own experiences.

According to Rogers, the self is a "process": an individual's field of experience is subject to what that person allows himself to perceive (psychological) and limited by what he is able to be aware of (biological). The basis for person-centred therapy is that people are capable of personal growth and development, and their self-understanding is based on past and present experience and aims for future goals (Frager & Fadiman, 1974). He defines psychotherapy as: "the releasing of an already existing capacity in a potentially competent individual; not the manipulation of a more or less passive personality" (Rogers, 1959, p. 221). He did not believe in psychotherapeutic intervention by an "expert", but thought the individual had within her a capacity (at least a latent capacity) "to understand the factors in (her) life which cause (her) unhappiness or pain, and to reorganise (her)self in such a way as to overcome those factors" (Rogers, 1952, p. 69). This is known as his "self-actualisation theory".

Rogers spent much of his authorial life and practice formulating and honing his theory of interpersonal relationships as "a part of the larger structure of theory in client-centred therapy" (1961, p. 339). This work negated much of the argument of his critics, such as Geller (1982), who rejected an authentic core of being which is actualised without reference to socialisation.

Steiner also has critics for his emphasis on the higher ego to the detriment of the individual as a social being (Robinson, 1992); however much of his work is also predicated on the I-thou relationship (Buber, 1965). On this topic, Steiner wrote "the separative tendency (of individualism) must consist in the cultivation of an active concern for his neighbour" (1976, p. 102).
Rogers did not include any religious or spiritual dimensions in his view of the human being; it was left to others to extend his ideas to include transcendental experiences (Campbell & McMahon, 1974; Fuller 1982). However, he did acknowledge and describe as "definitely appealing" the view of Arthur Koestler that "individual consciousness is but a fragment of cosmic consciousness" (Rogers, 1980, p. 88). Rogers is therefore sometimes referred to as someone upon whose work transpersonal psychotherapy is built. He cannot seriously be described as a transpersonal psychotherapist, although he saw his own evolution from a traditional therapist and academician, through person-centred therapy, to an increasing awareness "of the spiritual potential and dimension of the therapeutic relationship" (Rogers, quoted in Baldwin, 2000, p. 35). The following section will deal with Abraham Maslow, whose work is more robustly concerned with the transpersonal as a form of self-actualisation. It is this "self-actualising" quality of the person which gives them a sense of their own wellbeing, and is encouraged in all of the arts therapies.

**Abraham Maslow and the transpersonal**

Maslow, like Rogers, was sceptical about the problem-oriented nature of diagnosis and therapy. His opinion of Freud was scathing in this regard, stating: "To oversimplify the matter somewhat, it is as if Freud supplied to us the sick half of psychology and we must now fill it out with the healthy half" (1968, p. 5).

His own experience of psychoanalysis affected him deeply and showed him the dichotomy that sometimes exists between intellectual knowledge and lived experience. He is best known for his hierarchy of needs, of which self-actualisation is the highest human need (Frager & Fadiman, p. 345).
Maslow defined self-actualisation as "the full use and exploitation of talents, capacities, (and) potentialities" (1970, p. 150) and believed in what he called "metamotivation", by which he meant the use of energy to bring about growth in needs and values. Like Rogers, he believed that psychotherapy worked through a relationship of trust with another human being. He eschewed the theories of behaviourism, eventually realising that self-actualisation could reach an awareness of a greater unity than the self. He believed that without the transcendent and transpersonal "...we get sick, violent and nihilistic, or else hopeless and apathetic" (1968, p. iv). In other words, the participant extends his identity beyond individuality and personality. This activity was at one time the province of the shaman, but in Maslow's time, and under the influence of Carl Jung, it became the area of the psychologist.

In a survey of forty definitions of the field (Lajoie & Shapiro, 1992) the following definition was coined: "Transpersonal psychology is concerned with
the study of humanity's highest potential and the recognition, understanding, and realisation of unitive, spiritual and transcendent experiences" (p. 91).

Transpersonal psychology's links with quantum physics

With regard to unitive experiences, it is significant to compare the views of David Bohm with those of the transpersonal psychologists. Through his research in quantum theory, he discovered that the mental and the physical are "two poles" which are closely interlinked on many levels and that "at each level, information is the bridge or link between the two sides" (Bohm, 1990, p.282). He went on to extrapolate from what he considers "implicit" in quantum physics the following hypothesis:

For the human being, ...this implies a thoroughgoing wholeness, in which mental and physical sides participate very closely in each other. Likewise, intellect, emotion and the whole state of body are in a similar flux of fundamental participation. Thus, there is no real division between mind and matter, psyche and soma (p. 284).

He then goes on to extend this thinking to a transpersonal notion, comparing it to some of Jung's ideas "where the imperishable world erupted into this transitory one" (Jung, 1981, p. 4):

Extending this view, we see that each human being similarly participates in society and in the planet as a whole. What may be suggested further is that such participation goes on to a greater collective mind, and perhaps ultimately to some more comprehensive mind in principle capable of going indefinitely beyond even the human species as a whole (Bohm, 1990, p. 284).

When asked in an interview about the relationship of philosophy and psychology, Bohm replied that psychology had always been impacted by physics:

Classical physics caused psychology to look at separate egos and their interaction. The new understanding of the implicit order gives a more solid grounding for transpersonal psychology. (Bohm & Welwood, 1980, p. 29).

Transpersonal psychology, with its connection to this "new understanding" and its strong relationship to person centred care, informs this thesis by acknowledging the wholistic and more optimistic model of care for people with dementia. It offers the arts therapies, already "firmly rooted in this 'new
culture' philosophy'” (Knocker, 2001, pp. 4-5) an alignment with a new model of care where their spiritual as well as mental, physical needs are considered and QoL can be experienced even in the face of frontal lobe decline.

**Difficulties for a wholistic interpretation of phenomena when "evidence-based theory" is allowed to take over**

The fragmentation of the science which had been linked with philosophy (and to some extent with religion) from the time of the Greeks in Athens until early in the nineteenth century is articulated clearly in simile form by two quantum physicists (Bohm & Peat, 2000). Science can be compared to a patient who has a medical officer in attendance, a preliminary diagnosis and a specialist to give a second opinion. The trouble starts when a symptom is focused on to the exclusion of other aspects of the patient's health or illness. In a similar way, physics has been divided up into "elementary particles, nuclear, atomic, molecular, condensed matter, fluids, astrophysics and so on" (Bohm & Peat, 2000, p. 17). This not only muddies the waters of observation, but it prevents a clear insight into what is going on in a particular observation or experiment.

Bohm and Peat's example of the almost obsessive focus on a particular symptom, centred on brain activity for example, can be very destructive, as I have observed during my experience working in the mental health system. Patient trials of medications which kick-start the administration or reduction of dopamine or serotonin to the synapses can obscure the need for attention to the rest of the body. Very often mental health patients are not given a general examination which could reveal liver damage, epilepsy or diabetes, as well as metabolic or other dysfunctions which might be negatively affecting their mental health. These difficulties occur because the presence of a particular set of cognitive/sensory functions, such as hearing voices or mood disorders, fit together with current theories of mental illness, sometimes precluding attention to aetiology which may be physical in origin.
Bortoft expresses this notion of possible misrepresentation as "begin(ning) with the finished product, the object" instead of "looking instead at the coming-into-being of that object" (1999, p. 1). He says it would be more helpful if, as in Goethean science, relationships between phenomena were sought rather than attributing their appearance to a mechanistic source. Here he refers to Goethe's theory of colour:

Goethe’s approach was to avoid reducing the phenomenon to the mere effect of a mechanism hidden behind the scenes. Instead, he tried to find the unity and wholeness in the phenomena of colour by perceiving the relationships in these phenomena as they are observed (Bortoft, 1986, p. 8).

Ten years later, Bortoft writes of quantum physics:

Ten years later, Bortoft writes of quantum physics:

The point of quantum physics is not to differentiate into two levels but to look at the coming-into-being of entities (Bortoft, 1999, p. 1).

Thus quantum physics avoids the absolute binary the writer of this thesis also wishes to avoid.

Goethe’s mode of scientific enquiry allows that the application of experience and thought are valid ways of attributing meaning to phenomena, while at the same time contradicting Newton’s positivist position. Goethe showed that there are no invariable facts which are set in stone, because a fact can be altered by a change of meaning. Newtonian mathematics describes the phenomenon of colour by using a set of numbers rather than by observation and reflection. Goethe states that light and dark are needed for colours to appear and uses active perception to understand how this is achieved. Newton, on the other hand, after passing light through a glass prism, describes it in terms of a theory which "shows" that white light contains a mixture of colours as though it has been observed. Thus Newton perceives a meaning which is mistaken for observation of a phenomenon (Bortoft, 1986).

Feyerabend gives an analogy from the 1980s of how perception of meaning can change the facts. He describes how a person watching a movie for the very first time at the cinema might believe a visual change happened by means of the screen rather than by someone putting the film through a projector (Feyerabend, 1981). This example serves to illustrate the difference
between the Newtonian and Goethean pathways to their scientific conclusions. It also illustrates Bohm and Peat's (2000) reference to an unfortunate focus on one symptom to the exclusion of others and that in a cognitive problem-focused, evidence-based model of care, a person's wholistic needs can be overlooked.

Towards wholism
As the brief journey through some aspects of scientific philosophy in the modern period suggests, the epistemological and ontological frameworks change all the time, and our own time is no exception. When Richard Dawkins asks at the turn of this century, "if there is an appetite for wonder, isn't true science qualified to feed it?" (Dawkins, 1998, p. 58) the reader is at a loss to know what he means by the "true" science. Is it the neo-Darwinist, Newtonian science of Dawkins, or is it the new physics that has emerged from the debate about mechanistic science? As Kane opines:

The Newtonian conception of science-nature as a machine of parts, comprehensible in its dismantling – has been profoundly shaken (Kane, 1996, p. 25).

Considered by some as a critical rationalist (Ulrich, 2006; Rowbottom, 2010), Karl Popper declares there are no absolutes in scientific analysis:

Neither observation nor reason are authorities. Intellectual intuition and imagination are most important, but they are not reliable: they may show us things very clearly, and yet they may mislead us. The most important function of observation and reasoning, and even of intuition and imagination (my emphasis), is to help us in the critical examination of those bold conjectures which are the means by which we probe into the unknown (Popper, 2003, p. 279).

I have singled out the words in bold above because they interest me, representing as they do a kind of "double gesture" of disavowal and recognition that seems to be necessary for the integrity of the researcher.

Ken Wilber, like Popper, believes that falsifiability is important, just as Socrates did; in other words, genuine knowledge has to be open to disproof. This is an important contribution in the quest for human research. He says, however, that Popper is mistaken in restricting this principle to sensibilia
alone, "and thus mak(ing) 'falsifiable-by-sensory-data' the criteria for mental and spiritual knowledge". He regrets this kind of reductionism and its inability to be supported by its own falsifiability principle (Wilber, 2001, p. 78).

Wilber goes on to celebrate the fact that wholism, which he calls the "evolutionary holarchy" (a hierarchy of "holons" which are whole in one context and part of a wider whole) is common to many areas of human knowledge and endeavour. He quotes modern psychology as an example of a discipline where "every school of developmental psychology acknowledges some version of hierarchy...irreversible stages of growth and unfolding" (p. 44). The phrase "every school" includes Freudians, Jungians, Piagetians and others. Thus, wholism in healing is coming home to roost, and is able to be connected, not only with its beginnings in Greek philosophy, but with its roots in Eastern philosophies. Matter, body and mind are acknowledged by Wilber; however unfortunately soul and spirit are not accorded the same status as these other three (2001).

Laszlo, coming from a very different perspective - that of systems theory - believes that science as a specialist discipline has lost its relevance to the question of meaning in life (1972). He refers to Maslow's theory of self-actualisation, and indeed, this quality needs soul and spirit to engage it. Knocker (2001) writes about the difference between an old culture of "routinised physical care" (p. 4) which disregards a person's spiritual needs. She points to Kitwood's indicators of wellbeing, the signs of which "are evident as both the means and end of dramatherapy practice" (p.4) and bear no resemblance to Dawkins' so-called "true science".

**From wholism to spirituality**

After eighteen years working in the mental health system in Australia, it is my observation that Wilber's view of reductionism as "falsifiable-by-sensory (means)" continues to be true of the mainstream medical model. As a student of medical anthropology, it has often been uncomfortable to work wholistically, sometimes "under the radar", in a reductionist system. One of the main reasons for conducting my research using mixed methods has been
to try to conduct an enquiry which draws from positivist-objective and phenomenologist-subjective ideas, as set out in my introduction to this chapter.

Taussig shows how, in failing to recognise human relations embodied in positivist descriptions of symptomatology, we fail to demystify those relations and as a result we miss the factors that caused the illness. We reproduce instead a political assumption, disguising it in the science of physical things. He calls this process a "reification" of the patient and the alienation of his self-understanding (Taussig, 1980). He uses exempla from Turner and Levi-Strauss to show how the social and moral causes of sickness often lie in communal interrelationships which are antithetical to bureaucratic pragmatism.

Steiner also believed in wholistic healing which takes relationships into consideration and has left a legacy of a wholistic system of medical practice considering all aspects of the human being: body, mind, soul and spirit. He insists that every doctor have a mainstream training before attempting to diagnose patients according to anthroposophical medicine and counsels doctors to strengthen their imagination, inspiration and intuition, and not to throw out the idea of empirical science, but to bring it together with their fourfold understanding of the human being (Steiner, 1922).

Anthroposophical medicine acknowledges the physical, etheric, astral, and ego aspects of the human being which need to be in balance in order to maintain health (Steiner, 1993). The first (physical) is easy to understand in terms of the human body which is built of minerals in common with the earth itself. The second (etheric: also known as the "life body") is related to the "glow" described in Eastern medicine, and can be recognised by some as a field of energy or light around an individual (Brennan, 1994). Detection of its absence is easier when the observer is familiar with the healthy individual: for example, when a person is sick, there is a lack of energetic aura around that person. Steiner compares this with the life body of a plant and indeed relies on Goethean science for this view.
The etheric body is the "etheric double" of the material body. Man possesses it in common with the plants. It is not produced by the physical body as naturalists might be led to believe; on the contrary, the etheric body is the builder of every living organism. In the plant, as well as in man, it is the force of growth, rhythm and reproduction. (Steiner, 1906. Retrieved May 19, 2011).

The third, (astral) describes drives and emotions and the ability to feel pain and pleasure which humans share with animals. Steiner understands astrality as connected to the soul, reflecting our instincts and unconscious will. Its visible appearance is related to the coloured "aura" described in Eastern medicine (Leadbeater, 1909).

The fourth, the ego (higher self) he understands as the part of us connected with our conscious spiritual nature, and is not to be understood as the Freudian ego, which is the "sense of self" mediating between the id and the super-ego (Snowden, 2006). Instead, it is the element of the human makeup which helps us heal. Mehl-Madrona understands this well in his practice of integrative medicine:

> Spirituality is routinely ignored as a relevant part of medical history or a psychological assessment. But spirituality is making inroads into conventional medicine, as exemplified by the American Board of Psychiatry’s requirement that psychiatrists receive training in how to address spirituality with patients. Spirit knows no denomination (Mehl-Madrona, 2003, p. 114).

Steiner’s concept of the fourfold human being has inspired me to look at dramatherapy participants in each specific aspect. Firstly, observation of physical movement is an important feature of their embodiment in role, or in body sculpting or improvisation. Secondly, a sense of their state of health can be gained from observation of the etheric body: for example, the quality of skin, hair and eyes. Thirdly, distancing techniques, discussed in Chapter 2, need to be used by the dramatherapist once she has established the trajectory of affect and astrality. Fourthly, the reflection period allowed to the participant is a higher ego activity, since the participant is encouraged to be very conscious of the meaning and significance of the dramatic involvement to the client’s life.
What, the reader may ask, is the ontological status of the consciousness I am promoting? Steiner’s work is based on his spiritual-scientific a priori knowledge, but I am not, as an observer, in a position of such clairvoyance as regards my clients. His fourfold understanding of the human being is in conflict with the being-in-the-world status of contemporary phenomenological observation and understanding. Steiner’s method of achieving a state of consciousness is highly structured, and some would argue, untenable and indeed, unattainable.

Nevertheless, as I have stated, I am drawing on Steiner’s epistemology particularly because a theory of consciousness with mutual respect as a goal for human beings offers humanising possibilities for people living with dementia.

Steiner has left a legacy in his many lectures and books of varying stages of consciousness, and such references can be found throughout his work. His development of anthroposophy was intended to assist people to observe themselves, and this self observation is the beginning of a sense of the spirit (Steiner, 2007). He believes we should work on our "higher" consciousness and developed six exercises to help us to do this, all of which require some form of meditation (Steiner, 1969).

It is not always possible or desirable for most people to work in this way (I am especially bearing the volunteers in mind); even for most of us who are aware of Steiner's path to spiritual awareness through meditative exercises, it is a question of striving with our will forces to do the work required of us rather than reaching our goal. Wehr (2002) believes that only Steiner and a small handful of his pupils ever attained the desired higher consciousness, and the students only "to a certain degree" (p. 137).

The source that gives the clearest information about Steiner’s levels of consciousness is in his series of lectures7 which are published in book form (Steiner, 1927). He writes firstly about the consciousness we experience when we are awake and aware of the self as we perceive it in thinking,

---
7 Many of Steiner’s lectures are not published in books.
planning and active engagement. Secondly, he describes the consciousness we have in dreaming, which can be quite remote from our awareness when awake. Thirdly, he describes the imaginative consciousness. In this area of reality, we touch on the spiritual world. We become capable of thinking with the heart. In order to achieve this level of consciousness, Steiner once again says it is important to develop mature soul-capacities (Steiner, 1988).

My own position, in contrast to a total reliance on the anthroposophical standpoint, is one which is influenced by Heidegger, Merleau-Ponty and other phenomenologists and their sense of being-in-the-world. Their epistemologies are described and discussed below.

The ethics of endless naming and shaping of the conscious self as a "project" has often proven in practice to be egotistical in the extreme, and fruitless in community-building. The ethical position of anthroposophy has also resulted in privileging, in many countries, those who already have material or educational advantage. This can be observed to be the case overall in anthroposophical communities based on Steiner’s work, situated in some western countries. This situation, as with organised religion, should not be traced back to precepts, but rather to common human flaws in putting indications into practice; better still, making them our own in an authentic way. Steiner’s Threefold Social Order, a way of understanding practising truth and justice in the economic, political and cultural spheres (1977), is very demanding on society and has not been established in the world, in contrast with his educational and medical ideas which have taken root worldwide.

However, a conscious self-understanding of a kind is still needed in order for individuals to connect with one another. This I believe is Steiner’s major gift to us. Imaginative thinking, and above all heart-thinking (1985b) is needed for the third millennium. It is related to the intelligence of feeling. This kind of thinking brings with it a possibility for a more vital future for the marginalised "other", such as the person with dementia. It bears within it some of the energising quality proposed by the transpersonal thinkers and made manifest by the bold approach by Goethe. This robust attribute is extended by the quantum physicists when they seek what is actually present instead of relying
on an overarching theory. Their attitudes of mind are at work in the phenomenological enquiry I have chosen for my research, and the following section expands my interpretation of this method.

**My understanding of phenomenology for the purposes of my research question**

Steiner’s respect for conscious experience and phenomenological observation as opposed to empirical data gives me pause for thought, especially as one of his fellow-students under Franz Brentano at the University of Vienna was Husserl, who is often seen as the father of phenomenology. Both men (Steiner and Husserl) investigated the idea of consciousness. Husserl’s "act of pure seeing" can be aligned to Steiner’s view that we can become conscious of our own thinking (Steiner, 2000). By naming our sense-perceptions as "percepts" and our ideals as "concepts", Steiner shows how we can observe our activity of thinking and understand the reasons we act as we do, observing our own consciousness as a phenomenon. Majorek (2007) describes how Steiner recommends meditation in order to get an inner impression of our own individual thinking, free of all externals. Only then, he says can our will produce a sense of thought in us, before it actually becomes a thought. He aligns this second stage with Husserl’s Transcendental Reduction:

*It is clear that the intention here is to free the soul from its ordinary attitude of attachment to the world of the senses* (Majorek, 2007, p. 275).

**Phenomenological considerations**

It is necessary for the implications of the methodology in this study, with regard to the elderly in general, and people with dementia in particular, that the nature of the self be discussed and problematised, as well as the concept of power, vis-à-vis the therapist. As discussed by Biggs and Powell (2001) the involvement of insurance companies and biomedical preoccupation with old age have resulted in a spillover into the area of care of the elderly. This

---

8 My emphasis in bold font.
has resulted in the takeover of the ageing discourse, with implications that illness of one kind or another has come to represent ageing itself, with the medical sector performing rescuing heroics. I have no wish, as a health professional or a researcher, to take this kind of philosophical or political stance in research theory or practice.

This chapter concludes with a summary of my own understanding of the concept of phenomenology and its integrity as a methodological qualitative evidence-based modus operandi for the efficacy of dramatherapy with dementia sufferers. This section will include my own acknowledgement of the area of "not knowing" and a segue towards my own conception of what is happening with participants in a dramatherapy session. The final section and conclusion will deal with aspects of the therapeutic work which are likely to be illuminated by their application in assessment and evaluation.

**Husserl and his followers**

The origin of the term "phenomenology" appears to date back to the work of Lambert (1727-77), who published a treatise on epistemology dealing with the question of truth and illusion, entitled *New Organon, or Thoughts on the Search for Truth and the Distinction between Error and Appearance*. In this document he outlines a theory of illusion which he designates as phenomenological, as well as a theory of appearance (Zalta, 2009).

The above designation bears an odd resemblance to the post-modern, post-Husserlian reader, since to Lambert, an appearance (or phenomenon) is necessarily an illusion. In some present day understandings of the word, and since publication by Husserl and his followers, researchers have attempted to return philosophy to concrete experience and to reveal the essential structures and intentionality of consciousness. Through their efforts there has been a rescue operation to preserve the epistemic value of idealism rather than illusion, that has surrounded it since early last century (Hopp, 2009). Hopp sees this as a failing; however, perhaps the discourse surrounding idealism is an essential element of the qualitative integrity of the history of phenomenology.
Husserl developed the phenomenological method to make possible a description of the essential and direct nature of phenomena (Husserl, 2004). He eschews the philosopher's traditional habit of bringing assumptions into an observation of and reflection on the phenomena at hand. He admits that this type of inquiry is exceedingly difficult and that the risk of error confronts us at every step. Hopp maintains that the fallibility of his argument occurs with the agent or observer, rather than the methodology (2009). However, Husserl sees our observation as "an act of pure seeing" (Husserl, 1999, p. 43). This, despite Husserl's good intentions, appears to belong to the area of idealism, a tendency called into question by Heidegger and the phenomenologists of the French school.

Heidegger and Dasein

Martin Heidegger reflected, not upon "pure consciousness" or "pure seeing", but on human existence in the here-and-now, and his ultimate aim was to elucidate the meaning of Being itself, which for Heidegger was always being-in-the-world. He believed that in the two thousand years of philosophical thought that had preceded him, philosophers had lost touch with the concept of Being. He expresses being-in-the-world (Dasein) as follows:

Being-in is not a "property" which Dasein sometimes has and sometimes does not have, and without which it could just be, just as well as it could be with it. It is not the case that man "is" and then has, by way of an extra, a relationship-of-Being towards the "world"—a world with which he provides himself occasionally. Dasein is never "proximally" an entity which is, so to speak, free from Being-in, but which sometimes has the inclination to take up a "relationship" towards the world. Taking up relationships towards the world is possible only because Dasein, as Being-in-the-world, is as it is. This state of Being does not arise just because some entity is present-at-hand outside of Dasein and meets up with it. Such an entity can "meet up with" Dasein only in so far as it can, of its own accord, show itself within a world. (Heidegger, 1962, p. 84).

Dasein is of course extremely important to people with dementia. It is essential that they sense and feel their own identity in the here-and-now. Dasein, Heidegger argues, is a state which offers a human being the opportunity for consciousness and responsibility for its own existence. He also sees it as belonging to Western tradition (his main philosophical work is
called *Being and Time*) and therefore a history of language and meaning are of significance for Heidegger, and in need of transformation (*Destruktion*) for philosophical thought to progress.

Although influenced by Heidegger, Husserl’s way of thinking differs from his; firstly Husserl was not concerned with the history of philosophy and secondly he believed that philosophy should describe the experience of Being, rather than being-in-the-world.

Luebcke (1999) states that Husserl neither denies the thesis of ontological realism nor the statements expressing our common sense, scientific or epistemological assumptions about the world. Although telling the reader what it is not, affirms Luebcke, Husserl only gives us some indirect hints about what the *epoché* (phenomenological bracketing or *Einklammerung*) really is. This finds resonance in my own view that since the concept of pure consciousness eludes us for the most part, there is a certain idealistic notion within any phenomenological construct which must be borne in mind when approaching it as a methodology.

However, there are potentially irreconcilable tensions between Steiner’s tradition of the supremacy of human consciousness, strongly connected with the higher Ego or spiritual consciousness, as opposed to the Jungian ego as the "point of psychic balance" (Jung, 1959) and the post-Steiner position of being-in-the-world.

Gadamer was very much drawn to the philosophy of Heidegger, and is also judged by some to be more accessible (Lammi, 2008; Bernasconi, 1986). He looked for an alternative methodology to recover meaning (hermeneutics). Rather than using the reductionist, empirical method common to scientific investigation, he sought a way of understanding phenomena without founding it on any method or rule-set. This was not a rejection of important methodological concerns, but actually giving priority to understanding as a practical exercise (Zalta, 2009).

Gadamer’s principal text, *Truth and Method* (2004 [1975]), comprises three main sections: one on the retrieval of concepts, one on a broadening of the
scope of truth beyond the area of questions in epistemology and methodology and one on hermeneutics as part of a linguistic turn in ontology (Hodge, 2008). In the second, the broadening of truth’s compass, he comes down on the side of relativism rather than reductionism, since there are no absolute truths. He is asked when interviewed by Grondin how he manages to bring together “the thing itself” (in the language of Husserl and Heidegger), and the "event-character of pre-judgement" (2006, p. 89). (He goes on to explain this latter expression as the chronology, history and prejudice that may need to be deconstructed in order that the phenomenon reveal itself.) He is questioned as to this exclusion of the phenomenon by the prejudice of the observer.

He refers the questioner to Heidegger’s deconstruction or "uncovering of prejudices" (p. 90) and alludes to the prejudices as "unconscious". In this struggle for consciousness, Gadamer appears to refine the quality of the phenomenon, even in the area of dispute between two persons, which seems significant in the search for a reliable qualitative methodology. The prejudicial quality he assigns to understanding and interpretation here means we are involved in a dialogue between our individual self-understanding and our understanding of the problem we are dealing with.

This dialogue between understanding of self and other issues is very important for arts therapy. In comparison with visual art, though, where there is an object for (conscious) observation, the dramatherapy consciousness has to be embodied, and the body has to be "in the world" in order to perform. Indeed, in the translators' preface to Truth and Method (2004 [1975], p. xiv) it is pointed out that the word Darstellung...

...implies that something is immediately present, but as something with a shape or structure that is particularly brought out in presentation. The same term can be used for theatrical presentation, performance and recital ...Gadamer wants to stress that we find not mimetic repetition or aestheticist displacement of the real, but a process best described in neoplatonic language, where the original reality comes to its fullest self-presentation...and where the tie between original and picture is never broken (Weinsheimer & Marshall, [Trans.] 2004, p.xiv).
In other words, not only the consciousness is embodied in drama, but the being-in-the-world is connected with an original archetype - a circumstance which authenticates the Bildung or self-transformation. Levine interprets this structuring of ourselves as "form(ing) ourselves through a creative experience" (2009, p. 139). For the dramatherapist it is a privilege to observe this happening.

Gadamer’s "linguistic turn in ontology" (deriving from Kant’s ontological research) is interesting, in that language itself appears much more "embodied" and less abstract than in its strictly scientific use (This has later relevance for the views of Merleau-Ponty.) Gadamer tells Grondin:

*Of course there is a person who speaks, but not without being restricted by language, for it is not always the right word that comes to one. Hermeneutics helps us to realise that there is always much that remains unsaid when one says something. There is a lot in the same direction of meaning that almost completely escapes our attention because of the abstraction contained in concepts of modern science* (Grondin, 2006, p. 91).

This quotation is interesting in the light of Lacan’s view of language below, as well as the concept of embodied language, since movement and gesture can replace words generally, as well as the missing word. This is of particular relevance for people with dementia, who often miss or confuse words while expressing more articulately with body language.

The following section explores the meaning that is often hidden in embodied intention. The somatic gestures and movement of people with dementia can often speak more articulately than their words, especially as these become more difficult to recall in dementia’s later and final stages. Embodiment as it is related to consciousness is vital to the wholistic appreciation of the phenomena made available to the researcher.

**Towards a phenomenology of the body**

Merleau-Ponty’s book, *Phenomenology of Perception* (2002), describes a phenomenology of the body that emphasises the incarnate character of human existence (Levine, 2009). Merleau-Ponty insists that the human body
is the primary means by which the human being knows and becomes conscious of the world. He believes that the body is not just an object, but an important part of the openness to the world that informs perception and consciousness. This theory is borne out by the experience of the young child who learns to walk - she never actually gives up. Once verticality is achieved, the child can learn to stand upright throughout the challenge of its attainment over and over again.

Levine (2009) compares and contrasts the views of bodily expression of Merleau-Ponty, a philosopher, and Lacan, a psychoanalyst. Both of these French theorists have been influential in shaping contemporary European psychoanalytic and philosophical thought. However, whereas Lacan describes the notion of being as a "manque à être" - a lack in relation to being, or a want-to-be (Dews, 1999, p. 16), Merleau-Ponty sees bodily transcendence as "le corps propre" or "the lived body" (Levine, p. 122) and connects with Heidegger's Dasein or "being in the world" (1962, p. 84). Lacan's views derive from the child's view of her body in the mirror, which appears to be whole, but is in fact fragmented (Levine, 2009). In contrast, Merleau-Ponty starts from the position of the child's body taking hold of the world (2002) (my italics).

According to Levine, Lacan appears to be caught in the Cartesian dualism of mind and body, even though rejecting Descartes' concept of the ego as a substantial entity or "thinking thing" (Levine, p.122). He still locates subjectivity in opposition to bodily experience. Both Dews (1999) and Levine (2009) cite the non-pathological views of Merleau-Ponty in opposition to the Lacanian view which "projected back into the child's experience of the body the pathologies that are revealed in adult life" (Levine, 2009, p. 123).

For Merleau-Ponty, there is no radical gap or gulf between our openness to the world and the world itself. He sees the negativity implicit in the "manque" of Lacan as the "néant" of Sartre and Bergson, but contends that this is a "hollow", rather than a "hole". Dews states:

The significance of the metaphor of the hollow, or course, is that a hollow is not discontinuous with the surface in which it appears, and does not
allow a passage right through the surface to the other side (Dews, 1999, p. 17).

For Merleau-Ponty, the subject is to be understood “not as a nothingness...but as a unity of transgression or correlative overlapping of 'thing' and ‘world’” or as an écarts or space between the figure and its background (1962, pp. 245 and 254).

Merleau-Ponty’s work gives the dramatherapist significant information about gesture. His thinking reveals the importance of bodily gesture, where expression is not restricted to language. Levine (2009) argues that Merleau-Ponty’s concept of the "corps propre" or "lived body" is supported by his review of case-studies of brain-damaged patients. These show that in pathological cases, the unity of bodily experience is what is most severely disturbed. Neurological impairment prevents patients from enjoying the bodily sense of being. In cases where this is lacking, patients have to use their mental capacities to laboriously rebuild their existential situation. Oliver Sacks’ studies of the effect of neurological damage upon perception seem to confirm Merleau-Ponty’s analysis (Sacks, 1985).

Implications of the "embodied language" concept for work with people with dementia

In the case of dementia, it is interesting to reflect on laborious mental effort coming to the rescue through language, a circumstance which is often necessary for people who live with the condition in order to build their existential future. It is then useful to look at alternatives to this cognitive and speech-based struggle through the prism of embodiment. Merleau-Ponty argues that intentionality "does not come into being through the transparency of any (mental) consciousness, but takes for granted all the latent knowledge of itself that (our) body possesses" (1962, p. 233). This latent knowledge is a field of possible actions and movements the body "knows" how to perform, just as little children know how to get up off the floor and start again when learning to walk. In the case of adults, he gives the example of a scratch that needs to be itched, arguing that the scratcher bypasses the cognitive
conscious process in the action, relying on body memory to find the appropriate location of the scratch. Steiner (1989) calls this wisdom "the fingerprint on the etheric" (p.58). An understanding of the importance of this "body wisdom" gives the creative arts therapist a much better understanding of the significance of embodied practices for people with dementia (Coaten, 2011).

Hamilton (2008) gives an example from Kontos (2006), where she states that even when speech is incoherent and void of linguistic meaning, automaticity is displayed in the smooth and appropriate exchanges in "conversation" that consist of intonation contours that can (apparently) be "recognised, repeated, and/or responded to" (Hamilton, 2008, p. 101).

She quotes Kontos (2006) who describes the following interaction while two individuals with dementia were about to eat breakfast at two different tables in a long-term care facility's dining room.

Abe: [sat down] Bupalupah! [shouting]
Anna: [twisted around in her chair to be able to look at Abe]
Abe: [eyes wider, smiling] Brrrrrr! [shouting with rising to falling pitch]
Anna: Brrrrrr! [imitating volume and intonation contour]
Abe: Bah! [shouting, then pausing while looking at Anna]
Anna: Shah!
Abe: Bah!
Anna: Shah! [turned back around in her chair with her back to Abe]
Abe: Bupalupah! [shouting]
Anna: [raised one arm about her head, lowered it in a swift motion; both then began to eat breakfast] (Kontos, 2006, pp. 206–207).

Kontos (2006) claims that this exchange illustrates Merleau-Ponty's argument that "communication dwells in corporeality or, more specifically, in the body's capacity to gesture" (1964, p. 7). Importantly, the speakers
continued to exhibit intersubjectivity and displayed aspects of self-identity through their bodily posture and the repetition of syllables, volume, pitch, and intonation contours.

There is an immense danger of the therapist turning people with dementia into "the other", and falling into a power relationship which reinforces otherness. Foucault critiques this unhealthy relationship, calling on Nietzsche’s "will to truth" (Nietzsche, 1909, p. 5). Widder (2003) cites Foucault in his essay: Foucault and Power Revisited.

The modern will to truth, as Foucault’s genealogical works detail, seeks to define and delineate various forms of deviancy and delinquency in order to better police standards of normality and to compel individuals towards these nor against any resistances that might oppose this movement. In other words, it aims to secure the purity of an identity deemed to be good and healthy against identities that are defined as the opposite, as evil or sick, and in this sense it can be said to underpin a knowledge regime that “ties” individuals to their identities in constraining ways. (Widder, 2003. p. 12).

The "compulsion to norms" visited upon the elderly, as well as younger people with dementia, could well occupy a good deal of space in this chapter; however I shall save much of what I have to say for another place in this thesis. Nevertheless, there is a demonstrable rationale for a methodology (which does indeed belong here) which reduces the inequity of and equalises as far as possible the power relationship between a therapist and a person with dementia.

I am proposing that a phenomenological approach can assist in revealing truth, by using my own consciousness rather than a "will to truth" to appreciate the consciousness of others, and their unconsciousness as well.

My own definition of this methodology is as follows:

A methodology which aims to clarify, through human consciousness, the “true nature” of the phenomenon itself, and does not rely on empiricism and reductionist measures in order to do so. Corporeality and spaciality are also included in the methodology.

Thus, my particular approach to the dramatherapy work with participants encompasses and also includes the provisos that follow:
• The facilitator's own learning and experience is embraced by the methodology in a way that the extraction of hard empirical data cannot emulate
• The researcher enters into the phenomena, be it language, body language or affect, in tandem with the client
• Because of the transient and non-reductive nature of the assessment process, conscious post-sessional reflection is very much part of the process
• There is ample opportunity to "change tack" between sessions in order to give clients the chance to recover parts of themselves, depending on the appearance of new phenomena

At this point, having written about the true nature of the phenomena, it is pertinent to define what I mean by truth. Incorporated strongly within my ethics is the knowledge that I will not reach an absolute truth in this area. Consciousness as I understand it is an awareness and a cognisance of what is occurring internally and around me. For example, the character of an object – how and where it was made, its surfaces as well as its content and symbolic value – affect my relationship with that object in the world. In a personal relationship with another human being, an awareness of their personal story and their impact on my inner world affect my interaction with them in my search for authenticity.

My view of consciousness therefore differs from Husserl's consciousness of the world, incorporating as it does a consciousness of being in the world, and there is a tension here; however, consciousness for me includes movement and gesture, as well as voiced sound and language. Merleau Ponty's embodied consciousness or latent body wisdom is surely of some relevance here.

As already suggested, it is more than probable that my therapeutic judgement of the consciousness of others will from time to time miss the mark. This is partly because spoken language is not always involved (although of course verbal misunderstandings are probable too)! The client cannot, or does not choose to tell me in spoken language what his body is telling me, just as the object is silent about its patina or provenance. However, it is my firm belief that if I hold an attitude of openness,
contradictions will assist rather than hinder a wholistic and inclusive approach.

At the same time, as stated previously, I am working with a higher consciousness; also an ethical recognition of and respect for the higher ego of each person, as expressed by Steiner. This ego is not to be confused with the "little ego" of egotism, which is positioned in his discourse as diametrically opposed to the higher self. Spiritual presence seems to strengthen when people age (Moore, 1992; O'Neil and O'Neil, 1990). However, "suspending the demand" to seek this spiritual aspect of participants in the dramatherapy and just allowing them to be-in-the-world is also strongly advocated for this work!

**What would a phenomenological methodology elicit which could not be demonstrated by, say, biophysical evidence?**

Since the publication of Kitwood’s book, *Dementia Reconsidered* (1997), where he looks at the actual experience of dementia and how this plays out behaviourally for elderly people, there has been increased awareness of the value of person-centred therapy for this population. Although not clearly stated, Kitwood uses phenomenological methods to assist in defining remediable areas of distress for patients in aged care facilities.

McKeith and Cummings (2005) state in their phenomenological review and analysis of the various types of dementia, that behavioural and psychological symptoms of dementia (BPSD) have generally been thought to be of secondary importance to areas of physical function. New evidence, however, in the areas of neurology and pharmacology suggests that certain behaviours are important determinants of patients' distress, carer burden, and outcomes in dementia. Though they admit that pharmacological management is a commonly used option, it is often limited in its effects and can be associated with a substantial risk of side-effects. They recommend non-pharmacological interventions and include behavioural therapies, systematic changes of the care environment, exercise, and music instead.
From a phenomenological point of view, however, anecdotal material from many arts therapists, including dramatherapists, shows that a conscious connection on the part of the therapist can calm aggressive behaviour and allow for expression of grief, loss and other uncomfortable aspects of their feeling life. None of the questions asked about memory loss, loss of loved ones, dementia onset or failing abilities could be measured by neurobiological means, although these therapies certainly have their place. Insight and Theory of Mind have been successfully measured in fronto-temporal dementia through neuroimaging and phenomenological methodologies (Caixeta, 2001). Recent studies of the phenomenological experience and coping strategies of people with early stage Alzheimer’s disease (Clare, 2003) have demonstrated attempts to protect and maintain the sense of self and to integrate changes experienced to facilitate a modified sense of self (Clare, 2008).

Conclusion

A brief acquaintance with the provenance, history and qualitative nature of phenomenology as a choice of methodology has revealed advantages for dramatherapy with the elderly, in particular with those with dementia. The significance of the spoken word, of words left unsaid, as well as embodied language, movement and gesture have been considered in the choice of this methodology.

The tension between discourses of being-in-the-world on the one hand and Steiner’s spiritually conscious higher self and heart thinking on the other have, I hope, positioned my own views on consciousness and a regard for the phenomena that is simultaneously authentic, open and vulnerable.

In order to enter the world of the client in this population and to grasp as nearly as possible the experienced truths of conscious and unconscious behaviour as well as self-consciousness, qualitative measurement of this nature is essential. It will be significant to consider outcomes when they are placed side by side with neurobiological results, as it is the intention in my research in this area. Meanwhile, in the chapter that follows, the arguments
for triangulation of research with mixed methods are presented, introducing areas of discourse which shine a light on the polarities just discussed, of mainstream medicalised and wholistic treatment of people with a diagnosis of dementia.
Chapter 4: Mixed methods

Quantitative and qualitative research should never be thought of as opposites but rather as the right tools for performing two different kinds of job (Grainger, 1999, p. 76).

Not everything that can be counted counts, and not everything that counts can be counted (Cameron, 1963, p. 13).

Science is a process, not of deriving predictions from observations, but of finding explanations (Deutsch, 1998, p. 71).

This chapter includes an overview of the rationale for the mixed methods I have chosen. It will set out my hypothesis and research questions and will consider the value of the study. The chapter will include a discussion of practitioner research, the differences and similarities between therapy and research, and the quantitative and qualitative methods used. The literature search on the chosen methods for generating statistical research for the two-arm study will follow, as well as the results of the quantitative assessments. The methods chosen for qualitatively assessing the dramatherapy will also be described and discussed.

As stated in the introduction, the primary concern of the thesis is whether my research can demonstrate the efficacy of dramatherapy for a small group of people with dementia. The study hypothesises that experiential wellbeing and QoL can be achieved through dramatherapy. Wellbeing is understood as a positive feeling response which supports cognitive, psychosocial, spiritual and physical function, and assists in lessening the potential for critical incidents.

Three quantitative scales have been chosen to measure the mood, language, cognition and QoL of both groups in the two-arm study. Phenomenological research, incorporating narrative, ethnography and metaphor will provide data for qualitative findings. The Creative-Expressive Abilities Assessment (CEAA) (Gottlieb-Tanaka et al., 2008) as well as the Jones (1996) dramatherapeutic adaptation of the (1981) Sutton-Smith-Lazier Scale of Dramatic Involvement (JASDI) will be used to “quantify” the qualitative research.
Supplementary research questions

The questions below are intended to supplement and clarify the focus of this research. They address various aspects of the main focus of the thesis; that is, the efficacy of dramatherapy for dementia patients.

a) Can this study collect data that will contribute to an evidence base on dramatherapy as an intervention for older people with dementia?

b) What effect will this programme have on language retrieval and cognition over the 16 weeks in the group undertaking voluntary dramatherapy sessions, assessed using the Boston Naming Test short version (SBV-15) (Kaplan et al., 2001)?

c) Will mood improve for the participants in the dramatherapy group when assessed using the Geriatric Depression Scale for Alzheimer's Disease (GDS) (Yesavage & Brink, 1983)?

d) Will the quality of life of participants improve after 16 weekly sessions when measured against the control group with the Quality of Life Alzheimer's Disease (QoL-AD) (Logsdon, et al., 1999)?

e) Will improvements according to the qualitative assessments Creative-Expressive Abilities Assessment (CEAA) (Gottlieb-Tanaka et al., 2008) and Jones’ (1996) dramatherapeutic adaptation (JASDI) of the (1981) Sutton-Smith-Lazier Scale of Dramatic Involvement be transferable to other areas of the participants’ lives?

f) What can this research distinguish, from the experience and body language of the participants, which will provide insight into the journey of dementia and possibilities for improvement of the QoL of those with the diagnosis?

g) What can this thesis reveal with regard to the consciousness of participants with dementia by providing sixteen sessions of group drama psychotherapy?

h) How does this study provide information for researchers in the area, on the basis of this researcher's experience?
Value of the study

The value of this study is twofold. Firstly, it fills a gap in the literature on dramatherapy and dementia; literature which to date has provided very few studies using quantitative or mixed methods approaches. The more specific gap concerns literature on an elderly population who are suffering, in particular, from AD. In addressing this gap, the study aims to provide additional material to arts therapists, and to contribute to developing research priorities and guiding future studies in dramatherapy.

The second aim of the research is to broaden the debate about dementia in the community by challenging dominant views of it. The dominant view is that people with dementia are no longer living a fully human life and that pharmaceuticals are necessary to reduce symptoms. However, the qualitative arm of my study reveals a high level of understanding and self-awareness on the part of the participants that is generally unrecognised in the pharmacological literature. It is hoped that dementia associations such as Alzheimer’s Australia (AlzA), a key organisation in dementia care, as well as prospective employers of dramatherapists in this area can be alerted to the role that dramatherapy could play in dementia care, with a view to allowing the expression of this understanding and self-awareness by clients. This small study could open up the possibility of a larger post-doctoral research study after the completion of my PhD.

Although this thesis is needed to address the gap in dramatherapy research, discussed above, some quantitative and mixed method research in dementia does exist in other arts therapies, for example, music therapy – in a Cochrane Review by Vinks, Birks, Bruinsma, and Scholten, 2003 – and art therapy: in a randomised control trial (RCT) by Rusted, Sheppard and Waller, (2006). Such studies have proved extremely useful in my research and practice. In Chapter 2, I discussed some of the literature which shows the benefits of dramatherapy on QoL, lifting mood and giving physiological benefits to elderly people with dementia (Casson, 1994; Chin, 1996; Grainger, 1995; Johnson, 1986, 1987, 1992 & 2000). In this chapter, I will
include a discussion of the quantitative art therapy RCT with participants who have dementia (Rusted et al., 2006).

**Why am I using mixed methods in this thesis?**

The emphasis on the carer perspective in dementia research

In light of the arguments that the issues of carers are put before those of people with dementia, mixed methods can make a significant contribution to the discourse. This claim has been mentioned elsewhere in this thesis and it is important that a research framework is chosen which does not mimic “our biomedical approach to dementia (through which) we have created care environments around the needs of well care partners” (Power, 2011, p. x). The focus on the well care partner may also be responsible for a confusion of authorship in the field; it has been suggested that “there is a mushrooming of personal narratives that are attributed to individuals with dementia”, the exact identity of the authors being unclear (Reid, Ryan, & Enderby, 2001, p. 378). A possible reason for this is that, since researchers on the whole find it difficult to do primary research with people who have dementia, much of their inquiry relies on information from carers. Dramatherapy then is ideally placed to build the trust necessary to give participants permission to share their stories – in the form of improvisation, projective work and roleplay – in the absence of immediate carers or family members, as in the case of this research project.

In the Alzheimer’s Society Report (2010a) *My name is not dementia*, the following statement is telling in this regard:

*Studies involving in-depth qualitative research with people with dementia remain the exception and studies involving people with dementia from seldom heard groups are even rarer* (p. 8).

Some researchers have the best of intentions, with studies bringing carers together with their clients or family members to do creative work (Lepp et al., 2003). Other researchers have used theatre to try to increase minority participation in research (Fritsch, Betts Adams, Redd, Sias, & Herrup, 2006). Even so, I have found that carer information predominates in the area of
assessment. Often carers' advocacy for their clients or family members can induce them to present a more negative picture of the condition of those they care for, sometimes in order to access funding. Thus carers' assessments are by no means clear-cut.

One remedy for the tendency towards carer-driven research projects is to use the advantages of a particular approach to balance the deficits of another (Johnson & Onweugbuzie, 2004) and to more effectively support the findings, and indeed this is one of the reasons why I have chosen to design my research using mixed methods. Other researchers believe that a qualitative approach is more relevant to the clinical practice of arts therapy (Rogers, 1995; Tüpker, 1995). It is nevertheless significant that if a qualitative approach is slavishly followed, the wider healthcare research community, who use EBP models, may not recognise the effectiveness of arts therapy (Pothoulaki et al., 2006). EBP combined with high standards and a flexibility of approach has important consequences for many clinical practitioners who want to apply the results of research in the general area of health where the biomedical model is strongly supported (Evans, 2003).9

The optimum approach from my own point of view is a mixed methods inquiry at the very least; so that biomedical researchers begin to qualify as well as quantify their studies and are made more aware through the process that subjectivity will always be present in them.

**Mixed methods and integration**

Bazeley (2010b) broadly defines mixed methods as including studies where more than one methodological approach is selected for one identified purpose, whether or not these methods are defined as qualitative, quantitative or somewhere in-between. I am in agreement with her when she understands the integration of more than one paradigm as "having a sum greater than the parts" (p. 1). Greene (2007) takes a dialectical approach, celebrating tensions arising between the various methods, adding that this

---

9 Significantly, EBP can also be "slavishly followed" according to Grace and Everard. "To follow evidence-based medicine slavishly without interpretation in the context of your own practice environment is akin to flying a plane on automatic without a pilot." (2001, p. 723).
could lead eventually to a more profound understanding of the research data. In this thesis, the integration of various methods is intended to create a strong conclusion, reached through holding certain findings from one paradigm in tension with another, as in the discussion of participant change scores in Chapter 9.

Therefore the definition of mixed methods used in this research is as follows:

*research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry* (Creswell, 2007, p. 4).

An apparent lack of integration, in the language used for example, can present problems for researchers, particularly where improved findings could have resulted if all or both kinds of data had been merged (Bazeley, 2010b). One of the difficulties I have found concerns the language associated with qualitative and quantitative research; there is an extreme contrast in the language used to express statistical and phenomenological results. I have overcome this by employing two distinctive roles as author of the thesis, as I will describe later in this chapter.

**Phenomenological considerations**

As already discussed in Chapter 3, a phenomenological approach to the research is helpful to document the participants’ experience of dramatherapy, especially their intersubjective and unspoken/embodied experience. The quality of the relationship and the connections between therapist and participant are paramount in accompanying the journey of the individual (Grainger, 1999) and this concept is well-served by phenomenology. Analysis through ethnography, narrative and metaphor can uncover subtle areas of experience in participants which are not generally obvious or visible when using quantitative measures.

I am in agreement with Creswell who puts forward the phenomenological approach to research as one of his five favoured traditions for qualitative research (Creswell, 1998). He says that one of his criteria for this choice of five qualitative traditions (biography, phenomenology, ethnography, grounded
theory and case studies) is that each of the five illustrates a representative picture of approaches in the discipline being researched. Since I have already outlined my choice of a phenomenological approach to this thesis in Chapter 3, there is no need to repeat it here. Nevertheless, philosophy and psychology (two great interests of mine since the age of sixteen) are disciplines from which Creswell believes phenomenology actually emanates. While my interest in psychology is of a psychotherapeutic rather than an "experimental" nature and I question the idea that any approach can be free of ontological and epistemological assumptions, I believe my approach still fits well within Creswell’s primary choices of research design.

Triangulation

This method was originally popularised by Webb, Campbell, Schwartz, and Sechrest (1966) who advocated that:

\[
\text{once a proposition has been confirmed by two or more independent measurement processes, the uncertainty of its interpretation is greatly reduced. The most persuasive evidence comes through a triangulation of measurement processes (p. 3).}
\]

Bazeley (2010) suggests that triangulation is a surveying metaphor, and from this standpoint argues, through examining the mathematical procedures involved in land surveys, that it is an approach in which a complementarity of ways – rather than a corroboration of approaches – enables the researcher to reach a conclusion. This may well be true; however in a small study like this one, I suggest that both arguments are true. There is likely to be a small corroborative element between the approaches and a greater complementarity.

As explained in Chapter 3, triangulation is part of the chosen design for this research because I believe that this choice allows for the essential qualities and strengths of the methods used to support one another. As Andrea Gilroy writes of researching case studies in art therapy using the art work to triangulate,

\[
I \text{ agree with McLeod’s (1994) suggestion that the strongest case studies are systematic and pluralist, combining qualitative and quantitative data, the essential story-telling with outcomes, and of course including art therapy’s added extra of visual material (Gilroy, 2006. pp. 100-101).}
\]
This statement applies to my thesis which triangulates visual material against qualitative and quantitative data as well as the gathering of thematic information which communicates the experience of the dramatherapy group. Written material is also included; however photographs of individuals are excluded, as permission was not given to identify participants.

A second reason for using triangulation is its robust function as a methodological (and not necessarily land surveying) metaphor, smoothing the researcher’s path in attempting to clarify her theoretical hypotheses since it goes some way to addressing the binary between qualitative and quantitative enquiry. In healthcare especially, where the phenomena for study are so complex, triangulation can offer an appreciation of the connections between theory and empirical findings, challenge conventional ideas and help to develop new ones (Oestlund, Kidd, Wengstroem, & Rowa-Dewar, 2011).

Creswell, in his editorial comments introducing the first issue of the Journal of Mixed Methods Research (2007), records a search of academic databases which identifies a variety of studies in the health sciences as well as in the social and behavioural sciences under the explicit rubric of “mixed method”. It appears they were considered "mixed" because they used the two research approaches in "one or more of the following ways" (p. 4):

1. two types of research questions (with qualitative and quantitative approaches)
2. the manner in which the research questions are developed (participatory versus preplanned)
3. two types of sampling procedures (e.g., probability and purposive, see Teddlie and Yu, 2006),
4. two types of data collection procedures (e.g., focus groups and surveys),
5. two types of data (e.g., numerical and textual),
6. two types of data analysis (statistical and thematic), and
7. two types of conclusions (emic and etic representations, “objective” and “subjective”) (Creswell, 2007, p. 4).
I suggest that all but the third of these approaches are of relevance to this thesis. Firstly, the quantitative and emergent types of research questions are set out early in this chapter. Secondly, the manner in which the research questions were developed has been pre-planned. The third approach, as mentioned, is not relevant. Fourthly, there are two types of data collection procedures, self-assessment and observation. Fifthly, two types of data were collected: numerical and textual. Sixthly, statistical and thematic/metaphorical analyses were carried out; the observational assessment, CEAA (Gottlieb-Tanaka et al., 2008), is used both statistically and thematically. And finally, the seventh approach is also true of the emic and etic conclusions abductively reached in this thesis.

Returning to the topic of triangulation, Creswell's (2007) advice underpins not only my rationale for choosing this technique, but additionally brings together the phenomenological enquiry with the statistical analysis and forces me to examine my attitudes to them on many levels. With reference to the "two types of data" producing "two types of conclusions" (2007, p. 4), the thesis needs triangulation to work out whether the data and the findings support one another. My process of triangulating the methods on a phenomenological, symbolic and metaphoric level allows comparison and merging with the statistical analysis (see Chapter 10). It goes without saying that neither qualitative or quantitative research alone could have provided an arena for sorting through the various metalevels of enquiry in the same way to seek an amalgamated and synthesised conclusion. Triangulation allows for the invisible to be revealed and strengthened by statistical analysis.

The pragmatic approach

Pragmatism has a history, which stretches from 1860 to 1930 and neopragmatism from 1960 to the present (Maxcy, 2003). Emanating from the ideas of John Dewey, William James and George Herbert Mead (Cherryholmes, 1992), the pragmatic approach helps researchers to remind themselves of their own values and politics and how these connect with philosophical concerns (Morgan, 2007).
Some mixed methods theorists make firm connections between mixed methodology and pragmatism (Maxcy, 2003; Johnson & Onwuegbuzie, 2004). Like mixed methods, pragmatism takes a median position from a philosophical standpoint and suggests an action-based level of enquiry that is interested in outcomes (Johnson & Onwuegbuzie, 2004). Biesta (2010) argues that

*pragmatism...has some important things to offer, particularly in helping mixed methods researchers to ask better and more precise questions about the philosophical implications and justifications of their designs* (p. 114).

Johnson, Onwuegbouzie and Turner (2007) argue that pragmatism offers researchers the opportunity to use a number of different methods to integrate various approaches. It allows them to work through "the combination of methods and ideas that helps one best frame, address, and provide tentative answers to one’s research question(s)" (p. 125).

My research fits well within this paradigm since the applied reasoning in this type of research is abductive, as opposed to the deductive of the quantitative or the inductive of the qualitative methods. The New World Dictionary's explanation of abductive reasoning is as follows:

*Abduction, or inference to the best explanation, is a method of reasoning in which one chooses the hypothesis that would, if true, best explain the relevant evidence* (New World Dictionary, retrieved February 1, 2013).

**Quantitative research for this thesis**

The written style of this section of the thesis changes somewhat. Just as I have taken on a particular role in the playscript, as well as a role as myself in one of the personal narratives, my role in the area dealing with statistical evidence changes in nature and style. I am no longer using the first person singular here, as I wish the evidence-based material in the exploration below to be aligned with the generally accepted ways such research practice is presented.
Exploration of the preferred method of quantitative assessment

*The choice of the individual scale relies specifically on the question to be asked* (Burns, Lawlor, & Craig, 2002, p. 161).

The practice of dramatherapy in the mental health sector has administratively required the use of evidence-based practice (EBP), the requirement being partly informed by a desire to make "alternative" practices more acceptable to medical staff. For a health professional in the mental health area, it has been essential to assess groups in this way. For example, in a project inquiring into the efficacy of dramatherapy with people with co-morbid substance abuse, the Rosenberg Self Esteem Scale (Rosenberg, 1965) was administered, as well as measures from the Dartmouth Psychiatric Research Centre (Mueser, Drake, Clark, McHugo, Mercer-McFadden, & Ackerson, 1995) for evidence-based work on dual diagnosis (Jaaniste, 2008). The former scale comprises a short set of questions asking five positive and five negative questions about confidence. The latter scales are clinician-rated measures for alcohol and substance intake which elaborate changes in patterns of substance abuse pre- and post-group sessions.

Studies based on EBP in the area of dramatherapy with people with dementia are rare. A Cochrane Review has been undertaken with clients with dementia in the area of music therapy (Vink et al., 2003). The only existing Cochrane Review of dramatherapy has surveyed its use for schizophrenia, or schizophrenia-like illnesses. This latter review included all randomised controlled trials that compared dramatherapy, psychodrama and related approaches with standard care or other psychosocial interventions for such illnesses. Some data was excluded because more than half the participants discontinued and could therefore not be included in follow-up. The results were disappointing, since although 183 references were identified in the research, only five studies – of inpatient populations – met the reviewers’ criteria. Engagement in treatment as an outcome of the interventions was rated poorly, and because of sub-standard reporting, minimal data from the five studies could be used. Conclusive findings about the benefits or disadvantages of dramatherapy for participants with schizophrenia were not
apparent. Jones (2012) comments in connection with this review that collaboration within the dramatherapy profession needs to be fostered in order to increase research publications and build our EBP.

Quantitative research and its critics
An understanding of positivist psychology as well as neo-positivism and post-positivism are all necessary in conceptualising the quantitative framework for this research. Holding that the scientific method is the optimum means of measuring differing human behaviours, Auguste Comte maintained in the 19th century that we could predict outcomes through an understanding of science, and that action would necessarily follow. Comte, regarded by some as the father of sociology (Martineau, 1853), saw his approach as replacing theology and metaphysics. He believed that research could only be assessed by empirical data and recommended a quantitative approach to decision-making. This led to the behaviourist paradigm in psychology and also to an emphasis on replicability and reliability.

In Comte’s approach, it was assumed that there are patterns and outcomes which can always be replicated, given the same conditions. Post-positivist philosophers of science, led by Karl Popper, critiqued the notion that a belief can be established as true, and the critical realists who followed him objected to the notion that observation is infallible and recognised that all theory is revisable (Popper, 1959). We are seeing examples of such scepticism in 2013, as discoveries in neuroscience lead to disputes, for example, over the permanency of post-stroke paralysis. Instead, neuroscientists have discovered that through the mirror neurons’ ability to use imagination, physical movement can be re-engaged (Doidge, 2007).

Because of the potential revisability and fallibility of measurement, triangulation has been used across multiple areas of research – research which may contain errors – to get a better sense of what is actually happening. As I have said, it is with triangulation in mind that I am using qualitative and quantitative measures in this project. I believe this mix to be more accurate than a single quantitative approach, and the inclusion of
qualitative research has been chosen because of the impossibility of separating the subjectivity of the researcher from the research.

**The case for a randomised control approach and the art therapy experience**

The case is currently being built for stronger and more vigorous research in the creative arts therapies. In a recent article (Burton, 2009) which grouped studies of art therapy, drama therapy, music therapy and dance therapy, the almost exclusively observational and anecdotal evidence for the efficacy of arts therapies is regretted and a multi-centre, randomised controlled trial (RCT) of art therapy with people with dementia (Rusted et al., 2006) is lauded. Burton’s article was apparently written to alert all creative arts therapists to the importance of this polarity in research. He also refers to the Cochrane Review of music therapy for people with dementia (Vink et al., 2003) mentioned earlier. The Rusted et al. article is praised but the lack of methodological efficacy in five RCTs in the Vink et al. Cochrane Review is criticised. In this chapter I explore both Burton's article and the Review in order to assist me in the design of my own research project.

Burton makes the case for more rigour in the measurement of arts therapy interventions. He quotes Waller, a veteran and key researcher of the art therapy fraternity, describing the role of a new institute, the International Centre for Research in Arts Therapies at Imperial College, London, UK:

*The fact that art, music, and drama therapy are statutorily regulated in the UK, and that dance movement therapy shortly will be, demonstrates that they have met rigorous criteria in terms of there being a body of knowledge...*(and yet) *despite the enthusiasm among practitioners to carry out research, there has been virtually no coordination or high-level lead to ensure that sound projects are designed. Projects do not have to always be randomised studies or use quantitative methodology, but they do need to be very vigorous. Bringing more rigour into this area is what this new institute is about* (Burton, 2009, p.784).

Waller is one of the contributors to the multi-centre project mentioned above, which measured an art therapy intervention with people with dementia using an RCT design (Rusted et al., 2006). In their study, the forty-five people with dementia who met the inclusion criteria had diagnoses of mixed origin,
encompassing people with AD, multi-infarct dementia and unspecified dementia. The decision made with regard to selection of volunteers, therefore, appears to "muddy the waters" of the results. The multi-centre nature of the study is also ambivalent, as facilities included a day resource unit in a hospital, a privately owned rest home, and a rest home as well as a resource centre funded by social services. Clients were therefore either in long term care or day users.

In this study (Rusted et al., 2006), art therapy and activity groups took place in parallel in each centre over forty weeks. Group-interactive, psychodynamic methods were used in art therapy, and the activity groups were run by occupational therapists (OTs) who were instructed not to use formal OT methods or art/craft work in these control groups. Following the sessions, measures used were the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoiam, 1988), the Multi-observational Scale for the Elderly (MOSES) (Helmes, 1988), the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), the Rivermead Behavioural Memory Test (RBMT) (Wilson, Cockburn, & Baddeley, 1985), Tests of Everyday Attention (TEA) (Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994) and the Benton Fluency Test (BFT) (Benton & Hamsher, 1980). Within-session measures were the Bond-Lader Mood Scale (B-LMS) (Bond & Lader, 1974) and various subsets of questions to assess cooperative, agitated or anti-social behaviour within sessions.

An increase in depression over time in the art therapy group was recorded, in comparison with the control group, as reflected in both the CSDD and the MOSES, and there was no recorded difference in the MMSE. There were no group differences or changes over time reported for any of the measures of cognition, memory or attention (RBMT, BFT or TEA). The high depression scores rated on the CSDD at the end of nine months in the art therapy group are interpreted in an addendum in various ways: a) they coincided with the beginning of discussions about finishing the group; b) they represented a contra-indication for art therapy (thought to be unlikely on the basis of feedback from other art psychotherapists working with this group) and c) they
may have been affected by a possible growing negative perception of art therapy by key workers who were asked to rate their clients’ behaviour, for their own institution, over a particular period.

On the MMSE, RBMT, BFT and TEA, there were no group differences or changes over time; however, the B-LMS picture was very interesting. For the art therapy group, scores in mental acuity, physical involvement, sociability and calmness increased/improved over time, while in the activity group they decreased over time. The authors felt that all of the standardised measures selected met all the criteria for validation and reliability as reported in their original verification studies; however, this was the measure that produced the most compelling evidence for change through art therapy.

On the basis of the Rusted et al. study (2006) and in the light of the hypothesis that dramatherapy might improve the quality of life of people with dementia, it was at first thought that two groups could be randomised: one to participate in dramatherapy and the control group to participate in sessions of information or discussion. However, when it became obvious that there would not be sufficient participant volunteers at the chosen facility in Sydney of Alzheimer’s Australia (NSW), (AlzA), it was decided that a control film-watching group be organised at the Newcastle branch of that organisation.

The project then became a two-arm study, since allocation to the dramatherapy or film group was no longer based on a random coin toss approach but instead determined by the location of their residence. The Newcastle-based control group viewed films on sixteen occasions. The dramatherapy group met on sixteen occasions in Sydney. Both groups were assessed pre- and post-sessions.

It is essential to refer at this juncture to a small quantitative study carried out in 2009 by Mechael, Graybow and Cobham-Baobab, creative arts therapists, to research the effects of dramatherapy on two groups, each with 4 participants who had dementia, accessing Rusted’s advice on the research method. Their research showed “significant improvements in quantitative measures of attentiveness and engagement compared with those taking part in the activity group” (Mechael et al., 2009, p. 27). The authors claimed, in a
“Clinical Comment”\textsuperscript{10} in the journal \textit{Dramatherapy}, that their method was "similar to a Randomised Control Trial (RCT)" (p. 27) although admitting that the assessors were aware of the identity of group members, possibly influencing their interpretation of the data. Measurement appears to have been made by self-devised scales, rather than well-validated scales, as in the present study. Overall numbers were smaller than in the present research and there was no mixed methods inquiry in this case; also, two of their assessors dropped out before findings were made. It is interesting to note, however, that the results of their analysis support conclusions in this thesis (see Chapter 11). Their goal in supporting purpose and engagement towards the end of life also aligns with this research.

**The case for and against the use of biomarkers in this research**

It was at first considered that biomarkers could be used to track changes in the wellbeing and therefore the QoL of people with dementia. The history of dramatherapy assessment and evaluation has not included any of this type of evidence that I could discover, and it would have been a matter of "working in the dark" to some degree. There is little evidence of such studies in any of the arts therapies, although Virago (2007) chose to measure her participants, who were suffering from melanoma, through the use of biomedical markers to test the robustness of their immune systems after art therapy. She had a dilemma around this choice of evidence mechanism, and as she says:

\begin{quote}
A dilemma with which I have had to struggle is a tenacious hold to a mechanistic worldview dominant in the biomedical sciences which is at odds with both my personal philosophy and experience of interconnectedness, and the unfolding understanding and acceptance of the complexities of life which is reflected in such areas of research as consciousness and its lack of defined locality. My research illustrates that issue, because I have chosen to measure discrete physiological functions, in concert with psychological questionnaires, which adheres (sic) to a positivist ideal, while I recognise these discrete functions as transitory measurements in a complex system. In tandem with these quantitative measures is an illustration of a whole-body process, with a distinctly interpretive and phenomenological bent, as evidenced in the art psychotherapy process (Virago, 2007, pp. 110-111).
\end{quote}

\textsuperscript{10} Clinical Comments in the journal \textit{Dramatherapy} are not peer-reviewed and there is no reference list for this article.
From the outset my exploration of biomarkers was a difficult one for me; however, a literature search was pursued in which it was possible to discover certain deficits of knowledge in terms of biomarkers and dementia research. The intention of the search was to plan a sub-study which might show the efficacy of dramatherapy with this population, depending on the outcome of the inquiry. The sub-study was planned to take place simultaneously with other dramatherapy group research which would be measured qualitatively. When possible difficulties with the use of biomarkers in the assessment of people with AD arose therefore, it was decided to concentrate on more traditional neuropsychological and other clinical scales and measures. Some of these difficulties are identified below.

As a non-scientist, I was influenced by the following definition of a biomarker:

...a biological signature objectively measured and evaluated that is an indicator of normal biologic processes, pathogenic processes, or a pharmacologic response to a therapeutic intervention, and that adds value to treatment development. A biomarker might involve the analysis of a body fluid such as blood, cerebrospinal fluid (CSF), or urine for a specific molecule, or it might be a brain imaging measurement’ (Lyketsos, Szekely, Mielke, Rosenberg, & Zandi, 2008, p. 872).

Lyketsos et al. (2008) reviewed an approach to the use of biomarkers for the development of new treatments for AD. Their article informs readers of what is generally known about the biology of the disease, highlighting currently available treatment. The treatment involved the analysis of a body fluid (such as cortisol), or a brain-imaging measurement. Galasko (2004) points out that somatic markers (of a body fluid) could play a role in differential diagnosis or aid following the progression of the disease. (Following the progression of the disease is more pertinent for the purposes of this study, since diagnosis is outside the area of this thesis.) Galasko says that biomarkers can have a strong influence on the progress of dementia, and in particular on the effects of disease-modifying treatment. He believes these changes must correlate strongly with meaningful clinical changes that result from treatment, and that the mechanism by which the treatment affects the major clinical outcome(s) should ideally be the same mechanism by which the treatment affects the biomarker.
The literature search into biomarkers in therapy, principally for salivary collection, proved to be reasonably useful in terms of possible positive outcomes for physical exercise. (Salivary collection appeared to be the least expensive and intrusive of various tests available for the measurement of body fluids.) As already pointed out, there are very few available examples of arts therapy interventions where biomarkers have been used. However, certain experiments have taken place with muscle stretching and aerobic training. There are factors here which align themselves with dramatherapy, where participants are frequently required to move around, exercising muscles and engaging in somatic movement.

In a research project involving 15 control and 18 untreated subjects, all with irritable bowel syndrome (IBS), participants were required to undergo tests using salivary physiological stress markers induced by muscle stretching (Hamaguchi, Fukudo, Kanazawa, Tomiie, Shimizu, Oyama, & Sakurai, 2008). Salivary Chromogranin (CgA) levels were compared between controls and IBS subjects before and after stretching. The rationale for the research was that, because IBS is associated with both psychological and physiological disorder in patients, abdominal muscular stretching was considered a positive method for relaxation. Specific psychotherapy was not considered cost-effective. Salivary samples were collected immediately before and after stretching. When evaluated, the stress marker CgA was found and analysed. It showed that CgA levels, higher in IBS subjects than in normal individuals, became comparable with that of control participants after stretching.

Understanding of the circadian rhythm was important for the timing of the research, and a limitation of the study put forward by the authors was that medical history and lifestyle can affect many stress-related biomarkers (Schell, Theorell, Hasson, Arnetz, & Saraste, 2008, cited by Hamaguchi et al., 2008). This observation led to a research inquiry of circadian rhythms and levels of cortisol in people with dementia and AD in particular. The additional complication of circadian rhythms, which were at best arrhythmic and at worst erratic, plus my own lack of experience in the use of biomarkers
indicated that this was not the optimum area to pursue for the purposes of this study.

Many studies have measured levels of cortisol in elderly adults “with and without pathology” and have found that salivary cortisol levels are increased in patients with AD (Blennow & Hampel, 2003; Giubilei, Patacchioli, Antonini, Sepe Monti, Tisei, et al., 2001). Arsenault-Lapierre, Chertkow, and Lupien (2010) found substantial seasonal variations in bodily cortisol in both people with AD with moderate cognitive impairment (MCI) and in controls. They concluded that the results of their study show that there are serious methodological implications for showing the existence of seasonal variations in cortisol levels. Clinically, they reveal that, since the deleterious effects of chronic exposure to high levels of cortisol in the ageing process have been reported (Lupien, de Leon, de Santi, Convit, Tarshish, & Nair, 1998), attention should be given to these seasonal factors as well as to variations between AD, MCI and controls.

Twombly (2006), when reporting on the variations in uses of biomarkers in the diagnosis and treatment of cancer, presents the challenge of biomarkers as follows:

   A serious issue in biomarker research is introduction of bias into the experiment through different variables that can skew the results (Twombly, 2006, p. 11).

In the light of the small size of the study being considered here, this seems to be a statement that applies to the area of dementia.

As already stated it was decided, on the basis of potential bias and variability in cortisol levels in participants of this study, that any quantitative measures undertaken in this research would be by means of neuropsychological and other scales.

**Literature search for scales and measures**

A literature search was undertaken in order to define the appropriate method for the quantitative aspect of this research which sought to illuminate the impact of dramatherapy on QoL for people with dementia. Quantitative data
was to be generated using rating and outcomes scales measuring mood, language, cognition, memory and QoL assessed at baseline and at the end of the research.

The literature search targeted mood, cognition, language and QoL, and looked at outcome measures for pharmacological treatment of depression and associated symptoms of dementia generally (Libon, Xie, Eppig, Wicas, Lamar, et al., 2008) as well as for non-pharmacological interventions. The search focused on measures used in Libon’s study as well as others, together with the rationale for their use. Assessments using scales and measures, or alternatively a lack of quantitative data, in the arts therapies and associated complementary therapies were also investigated. As previously indicated, creative arts therapies in particular share many perspectives with dramatherapy.

For the purposes of this research, measures for cognitive ability, mood, verbal fluency and QoL were selected, since QoL depends on our thinking capacity, emotional life and ability to communicate. QoL scales were searched as a source of comparison and to measure how dramatherapy adds value to clients’ lives over and above these abilities.

**Mood**

Mood is extremely important for people with AD, as it gives a strong indication of the presence of depression. Therefore, it is crucial to work with a measure which gives an assessment of mood changes within a session. Of elderly people, 40-70% have a mood disorder, and 15-25%, a major depression (Ghika, 2002). There is evidence that even though Depression in AD (dAD) has similarities to Major Depressive Disorder (MDD), it has a unique clinical character. According to Kozauer and his colleagues, dAD includes "symptoms of irritability and social isolation/withdrawal" (Kozauer, Rosenberg, & Lyketsos, 2006, p. 2), once again indicating changes in mood.

The Geriatric Depression Scale (GDS) (Yesavage & Brink, 1983) was selected, as it was developed explicitly for older adults and has been extensively researched and applied in clinical settings. Several studies have
examined the discriminate validity of the GDS by comparing scores from depressed and non-depressed older adults (reviewed by Montorio & Izal, 1996). In comparison to other screening tools, sensitivity and specificity are quite good for this measure (McDowell & Newell, 1996).

The DSM-IV-TR (American Psychiatric Association, 2000) "five or more" criteria for major depressive illness include synonyms for or paraphrases of disturbances of mood, cognition, language and QoL. Dramatherapy has the potential to counteract certain deleterious effects of such symptoms through working with activity which requires connection and mirroring, movement and spontaneity. Since there is a distinct connection between these active elements and QoL for elders who are close to the end of life and often more introspective than people at other stages, this is an essential element for their wellbeing. It goes without saying that physical involvement brings activity, which is also beneficial.

In the previously cited art therapy RCT for older people with dementia, Rusted et al. (2006) collapsed data across five week time bins in a 40-week programme, using the Bond and Lader Mood Scale (BLMS) (Bond & Lader, 1974). Their aim was to test the premise that participation of people with dementia in art therapy groups effects significant positive change in mood and cognition. The BLMS tests were administered both within sessions and later within the day care/residential settings. The control groups were activity-based, and the assessors used paired sample t-tests to examine data from each group at baseline and at termination. For the art therapy group, all four factors tested – physical involvement, mental acuity, calmness and sociability – showed significant positive changes between the first five and the last five weeks of sessions. This result was unlike that of the activity group where scores decreased. The project was cited as successful compared with other studies, which included a Cochrane Review music therapy research project where no methodologies were of acceptable quality for final conclusions to be drawn (Burton, 2009).

The BLMS (1974) is mentioned here because of its significant contribution to the art therapy study (Rusted et al., 2006). However, on perusal of the
original article it became obvious that this scale had been tested by the authors using subjects within an age range of 16-64 years, and that the aim was to rate changes of mood in the administration of the effects of drugs. It appeared to this researcher that a superior method would be to use questions which required yes/no answers on a scale with a history of validated use with people with dementia. A secondary reason for asking these questions was due to the researcher’s previous experience using the Depression Anxiety Stress Scale (DASS) (Lovibond & Lovibond, 1995) with people with depression and mood disorders, due to its availability and clarity of administration through yes/no answers. It is similar in design to the GDS.

Since this project needs to use scales that are as simple and easy to administer as possible, the GDS-15 was chosen for the research. The scale is a shortened form of the GDS, comprising 15 items (Sheikh & Yesavage, 1986) and only needs 7-10 minutes for administration. There is a set of questions for the client and one for the carer or family member. Some commentators believe the question: "Do you feel that your life is empty?" (appearing in both sets of questions) is the very best question for detecting depression in elderly care home residents (D’Ath, Katona, & Mullan, 1994). Whelan, Gaughran, Walwyn, and Chatterton (2008) tested this one-off question against the Cornell Scale for Depression, finding as expected that the latter scale had more specificity and sensitivity. However, when the answer to the question was "yes", more testing could be done on the person being assessed.

The value of the enquiry: "Do you feel that your life is empty?" for a mood scale, as an affirmative answer gives important information about the questionable mental state of the client, as well as information regarding relationships, communication and interests. A yes/no answer also appears much clearer than a choice between "Alert/Drowsy" or "Calm/Excited" in the BLMS (1974), which could be more confusing for people with dementia.

The GDS has been shown to be a valid and reliable measure of depression and is able as a self-report assessment to uncover mood and internal states that are not generally observable (Herndon, 2006). It is also in the public
domain, as attested on the questionnaire for the GDS-15 (Thomas, 2009). It has been claimed by Herndon that the measure is easy to administer, needs no prior psychiatric knowledge and has been well-validated (Yesavage & Brink, 1983; Brink, Yesavage, Lum, Heersema, Adey, & Rose, 1982). In comparison to other mood assessment scales, for example the Dementia Mood Assessment Scale (DMAS) (Sunderland & Minichiello, 1996), the GDS is simpler to administer and avoids such topics as psychosomatic illness and receptive cognitive capacity. These would be difficult to address for many clients. The Mood Scales - Elderly (MS-E) (Raskin & Crook, 1988) rate well on validity, but take 25 minutes to administer, which would diminish compliance (Burns, 2004).

The psychometric properties of the GDS-15 are excellent. Test-retest reliability was shown to be high (.84 to .85) in cognitively intact older individuals (Mui, Burnette, & Chen, 2001). Parmelee, Lawton, and Katz (1989) report that 1-year reliabilities were high with nursing home and congregate apartment residents: (.86) in cognitively intact as well as impaired individuals. They also quote the cross-validation of the GDS and the DSM-III-R (American Psychiatric Association, 1987) correlated at (κ = .42) in complete agreement on level of depression, and at (κ = .52) on presence versus absence of depression.\(^\text{11}\)

**Language retrieval and cognition**

The DSM-IV-TR (APA, 2000) definition of dementia states that the client with the disease has memory impairment as well as one of four cognitive disturbances. These include aphasia, or the loss of a previously held ability to speak or understand spoken or written language, due to disease or injury of the brain. Language and cognition are important aspects of functioning; disruption in both areas are both common outcomes of dementia.

The Boston Naming Test (BNT) (Kaplan, Goodglass, & Weintraub, 1983) has been selected for language and cognitive assessment and there is a shortened version of the scale which takes less time to administer. It tests

\(^{11}\) The GDS scale and score sheet can be found in Appendix 15.
short term memory, general cognitive ability, word retrieval and word recognition with cues provided for recognition errors. This version is variously known as the BNT-15 or the SBV-15 (Shortened Boston Version-15). For the purposes of this analysis, it will be known as the SBV-15. It has been well standardised across ages 25-97. The BNT consists of 60 line drawings of items ranging from highly frequent items at the beginning of the test (e.g., tree, pencil) to less frequent items at the end of the test (e.g., sphinx, trellis). Participants are asked to name the items.

The short version (SBV-15) has been chosen because it is simple to administer and because language retrieval and short term memory strength add to the QoL of the participants and their measurement can validate the dramatherapy work. It is hypothesised that the social nature of the group work, as well as the psychotherapeutic element may enhance the linguistic ability of the participants. This measure is often chosen as an assessment of cognition in batteries of neuropsychological tests (Kozora, Emery, Kaplan, Wamboldt, Zhang, & Make, 2008) or for reliable measurement of cognitive ability (Sachs, Lucas, Smith, Ivnik, Petersen, et al., 2012).

It has been shown that the SBV-15 has worked well with Spanish participants of a low educational level, and that results are consistent with the MMSE (Folstein, Folstein, & McHugh, 1975) as well as the BNT (Calero, Arnedo, Navarro, Ruiz-Pedrosa, & Carnero, 2002). This is important for culture and language diverse (CALD) clients as well as for ease of administration and compliance of those being tested.

The BNT appears to be superior to the FAS\textsuperscript{12} (Spreen & Strauss, 1998) neuropsychological measure for semantic fluency. The SBV-15 does not measure category fluency as the FAS does; however, Loonstra, Tarlow and Sellars (2001) searched the statistics in many studies using small samples where the FAS had been used, finding that differences may exist in verbal fluency results depending on age, gender and level of education. The SBV-15, however, is not as dependent on vocabulary knowledge gained through

\textsuperscript{12} This test requires the participant to write down as many animal names as possible which begin with F, A or S within a certain time frame.
education, since the picture stimulus for word retrieval provides a more generalised awareness than a sixty second abstracted search for words beginning with the letters F, A and S.

The psychometric properties of this shortened version of the BNT, the SBV-15, are excellent. The test re-test reliability of the SBV-15 was .84, correlating with the BNT-60 at .93, with 79 people diagnosed with mild AD or AD in combination with vascular dementia (Graves, Bezeau, Fogarty, & Blair, 2004). Criterion validity was examined between the full BNT and the SBV-15 and MMSE in a population of low-education elderly persons with dementia (Calero, Arnedo, Navarro, Ruiz-Pedrosa, & Carnero, 2002). Complete agreement between the short versus the long version was ($r = 0.855$) and between the short version versus the MMSE was ($r = 0.835$).  

**Quality of Life**

QoL, like cognitive ability, is a complex area because of the inherent problems in defining this term and the fact that it invariably means different things to different people. This difficulty is reflected in the manner in which psychometric properties of the chosen scale are expressed at the end of this section. Even though the "state of mood" question ("Do you experience loneliness...") in the GDS is seen to be sufficient to explore QoL by some (Holmen et al., 1999), there have been other authors who see QoL in dementia as having been largely ignored and worthy of much greater examination (Moyle, McAllister, Venturato, & Adams, 2007).

Wendy Moyle is an adherent of the person-centred paradigm which influences many of the arguments in this thesis. Connected with this paradigm, Brod, Steward, Sands, and Walton, (1999) indicate that the person’s own appraisal (rather than relying on objective observations) of their personal and environmental circumstances leads to the quality of life experienced by the individual. Person-centred care demands the centrality of subjective measures for the elderly (Merchant & Hope, 2004). The World Health Organisation in 1995 defined QoL as:

13 Since the SBV-15 scale is not available in the public domain, it does not appear in the Appendices.
...the individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards (World Health Organisation-QoL-100, 1995. Retrieved June 12, 2012).

The measure of quality of life in dementia, QoL-AD (Logsdon, Gibbons, McCurry, & Teri, 1999), does not reinforce pathology or limit QoL to absence of illness. Even though there are four qualitative levels of rating which range from poor to excellent, the 13 questions are phrased in simple language. They refer to physical health, energy, mood, living situation, memory, family, marriage, friends, self, housework, fun, money and life as a whole. The questions appear to be appropriate for people with mild to moderate dementia (describing the sample at AlzA) and the measure appears to be reliable and valid for individuals with MMSE scores greater than 10 (Logsdon et al., 2002). The measure is easily available, and has instructions for the interviewer to follow (Burns et al., 2004). The scale takes a maximum of ten minutes to administer, and appears to have psychometric validity, correlating with measures of depression, day-to-day functioning and pleasant events frequency. The questions on "life as a whole" and relationships with others tie in with the spiritual aspect which I have emphasised elsewhere in this research. The measure can be administered to caregivers for observational purposes, however the scoring is weighted towards the participant’s completed questionnaire, rather than that of their carer. It is considered suitable for this project, because it is dementia-specific and there is a likelihood that it will be sensitive to change after an intervention (Brod, Steward, Sands, & Walton, 1999).

The psychometric properties of this scale are considered strong. The test-retest reliability of this scale for reports both from patients with cognitive impairment and from caregivers was 0.83 to 0.90 (Logsdon, Gibbons, McCurry, & Teri, 2002). Convergent validity was examined by looking at patients’ depression levels as measured by the GDS ($r = 0.51$) and between the QoL-AD and a number of scales purported to measure elements commensurate with their quality of life. Specifically, concurrent validity of this scale with measures of depression assessed by the GDS was ($r = 0.51$) for
patients and ( - 0.52) for caregivers. The relationship between this scale and the Medical Outcomes Study (MOS) for day to day functioning was 0.22 for patients and 0.43 for caregivers. (Logsdon et al., 2002).14

Protocol and Design

Quantitative aspects of the study were designed with the above literature search findings in mind. The intention was to ascertain any measurable differences between the dramatherapy group and the film-watching group in the areas of mood, language, cognition or QoL. It was decided to offer participants each of the chosen scales (GDS-15, the SBV-15 and the QoL-AD) at baseline and after the 16 sessions. In this way, findings for pre- and post-group mood, language, cognition and QoL could be compared between the dramatherapy and the film-watching groups.

The researcher visited the Newcastle and Sydney sites on several occasions for four weeks before the group started once invitations to participants and their carers had been sent out and accepted (see section on participants below). In this way she could oversee the assessment process, which was assisted by an art therapy student and AlzA staff. The carer version of QoL-AD was given to family members and the participant versions of this scale, the SBV-15 and GDS-15 to participants only. No within-session observational assessments were given to the filmwatching group; the qualitative evaluation was carried out solely with the dramatherapy group in Sydney. This decision was made due to lack of funding and staff/student availability to carry out observations of participants. Consent forms can be found in Appendices 6-10.

Qualitative data was collected in the dramatherapy group for the CEAA (Gottlieb-Tanaka et al., 2008) and the JASDI (Sutton-Smith Lazier, 1981, adapted by Jones, 1996) which has been re-adapted for this study. The note-taking for phenomenological documentation, narrative and metaphor are

14 The QoL-AD scale for people with dementia and their carers can be found in Appendices 13 and 14.
described and discussed in Chapters 9 and 10 where there is further description and discussion of these two scales.

Participants

Originally the intention was to have at least 16 participants with dementia, all with a similar diagnosis, for an RCT trial. It soon became clear, as mentioned earlier, that this was not practicable. As in the Rusted et al. (2006) study, participants with exactly the same diagnosis and level of dementia would not be forthcoming. It was explained to me that not all the people with dementia who attended the AlzA venue had expressed an interest in joining groups. It would therefore be wise to try to invite volunteer participants who had already taken part in the "Living with memory loss" groups in AlzA, Newcastle as well as in AlzA, Ryde. This would mean a greater likelihood of my finding my enrollees from a list of eighty possible names and it would ensure that candidates for the programme would be people with mild or moderate dementia. The memory loss programme does not accept participants with a diagnosis of severe dementia. It was at this point that it became obvious that the RCT would not be possible, since randomisation of participants was not feasible, since they lived in separate cities.

It was agreed at a first meeting at AlzA that the research would be welcomed. The inclusion criteria was a diagnosis by a medical practitioner of dementia of mixed origin, although by far the largest cohort of participants had been diagnosed with AD. Of the eighty people who were contacted, seventeen volunteered to take part in the project. Any co-morbid psychiatric conditions that had been formally diagnosed precluded volunteers from joining the study and were regarded as exclusion criteria. The diagnostic profile of the entire group was dementia of the Alzheimer type (N=14; 2 females) and unspecified dementia (N=3, 2 females and 1 male). The average age of women was 77.75 years (range 70-88); men 73.92 (range 61-88)\textsuperscript{15}.

\textsuperscript{15} The method has been described for an article exploring the results of the QoL-AD only (Jaaniste & Slewa-Younan, 2013, in press).
At a second meeting with the AlzA employee delegated to look after groups and therefore a staff-based advisor to the project, participant confidentiality and signed releases were discussed. The researcher was informed that all those previously involved in the "Living with memory loss" programme had given permission for their carers and themselves to be contacted if further new programmes or opportunities arose for them. This information turned out to be incorrect. Later developments from the administrative error are documented in the section on ethics in Appendix 2.

Letters of invitation were sent to each of the volunteers, and these were followed up by telephone calls once they and their carers had expressed interest in the project. A copy of the generic letters may be found in Appendices 1-5.

All participation was voluntary and participants and/or their carers were advised that they had the right to withdraw at any time, without repercussions or undue persuasion from the researcher and/or therapist. Carers were represented as next of kin, with power of attorney. Signed releases to this effect and with confidentiality clauses are to be found in Appendices 6-10.

**My chosen qualitative methods**

The opposition to positive science by the post-positivists...and the post-structuralists is seen as an attack on reason and truth. At the same time, the positive science attack on qualitative research is regarded as an attempt to legislate one version of truth over another (Denzin & Lincoln, 1998, p. 7).

The many-faceted available forms of qualitative enquiry are surely useful in any research venture where human beings are involved; I believe that in the case of research with the therapist as researcher, they are absolutely essential. Grainger believes that control, in the sense of the identification of unforeseen influences as definite causes for change, is not essential or available to qualitative research as it is to quantitative research (Grainger, 1999). Qualitative research is a process where, however carefully the design has been drawn up, suppositions about the cause of change have to be considered at each step of the inquiry. Early "conclusions" often need to be
abandoned in favour of new information drawn from emergent theory which opens the way for further evaluation of progress and causation. It is important to be familiar with the hypotheses and expectations; however, the unexpected must always be anticipated and the qualitatively-oriented hypothetical questions should reflect this possibility.

For me, the gap between the two types of research, quantitative and qualitative, was larger than I ever imagined it would be, and so I needed a method of bringing the positivist and the hermeneutic into greater harmony. Abductive reasoning allows me to explore several possible reasons for the outcomes of both methods.

The research project includes a form of performance narrative, based on therapeutic decisions made through the deep reflection resulting from the clinical supervision. The supervision has supported and sustained the therapist’s ongoing observational and witnessing work. The performance narrative of the sixteen sessions of dramatherapy is entitled *The Drama of the Fieldwork* and includes various forms of dialogue, stage directions, narrative and ethnographic description which are designated and defined below. It seemed highly appropriate to relate each of the sixteen sessions to dramatic performance in this way, since during much of the time the participants were on their feet and warming up or performing. Much of the verbal reflection on their part was stimulated by performance. The findings of an observational assessment (CEAA, Gottlieb-Tanaka et al., 2008) are elicited from observations made by staff and student assistants. These observers not only took the performance into account but also the participants’ own responses to the drama just engaged in.

All methods described below demonstrate supervised dramatherapy as a form of data collection. These are supported by a journal, keeping records of the sub-conscious imagery brought to consciousness through the PhD journey, as well as linked conversations and theatre performances attended, which shed light on the process. The clinical supervision aspect of the therapist’s journey is significant. It is referred to again in Chapters 7 and 8.
**Ethnographic drama**

An ethnographic drama\(^6\), also known as an ethnodrama, *For Love of the World*, uses dramatic metaphor, role theory and poetic narrative to engage the reader/listener. The ethnodrama positions the researcher in her role as the designer and author of the thesis, with particular reference to methodology and method.

The play, (Chapter 6), which characterises qualitative and quantitative methods, can be seen as a metaphor for the difficulty of combining the two methodologies in my research. At the time of writing the play, I was delighted to discover the recommendations of qualitative methodologists who themselves have written ethnodramas believing this strategy could be helpful to the researcher in working through data (Richardson & St. Pierre, 2005). Following Miles and Huberman (1994) who believe that one should "display" research, Saldaña (2008) suggests that, just as a project's findings can be portrayed through visuals within the text, "an ethnodrama is a written, artistically composed arrangement of qualitative data using such dramatic literary conventions as monologue, dialogue, and stage directions" (p. 196).\(^7\) He considers that as long as fictional constructs are securely rooted in the data, the dialogue goes much further than a mere conversation, but represents "the character-participants' negotiations over an issue, an opposition of wills, or a tense, conflict-laden exchange" (p. 196).

The nature of the conflicted theme and its eventual mediation by one of the characters in the play fits well within the genre of ethnographic drama and within the thesis as a whole. The play incorporates a set of binaries held in productive tension between the characters in order to challenge the Cartesian split between mind and body and the split's effects on the treatment of people living with dementia. In Descartes' view, the mind far outweighs the senses in importance and, unlike the quantum physicists, Descartes believed a thought is totally unrelated to the object of that thought (Descartes, 1960). Because we in the West have still not outgrown this

\(^6\) A compact disc of this play, recorded in the form of a radio play, accompanies this thesis.

\(^7\) *The Drama of the Fieldwork* contains elements of ethnodrama also.
epistemological division, treatments of the elderly with dementia, as described earlier in this thesis, tend to emphasise cognitive deficit.

By using ethnographic techniques, I was not wishing to turn a questionnaire into a dialogue, categorising responses according to tactics or emotion as is often de rigeur in ethnographic analysis or dramaturgical coding (Saldaña, 2009; Canon, 2012). Additionally, I did not wish to use any of the available software packages, to corral my attitudes to research options into some kind of coded dialogue where each sentence could be identified precisely as a response to phenomenological enquiry or statistical analysis. However, I did want to find a way, along the lines of Donmoyer and Donmoyer's advice to those writing ethnodramatically about the subtle nuances and the "roundness" (2005, p. 404) that could be captured by this means.

In the process of writing an ethnodrama, I thought, questions could be clarified, such as: which of the methodologies gets the final word? Where do I, the researcher, feel more comfortable? Who speaks and who stays silent? In addition, and most significantly of all, since my script is written in poetic form, which style of verse accords with which method, and what does it say about the methodology?

In the play, positivism and heuristic method, in the shape of the two main characters, Klingsor and Amfortas, sort out their differences in an effort to overcome the Cartesian split. They are assisted to do so by a third character (Sophia, the Soul of the World) who symbolises the triangulation of the qualitative and quantitative methods I have used.

Because of my lack of experience with statistics and early uncertainty about the potential outcomes of the scales, the character representing the quantitative approach (Klingsor) is represented as a threat to my own value as a researcher (Joanna in role) and the character representing the qualitative research (Amfortas) is more friendly.

The play is finally resolved, through the mediation provided by Sophia, since Klingsor comes to understand Joanna’s choice of pragmatic mixed methods. It has helped me as a researcher to create the ethnodrama, since it deals
with some of the difficulties of "using the strengths of one method to enhance the other" (Sale, Lohfield, & Brazil, 2002, p. 48).

By using more than one poetic style in the ethnodrama to suit the characters, and by using a Grail legend filled with twists and turns, I have aimed to depict the methodologies employed in this thesis in a manner that is immediate and striking. The drama references a twelfth century Arthurian legend entitled Parsifal (von Eschenbach, 1980), in which Klingsor is depicted as evil and Amfortas, the Fisher King, as the wounded healer. Parsifal is a very early novel which lends itself admirably to an endeavour such as my present study, since it concerns a quest to find the truth through many trials, where the (re)searcher is confronted by a series of tests much as the participants and I have been. These tests eventually lead Parsifal to the Holy Grail, and transformation!

The scene takes place in my garden, where I live (on Percival [Parsifal] Street!), where among other characters, there is a "Woman from the land of Dementia", Joanna in her own role as (re)searcher, and the goddess Sophia as mediator. Sophia is there in the form she takes as the wise female spiritual figure in the tradition of Isis and the Virgin Mary (Sardello, 2008; Matthews, 1991). The audience hears the voices of the research methodologies: the positivist voice of Klingsor, single-minded and purposeful, and that of Amfortas, more inclusive and compassionate. The woman from Dementia is portrayed as having a certain wisdom about the "spaces between"; in other words, she has a consciousness that does not rely on information alone.

Like Laurel Richardson (1997), "I had not intended to create an ethnographic drama when I took my field notes" (p. 154). In an earlier incarnation of her playscript, Richardson had written a poem about an unwed mother, Louisa May, and at a conference handed out the poem and read her paper about her, speaking the poem using Louisa's southern American accent. The drama was born from the field notes she took during the ensuing discussion.

18 I cannot agree with Saldaña (2008) when he derides "content (and) intellectual debate" (p. 204) in ethnodramatic form. I believe the characters have enough energy and archetypal depth in their discourse to render them credible and often humorous within the genre.
of her research methodology, in which she became a "participant-observer" (p. 156). Like Richardson,\textsuperscript{19} I had asked myself about the ethical position of my representation of the Dementian Woman. Had I taken an offensive ontological position by "othering" her, a position I so strongly opposed in my Chapter 3? On reflection, however, I realised that the opposite was the case. By presenting an iconic figure who stood for all those with dementia as people who have the wisdom to understand the spaces in between, I believe I have encapsulated the wisdom and perception of the participants in my group, as represented in Chapters 7 and 8. At the same time, the characters of Amfortas and Sophia act as firm advocates for the wellbeing of people with dementia.

It is important to me to include the reader in my research journey of sociological enquiry so that they can engage their own "intelligence of feeling" and be actively moved by metaphor, as well as intellectually validated. Clarity of thinking is all very well; however there are times when the heart needs to be involved in what otherwise would be a mini Cartesian split. The use of metaphor is an important aspect of the research which will be discussed below.

A further tension dealt with by the drama is the struggle between my two roles as a practitioner and a researcher. Wrestling with the issues in this arena is like taking on the role of the Christian and the Lion (or of Amfortas, the wounded healer and Klingsor, the Black Knight from Evidence Base)! I do enjoy taking on roles, and especially those I suppose myself to be unfamiliar with, and which turn out to be all too familiar, in the Jungian tradition of the "shadow archetype" (Jung, 1991). The experience of enjoyment, however, does not in any way prevent the discomfort of striving to bring together these two roles. I have spent so many years in the practitioner role, which comes so easily to me. "En-roling" as a researcher presents me with a learning curve which illuminates my biases and acts as a humbling mediator for the creative energy of the practitioner.

\textsuperscript{19} Richardson has also written a play about her research:
The ethnodrama uses a "doggerel-balladic" rhyming style and some metaphor in order to bring to the reader/listener the humour of an extreme version of positivism (Klingsor's), where no flexibility is given for subjectivity. It is interesting that, even in the most formal, evidence-based context, the terms "structure", "construct" and "framework" are used, which are in themselves metaphors from the building industry. Shapiro (1986) points out that the positivist empiricists use language as a "tool"; they also use management metaphor, as they "manage" data, "manipulate" variables and "test" models. The tenor of this kind of language implies the kind of control that forces out subjectivity at any cost; the irony appears to be lost on the "managers" that this is not actually possible!

The style of verse and quality of content varies from character to character. The genre used by the proponent of qualitative research (Amfortas) employs lyrical blank verse. The rhythm of the poetry is lilting in tone, offering more movement than the strict rhyming of every second and fourth line in Klingsor's speech. Amfortas’ exploration of the spaces between is a means for the researcher to portray the invisible elements of the fieldwork. The therapist brings these elements into focus through the phenomenological discourse and the metaphors offered by the participants as well as by other aspects of the narrative. Both the Dementian Woman, with her unwillingness to be seen as demented, and Sophia with her conscious mastery of the methodological challenge of the plot, play their own parts in resolving the conflict between the two key "methods figures". The binary of the tension between the being-in-the-world and spiritual aspects of the research participants' offerings is also altered and mediated (triangulated) by the thrust of the drama.

The ethnodrama has been read aloud by two quite different groups of people, which has enabled the editing of the play and the honing of the characters. The first reading was performed by people with whom I normally study the works of Robert Sardello on a monthly basis. (Sardello is influenced in his work by both Jung and Steiner, as I am myself, and a great believer in the negative effects when the concept of soul is denied, as often experienced in
the 21st century. My reading of his work has borne significant weight in my choice of content for this play). The play reading was by way of a trial, to decide whether any changes were needed. Then, with actors including two professionals reading the lines, I asked a sound engineer to make a recording merged with sound effects, such that not everyone needed to go into the studio at the one time. This approach enabled a more helpful and seamless timing of the project involving busy people. The result is the CD of the "play for radio" that accompanies this thesis.

**Narrative**

By creating flat caricatures we may indeed be undermining an opportunity for ourselves as social researchers to "come clean" about the contradictory stances, politics, perspectives and histories we import to our work. Rendering fluid, and not fixed, our constructions of Selves and Others, and the narratives produced as qualitative research, can reveal our partialities and pluralities (Fine, 1988, p. 148).

I have chosen a narrative, ethnographic method of research in order to draw out the invisible qualities and elements contained within this project, and to make them visible; at my disposal I have many alternative ways to use this genre. However, I have been warned against the coercive power of the master narrative (Fine, 1998), which "is rooted in the inherent bias of the social sciences" (Ladner, 1971, p. vii). This type of narrative has "clean edges... secured by the frayed borders of the Other" (Fine, 1998, p. 136); an apt metaphor to describe the kind of research that owes some of its qualitative findings to a neo-colonial mentality. Such a perspective means that the "subjects" of the research (an interesting descriptor vis-a-vis "royal" researcher status! 20) are themselves destined to be put under the microscope. Simultaneously the researcher is somehow given a box seat and protected through academic privilege, in a comfortable position far distant from the microscope's gaze.

In Chapter 3, the concepts of "othering" and reification were discussed. I have already mentioned, in the prologue to this thesis, that I belong to a

---

20 Even though I have used the language of quantitative research in this chapter and the one following, I have not as already stated been willing to use the term "subject" normally used in such research, but have instead usually substituted the word "participant".
similar dementia-dangerous age group to that of the dramatherapy participants in the two-arm study. Another issue related to the idea of reification is that the participants in the dramatherapy research are mostly middle class and educated to a similar standard as myself. During most of my working life as a teacher and a therapist I have been involved with students and clients from poor and disadvantaged multicultural backgrounds. It is therefore very new for me as a white middle class researcher to be sharing this background with participants, and I had some early doubts as to whether I would enjoy working with them! These doubts caused me to identify with some of Fine’s embarrassment that maybe I had set up a belief for myself that "poverty was in" (1998, p. 136); that is, a belief that being middle class implies a level of discomfort about the opportunities one has been afforded. Fine suspected as much in her own case when one of her students felt the need to actually ask permission to design her research around elite white women. In fact, on thinking this through, I need not have worried. As a therapist, I was accustomed to being confronted with a new learning curve each time I met a new client, and I found straight away that my participants had a great deal to teach me. My main challenge as a researcher was to make this state of affairs transparent in the qualitative research.

**Performance ethnography - The Dementia Drama of Chapter 8**

Research as a performance and performance as research have been with us for a very short time in the academic sense, as I have indicated; however, since ancient times drama has been a vehicle to explore the unknown, which is also what research is: unveiling mysteries. The Egyptians performed a funerary boat-journey into the imagined other world. The Greeks staged a Deus-ex-Machina to bring together the worlds of humans and gods. The mediaeval Christians used pageant wagons with theatre sets on their Corpus Christi Day public holiday so that audiences could make sense of the Bible. Each of these civilizations was looking into the mysterious aspects of life and using performance as a vehicle for understanding them more clearly, as a medium for non-literate people.
For *The Dementia Drama* I have used a traditional playscript method of presenting the trajectory of the sixteen group sessions. This has been prefaced by an introduction to the venue and location of the play's performance, and a list of sessions and their themes in the form of four Acts comprising sixteen scenes. There is a cast list, an auditioning process (the first assessment with volunteers and carers) and a description of how the scenery was erected and the room prepared. An "intermission" is described where the participants were given a break between Acts II and III, and a "theatre critique" is given at the end.

My main aim in documenting the sessions in this way in Chapter 8 is to give the reader of this thesis, who cannot see the video, a sense of the drama and the performance. Descriptions of the participants as they speak or move have been expressed from time to time in stage direction form, and conversations are written in dialogue where they are not cited within the text. The earlier sessions/scenes are reality-oriented rather than dealing with personal growth, such as *Getting to Know You, The Seasons* and *Colour*. Later scenes build to a dramatic climax, dealing with memory loss, grief and problem-solving in relationship. The therapy is often grounded in the metaphorical content which is referred to throughout the chapter.

**Metaphor**

*In metaphor it is (thus) not about describing what is on hand in an empirical reality, but rather about making visible in a being something that was not previously seen. The poem produces the image…a coming to be of an expression and a coming to be of being* (Vedder, 2002, pp. 206-207).

The use of metaphor is significant in any research, and is described by Richardson as "the backbone of social science writing" (1990, p. 18). This is a strong metaphor in itself and on the topic of backbones, it might also surprise some writers of scientific research that Darwin, in his foundational work *On the Origin of Species* (1996), expressed himself prolifically in metaphor (Young, 1985).

The power of metaphor lies in its Greek origin, meaning to transfer or "carry across". As researchers, we are provided with a method of meta-analysis,
enabling us to combine two different areas of experience and explore more than one level of meaning (Mann, 1996). Metaphor allows us to transform our concepts and perceptions by transferring them to and "through sensory, affective and abstract conceptual spaces" (Kirmayer, 2004, p. 37). This seems to me to be a robust and feeling-intelligence-engaged method by which to deal with the tension between the quantitative and qualitative methodologies.

The qualitative approach to metaphor provides the researcher with the means to analyse it in relation to context and biographical situation. Lakoff and Johnson (1980, pp. 192-193) argue for an "experientialist synthesis" or "imaginative rationality" that unites the rational and the imaginative in their exploration of metaphor. We try to understand our world through a context that is cultural and subjective in the sense that it is grounded in our cultural experience. They argue that metaphoric expression also arises from the objective view of the world, where objects, including those expressed in language, are part of the "real" world. The understanding of the experience being described can then be seen as having both intuitive and rational elements involved within it.

Metaphor in visual form has been provided by the video, and embodiment was a significant aspect of unspoken meaning. Through watching the film, I have been able to identify important metaphors which can be understood as giving biographical information and/or contributing to group themes. This is another very important way in which the metaphor speaks with the participants' voice(s). When word retrieval is difficult and memory loss a regular occurrence, metaphor carries across the meaning. As a therapist, my job is to listen carefully, watching facial expression and noting changes in breathing and body language. Vocalisation is important too, and as John Killick says, while cognitive capacity fades, "talk blooms with metaphor, allusion... the currents of feeling are reflected in rhythm and cadence...the natural language of those with dementia is poetry" (1997, p. 7). As a mixed methods researcher, it is my job to identify themes that emerge from the process involving metaphor and align the themes with the quantitative data.
The other important aspect of visual metaphor is to be seen in the art works. These creative works are a way of bringing themes to life in paint and pastel, giving another dimension to the drama. Pat Baines (2007) points out that the diagnosis of memory loss can be a gateway to finding new means to allow creative expression. Miller (1984) explains that:

*art therapy has developed, in part at least, to allow people who have difficulty with words to express themselves and to enable the unsayable to be said. It follows therefore that art therapy can be of great service to workers with the elderly* (p. 119).

Visual memory is often superior to cognitive memory in the recall of events; therefore the metaphors of suffering (David's depiction of his marriage); humour (Paul signing his painting with a "partial Picasso") and social justice (Neil's Indigenous dots on the new Aussie flag) are often more readily "carried across". It was powerful to witness the drawings of seemingly dead twigs in the second grief and loss session, and David's poignant drawing of his dead brother's aerobatic machine, *Flying into the sunset*.

**Ethics**

The Nuffield Council of Bioethics in their report on dementia (2009, retrieved September 25, 2013) makes it quite clear that ethical decisions in dementia should be reached on a case-by-case basis and points out that valid consent should be sought. They advise health professionals to:

.Apply ethical values (e.g. well-being, avoidance of harm, freedom to make own decisions), to the facts identified* (Chapter 3, p. 37).

The authors of the report strongly suggest that carers should be involved in decision-making where the person with dementia is unable to decide on their own. In an editorial commenting on this topic, Laakonen and Pitkälä (2009) affirm that family support of their autonomous choices "can improve the QoL, wellbeing and dignity of people with dementia" (p. 3393). The stigma of dementia amongst some members of the community should never be reinforced by caregivers or researchers.

For this study, release forms (Appendices 6-9) were discussed with and signed by participants and their carers to give permission for the research to
be published in a book or in journal articles; creative works to be reproduced in this thesis and elsewhere, without any identification. No permission has been granted to show images of the volunteers for this project. Release forms for staff members and student assistants appear in Appendix 10.

This mixed method study was approved by the Ethics Committee of the University of Western Sydney.

**Research bias**

It is important to acknowledge my own bias as a dramatherapist who wore two hats throughout the project field work: those of a researcher and a therapist. This bias led me to believe I would see a positive change in all quantitative scales. The small numbers of participants and the disparity in numbers of volunteers between the two groups are also factors for consideration of the effects of bias in the study.

**Conclusion**

It has been a very satisfying process to bring together various types of method in order to balance the quantitative and qualitative research. As mentioned in my introductory chapter, the qualitative work took precedence over the quantitative, and this is as it should be, since it holds the greater interest for me in this significant area of QoL and assists the otherwise "unseeable" to be seen.

The question of QoL and wellbeing will be discussed further in later chapters; however, in concluding this chapter it suffices to say that, while it is important to quantify improvements in QoL with evidence based practice (EBP), as discussed in Chapters 1 and 3, qualitative description may be a richer medium with which to examine a discursively complex area. It is often in the area of the imagination that people are able to find quality in their own being, and this is a part of human identity that cannot be measured.

In the following chapter the findings of the quantitative data are presented, analysed and discussed.
Chapter 5: Quantitative analysis and findings

The main aim of this chapter is to analyse the assessments carried out in the two-arm study and to evaluate the effect of dramatherapy on the QoL of participants with dementia. It has been pointed out above that the QoL-AD (Logsdon et al., 1999) was important to this thesis, principally because it was always going to supply the main data for my hypothesis: *Can dramatherapy improve the quality of life of people with dementia?* As already established, three scales were chosen because the areas of mood, language and cognition contribute to the wellbeing and QoL of human beings, whether or not they suffer from dementia. The sub-hypotheses for this thesis, set out in Chapters 4 and 11, are mainly concerned with the ability of each scale to show whether an improvement in those areas occurs. A secondary aim of this section is to find evidence which, when triangulated with the qualitative aspect of the mixed methods research, gives a clear indication of such improvements.

The chapter includes a brief description of each scale, gives an overview of the two-arm study and records the quantitative results from the measures. The discussion then elucidates some of the rationale for the results of each of the scales, names some limitations of the research and ends with the researcher’s conclusions regarding the implications of the findings.

Assessments and measures

**Quality of Life Alzheimer’s Disease (QoL-AD)**

This QoL-AD scale is a 13-item self- and caregiver-measure of QoL (Logsdon et al., 1999) which is rated on a 4-point scale, with 1 assessed as poor and 4 as excellent, bringing the total possible score to within a range of 13 to 52. The authors of the measure (Logsdon et al., 1999) describe their scale as giving the person with dementia the opportunity to be self-determined in completing the questions, and Moyle et al. (2007) recommend it for its lack of emphasis on pathology. In their comparison of two QoL scales, Moyle et al. (2007) suggest that for the person with mild or moderate
Dementia this scale has better rates of completion and internal reliability than the Dementia Quality of Life questionnaire (DQoL) (Brod et al., 1999). They recommend its use with at least two other measurements. The author of this thesis recommends the QoL-AD since she considers its strengths to be firstly, offering empowerment to people with dementia to assess their own QoL and secondly giving them independence from the "disease narrative" encompassed by other QoL measures. The scale allows for carers to complete the same questions; however, the scoring is weighted towards the response of the person with dementia. Their score is multiplied by 2 and added to caregiver's score which has also been doubled, whereupon the sum of the scores is divided by 3 to arrive at a score for the person with dementia (Logsdon et al., 1999).

**Mood: Geriatric Depression Scale (GDS)**

This scale (Brink et al., 1982; Yesavage & Brink, 1983) is a self-report measure designed to indicate levels of depression in older people. The GDS-15 which has only 15 questions as opposed to the GDS-60 or GDS-30 (Sheikh & Yesavage, 1986), has been used here because its brevity makes it easier to use with subjects who have been diagnosed with dementia. Arguments for its use with the participants in this project can be found in Chapter 4. The scale requires yes/no responses and has a possible range from 0 (no depression) to 15 (severe depression) so that lower scores indicate lower levels of depression.

**Language and cognition: Boston Naming Test (SBV-15)**

This widely-used test (Kaplan et al., 1978) has been applied here in one of its short forms - the SBV-15. Its main purposes are to assess visual naming ability and cognitive competence in word retrieval. The earlier experimental version was revised to a 60-item test and included this briefer 15-item version. The stimuli to be identified are simple black and white line drawings of items of increasing difficulty, ranging from more obvious words such as *toothbrush* to rarely used words such as *unicorn*. Clues – of a semantic, phonemic or multiple choice nature – can be given if the first guess is
incorrect. The scoring instructions are difficult to follow, and have been the subject of much debate (Lopez, Arias, Hunter, Charter, & Scott, 2003). The scoring adopted by some researchers is to give a qualifying mark for each image spontaneously recognised, or with one prompt only, such as “a mythical animal” for the word *unicorn* (Strauss, Sherman, & Spreen, 2006, p. 903). A rule of thumb, described by Lansing, Ivnik, Cullum, and Randolph, (1999), is as follows:

> ...to allow full credit for uncued naming responses as well as for the correct naming of drawings in response to stimulus (semantic) cues when patients are apparently misperceiving the target item (Lansing, et al., 1999, p. 482).

Lansing and his co-authors then point out that phonemic cueing does not contribute to the overall score.

**Procedure**

A two-arm study was designed such that 11 volunteers were assigned to a normal diversional activity (movie-watching) in Newcastle, and 6 were assigned to a dramatherapy group in Sydney. The researcher and her supervisory panel had already discussed with employees the feasibility of setting up a dramatherapy group and another scheduled activity at the two centres which hosted the project. Staff were happy as a result of discussions to commit space and time to the project, assisting with finding a suitable room and with assessment procedures.

For the filmwatching group, the student on placement in Newcastle developed a diversional programme of movies which allowed participants a certain amount of freedom of choice. A darkened room with a cinematic atmosphere was set up, providing confectionery of the type that would have been remembered from early in the lives of participants. For the dramatherapy group, the two students in Sydney assisted with the development of the group, including videofilming each session, as well as providing artistic media and other resources for the sessions and
photographing art works completed during sessions. The students were
given regular supervision by UWS staff, and twice by the dramatherapist.

All assessments were carried out pre (Time 1) and post (Time 2) the 16
sessions of dramatherapy and filmwatching. The researcher travelled the 120
kilometers from Sydney to Newcastle in order to oversee these assessments,
which were cooperatively undertaken by staff members of AlzA and art
therapy students at each of the facilities. For the dramatherapy sessions, a
group-interactive procedure was adopted using drama-psychotherapeutic
methods with projective material, improvisation, story work, roleplay and
qualitative phenomenological process interventions. Two of the interventions
employed are developmental in nature: the Embodiment, Projection and Role
developmental stages (Jennings, 1999), which were reversed in old age
(Jaaniste, 2011) and Developmental Transformations (Johnson, 1986;
Johnson et al., 2002; Johnson & Sandel, 1987).

From the 17 volunteers invited to take part in the research project, a total of
13 in all completed, in the dramatherapy group (N=4) and the movie-
watching group (N=9). In the movie group, one participant died soon after T1
baseline assessment and one found it too difficult to concentrate on movies,
however he completed both assessments. In the dramatherapy group, one
discontinued after the first assessment, one became depressed and entered
a nursing home and the fourth had a bad fall after the thirteenth
dramatherapy session and was hospitalised. The remaining 13 participants
attended all assessments. Attendance in both groups was regular, except for
illnesses and important celebrations such as weddings and funerals.

Both groups met for two hours per week, including an initial tea break, for 16
sessions. Since the time frame involved assessment at Times 1 and 2, a
period of seven months was needed in order to complete these. There was a
one-week break for Easter in April, and a three-week median break between
Sessions 8 and 9. Sessions were held in Sydney on a Friday and in
Newcastle on the following Monday.
Statistical analyses

In order to provide a comparison between the two groups, demographic and study characteristics were analysed between the dramatherapy and diversional filmwatching groups using independent samples t-test, chi-square or Fisher's exact test, as appropriate (see Table 2 for the 13 participants who completed the final assessment).

To examine alterations in scale scores over time and between groups, a change score was calculated for each measure by subtracting participants' scores at Time 1 (at baseline) from Time 2 (at completion of the intervention). Next, an independent samples t-test was undertaken to examine the difference in the change score between the drama therapy versus the filmwatching groups (see Table 3). All analyses were carried out using SPSS Version 20.0 software (SPSS, 2012).

Quantitative results

Table 2: The characteristics of the dramatherapy and filmwatching groups

<table>
<thead>
<tr>
<th>Variables</th>
<th>Level</th>
<th>Dramatherapy n=4</th>
<th>Filmwatching n=9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, Mean (SD)</td>
<td>70.50 (7.14)</td>
<td>74.00 (7.67)</td>
<td></td>
</tr>
<tr>
<td>Gender, n</td>
<td>Male 3</td>
<td>Female 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Level of Education, n</td>
<td>High school only 1</td>
<td>Tertiary degree 3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Alzheimer's Disease 3</td>
<td>Other Dementias 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

The samples in Table 2 did not differ statistically in age $t(11) = 0.797$, $p = 0.46$ or gender, $\chi^2(1, n = 13) = 2.44$, $p = 0.308$. When examining the levels of educational attainment between the two groups, no significant difference was noted, $\chi^2(1, n = 13) = 1.935$, $p = 0.217$. Finally, no differences between the
types of dementia were noted between the two groups \( \chi^2(1, n = 13) = 2.438, \ p = .0.308 \).

*Table 3: Difference in the change scores between the groups*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Level</th>
<th>Dramatherapy n = 4</th>
<th>Filmwatching n = 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL Score</td>
<td>Time 1 (baseline)</td>
<td>46.98 (4.42)</td>
<td>48.33 (6.45)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Time 2</td>
<td>47.95 (4.71)</td>
<td>46.95 (6.07)</td>
</tr>
<tr>
<td>GDS Score</td>
<td>Time 1 (baseline)</td>
<td>1.50 (.577)</td>
<td>2.78 (2.58)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Time 2</td>
<td>2.50 (3.00)</td>
<td>2.89 (2.36)</td>
</tr>
<tr>
<td>BNT Score</td>
<td>Time 1 (baseline)</td>
<td>10.25 (2.87)</td>
<td>10.25 (3.24)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Time 2</td>
<td>10.00 (4.76)</td>
<td>11.62 (2.72)</td>
</tr>
</tbody>
</table>

**Quality of Life Alzheimer's Disease (QoL-AD)**

*Figure 2: Quality of Life Scores over Time by Group*
Figure 2 displays mean Quality of Life Scores over time of the two groups. With reference to the QoL-AD data, participants in the dramatherapy group reported an increase in their QoL scores following the intervention whereas the QoL scores in the filmwatching group appeared to decrease over time, however this was not statistically significant ($p = 0.332$).

**Geriatric Depression Scale (GDS)**

*Figure 3: Geriatric Depression Scores over Time by Group.*

![Geriatric Depression Scores over Time by Group](image-url)

Figure 3 displays the mean GDS scores across the two time points for the two groups.

Referring to the GDS data, it was noted that the film group had a higher score at T1 compared with the dramatherapy group as noted in Figure 3. Following intervention, both groups demonstrated an increase in their depression levels however this change-over-time score was not statistically significant between the two groups ($p = 0.525$).
Figure 4 displays the mean SBV-15 scores across the two time points for the two groups.

When examining the SBV-15 data results it was noted that at T1 both group scores were equivalent as demonstrated in Figure 4. Following intervention the dramatherapy group displayed a deterioration in their mean score compared to the film group; however this change over time was not statistically significant between the groups (p = 0.402).

**Discussion**

It is acknowledged that while discussion of null results are rarely undertaken, since this is one of the first studies to date that has used both quantitative and qualitative measures to examine the impact of dramatherapy on people with dementia, a discussion of the direction of the results will be attempted.

**Quality of Life and the QoL-AD**

With regard to the major aim of this study, namely, the efficacy of dramatherapy on the QoL of participants with dementia, the findings indicate
that an improvement in QoL was experienced by the dramatherapy group participants compared to those who watched films, although this was not statistically significant. It is important to observe that this improvement was demonstrated in the context of the fact that the dramatherapy group's mean score at baseline was lower, but by the end of the project had reversed and the participants watching movies had a mean group score at a lower level (as seen in Figure 2).

The secondary purpose of this study was to collect data in order to establish an evidence base for dramatherapy as an intervention for older people with dementia. The findings showed that there was a non-significant improvement in QoL following the 16 session programme of dramatherapy. There are a number of reasons that can be put forward to account for the lack of statistical significance.

Firstly, there were only 13 volunteers out of 80 possible participants identified at the start of the programme from the AlzA "Living with Memory Loss" database who went on to complete all 16 sessions and all final assessments. As a result, the potential of the study in being able to identify the change in the QoL-AD, GDS and SBV-15 scores was compromised by the small sample size. Secondly, the small sample size meant there was a limited ability to match participants on factors such as baseline QoL, diagnosis, gender and age (Jaaniste & Slewa-Younan, 2013, in press). This is also true of mood, language and cognition, which meant that both groups were not starting at an even point.

It is possible that this uneven starting point may also be related to participant expectations. Many of the subjects in the Newcastle location (Film Group) had moved there in retirement. In Sydney, this was not the case, and subjects were living where they had lived while they were working. It is quite possible that participants from the control group who had relocated were more relaxed and happy in their new life choices and were therefore on a higher level of the QoL-AD score at T1.

Additionally, even though there was no statistically significant variation in education levels, it can be observed from Table 2 that the level of education
in the dramatherapy group is higher than that in the film group. Out of the 13 participants in the two arm study who completed the T2 assessment, 3 out of the 4 participants in the dramatherapy group and 3 out of 9 in the film group had completed tertiary study. Even though there is important evidence that QoL is not affected to any great extent by cognition (Bannerjee, Smith, Lamping, Harwood, Foley, Smith, Murray et al., 2006; Hoe, Katona, Roch, & Livingston, 2005), there are some authors who believe that more years of education possibly relate to a better QoL (Logsdon et al., 1999) although they agree that this question needs further research. Wendy Moyle and others do not associate education with QoL in their research on the person with dementia’s ability to have their voice heard, and they quote the World Health Organisation in their estimation of an individual's perception of their position in life

...in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to their environment. (WHO, 2004, quoted in Moyle et al., 2007, p. 176).

In comparing the two groups, it can be observed from Figure 1 that although there was no statistically significant difference between the two groups at the end point of the project (T2) the dramatherapy group’s average score increased from T1 to T2 while the film group’s average score decreased from T1 to T2. It is likely that with a larger sample size this direction of results may have been statistically significant and it certainly warrants further investigation.

**Geriatric Depression Scale (GDS)**

With regard to the GDS data, it was noted that the film group had a higher score at T1 compared with the dramatherapy group as noted in figure 3. Following intervention however, both groups demonstrated an increase in

---

21 Certainly, elevated academic ability is no protection, as can be found in the biography of Iris Murdoch, academic, novelist and philosopher, whose dementia was severe (Conradi, 2001).
their depression levels although this score change over time was not statistically significant between the two groups.

It may well be that some of the work in the dramatherapy group affected the mood of participants, since childhood issues were being dealt with up to the 15th session out of the total of 16. The T2 assessment took place only two weeks after the 15th session; that is, close to the time of dealing with those issues. There is a case for working with difficult issues which occurred early in life, since if they can be laid to rest, there is hope of fewer troubling recurrent thoughts for the person with dementia. However, it may be possible that certain stirred-up memories had the opposite effect, or that a participant such as participant 11, who could see others dealing with their own issues, was not able to deal with his own and this altered his mood. It is appropriate for people to feel sad in this case, and the scale does not actually discriminate between depression and normal sadness.

Lois Carey reports that "by the time adult survivors of abuse seek treatment, they usually have problems in many areas, and often carry multiple psychiatric diagnoses" (2006, p. 11). Watching movies is an activity that does not necessarily bear the same personal psychological conceptual framework. More information and discussion will be presented in Chapter 9 in this regard, in the section on individual change scores, triangulated with the qualitative research.

**Boston Naming Test - Short Boston Version (SBV-15)**

With regard to the SBV-15, participants in both groups started at a similar score at T1; however at the end of the intervention there was a deterioration in the scores of both groups, with a larger but non-significant deterioration in the dramatherapy group.

It is interesting to hypothesise as to why the language facility did not improve in the dramatherapy group to the extent that was envisaged. No significant difference was noted between the groups in the area of education and some researchers have found that education has no influence on the SBV-15 score (Au, Joung, Nicholas, Obler, Kass, & Albert, 1995; Farmer, 1990). Au et al.
(1995) in a longitudinal study conclude that naming deterioration is a normal part of ageing.

This discussion is highly politicised in Australia at the moment, where recent statements publicising a well-attended aged care conference in Sydney included those of regret at an obsession with finding a cure for AD as it was "a normal part of ageing" (Spektor, 2012, June 28). Alzheimer's Australia (NSW) on the other hand argues for sustained research in "tackling dementia" (Baume, 2012).

Certain difficulties were experienced with this scale in the area of cultural appropriateness. With regard to image recognition, cognition and language retrieval competence, the use of the SBV-15 proved somewhat problematic, since one of the images represented was that of a beaver which is an American animal and not well-known to Australians. At T1, five out of seven participants in the dramatherapy group and eight out of nine in the film group missed the "beaver" image. Worrall et al. (1995) replaced the image of the beaver with that of a platypus. Their results indicated that an increase in overall group mean resulted in an improvement of only .5 of an item, indicating that although some items seem biased in a cultural sense, replacing them does not significantly affect performance. Kent and Luszcz decided not to replace such items with culturally appropriate Australian ones, "but to score as correct, terms currently used in Australia" (2002, p. 562). The image of the canoe was modelled on a native American canoe, unlike the longer, flatter Australian indigenous canoe. The cactus also, is a more typical member of the American flora and has been introduced to Australia as an exotic garden plant. It is possible that results were influenced by this culturally inappropriate scale.

**Limitations of the study**

A number of limitations are noted in this study. Firstly, the small sample size limits the generalisability and power of the findings. Moreover, the study has not been randomised, due to the two-arm study needing to be located in two different cities. Additionally, participants were not matched at the start on
education, age and baseline scale measures, although the researcher is confident that statistical difference in this case is insignificant and would not have been a confounding factor.

**Conclusion**

QoL is a growing concern of carers and aged care facilities for ageing populations worldwide. Future randomised research that includes recruiting a larger sample of participants (see Chapter 11) would be an asset to the profession of dramatherapy. It would also better represent the wider community of people with dementia. The quantitative findings from the QoL-AD measure indicate that dramatherapy has a small, although not statistically significant effect on the QoL of people with dementia. These outcomes nevertheless suggest a possible improvement and further dramatherapy work is recommended.

The GDS and the SBV-15 are not recommended for assessment of participants in such an endeavour. As discussed in Chapters 10 and 11, the CEAA observation measure (Gottlieb-Tanaka et al., 2008), in conjunction with the QoL-AD, is recommended for such future research.

In the following chapters, 6 and 7 two ethnographic dramas, *For Love of the World* and *The Dementia Drama*, are presented. In Chapter 6, the ethnography works on two levels: firstly, social justice issues are represented in the characters of the “Woman from Dementia” and those who are advocating for research which will assist and promote her wellbeing. Secondly, quantitative and qualitative aspects of the research have been drawn upon in the creation of the main characters, representing Joanna’s struggle, as the researcher, in triangulating and bringing together the two categories of data.

In Chapter 7, the ethnographic method has been employed differently. It is intended that the reader, who is unable to watch the video or see photographs of the participants for ethical reasons, will experience a sense of the drama of the fieldwork through a re-framing of field notes in the form of a
playscript. The chapter takes the form of an "auditioning" process, a "scene-setting" process a cast list and a "script", where sessions are described, but the narrative is interspersed with stage directions and dialogue. The "scenes" are organised so that coherent leitmotifs are apparent. These are traced throughout the "play", emphasising the transitions made by the "players".
Chapter 6: “For Love of the World”
(A one-act play exploring mixed methods research with the world at heart)

Red Dragon by William Blake

(it is a beautiful spring day in Sydney. Joanna is sitting in her Lilyfield garden, having some lunch before returning to her laptop to do some more writing for her PhD thesis. The birds are singing and all seems well with the world. However, the camellias part, and a gnarled and deformed character wearing armour, his sword in a scabbard, makes his way into the garden, clearing his throat.)

Joanna: Who are you?

Klingsor: (In a rasping voice) My name is Klingsor. I am the messenger from Evidence Base. They have sent me to warn you.

Joanna: (surprised) Warn me of what?

Klingsor: (cunningly, with a whine) Are you enjoying writing this thesis?

Joanna: Yes, I’m loving it. I like writing, and sorting out my ideas for why dramatherapy works with people with dementia, and the rationale for doing dramatherapy with them.

Klingsor: You won’t feel like that for long. I can assure you, your statistics won’t match up, and they will be invalid – there’s no point to going on with it.

Joanna: How do you know?
Klingsor: Perhaps it would be best if I read you my proclamation from the administrative warriors of Evidence Base.

Joanna: All right – go ahead. I’m all ears, although I don’t actually believe that if the stats are not statistically significant, it will make all that much difference.

Klingsor: (with cynical laughter): All right – you asked for it! (He pulls out some expertly filed papers from his briefcase and declaims loudly)

If you wish to be successful
In this world of square and line
You will have to pull your socks up
Otherwise you must resign.
Your image will be dented
And your scholarship withdrawn
You will ever be regarded
As a miserable pawn
In the game of academia,
Rationalistic and hard data!
Your fate will be to fail at this –
Do you want to be a martyr?
You have worked in the health system
For sixteen years or so
And have never impressed anyone
Of note, that you’re a pro.
You insist on creativity
And strengthening of self,
Yet for all your paltry efforts
You remain upon the shelf.
I only speak with clarity
Let me make this crystal clear –
Your work will be forgotten
After leaving there next year,
And the same at university
Where you had hoped to shine
Unfortunately you just don’t count
In the world of square and line.

**Joanna:** *(visibly upset)* And you have come all this way to tell me this? I don’t know whether to believe you...um...er...not all of this is true. What about the qualitative work?

**Klingsor:** *(aggressively)*
There’s more here about that piffle. I’ll just read on.

**Joanna:** *(sniffing, hesitantly)* If you must, OK.

**Klingsor:** *(warming to his subject now)*
And as for qualitative results
(As if they really matter...)
They are as vague as my old gran
This world they’ll never shatter.
Do you really never question why
The Evidence Base Committee
Accept no praise at all for them
Appraising them with pity.
If ever I see that Fisher King
(Amfortas is his name)
I’ll give him an irrefutable stare
And tell him much the same.
He loves all that subjective stuff
It is his Holy Grail
You’re listening all the time to him
And his anti-rational tale
For what you call qual-evidence
Is nothing but a lie
At Base, we know you make it up
And we know the reason why.
You think that all this flaky stuff
Is what it’s all about.
Your many hours spent on it
Don’t give you any doubt?
But mark my words, your sorriness
Of all this wasted time
Will give you grief when all my words
Confront you later with your crime.

Joanna: *(more boldly now)* What on earth do you mean, crime? I haven’t done anything wrong.

Klingsor: *(malevolently)*
Oh yes you have, you have indeed!
It's all in the design -
You haven't worked this out before
And tested every line.

Joanna: Are you still reading from the script you brought with you? I believe you are making it up as you go along!

Klingsor: *(shouting, now)* How dare you accuse me of these things! I shall take your rudeness straight back to Evidence Base! You'll be sorry, you'll be sorry...

*(with that, Klingsor disappears into a kind of whirlwind, which unbelievably recedes into low hanging clouds...)*

Joanna: *(to herself)* This is horrible! How can I make up for all the work I have done - do I have to? – I wish I knew! This is like being Alice in Wonderland, except that he is no White Rabbit - what on earth am I meant to learn from this?

*(She tries to calm herself, walking around the garden and smelling the flowers, searching for bees, and stroking the leaves. She starts singing to herself, not because she really wants to, but to try to get Klingsor out of her mind...she is amazed to hear a soft tenor voice joining in...)*

Joanna: *(spinning around quickly)* What the..?

*(In front of the therapy room door at the back of the garden, she sees a handsome, middle-aged man. He is limping slightly, and has obviously been wounded. However, he looks strong and confident, and he is smiling at her...)*

Joanna: Who are you?

Stranger: My name is Amfortas. I believe you have just met our "friend" Klingsor. You responded boldly to him. Most people using mixed methods for a PhD burst into tears when he approaches with his messages from Evidence Base.
Joanna: You know him then? He treats other candidates like this? Why is this allowed to happen?

Amfortas: Don’t you realise, you are being tested? He is here to try to stop you from seeing into the spaces between.

Joanna: *(bemused)* What do you mean, the spaces between?

Amfortas: I think you know what I mean. The pause between two notes of music and the caesura between the lap-lap of the water. You know what T. S. Eliot said?

The voice of the hidden waterfall
And the children in the apple-tree
Not known, because not looked-for
But heard, half-heard, in the stillness
Between two waves of the sea.

Joanna: *(warming to the subject at hand)* Yes, from *Little Gidding*²², I love that poem.

Amfortas: But do you remember its main title?

Joanna: The Wasteland.

Amfortas: Indeed. Don’t you realise that Klingsor wants you to join the Wasteland? He was all right when you were going to try for a randomised control test for your study. He and his committee have become more and more vicious as you pulled back to a two-arm study and then couldn’t get exactly the same number of exactly the same gender and diagnosis in each group, and people dropped out. Would you like me to tell you where I come from?

Joanna: Sure, please sit down.

*(They sit together on a rustic bench in the garden, while Amfortas unfolds some handmade paper. He folds it up again, and speaks without the paper.)*

Amfortas: *(looking steadily at Joanna)*

We work in silent spaces and we trust in breath and gesture
And know heart feeling lives there, in present life responses
Between two souls or even more, in real life interaction
And that is why we measure not in standard deviations.

---

²² (Eliot, 1971, p. 49). The lines are from *Little Gidding*, rather than *The Wasteland* section of the book; however Amfortas needs to make an important point here and is allowed “poetic licence”.
We live in spaces in between, small movements and still breathing,
In currents of relationship, in sounds as well as words.
We trust the soul's embodiment, and what it is conveying
Sometimes loud and sometimes soft, revealing shades of meaning.

The language of dementia, now, defies all definition
And speaks in movement, sound and breath as well as coining words
Such language can't be understood by stats or calculation
Instead it needs ear, eye and heart interpreting expression.

We at Monsalvaesche are watching your researching.
We gladden at the shape your work with elders is revealing
And understand how subtle are the workings of communing
And the qualitative mode of telling stories of their lives.

**Joanna:** *(smiling)* This is very heartwarming, Amfortas, and gives me strength to continue. Quantitative research has little heart for metaphor.

**Amfortas:**

Metaphor – the word reminds of one that’s also Grecian -
Metanoia: changes in perception or "beyond our understanding"
However, friendly Metaphor - join us on our journey
Carrying us across to seek the land of Metanoia.

This research of yours, my dear: a long and lonely journey
Through wilderness of spooks and goblins, waiting just to trick you
Hiding in the undergrowth so you will miss the turning
Attempting to conceal the boat that carries you across...

I am here to tell you that you need to keep your faith, now
More significant than ever your belief is strongly held
Dementia is a region in the land of Metanoia
And the elders know that country better than you can be aware.

**Joanna:** This is wonderful and mysterious, Amfortas, and maybe I am on the right track after all. Just a minute, I can see someone wandering into the garden. Even though I still have questions for you about how to read the
signposts in the land of Metanoia, I believe we should ask her what she thinks.

**Amfortas:** (holding out his arms to the old woman)

Welcome to Joanna’s garden, woman of the elders
You alone can show the turning of Dementia portal's key.
Enlighten her about research expressing life as lived now
And how it feels to be a native of that far-off land.

**Joanna:** A warm invitation indeed, Amfortas; however, I don't know that the
land is all that far off – not from me, anyway!

**Dementian Woman:** (sitting down on a garden chair and giving them a
corner look)

I search for words, and when they come they’re like soft rain from heaven,
And when they fly away from here, my mind runs after them…
But when they race away from me, then cracks appear like craters
And what to do with all the gaps is not an easy task.

I search for meaning down the years, and there I gain some comfort –
I have some lovely memories and pictures in my mind
But now I have less use for all the short-term information
And so I have to weave my words as though I really know…

My family don’t realise just how wonderfully creative
This mind of mine can be when I pretend I understand.
But when this gets too tedious, the masking and mythmaking
I wrap myself in silence, because silence is my friend.

I still have my intelligence, the intelligence of feeling
It helps me understand and love my fellow human friends
But if only you could picture now my clearest golden moments
You never would confuse me with demented people, no!

**Joanna:** This is wonderful...thank you for explaining what goes on inside
your mind. Do you think we can ever get Amfortas and Klingsor to agree? By
the way, what is your name?
Dementian Woman:
My name is Cundamours; no doubt you will remember
Two strong and valiant heroines, one, Cundrie, loathly lady
As ugly as a werewolf she, strange messenger of the Grail.
And then there is Condwiramurs who’s loyal, true and loving
The combination augurs well for mixed methodology.

Joanna: Cundamours is a beautiful name, and binds together the dark and the light. But what do you mean, dear woman, about the mixed methods? I’m trying not to give a binary a presence in my research, so how can I resist it?

Cundamours:
Please help us, dear Amfortas, whose name means strength of spirit
Show how her work can prosper now, unharmed by mortal split.
Is there a way of bringing these two methods, held in tension,
Into more harmonious communication with a third?

Amfortas:
I do believe there is a way – we need our planet’s spirit
Without the love of this our world, research is all in vain.
If we can call Earth’s gracious self to meet with us and Klingsor
There’s just a chance that tension can be held for our world’s sake.

Joanna: I’m not sure I understand. Will the Being of the World be interested enough in my small efforts? And more to the point, would Klingsor ever agree to come along?

Amfortas:
Now tell me, dear Joanna, and answer me this question –
Why have you chosen this research with all that it involves?
Will it, when bound, stay on the shelves of dark and dusty libraries,
Or will it be a guiding help for good dementian souls?

Joanna: (passionately) Of course I don’t want it sitting on a dusty library shelf! The most important core of the research concerns the participants themselves. They are owed dramatherapy, in day centres and nursing homes.
(At this juncture, Cundamours nods her approval and assent, and she does a little dance on the spot to emphasise this.)

**Amfortas:**

I think we could ask Klingsor, if Earth were here beside us.  
Let’s try that Great One first; hear the views of her wise Being.  
Trust me please, I have a way to bring Sophia hither,  
And it will be made clearer how we work from this point on.  
(With this speech, Amfortas makes a low, clear baritone chanting sound.)

(In the background, some lyrical music is heard, and Sophia enters, much to the delight and astonishment of Cundamours and Joanna. She is dressed in a robe of light, and moves with grace and dignity.)

**Sophia:**  
I heard your call, Amfortas, and thought to come directly  
As you have never called to me for trivialities.  
Utter your request now, that I may then consider  
Just how to help your comrades, (gesturing towards Cundamours and Joanna) for such I think these are.

**Amfortas:**  
Indeed they are, respected friend. I knew you would support us.  
We need your help to harmonise the evil with the good.  
Klingsor, from Evidential Base, tried to dismay Joanna  
Assuring her the research work would absolutely fail.

**Sophia:**  
I understand completely and this is not the first time  
That he has tried to split mixed methodology.  
For as I understand it, Joanna, you have chosen  
To work qualitatively too, else Amfortas were not here.  
(Joanna nods her assent.)

And may I ask who you are – I deem you’re from Dementia?

**Cundamours:**  
I am indeed, my lady, and I’ve often longed to meet you,
As I believe you understand the musings of the old.
And now I see that you are here to help us with this thesis
Not only that, for you have come to show us love of World.

**Sophia:**
From far away I heard my presence was invited,
Since love of World can harmonise the evil and the good,
And even Klingsor understands he cannot win his battles
When love of World stands in between phenomena and stats.

**Amfortas:**
Then are we ready, friends, for bellicose Sir Klingsor;
To hear his abject lack of faith turn toward understanding
Once he perceives the wise, calm light of the World-Wise Sophia
Do we believe it's possible to happen here and now?

**Joanna:** Please, let's try it – Sophia, your strong, light-filled presence calms my fears and Amfortas and Cundamours, your faith in me helps me to feel more confident about a resolution.

*(Suddenly the garden is enveloped in grey mist – the birds are no longer singing, and it's as though a dark cloud has lowered itself and is hovering above the grass...Interestingly, Sophia's light shines more brightly.)*

**Joanna:** *(To herself)* Oh, he's here already – I must be strong and not allow him to deter me from my task.

*(Klingsor arrives with lowering brows and an angry countenance.)*

**Sophia:** *(stepping forward)*
Ah, Klingsor – you have joined us and we welcome you among us.
Of Amfortas you are well aware *(they nod to one another).* Now meet Cundamours. She comes representing the good souls of Dementia.

*(Klingsor gives a perfunctory nod to Cundamours, turning his back on Joanna).*

**Klingsor:**
If this meeting is arranged for HER *(pointing to Joanna, with irritation, but with a grudging respect for Sophia)*
Then reconsider your position
As she's not worth your trouble, since
Evidence is not her mission.
She treated me with rudeness
When I saw her earlier on
And at the Base, they’re adamant
Her merit is long gone.
If I were you, I’d drop her like
The hottest of hot cakes
And work with other candidates
Who have got what it takes.

Sophia:
In my role as this world’s soul, I have to weigh quite carefully
Exactly how much will be gained by arguing this way.
You will agree, Sir Klingsor, that it is of high importance
These add a certain value to the plight of those we serve.
Humans argue now about the care of many Elders;
People here, like Cundamours, who’s from Dementia Land.
These elders need creative work; indeed, need dramatherapy.
This thesis could inspire them into heart-filled benefits.

Klingsor: (Still annoyed, yet prepared to listen).
If she’s finding it so difficult
Why does Joanna bother?

Amfortas:
Perhaps I can be of some use: I do believe Joanna
Would like to write a thesis of mixed methodology
In order that the doctors and the other health professionals
Can see from their own point of view how this research stands up.
John Dewey, William James as well George H. Mead, Sir,
Believed researchers should select a type that suits them best.
Joanna, is it not the case that you would like this research
To have a role in bringing light to this your own profession
So more research can happen and its practice then will spread?
There is a dearth of evidence in some of the arts therapies

157
And surely, at this time of need, it should be in the world.

**Sophia:**
You see, Klingsor, how you can help the beauty of the World, Sir –
If you can confidently shake Amfortas by the hand.
Then Cundamours can take the news back to Dementian people
And then Joanna, you continue on with your research;
Your mixed methodology in the new "pragmatic" mode.

**Klingsor:**
Did I hear the word "Pragmatic"
It's a word that sounds familiar
And it rhymes with "Automatic"
As with other words I like!

**Joanna:** *(enthusiastically now)* You see, Klingsor, those venerable scholars mentioned by Sophia have inspired others to devise a mixed method that is, in fact, pragmatic. It is certainly not automatic, but relies on abductive reasoning, rather than the deductive of the quantitative or the inductive of the qualitative.

**Klingsor:** *(yielding somewhat)*
Well this is quite surprising
*(pointing at Joanna)*
From an addict to qual research
And I feel within me rising
Some slight warmth towards this view.
However, I should warn you
If it were not for Sophia
We would continue to scorn you
At the Base, and your research.

**Joanna:** I know, I realise this, Klingsor. I am so grateful to you, Sophia, for coming and mediating in this case. And Amfortas, too, for your wise words.

**Sophia:**
For the sake of this world's harmony, there is something left unfinished
And that is for dear Cundamours to give her point of view.
**Cundamours:**

I will take a hopeful message now, returning to Dementia
And share with all my comrades there the joy of harmony.
For I will take love of the world, as well as satisfaction
Of knowing that Joanna’s work can really make it through.

**Amfortas:**

I thank you, Cundamours, for your wisdom and perception
And for your conscious presence which has helped our words to flow
And Klingsor, Sir, respectfully I offer you a handshake
For as a wounded healer, I can understand your pain. *(stretches out his hand)*

**Klingsor:** *(Somewhat unwillingly, offering his own hand)*

With surprise at my changed mind
As I was far from willing
To give assent of any kind
For Joanna’s strange research.
But now I see she has support
From strong and steadfast forces
I shall return, and can report
I’ve changed my point of view.

**Joanna:** Thank you, thank you all for your blessed unanimity.

*(The others respond by joining hands and forming a circle. Each one in turn says, looking at Sophia):*

For love of the world

*(Then all stretch out into a line with Sophia in the centre, saying in chorus, then bowing:)*

**All:** For love of the world

END
Chapter 7: The Dementia Drama

Because we had a theory leading us to expect elderly adult disengagement, it took some time for people to understand that disengagement needn’t result from getting older (Langer, 2009, p. 39).

Setting the scene

The scene began to be set in September 2010 during my visit, together with my three supervisors, to the Sydney venue of Alzheimer’s Australia (NSW) (AlzA). Yet how was I to fit the drama within the walls of this heritage building in suburban Sydney, which looked thoroughly clean, neat and hardly a place of drama? The pictures on the walls were very old or sentimental and “safe”, and although I knew the cast would have to be kept safe, I wanted events to happen which would enable them to have new, edgy and exotic experiences.

I felt very supported by my supervisors, as suggestions were made for setting up two groups. It was only later that I realised that if we used AlzA Newcastle as a venue for the second group, there would be no RCT, since participants would not have a choice of which group to attend, as they would be totally unable to travel the 120 kilometres to the other city!

My thoughts at this time were affected by a play I had just seen, which reminded me of the characters in the cast of the play at AlzA. In Diary of a Madman, Geoffrey Rush showed skilfully how a false persona and delusions can arise in someone who lives a totally mundane existence. I wondered about the people with dementia – could their situation after diagnosis become so banal that it could be a self-fulfilling prophecy for both carers and themselves, that they actually became delusional? Would the dramatherapy help or hinder that process?

23 My experience in mental health has often brought requests to help clients to dramatise their delusions. I have not considered this to be a helpful intervention and, in the process, I have disappointed some clients with schizophrenia. I see my role as assisting such clients to distinguish between delusion and reality, and so even though the delusions have acted as points of reference on occasion, they have not been improvised. My reading in the medicalised literature had alerted me to the possibility of delusional material being present.
Playscript proposal

The playscript proposal was in two sections: pre- and post-intermission. I wanted the audience, as well as the players, to move gradually into the story.

**A Play in Four Acts**

Act I, Scene 1: *Getting to Know You* (together with contract and aims)

Act I, Scene 2: *The Weather* (a way of "taking the temperature")

Act I, Scene 3: *Finding Treasure* (a 'way in' to finding unseen riches under the surface)

Act I, Scene 4: *Colour* (a feast for the senses, with all its symbolism, personal and more general)

Then, there is a move to a more biographical approach:

Act II, Scene 1: *Planting Seeds* (sharing life's memories and achievements)

Act II, Scene 2: *The Joys and Woes of Memory* (sharing the dementia experience)

Act II, Scene 3: *Grief and Loss* (sharing losses of all kinds, and looking towards an ending prior to Intermission)

Act II, Scene 4: *Celebrating Ourselves* (pre-intermission celebration)

**Intermission of 3 weeks** (after intermission, the play and the issues have more depth, and there is a gesture towards resolution of grief, loss and other issues).

Act III, Scene 1: *Animal Kingdom with Art Therapy* (a fun way of re-connecting)

Act III, Scene 2: *Magic Shop* (a chance to look at what to let go of and what to aim for)

Act III, Scene 3: *Dealing with difficult people* (the stumbling blocks of the "cared for" rather than the carers)

Act III, Scene 4: *In the Land of Forgetfulness* (an opportunity to look at some of the annoying - and convenient - aspects of forgetting)

Act IV, Scene 1 *The Joys and Woes of Memory 2* (deepening the dementia experience)
The cast of actors - auditioning!

Once all the phone calls had been made and a production protocol set up, we had a cast of actors. It was wonderful to have two art therapy students on the production team to help with the assessments and signing of releases. (I was driving up and down the F3 to assess people in Newcastle and help a third “backstage” art therapy student, Susie, set up the film group there.)

Just as I had been considering how to respond to the possibility of delusional ideas in the actors, I began to wonder whether family secrets would emerge, as there is often disinhibition in dementia. I had watched a movie called Sarah’s Key (Hugo Productions, 2010) in November 2010. It was a story of the Holocaust and secrecy in families, and how two old, bedridden people were able to die peacefully because they finally knew the truth about family. Both of them were able to jump out of bed with renewed energy once they knew the true story of Jewish Sarah. In clinical supervision I was reminded that the elderly are never too old or frail to know the truth, and knowing it gives renewed energy. Little did I know there would be a participant (Tanya) with memories of the Holocaust.

Cast list (in alphabetical order)

Ben - a man of 73 years, who had been a soldier at a very young age for a few years, and then a media professional with a strong love of music

David - a man of 78 years who had been a solicitor all his working life, with a history of piloting, aerobatics and lifesaving

Delyse - a female staff member at AlzA

Kathy & Katsuko - Art Therapy MA students, both women, on placement at AlzA
Susie – a female Art Therapy MA student who worked "backstage" in Newcastle

Leanne - a woman of 70; an ex-teacher with piano-playing skills

Neil - a male ex-priest aged 61; an ex-counsellor, with strong spiritual beliefs and psychological understanding

Paul - a retired architect of 88; a man with language skills and a degree in Italian history

Tanya - an 89 year old female Jewish refugee and ex-nurse who had been involved in activism and social justice pursuits

Yolande - a female staff member at AlzA

Erecting the scenery

We were ready to start on April 4th, 2011! I had decided on the themes for the first two acts and the first was entitled Getting to know you. The stage was set, and the curtains were about to part. Morning coffee was there ready, along with balls, ipod, cloths, and large photographs for the central event. The room was set up as a lounge room with lots of deep armchairs and sofas. I chose to keep it that way for the moment, as several of the cast had visited the venue before, and I wanted them to be as comfortable as possible, as they would be doing many activities that were definitely not familiar. (By Session 4 this had changed, with everyone on hard chairs more suitable for group work, chairs which they helped put away afterwards!)

Theatrical Review

After the "performance", a "theatrical review" would be made. Elin Diamond speaks to the politics of performance as follows:

   as soon as performativity comes to rest on a performance, questions of embodiment, of social relations, of ideological interpellations, of emotional and political effects, all become discussable (Diamond, 1996, pp. 1-2).

In this fashion, the sessional process could be understood and interpreted: not just in dramaturgical terms, where the phenomena described would take
the form of thematic and dramatic highlights, but as an investigation of the social construction of dementia and the discourse that ensued from embodiment, intersubjective exchange, interpersonal roles and the politics of human behaviour. Above all, there would be no audience. The audience would consist, I believe, of carers and institutions in absentia. It actually had to be that way, in order that therapy could take place; however, there would be gardeners hovering outside the french doors and sounds which resounded in the corridors. Somehow, the old adage that "walls have ears" would have meaning in this discourse, and the institution will never be quite the same again.

**Act I, Scene 1 Getting to Know You**

The first session was awkward of course for everybody. There is a certain discomfort about making a contract and introducing actors to audience and vice-versa. However, despite my reticence as to the room set-up, there were feisty comments about the contract – three people were the main providers of them.

Tanya (*pointing and gesturing*): Look, anything in any way private or whatever should stay with us...no outsiders. In any way whatsoever.

David and Neil (*in unison*): One person speaking at a time.

David: She'll probably remember everything much better than us.

David's sabotage – placing me on a director's podium of memory brilliance! – was *not* helpful for this facilitator's style.

There was lots of talk about football, and "boysie" conversations, especially between two of the men, which may have been in defensive response to Tanya's continual complaints about losing her brain and forgetting. There was a general lack of self-esteem, laced with bravado and some real signs of the wisdom that would follow from Paul, who felt that he had talked too much, and not allowed the Parsee staff member, Yolande, to speak. (Her culture was important to him, because he had a great sense of social justice which showed itself more and more, especially with regard to race. The racism topic
had already emerged, since Prince Alfred Hospital had rejected Tanya as a prospective nurse in her youth, as she was an enemy alien during World War II.) My preoccupation was with the question of whether they would actually get to know one another and make the private football conversations more inclusive!

When the cast started moving around, embodiment and gesture told me a lot. Paul saluted in the name game (we learned later that his father was in the Indian Army); Neil sang his name to a hymn tune, showing us the religious affiliations that became ever more present, and Ben stood still with hands by sides, a pose which was to soften and extend considerably as time went on. When they looked at their photographs, chosen from a large assortment, they showed me more. Leanne chose a photo of a child walking through a barren landscape:

**Joanna:** What's in your picture, Leanne?

**Leanne** (*pointing at the child*): A little boy. His boots are too big. And his head is down...that is quite strange, because children don't usually walk with their heads down.

She had begun to open the curtain on herself with what transpired to be her big, unresolved issue of being barred from childhood play. People were unfolding themselves, like dried, curled-up autumn leaves which had decided to prolong their autumn glory, opening up a little more before winter. Delyse drew a picture of these leaves at the next scene change, in Scene 2. The group sang *Getting to know you* (Rodgers, 1951).

**Act I, Scene 2 The Weather**

This scene was all about seasons and weather: would it be fair or foul? There was already some interpersonal rivalry happening: Neil, originally from Queensland, was absent in that state at a wedding, and Ben said he could "do without Queenslanders". In the last scene, Neil, close to tears, had told us he had difficulty just fronting up to the session, so Ben's apparent distaste for people from the north could signify stormy seas ahead. However, Ben
informed us that people "very quickly see the advantage of having a small place to talk about these things as you go through". Peter was at a loss because his wife was in hospital having a heart bypass, and had thoughts of suicide, like Tanya.

Mood is one of the important areas for quality of life, and these two people were at risk, although it appeared to help both of them to talk about suicidal ideation without professionals running for the telephone or filling in forms. David's mood was also low. He told us he was "rusting out" - a great metaphor for being unable (or not wanting to) do the activities he was used to.

For Leanne, the weather was a perfect metaphor for dementia. "There's nobody you can say, 'Get it straight, will you?'...it just comes...and you just have to live with it". The group threw more than one ball in a pattern - a stuttering kind of performance that Tanya complained about as there was too much to remember; however, it worked quite well and she was good at it once she got going. They began to learn the game of "Shoo, Fin, Bounce" to get limbs, gestures and laughter muscles going. Then, walking in the rain, Leanne saying, "You don't look up, you look down", and there was the young child again with the big boots from Scene 1. We built a snowman in improvisation, once it started to snow, and David said he was warming up; as a skier, he was getting interested. Then, as the sun started to shine, people basked:

Tanya: Of course, this is Australia!

Joanna: One word about what it feels like to get warmer.

Ben: I'm getting little characterisations.

Paul: *(beating his arms against his chest)* It feels like you are getting warmer.

Then they drew pictures: Leanne's, a child carrying a bubbly drink, and not looking down; Tanya walking in the Vienna Woods as a child with the sun shining; David with his long deceased twin brother, killed in an aerobatic
accident, in the surf, now safely between the flags. Peter sketched animals, and this was Ben's written contribution:

A first approach to calm the news, as the rain approaches. All is well as the hail sets in place, but sadly a belated number of difficult snowmen.

Was this "news" the diagnosis, which after all is "heavy weather"? And who were the difficult snowmen - not really surprising they were difficult, as hail can sting. The varying types of weather used in his poem give me some clues about attitudes to dementia; surely the "news" of the diagnosis needs to be "calmed" somehow, as well as presenting a picture of Ben's deteriorating state of cognitive health despite his group involvement, as his dementia "sets in place".

Tanya felt it was nice to be "in a group where everyone is totally accepted". Paul felt optimistic, despite his early distress, and for Leanne, no one was "trying to butt everybody else out". Scene 2 finished with a song: Every time it rains, it rains pennies from heaven (Johnston and Burke, 1936).

Act I, Scene 3 Finding Treasure

Neil was back from Queensland, feeling a little better about being in this group with "strange people" and Paul's wife had returned home and this session was a first attempt at playing with objects: projection before improvisation as the general rule in the Embodiment, Projection, Role paradigm (Jennings, 1999). However, before this could happen, Tanya's early life caught up with us:

Tanya: (shaking her head in her hands) You know, to see all those Nazis walking down, yelling "Heil Hitler", and all that sort of stuff, and my father who was a social democrat and in the left wing party, well and truly exposed... and I was sixteen, seventeen...somehow we got on a train to Europe, to Holland and I don't know how we got there, but I remember the guard coming...and looking for passports and things like that, and we weren't quite sure if we would get out, you know, if they would stop us or whatever. It was just so horrible (crying into her handkerchief).

Tanya's images of the terror of being in Vienna when Hitler's troops marched in were so horrific that we all joined her in her nostalgic escape from Austria, on a train to Holland. There we were, only two and a bit sessions into the
programme, rocking and shaking to the rhythm of the steam train as it chugged through the Viennese countryside, hanging on for dear life and feeling very insecure - as Paul said, unaware of whether we could get out at the end. (It is important to note here, however, that the group contract as well as the time and content structures had given the opportunity for participants to feel safe enough for this "as if" of insecurity).

Eventually our "train" stopped, just as Tanya's had in Holland, and everyone climbed out and breathed and verbalised what it was like to feel free. It seemed the participants were "freeing up", with words expressed like "relief", "joyful", "happy" and "surprised". The language was changing. I had felt the power and pressure of that diagnosis again in that train, and then experienced the lightness that came once people realised there were still feelings to be expressed and pleasure to be gained. There were more warmups - Group Mood (Emunah, 1994, p. 157) and body sculpts. These "sculptures" are formed when individuals are turned into statues by a partner who moves their head, limbs and expressions) representing feelings, to try to allow people to be in touch with their experience, rather than trying to "stay in their heads" (Emunah, 1994, p. 148).

We were finding treasure in this scene, so after these warmups to access people’s feeling life, each person put a hand into a bag and selected a previously unknown object. Tanya drew out a box of matches; however, when she saw the baboushka doll she pounced on it and clutched it - then immediately wailed that her brain was missing - "It's somewhere in Vienna with the Nazis walking in". Quick as a flash came Ben's rejoinder: "What about - that's not it there, in your hands?" This was a wonderful way of reconnecting her with her brain as well as her choice of object, so that she could then explore the baboushka’s layers in a thoughtful way, engaging with her memory of the similar doll her father had brought her from Russia, all those years ago.
There were several layers to this transformation. The doll was a reminder of the embodiment we all share as little children, and Tanya was able to experience it in the object, rather than in her own arthritic body which impeded her movement. There were the memories of her father, who had been in prison in Russia, she told us. The father she adored had saved his family by organising their flight to Holland, and later to Australia. Then there was the sense that Tanya understood entirely despite her dementia, that we are many-layered creatures, and she had already spoken about the subconscious in an earlier session.

Paul, like Tanya, had rejected his first object in favour of one of the crystal glasses that stood on the Victorian sideboard in the room. Being a person who loves gourmet food and the good things in life, it gave him memories of his parents and happy times with them.

The objects generally took people back in their lives. David had a torch which reminded him of his camping days, and Leanne, a serviette ring which told her that those were things that "stayed in the drawer" at her place when she was growing up. When you live "hand to mouth" as she later disclosed, you don't have much use for serviette rings. Ben loved text, so read the angelic message on Neil's candle holder together with him, even though his own 1950s Foster's beer-pull plaque didn't mean much to him. The information that Neil believed in angels (not the "floaty kind", but "spirits which stayed around" him) was revelatory.
**Act I, Scene 4 Colour**

This was a very definite "turn" in the action of the drama. Elsewhere (Jaaniste, 2013a, in press) I have written about the Scene 4 protest march, coinciding as it did with the usual "storming" phase of group development (Tuckman, 1965). It is worth noting that it is also a celebration of "de-pathologising" of storming. Yalom (1995) describes storming as an "adolescent" stage of group development. However, from the moment the curtain went up on this scene - one of the most intense of all sixteen - there was a mood of anger at the diagnosis and the "sentence" of ageing with memory loss. There was a sense of a more conscious storming phase than I have experienced in many other groups, where the problem has been more generally the group content or focus.

This scene, however, acts as a critique of some of Yalom's ideas, and is a mature social justice response and a powerful manifestation of the group members’ wish to change the status quo, politically and socially. In earlier scenes, the group had developed a contract and had voiced objections to breaches in confidentiality and had questioned the group paradigm - was I a psychologist? would I show the video? and so on. This questioning and verbal confrontation represented their actual storming behaviour in a group process sense. Perhaps this group had de-pathologised storming and dignified it instead!

At this fourth meeting, Tanya had entered saying she wanted to stamp, so we stamped. Coloured silk cloths were used, carefully chosen by each participant. Ben's was khaki for his army days, Neil's was blue, his favourite colour, and Tanya grabbed the red before anyone else could - it stood for socialism and anti-Nazi protest. Malcolm (1997) describes what was about to take place "on stage" as follows:-

* A dramatherapy session can comprise a ritual journey from everyday reality, over a threshold into a space where transformation can take place, towards a future which has the promise of new possibilities (Malcolm, 1997, p. 5).
After some warm-ups, each participant painted on a large sheet of paper in the colour of their chosen cloth. Neil and Tanya were the stars. Neil silently created a new Australian flag with dot painting to represent Indigenous people, and a simple St. Andrew’s Cross rather than the Union Jack. Tanya described in intense language the May Day protests (Sydney May Day was the following day!) in Vienna as flags were waved and blood was spilt, perhaps not on that day, but on many days around the Anschluss of March 1938.

Tanya managed to get red paint on her white cardigan, and noted poignantly that it wouldn’t come out. She was positive that the red arrows she drew on her flag encapsulated the symbol of the Socialist Party at that time. She was Jewish and I found through researching that there had already been many anti-Jewish Nazi demonstrations in Vienna at that time. Jews were being disenfranchised, and some were committing suicide. On March 13th, 1938 Hitler entered Vienna with his troops and with the Austrian Chancellor who had earlier capitulated, at his side. Tanya’s sixteenth birthday was mid-May, and she told us she left Vienna with her parents at that age, so she was possibly there for May Day before she left.24

I asked Neil a few questions about his flag, and he called for funding to carry it to Parliament House and symbolically, Tanya gave him "sixpence". (Katsuko gave him "$100"!) Then he started lobbying for opinions of his flag. I asked participants in the march to give themselves different names so that they could de-role at the end. Neil said, "Then ASIO won’t be able to keep track of them" causing me to wonder if this was an allusion to the stigma of dementia - for Tanya, perhaps her Jewishness (do they know if I have dementia or not?).

24 There is footage available of the May Day celebrations in Vienna in 1938 by arrangement with the Holocaust Museum (U.S. Holocaust Memorial Museum, accessed 21.05.12).
For Jewish people then, there was a similar kind of "nameless, faceless" perspective, put out by the Third Reich bureaucracy, as the attitude still pervading today with regard to dementia. All Jewish women were to be given the name of Sarah after the Anschluss, and all Jewish men, the name of Israel. The archives in Vienna were set up under the jurisdiction of Eichmann. For further detail, see Appendix 19, from *The Hare with Amber Eyes*, (De Waal, 2011).

Leanne in her new role didn't initially like the flag; however, when asked why our Aussie flag needed changing, she told "Tony Abbott" firmly, "It's not fundamentally right at this time". Delyse was chosen to be Abbott, and Neil, as Bruce, started a chant: "We want to change the flag". Tony Abbott (Leader of the Opposition) was suitably hypocritical in his reception of the protesters, and pretended he would "get back to them". Neil remarked that politicians don't listen.
In the group's reflection on the performance, with all its undertones of protest about dementia, Paul, who had been quiet and had not joined in, said, "What about the first people?" meaning our Indigenous people, of course. This was important food for thought; the dot painting was there on the flag, but we needed something more. So Paul gave us a strong rendition of La Marseillaise (Rouget de Lisle, 1792), and all our voices contributed.

**Act II, Scene 1 Planting Seeds**

When the scene began, the conversation was about Tanya who had apparently had a fall and would probably have to go into hospital. When asked if he could speak louder so that I could hear when watching the video, Ben said, poignantly, "Yes, it is a bit of a backward glance, isn't it? You can use that".

It seemed almost remarkable that someone whose cognitive skills were dropping away could put himself in my shoes, as the watcher of the video. This "backward glance" led to a discussion of dementia, which was varied and interesting. Neil said the diagnosis was harsh, and a reality check, Paul had to resign himself to being unable to drive after being controlled by Road Transport Association legalities, and Leanne couldn't accept it; she wanted a car of her own. She was sick of being driven by her husband, and didn't have the insight to realise that she wouldn't be able to drive safely. David was
frustrated because he couldn't do the sporty things he used to do, and was "stuck at home".

We worked with embodiment, leading with various parts of the anatomy and then pulling faces and mirroring each other to get the facial muscles going. Our theme was *Planting seeds*, and these movements led to improvising the growth of plants of choice. Leanne became an oak tree, Ben a "tyrant rose". Perhaps he was bored by the plant theme, and was flexing his emotional muscles. He wasn't interested in the improvisations, so when he saw a chance to write on cards about growth, he was engaged. He wrote, "Growth of flowers, well in stock", and people took partners and cards with growth words written on them, to talk about seeds they had planted in their lives. From there, we moved into body sculpts of people's achievements - David of course was a lifesaver, and Paul's sculpt represented his children and grandchildren. They were embarrassed about referring to their achievements, and found it difficult.

Finally, all the sculpts were incorporated into a well-known dance-movement therapy exercise, where people were divided into two groups and each watched the other perform, using their shared body sculpts. It was revelatory for me to see these elderly people moving to the music and discovering one another's movements. It was the climax of the embodiment process. Richard Coaten describes the process of hand movements which expand, ending up in full body movements as follows:

_The most important aspect of this experiential work...is to remember to take pleasure in it all. If it can remain pleasurable, observed "well-being" will have increased and "ill-being" decreased. Together, you will have played and danced in embodied ways that truly offer hope in going by way of the body in dementia care, when words are not enough_ (Coaten, 2011, p. 88).

Body movement seemed to prepare the group to plant their crocus bulbs. Yolande asked for peace on earth as she did so. Ben told the bulb it would be very hard for it to come up, and David said, "Grow tall and straight"

---

25 The crocus flower in Greek mythology is representative of Persephone, who was gathering crocus among other flowers when taken down to Hades. It is symbolic of resurrection, which seems appropriate here. (Retrieved July 7, 2012, from Suite 101.com). Kate Greenaway has "abuse not" written against "crocus" in The Language of Flowers (1979, p.13).
(interesting regarding his legal difficulties with money reported to us by his wife). Neil said "branch out", Leanne, "grow", Paul, "Honi soit qui mal y pense" and Katsuko, "keep well". After each wish, all group members repeated them... and yes, all the plants did come up, although not all of them flowered.

**Act II, Scene 2 The Joys and Woes of Memory**

In this scene, we got down to brass tacks about memory. There was general chat to begin with, as we wondered if Tanya was going to come back. Memory was seen as "a pain in the arse" (Neil); "few bad times but mainly good times" (David); "a pretty sight from where I sit and look" (Ben); "the past was a happy memory, and there was a chance of continuing that..." (Paul). However when Leanne spoke, it was about her teacher in primary school who refused to let her play and she was already "hot under the collar". Leanne's conversation got more angry, and what she said alerted me to start a DvT session, so that we could have a designated space to play where the anger could be contained. We brought down the magic curtain from the ceiling and started with a Magic Box session which later turned into an Emotional Soup. I chose this intervention to contain and externalise strong feelings, and describe it elsewhere as follows:

> As suggested by Johnson, the magic box can later become an Emotional Soup (Johnson, 1986, p. 23). Participants can pull out emotions and return them to the soup with sounds and facial expressions. For this group, at this stage, anger began to boil and bubble (Jaaniste, 2012, in press).

Leanne's words as she threw in anger and her resentment that this teacher had taught her to hate are reproduced in her narrative in Chapter 8 of this thesis. David had thrown in "the bad times" and Neil the anger of a man who climbed high onto the Harbour Bridge in protest that he didn't have access to his children. There was a great deal of anger present, and I asked them what they wanted to do with the soup. Leanne suggested we "chuck it out the window", but it was too heavy, so we squeezed it through the glass doors

---

26 This proverb means "shamed be he who thinks evil of it".
and left it in the garden. This part of the scene, even more than the reminiscences of the participants' life stages, was really the beginning of Leanne’s healing journey with regard to being prevented from playing as a child.

The following activity was a walk through all developmental periods. The room had been set up so that Childhood was in one space, with objects and pictures representing this era, then Adolescence, Young Adulthood, etc. Along the way, we were to learn much about people’s biographies. Neil loved being read to in bed as a child; David shared his beautiful Alsatian dog with his twin for the first nine years of life; Ben enjoyed junior footie. For the men, in adolescence, there were the ups and downs of meeting girls. The Queen reviewed the lifesavers when David was in the team at Bondi Beach. We found out that Leanne was poor, and had to stay home as a teenager and make her own clothes, as the family could not afford to buy them. Ben seemed to have been at Sydney Grammar, a "posh" school, with little money to do the activities that were "hot stuff".

Then as a young adult, Leanne became a very different kind of teacher to the one who had submitted her to "foul play". David trained with the Solicitors' Admission Board, and earned two pounds a week. Neil didn't become an adult until he was about thirty, as he had been "held back" by lots of study. He had married late - we were now at the Marriage Place, and all were married to their carers.

Neil (with emphasis): J_____ is my lover. Full stop.

Paul (with a broad smile): I have only ever wanted one wife.

Leanne: I'm married...and I like it...and my husband is...a beautiful man.

Ben: An extraordinarily good way to go.

From David we heard more about the "great institution of marriage", not really convincing when we remembered his painting of himself and his wife on the day of the royal wedding (of William and Kate), standing miles apart in stiff, geometric positions.
Everyone then visited the *Children and Grandchildren* areas, and were given small baskets to collect any treasures or objects from any the of the sections to bring back and share with the group. Leanne chose a baby photo. Once again she was reminded of childhood. Neil chose a picture of a soldier, like his dad who had died some time ago, and we heard about Neil's grief and "unresolved matter", which was to emerge again in the next scene. David picked up an egg-timer, which showed that the sands of time run out in the end for all. Paul had a patterned cloth which reminded him of buildings, and when asked if he'd designed them, he said: "No, buildings have designed me, more like".

We all sang *Thanks for the Memory* (Robin and Rainger, 1938), and then I was reminded that I had promised Neil we would send energy to all the fathers who hadn't got proper access to their children, so they could protest. A fitting way for the scene to finish, with a "whoosh" of energy from the group.

### Act II, Scene 3 Grief and Loss

The scene opened with Leanne feeling "written off". It is amazing how often the early group process can encapsulate the theme of the day. She had undergone work for a torn retina, and had an eye patch on her left eye. Since this was a session about grief and loss, it could be seen as a circumstance where our loved ones were "written off", or even ourselves, since we as individuals are often seen through the eyes of others, especially parents. And the expression describes the dementia diagnosis very effectively.

Our first warmup was a trust exercise, where people were taken around the room with a partner, "blind"; in other words one person was blindfolded and led by another. Leanne did not take part. This game was not as risky in the seventh meeting as it would have been earlier. Most people were reasonably comfortable with being led, except for David, who found it unpleasant, and was thankful he could see. It seemed like another example of being unable or unwilling to let go of a pre-dementia experience, in order to accept what was
ahead. (I also experience that kind of stubbornness in relinquishing my organisational ability, physical deterioration, etc.)

Words were passed around with ball throwing about losses: loss of work (Neil), loss of his dog (David); feeling threatened (Leanne); anger (Leanne). I then told the story of *Ulu and the Breadfruit Tree* (Gersie and King, 1991, pp. 132-133). It is a story of a father who sacrifices his life, after a meditation at the temple, for the sake of his sick son. He instructs his wife to bury his body in the garden; from his buried remains a breadfruit tree grows, the fruit of which saves his son's life. It is a story of loss and regeneration. I would simply say that the experience of this roleplay encouraged Neil to realise, after playing the role of the person who died and was buried, that being buried in the earth after he died was an option he could live with.

Joanna: What do you like about the character, and what do you not like about him?

Neil: I have a sense of, um, being okay about, um, sort of disappearing into the earth. I had a sense of that and I sort of liked that strange way that I would; that my body would be part of this soil again.

For Neil, this performance encouraged him also in his difficult experience with his late father, with whom he still had issues. He stated that he also had a sense of his father being around "in some form or another, a bit like the play". He also felt a sense of hope, even though the word "hope" did not occur in the story, and based this on an important view of his own that, without belief, nothing can arise from such a (sad) situation. This view appeared to influence David, who said it was the belief of the parents (of the sick child who was healed by the breadfruit, which grew out of his father's buried body) that something could be achieved and the problem overcome.

An interesting aspect of this scene was that Paul objected strongly to such a story being told out of the context of its Polynesian roots, and appeared quite annoyed with me for doing so. Once he saw the story performed, however, and heard some early reflections on it, he thought differently. (Arguably, almost everyone was influenced by each other in this scene).

Paul *(using his hands and arms to emphasise his point of view: I think the concept of the ah, um, man who has died, wanting to, um, help the people*
who are left behind, is obviously good. But to direct the people who are not there and turn them into something that is worried and desperate is not a helpful thing.

"The people who are not there" are probably the Polynesian native people in the story, and this may be an allusion to misappropriation of another’s cultural heritage, if seen in the light of Paul’s strong cosmopolitan social justice orientation. A clue to other considerations came towards the end of the scene, when Paul spoke about German aliens who had been maltreated and sometimes asked to leave Australia during World War II. The question of enemy aliens had come up earlier in Act I, Scene I when Tanya’s career had almost been stymied because of her nationality. However, the expression "the people who are not there" could also be a metaphor for the stigma of people with dementia, a bit like Ben saying, "watch this space" when he did not know the answer to a question.

At the end of the session, each participant took a flower or feather from a basket and laid it on a grief table placed there to express their grief (Chin, 1996, p. 39). David put a feather there for his twin brother, who was an aviator and was killed doing aerobatics. Paul laid a flower on the table for all those killed in war, in his all-encompassing style. Leanne placed a flower there for her lost vision, and Neil placed one in remembrance of his father, who fought the Japanese in World War II. Katsuko’s was for those killed in the Tsunami of 2011 in Japan and Kathy’s was for her mother, who had recently died. Everyone sang We’ll meet again (Parker, 1943) after this little ceremony, and they asked for the singing of it to be repeated.

**Act II, Scene 4 Celebrating Ourselves**

There was a certain amount of cheeky humour in this scene, with Neil bringing in a Queensland football scarf, purposely to annoy anyone like Ben and David who barracked for the NSW Blues. David said he felt good, and it was great to be alive, but his fun would be over when his wife got back from her visit to the US in a few days. No one remembered very clearly what had happened the previous week; however people seemed much more able to tease one another, and there was a jovial atmosphere in this session which
was mainly about celebrating themselves. We played *Cat and Mouse* (Farmer, 2012), *Grandmother’s Footsteps* (Farmer, 2007) and the participants were paired up as cat and dog, and "spoke" to one another in cat and dog language. Then we pulled down the curtain and used a Developmental Transformations format to play.

Paul’s liking for good cheese took us off into a restaurant scene, until we were told by Neil that we were "in the wrong era", and we should be in 1924. The first world war was over, and the depression was coming up. Quick as a flash, Paul said, "Depressions don't come up – they go down". So we got down onto the floor, and this was the moment when Leanne told us to "roll" when we wanted to get out of depression.

It has been my experience that to play another role is a great way to get out of depression, even temporarily. For example, individuals with severe depression can find strengths in themselves they believe they had lost, just by playing the psychiatrist's role.

> *Taking on roles of real life, such as parent, boss at work, or the peacemaker, allows clients to consider the roles they have in reality, experiment with new roles and alter existing ones if desired* (Langley, 2006, p. 24).

Finally we were able to get up on our feet again because Ben was handing out some sort of antidote to depression in improvised form, named by Neil as laughing gas. Ben was not sure that he liked the laughter at first; however, when Yolande said it had brought her out of a depressed mood, he wanted us to "start laughing and start to play some things". Ben’s words were becoming less and less easy to understand; his grasp of language was slipping, and so his wish to play was heartening, as executive function is not required. Yolande had provided the social impulse which opened up Ben's imagination, and he changed his mind.

Ben added a request: "With the art, I think, if you could get hold of certain material..." Of course, he wanted the silk cloths involved (intention and

---

27 A wonderful way for people with dementia to warm up (Howe, 2010).
problem-solving), and although unwilling to initiate, he was happy to suggest a way of playing. In fact, Ben's idea stimulated Paul to stand in the pose of a classical Roman statue, which was gradually surrounded by eight silk cloths of every colour, carefully laid by each participant like tributes at his feet. As Blatner tells us, spontaneous play "is more than mere impulsivity because it requires some intention to achieve an aesthetic or constructive effect" (1997, p.5).

Soon afterwards, people began to put on hats, and Neil became Beatrice (I can't help wondering if Paul was Dante!) and I became a schoolgirl who hated school, probably chiming in with Leanne's strong hatred of her teacher. Ben chose a soldier's hat, and called himself "Digger". Neil called me Buggerlugs, reminding me in my role of being bullied at primary school. David heard it, and quick as a flash, said, "You should have picked up the roses, shouldn't you", reminding me that he himself had probably needed to do that on a few occasions for his wife! He then "picked up the roses" himself, quite literally, donning a floral headband and saying he was "feeling gay". It is a delightful opportunity, I believe, that someone who has spent most of his life in a very formal profession and has been married twice, has got the chance to sashay around, expressing the "gay" part of himself.

Once everyone had de-rolled from the hats episode, I asked them to walk around and validate others for their special gifts, since this had been the final session of eight before a break. Neil told Leanne about her artistic prowess, and Katsuko told him about his sincerity and honesty and then admitted to sometimes being scared. This prompted a disclosure about himself that was poignant and moving:

Neil (shyly): I get embarrassed, because I think other people know more, or have got more, or whatever, but I don't; but here, it's like, a very easy place to be. You can be as silly as you like.

And about his own fear:

(using a stronger tone): I guess I should remember that. It's important for me to remember (what I can do) rather than what I can't do now. You know, I can't do a lot of things now, and I need to remind myself that I was able to.
'Cause if you feel, if you feel like, um, you can't do anything then, um, I forget, I can forget that I have achieved things in my life.

It seems very likely that all the play and spontaneous improvisation, as well as Katsuko's perceptive observation and personal disclosure, had prompted this touching vulnerability in Neil. The session ended with a farewell ritual, as we would not be meeting again for three weeks.

**Intermission**

Reflecting on the first two acts of this play, it is heartwarming to see how the dynamics shifted in favour of the men's relationship with one another, mainly through play. Instead of the endless football talk, they built a real camaraderie between themselves, especially in the scene just described. Neil, who understood himself well, had often been the spokesperson for the group, allowing himself to be made extremely vulnerable; others showed their openness in lesser degrees. Tanya, for all her lamenting over the state of her brain, had been able to give us a firm psychotherapeutic base to work from, through her remarks about confidentiality, childhood memories and psychology. After Tanya left, Leanne barely seemed to notice that she was the only woman in the group, and as will be seen in the remainder of the action, did not allow herself to be inhibited in working on the issue of emotional abuse from a teacher at an early age.

**Act III, Scene 1 Animal Kingdom with Art Therapy**

The scene opened with a conversation about the relativity of time. It was an apt way to begin, as of course there was a vast polarity between the busyness of my ongoing field work in Sydney and Newcastle prior to its completion date, and the lives of those in the group who on the whole did very little every day. Participants appeared to be refreshed after their break.

Ben had begun to make less sense with his speech, but talked about play, so perhaps he was remembering Act II, Scene IV and his own suggestions for cloth activity. Early on, he came up with a sentence which aptly summed up
the performing stage of the group (Yalom, 1995, pp. 194-196)28: “For the people who have been coming for so long, it’s doing its own thing, really”.

I asked what the group seemed to be doing (or not doing) for other participants, and got this reply from Paul: “But ah, you know, sort of makes you concentrate a little bit on what you’re doing and what’s happening to you”.

There was a conversation about safety which followed once I had asked if they had any more personal aims for the dramatherapy. It appeared to be a fairly solid way to take up from where we had left off. There was ballthrowing and clapping, as well as a repetition of *Cat and Mouse* (Farmer, 2012). During this game, Ben described a situation at Manly Beach where there were lots of children in the surf and their parents came too, information which he followed with a "Hallelujah!". Ben clearly had issues about childhood safety, as this topic was one he brought often to the circle.

Then animal roles (Paul’s suggestion) written on scraps of paper were placed in a hat, and everyone picked one and found a partner with a matching role. They played various activities together, such as waking up, arguing, sniffing around one another, and then made their animals out of clay.

Leanne found the roleplay pompous, silly and crazy. I told her I could be all of those things, could she? "Crazy" was the answer, but she added as an afterthought, "...at the right time". Leanne appeared to have very definite protections where behaviour was concerned, which helped her face the world with her moderate dementia. There was a lot of hilarity around the roleplays. Ben and Neil both became monkeys, with Ben’s monkey peeing against a lamp post, canine style. Neil called his monkey Monk, which was quite revealing in an ex-priest with religious moral values.

---

28 Yalom (1995) discussed the phases of group life as: ‘forming, storming, norming and performing’ (see Figure 5).
Leanne’s dog was Jack – "a nice, sensible name" – and my cat was Ratcatcher, causing a lot of laughter when she sympathised with the poor rats. David’s clay lion turned into a bulldog, which was an interesting accompaniment to his pugnacious gestures in early sessions, as was the distance there always seemed to be between himself and others.

Ben had written down a verse while participants had been modelling their animals, which read: "For the use of major guns and roses and of course the young men who went to war". This writing picked up major themes from earlier sessions. Ben’s "tyrant rose" of Act I, Scene 4 was one instance, and the references to Ben as Digger with his early army experience. Another theme was David’s admonition to Neil about "picking up roses" with the implication that roses act as compensation for poor male behaviour, followed
by David's own "picking up" of a rose-covered headband, to take the role of a gay man.

Since we had discovered that Leanne played the piano, and I had brought songsheets of *Tie me Kangaroo Down* (Harris, 1960), I asked Ben to read the first part of the song about an old Australian stockman who lay dying. It reminded him of young soldiers dying and was perhaps survivor guilt as Bertman (1999) suggests, since he would often speak of war, and his time in the army. He had been the right age to be sent to Vietnam; however he never spoke of his actual experience of war. He ended the session by telling us how horrible the scenes of World War I were in his mind, perhaps from films he had seen.

Leanne said there had been a lot of fun and "getting into things". For David, it was a "get-together" (and seemed to be one of his closer encounters), for Neil it was "a time to be creative" and for Paul, a good introduction to a festival he knew was on in Melbourne – "art galore".

**Act III, Scene 2 Magic Shop**

Leanne actually remembered something about the previous session, a first for her. She remembered barking like a dog which was interesting in the light of her ambivalence about crazy play. People had caught winter colds, and there was a conversation about handkerchiefs, which three of the participants were carrying, another reminder of this generation's habits and rituals.

I asked about participants' views on magic, as the session was called *The Magic Shop*, a game taught to me by my clinical supervisor for many years (Miller, September 8, 1996, personal communication). Paul believed in magic – "things which happen which you are not expecting to happen" – and Ben agreed with him. David believed it was "sleight of hand", Yolande had a lot of experience of magicians in India, and Neil did not comment, perhaps because of his religious beliefs.

After an activity in which a balloon was passed under the chin in order to bring the group together (Jennings, 1986, p.82), there was an action-
guessing game. Most people coped with it very well, although it was difficult for Ben to mime an activity on his own, and he protested to me: "What, without you being there? One straight person?" Finally, after much prompting from most participants, he managed to greet everyone in the circle. It was significant that this final gesture was an embodiment of his social self, which appeared to be strengthening, even as his cognitive abilities were deteriorating.

**Act III, Scene 3 Dealing with Difficult People**

So much of the literature deals with the difficulties people with dementia appear to cause for their carers, rather than the other way around (Marrott, Donaldson, Tarrier, & Burns 2000; Torti, Gwyther, Reed, Friedman, & Schulman 2004). Whilst acknowledging the positive aspects of caring for others in substantial need, Kitwood realistically points out the martyrdom, neediness and low self-esteem that often drives people to be professional carers or impacts on the caring styles of those who become carers by default (Kitwood, 1997). The inability to sort out their own desires and needs from those of others can cause substantial stumbling blocks to the people they are caring for. We had already heard about the husband who wouldn't allow Leanne to drive, and the wife who apparently didn't let David "off the leash", and it seemed only right to explore the impact of these (possibly very sensible) decisions on the participants.

I was able to describe to the group my own situation during a conversation with a professional colleague who had poor self-care abilities, who was irritating me, a response which probably reflected my own past and present deficits in this area. Neil immediately mirrored self care to us by informing us he would not be shaking hands with anyone there, since he had had laser treatment on areas of potential skin cancer on his hands. Ben nodded wisely and then began talking about put-downs. David said, "Why be difficult? With a bit more effort, you could be bloody impossible!" Paul thought today was fine, as a result of it not being yesterday, which was a bad day.
We played the *Hand Game*, which can be quite confusing as to which hand to move, once everyone's hands are alternated, spread flat around the edge of a circular table - a further difficulty. This was followed by conversations between partnered cats and dogs, which had become a firm favourite of the group. This animated "cat-and-dogawauling" was followed by more partner work, where each person sculpted the other into a position. For example, Paul sculpted me into an angry position, and Leanne called me *The Lost Cause* (perhaps *loss* as a cause). Neil called his sculpt of David *The Tackler* and Leanne sculpted Delyse and called her *Shhhh*, announcing that she "liked doing that" (quietening her down) and Ben put Katsuko in a rampant position and called her *The Challenger*. Then each sculptor took the position of the sculpted, so they could experience how that felt.

Old memories came up for Leanne, perhaps stimulated by her assertiveness in silencing Delyse. She told the group again of her experience as a primary school child, having to stand beside the principal every lunchtime, and not being allowed to play. I took the role of the principal, and asked Leanne to tell me (in role) what she thought of me, so she was able to say how much she hated this woman and resented her curtailed playtime. This intervention worked to some extent; however Leanne was eventually confused about the role play, and could not sustain it. From that point of view it was unsatisfactory, since a projective technique would have been a more helpful intervention at that point; however, Leanne was able to say how she felt about her treatment:

*Alone. Miserable. And quite a few other things. You know...I mean, my mother went down to see her and she just told her as soon as she...as soon as she saw my mum who was a beautiful woman and she just said, "Get out - I don't want to see you". I had nothing then. No one. Not even my mum.*

---

29 For people with moderate dementia like Leanne, projective techniques are more distanced and therefore less threatening than roleplay. Another participant could have stood in for her, or a puppet or doll. More information about Embodiment, Projection and Role (Jennings, 1999) can be found in Chapters 2 and 9.
Leanne was highly distressed by this memory, as her words suggest, and it was only when she was encouraged to look carefully at the empathic faces of some members of the group that she felt supported.

Delyse responded to an invitation to have a good argument with someone, and named herself Dishonesty in the role of a bathroom tiler. She improvised with David who called himself the Country Squire. In the roleplay, Delyse in her role duped the Country Squire into thinking she had tiled his bathroom well, whereas in fact she had cut corners, not finished the job and managed to get paid by the Squire before she had fulfilled the contract. It was an interesting interaction, in the light of David's own experience, disclosed by his wife earlier on, of losing money in his legal firm, which resulted in the loss of their house. This was especially ironic, in the light of David's past professional life. Delyse admitted to being gullible and having been cheated herself over such a situation.

The metaphor that underpinned these two scenarios was also observable in a third. Neil described how, when he was walking round the room warming up to this work with difficult people, he had a memory of being in Year 10 at school, helping younger boys with sport in the lunch hour, and carrying basketballs down the corridor with a sandwich in his mouth, as he had no way of holding it. He was given the cane for being in the corridor at lunch time, and for lack of permission to help the younger boys.

It seemed that in all these cases, there had been an expectation on the part of protaganists that there would be playtime (as with this group - I am actually giving them playtime throughout the project!). The expectation had been that a contract would be honoured and that a service could be provided to younger people, but punishment of one sort or another ensued instead. Kitwood (1997, p. 89) calls this "the diminution of persons as a norm in everyday life" which becomes apparent so easily in a context such as dementia care, but is a "malignant social psychology" occurring often in ordinary life, whose effect could be compared to "a low-level background radiation" (Kitwood, 1997, p. 89).
There was a sense of the unfairness in all the stories, and a general sense of empathy for one another from those who had also experienced unfairness in their lives.

**Act III, Scene 4 In the Land of Forgetfulness**

There was a lot of conversation at the beginning about forgetting, as follows:-

Paul: I discovered a lot of things about memory, or lack of memory.

Joanna: What have you discovered?

Paul: Well, I forget things left, right and centre. Forgotten. *(broad smile)*

Leanne: Gone, gone, gone.

Neil *(laughing)*: Very good. Ah, good one!

We played a game that was new to the group, called *Fruit Bowl* (Farmer, 2012, p. 3). It tended to be quite fun and active, unless Ben was caught in the centre as the one who was "out", and then he had no idea that he was supposed to call out fruit names, then grab and sit on an empty chair. When an identifying name was called: *apple, orange, banana* or *fruit bowl* for everyone, people were meant to swap chairs. It was very hard for Ben to move back into the game. A perfect picture of the land of forgetfulness!

After the game was over, we played a trust game called *Adam and Eve* (Scher & Verrall, 1975). I was playing Eve to Paul's Adam, and we were both blindfolded and had to find one another in the space. I called out that I didn't know where the sound was coming from, and Paul amusingly called back, "it's coming from my mouth" (how sensible, if concrete!).

Then we walked around, owning the space and limbering up for more Developmental Transformations (DvT). Once inside the "curtain", there were sticks of anger, stones of fear, petals and leaves of grief, and bowls of emptiness (Macy & Young Brown, 1998, p. 101). These objects were used to transform some of the feelings that emanate from unwanted forgetfulness, and it was explained to participants that they could take items from these groups of objects with their suggested symbolism. They worked in pairs once
they had chosen their objects, talking among themselves. Finally, we reflected on this process in the whole group.

In DvT, there is generally no verbal reflection after the drama, as this process is meant to take place in the playspace as part of the improvisation. There are also usually no concrete objects in the playspace; however, David Johnson tells me that he sometimes uses objects there to stimulate the imaginations of participants, something that is particularly important to these group members. Group reflection time was outside the playspace, and Johnson is fine with this method, despite its variation from the usual stages of his DVT intervention (Johnson, March 17, 2012, personal communication).

In the playspace, Ben had spontaneously mentioned tears, but said they were not his own. I wondered if they were his wife's, because as I have mentioned, she was sad at having to lock the house doors for the first time ever, locking Ben in, in case he absconded again. Ben wanted to tell us right at the start about a possible transformation for him:

Ben: once people get older, as they tend to do, (they) should be given every opportunity in the whole place. We've all gone around to turn that into a place for good cheer.

Leanne had said her stone was heavy; however, outside the playspace, she found that her stone of fear had another quality, as she showed us "that magnificent chunk of splendour".

Leanne: It's beautiful, it's endurable...It's intriguing, because it's got a brown stripe around it, and when you come to the top, it's beautifully sparkled all over. So there's something hidden somewhere.

Paul told her, "the sparkles wouldn't be there if it wasn't for that", indicating the dull brown foundation of the rock. (A wise Jungian point of balance there!)

Then Leanne continued in aesthetic mode that could well be noted by the architects and designers of retirement villages:

Leanne (dreamily): It's beautiful...we need to see beauty, because if we don't see it, something dies in us...you've got to search for the good stuff, and it's always a joy to see it...incredible, isn't it, it grows from that stuff (pointing to the brown stripe) to that stuff (pointing out the sparkling amethyst crystal).

Neil showed us his collection of petals, and then spoke to us:
Neil *(filled with feeling)*: I was seeing beauty in the flowers and I was thinking, "Oh, that's nice", and then all of a sudden I just felt tears and then we got together and started talking about...

Joanna: What were the tears about?

Neil: Oh, the sadness of family issues, death of parents, mmm.

Ben showed us a stone he had picked up, and said something that appeared to be a metaphor for this exhausting disease and needing help with his dementia: "I can't give it any more, other than someone who can clean the thing up again and give it some shine".

Paul had picked up a chopstick among the sticks that stood for anger, and this reminded him of the Japanese influence on his family, and almost certainly acknowledging Katsuko:

Paul: One of my sons married a Japanese girl, and she brought new thinking, forms of thinking, and so did the fathers and uncles and so forth...the Japanese connections have been very strong, and very, very much appreciated by me *(broad smile)*.

There was commentary about growing up with fear, and not instilling it in one's children, by one staff member, and seeing a mother robbed of memory by Alzheimer's by another. There was a "feeling of humanity" for Paul, "certain touches and tastes of the music" for Ben, and "I think I feel at home here...which means that I wasn't before" from Neil. It seemed as though some part of the transformation of the sticks, stones, petals and bowls had been valuable.

I had picked up a piece of petrified wood from among the stones, associated with a fear of losing my memory as my own mother had before she died. However, the feeling of privilege, in accompanying these people talking about their losses and the appreciation of what they still had, had overtaken my fear and transformed it.

**Act IV, Scene I The Joys and Woes of Memory**

This scene begins the final Act of the fieldwork drama. We heard some details about the funeral David attended the week before, and ironically, the
deceased was one of David's old lifesaving mates. This polarity was a good reminder to participants that there were only three sessions to go until it was all over. Leanne said she had hoped the dramatherapy would go on longer than this.

The memories of the week before were as follows: Paul immediately remembered France, prompted by his attendance at a Bastille Day party the previous day. David remembered that his wife was in Melbourne, so he felt very relaxed. Neil had drunk a relaxing cup of coffee with his wife before coming to the group, although he said it was no longer meant to relax him in his ambivalence towards the session, but it refreshed him after a long drive from home. Ben's contribution was very muddled, but seemed to link with the previous session; he said, "it gets the people to help them through certain things..."

The main theme of this scene was the identification of various scents, and unfortunately, at this point my research had not yet revealed that people who have dementia, or are about to have it, lose their sense of smell. Since then, research on olfactory deficits and their role in predicting later onset of dementia (Wilson et al., 2009) has explained this previously unknown aspect of the condition. I had been hoping to find out whether scents would bring back memories, and fortunately each person recognised at least one smell, so that memories began to form small improvised dramas that took place over this scene and the next.

Our first warmup was a dance-movement therapy exercise to music, where everyone moved holding onto a stretchy cloth. The more daring people (including Leanne, as it turned out!) could dart underneath the cloth while others moved or stretched it as they wished. It was an easy warmup for what turned out to be a difficult task for people, since they had so much trouble identifying scents. We then played *Who Started the Motion?* (Emunah, 1994, p. 181) which was about as tricky visually as the smelling game was going to be in an olfactory sense. Participants had to observe carefully to see who was changing the activity in the group, as I walked around the backs of
people and brushed someone's shoulder, unseen by the players, and they would initiate a new body percussion movement.

This exercise was followed by the *Emotion Machine* (Scher & Verral, 1975, p. 50), a Playback Theatre exercise we had done before; however this time, participants were much more willing to touch one another and to make the sound of their individual machine part as they stepped in to contribute, with a particular feeling in mind.

The machine morphed into an *I Remember When* activity. People called out the name of an activity they remembered doing in the past, and everyone else copied it. Yolande remembered dancing, Indian classical style; Neil lay on an imaginary inner tube of a car tyre, floating on the water; Ben suggested rock 'n' roll from his dancing days; and David was "hangin' five" in the surf.

Paul wanted us to go to France, and so suddenly we were all in a restaurant in improvisation mode, ordering food. I was the waitress, and there were complaints about the meal: it was cold, there was a fly in the soup, and so on. It was a great opportunity for the group members to complain about me and aspects of group practice, in a veiled manner, when they may have been too polite to do so openly.

Another possibility, however, is that they enjoyed the search for scents. By far the most often recognised scent was that of the orange, variously described as peach, apricot, or more generally, fruit. David was reminded of his boarding school days when he was stealing fruit at night in the orchard, and a nun came down shining her torch, as he jumped into a bush to hide. Quite spectacular, especially as Neil volunteered to play the bush! Once again, David had escaped from the scene without repercussions, and I often wondered if he would have liked to have disappeared into the wide blue yonder earlier in his life when his aerobatic and much admired twin brother met his demise.

The fruit scent was important to Neil, too, and reminded him of intimacy and connection with his mother, with a scene in the kitchen as a seven-year-old. As time for this scene was running out, I asked him to keep it for the following
week. Ben was reminded by the rosemary, which he described as "fine pine scent...of peaceful celebration" (of course rosemary is for remembrance and is used in Australia in peacetime to honour dead soldiers). It was very touching that at the end of the group, Peter said he was taking away:

...a much better understanding of myself and my own sort of relationship to smells and things of that sort, and also...the near friends, dear friends\(^{30}\) so that I think it is nice and beautiful and does, in fact, make it for me, a sort of happy situation.

This was to be Paul’s last session. He had a bad fall during the following week and ended up in hospital, unable to return to the group or to the final assessment.

**Act IV, Scene 2 Future Wants and Needs**

We heard the news that Paul had fallen during the week. At this stage, we had no idea that the fall had affected his health badly and it would be impossible for him to return to the group.

Neil remembered the scents from the previous week, and said it was about mood and memory. He had experienced a difficult week being "locked in" at home, because it was raining all the time. Delyse had a feeling of wanting to curl up into a ball and not move, and Katsuko a feeling of dread about getting back to work at uni. The metaphor of being frozen, or locked in, reminded me of Ben's tears ("not mine!" as he had protested) in Act III, Scene 4, which may have been about his wife finally having to lock him inside their house. This was to be a difficult session for Ben, as it connected with memories of his childhood and adolescence.

David talked about "getting off the leash", because he would be going off to the snow country with eighteen mates at the end of the week. It seemed as though Paul's absence had frozen everyone, maybe because he had never missed a beat attendance-wise and was the "elder" of the group. For me, his

\(^{30}\) This was the title of one of the songs we had sung twice to end the sessions (Watts, 2006).
absence provoked an inner sense of dread that somehow I wouldn't end up with enough people to represent my research findings convincingly. Leanne was obviously insecure about the fact that her husband was about to go overseas, and about not knowing when he would go or what he was doing there. Yolande was not feeling well.

We played another a game of Fruit Bowl, where everyone warmed up except for Ben, who just could not understand the rules and found the same obstacles to his enjoyment as before. Neil said, in relation to the work the previous week: "it wasn't about the actual little parcels you created but it went to another stage". And then: "it sort of shifted away from that smell to...I wasn't thinking about fruit, ordinary things like that - I was thinking about my mother".

Participants were already quite warmed up. However, it was essential to get the group into embodiment-sensitive mode if we were to improvise Neil's memory from last week. Two games were played where we used flexible strength, either pushing against one another or pretending to enact a tug of war. Ben very sensibly asked if we had a rope to pull, and even though he was becoming cognitively more confused, (or perhaps because of this!) he was able to accept the imaginary rope. Then a quick repeat game of Cat and Mouse, where there was a certain degree of protection of the mouse by the group, against the pouncing of the cat, acting as a preparation for Neil's memory of his mum's loving playfulness.

We set the family kitchen up according to Neil's memory. Pivotal recollections of Zerka Moreno's advice, gained from a masterclass with her in USA (personal communication, September, 2005) stayed with me in the descriptive detail I required of him for the scene, right down to the pattern of lino on the floor.

Neil told us he pictured himself as a six or seven year old in this kitchen scene. He wished to be seated at the kitchen table, where his mother was standing cutting up fruit: "probably apples". He knew there was a stove (Ben suggested this, and I gave him the role) and a window facing the backyard. The addition of the window was accompanied by Neil's "Get up here, David".
However, there was a gracious invitation to Leanne: "Would you like to be my mother?" and although I knew that roleplay would not be easy for her, it would have been counter-productive to prevent this touching impro from happening as Neil wished. He instructed her on all she needed to do at the table, and then she said, "The audience needs to see my face", which seemed to be a powerful expression of unveiling her identity, both as a mother and as a performer.

There was gentle teasing on the part of the mother, when Neil sneaked some of the fruit off the table, and Leanne told him, "You naughty boy", and pretended to chase him around the kitchen as we went through the scene a couple of times. Neil didn't even try to hide his action, but just giggled and told his "mum" she would never catch him once he had stolen the fruit.

In the reflection on the scene, Ben said he was very clear that "those things just don't happen in houses". This may or may not have been a comment about his own house, but a little later, he said, "I'd like to encourage people to do these things" (probably meaning re-enactments of past memories). David said it was a very homely atmosphere, and, as the window, he had liked looking into a happy home. When asked what adult Neil would say to little Neil about the incident, he said: "you're a very lucky boy to have a mum who was playful". Leanne said, after de-roling, "Oh, it's very nice and cosy". Most of us were aware that she had played the playful person she wished she'd had as a teacher, and maybe as a mother too.

Neil said he was "a bit teary" at the flashback, and "the loss of Mum". Leanne said she didn't really enjoy playing the role, "because I wasn't sure where I stood". That made perfect sense from a developmental Role, Projection, Embodiment perspective (RPE), explained in Chapter 2.

Ben asked Leanne how she had felt as the mother, and she replied that she had felt safe. He then made the statement that "it was a shameful kitchen...no real things to come home with (sic)". He said simply that it reminded him of his own kitchen. He told us that at aged fourteen, people left each other notes, and his Dad was hardly ever there - "I am not at peace with
that thing...shocking business”. His remarks then added weight to the earlier one, that such things don't happen in houses.

The session ended with David, who had roleplayed the window, telling us a story of how he pushed his twin brother through a glass window one Saturday morning when his Grandad was minding them. Interesting that there was a glass window between David and his protective family member. Once again, David the rebel was present, together with his much-loved twin brother. It seemed as though Neil's story had alerted David and Ben to incidents which contrasted completely with the playfulness and simplicity of Neil’s relationship with his mother.

Ben commented on the amount of courage that was in the room. Certainly Delyse was very honest, admitting that she was more impatient with her sons than Neil's mother had been, and less playful, and she was going to talk to them about it now that they were adults. I was reminded of coming home to a woman my mother had employed to do the ironing, while my Mum was resting on her bed or not at home. I hated that, and received warmth from Ben when I spoke of it.

At the end, people drew pictures, and Neil wrote about the qualities his father had given him. David made a beautiful art work of his brother and himself flying into the sunset. Leanne drew flowers, since she wanted flowers all around her, always. She was able to get the hang of the piano music to *Near friends, dear friends* (Watts, 2006) which we sang to finish the session.

**Act IV, Scene 3 Grief and Loss**

Leanne was very upset that the group was about to cease meeting the following week. She liked the group, and so it was a shock, because although reminded the previous week, her short term memory had betrayed her. She was also, as she expressed it, "under surveillance". This was because she was either with her daughter while her husband was overseas, or else she was sent to respite at a retirement village, so was feeling lost. I imagined the other participants had similar feelings. Leanne must have been feeling very sensitive, because when Katsuko took photos of the art works they had
made, before the session started, she was worried about where they would end up. She was comforted by the fact that she had signed a release to say they could be published in photographic form and she could take the originals home.

Ben, who loved the printed word, had been reading the group contract again, which he said was wonderful. He explained that it was "easy enough to come through, if you're a person as part of this". It was great to know that, despite the growing confusion of his thinking, Ben was "coming through"! Also, it was another example of his prescience, since the session ended up as Leanne's "breakthrough" session.

The scene was set for grief and loss. Moore and Myerhoff (1977) give advice on aspects of ritual, recommending explicit purpose, symbols and messages, implicit statements, social relationships and culture versus chaos. I was hoping these elements would be present in the session. There was a definite reluctance to finish the dramatherapy - Ben said in his awkward but easily understandable way, "I'd be very happy if it maintains its situation with the house and the people..". When Neil was asked about the previous week, he remembered so much more than usual, and said:

Neil:...everything that was done, was done very purposefully...I think your leadership was the key thing about that. I don't know how to describe it but I knew there was something happening here that was very organised and purposeful.

Neil had really had a hand in that sense of order and clarity, since there was such integrity and intuitive purpose in his memory work.

The grief work began with a blindfolded trust exercise, where it was important for participants to check in with their partners when they were leading them, and make sure they were feeling all right about moving around the room. This was followed by reflection on the experience, together with partners, and then in the complete group, one-word and one-line contributions to the idea of grief and loss, with eyes closed. Among the phrases, "I'm sorry I wasn't there", "I wanted you to be here forever" and "sadness", Leanne's "anger"
stood out from the others, as a completely different stage in the grieving process (Kübler-Ross, 1969).

When they opened their eyes, there were baskets of twigs in front of them, and the instruction was to take a twig and draw the tree that the twig came from. Leanne burst into tears. Once again, she described the dreadful isolated playtimes she had experienced at school as a punishment by the principal.

Joanna: What was your loss?

Leanne: *(fists clenched, jaw set and body tense)* I didn't ever get to play. She just - she was just there, and I had to stand beside her every day, and I hated it.

She wrote some words in green and yellow - her favourite colours - and then I went to help others. Eventually, participants put their pictures near to their twigs, and chose grief cards to place beside them. Suddenly, Leanne said: "Can I just say to the group why I got so upset about it? I just want to tell you".

That was all; everyone knew what it was about. Then Ben talked about a friend he had lost, Neil spoke about the assumption that he thought he would have his mum for ever, and it was hard to realise this was not the case. Kathy spoke about her mum, who had died just a few weeks before, and
Yolande about hers, whom she had lost as a young child: "and my life was bare, like the twig, for a very long time".

When each person had spoken, I asked Leanne if she would like to express dramatically how terrible it was, not being allowed to play. She had been eight or nine, she said. She had suffered loss, because she didn't have any childhood. She picked out a chair for the teacher, Mrs. Lackey, and took some silk scarves for herself to wear in her own favourite colours. Then she picked black and grey for Mrs. Lackey's chair, and the chair became Mrs. Lackey. I tied Leanne to the chair, and explained that people in the group were to be her "releasers". We all began to play, like children around her age at the time, and gradually she was released from her bonds. We played ball, *Stuck in the Mud*, hide and seek, and everyone got involved. Neil started to "booh" Mrs. Lackey, and we encouraged Leanne to insult her, so when she realised what was happening, she said, "You're horrid - you're a thorough bastard!" Neil told her she was the "worst teacher in the world" and Ben looked at the chair and said, "horrible!" Finally, Leanne said: "Mrs. Lackey, get out of my hair! I don't want to see you, hear you, smell you or anything ever again!"

Leanne wanted once again to "chuck her out of the window", but her playmates helped her to get her out of the door, and leave her in the garden. It was a struggle, but finally the door was shut on the Mrs. Lackey chair, and we left her outside. The group came inside and we played with the stretchy cloth again, encouraging Leanne to pull it, as it wouldn't break. Neil said, "you won't break, either, Leanne...you're the queen of the castle".

In the reflection time, Ben said that "it was certainly times coming to clear all those things that mattered". Neil told her she brought joy to the group on a regular basis, and that she had a good sense of humour. Leanne said it had been "very therapatic (sic) for me...thank you, thank you all of you".

The group ended with two songs: *Thanks for the memory* (Robin & Rainger, 1938) and *Near friends, dear friends* (Watts, 2006).
Act IV, Scene 4 Celebrating Ourselves

_Last scene of all that ends this strange, eventful history_ (Shakespeare, 2007, p. 497).

Is this really going to be a tale "sans teeth, sans eyes, sans ears, sans everything" (Shakespeare, 2007, p.497). I think not. Let's wait and see...

BUT IT WILL BE A SCENE OF MIXED FEELINGS.

There was some sadness at the beginning, that Leanne hadn't arrived (her carer forgot), and that Paul wasn't returning. Ben started with a most apt and unmuddled question: "What happened to Paul, if you don't mind me asking?" Paul had fallen and cut his head while in hospital, and had to go to a nursing home. This discussion morphed into David's experience of being away at the snow - he'd had a wonderful time, and had driven the skiddoo. "When you've got the sun out and clear visibility, you can just let yourself go; otherwise you've got to be a bit careful".

This is such a great metaphor for what it might be like to have dementia, especially if David didn't want it to show, or to be Paul at that time. And then Ben began to tell us, I believe, about what dramatherapy could do for others:

Ben: (gesturing, so that we would get the point) There are a lot of people now who have no sense of play...and it's here for example someone in another place comes along...and goes into the situation. There might very well be a good idea for asking that person to go through what you need to do.

Kathy said she felt as though she had been "pulled through a hedge backwards" (part of the title of this thesis) and Neil remarked that there were "a few hedges out there". He was feeling "a sort of emptiness". He had made connections through the programme. "Even simple things, like the songs". Some of the words people said at the beginning were: "fun", "play", "solo" (when you first take off on your own), "chocolate box", "grateful", "company", "friendship", "bonding", "mix of joy and sadness", "big smile", "mixed feelings", and "shared space".

Ben remembered the coloured silk cloths, so we got them out for him and David was a bullfighter, choosing Delyse to be the bull. "Red rag to a bull",
said Neil, and I remembered Tanya, and then the Tiler and Country Squire scene from Act III, Scene 3! Ben and Katsuko played with black and yellow cloths - dark and light - "that black one because there's so much dark stuff around these days" said Ben, and this encouraged everyone into cloth play using movement and gesture. Then the DvT curtain came down, and we all stepped through, to be greeted by the imaginary box. Crystals were found there and handed out, sticky "gloop", friendship rings and then a tree began to grow out of the box. It was a colourful, magical tree, and was growing right up to the ceiling. It appeared to be symbolising some of the growth that had been attained by the group and all of us individuals in it. Many gifts were found, given and received from the Magic Box.

Once we had stepped out of the playspace again, Ben talked endlessly about going to the doctor and giving him a prescription. He agreed to sit in a chair while we placed our hands on his shoulder in turn, and suggested a prescription he could give to the doctor. I started with a prescription for human kindness, Neil tied him to the chair, because his own doctor had "left him in the lurch" and gone on holidays. David said he was prescribing that he, David, didn't want to see him. Delyse told the doctor to "get down off your big chair and attend to your feelings and your patients' feelings". Kathy gave a recipe for fairy cakes, and Katsuko said she didn't want to go to him for a very long time. Ben didn't want to de-role; he seemed to enjoy being the doctor. It appeared as though the medical profession was getting very short shrift, however! Ben said he would tell his doctor a few things, and then:

*I'll sort him out up there, and what happens then is, I'll ask you, could I come back with you and have him sort it out up there while I sort it out down here...down here's amazing!*

The next activity was a ritualised celebration of the dramatherapy group, where each person took a fruit or a flower out of a basket and placed it on a table to celebrate the ending of the group sessions. Neil picked up a flower, and placed it there for companionship. Delyse's gift was for "almonds and raisins" - the Jewish saying for bitter-sweet, and there was a memory of Jewish Tanya in there. Kathy spoke of the richness of the group. Ben said it
was "everything one could sort of...expect...wonderful". David said, "I first thought it was school that mattered...but thank you".

Finally, before a celebratory morning tea, we all sang, *Near friends, dear friends* (Watts, 2006) in parts and then came Ben's favourite expression - "it worked!"

**Theatrical review**

Even though some characters had to play two roles (Katsuko and Kathy were sharing the filming and towards the end some group members seemed happy to take over the facilitation process from me), the number of cast members appeared to be effective. If a therapy group is too large, there can be problems, because participants are nervous of exposing personal material. It was fortunate that staff members and art therapy students were present, since otherwise the final group would have been on the small side by Act IV, Scene 4 when Leanne’s carers forgot about her dramatherapy appointment.

It can be observed from this play that the intersubjective space allowed everyone in the cast (with or without dementia) to become greater than they usually experience themselves to be, or are described as being in the medical model. This especially applied to Ben, whose dementia was becoming more and more severe. His experience can be compared to the participant in group psychotherapy described by Watkins et al. (2003) whose scores in the Cornell assessment (Alexopoulos et al., 1988) and Rating for Anxiety in Dementia: RAID (Shankar et al., 1999) increased. Watkins' participant had actually denied having AD on entering the psychotherapy group, but later showed qualitative therapeutic change. Ben’s quantitative scores did not demonstrate the change that occurred in the final scenes of the Dementia Drama. (This data will be further explored in Chapter 10, together with the CEAA and JASDI). Cognition and re-cognition will also be discussed further in Chapter 9.

Connected with the social cohesion aspects of the Dementia Drama, there was an unfolding re-cognition of common experience which was remarkable,
even in people with moderate dementia. This was particularly noticeable in Ben’s case, as his condition may well have been diagnosed as severe in the end. The experience also shows that feelings of isolation were considerably reduced, as participants finally learned one another’s names and started to show concern for each other. The pain of emotional abuse, such as that experienced by Leanne, and the sharing of that abuse from her primary school teacher as all “playmates” punished the “persecutor”, gave them permission to offer empathic support and re-cognise one another in the remembered distress.

The dynamics changed considerably after Tanya left; however, her presence in the first four scenes was very important, since she “kick-started” the group’s undertone of significant personal issues, as referred to briefly in the Intermission. She also brought up the potential depth of the material that would be brought to the sessions by making reference to the importance of confidentiality and childhood experiences. This feisty gesture was underscored with a rich profundity once it became obvious that she had been an adolescent in Anschluss Vienna – the city of Freud and Adler.

The absence of one or other of the AlzA staff members was unfortunate, and was noticed by participants. This was one of the Drama’s limitations, as it broke continuity somewhat. A second limitation was the large amount of furniture in the room. Some pieces were placed outside on the verandah each week; however there would have been a freer space for participants to explore had we been able to physically move more items out of it.

Act III, Scene 1, the olfactory scene was a disappointment to me and engendered a similar response in the "actors" when they found the exercise of recognising scents so problematic. However, it is important not to forget that Neil’s touching kitchen scenario was inspired by the one scent of orange peel, which he had identified as “fruit”, and it did seem to be a fruitful scene for him.

The discovery that Leanne could play the piano was a great blessing to the production, particularly where ritual was concerned. One of the high points was her ability to play Near Friends, Dear Friends (Watts, 2006) once it had
been adopted as the preferred "closure song". It came at the very moment when people were actually naming one another socially and noticing if someone was absent, so contributed to personal creativity as well as group cohesion.

Healthy assertiveness became apparent from Act II, Scene 3, when Neil was able to share his difficulties with his father, David was courageous enough to take the role of the dying child, and Paul could speak his mind about the hijacking of ethnic stories. This ability to find a personal voice is vital for QoL. Act II, Scene 4 and Act III Scene 1 then opened the doors to harmonious tomfoolery and humour in a way that had not been experienced earlier on. Before this, participants did not actually know who they were dealing with and trust had not been developed. It is also very clear that QoL is contextual, and the production contains many signposts besides assertiveness which the audience can live with and learn from in connection with the QoL of all of us.

With regard to the scoring of QoL, there is an obvious triangulation of the Dementia Drama and the observational assessments on the Creative Expressive Abilities Assessment (Gottlieb-Tanaka et al., 2008) and JASDI (Jones, 1996) with the quantitative research. (The quantitative scores [see Chapter 6] show an improvement in the QoL scores for the dramatherapy group. 31) For example, group scores for "feelings expressed in music anecdotes and stories" began with a total of 2.1 out of a possible total of 4 for Act I, Scene 1. Their score as a group for Act IV, Scene 3 was 3.6 and for Act IV, Scene 4 was 3.1. For "deep thoughts and speaking from the heart", the scores were an enthusiastic 2.6 in Act I, Scene 1 and by the end of the play had reached 3.6 in Act IV, Scene 3, although they dropped to 2.5 in Scene 4. These scores are shown in graph form in Chapter 10.

The lower level in this case, at the very end, could well have been because we were Celebrating ourselves, and the deep and meaningful work had been done in the grief session the previous week. The JASDI shows improvement

31 Observation scores are as follows: 1=never observed; 2=rarely observed; 3=observed some of the time; 4=most of the time (Gottlieb Tanaka et al., 2008).
for most participants in dramatic involvement and embodiment and facial expression generally. Ben’s and David’s scores are detailed in Chapter 10.

These examples of increase in general expression of feeling, honesty and sociability shown in each scene combine well with increased body expression and collaboration. Together with the quantitative scores they show an improvement in quality of life in the dramatherapy participants.

The chapter that follows presents in-depth narratives of four of the participants: Tanya, Paul, Leanne and Neil, as well as my own narrative, incorporating aspects of clinical supervision.
Chapter 8: Narratives

Narrative medicine has always interested me in the area of mental health. The information that is required to be documented in systemic client files is often of a problematic nature and bears little resemblance to the client's healing story. Rachel Remen, a physician and medical educator who is "on intimate terms with life" (1996, p. 3), believes that doctors should connect more strongly with story to assist with healing, and that "story is one of the most potent containers for healing" (2006, p. 93).

I have chosen this narrative form of storymaking in order to gather data about the process of four individual participants and the high points in their process during the sixteen weeks. I have also chosen to relate my own narrative, including a brief description of my clinical supervision process.

The narratives should not be seen as case study formats, since they will contain no anamnesis or formalised history, but are purely based on familiarity with the individual participants in the context of the group.

Tanya

Tanya (not her real name), the oldest participant in the research, was an 89-year-old German woman (88 at T1), who had been born in Vienna. A teenage escapee from Nazi Austria, she had fled with her family by train to Holland, and had then come to Australia on a cargo ship. She had enrolled as a nurse in Sydney with a great deal of difficulty, because as a German citizen she was classed as an alien.

She had been a member of a group of women interested in social justice. In the 1970s, she had protested about the threat of development of an environmentally important strip of bushland in Sydney which had been under a Green Ban from the Builders Labourers Federation. She and others joined the unions to fight on until the early 80s, when the Premier announced that the government had purchased the area for open space, saying it "represents a victory for environmentalists generally" (Sydney Magazine, date withheld for confidentiality). Control of the land was handed over to the
local council early in the 90s, and a plaque unveiled to commemorate the conservation victory. Tanya was awarded her OAM partly on the strength of this fight. The edition of the Sydney Magazine referred to has details of the historical events and stories of all the women involved, including Tanya. It was a wonderful irony that I discovered the magazine containing these details a few days after beginning the group.

Tanya only joined us for four sessions of the dramatherapy group. She was already depressed when she came, and although no diagnosis was given except that of dementia, she appeared very stressed and anxious, and indeed wished out loud that she would "go to sleep and not wake up".

Tanya's sense of identity was not always present. There has been considerable argument about a sense of identity and dementia; for example (Sabat, 2001) as well as preservation of identity through socio-biographical work and embodiment (Surr, 2006). Kitwood maintains that for some people with dementia a sense of identity is assisted through therapy, reminiscence work, and through empathy and communication (1997). Tanya certainly made progress through these means while a member of the programme.

She was in a heightened state of arousal, from the very first session, appearing excited at assessment about the prospect of joining the group. She was, however, very lame with arthritis and walked with a stick, and her excitement rarely translated into contributing to the movement work, although she occasionally engaged in the warmups, most of which required people to stand.

There was a polarity between her robust assertiveness (she was insistent we knew that part of her name meant "spear" in German\(^{32}\)) and her loss of a place in the world. Tanya would often tell us, "I don’t know how I got here". This seemed to be a metaphor for her dementia; in other words, she didn’t really know how she came to be so forgetful or how her mind had deteriorated: "What has happened to my brain?" she would often ask, and

---

\(^{32}\) This is too small and obscure a part of her name to lead to the identification of the client.
almost as often we in the group would search for it. She would then order it back: "Come back, brain!" Once, when asked to move back so people could see one another, she described herself as "not anywhere".

The statement, that Tanya was "not anywhere" affected me considerably. Through clinical supervision, I realised that my own journey may be towards dementia. After all, at the time of writing I was 69 years old, older than some of the research participants. My own fears remained in the background for much of the duration of the sessions, and it was at times like this that they came to the fore. It is as necessary to say this at the outset as it is to discuss dementia with the participants (referred to in greater depth in Chapter 7).

Tanya cried a great deal in the first session, and to a lesser extent in each of the following sessions with the exception of the last. However, she usually managed to engage in activity, and there was often applause from others when she could successfully catch a ball or perform a body sculpt.

Even though Tanya showed that she was depressed from the moment she entered the group, there was an opportunity for her to reminisce on her biography, to be creative and to assist others to be so, bringing her mood to a more balanced level. The drawing she made to represent a sunny moment in her childhood, walking in the Vienna Woods with her father showed clarity and happiness, depicted in red, as the socialist she always felt herself to be, and in sunshine as she walked among the fir trees.

![In the Vienna Woods by Tanya](image)

Tanya was adventurous. Even in the first session, she enthusiastically asked Neil if he had ever been hang-gliding, and queried David, when discussing
his skiing exploits, "Did you ever get over onto the main range?" This would have been unremarkable, except for the fact that she did not question other participants about their lives to any great extent. It seemed to be the risky nature of people's (potential) exploits which interested her.

In Session 2, the group heard about Tanya’s journey at the age of sixteen, escaping by train from Vienna to the relative safety of the Netherlands. This appeared to be a strong metaphor for everyone for the journey of dementia. The journey was re-enacted by the whole group in Session 3, as it seemed important for Tanya as well as others to express this unknowing discomfort. Tanya said that it was very dramatic being in that railway carriage. It seemed as though the whole group was speaking for her, and at the same time for themselves. It was upsetting and suffocating for all to be on this journey of dementia, not knowing whether their lives would deteriorate further.

When we finally arrived in "Holland" (perhaps an oasis from dementia’s relentless onset), members of the group expressed feelings of freedom after exposure to risk and anxiety in role. Exposure therapy aims at desensitising victims to stimuli they associate with the trauma. Exposure to such trauma can allow feelings to be expressed which have been shut down, sometimes since the trauma occurred. "Expressions of vulnerability or anger or sadness can become triggers for the memory of the trauma itself, and are therefore forbidden" (Carey, 2006, p. 60).

Systematic desensitisation is not possible in a group where all participants need to be considered. However, the intervention described above included all members of the group, and had a dual purpose: that of defending against the creeping arrival of dementia with its doubts and fears as well as being a means of group cohesiveness or "the result of all the forces acting on all the members to remain in the group" (Bundey et al., 1994, p. E108).

In this third session, Tanya tested confidentiality rules once again, asking to whom the group video would be shown. With assurances and a reminder of her signed release, Tanya said: "I know, I know, but then I don’t know". For me, this pivotal statement is one which reflects my own sense of doubt. In other words, I knew where I wanted to go with these people and the
opportunities I wanted to give them; however, on the other hand, I felt I didn’t know anything because I had not (yet) personally visited the Land of Dementia.

By this third session, Tanya was somewhat comfortable with the group: "My memory is up to shit…". Then Paul showed his drawing and she complained, "It’s very hard to see it". He replied, "It’s not hard to see it if you come close". Both were elders of the group, and later on Tanya addressed him as "sir", showing respect, in contrast with the distance she kept from other participants.

Tanya had a great sense of irony and, on a good day, of self-deprecation also. Participants were playing a Group Mood game (Emunah, 1994), in which someone had to leave the room and come back when the other group members had prepared to perform a particular feeling. As the group chose the feeling and the word "puzzled" was mentioned, Tanya said: "that shouldn’t be difficult – puzzled!" reflecting her own familiar confused state.

When the objects came out, Tanya first of all took a box of matches, but when she saw the baboushka doll she was immediately attracted by it. I recognised that the doll was more important to her. It offered memories, and seemed to take her back to a more pleasant life stage for a little while – the times she experienced when she would sing the one-liner: "Those were the days, my friend, we thought they’d never end…" (Hopkin, 1968).

It seemed to me that the baboushka, with all its layers comprising six dolls, one inside the other, was a perfect choice for a woman who was aware of her subconscious, a highly intelligent woman of European disposition. She appeared comforted by the doll, and instead of asking the identity of accompanying carers, she said confidently, "I expect someone is coming to take me home". It did not seem to matter that she might not remember this interchange with projective objects for long (Baines, 2011).

As though connected for the moment by the doll to the theme of family and mother-bond, Tanya was the only person in the group to actually verbalise the expression "Easter egg", as I handed out small chocolate eggs to each
person in the group at the end. Easter was a week away, and the next Friday would be missed, as it was Good Friday. Robert Landy (1983, p. 179) sees dolls and puppets as “allowing most clients a safe margin of overdistance”.

Tanya’s final session, the group’s fourth, was an important one for the whole group, but especially for her, as it culminated in the protest performance at Parliament House. Perhaps pre-empting feminist topics which were yet to emerge in the group, Tanya wanted to stamp her feet, so we all did this. Little did I realise how strongly the group would use this action later in the session!

Since the theme of the fourth session was Colour, multi-coloured silk squares were planted in the centre of the circle and each person asked to choose one. Tanya adventurously went in first and grabbed the red cloth. She explained loudly, "Red, darling, I’m a bloody communist (laughter) not to say socialist, but red it was". She said that in Vienna, red was the socialist colour (I note that Marx, too, came from Vienna). "They were marching", she told us.

All participants were then instructed to wrap cloths around themselves and march. Tanya changed the words of the Hopkin (1968) song: "Those were the days my friends, when we were young and game...", describing Vienna to us all. Once the paints came out she depicted a red socialist flag with arrows on it. She described the 1st May demonstrations and we realised "tomorrow" was 1st May.

Tanya’s experiences in Vienna in 1938 have been fully described in Chapter 7, Act I, Scene 4. Her choice of the socialist flag appeared to help her re-live her sixteen-year-old memories. By this fourth scene, she had been able to grieve her poor recall and deeply mourn her unwanted wartime memories, "stamping out" her frustrations and joining with others in her familiar activity of protesting. Social justice had given her a sense of achievement throughout the years of lobbying with her neighbours for the local bushland to be saved.

By the time of this fourth session, Tanya had laughed as well as cried, and made others laugh. She had rejoiced in her carefree childhood before the Anschluss, walking in sunshine in the Vienna Woods. At times she had even been able to abandon her walking stick and play.
Powerful work with the Holocaust has been done with objects in dramatherapy. For example, Yehudit Silverman worked with Sarah, a training therapist and child of survivors, who suffered from constant bad dreams and silence in the family about the parents’ and grandparents’ experiences (Silverman, 2004). As a result of researching stories, Sarah created a beautiful box and filled it with symbols of the Holocaust, including her father’s Star of David that he was made to wear at that time, to identify him as a German Jud. She then created a special ceremony where she lit candles, scattered ash and remembered all family members murdered in the camps. Following the process, she told the dramatherapist:

*I really needed the distance provided by working outside of myself. I had many issues surrounding the Holocaust and through this process was able to get to the edge and face the fear* (Silverman, 2004, p. 135).

In Tanya’s case, there was no pre-reading or careful construction, there was just the colour red. For her, however, the colour worked its magic power and enabled her not only to pay respect to her father’s position at that terrible time, but to assist substantially in opening the door to social justice protest for the whole group. It also gave her the opportunity to show others an important raison d’être of her own existence.

We ended this session by doing some more stamping at my suggestion, but we still had not performed our ritual song. Paul suddenly suggested *La Marseillaise* and led us in the French version:

*Allons enfants de la patrie, le jour de gloire est arrivé! Contre nous de la tyrannie l'étendard sanglant est levé!* (Rouget de l'Isle, [1792] in Davies, 1996).

The translation of this song is as follows:

*Let’s go, children of the fatherland, the day of glory has arrived! Against us tyranny’s bloody flag is raised!*

This was a fitting end to Tanya’s last session. Her feisty appearance and disappearance (she went to a nursing home due to a fall) bears some likeness to that of the resistance socialists in the Third Reich (Funder, 2011), as well as to the vagaries of dementia. Her depression lessened somewhat in the latter sessions, and it is likely that, had she completed a further
assessment, her mood and cognition would have shown improvement. Her quality of life index (QoL-AD) may have done the same, as she was able to re-live a difficult but triumphant aspect of her past, and one that reappeared at later stages of her life.

Although Tanya's mood was depressed after leaving us, she had been able to protest and have her terrible story witnessed, had celebrated her courage with others and had been able to express strong intelligence of feeling. Most of her assessment scores stayed the same or weakened over the four weeks on the CEAA (Gottlieb-Tanaka et al., 2008). However, the figures for her feeling expression and "sharing deep thoughts and speaking from the heart, through words, the arts or through movement" include a 4 in Session 1; three 4s (Session 2); one 4 and one 3.5 (Session 3) and one 4 and one 3.5 (Session 4).

There is an observational assessment backup of the improvement in intelligent expression of feeling visible on video and addressed phenomenologically. Her JADSI score was excellent for facial expression, although not applicable to most aspects of drama involvement, as she was in her chair much of the time and often had to be encouraged to interact with others.

**Paul**

Just as Tanya was the "grandmother" of the group, Paul at 88 was the "grandfather". He had been an architect until retirement, and had then taken a degree in Italian language and Renaissance history, and guided groups around Italy for a University Extension Course. He was cosmopolitan in his outlook and believed in human relationship, particularly family, telling us that his purpose in coming to dramatherapy was to understand others. He mentioned once that he liked to go back in time, and that made "Your ancient ancestors…as near to you as your new children". Paul barely spoke during sessions however, and sometimes when he did, admitted to feeling guilty about dominating the conversation.
Right from the start Paul told us that he needed to control the amount he spoke, because he always talked too much. This is particularly significant, since a symptom of Lewy Bodies Parkinsonian dementia, which Paul had, is for speech to vary considerably from day to day (see Chapter 1 and Appendix 17). In other words, one day he might be speechless and staring in front of him, and another day he might be very chatty. So Paul made up for his silences on his talkative days.

When Paul came in for the second session, it appeared that he had forgotten his presence there the previous week. Variations in attention and alertness are also common with his diagnosis and he occasionally needed help from others in filling in the gaps of words in his sentences. He was also visibly upset about his wife being in hospital having a bypass operation.

Later on, in the warmups, Paul said he had to be careful about sitting up. Perhaps he meant getting up. He sometimes seemed depressed about his drawings, and said he had "made a mess". He told us he had the feeling that everything was going wrong, and then of course "the worst thing is...that you could feel that you wanted to commit suicide or something". I vicariously felt some of the deep misery of Paul and Tanya with regard to their sense of being tired of living, and the despair that must be there for someone elderly with dementia.

By the following session, Paul was feeling much better and his wife was home, although she was not driving yet, so he had come by taxi. We began by showing the pictures he had made from the previous week, and people said they were hard to see. It seemed that when Paul made a remark about coming up closer, he was actually wanting people to get nearer to him, connecting with the value he placed on relationship. When our improvisation took us rattling along in the train from Vienna to Holland, Paul offered some gallows humour, saying, "and we're not going to get out might be the...", resulting in some grim laughter from the group. The metaphor of the possibility of there being no escape from dementia was well and truly alive.

Paul was not really happy with any of the objects in the Finding Treasure session and when asked what was in the crystal glass he preferred to take
from the sideboard, he said, "Probably chardonnay". He presented as someone who relished the finer things of life, and often mentioned European cheeses and wines, etc. This may be because they brought memories of lighter days and lit up his otherwise quite confined life.

Paul's cosmopolitan perspective had encouraged him to travel a great deal. Delyse’s Dutch clogs reminded him of Vollendam, a town in Holland where he believed Picasso and Renoir both spent time. What Paul said was that groups in paintings "grouped and moved around". He may have been thinking of a guided tour in Vollendam; however, it is likely that the "groups moving around" could have been about the dramatherapy group as well, because he had told us that he liked to be among people. He told us in Session 4 that this made him feel normal. So, like Leanne, he was helped by normality to overcome stigma.

By Session 4, Paul was feeling better, and appeared a lot happier about the health of his carer wife. Instead of calling his drawing messy as he had done before, he said about this latest painting, "There's a semi-written Picasso in it" and sure enough, there was.

A semi-written Picasso by Paul
Paul refused a role in the march to Parliament House in this session, but afterwards in reflection he reminded us about the first Australians. "Were they included in the flag?" His social justice ideals seemed to encourage his suggestion that the author of the flag, Neil, had included them in the form of dot painting. He acted the role of the "witness" in the dramatherapy improvisation, a concept that has been widely debated in drama and dramatherapy circles (Brook, 1988, p. 127; Jones, 1993, p. 48; Jenkyns, 1996, p. 20). Jones refers to the audience’s presence as "guide" in this witnessing role (Jones, 1996, p. 112) and in some ways the description fits Paul. He brought the stirring strains of La Marseillaise (Rouget-de-Lisle, 1792) to us in French at the end of the session, and we sang it together, consolidating our theme of social injustice and particularly the lack of freedom suffered by our Indigenous people and many others. It seemed to me that Paul, who suffered a great deal from memory loss and lack of attention, often showed us that his inner core was "essentially both self-preserving and social" (Rogers, 1961, p. 92).

Early in Session 5, he gave an articulate description of what it was like being asked not to drive once diagnosed. He said he gave up driving because he was "getting muddled with things" and the government was changing everything. Then he said the following, reflecting the pre- and post-diagnosis situations as well as the endless regulations attached to road signs:

...you did just come out of the drive and drive off like that. You had to come out of, out of the other thing and check whether it was Tuesday, Wednesday, Thursday, Friday, Saturday and then you had to sort of work out whether it was something that you were, um, allowed to do or not allowed to do...

It is easy to see how driving as a form of occupation can be essential to the self-esteem of a person, and as Kitwood (1997, p. 83) says, "If people are deprived of occupation, their abilities begin to atrophy, and self-esteem drains away". Paul's is a very full description of the transition of the intelligent, moral and independent person from living a full, busy life to the life of someone with a dementia diagnosis. However, he had adjusted his
thinking to accept the inevitable, and instead of "something controlling (him)", he felt after a chat with his doctor that he had no wish to drive in the future.

When the time came to plant bulbs, Paul informed the group that he had done some good things in his life, like influencing his children to become architects, and was proud of his long marriage relationship. He said, "if you marry someone, you change them". He ended the session with an aphorism he often mentioned, *Honi soit qui mal y pense* referring to his life, meaning *Shame be to him who thinks evil of it*. I wonder if this is about dementia as much as his own biography, and about people’s views of dementia (including my own). Paul had a very positive outlook, and perhaps, for him, dementia could be simply a way of providing a rest for a part of his brain.

In Session 6, which was all about memory, Paul said it was "a wonderful thing" and enabled one to be reminded. He was all for positivity in this session too, and did not want to deal with negatives at all. He had difficulty with role-taking, because he was in the moderate stage of dementia, and projection was much easier for him.

Paul's first childhood memory was of animals, and as to teenage memories, he mentioned dancing. "We used to go to dances...first introduction to females really". In his early working life, he remembered having a degree of autonomy in decision-making – he liked reading and studying. As far as marriage was concerned he’d only had or ever wanted one wife. Marriage had been "a great occasion", he said.

At the start of Session 7, Paul was quite perky for two reasons: firstly because he had remembered where he was going during the drive to AlzA, and secondly because of excitement about a Chilean wine. Paul drank wine in his "wicked moments" and it had a shadow-sounding name (my feeling, not his!) *The Devil’s Castle* from Black Garto. He had written the name on a piece of paper, and duly translated it from the Spanish, demonstrating an interest in languages as well as wines and remembering exactly where he kept that piece of paper on his person.
This kind of memorial intelligence shows me that when something of great personal interest occurs, it is easier to remember; this is a no-brainer in some ways, but needs attention in dementia prevention and care. On this subject, David Snowden’s work with nuns shows that people who have had a passionate interest in a topic may have autopsy evidence of severe neural tangles after death, although they showed little or no evidence of dementia in their lives. After autopsy, many of these nuns’ symptoms were found not to be consistent with competence in cognitive assessment during life. A quotation from Snowden’s book shows how one of the nuns reported how a passionate drive to help others had protected the nuns from losing their identity:

Our sisters have spent their entire adult lives trying to help other people in the community. Even in their retirement, they have a deep passion and drive to help others. I think they would see your study as a way to continue their lifelong mission of helping others, of educating others (Snowden, 2001, p. 15).

We also know that in situations where a feeling is concerned, like Paul’s obvious passionate attachment to gourmet food and drink, the hippocampal complex can influence the amygdala in the area of encoding memories. We also know that the amygdala has an effect on short-term and long-term memory function (LeDoux, 1996). Explorations into the neural theory of memory and feeling are showing that there are complex interactions between them, with much more research still to be achieved (Phelps, 2004).

(Just after I wrote this, I found the very next quotation from Paul in the session to be apt, as follows:-

Paul was reminded to take his book with him when he left. His reply was very interesting, in connection with the content of what I have just written:

I won’t forget that. I might forget what’s in it. Yeah. My great hero is Leonardo. Yes, not only did he design things, and build buildings and things like that, he also, and it sounds gory, he used to get hold of bodies when they died so that he could have autopsies and find out how they worked, so that he could see the bodies made up this way or that way.)

In the first grieving session, Paul did not have feelings of grief, but feelings of relationships. He had said he was "not alone any more", and this told us how
pleased he felt to have M___ back. He called the storytelling session a "waste of time" saying that if it was the middle of a war, it might have been relevant, but it was not. He didn’t seem to have a conception of the role a grieving session might perform. However, he conceded that a man dying who wanted to help those left behind (the drama’s theme) was "obviously good", and when it came to placing his flower on the altar, he remembered the victims of all wars.

Despite his memory of his own father, Paul couldn’t feel empathy for Neil when he spoke about his dad with whom he had conflict, and whose name he had been given. He rattled on about his own father and the family name G____ comparing it to Neil’s family name of P____, rather than respecting Neil’s memory of his father’s death. It was as though Paul could see the big picture social justice, rather than the individual relationship; perhaps it was the Lewy Bodies problem chiming in with day-to-day inconsistency in behaviour.

However, in the following session, Paul remembered his thoughts of his late father from the previous week, even though his father had only been mentioned in passing. He played with a balloon in this eighth session, which he called a "Double Gloucester cheese" in the playspace. He was silent after this, and then others surrounded him with coloured cloths and placed them at his feet as he stood like a statue – there was a sense that he was really important to the group – the elder – with real status. Of course, when the "statue" finally spoke, it spoke in Italian!

In Session 9, Paul talked enthusiastically about the book his architect daughter had written about children’s safety and spoke about elders’ safety, suggesting that the book could have been written for them as well. There is a metaphor here about children and old people. "They should look at ancients like me and do the same thing…in fact we’re just as likely to fall over and do something silly as a child (does)".

In Session 10, Paul remembered that he had "barked a lot" in the previous session, another proof that short-term memory was still engaged. When all participants took part in some DvT, he like others became a tree, but
interestingly he was no longer a revered elder, but a "broken tree (needing) propping up". He chose the mango tree (Leanne) to help prop him with one of her branches – perhaps he admired the strength she had been showing in working with a painful childhood issue – and most members of the group mimed pouring water on his roots to heal him. This, like the homage of the rainbow cloths in Session 8 was a moving comment on his elderhood within the group and a sign that he needed others in order to grow. From the tree's broken state where he said, "I'm gradually about to break" to the point where he said "yes" when asked if he was growing on his own, there was the sense of a real transition in affirming his fellow-participants for offering him healing gestures. The broken tree engagement and prescience is interesting in view of his later fall which affected him so negatively after the 13th session.

Early on in Session 11, *Dealing with Difficult People*, when Paul was asked how he was feeling, he said he was glad that yesterday had gone. It transpired that when he was asked if he had difficult people to deal with, since this was the day's theme, he said, "No, only me". He had difficulty holding onto the back of David in the sound and movement line, and kept talking about "slips". I wondered if he meant that he or David might slip - after all, Paul suffered from Parkinsonism. He had very little to do with David throughout the entire thirteen weeks of sessions attended, and may not have trusted him. At other times, his Parkinsonism did not appear to affect him. In a later session, for example, Paul was able to get down on the floor despite it, refusing a knee-cushion, to play the *Hand Game*, a fairly complex warmup performed from a kneeling position.

Since the previous day had been difficult for him he may have sculpted me (Leanne naming me as *The Lost Cause*) according to the problem he had had with himself. The Jungian approach to projection can be of assistance here:

*Projection may be seen as…a defence against anxiety. Difficult emotions or unacceptable parts of the personality may be located in a person or object external to the subject* (Samuels et al., 1986, p. 113).
Paul did not apply any of Leanne’s personal schoolgirl difficulties to himself. Even while she was undergoing bad memories of her school principal, he was noticing a bird singing sweetly outside. When David spoke of his hard time being caned at school, Paul protested that this kind of thing never happened in his schooldays: "we would have told our parents". Yet, at the end of the session, he gently said, "What has been said today and talked about today produced memories of other things".

In Session 12, Paul showed the group once again how much he appreciated his family, as well as bringing his passion for multicultural experience very much to the fore. This session was about memory, and he described how he had discovered a lot about his own and that he was forgetting things "right, left and centre". He had spoken three times about feeling "better than yesterday", or "better than earlier in the week". This presupposed that he enjoyed being in the sessions, even though his wife told us he forgot everything about them later.

When participants were observing their stones and rocks, Paul wisely noticed that if, on Leanne’s crystal, the mud coloured band had not formed the amethyst base, the sparkles would not be happening. This shows a probable recognition of the dark and the light in life: we need the ordinary and the mundane or the darkness in order to see the brightness of the stars.

At the end of Session 13, Paul’s last with us, he metaphorically whisked us off to France (in the DvT space) to a restaurant, where we ate French food, which was one of his favourite pastimes. He found it hard to smell the scents that were on offer in the session, despite being helped by Katsu. At the very end of the session, he told us that he was taking away with him a much better sense of himself and his relationships, a sentiment that was entirely consistent with his aim for the group.

To sum up, I do believe that Paul gained much from the social aspects of the group, and through the work he achieved more of his own kind of self-understanding. He managed this despite his reluctance to volunteer in improvisations. The DvT was extremely useful in engaging his imagination in others’ activities, since he was swept along by the improvisations of others.
Firstly, Paul was the "elder statesman" in lots of ways, giving advice about morality and social justice. Secondly, he made it very clear how interested he was in art, culture and gourmet food, without bringing much personal insight about his childhood, and seemed to have reached a place of peace regarding early disappointments. Thirdly, he was very interested in the ongoing thread through his family, from ancestors to children’s children. His quality of life seemed to be nurtured by this broad picture of himself as a link in the family and the human family chain. It brought a peace and humility to the group which was fostered by the dramatherapy experience, I believe.

He was a very erudite and artistic man, with a strong sense of fairness. I feel very sad that, after attending every session from the 1st to the 13th, his fall put him in hospital and then in a nursing home, and that he felt so unwell that he was unable to complete the final assessment.

(Even Paul’s clay animal, made in Act III, Scene 1, Animal Kingdom, seemed to be rolling over on its back, waiting to have its tummy tickled.)

**Leanne**

There were very few women in the whole research cohort of 17 participants. Participant 4 failed to turn up after the first assessment for the Dramatherapy
group, and participant 14 died before she could ever come to the Film group. Once I asked an unrelated question, and Tanya, the other female participant called out, "I'm not the only one, then". Leanne called out "no" and this connection seemed to be about the female presence in the group and an early sisterhood gesture. However, after Session 4 of the Dramatherapy Group, Leanne was the only female participant remaining in the entire research project.

In the introductory session, both the video and transcript record a considerable amount of feeling from Leanne when talking to Delyse. When Kathy had nearly finished her self-introduction, she mentioned the next 16 weeks of sessions, and Leanne spoke the word "adventure". (This resonated with me, as I thought it was an adventure too.) Leanne called Delyse a "nice lady, who gives (me) smiles". However, then she added, poignantly, "So, apart from that, usually by that time you're getting bustled out of the place. But I enjoy it, coming here".

For a participant who came into Session 1 saying she "keeps busy and feeling normal", Leanne made huge strides in her quality of life improvement, eventually showing herself and us much more of who she really was. She was in denial of many of her feelings before she came, except for her anger, which others at AlzA often witnessed in their sessions. The anger was about her childhood emotional abuse at school, which we worked with three times over the period.

Despite her anger, Leanne was able to make the kind of art that took her into a kinder and gentler natural world. She was able to do this in art therapy, and also on the few occasions when participants made art in dramatherapy sessions. (Even the animal head that appears [to me] from the painting below seems docile, rather than angry! However, Leanne did not describe this painting in any way except for mentioning it as a reminder of the natural world.)
One of my goals during the sessions was to try to assist Leanne in her habit of smoothing over any contribution or comment that was associated with negative feelings, and her constant rescuing of Tanya. When Tanya was crying, Leanne would place her hand on Tanya’s arm, or when her brain had “disappeared”, Leanne would say comfortingly, "you're right", or "you'll be right".

We saw the first glimmerings of what, for Leanne, would be the most important issue she brought to the sessions when, in Session 1, she chose a photo of a little boy with big boots. She said the boots didn’t fit. She explained that the boy was walking with his head down, and was not a "happy chappie". Because he was looking down, she told us, "I think he’s feeling a bit subdued at the moment". This could have been how Leanne’s inner child was feeling as she began to realise we would be playing a great deal – an activity she was denied as a child in primary school. The boots did not fit, because they were adult boots. We were seeing the beginnings of:

*a split between a state of shut-down where expression of sadness or loss might trigger their own associations of childhood trauma, and the*
expression of overwhelming feelings when the memory of the trauma surfaced (Carey, 2006, p. 34).

Would her child be able to play? It's also very difficult to play in big boots, as I remember from my own childhood in England where gumboots were often the order of the day. She also expressed a hope that we were going to be "dramatic"; her wish in this area was eventually fulfilled and her therapy was probably more dramatic than anyone else's over the 16 weeks.

Session 2 was interesting on this level, since when we were improvising she began by walking in the rain with her head down, but then engaged with the improvisation very quickly. When it started to "snow", I threw a "snowball" to her, and she said, "I dropped it". She was happy to make "errgh" and "arrgh" sounds as the weather was becoming warmer. She drew a picture of a more cheerful child with a fizzy drink and no big boots. Perhaps her inner child was anticipating this change from a melancholic mood, and was getting excited about playing.

It appeared that Leanne was becoming more confident, and was relating to Tanya’s admonitions and grumbles in a more grounded manner; Leanne had told us she (Leanne) felt "alive and on two feet". However, when the group improvised Tanya’s journey from Vienna to Holland to escape the Nazis, Leanne was again in denial mode, saying "it could be worse" and "we are all
happy, aren't we?" (Personally I cannot think of a much more terrifying situation than being of Jewish ethnicity at that time!)

In the Finding Treasure routine, she pulled a silver serviette ring out of the mystery bag. Such an object had not been used at home, she said, and I wondered whether other things, perhaps of a psychic nature, "stayed in the drawer".

Leanne left the session quite happily, telling a complaining Tanya that "they've got it all worked out". It seemed that Leanne had let go of a lot of responsibility in her life; also, she was a retired teacher, and this may have been a teacherly response. As the sessions progressed and she began to play, she was able to let go in a way that was inspiring to all of us. Neil in particular wrote on his (signed) evaluation form at the end: "Group stuff with Leanne was remarkable".

At the beginning of Session 4, Leanne used short, generalised words that are fairly typical of moderate dementia. She said she felt normal and when asked to expand on this, she said, "Normal’s normal". She explained by saying, "I don’t collapse...I just do what I have to do and if something is there to be done, well it’s got to be done" - very stoic. As though irked by this flatlined description of feelings, Neil said he thought this group was a strange group of people. Leanne was furious: "How dare you call us strange?" This was definitely the "storming" session, and she was beginning to show her true colours, matched by the session’s title. She had been so busy being "normal" that she had not been able to show her innermost feelings!

When Neil’s flag was carried to Parliament House, Leanne took on a protester role, and became Kate. While "Tony Abbott" was making his speech, she wondered, as Kate, why the flag had to be changed. However, she soon caught the tone of what was happening at Parliament House and admitted the flag was "fundamentally wrong for the time". Leanne’s language was changing.

At the start of Session 5, however, Leanne was once more showing self-deprecating traits. She very assertively asked Ben to speak up on two
occasions, and then reverted to an "I must be going deaf" response, displaying a victim approach. Miesen (1992) believes that people often experience situations as unfamiliar or unusual in dementia, and then their need for attachment is engaged. Kitwood (1997) says there is good evidence to consider that attachment need remains when someone has dementia, and in Leanne's case this is likely to be true. Leanne brought a story of rejection and victimisation by an authority figure in primary school to the next session. She told us later that her mother, also a teacher, did not have the ability to get that teacher to see sense in Leanne’s situation. The lack of self-esteem and neediness experienced through lack of attachment encourages people with dementia to take responsibility for problems (such as inability to hear) rather than to see it as the other person’s problem. Later in the session Leanne expressed a wish for a car of her own to get about in. It seemed as though she was starting to trust the group enough to start saying what she really wanted, however impossible it might seem.

Session 6 was an important one for Leanne; it was the opportunity that she had been waiting for to describe her alienation as a nine year old child at primary school. The group had been playing with a Magic Box - a DvT technique (Johnson, 1986). In this narrative, I do not refer much to the work done in connection with her play restrictions at primary school at the age of ten, as their descriptions are documented in full in Chapter 7. An exception to this is her quotation below, as it is the kind of dialogue her carers and therapists had become used to and described as obsessive. It seems to me remarkable that, up to several weeks after the end of the last session, the art therapy students were all reporting that her angry complaints about those incidents had ceased, thus improving her QoL.

*My most live memory (of rage) was when I was about – at school, and one of the teachers, um, decided that she, that I had to stand beside her every lunch time. I could have eaten her – I was so angry for a long time because everybody else went out to play and I had to stand beside that loathsome woman and learn to hate. I’d never learned to hate before.*
Her carer/husband had also mentioned it as an obsessive memory and told me one year later that he had not heard this again.\textsuperscript{33} This was a surprising and pleasing piece of information that supports the mixed method results for drama as a psychotherapy. The intervention in the sixth session was the beginning of the group’s healing support of Leanne’s lost playtime at primary school.

When the group started a memory walk through the stages of life, Leanne remembered her rollerskates – perhaps childhood was a bit of a rollercoaster? From her teenage era, she remembered very little, except that she stayed home and made her own clothes for some years, as they were poor. She talked more about her inability to play, and mentioned "foul play". Then in answer to David’s question, "What reform school was that?" Leanne said that the woman "didn’t know how to play the game". (In a way, I believe Leanne does know how to play the game of dementia, and her anger had made her more articulate than usual. She was to work on the memory, using this anger more keenly, in future sessions.) Norman Fedder explains how this works:

\begin{quote}
Rather than discussing and analysing personal problems with a therapist, you’re guided through the embodiment of them. You have the opportunity not only to play yourself in relationship to the threatening figures in your life and mind, but also to rehearse more effective ways of dealing with them (Trainin Blank, 2012, p. 10).
\end{quote}

In Sessions 7 and 8, Leanne was in an uncomfortable situation physically, as she was suffering from a torn retina and poor sight. She was anxious and didn’t know what "they" had done to her. This transition from the confidence of being able to deal with the difficult childhood memory and then to have the shock of an eye operation must have been painful. The metaphor of partial sight is also relevant here. She admitted during the session to "feel(ing) threatened", even though not asked to take part in many of the activities. This feeling of an eyesight deficit is a loss to the psyche and we were in a powerful session on grief and loss. She explained: "I have two images coming out of me at the same time". This makes sense in my own personal

\textsuperscript{33} See also Chapter 11, question e) on transferability of improvement to the rest of participants’ lives.
process – the image of the courageous, creative elder allowing therapy to take place and the confused elder with dementia, not understanding place, time or activity.

When I said I was going to tell a story, Leanne called out: “tell me a story, tell me a story”, like a child wanting comfort. She was unable to concentrate on the story or its improvisation or to place a flower on our little memory altar, so I did this for her.

Leanne's confusion was also apparent in the following session: *Celebrating Ourselves*, although she certainly had an inspiration when we were in the DvT playspace. The Great Depression was mentioned, and we all got down on the floor, except for Ben, into a physical "depression". Leanne’s escape strategy was to roll, and we followed her, rolling back and forth out of the depression. Again, it seemed like a comforting way to deal with depression.

It was fascinating to see how Leanne would arrive feeling out of sorts, and as soon as we would start to play, she would become more lively and the offending eye would cease to trouble her. While passively sitting and watching the group or listening on the other hand, she could not feel comfortable at all. The experience of sitting out and observing a trust exercise where others led a partner around blindfolded was understandably described by her as "scary".

After a break, at the end of Session 9, Leanne played *Tie me Kangaroo Down Sport* (Harris, 1960) for us on the piano. It was the first time she had played for us, as I had only just discovered her musical ability, and it brought her added confidence.

Leanne brought a handkerchief to Session 10, as though she had a lot of tears to cry. Once we had become involved in the emotion machine, she wondered whether Ben was going to fall over. She also echoed others’ words which may have applied to her inner child: "lost child" and "disease to children". When Paul said he was a broken tree and needed help, she said she had a "sinking feeling", as though her mirror neurons were working overtime (Berrol, 2006). However, in the improvisation, she fetched water to
"heal" the broken tree, even making the sound of water. Leanne seemed to be recognising the power of healing in this session.

In the Magic Shop, she protested that she had everything that she wanted when offered the possibility of future aspiration. When pressed, she said she "had everything she could get away with" and I wondered if this meant that she managed to get around the carer’s agenda for what she should have? She didn’t have any bad habits and was "just ordinary", so I asked her if she would like to trade some of her ordinariness for energy, which she had already told us she needed. She didn’t know; she hadn’t tried it yet.

Leanne played We’ll meet again (Parker, 1943) on the piano. She was not familiar with the tune; however, she tried her best, and it was just recognisable.

In Session 11, Leanne sculpted Delyse and took ages to think of a name for her, until she came up with Shh. Interesting. She said she thought she liked doing this Shh (is it about shutting up teachers such as the despised Mrs. Lackey?). When we talked about difficult people – the theme for the morning – she spoke about "old memories".

Adrian Burton, in his Lancet article citing the arts therapies in dementia, warns the therapist to be vigilant due to the risks involved in bringing up old memories:

Risks might include eliciting counterproductive reactions in patients who feel uncomfortable being involved in interactive drama or similar activities. “As with any treatment, the response could vary, depending upon a person’s past experience and personality”, explains Peter Coleman (University of Southampton, UK). “The type of patients that might or might not benefit from this kind of intervention has to be well established. Further, we need to be aware that such interventions could cause memories of past traumas to resurface, thereby worsening quality of life” (Burton, A., 2009, p. 785).

On the other hand, Mills (1997) writes about the messages inspired by the feelings attached to the memories of participants in her study of a small group of people with dementia. An understanding of their feelings diminished their anxiety, and enabled their recall ability to function more effectively. It is
possible, she hypothesises, that this understanding reduced difficult effects of attachment, allowing participants to feel safer (Mills, 1997).

Leanne said she was trying very hard to "bury" the memory of being deprived of play. Bearing in mind probabilities such as Mills’ theory just referred to, I pointed out to her that this is not always a good idea. The roleplay I chose to do with her did not work well, as mentioned in Chapter 7; she called out: "it hurts, it hurts". The group supported her in this rather dysfunctional intervention, however, and spontaneously clapped her when completed. In the reflection, I could see that she was totally unable to comprehend the concept of the inner child, inasmuch as the adult needed to be aware of the wounded child part of self; however later in the session she referred quite stridently to Mrs. Lackey, the principal, as "bastard". That finally alerted me as to how to deal with it in a projective way, should it come up again, which indeed it did in Session 15. I then realised I needed to follow the principles of RPE (Jennings, 1999; Jaaniste, 2011b).

When Kathy referred to the previous week’s piano playing, saying that she loved it, Leanne answered that "some of the notes didn’t come through, though". (This may be a metaphor for the role-reversal attempt, which had been much too sophisticated and difficult for her. She may have been attempting to tell me that her issue needed more work).

In Session 12 Leanne showed her acknowledgement of her light having been under a bushel in the past, when she took the centre of the circle in *Fruit Bowl*: "Oh well, there, I am in the middle, right under the lights. Never been there before". This may well be true, and perhaps this dramatherapy group has been an opportunity for her to shine.

In contrast to this self-deprecation, I felt Session 12 was important for her, as she really showed us her sense of beauty that she was always willing to show in her drawings. When asked what she had brought out of the playspace, which had been filled with the concrete material of stones of fear, sticks of anger, petals of tears and bowls of emptiness, Leanne said, "A beautiful chunk of splendour". This showed her ability to transform these symbols. She had already used the contrasting descriptions of *heavy* and
light to compare the stones with the feathers. Then she turned to her stone of fear, noticing its beauty and durability - "there's something hidden somewhere". (She could have been talking about herself). She described the brown bottom part of the stone as "something you'd throw away", but it was suggested that it helped to grow the beauty. Leanne agreed, appearing to be re-framing the "less than OK".

In the thirteenth session, Leanne was very playful, taking a few risks in the dance movement exercise, running underneath the stretched cloth that everyone was holding onto. In the fourteenth session, she was glad the rules of Fruit Bowl made sense, but then added: "crazy sense". This oxymoron seemed to be helping her to leave behind her view of self as "normal".

When she was chosen to be Neil's mum in his kitchen drama, she surprisingly said, "the audience has to see my face". I believe this showed how far she had come since the first session, as she was much less confident then, and unwilling to show her feelings. It was difficult for her to play the role, as she had moderate dementia. However, she managed a little better this time, chasing Neil around the "kitchen" and appearing to enjoy it. Leanne was able to reflect quite articulately on her part in Neil's small drama, telling him that he was lucky to have a nice family, although she may not have completely understood her role.

In Session 15 (Grief and Loss 2), everyone chose a bare twig without leaves from a basket, so that they could experience the loss of foliage. She mentioned anger, and spoke about her lost playtime. Because of this, I suggested she draw herself playing, instead of joining the others in depicting the tree the twig had come from. She then requested in several different ways that she tell the group about her loss of play. Her questions demonstrated a substantial difference in the way Leanne approached the work towards the end of the programme, in comparison with earlier sessions. When I suggested that there would be time in a few moments, she replied with one word: "anger".

Leanne's projected drama with Mrs. Lackey as a chair festooned with black and grey cloths is fully documented in the previous chapter. It was the third
time she had visited this memory, and it seemed to have settled her down in a way that the two earlier improvisations had failed to do. There was a wonderful irony as we sang *Thanks for the memory* (Robin & Rainger, 1938). It was Leanne's last session, as family members had forgotten to instruct the carer to bring her for the final time. This was unfortunate, as she had attended every previous group and had expressed her disappointment that the programme would be finishing.

Leanne's average scores from the first session had begun in the low 2s, indicating that most of the assessments were only rarely observable. Gradually these averages climbed towards the 3s (2.94 in Session 6) where 3 denotes "sometimes observed". After her eye operation, the scores declined, and reached rock bottom in Session 8, when her average was 1.84, meaning that most assessments were barely observable (1 = never observed). However, after two weeks rest, her average was 2.96, and thereafter always in the 3s except for Session 14, when it again reverted to 2.46. It peaked again at 3.31 in the last session she attended, which was the significant scene where she got rid of troubling anger about her abusive teacher, apparently for good. Her scores were fairly consistent across all areas: memory, attention, language, etc., and in Session 8 had all been consistently low.

There was also a definite building of self-esteem that took place in the last two sessions she attended (3 and 3.5 on the CEAA), although her earlier confidence scores had been lower during the programme.

**Neil**

Neil was fairly reluctant to commit to the programme from the first invitation to join the Dramatherapy group. His carer, who worked three days a week, was willing to take him from their home to AlzA on one of her free days to give him an interest, since he was often alone at home. This carer was also aware and sensitive about Neil's own freedom of choice, and it is unlikely that he would have been under pressure in this situation.
As it turned out, he was an energetic role model in the group, unable to prevent himself from taking cues, modelling collaborative behaviour and encouraging the hesitant steps of others. The dynamic was probably familiar to him from his days as a counsellor and a priest. He was open and honest about his difficulties, and his candid approach appeared to be rewarded when others followed his lead.

When the photos were chosen in Session 1, Neil chose a hang-gliding picture. I asked him if he has done any hang-gliding. He replied in the negative, and then informed us that he was "a heavy sort of person, not as in weight but as in..." and was unable to finish this sentence. I suggested "mood", and he agreed, and also said he was a bit slow. He had chosen the picture because hang-gliding was a very elevating kind of activity, with the understanding that it was a polar opposite to his reality.

When we enacted the intense train journey from Vienna to Holland, and the train finally stopped, Neil suggested firmly that we breathe. It was an instruction to all; he was showing his awareness of what the group might need. He said he felt relief at getting out of the train at the end. In the Group Mood game, Neil pointed to the chair next to the door for Ben, saying that if he sat there, he could "make an escape". (I wondered if it was actually Neil who would have liked to beat a retreat.)

It took Neil a long time to feel comfortable in the group. It was easy to understand why. As he was the person with dementia in its mildest form, the people around him seemed weird and he said so. He was entirely open about his religious affiliations, right from the word go, when he sang his name to a religious tune, when others were embodying theirs where they could. In Act I, Scene 3 (Session 3 - Finding Treasure) he picked a candle with an angelic message from the object bag and made it obvious that he believed in some kind of spiritual beings who accompany us.

In Session 4 Neil didn’t speak much while painting, finally showing us the Australian flag he had designed, completed with dot-painting in blue and white. Later, I asked him if he would like to make a performance inspired by his flag. He spontaneously agreed. Then Ben and Neil had a bit of an
argument about what was in the flag, and Neil said he thought Ben "a bit wobbly about it", and that they had to be strong. "You've got to go for it mate – this is really important", he said. He did a great job of getting people on side in believing this should be a new Australian flag. He was not shy of asking opinions about it, and there was a delay while others proffered differing thoughts. He continued to encourage the group to be strong (a favourite adjective). Then he was "off to Canberra", leading the line of protesters and saying he wanted people to be waving the flag, marching around Parliament House.

Participants were assigned names other than their own for de-roling purposes. However Neil suggested the name change was to evade the spies from ASIO. (In my own life I have gone from Esme to Joey to Jo to Joanna, and all of these names give me space for exercising a different part of myself.) On this occasion, Neil chose the name Bruce, a very Australian name for his new national flag protest. This scene is pivotal in the story of the dramatherapy group, and sits squarely in the "storming" stage of group practice (Tuckman & Jensen, 1965; Yalom, 1995). It is also a protest against dementia, as mentioned earlier.

Figure 5. 'Forming, storming, norming and performing' Yalom

(Google, Retrieved April 19, 2013).

Once a politician had been chosen (Delyse as Abbott) to stand outside Parliament House, people started to march in protest. This marching action was started by Neil, and there appeared to be a body identification and empathic connection, similar to that recorded by dance-movement therapist Berrol (2006), picked up neurologically through the mirror neurons: "While
not an identical replication or echoing, a qualitative mutuality is reflected" (p. 310).

In reflection on the political protest afterwards, Neil said he saw himself as a fairly quiet person, although he enjoyed performing. Also, whatever his opinions, he admired his character Bruce for his willingness to speak out, "and a lot of Australians don't do that". He did not like Bruce's ability to turn people off because he couldn't calm down. "It takes all types, doesn't it?" (This is significant, in view of Neil's initial comment that people seemed strange.)

Later on, when Paul said, "What about the first people?" Neil thought it a good point, and they should have been more outspoken (to "Tony Abbott") about Indigenous people being represented. (It is quite interesting, in the light of all this, that AlzA is now headlining "Fight Alzheimer's Disease" in its promotional material and in its newsletter [Alzheimer's Australia Newsletter, 2012]. It's almost as though these people were ahead of their time!) Neil, ever interested in strength, said "that's a strong, strong voice" when Paul suggested La Marseillaise (Rouget-de-Lisle, 1792) and led the singing.

In Session 5, we talked about dementia. Neil regarded the diagnosis as a "very harsh thing" when first diagnosed, and "there were more than fears, as if, you know, (you) fell off the side of a building". (Since I had prefaced the discussion by asking what it meant for the rest of people’s lives, this was a suicidal thought.)

Neil picked up on Leanne's colourful expression about being "corralled" at home: "Yeah – wow. I was jumping when you said that - corralled". (Remembering that his wife was at work two days a week, there was plenty of time at home alone with his "harsh diagnosis" to reflect upon). Neil's admiration of strength seemed to be an antidote to it, as though he had to be feisty to undergo this illness, the taint of this diagnosis, and rebel against it.

When we finished the session early, Neil said, "early release". When asked to develop this phrase further, he compared it to people in jail. "It's a very strong expression" - that word again. As I write this narrative, I am aware of
how difficult it was for Neil to take part in the group. Yet he spoke for the group so often. It also occurs to me that an "early release" from the prison of dementia might be death.

In Session 6, the group was initiated into DvT. Neil was hauling a rope, but had no idea what was on the end of it, except that it was heavy. The group generally didn’t know what they were hauling, but Neil seemed to think it might be gold. This appeared to be a metaphor for the fear of the unknown in the progression of the disease.

For Neil, however, it was an important find, especially as later in the Magic Box episode, there turned out to be treasure inside the box. "Mmmm – gold", said Neil, the rope-puller. Elsewhere, I have written that Neil was getting used to the idea of being in this group, and beginning to find gold there (Jaaniste, 2013a, in press).

When the Magic Box became an Emotional Soup, Neil threw in the anger of men who did not have access to their children. I wondered if this was about the children (his nieces ad nephews) who did not visit. Neil had no children; however he had empathy for those who did. He said later in session that he and his wife, who had married late, made a decision not to have children. There were perhaps stirrings within Neil about the future – will nieces and nephews visit if and when dementia debilitates him further?

For Neil, a walk through the childhood area of life stages was connected to the above theme and he remembered being read to in bed as a child, and, as a teenager, being extremely shy with girls. He didn’t become an adult until 30, he said, because of all the training he received after his years at school. He did have nieces and nephews, as indicated above.

In Session 7, the story of Ulu and the Breadfruit Tree (Gersie & King, 1992, p. 237) was narrated, and Neil said much later – weeks later – that he had chosen his because Ulu died, so he wouldn’t have to do much in the scene! After the enactment he was inspired by its message of hope: "Without hope or belief, nothing arises out of it".
At the time of the performance of the story, Neil was quite concerned about people not being able to make the transition from the tribal sense of the story to the present day. However, he entered into the role to a surprising extent, sometimes being prompted by me, and sometimes taking his own initiative. Before he de-roled from the father role, he said: "I am happy to have passed on to my son all that I have known, and all that I have been".

I have written elsewhere about the "feeling intelligence" shown by Neil in this roleplay (Jaaniste, 2013a, in press). After the story had been improvised and Neil as Ulu had gone to the temple and found out from his god that he was to die so that his son could live, he was buried in the earth by his wife. In the story, a breadfruit tree grows from his burial place and the fruit of the tree cures his son. In this role, Neil, as Ulu, told the son: "I don't want to put you in the box", then turned away to pay his visit to the temple to pray for advice, returning to advise his wife on what will happen after death, and then dying at home and was buried by her.

His reflections on his roleplaying helped him to express his grief about unresolved matters with his father, when later on, at the end of the session, Neil placed a flower on the grief altar and expressed his feelings towards his father and earlier conflict with him, sensing that he was still around somewhere. After someone close to us dies, we feel very lost and we are no longer seen through their eyes. Alida Gersie writes that:

\[
\text{we want to recover the person who died. We owe them the debt of attempted retrieval, for otherwise our love may be proven to have been non-existent. The faint whisper of emerging guilt can be discerned} \quad (\text{Gersie, 1991, p. 93}).
\]

There was a significant connection between the father/son relationship in the play and the healing relationship between Neil and his dead father. Along with his realisation that he would now feel comfortable about being in the earth himself, this session was pivotal for Neil.

Neil expressed great satisfaction with the roleplay and dramatic ritual, which is hardly surprising. Anthony Storr, Jungian psychiatrist, describes the satisfaction obtained by creative expression as follows:
Part of the satisfaction which a creative person obtains from his achievement may be the feeling that, at last, some part of his inner life is being accepted which has never been accorded recognition before (Storr, 1985, p. 58).

Early in Session 8, when he started to play in the DvT space, Neil had the initiative to suggest that we "step back" because we were in the "wrong era". We were in the World War I era, and stepped back (rather than forward) into the Great Depression, and the conversation turned to money. I find it significant that the Depression mirrored that felt by some clients; for example, Tanya had been depressed from the moment she arrived in the group, and for all four sessions she attended. Others, for example Paul, also seemed depressed from time to time.

The poignant interaction that took place between Neil and Katsuko, described in Act II, Scene 4, was significant for the whole group. He was glad to be reminded of his abilities rather than his disabilities. Neil found the courage to say what many of us feel from time to time and he did not brush off a compliment as David often did. He also used the first person singular to describe his abilities, whereas most people are not good at this. His background as a counsellor may have assisted him with the language of "I" rather than "you".

At the end of the session, he said he felt uncomfortable with the activity of complimenting one another that I encouraged participants to do; however he expressed that it was good to break through barriers, and also to be reminded of his strengths. (It is interesting that this was the last session of eight, and people had been reminded several times that they would then have a break from sessions. My interest is sparked by the fact that at the end of a group of sessions, big issues come up. Neil was breaking through uncomfortable barriers and getting in touch with his own self-confidence, an essential ingredient in QoL, and borne out by his CEAA scores.)

In the ninth session, (the first of the second half of the programme) there had been time for Neil to re-visit his resistance to attending. He initially said he "would rather be snorkelling down at the bay". Yet he mentioned he could
say anything in this group, other than harmful things, and was getting to know people. When he became the mouse in the game, he called himself "a sly one", perhaps acknowledging ambivalence. He asked a few facilitator's questions which had the effect of speeding up the game: "Who hasn't had a turn?" and "so who's doing what now?" Again, once the Animal Cards activity started, he asked Ben: "Are you a monkey?" "Have you got one of these (cards)?" "See? We're both monkeys".

There was a lot of hilarity around the shaping of the animals from clay, as well as when Ben lifted his leg like a dog, as a monkey (Neil: "Did I see something?"). There was also amusement in "getting them to stand upright is another matter" and in introducing the idea of an easily sculpted snake to David, who wondered how you made a "bloody lion". He appreciated having the time to be creative, and "making creatures". He made the letters of the title "Monkey" out of clay to explain what his clay offering actually was.

In the Magic Shop, Neil wanted to "buy" a sense of beauty for his wife to show her that he respected her. He would sacrifice (and "pay") his beard for her, because she had never liked it. He wore it as a reminder of an earlier time in his life when young men had long hair and beards. On reflection, Neil said his partner was always doing things for him, and he wanted to give something back, so it made him feel good. He did not want anything for himself except parts for his bike, probably representing being able to get about when his wife wasn't around (an antidote to being corralled or imprisoned). He hoped the barber wouldn't do a terrible job, and he would have a word in his ear about the beard.

In Session 11, Neil had come in with a burned hand and other parts of his body had been lasered to control skin cancers. He said he wouldn't take much part in the session. He called Ben "very strange" in reply to Ben’s "do you think I am strange, or something?" Ben had possibly not forgotten this insult of Neil's from Session 3.

In the Statues exercise, Neil named David, The Tackler, a good name for him, as he was in a pugilistic pose, and often tended to push people away. He listened carefully to David and Delyse's interactive roleplay, and
suggested that the Country Squire (David’s role) might have "wheedled his way out of it" – *it* being the deal with the dishonest tiler (Delyse’s role) – "and got someone else to do the job". (This is a big difference between Neil and David – one plain speaking and open, and the other enmeshed and "covering up"). This may have given David the idea to sue for faulty workmanship. (The group had been together long enough for them to give each other ideas – not fed by the facilitator all the time.) Interesting that we then came across a situation where initiative was shown, and the person was punished for it.

Then Neil said that when he was wandering around, "seemingly aimlessly", there was something that came back from schooldays. A memory came up from Year 10, which has been related in the previous chapter, where he was caned for carrying basketballs for the younger students at lunchtime. "It would have been different if I had been jumping in and out of windows". Here was another example of the memories of unfairness that can come with dementia.

When I asked Neil if this remembered scenario allowed him to empathise with Leanne, he said the two situations were different; he described this as a one-off, whereas hers was "constant torture". She agreed, but told him they weren’t allowed to cane girls. Neil said his memory had surfaced for a reason – "something that was dead and buried (that expression again!) 45 years or something". (I think this is another instance of Neil seeing life and death as inextricably linked – just as in his Ulu experience with a burial in the earth and his dead father's spiritual closeness.) He told us the trigger was picking up a baseball cap and putting it on back to front as he might have done at recess in school. It encouraged him to "kick the paintwork", to stomp around a bit and be a bit stroppy. He said he was taking away "just hearing people’s (stories) – all the tension and the resolution of that".

Tian Dayton comments on qualities of psychodrama which assist a gradual movement from activity to resolution, which could equally be seen as a description of movement accompanied by simple dressups in dramatherapy:

*The beauty of exploring the emotion through action is that the emotion can surface as originally felt, and can be explored from that perspective*
first – before it is edited or reflected upon in any way. This is a process of joining and moving into a person’s inner reality, of validating it as it exists within that person, with no attempt to manipulate it to conform to other people’s perceptions (Dayton, 1994, p.2).

In Session 12, Neil contributed also to the reflection of the session, in that he was just going along looking at the concrete material, and then had the experience of thinking about "what we can do and what we can't do", and then remembering the death of his parents. (Neil’s partner in this exercise was Delyse, who had lost her mother 20 weeks before.)

This partnership finally enabled Delyse to share some of her grief about her mother, as well as some of the gifts that her mother’s death had left her with. Also, right at the end, Neil said he felt at home (for the first time - a big step!).

In the next session, our thirteenth, he showed trust in the intervention planned for that purpose, and although he found the smelling exercise difficult, he really enjoyed the dance-movement stretched cloth exercise. His I Remember When impro was a huge contrast to David's, who was back in the surf again, but without any feelings, just with achievement. Neil said of his own childhood memory: "It was just an amazing moment and it was scary but I loved it". He was referring to the first time he ever floated, on an old tyre inner tube. He stood and watched others improvising this experience, and said, "Don't drown". This seemed to be a metaphor for "Don't let your dementia get the better of you".

His "scent memory" of the fruit reminded him of his relationship as a child, with his mother. This memory morphed into improvisation in the fourteenth session, when we tried to remember scents that had been experienced the week before. At the start of this session, Neil reminded us that the smelling exercise had shifted for him from the small bags to memories of his mother: "So it wasn't actually about the little parcels you created but it went to another stage". After the Fruit Bowl game, which was difficult for others, and which he helped to organise, Neil had the opportunity to improvise the scene in the kitchen with his mum.
Neil was 6 or 7 years old, in his mother’s kitchen. He selected Leanne to be his mum, and described the scene and his interaction with his mother in detail. Ben and David took part in the scene as well, and six-year-old Neil taunted his mother, "You can't catch me. Get onto my little brother!". It unfolded in the reflection that he had been perfectly well aware as a child that the scolding was playful, and she wanted him to be around – a powerful affirmation of having been loved by her. Neil's scene was a stimulus for other memories for Ben and a dramatised memory from childhood for David.

The following week, Neil had a clear memory of having improvised the scene with Leanne as his mother. He went on to be complimentary about my facilitation of the group, telling me metaphorically that I was actually a "good enough mother" to the group (Winnicott, 1971). Among other comments, he told me: "you could skip this way, and you could skip that way". As Winnicott (1971) has suggested, writing about the therapist holding the group:

> Perfection belongs to machines, and the imperfections that are characteristic of human adaptation are an essential quality in the environment that facilitates (Winnicott, 1971, p. 139).

Neil was positive when we undertook our second trust exercise as well. He could not believe he was taking a large number of steps and had not bumped into anything. He told his partner Kathy she was doing a very good job. In the group invitation for participants to speak words encapsulating grief and loss, he contributed, "I wanted you to be here for ever" and "letting me go". His picture (shown below) depicts the flying away of the blossoms from the twig chosen by him in the final session of *Grief and Loss* when he had just performed in the kitchen improvisation. There is a poignancy about the patch of sunlight on the terracotta tiles, where Neil is still walking the earth.

When it came to Leanne’s last interaction with Mrs. Lackey, he supported her all the way. It was as though he held her in higher esteem for playing the role of his mum. He shouted, "Go for it!", booing Mrs. Lackey. He reckoned she did not deserve a nice colour (like Leanne’s self-selected colourful cloths).
He encouraged Leanne to get her out of the room - "Come on Leanne, get in there", and "Put her out there - this is too close - keep your colours". He showered Leanne with compliments and took with him from the group "the gift of life".

In the last session, Neil did not have a great deal to say. When it came to talking about the group ending that day, he said he felt an emptiness, but that it would take a couple of weeks for him to make more connections, although he had made connections, especially through song - "I love that". When we threw the ball and called out what we would miss about the group, he said, "play", "company", "a mixture of joy and sadness" and "laughter". I was reminded of a verse from Blake’s poem, Auguries of Innocence:

Joy and woe are woven fine,
A clothing for the soul divine.
Under every grief and pine
Runs a joy with silken twine.
(Blake, W., 1988, p. 490).

Neil remembered the coloured cloths which he liked and as soon as they appeared, he encouraged David and Delyse in their bull-fighting activity. He was always a great encourager. Later, in the Magic Box exercise, when we
got into the playspace, he found memories growing out of the container, and with the help of the group this turned into a memory tree. He did not try to "own" the tree, but left it to others to fill in the details imaginatively. Then Kathy "saw" the twigs from the previous week in the box, and took them out in mime, giving one to each person. Neil remembered that his had been covered in buds, and was "alive".

When he was asked to place a flower in the basket provided and say a word about what the group had given him, Neil said, "companionship": bitter-sweet, as we knew he spent days on his own by himself. At the very end, once we had sung Thanks for the Memory (Robin & Rainger, 1938), Neil called out, "another one, another one", so we sang Near Friends, dear Friends (Watts, 2006).

Neil began the first session with fourteen 4’s in the CEAA, and this number went down to four 4’s in the third session (he did not attend the second). This negative development appears to show that he was having second thoughts about attending the group. However, in Act I, Scene 4 (Session 4) Neil’s leadership of the protest march was a turning point for him. He became much more sure of himself and willing to take the lead, rather than running himself down.

In the following session, Neil’s scores were low. He shared with the group the harshness of the dementia diagnosis, his resistance to continuing to come, his isolation from society when at home, and his relief that the group finished early. Unsurprisingly, his psychosocial scores were generally much lower than usual. He was not rated as attracting the attention of others in warmups, nor commenting on others’ creative expression. However, this picked up again in the following session, and his confidence rating continued to be assessed at 4 each week except for one, until the end of the programme.

Neil’s language ability and body language appeared to suffer in Act III, Scene 1 - Animal Kingdom (Session 9 after a three week break). His resistance had returned, and even though joining in the clay work, he appeared to want to leave the drama activity to other people. His memory was also poor, and it
became more obvious that the act of making a transition after a break was not a simple matter for him.

In Act III, Scene 3 (Session 11) when Neil was prompted to kick the wall and express how he felt about it, his confidence was still assessed as fairly low, at 2.5; however he was given an almost perfect score for expression of feeling - three 4's and one 3.

In the final two sessions (Act IV, Scenes 3 & 4 - Grief and Loss 2 and Celebrating Ourselves 2) Neil's scores on the CEAA were extraordinarily high. In Session 15, he was assigned all 4s, except for two 3’s and a 1. In Session 16, he achieved 4's in every case except for four scores of 3.5, and a 1. It is difficult to predict why his quantitative assessment one week later had deteriorated in some of the scales, and this will be discussed further in the following chapter.

**Joanna's narrative and clinical supervision process**

This narrative takes the form of the consciousness I experienced of my own conscious perception, and is an exercise in exploring the phenomena offered to me during the fieldwork by the participants. It seems important to trace my role in the quest to overcome the Cartesian split between mind and body, described in Chapter 3, from a personal point of view. This was done phenomenologically, and also through asking questions about the nature of dementia, the character of grief, and other topics that seemed relevant for our life stage. My own consciousness will be discussed below. Meanwhile there were significant media influences that were brought to bear on my fieldwork, and my clinical supervision also had an important bearing on my process.

Notes were written after each session, so that as well as being able to watch the videotape, I documented the salient points of the session and my own responses to what occurred. I worked with certain aspects of sessions in clinical supervision. Aspects of my observations are described in this narrative, as are topics brought up and worked with creatively in the supervision sessions. Occasionally my description is intertwined with ideas
that came to me through my visits to the theatre or cinema during the five month process of assessment, facilitating the sessions and final assessment in two cities.

From very early on in 2010, I had also been collecting newspaper articles about the elderly and people with dementia, even in the realm of how to dress the "More Mature Laydee" in such garments as "elastic waist pants, tunic tops and artfully draped dresses" (Alderson, 26th June, 2010, p.39). By the following week in the same magazine: Good Weekend, Alderson had changed her mind about sensible clothes for oldies, and was promoting the idea of "growing old disgracefully", telling the reader about the sartorially extroverted Anna Piaggi. Alderson had once thought Piaggi looked "like a heap of old clothes" but realised now that this 79 year old "female Quentin Crisp...not beautiful in face nor figure, (had) found another way to be extraordinary" (3rd July, 2010, p. 39). This was apparently the answer to the now disregarded elastic waists of the previous week!

I was experiencing the media's ambivalent attitudes to old age, and although this reference was perhaps a lot closer to "infotainment" than ontological discourse, it was somewhat representative of the views of old age that appear in a range of (not always populist) media. Obviously, the thinking goes, if one cannot hide the ageing body, it is important to be outrageous. Somehow though, for me, the expression "a heap of old clothes" held within it a metaphor for the homeless old person who, in the affluent societal view, would almost certainly have dementia. It also reminded me of the tell-tale ageing of my own body, and the fact that one of the participants was younger than myself.

From the very first session, I was struck by how well turned out these people were in their appearance. This was probably more due to the responsibility taken by their spouses; their own choices may have been far less conservative and more eccentric. It seemed as though their spouses were trying to save them from dementia, or at least its outward appearance, and Paul's wife was forever telling me she often had to ask him to dress himself again, or help him with this, when he had his pyjama trousers underneath his
street clothes. Almost all of the carers were women, and I am persuaded that this not only meant that participants looked well-groomed, but also that they had come at all. I cannot imagine what would have occurred if the reverse situation had been true, and the males had been in the position of taking the initiative and assisting their spouses to enrol in a project associated with dramatherapy. I doubt that the same would have been the case. To a lesser extent (due to my less frequent opportunities to observe) this was also true in Newcastle, where the only female who enrolled died before she could experience the film group.

My observations began by looking at the participant's physical self: his gait, how he moved as he entered the room or sat down and whether his step was heavier or lighter than usual. Then I would look at his skin and hair, and evidence of his energy, as signs of etheric life. These signs are important, because often they show how the person really is, healthwise, rather than whatever they may admit to about their wellbeing. The consciousness I was trying to hold felt somewhat like the conscious deep breathing in Pranayama or meditation (Light on Yoga Resource Trust, 1990, p. 78) as opposed to ordinary unconscious breathing.

Then I looked for the astral signs, which were often easier to pick up; in other words, how were they feeling, and did their actions fit with their words? For someone like Leanne, for example, who wanted to fit in at all costs, and never wanted to appear strange, as she told Neil in Act I, Scene 3, these signs along with the body language were key elements in my role as the dramatherapist. Lastly, I looked for signs of a healthy "I" in the participants; for example when Paul stood up for the people of Polynesia and appeared to express his views on appropriating an ethnic story for the purposes of a session for Australians on grief and loss. Another example of this steadfastness of the authentic "I" is when Neil realised firstly, just how competent he had been in the past, when complimented on his honesty and sincerity, and secondly, how important it was to remember what he could still do, rather than to remember only his disabilities.
In June 2010, when I was still at the stage of searching the literature, I went to a compelling production of *Waiting for Godot* at the Sydney Opera House. Sir Ian McLennan played an understated Estragon, and I have written elsewhere about the poignancy of this play in connection with dementia (Jaaniste, 2011b; Chapter 2 of this thesis). The barrenness of the set with the leafless tree was preparing me for the fieldwork I was about to begin, with a powerful visual and performance-oriented realisation of the negative aspects of dementia. Then there was the refrain at the end of each Act: "let's go", and the stage direction, "they do not move" (Beckett, 2006, pp. 47 and 87).

Later on, in the first few sessions of the field work, I was to be consumed with trepidation that this would happen, that I would say "Let's do..." some activity or other, and they would not move! (It is difficult to be conscious when one is consumed with trepidation, so these were times when the phenomena were lost in a haze of my own making!) A difficulty with walking was particularly obvious with Tanya, and a couple of times I had my heart in my mouth when I insisted she stand up, or in her last session, had her sitting on a simple plastic chair so that she could stand more easily. However, the movement, standing and even the way she was eventually seated all resulted in her being less tearful and appearing less depressed, for longer periods than was earlier the case. All this showed me that she was possible happier when her very strong will was engaged.

There was a sense for me that participants – even Neil – were happy to come, despite omitting to say so, a kind of bonhomie that cannot be measured. How do I know this? Participants fell into little rituals: Ben's wearing of a French beret or some other rakish hat on entry; Paul's reiteration of having his coffee "solo" on arrival – meaning without milk – but also bearing a meaning for me that this was his place, not his wife's; he was "flying solo". Even David's joking about being "let off the leash", although annoying to me as the therapist who would have liked him to unpack that somewhat, was good for the researcher to hear. There was a sense that, in this role, it was helpful for me to have signals that people were not being
dragged kicking and screaming to take part in the project. The growing sense of belonging that happened in the group was heart-warming.

At the same time as belonging, there was an "alone-ness" for everyone, including myself. Even though I was accompanied by helpful students, and the organisation had provided everything I had asked for, the early morning drive from my home was accompanied by a catalogue of "what ifs" going around in my brain. If anyone rang my mobile phone, it was sure, according to my astral, unconscious self, to be someone saying a participant had had a crisis and would not be turning up. I would try to envisage the session and often pictured a lack of engagement. I had a sense that participants may have experienced a similar paranoia; at least Neil was always open and honest about his dread at coming, or his preference for going to the beach if the weather was fine.

Watching the movie *The King's Speech* (Canning et al., 2010) helped me with this. It was not until Lionel Logue made mistakes (the speech therapist, played by Geoffrey Rush) that the therapy began to work. He offended the future king by calling him "Bertie", and when he tried to apologise and then let go, Bertie realised he did indeed have the personal strength to become King George VI. Rush's extraordinary skill in acting the role turned the film into dramatherapy for me.

**Clinical supervision**

Clinical supervision was a great help with my own process. I therefore add to this narrative a few paragraphs which briefly describe aspects of the supervision that assisted me in my relationship with dementia and with the group as a whole.

*Without supervision, I would become less flexible in my ways of thinking, would see a narrow understanding rather than a broader one (someone else’s eyes), have less creativity and be less emotionally aware* (Jones, 2008, p. 63).

Since I work in supervision using all of the creative arts therapies, my own process has often given voice through song, enacted through movement and drama or recorded in artmaking. My difficulties with some aspects of group
process, interlaced as it was with my own process, was often expressed in supervision sessions in my growth in the role of a tree, my journey through the water as a fish or enacting the role of a person with dementia. In this way I could reverse roles and reply as the dramatherapist or as the researcher.

These forays into all of the arts modalities enabled me to see more clearly when I was trying to force actions or reflective conversations with the participants or when I was less conscious and full of fear about the risk to myself – of "catching" dementia. Supervision helped me to work out what was happening in a group session and plan the next one. For example, the For
getfulness session (Act III, Scene 4) needed to have plenty of freedom for the participants to work regarding their own memory loss and be assisted in this with concrete material. An exploration of my own losses through a drama exercise enabled me to understand that I needed to bring objects into the Developmental Transformations (DvT) playspace (unusual in this model), and led me to the Macy and Young Brown (1998, pp. 91-94) exercise mentioned in Act II, Sc.4, and to using the sticks, stones, petals and bowls in the playspace.

To return to the tricky topic of consciousness: there were moments for me during the sessions when I needed to depart from my plan. Clinical
supervision was a great help in this area. After the third session, in April 2011, I was assisted by performing my own drama, as a fish who jumped out of the water, in making the changes I needed to make. In role as the fish, I felt the "dryness" and creakiness of the first three sessions, realising that in old age, there is a drying process, as in the autumn leaves which had been depicted in a drawing in Session 2. As well as the lack of moisture in the skin, eye lubrication dries out so that there are often no tears to cry when there is grief. I felt the sense of being a "fish out of water" in my drama, aware that the metaphor connects with the persona of the person with dementia. I reversed roles with a tree growing beside the pool, realising that the tree symbolised the dramatherapy, and that the fish had to keep checking on its roots. It could only do so from under the water, where I was no longer dry (being conscious of the security and fundamental growth of the dramatherapy). However, the fish also represented the participants with dementia who wanted to be seen, because so often they were invisible, and unrepresented in decision-making by their carers, and therefore "jumped out of the water". The illustrations for this supervision session appear below.

![Illustrations of drama session notes]

Notes on *A fish out of water* by Joanna

The supervised session taught me to "go with the flow" more easily, but not to be "washed away". I went into the fourth dramatherapy session much
more ready to change tack, and this paid dividends, since it was a significant
session where demands were made by the participants about changing the
Australian flag. The change was probably about altering attitudes about
dementia, as I have explained in Act I, Scene 4 of the *Dementia Drama*.

The above realisation meant that I became more conscious of what was
really happening in the group; for example, turning the *Magic Box* into an
*Emotional Soup* in Act II, Scene 2 so that Leanne could express her anger. It
also referred to my suggestion that she cease roleplaying herself with me as
Mrs. Lackey in Act III, Scene 3 when it was obviously not working for her and
she was talking about "bury(ing) the memory".

In conclusion, it has been extraordinary to find through working with narrative
that, although my main experience has been in the mental health area, the
phenomenological approach I have always brought to my work there has
"worked" in this area. It should be no surprise either, that the love of drama,
with me since childhood, has been apparent in the group.

It was a surprise to me, however, that the participants' disinhibition (a feature
of dementia which is also regarded as a symptom) enabled them to engage
with the "as if" experience at a higher level than I was used to with other
client groups. By assisting me to sort out what belonged to them and what
was mine, clinical supervision assisted in showing me the extent of their
abilities in this regard. A new experience for me also, was to consciously
engage their consciousness, and it was a privilege to find out how aware they
were.
Chapter 9: Qualitative analysis and findings

This chapter aims to bring together various stages and types of the qualitative analysis and goes on to interpret the mixed method data in the light of the qualitative findings. A brief literature search on qualitative analysis leads into a discussion from the perspective of the ethical constraints that need to be observed by the researcher when dealing with personal stories. In the following section entitled *Phases of the analysis*, several forms of analysis are described.

Sections on the video watching and the mining of the transcript reveal two different ways of analysing the data - visually and through dialogue. The art works again present visual interpretations of the participants' individual journeys. The analysis of the drama includes the following: evaluation of the Developmental Transformations (DvT) interventions, the RPE paradigm (Jennings, 1999) and participants' embodiment processes in the Jones (1996) Adaptation of the Scale of Dramatic Involvement (JASDI). The ways in which these interventions revealed meaning are examined.

A reflection on the qualitative methods analysis leads on from this examination, where the two participants not included in the Chapter 8 narratives are discussed. This individual analysis and description is followed by thematic descriptions under the headings of Anger and Frustration, Family, Grief and Loss and Memory. The chapter ends with three tables, one for each quantitative scale, where individual change scores over the sixteen sessions are triangulated with qualitative data.

**Analysis**

It is of great significance, as I have intimated throughout in this thesis, that the researcher should question herself and her belief system at all times. In a narrative inquiry into nurses' work with people with dementia (Graham, 1999), one of the nurses commented, "really being involved with somebody's life really (sic) requires you to dig deep into your knowledge and question that knowledge continually because it may not be okay" (p. 682). I believe that the
nurse's view expresses a pertinent warning for any researcher seeking narrative "truths", and that dealing with the data emerging from the transcript may mean reading and reflecting on it many times over. I have tried to ask myself questions throughout this enquiry - to "dig deep".

On the question of methodological inquiry into participants' dialogue and dramatic/artistic expression, Stanfield (1998) suggests that:

...since the social, the emotional, and the spiritual (are) integral parts of a whole person linked with the environment, it would also be crucial for such a qualitative methods epistemology to be grounded in holistic rather than fragmented and dichotomised notions of human beings (p. 353).

This gesture towards holism is well nigh impossible to encapsulate in any quantitative enquiry. Critical Realism is helpful in its post-positivist belief that all appearances are available for correction and in need of triangulation. One of its foundational proponents, Bhaskar, (1993, 2002) believes that those non-dual aspects of our being: spiritual energy, intelligence and creativity, balance our world. Through these means, he says, we can overcome our dystopian aspects of disaster, oppression and many other ills, a view in certain aspects in line with Steiner's (1986).

With regard to meta-analysis, Polkinghorne (1995) suggests that qualitative researchers "examine the data for common themes and ideas" (p. 10) and this has been useful in gathering data which is helpful in evaluating QoL improvements (see section on themes below). He also suggests that, rather than the words on the paper, it is the meanings involved in these words that constitute the data. "It is not the words themselves that can be analysed by counting how many times a particular word appears in the text...the evidence is the ideas and thoughts that are expressed by the participants" (Polkinghorne, 2005, p. 10).

The fieldwork numbers are small, and I have not used any computer software in this process, so have not been involved in word-counting. The last thing I want to do, whatever the cohort size, is to go around the world "counting cats in Zanzibar", suggested as a useless pastime for qualitative research by Sandelowski, (2004, p. 216), quoting Geertz, (1973, p. 48).
Smith & Osborne (2003) believe that in using interpretative qualitative analysis, it is "important to remember that qualitative analysis is inevitably a personal process" (p. 67). Since my methodology is phenomenological, it is also essential to be able to describe as authentically as possible what an experience means for a participant or participants. I therefore wish to avoid the trap of writing a thesis using methods that are predominantly autobiographical or in some way overly-contaminated by subjective bias.

According to Giorgi (1985, 2007; Giorgi & Giorgi, 2003) there are five steps to his (and their) model of phenomenological psychological research methodology:

1. Through reading (a transcript), acquiring a sense of the whole document
2. Sorting through text again and establishing "meaning units" from significant data
3. Transforming these into psychological language that conveys their essence
4. Synthesising these transformed units of meaning into a structure for each participant
5. Finally synthesising the transformed elements of each participant's experience into one statement which encapsulates the essence of the experience being studied (Giorgi, 1985; 2007; Giorgi & Giorgi, 2003)

Apart from the "psychological language" aspect of these methodological steps, I find this guide quite helpful. They act as a map, but then I need to throw the map aside. In practice, I find Langdridge's advice still more helpful, since he suggests that the researcher need not attempt to make clear delineations between description and interpretation, as “Such boundaries would be antithetical to the spirit of the phenomenological tradition that prizes individuality and creativity” (Langdridge, 2008, p.1131). St. Pierre's experience has been helpful here:

I use writing as a method of data analysis by using writing to think; that is, I wrote my way into particular spaces I could not have occupied by

---

34 My italics
35 I am using various forms of language in my narratives; for example psychotherapeutic, person-centred and the "language of feeling", rather than the "language of affect". This latter expression is psychological language.
sorting data with a computer program or by analytic induction (Richardson & St. Pierre, 2005, p. 970).

Ethics of analysis

Just as it is important to engage oneself thoroughly with the data, it is also essential for the researcher to be prepared to be at the very least open, and occasionally astonished, at what the research might reveal (Finlay, 2008). The phenomenon must be allowed to present itself per se. Dahlberg expresses this kind of openness as "the mark of a true willingness to listen, see and understand. It involves respect and certain humility toward the phenomenon, as well as sensitivity and flexibility" (Dahlberg et al., 2001, p. 97).

Whether the researcher uses a systematic approach or awaits the arrival of spontaneous intuition, Wertz recommends "an extreme form of care that savours the situations described in a slow, meditative way and attends to, even magnifies, all the details" Wertz (2005, p. 172). In any case, the researcher is privileged to observe/hear the stories of participants and it is her job to try to interpret the world as the participants see it. As the therapist, I could not be "invisible", especially as I was also a group therapist with a responsibility to use my group work skills to accompany participants in the group journey. However, I was "invisible" in the sense that I could allow my ego to disappear. As the researcher, it was equally important during the fieldwork to step back and essential to dismiss my ego also, although in a different way, so that participants could be more clearly seen.

Phases of the analysis

Watching the video

Initially I thought that the footage was of no use. It was of no use in telling me whether creative sessions are beneficial for her, but maybe it can tell me something else. Maybe it can tell me of the isolation a woman with dementia can feel, in a setting where staff are not trained to work that extra bit in order to reach her (Kelly, 2007, p. 111, [researching in a nursing home]).
Kelly wonders in this citation whether the filming has been of any use to the participant, hypothesising that it can tell the researcher "something else". This "something else" for me is the "talkative" body expression documented by Kontos (2005), as well as Jennings’ (1999) Embodiment, Projection & Role (EPR) model (pp. 32-33) reversed in old age which have been visible on film, and monitored with the Jones Adaptation Scale of Dramatic Involvement (1996) (JASDI). The documentation on film of the fieldwork, has been enriching and far superior to relying only on session notes, or even a sound recording.

In Chapters 3 and 4, I have expressed an interest in Merleau-Ponty’s views on body intentionality and Steiner’s (1975) body wisdom as a "fingerprint on the etheric" (p. 58). Although in the research there were no participants diagnosed with severe dementia, where as I have stated, body language is of high importance for communication, it was obvious that Ben’s cognitive ability was deteriorating over the last part of the programme. At the same time his body movement became more demonstrative. This was just one example of the video’s contribution to my understanding of forms of expression and use of dramatic space.

Facial expressions, also, were important phenomena in the interpretation of mood, and constitute one of the items on the JASDI (Jones, 1996). Moments when light fell on a person or an object were magical, as may be seen illuminating the ground in the plate of Neil’s drawing of the buds leaving the twig (see Neil’s narrative in Chapter 8). Since it is impossible to import any part of the video to this thesis, and would in any case breach ethical standards of participant identification, this picture as a symbol stands for the tricks of light, as well as other synchronistic accompaniments to the dramatherapy. All of these phenomena of being-in-the-world assisted in my hermeneutic exploration of the work.

**Deep dive into the transcript**

*The entextualisation of talk via transcription is only one of the many contextual transformations that discourse undergoes as it moves from spoken interaction to published text, and there is no reason to expect or*
demand that it must remain unchanged throughout this process of recontextualisation (Bucholtz, 2007, p. 802).

The transcript was revealing in a different way from the video, as I had a chance to consider the processes of language and dialogue, reflecting on voice and response, as well as realising what an unexpectedly large number of questions I had asked the participants. I have read through the transcript of each session several times, sometimes returning to the video and then writing about the richest and most interesting parts of each session under an individual heading for each participant. In this manner, I have been able more closely to perceive what each session may have meant for each person.

When I wrote the narratives for four of the participants and myself, I discarded a large portion of the material from my "transcribing the transcripts" exercise. Such editing reveals that there is endless richness in the intersubjective drama experience, as well as participants' reflection on it. The phenomenological method illuminates a wealth of discarded material, showing me how significant this research is and that what I am offering here is "the tip of the iceberg". Those participants (David and Ben) who have not been given their own narrative in this thesis have nonetheless had their journeys recorded in the form of individual analyses below.

The immersion in the writing from the transcripts, culminating in the shaping of the narratives and the creation of The Dementia Drama have enabled me to ‘re-cognise’ the participants and to find the treasure that is the qualitative outcome. Entwined in this re-cognition are the individual lifestages of each of the participants, drawn from spontaneous memories as well as from structured sessions such as Act I, Scene 3 Finding Treasure, and Act II, Scene 2, The Joys and Woes of Memory.

The art works

With the available data, no single brain region, pathway or cerebral hemisphere can explain the brain/art relationship. By contrast, it has been possible to ascertain language localisation in the left hemisphere. This is partly due to the fact that art is a complex system where single definable units are not amenable to formulation, unlike those of language (Zaidel, 2010, p. 182).
The artmaking and occasional writing by the participants helped in many ways to harness the drama and gave everyone, including myself, a concrete anchor for reflection when the words would not come or the drama had been overwhelming. David’s picture of himself and his wife on the day of the royal wedding enabled me to see that he felt alienated from his wife; before this, I only had her view, shared with one of the students, that their relationship was difficult. Leanne’s “figure with bubbles” in Session 3 allowed a sense that she probably did not want to stay stuck in boots that were too large for her, with her head down (“not a happy chappie”) from Session 1, and that she wanted above all to play. This overall information contributed towards the uncovering of the invisible which would lead to outcomes that were corroborated by the JASDI (Jones, 1996) table, as well as by the CEAA (Gottlieb-Tanaka et al., 2008) graphs in Chapter 10.

Through their art works, the participants allowed themselves to be "seen". David was allowing us to perceive beneath the "boysie" surface he chose to present and Leanne was in the early stages of releasing herself from the thrall of “behaving nicely” no matter what, which appeared to have dogged her since childhood. By Act III, Scene 1, Ben had actively portrayed his monkey peeing against a lamp-post, so that his reluctance to form a monkey out of clay didn’t seem to matter to him or anyone else. His entire body language was opening up.

The drama

One section of the audience...was seated on the stage, behind the protaganists. Not only did we see the action differently than we would in the "normal" position of audience members,...we became part of the drama for (the other spectators). The effect was to involve us in the action in a way that made us question our own perspective (Levine, 2009).

Developmental Transformations

In DvT group work, the playspace is a clearly defined and safe boundary which can encourage the establishment of robust intersubjective relationships among the group through a clear definition of the environment
designated for play. Dramatic interaction can ensue, using voice and embodiment as well as allowing meaningful integration through reminiscence, re-membering improvisation and being unafraid to refer to bodily and other limitations (Johnson, 1986; Johnson, Sandel & Margolis, 1982). I have made these recommendations elsewhere, citing Johnson, (1986) and Johnson et al., (1982); (Jaaniste, 2013a, in press).

The following steps are usually taken in setting up the DvT: the clients first stand in a circle and and a make-believe curtain is brought down from the ceiling. An imaginary gap in the curtain is found to step through, and then anything can happen. It is part of the facilitator’s role to anticipate potential scene changes using her awareness of themes and group and individual needs.

In the first stage, I used a unifying activity with sound and movement to assist participants to work together, then asking one member to lead it, giving greater confidence to each individual. In the following stages, I helped to define themes or activities, and then identifying, asking participants what it reminded them of, until they were ready for a personification or role-playing stage (Johnson, 1986; Johnson, Sandel & Margolis, 1982).

Leanne’s “flying cockroach” in Session 6 was a personification, although she did not seem to be aware of what it was all about. The improvisation seemed to be a need to lift herself out of the mundane (dark corners and under furniture where cockroaches are likely to gather) and be free to play. At all times there was an awareness of themes - most of the time on my part, but occasionally on others’ - for example, the theme of being allowed to play, emerging from Leanne’s personal material.

The process can then be deepened through surface play, persona play, intimate play and deep play (Johnson, 2005, p. 19). These are stepwise levels of the participant letting go of their everyday concerns and their actions become more inclusive, encompassing the "I-thou" experience identified by Buber (1965, p. 60) as a real connection with another.
The initial step of *Letting go* is assisted by the *Magic Box* technique mentioned in Chapters 2 and 4, which was often used. Here, an imaginary container in the playspace is the source of whatever the group desires (Johnson, 1986, p. 22). The episode in Session 6 where the *Magic Box* technique was used, as explained in Chapter 7, was poignant, where Neil pulled on a rope, found treasure in the form of gold, where others were having quite different experiences. I have explained elsewhere (Jaaniste, 2013a, in press) that such *surface play* can contain "very important issues, feelings, and experiences" (Johnson, 2006, p. 19).

As already mentioned, Johnson believes this work does not necessitate verbal reflection afterwards. It was obvious, however, that this group wanted to talk about their experience. This "find" had helped Neil, as through it, in session six, he was able to tell us how uncomfortable he had been in joining the group initially, and even though he had given his consent, he had always felt reluctant to participate as he approached the venue. By now, though, having earlier dreaded what was "at the end of his rope" he was feeling more comfortable and less afraid of what was coming next. Neil’s feeling intelligence was engaged, and he told us he was glad he was there. What was "pirate’s gold" to one participant and "chocolate coins" to another was true gold for him. This discovery showed us his feeling intelligence that would culminate in Session 12 when he used a more concrete way of saying he felt "at home... which means that maybe I wasn't before".

As suggested by Johnson, the *Magic Box* can later become an *Emotional Soup* (Johnson, 1986, p. 23), mentioned in Chapters 2 and 7. Participants can pull out emotions and return them to the soup with sounds and facial expressions, and most people did so. For this group, anger became the salient emotion. Leanne used this opportunity to throw in anger and take out rage.

Others - a carer, as well as art therapy students in supervision - had described a painful memory of Leanne’s early emotional abuse on several occasions. Her carer had also mentioned it as an "obsessive memory" and
Leanne's rage was about this memory. She was asked what she would like to do with the soup tureen's contents. Somehow, we managed to stretch the "curtains" of our magic playspace so we could fit it through the garden door.

This intervention in the sixth session was the beginning of the group’s healing support of Leanne's lost playtime at primary school. Johnson emphasises that it is not particularly helpful to the group to have one individual concentrated upon. However, in Leanne's case, there was real group momentum behind the Emotional Soup improvisation, and it appeared to carry significance for the unfairness of having dementia as well as compassion for her lack of play. It was important for group closure to return the ritual curtain to the ceiling after the intervention and step out into the room again.36

This issue was dealt with twice more in other ways during the course of the 16 sessions, and I have referred above to the fact that Leanne did not mention the episode again during more than one year after the programme.

Embodiment

It has been extremely useful to apply the JASDI, Jones' adaptation (1996, pp. 273-4) of the Sutton-Smith Lazier Scale of Dramatic Involvement (1981) which describes the body awareness and use of space by participants. The scale contains indications for such aspects of the drama as focus, use of imaginary objects and of space in the room, facial expression and body movement.

It is noteworthy that the scale details in many instances how connected a participant can be in their body language with others in the group. This kind of collaborative embodiment can be part of their miming of imaginary objects, their elaboration of a group improvisation, their use of space in relationship with others, as well as their social relationships and responses. In this way, the scale supports the CEAA psychosocial items (P13 - P16), all of which involve the attention to or responses of others in participants' creativity. The

---

36 There are further stages of the DvT technique, unstructured play being an important one which was employed over the 16 week programme.
CEAA is not an assessment tool specific to drama, and it has therefore been helpful to watch the videoed sessions with the items on the JASDI in mind.

It became very clear as I observed particular participants throughout the programme on video that their body movement initiatives gradually changed as the sessions progressed. Body movement, as pointed out in previous chapters, has implications for the phenomenological aspects of this thesis as well as the reversal of Jennings' (1999) EPR developmental characteristics of mild, moderate and especially severe dementia.

For the JASDI assessment, I chose the dramatic involvement processes of two participants, neither of whose stories appear in the narratives of Chapter 8, and followed their progress through all of the sessions. Once this was achieved, I chose an earlier and a later session for each one and adapted the scale once again to a scoring system where two sessions were assessed. Their first instances of reporting are in identical sessions: Session 2. However, David's Act III, Scene 3 (Session 11) was the most expressive dramatically, and I believe this was because there were dressups and concrete material for him to use in his body expression and use of space. Having been a solicitor sitting behind a desk or else in court all his working life, it was difficult for him to use his body expressively. Ben's most active Scene was IV, 4 (Session 16) where I believe his dementia was deteriorating and he was finally more comfortable in his body.

**Projection**

A great deal of projective material was available in the dramatherapy, used by me to ease people gradually into improvisation over time and give them an early sense of movement, as balls could be thrown and silk squares waved and worn in a relaxed way. Objects were used for *Finding Treasure* in Act I, Scene 3 (Session 3) and people were provided with reminiscence objects; in my earlier professional experience with people who have dementia I had found these helpful. Objects can take people back to a time which should not be understood as simple nostalgia. As Knocker (2001) points out, when the time-shift happens, the person may be trying to give a
message that concerns their identity: "I have not always been like this. There was a time when I was competent and valued by others" (Knocker, 2001, p. 8).

Roleplay
As the sessions progressed, more roleplay took place. The grief story in Act II, Scene 3 (Session 7) was still mostly "directed" by myself as therapist; however, the role-identification that came from Neil was powerful and affected others during the reflection phase of the session. This roleplayed story laid the foundation for small improvisations in Act II, Scene 4 (the Country Squire and Dishonesty sketch, for example) which was motivated and chosen through the projective stimulus of hats by David and Delyse. Later, of course, the Mother/Son Kitchen drama in Act IV, Scene 2 (Session 14) which had segued from the smelling game in the previous scene (Session 13) was almost entirely directed by Neil. Accordingly, the Mrs. Lackey drama the following week was mainly directed by Leanne and the other participants. These later dramas can be seen as resolution therapy in the Rogerian sense, and as such have a significant bearing on improved QoL.
Trust and disinhibition

My choice of method was encouraged by the unexpected level of trust in the the participants. At the same time I was surprised by their level of disinhibition which could be mistaken for trust and is a recognised symptom of dementia (Zamboni, Huey, Krueger, Nichelli, & Grafman, 2008). These combined factors meant that I was able to let go of some structure earlier than I had supposed (the "train" improvisation leaving Vienna for Holland as early as Act I, Scene 3 [Session 3], for example), as there was a group willingness to perform. This was surprising because of their levels of dementia being for the most part mild or moderate - in other words, if these had been severe, they would possibly have been much more disinhibited (National Dementia Helpline, retrieved October 7, 2012). It was not until Act II, Scene 2 (Session 6) that the drama really took off with the Magic Box (DvT) exercise and people began to find "rope", and a "treasure box" at the end of it. This segued to the Box becoming a Soup, and the "eviction of the soup" to the garden was led by Leanne, wanting to express anger about her obsessive memory of being emotionally abused by her teacher when she was a child. After this dramatic turn, I was able to let the structure go to some degree and allow more freedom of choice.

Reflection on the qualitative methods analysis

Qualitative results, borne out by the CEAA (Gottlieb-Tanaka et al., 2008) and JASDI (Jones, 1996) underpin outcomes based on methods described in Chapter 4, showing that the methods used were generally helpful in "making the invisible visible". Furthermore, for the group as a whole and for all participants concerned, there was evidence of improved QoL. This analysis gives way to suggested QoL improvements for the two participants in the dramatherapy group who, because of lack of space, do not have a narrative to themselves.

37 My bold font, indicating the surprise value of Leanne leading.
David

David was able to explore his relationship with his deceased twin brother throughout the sixteen sessions of dramatherapy and express his apparent marriage difficulties through a painting, as well as through apparent “throwaway lines”. He had been very close to his twin brother, and yet was not able to say how he felt about him except through art works. He had been a surf lifesaver, who loved skiing, camping and picked out a torch in Finding Treasure which reminded him of going camping with others. He was a life member of his lifesaving club, so it was very poignant that he drew the picture below, with its illustrative advisory to "swim between the flags”.

It was almost as though nothing as bad as his twin brother’s death could happen in flight during an aerobatics display if only he was careful enough from now on. There they are in the drawing, the two of them as they had been in life, swimming safely. David mentioned his brother many times during the life of the dramatherapy group, and it may have been vitally helpful for him to hear himself speak, act or see himself draw about his soulmate. Later on, in the first grief and loss session, Act II, Scene 3, he placed a flower on the grief table and said, "for my brother". This seemed to show resilience in the face of regret, in front of witnesses.

![Swim between the flags by David](image)

There is no photograph of David’s “Royal Wedding” portrait of himself and his wife described earlier. It may be that the couple were able to talk about the
couple's apparent alienation in the painting, which would have been very healthy. I surmise, however, that this discussion was unlikely to have occurred. He had come into that session complaining that he was "rusting out", and it is just possible that an expression of his relationship could have assisted his QoL if he could have told his wife how he was feeling. His only comment on the painting was in the third person, "They are man and wife", even though he printed his own initials and his wife's beneath their portraits.

There were many times when David spoke about his relationship in macho terms, such as "I'm off the leash" or "The war office (his wife) is now in Melbourne, so I'm completely relaxed".

In Act II, Scene 4 (Session 8), he was able to experiment with the role of a gay person, which he did through movement (without stereotyping the role by flapping his hands or wiggling his hips). It seemed as though this role helped him to become less protective of himself, and there were times when he was able to throw himself into the drama more fully. He took on the role as The Country Squire in Act III, Scene 3, where he was "ripped off" by Delyse’s role of Dishonesty and may have recognised the projection in the roleplay, since his wife had told us he had lost their savings through bad judgement, resulting in the loss of their home. Yetsuko had complimented him on his honesty in Act II, Scene 4, and he had replied, "Me? She doesn't know me well, does she?"
David was able, in later sessions, to improvise several escapades from his life which were risky and which he survived. He was able to disclose being badly physically abused at school. We know he attended a school which has since become notorious from the 1960s for sexual abuse of the boys by certain priests and this may have also been the case earlier, in his own schooldays. Craig Haen says of such children:

_Boys who have been sexually abused present strong clinical challenges; guarded, evasive, tentative, angry and terribly afraid to trust._ (Haen, 2007, p. 250).

So although David did not admit to being sexually abused, he displayed some of these characteristics. I submit that those mentioned here by Haen can apply to boys who have been physically abused as well. It is likely that for a grown man who has never received therapy, using metaphor could be self-protective and an avoidance vehicle to hide deep hurt and anguish over the beatings or worse. This could be a reason for his sometimes inappropriate humour and satire.

There is sometimes a relationship between known or imputed histories and performed narratives in such stories. It is likely that the dramatherapy was able to release some unhappy memories, although David never admitted to this. He used the work to emphasise, possibly to himself as well as others, that he was a survivor - another gain for his QoL.

David's early weekly average observational score was 2.66 on the CEAA (Gottlieb-Tanaka et al., 2008) and towards the end entered the 3's twice, ending up at 3.38 and 3.04 during the last two sessions he attended. His score on feelings was highest at Session 13 where it entered the 3's for the first and only time – he improvised himself as a schoolboy stealing fruit from the school orchard at night and then jumping into a bush and hiding from the nun (the not so good mother?) who came to find out who was truanting. (His wife was in Melbourne also, and he was feeling very free, and "truanting" in a way). His (signed) evaluation of the programme was all in the "excellent/very

---

270

38 0 = No Observation; 1 = Never; 2 = Rarely; 3 = Sometimes; 4 = (nearly) Always
good" range, except for the question on his self-development over the time, which he marked as "good".

There was certainly an overall softening of his relationships and increasing enjoyment with others, and an apparent improvement in QoL which is also borne out by the JASDI, where his drama involvement and body language went from a score of 46% to 72% between the second and the eleventh sessions.

**Ben**

Ben’s journey towards severe dementia has been partially documented in Chapter 9 from the point of view of decision-making and problem-solving. Observations and scores appeared to move in a direction which is unexpected, given his apparent cognitive decline. The present analysis will therefore deal with other aspects of his participation in the dramatherapy programme.

Ben’s first words in the very first session were, "Join the crowd". This is fundamentally how this man liked to be – talking about talking rather than connecting with his own feeling life. Oliver Sacks writes about the loss of Mr. Thompson’s biography, where it is easier for him to join the crowd, healing the breaches in memory through ceaseless chatter:

*Is he in a torment all the while – the torment of a man lost in unreality, struggling to rescue himself but sinking himself, by ceaseless inventions, illusions, themselves quite unreal?* (Sacks, 1986, p. 107).
Ben’s received diagnosis of “dementia with behavioural problems” by no means wholly explained his idiosyncratic sociability. He usually wanted people to feel comfortable, and he threw around many comments - “Fantastic”, “Terrific”, “Sweet”, to name a few. I suspect they were useful when he could not think of what else to say. His social sense was often finely tuned, although he loved to talk to excess. However, from the earliest sessions, he had a pithy sense of what the group could offer to others, although never, it seemed, to himself. When the arts therapy students were saying how much they enjoyed dramatherapy, Ben said, "It’s getting to a need, that’s what it is”.

Ben liked to make "boysie" football conversation, especially with David, but this diminished as time went on. When David said they should get up close (meaning to the "Aims for Dramatherapy" sheet attached to the wall), he said, "We both are, mate", showing a need for companionship early on in the programme.

As time went on, Ben showed his feelings more readily, rather than relying on double-entendre; not before, however, he had made the above offering in Act I, Scene 2 (Seasons & Weather).

His contribution was a poem which could be read as a weather forecast. It is possibly a description of the "weather" which existed and was still to be experienced in the group. "A first approach to calm the news" could be the early part of the fieldwork during which people got to know one another, and were not yet very boisterous as a group. Then, "as the rain approaches" could mean that the group was gradually getting into some heavier weather, (which indeed the group was about to do!). "All is well as the hail sets in..."
place" could signify the robustness of the group in its future "storming" stage. "And sadly a belated number of difficult snowmen" perhaps signified the people who would drop out, except that right at the end of the session he said that he was not dropping out.

Using silk cloths for movement and roleplay gave Ben the opportunity for touch. Richard Coaten, dance-movement therapist emphasises the importance of the former:

*Touch is of great importance to people compromised cognitively and struggling in so many ways to cope with the manifold losses involved* (Coaten, 2011, p. 86).

This sensation of touch was a key for Ben to starting to unbend, to show more interest in others and to talk about himself. He was certainly ready to do this by the next *Finding Treasure* session. He asked himself, "What am I looking for?" when offered a bag of objects to choose from, simulating a Lucky Dip. Later, when Tanya wondered where her brain was, while holding a many-layered baboushka, he noticed that the babouschka could actually be connected to her brain.

Susana Pendzik, in her explanation of the 6-Key method in dramatherapy, gives the following advice to the dramatherapist (who certainly followed it in this case!):

*Ride on accurate metaphors – find concrete ways of expressing them and...allow them to unfold and mutate* (Pendzik, 2008, p. 352).

Ben certainly understood the language of metaphor, and I believe this enabled him to feel more and more comfortable in the group, as his brand of metaphor was accepted and worked with.

By Act II, Scene 2 (*The Joys and Woes of Memory*), Ben was beginning to let us know how he felt inside. He was not yet naming feelings, but when his difficult adolescent experience of having to walk everywhere without much money in his pocket was described and connected with comments in later sessions, it was obvious that life was extremely hard.
By telling us at this stage that "you can’t afford to let it go", it seems he was keeping this (now group knowledge) for later. Coming home to a "shameful kitchen" has already been mentioned, and in another session (Dealing with difficult people), he said, "it was the young bloke versus all the rest", conveying a sense of isolation in his youth. As a very young man, he had been in the army, and there were several points during the programme where he spoke of war and how terrible it was, even though, as far as I know, he was not sent to war himself.

By Act IV, Scene 3 (Session 15 – Grief and Loss 2) Ben was telling us that "sadness are (sic) a huge thing to have around the house". With this expression Ben was finally able to acknowledge a feeling. It appeared to be in the "royal plural" perhaps partly because his wife had reluctantly had to lock him into their house as a sad necessity. She had done so because Ben had absconded for 20 hours, finally ending up in a cinema (looking for some kind of drama, perhaps?).

Ben’s ability to join in and insist on a group circle during games and exercises was indicative of his socialisation and a mark of his socio-professional abilities earlier in life. (I was later able to find him on YouTube as a media operator in an artistic field and had seen how easily he was able to bring people together.)

Having spent so much of the early sessions trying to talk football, it was a huge change in the sixteenth to see Ben using the space well and involving himself with others, as can be seen from the JASDI scale, where his score had reached 64% from 14% in Session 2. He took two of his beloved silk cloths and played with them – yellow and black - ostensibly the colours of the Tigers rugby team. Hiding underneath this sporting reference was another strong metaphor. He named the yellow "beautiful" and took the black because it reminded him of the darkness in the world. He ended up wearing them like a cloak.

It seemed as though Ben’s quality of life had ended up in a more balanced way, with his bright and dark cloths, than it had begun, and as he constantly reminded us, "It works".
Themes emerging in the dramatherapy

Choice of session themes
Session themes (listed in Chapter 7) were chosen on the basis of my awareness of stepwise group practice. There is normally a group cohesion which takes place slowly, and it was with this in mind that the themes for each session, along with session structure, were chosen. One of my goals was not so much to minimise group conflict as to engender respect and trust, as this can assist cohesion which can in turn lead to healthy group functioning.

It is rarely possible to predict which themes will emerge and in what order; however it is usually clear that certain issues are likely to be prevalent, for example, needing nurture, questions of interrelationship, issues of anger, power and control (Whitaker, 1992).

The themes which would normally occur in a group of people with dementia are slightly different from many other targeted groups, and I have been guided by Dorothy Langley (2006) in her advice on socialisation and by David Johnson (1986) on end of life issues in my choice of themes. Thus, Getting to know you and The Weather featured early in the group’s life, and themes to do with memory and loss of skills and loved ones later on. Below, I will be dealing with the themes of anger and frustration, family members, dementia/memory loss and grief that came up over the duration of the programme.

Anger and frustration
My own frustration appeared early in the establishment of the work, since I had wanted at least eight people in the group, and when I found on Day One that I only had six, and seventeen in the two arm study, I felt somewhat cheated after making eighty phonecalls. Would my research be ordinary? It had better not be!

Very early in the life of the group, Tanya, who often spoke for other participants, voiced frustration that she had lost her brain, or that she had no
idea who had brought her to the facility. Leanne wanted adventure from her experience of dramatherapy, and this seemed to be born of her frustration that she was "ordinary" as she would have had us believe.

The photographs chosen by participants in Session 1 speak volumes about this theme. When I look carefully at Tanya's photo, the farmer is having to pour grain out of his bag onto a grassless field for his sheep, surrounded by heat haze. None of us noticed this portrait of drought at the time she chose it, but it looked like a hard and thankless task; getting up in the mornings must have been like that for most participants, even though they did not say so. Neil said he was heavier in mood than he had been. Somewhere in this frustration may have been the hopes (Neil's hang-gliding picture of lightness from that session and Tanya's hope that she would be "fed" like the hungry sheep).

As time went on, participants embodied their frustrations. David, who had introduced himself on the first day with his fists at the ready, improvised a bull-fight. He was always encouraged to talk about his anger, often recommended in the talking therapies, but dramatic opportunities such as this seemed to work much better. It is significant that the two spontaneous, all-encompassing dramas of the programme where all participants were represented were both concerned with these strong feelings of anger and frustration: the protest march to Parliament House waving banners and the expulsion of the abusive teacher from the dramatherapy space.

Difficulty in articulating thoughts, painful feelings of being a disappointment to carers and fear of abandonment can all be factors in bringing these frustrations and anger to the group sessions. Inarticulate and irrational feelings that are usually contained in the body can often come to the surface through dramatherapy (Emunah, 1994), and they certainly did.

**Family**

There were times when participants' family members were "present" within the space. This was not at all surprising, as each of the participants had a relative as a carer. Occasionally, one of them was extremely present - for
example when Neil would not choose the new opportunity or gift for himself that he was offered in Act III, Scene 2 (Session 10 - The Magic Shop), but instead wanted to give his wife something special - he went away thinking about shaving off his beard for her. He never actually arranged this, but in session he transferred his own opportunity for life improvement to another, perhaps because he felt he owed her a lot, or perhaps magic did not fit with his religious beliefs.

Despite my earlier reservations about working with middleclass people expressed in Chapter 4, I learned in the process of the fieldwork that there were hard times early in the lives of more than one of the participants. In Leanne’s case her parents had been poor - she had led a "hand to mouth" existence, as she told us. Her mother had not been able to get her school principal to change her abusive behaviour towards her daughter. Ben had taken the role of a stove in a kitchen where people left notes for each other when he was a teenager, and his father was hardly at home. Drama allowed Paul the opportunity to celebrate parents, children and wife, and the babushka doll offered Tanya memories of her brave father who made sure they left their occupied country close to wartime. David sat in role, snuggled up with the dog, Juna, and his lost twin brother in a memory of diving through the glass window between them and their grandfather - to get the attention, perhaps, he never was given as a child between home and boarding school.

The story of *Ulu and the Breadfruit Tree* (Gersie & King, 1990) was roleplayed by two of the participants: Neil and David, together with Yolande and Kathy. Once again, David was able to get attention in the role of young son, and Neil played the dying father, allowing him to grieve and resolve the paternal relationship.

Situations with family members and others emerged in the DvT, in the storymaking and in the improvisations, allowing others to witness loving, joyful, uncomfortable, burdensome and sad family times without emphasising or stereotyping anyone as elderly or having dementia. The movement of the sessions from warm-ups to play, to "main event", to reflection and closure
allowed rigid or stuck memories to flow, and for participants to be free from their carers' expectations for a while.

**Grief and loss**

There is a fine line between this theme and the next - there is so much memory loss with dementia, so I shall try to confine my theme analysis to the significant points of grieving.

In her article dealing with death anxiety in older adults through DvT, Ann Grunberg Smith uses case examples to show how this technique can show

> how, even though we are all born alone and die alone, we can be together in our aloneness. Coming up against the bony truths of the existential givens of life, the older adults in this nursing home found a soft resting place within the Developmental Transformations group (Grunberg Smith, 2000, p. 331).

The safety of the contract that was made was a foundation for this grief, as well as trust exercises in the form of warm-ups in the two sessions designated for grief and loss. Safety boundaries presented opportunities for participants to come up against these "bony truths". One of the art therapy students lost her mother during the course of the group and there were many small instances of loss and mourning, for example when a question was asked, the answer was, "I don't know – I've got dementia".

Dramatic examples were manifold, partly because two specific grief and loss sessions were factored in, and partly because the participants themselves realised this was a forum for memories; for example, it was a natural progression for Neil to "re-cognise" a scent in the smelling game in Act III, Scene 1 (Session 13) and go on to celebrate his mother, feeling the yearning that came when he realised she could not live for ever. Art therapists Byers and Wilks document the impact of other losses besides bereavement for people with dementia, such as friends, employment and health (1992).

Early in the first grief and loss session, Leanne criticised the lack of consideration of those who advise the grieving person to "get over it". In the reflection time after a trust exercise the story of Ulu was told (Gersie & King,
1990). Paul told us of some German immigrants who were not allowed to stay in Australia after being incarcerated during World War II.

When I reflect that two of the males in the group regretted wartime deaths (all those killed in war, a father who fought in World War II), and a twin’s death in aerobatic flight, it reminds me that dementia is a struggle and a fight for sanity in so many ways. The relatives’ losses can sometimes be their own losses if they have not grieved sufficiently before their diagnosis. In the second grief and loss session, this struggle was palpable in the feelings that were released of anger, sadness, “letting me go”; “I never got to play” and unhappiness. Ben talked about a “sad house” and it turned out that he was twelve or thirteen at the time.

Leanne told us after her huge and dramatic group collaboration of her abusive teacher’s power over her that she “didn’t want to be one of those people who’s always looking down and feeling miserable”. When this statement is compared with her very first choice of photograph in Session 1, a figure whom she had described as unhappy because he was looking down, it seemed to be her way of linking this catharsis of grief and shame to the earliest stage of the programme. The comments of her co-participants at the end brought the session to a warm and cohesive close. This embodied experience in the dramatherapy space had freed her of bleak memories and enhanced her intimate feelings for the therapist and others in the group (Grunberg Smith, 2000). Yalom writes about isolation in nursing home residents (1980) and how “love and intimacy compensates for the pain of isolation” (quoted in Grunberg Smith (2000, p. 331). These participants did not live in a nursing home; however, the work with grief and loss went a long way towards improving their QoL.

Memory
In our first memory session, Act II, Scene 2 - *The joys and woes of memory* (Session 6) there were some poignant moments in participants' professional lives as David remembered being articled as a solicitor’s clerk for £2 a week, Paul picked up an architect's pen and fondly remembered his life's work
designing buildings and Leanne took a cotton reel which reminded her that she had made her own clothes right through her adolescence. It became obvious that working life for the men especially was important to them and gave them the status they no longer had.

For Leanne, the only woman participant, there was a more homely memory - she rarely spoke of her teaching career except to say that she was a very different kind of teacher from her abuser. The act of choosing a cotton reel helped her to remember how she had made her own clothes as an adolescent, as there was very little money in the home to spend on them.

In Act III, Scene 4 - *In the Land of Dementia* (Session 12) there was early conversation about dementia and memory. There was an amusing discourse, delivered with humour and recorded in Chapter 8 about forgetting and the unforgiving and slippery power of words to hide and vanish. Paul rubbed his head and talked about how his hair had vanished, leaving his head quite bare and spotty, and this was clearly a metaphor for his deteriorating cognitive abilities. Ben, whose word retrieval ability was diminishing quickly it seemed, was completely at sea in the *Fruit Bowl* game, where each time he was *it*, in the centre of the circle and called out "apples", "bananas" or "oranges", he completely forgot to find himself a chair after everyone swapped places, and so found himself back in the middle. (In this sense, a warm-up game can be a handy diagnostic exercise.)

Later in that scene, Neil spoke about his experience of picking up the sticks of anger, stones of fear, petals of tears and bowls of emptiness and talking with his partner, Delyse:

*we talked about I suppose the bigger picture, our part in the bigger picture, what we can do and what we can't do. Do you have any thoughts? Can you remember?*

He cried as he remembered family members, and his conversation assisted Delyse to talk about the loss of her mother. Leanne practised a tune on the piano, as Kathy and I sang *Hey, ho, nobody home?* (Simon, 1981, p. 194). This happened to be the same tune as *Near Friends, Dear Friends* (Watts, 2006) which we would sing later on in the session. When Leanne heard us
sing the first version, she said that it pressed her buttons. Her mother worked, because they needed the money, and it is probable that in her memory, there was nobody at home.

**Qualitative/mixed method findings**

This section deals with individual change scores from the three quantitative scales for the dramatherapy participants, measured at T1 and T2 and triangulated with relevant qualitative data. Participants in the film group are also considered where anecdotal material connects with findings for the Newcastle arm of the study. Findings connected with the Sydney group are also associated with the CEAA tool (Gottlieb-Tanaka et al., 2008) and the JASDI (Jones, 1996), which have proved useful in defining changes in wellbeing and QoL. I will first show tables for and discuss changes in the QoL-AD scores. I will then do the same, for the GDS and SBV-15.

**Individual change scores: triangulation with qualitative data**

(Analysis of these scores are made with the caution that the quantitative data is not statistically significant.)

In the Dramatherapy group, the change scores for the individuals who completed the final assessment are interesting in the light of the qualitative evidence. Participant 10 (Neil) reported early dissatisfaction with the group; for example, his carer used to bring him to sessions early, so that they could have coffee together at a nearby café in order to calm him down, since he was ambivalent about joining "yet another group". His body movements were extremely static in the first half of the programme. However, by the ninth session, he reported that he no longer experienced those feelings, and his dramatic involvement was relaxed and his movements and facial expression considerably more vibrant than before.

It is likely that the small 0.6 improvement for this participant has some relevance to Neil's sense of belonging to the group. Neil gradually became more positive about his participation in the group experience; for example, on
his final evaluation he wrote that "starting new thing (sic) is challenging" and that "(I was) sad to let go of the activity".

Table 4: Change Scores for QoL-AD

(Participants completing assessment shown in yellow)

<table>
<thead>
<tr>
<th>Participant no.</th>
<th>T1</th>
<th>T2</th>
<th>T2-T1</th>
<th>Participant no.</th>
<th>T1</th>
<th>T2</th>
<th>T2-T1</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>44</td>
<td>44.6</td>
<td>0.6</td>
<td>1</td>
<td>49.3</td>
<td>46</td>
<td>-3.3</td>
</tr>
<tr>
<td>11</td>
<td>42.6</td>
<td>44.6</td>
<td>2</td>
<td>2</td>
<td>47.3</td>
<td>57.3</td>
<td>10</td>
</tr>
<tr>
<td>12</td>
<td>49.3</td>
<td>54.6</td>
<td>5.3</td>
<td>6</td>
<td>59.3</td>
<td>48</td>
<td>-11.3</td>
</tr>
<tr>
<td>13</td>
<td>52</td>
<td>48</td>
<td>-4</td>
<td>7</td>
<td>49.3</td>
<td>46</td>
<td>-3.3</td>
</tr>
<tr>
<td>3</td>
<td>39.3</td>
<td></td>
<td></td>
<td>8</td>
<td>41.3</td>
<td>39.3</td>
<td>-2</td>
</tr>
<tr>
<td>4</td>
<td>52.6</td>
<td></td>
<td></td>
<td>9</td>
<td>55.3</td>
<td>52.6</td>
<td>-2.7</td>
</tr>
<tr>
<td>5</td>
<td>48</td>
<td></td>
<td></td>
<td>15</td>
<td>50</td>
<td>47.3</td>
<td>-2.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16</td>
<td>38.6</td>
<td>37.3</td>
<td>-1.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17</td>
<td>44.6</td>
<td>45.3</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14</td>
<td>50.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ave.</td>
<td>46.9</td>
<td>75</td>
<td>47.95</td>
<td>48.333</td>
<td>46.5</td>
<td>6667</td>
<td></td>
</tr>
</tbody>
</table>

For participant 11 (David), the increase in his score by 2 points is likely to have been connected with his ability to relax and to try out new experiences, such as taking on a "gay" role and putting to rest some of his grief about the death of his twin. The increase may also have been connected to the short break he had just experienced at the snowfields with eighteen friends and acquaintances. Participant 12 (Leanne) had put to rest an obsessive memory from childhood after dealing with it on three occasions. She had been given permission to complain about her carer's lack of communication on some
topics, and above all had been allowed to play and "lift her head" unlike the small boy with big boots and more like her drawing of the child with bubbles. She had also had the opportunity to play the piano for the group on at least six occasions, and this undoubtedly lifted her confidence. These possibilities seem to be instrumental in her considerably improved QoL score (by 5.3 points) and therefore her wellbeing, and are therefore very real recommendations for dramatherapeutic work on old issues that have probably not been dealt with, certainly not through previous therapy of any kind.

In the case of Participant 13 (Ben), there is no improvement; in fact there is a deterioration of -4 points, which can be partially explained by the time lag of one week in the administration of the T2 assessment, since plans were then being made for Ben to go to a day centre near his home on two days a week. He had seemed to enjoy the group so much, and since he was being locked into his house because of possible wandering, this may well have affected his QoL.

There is one outstandingly high QoL score in the Film Group for T2, which has been significant in keeping the QoL difference between the two groups much smaller than it would otherwise have been. This was participant 2, who had been a priest by profession and had not enjoyed the kind of socialisation without responsibility he subsequently enjoyed in the film group. He described how he had enjoyed the social opportunities enormously and his carer described his retirement, from a job that he loved, as being problematic. He had come to his first assessment unsure if he would enjoy the films to be shown every Monday. His literary tastes were richly cultural and intellectual; however it did not seem to perturb him that there was an eclectic mix of musical entertainment, Westerns and documentary films over the sixteen sessions.

The participant in the Film Group who scored -11.3 (a score which was somewhat balanced by the 10 score mentioned above) at T2 had bouts of illness over the time, and, according to his wife/carer, his dementia had deteriorated considerably during the 16 weeks.
Table 5: Change Scores for GDS

(Participants completing assessment shown in green)

<table>
<thead>
<tr>
<th>GDS</th>
<th>Drama therapy</th>
<th>Film</th>
<th>(Low score better)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1</td>
<td>T2</td>
<td>Change</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>13</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Ave</td>
<td>1.5</td>
<td>2.5</td>
<td>2.777778</td>
</tr>
</tbody>
</table>

Even though in general, researchers associate QoL with mood (Logsdon et al. 1999; Selwood, Thorgrimsen, & Orrell, 2005), Selwood and his colleagues found that their one-year follow up study on higher levels of QoL correlated with lower levels of depression. Although not correlating with cognition, some individual findings here show that this possibility may not describe all cases. For example, participant 10 (Neil) has quite a high score of 4, signifying a higher incidence of depression. This is in contrast to his improvement, admittedly small, in QoL of 0.6. I suspect this QoL improvement may have been higher and the GDS score lower if the activity had not involved starting something new, since it took him a long time to get used to the group. My information was that he was about to involve himself in further AD research at a Sydney hospital.

It is of interest that Neil marked his T2 questions about memory and money as poor, whereas only memory had been designated as poor at T1. There
may therefore have been some financial problems in the interim. David and Leanne both have perfect scores, as their T2 assessments cancel out their incidence of depression before the programme began, and this correlates well with their levels of QoL at T2 (change scores of 2 and 5.3 respectively).

Ben, on the other hand, has a score of 2 which correlates well with his change in QoL of -4. I suspect this change has occurred for similar reasons as stated above for the QoL-AD. It is interesting to note that at T1 in the QoL-AD assessment, the only aspect of his life that was not assessed by him as Good or Excellent was memory, which he said was Fair. However, at T2, memory as well as the ability to do chores, to have fun and to have enough money were all seen by him as Poor.

In the Film group, participants started off more depressed than the Dramatherapy group and stayed fairly constant, and the only participants to make a positive change (lower scores) were participants 16 and 17. Participant 16 had a 1.3 reduction in his QoL score, but had done much better on his SBV-15 score, although this is not recorded since his T1 assessment was incomplete. Both participants reported enjoying the social side of the Film group, and this could be an explanation for their change scores.

There is a possibility that the Film group, most of whom attended the same General Practitioner in Newcastle, were being given psychiatric medication which did not allow them to relapse in mood over the period. However, this hypothesis has not been investigated at this juncture.

The most significant change score for the SBV-15 is the T2 - T1 score for participant 10 (Neil), who managed to achieve full marks for the final assessment. The only other person to achieve full marks was participant 17 from the Film group, who managed this at both T1 and T2. It is a credit to Neil that his cognition and language ability showed an improvement despite his alteration in mood. This may have occurred because he became more comfortable with others as they shared in each others' roleplays and improvisations: Leanne's "excommunication" of Mrs. Lackey and his own moving dramatic experience in his mother's kitchen for example. As
suggested in the previous commentary, it is unlikely but still possible that QoL improves when cognition improves. Also, despite his acknowledgement that his memory was poor at T1, he described it as "Fair" at T2.

Table 6: Change Scores for SBV-15

(Participants completing assessments shown in orange)

<table>
<thead>
<tr>
<th>BNT</th>
<th>Drama therapy</th>
<th>Film</th>
<th>(High score better)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant no</td>
<td>T1</td>
<td>T2</td>
<td>Participant no</td>
</tr>
<tr>
<td>3</td>
<td>14</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>12</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>10</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>12</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>12</td>
<td>7</td>
<td>-5</td>
</tr>
<tr>
<td>12</td>
<td>6</td>
<td>5</td>
<td>-1</td>
</tr>
<tr>
<td>13</td>
<td>9</td>
<td>7</td>
<td>-2</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ave</td>
<td>9.75</td>
<td>8.5</td>
<td></td>
</tr>
</tbody>
</table>

Cognitive deterioration for David was substantial between the two assessments, but although he did not appear less confident, his wife/carer reported he was no longer capable of going skiing, as it was too dangerous for him on the slopes and on skis. I believe that, for David, knowing skiing and dramatherapy were both at an end could have been disappointing and may have influenced his score.

Leanne dropped by one point. Ben dropped by two points, which is understandable in view of his deteriorating dementia.
Conclusion

This chapter has described a brief search of the literature on qualitative analysis, emphasising the necessity for the researcher to choose investigative methods which suit her purpose. The ethics of analysis have been presented and phases of the analysis defined. Reflection on particular dramatherapy interventions as a form of investigation have been considered, as well as the individual work of two participants and a discussion of emergent themes over the sixteen sessions. Finally, change scores elicited from the quantitative data have been triangulated with qualitative findings.

The chapter that follows helps to "quantify the qualitative" findings, using two observational tools, the CEAA (Gottlieb-Tanaka et al., 2008) and the JASDI (Jones, 1996).
Chapter 10: Quantifying Quality of Life

This chapter presents findings from the Creative Expressive Abilities Assessment (CEAA) (Gottlieb-Tanaka et al., 2008) comprising seven graphs which demonstrate average scores of all participants in the core domains of this assessment which cover important areas of awareness in any consideration of QoL. One participant is accorded a separate set of graphs for the problem-solving domain. The graphs describe the trajectory of each attribute over the 16 sessions and the findings of the directional movement are discussed.

The Jones' Adaptation of the Sutton-Smith - Lazier Scale of Dramatic Involvement (JASDI) (Jones, 1996) is also considered in the chapter. The scale has been re-adapted by the researcher from Jones' version and describes and considers the dramatic involvement of two of the participants over the 16 sessions. The assessment measures embodiment as it relates to dramatic involvement in a group.

Both scales depend on post-sessional dramatherapy observation; the CEAA by staff and assistants immediately after the sessions and the JASDI after watching video footage of participants.

Creative Expressive Abilities Assessment (CEAA)

I was introduced to the Creative Expressive Abilities Assessment (CEAA) (Gottlieb-Tanaka et al., 2008)\(^{39}\) by Hilary Lee of Dementia Australia, WA, one of the authors of the assessment scale. I had used it in my work with people with dementia at a residential home in Sydney; there, we tracked aspects of the residents' language – verbal as well as non-verbal – as well as evidence of the other six core domains: memory, attention, sociability, problem-solving, feelings and cultural sharing as they occurred in the sessions.

The CEAA tool was created by authors who believed it could show evidence that creative activities for people at any stage of life can improve their quality

\(^{39}\) The CEAA pro-forma will not appear in the Appendices, as it is not in the public domain. However, information on the assessment form can be obtained at the following website: www.dementia-activities.com
of life (Runco, Ebersole & Marz, 1990; Runco & Richards, 1997). Because these authors were all interested in gerontology and dementia, they wanted to enable the type of data collection that would answer questions about the effectiveness and intensity of various forms of creative-expressive work for seniors.

The authors also wanted to find out through observation whether there were variations in the benefits of the programmes for people with different degrees of dementia. They were not specific about the number of observers needed. In Julie Gross Macadam's research (2012, pp. 243-278) on an art therapy experience to establish wellbeing in participants, the tool has been used with one observer present and two observers watching a video of the sessions. In contrast, in the research for this PhD, four or five observers shared observations after each session, and came to an agreement about the score on each of 25-27 items for each client after the close of each session. Macadam has used the tool as one matrix in a three-matrix method, combining firstly a clearly-defined 39-item dementia-specific art-making process, secondly, eight of Kitwood's tenets for improving person-centred care in dementia and thirdly the CEAA tool (1997, p. 63).

The CEAA has been designed with 25 core items along with two optional writing items, which are there for use in programmes which offer some kind of creative writing involvement. This option was useful in Ben's case, since he was much more comfortable with writing and script than with drawing and painting.

A statistical analysis of the data from the final 25-item CEAA showed it to have good internal consistency, with a Cronbach’s alpha score = .86, thereby indicating that all of the items are sensitive to the same general underlying construct. Across the individual items, the Cohen’s κ scores ranged from a low of .20 to a high of .75. An analysis of the total scores, defined as the sum of all item scores across the 25-item CEAA, produced a Cramér’s V score of .825 (Cramér, 1999) and a contingency coefficient of .975 (Gottlieb-Tanaka et al., 2008).
The assessment tool comprising 27 items was filled out by myself, two staff members and the two art therapy students after each group session. It was interesting to compare the sessional averages of individuals and groups, especially in the area of memory and emotions.

This assessment tool was used after each of the sixteen sessions of dramatherapy, but was not used in the control group, as participants were mainly seated spectators, and some of the films were lengthy, leaving little or no time for discussion of the movie afterwards.

Although not precise in the same way as the quantitative research where participants gave their own personal assessments, these observations give a guide, from the point of view of health professionals, staff and students, as to what actually changed and why change occurred during the sixteen weeks. It is of benefit to this study to point out that in almost all cases, except for the cultural section (C25-27), there was an overall improvement in the group.

The following graphs represent group results from the CEAA assessments. Each of these graphs represents a core domain, averaging the items within that domain. There are three averaged items under Memory below, representing various forms of reminiscence or recall of lived experience; yet there is only one core item under Attention, referring to participants’ ability to stay engaged. The graphs represent group averages of combined scores for all such scores in the expressive domain. There are five possible scores: for each participant’s expressive ability in each area: 0 = no observation; 1 = never observed; 2 = rarely observed; 3 = sometimes observed and 4 = (nearly) always observed. Those rating the abilities familiarised themselves with the rating method in advance of the group sessions. The scores for each of the items below have been averaged for the group, the blue line representing the average tally for each session and the green line showing the linear progress or decline.

**Memory**
This domain has three main items. Evidence of memory is shown by speaking about or enacting incidents which occurred in the recent or remote
past (M1); recalling songs, stories or jokes (M2); adding relevant information to a discussion or performance (M3).

M1: Reminisces about people, events and personal experiences/life

M2: Recites poems, songs and jokes

M3: Invents/relives realities and anticipates experiences (past, present and future)

Figure 6: Average Memory Score over time

The peaks (blue line) at Sessions 7, 10, 11, and a steady rise at Session 15 appear to describe the following:

Session 7 was a grief and loss session, where participants had meaningful reflections on personal loss in the story of Momo. The next peak was at Session 11. Here reminiscence was strong for participants dealing with difficult people (Neil's Year 10 memory and Leanne's memory of being barred from playtime). The next peak was at Session 15, in Leanne's enactment of the entire Mrs. Lackey issue. The graph shows that intentional thematic facilitation of problematic issues from the past can inform the drama in a way which enhances memory.

**Attention**

This domain contains one item only (A4), which refers to the length of time participants are able to pay attention to the drama when there is activity, or to the conversation during reflection.
A4: Stays engaged

*Figure 7: Average Attention score over time*

![Average Group "A" Score over Time](image)

This graph shows that participants at Session 1 were prepared to engage; however, engagement dipped to 2 in Sessions 2 to 4, and rose above 3 in Session 5. From then until Session 16, the group was engaged for some of the time, approaching 3.5 in Session 14.

The advice given by staff at Alza had been that three quarters of an hour to an hour was the maximum length of time during which participants could concentrate on what was happening. From my experience in mental health and dementia, I was fairly certain that 30 minutes for morning tea and 90 minutes for group work would work for the participants. In fact, the participants were brought early by their carers, and once the participants had had their cup of tea or coffee, they agreed to start early on most days.

The sessions where there was low engagement were Sessions 2 to 4, which is understandable from the point of view of Tanya's intense feelings of depression and sadness. Even though Session 4 was very active at the time of the "protest march", there were still long periods where participants were chatting or reflecting, and they were slow to work up enthusiasm for the one active warm-up – each person finding an action with a chosen coloured cloth and improvising for the rest of the group. There was a jump of more than one point between Sessions 4 and 5; therefore the more interesting question is: What was so engaging about Session 5?

There appear to be two main reasons for the graph's upward swing in this session. Firstly, Session 4’s collaborative drama had made an impact on the
"performing" of the group, and therefore a building of trust, and secondly, the dance-movement activity involved in Session 5 brought people together again in their embodiment work, as they planned and executed small-group dances.

**Language**

This domain comprises eight items. The first two items are rated on the participant’s ability to write (L5) or speak (L6) full words and complete sentences that convey a meaningful message. Item L7 asks for a rating of relevant body language with spoken words. Items L8 and L9 are concerned with writing or speaking with humour, wit or teasing, or for noticing the humour in a situation. Item L10 is concerned with the narrating of reality-based situations that have occurred in a participant’s life, or of invented situations. Item L11 describes the kind of rhythmic body language or facial expressions used by participants when listening to music and L12 to singing along or moving their lips at concurrently.

L5 & 6: Produces complete grammatical sentences when writing or speaking

L7: Uses key words and simple sentences with appropriate body language

L8 & 9: Uses humour (wit, joking, irony and sarcasm) when writing or speaking

L10: Provides elaborate/informative descriptions of objects, actions or events

L11: Uses facial expressions/body language to communicate/indicate understanding

L12: Makes vocal and body responses to music
In line with the quantitative SBV-15, the language scores did not shift greatly. They started at about 2.8 and moved to an end point of about 3.4. All of the participants were Anglo-Celtic in origin except for Tanya, who was of Germanic origin, but her English was exemplary. Facility with English may be one reason why the score was so high to begin with; a secondary reason could be that the monitors were not yet used to judging scores, and there were eight boxes to tick in this section.

It is postulated that the end rise at Session 16 was assisted by L11 and 12, since the expression and body language was stronger in this session, and there was more singing.

**Psychosocial**

The psychological and social aspects of participant expression involve eye contact, use of voice and expression of feeling when telling a story or anecdote (P13), singing (P14) or performing (P15). The eye contact, facial expressions and gestures of the hearers/viewers relay information about their levels of attention to the participant’s narration or performance. Item P16 rates the response to others’ contributions; a meaningful comment or elaboration would attract a higher score and a one-word answer a lower score. Item P17 relates mainly to the participant’s communication about their own or their family’s accomplishments and their future plans. Grooming (P18) refers to a participant’s dress and cleanliness as well as their interest in how they look.
P13, 14 & 15: Attracts/holds attention of other(s) when telling a story, joke or anecdote or when singing a song, or when dancing, performing or playing an instrument

P16: Responds to (comments, shows compassion for, reflects or elaborates on) productions (all forms) of others

P17: Shows self-esteem/confidence

P18: Shows interest in/concern for grooming and clothing

Figure 9: Average psychosocial score over time

Once again, there was a small lift in the psychosocial level from Sessions 1 to 16, from approximately 2.7 to 3.2. Confidence peaked (Series 1) at Session 4, where the protest improvisation took place, and that score was very much lifted by Neil, who was marked at 4 on every item in this domain except for P14. There was more interest in the productions of others as the time went on, showing sociability, with scores of mainly one or two in week three, rising to mainly three or four in week sixteen. This graph is totally in step with the idea of “responding to productions of others”, as may be seen in Chapter 8, Session 3, from the time when Ben empathised with Paul whose wife was in hospital; when Paul was honoured with coloured cloths at his feet; when Leanne was told by Neil she had a great sense of humour, and Ben commented that Leanne's issue was one that had needed resolving.
Reasoning/problem solving
In this domain, the kinds of insight demonstrated for rating are those which, for item R19, comment on the dramatic performance (e.g., where someone should stand at a certain time), the placement of objects or spatial arrangement. For item R20, rating is given on the basis of personal choices made in the process of performance or conversation/reflection.

R19: Shows insight into problems (e.g., puzzles, compositions in visual and performing arts) by commenting on plans/designs of spaces and objects, by analysing music, by offering solutions, reasons and explanations.

R20: Makes clear choices and decisions

Figure 10: Average reasoning/problem solving scores over time

Over the 16 sessions, the group insight and reasoning ability started at about 2.3, with the Series 1 blue line dropping as low as 1.8 in Session 3. There was also a drop in Session 3 in the memory and psychosocial areas. All of this suggests a slump in Session 3 which coincides with the beginning of the "storming" period referred to elsewhere. The session was very static, and a great deal of it was taken up by Tanya's difficulties as an emigrating teenager and the group had to then handle the enormity of the journey. However, the linear reading of the graph shows a much greater autonomy in reasoning and decision-making towards the end of the period, when Leanne was dealing finally with her childhood issue and participants were taking responsibility for finding solutions and making decisions. An individual example taken from Ben's record follows. It indicates his strong sense of autonomy in the area of
reasoning and problem-solving, despite his apparently deteriorating dementia.

**Ben and the CEAA, R19 (insight into problems) and R20 (decision-making)**

It was extraordinary that, even though Ben's scores in the quantitative data fell quite considerably, (BNT: T2 - T1 = -4; QoL-AD: T2 - T1 = -4) or rose when a low score showed less depression (GDS: T2 - T1 = + 2), his actual decision-making ability (CEAA R20) increased and his insight into problems (CEAA R19) improved to some extent.

*Figure 11: Ben's R19 (Insight) scores over time*

*Figure 12: Ben's R20 (Decision-making) scores over time*

R19: The slight change in Ben’s R19 scores may be due to his feeling more comfortable with the group. He had started off in Session 1 showing some insight (R19), saying the group should have a name and that it was "getting to a need". In the second session, he said that if one of the students were absent, "we might need help", which was true. This insight faded from the scene until Session 9, where he became very concerned about the fate of
children at the beach and in the water, when the parents had no idea where they were. He also found pictures of WW1 "very hard to come to terms with" and they may have reminded him of youthful army days. In Session 10, his insight (R19) went up to a score of 3, where he was again concerned about the children and suggested a drama scenario to show potential danger in the surf.

Later on, he brought "water" to ensure the survival of Paul's improvised "broken tree", and in the Magic Shop, made a wish for "really good lifesavers" at the beach, connecting once again with danger to children. In Sessions 13 and 14, his questions showed insight: "What should I be doing?"; "Do we need more chairs around?" and "Do we have a rope to pull?"

The graph rose again in the last session for R19, when Ben showed concern about David's skiing accident, and informed us, "a lot of people have no sense of play".

R20: The graph did not rise until Session 5 for this decision-making assessment; however, thereafter there was a steady rise of two whole units. Ben said categorically in the fifth session that it was very important that there was no right or wrong in the group. He also showed definite insight about the future of the bulb he planted: "It will be very, very hard for you coming up". In Session 9, he made a remark about dramatherapy: "It's deep", which also appeared to be a decision he had come to. He also expressed a wish to play, and told everyone about it.

In the following session, where both R19 and R20 peaked at 3, he told us, "I like the short ones (warmups) that involve people in it (sic)". In Session 12, he made several decisions. After the Hand Game on the floor, he said: "Now we've got to get up" and when we were observing stones people had chosen: "clean up the stones and look at them closely". He said he believed that "when people get older, they should give them every opportunity" and at the end of the session, "I am taking away certain touches and tastes of the music in this room". After mentioning "rules" as early as Session 3, it seemed as though Ben was making his own rules by the twelfth session. He went on to inform us in Session 15 that "it works - it works" (apparently meaning the
group work) and after Leanne's major scene with Mrs. Lackey, to state in a forthright manner, "It was certainly time to clear all those things... and do something about it".

**Emotions**

Regarding this complex area of feeling life, item E21 rates as the wide opening of eyes, the nodding, frowning or smiling of a participant. E22 refers to these kind of responses as a result of looking at a painting or photograph, attending to a drama performance or another's roleplay. Body language and rhythmic movement as well as conversation about the music the participant is hearing or singing constitute a rating for E23. Item E24 concerns the enthusiasm or interest the participant conveys when relating incidents or stories of their life.

E21: Uses facial expression to communicate moods and emotions
E22: Expresses moods and emotions in visual displays
E23: Expresses moods and emotions in music
E24: Expresses moods and emotions in anecdotes/stories

*Figure 13: Average emotion scores over time*

Elsewhere I have referred to a preference for the word "feelings" rather than "emotions" (Chapter 1; see also, Jaaniste 2013a) because the latter refers more accurately to the intelligent/conscious genre of emotion. Emotion accessed in psychotherapy often presents clients with a binary between "functional and disfunctional emotions" (Ellis, 1994; David et al., 2004).
If the blue line (Series 1) is followed in the above graph, it can be observed that the expression of feeling was fairly flat for the first three sessions and then began to rise until it reached its first peak in Session 5 where the dance-movement work was achieved, and the seeds were planted. This rise begins in Session 4, with the protest march. Progress then remains level until Session 12 when there is a small peak, and a larger one of about 3.7 at Session 15. The mood lifted in Session 12 where members of the group chose sticks of anger, stones of fear, leaves and petals of tears and bowls of emptiness, and transformed these into symbols of beauty and mystery. In Session 15, where the participants helped Leanne to "dismiss" Mrs. Lackey from the "playground", the expression of mood and feelings show a clear lift. In fact, the graph rises to a surprisingly high level.

**Culture: Spirituality, Religion, Traditions, Customs**

This section refers to religious belief, the nature of such belief and views on the supernatural, cultural mores and ritual. C25 concerns the occasions when a participant shares deep thoughts or feelings from the heart in a meaningful way, verbally or through performance or movement. Tone of voice is taken into consideration in observation as well as cultural background. C26 comprises philosophical or moral advice or lessons about life. It can also touch on regrets or situations still to be resolved. C27 refers to questions about religion and the existence of God, reward for good deeds and the difference between good and evil.

C25: Shares deep thoughts; speaks from the heart through words, the arts or through movement

C26: Shares wisdom and life experiences; teaches lessons about life

C27: Engages in discussion with others on the meaning of culture, spirituality, religion, tradition and customs
This graph is the only one in the series to have a downward trajectory, indicating that it does not reveal the comments and performance on the "C" figure as increasing over time. It is understandable that early sessions did not provide examples of wisdom or spiritual input, as participants were getting to know one another. Session 6 (2.5) is the first occasion when the graph peaked; Leanne and Neil both had wise and deep thoughts about child abuse and lack of connection between some fathers and their children. In the same session, participants walked through their life stages, commenting on traditions and rituals which had affected their lives. Once again, in Session 9 (2.6), life and death in the era of WW1 was discussed, and Neil called his sculpted monkey "Monk". Paul made a wise comment about the group alerting him to concentrate on what he was "doing or not doing" and what was happening to him. The moral values of parenthood were performed and expressed verbally, when children were allowed in the surf when parents were not present. All of this energetic talk and activity may have been connected with participants having a rest of three weeks from the group.

The first trough in the blue line at 1.4 could have been a result of the Magic Shop (Session 10) being extremely flat, as one of the art therapy students described it. The only participant in this session with high score was Neil. In Session 13, Paul's wise words about self-understanding and Neil's heartfelt words about family and performance as a child in his mother's kitchen were not enough to raise the group score. It is likely that the low 1.7 score of the ending of dramatherapy sessions left participants feeling sad at Session 16.
Jones' Adaptation of Scale of Dramatic Involvement (1996)

This JASDI scale, originally the Sutton-Smith Lazier Scale of Dramatic Involvement (Sutton-Smith, 1981), was designed originally for drama, rather than for dramatherapy. Jones (1996) adapted it for the purposes of dramatherapy, and I have re-adapted it here, simplifying the scale, by showing the scoring system as percentages of full involvement. Here, the progress of two clients, Ben and David, is shown.

As mentioned in Chapter 6, two sessions – an earlier and a later session – have been focused on for each of these two participants in order to discuss changes in capacities such as body movement, use of space and elaboration. In the early session, Act I Scene 2, when the participants were walking around in various "weathers", neither Ben nor David improvised or interacted with others when the "weather" changed from rain, to snow to sunshine. Both stood still looking awkward while others improvised the building of a snowman, despite staff's, students' and my own endeavours to assist them to join in. Neither showed any facial expression, even though they were both able to engage in conversation. Once the group had been through improvisations of all types of weather, there had been a snowball fight which neither Ben nor David engaged in, although they both took art materials and wrote, yet neither showed any facial expression.

In Act III, Scene 3, (Session 11), David showed more bodily and facial expression. The topic was Dealing with Difficult People and he was involved in two improvisations, the first where he had to deal with a deceitful worker and the second which related to himself as a rebellious lad at school. In this session also, he was involved with an improvised bullfight, and dressed and moved around as a gay man.

Ben's involvement in movement in Act IV, Scene 4 (Session 16) had to be encouraged at the start, but gained its own momentum as he took the role of a doctor to whom we all gave prescriptions. He later enjoyed swirling around with two contrasting silk cloths which he had chosen. Having shown little
initiative throughout the programme, he picked up the cloths again, making his own decision about performing the closing ritual and involving others in it.

**Client Assessment using Jones's Adaptation of Sutton-Smith, Lazier Scale of Dramatic Involvement**

Below is a table which shows Client Attributes expressed as percentages during one early and one later session each for Ben (Sessions 2 and 16) and David (Sessions 2 and 11). Percentages have been chosen because the original scale designated 1, 2, 3, 4, or 5 part attributes; each part is thus given a value in the final score on the chart.

The original adapted scale (Jones, 1996) can be found in Appendix 18. A great deal of work was involved in operationalising the Jones’ SDI for this study. The candidate took a very simple assessment requiring only yes/no answers and adapted them in percentage form to produce attributes encompassing a varying number of points: for example, an attribute which had three points might be as follows:-

**Attribute:** Completion of tasks

**Points:** Completes all tasks; Completes some tasks; Completes no tasks

Scores are given for a three-point attribute as follows:

Completes all tasks: (67-100%) 83
Completes some tasks: (34-66%) 50
Completes no tasks: (0-33%)16

(Two and five-point attributes attract different scores to the above).

Since there were nine attributes in all, with a variable number of points as stated, this table required a degree of time-consuming work in its operationalisation and adaptation. Since the thesis is over 105,000 words, it was considered wise not to spend a great deal of time discussing these results. This decision resulted in briefer discussion and presented an opportunity for the table to speak for itself.

*Table 7: Client Assessment using Jones’s Adaptation of Sutton-Smith, Lazier Scale of Dramatic Involvement (next page)*
### CLIENT ASSESSMENT USING JONES’ ADAPTION OF SCALE OF DRAMATIC INVOLVEMENT

<table>
<thead>
<tr>
<th>Client ID</th>
<th>Session</th>
<th>Focus within activity as a whole</th>
<th>Focus with &quot;as if&quot; behaviours</th>
<th>Completion</th>
<th>Use of imaginary objects - pretended objects</th>
<th>Use of imaginary objects - disengage at end</th>
<th>Use of imaginary objects - other's objects</th>
<th>Elaboration - initiate own ideas</th>
<th>Elaboration - engage with others’ elaboration</th>
<th>Use of space</th>
<th>Facial expression</th>
<th>Body movement - using own body</th>
<th>Body movement - understanding other's bodies</th>
<th>Vocal expression</th>
<th>Social relationships</th>
<th>Attributes compilation (average of Attributes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ben</td>
<td>2</td>
<td>38</td>
<td>12</td>
<td>16</td>
<td>0</td>
<td>0</td>
<td>12</td>
<td>16</td>
<td>0</td>
<td>16</td>
<td>16</td>
<td>16</td>
<td>16</td>
<td>16</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td>Ben</td>
<td>16</td>
<td>63</td>
<td>63</td>
<td>50</td>
<td>100</td>
<td>100</td>
<td>88</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>64</td>
</tr>
<tr>
<td>David</td>
<td>2</td>
<td>63</td>
<td>38</td>
<td>50</td>
<td>100</td>
<td>100</td>
<td>12</td>
<td>50</td>
<td>0</td>
<td>50</td>
<td>16</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>16</td>
</tr>
<tr>
<td>David</td>
<td>11</td>
<td>88</td>
<td>88</td>
<td>83</td>
<td>100</td>
<td>100</td>
<td>63</td>
<td>50</td>
<td>75</td>
<td>50</td>
<td>83</td>
<td>83</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>72</td>
</tr>
</tbody>
</table>

**DETAILED DESCRIPTION OF ATTRIBUTES:**
- **Focus (a)**, within the dramatic activity as a whole
- **Focus (b)**, in engaging with "as if" behaviours
- **Completion**, the degree to which the client completes tasks
- **Use of imaginary objects (a)** - can create and sustain pretended objects
- **Use of imaginary objects (b)** - can disengage from object at end of the activity
- **Use of imaginary objects (c)** - can engage with others’ created objects
- **Elaboration (a)**, demonstrating the capacity to develop and initiate ideas with improvisation or play
- **Elaboration (b)**, extent of engagement with others’ elaboration
- **Use of space**, within dramatic activity; movement in improvisation, group or character-based work
- **Facial expression**, use of face to depict appropriate emotions or responses in pretend or improvised activity
- **Body movement (a)**, using body effectively and appropriately to dramatic activity or character, communicating information or messages effectively
- **Body movement (b)**, understanding information or messages communicated by others’ bodies with dramatic work
- **Vocal expression**, emotional relevance and projection within activities
- **Social relationships**, awareness and response to others within the activities

**NOTE**
Client Attributes are assessed on a spectrum, most positive to most negative.
Each Attribute Element (e.g. "Focus") has either two, three, four, or five assessed spectrum points
Scores given in Table are given as percentages and are allocated according to setting below.

<table>
<thead>
<tr>
<th></th>
<th>2-Point attribute</th>
<th>3-Point attribute</th>
<th>4-Point attribute</th>
<th>5-Point attribute</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(0 to 25)</td>
<td>(26 to 50)</td>
<td>(51 to 75)</td>
<td>(61 to 80)</td>
</tr>
<tr>
<td>most negative</td>
<td>0</td>
<td>16</td>
<td>38</td>
<td>50</td>
</tr>
<tr>
<td>negative</td>
<td>none</td>
<td>(0 to 33)</td>
<td>(26 to 50)</td>
<td>(41 to 60)</td>
</tr>
<tr>
<td>neutral</td>
<td>yes</td>
<td>75</td>
<td>(67 to 100)</td>
<td>(81 to 100)</td>
</tr>
<tr>
<td>positive</td>
<td>yes</td>
<td>75</td>
<td>(67 to 100)</td>
<td>(81 to 100)</td>
</tr>
<tr>
<td>most positive</td>
<td>no</td>
<td>0</td>
<td>(0 to 25)</td>
<td>(0 to 20)</td>
</tr>
</tbody>
</table>
Conclusion

This chapter has considered the CEAA and its authors' recommendations for its use in the arts and arts therapies, as well as its internal consistency. The chapter has aimed to explain the seven domains covered by this 25/27 item assessment tool.

Graphs representing whole group average CEAA scores have been presented, covering the 16 sessions of dramatherapy. One individual participant's results have also been graphed, showing results in his insight/reasoning and decision-making processes. The chapter ends with an explanation of the JASDI Scale, together with a description of two participants' session scores using this assessment tool. Their individual scores for attributes expressed on a percentage scale are then shown in detail on the JASDI table which concludes the chapter.

Further discussion of the research questions, limitations and future research, together with my conclusion to the thesis, are to be found below.
Chapter 11: Further discussion and conclusion

This thesis is a mixed methods enquiry hypothesising that experiential wellbeing and QoL for people with dementia can be achieved through dramatherapy. QoL has been established in this thesis as a robust and essential ingredient of existence which can engender and be engendered by the person-centred respect that I believe is due to people with dementia. Additionally, the recognition and implementation of their wholistic physical, spiritual, social and psychological needs are crucial for QoL. I have mentioned in Chapter 4 that this thesis aims to challenge the dominant view that the life led by many elders is no longer fully human and that those with dementia need medication. This study has broadened the debate about dementia in the community, showing that a more compassionate and social justice aligned approach is possible, without a primary reliance on anti-psychotic medication for restlessness and aggression. This type of medication is still given to people with dementia, even as awareness of person-centred care becomes more widespread. The qualitative arm of the research has also shown that people with mild, moderate, or even early severe dementia have a high level of self-awareness which can be engaged and is not apparent from the biomedical literature (Jaaniste, 2013c).

A mixed methods approach has been adopted with the aim of establishing and triangulating empirical and qualitative evidence for the benefits of dramatherapy interventions for people with dementia, with these qualities and needs in mind. The assessment results from the two-arm study which add, when comparisons are made, a valuable contribution to the gap in research in the area. They also support a successful, cost-effective way of promoting the above mentioned wholistic and person-centred approach to the QoL of such people.

In addition, this study has broadened the debate on the use of mixed methods in this type of research. To my knowledge, there has been no other mixed methods study using dramatherapy on the QoL of people with dementia. Leaving aside for the present the main research question of
whether dramatherapy can improve the quality of life of such people, this chapter will discuss the original contribution made by this thesis to the supplementary research questions which were first posed in Chapter 4.

**Supplementary questions**

a) Can this study collect data in order to establish an evidence base on dramatherapy as an intervention for older people with dementia?

This question, intrinsically connected as it is with the QoL-AD assessment, which has shown a non-statistically significant trend of improvement, clearly refers to the main topic of this thesis, which is the QoL of people with dementia. Although the quantitative scales were chosen with a view to salient elements of QoL: mood, cognition and language, the QoL-AD scale has been found to have shown an improvement in the wellbeing of the participants in the Dramatherapy group, when compared with the Film group. Although not statistically significant in terms of quantitative research, the results show a trend that is without doubt worthy of further research.

As pointed out in the previous chapter, the quantitative research findings, even though not statistically significant, demonstrate that after sixteen sessions, dramatherapy is a promising modality for the improvement of QoL for people with dementia. Also, the CEAA (Gottlieb-Tanaka et al., 2008) and JASDI (Jones, 1996) have been essential tools in backing up the findings of the QoL-AD. The evidence base has been enhanced through the use of the CEAA, resulting in, as was the case with Rusted et al. (2006), a correlation between quantitative and observational data. In their research an improvement was noted, "includ(ing) changes both in recognition of group members outside of sessions and better person-to-person communication between clients and carers" (p.531). The JASDI (Jones, 1996) has shown an increase in movement, facial expression, and social inclusion which also point to an improvement in QoL.
b) Will mood improve for the participants in the dramatherapy group when assessed using the Geriatric Depression Scale (GDS) (Yesavage & Brink, 1983)?

Explanation for the lack of validation of the scores at T2 in the Dramatherapy group in comparison with the Film Group (Chapter 5) has already been made in reference to the childhood issues brought up towards the end of the programme, with accompanying discomfort or low mood. This mild depression may not last and it is probably worthwhile for participants to experience low mood in response to such issues if it is temporary, as was the case for Leanne when her issue was dealt with. Gregoire (1998) believes that professionals and carers are just starting to acknowledge the importance of psychotherapeutic help for the elderly, and Kitwood respects the fact that people with dementia “may be more open than others to therapeutic change” (1997, p. 98). There is also a case for the fact that participants simply felt sad (a natural human feeling) that the group had come to an end.

The CEAA “E” scores dealing with expressions of feeling are high for Sessions 14, 15 and 16; however, expressed emotion can signify positive or negative feelings, so it is important to compare those results with P17 on the CEAA, the score for self-esteem and confidence. When this enquiry is made, it can be established that Ben's score of 2.5 has on these three occasions brought down the median score for confidence, which has been higher in all sessions since Session 7. In other words, Ben's deteriorating dementia, combined with his different home circumstances and carer's plans for him to attend a day centre, probably influenced the declining score. These changes have affected the median score since there were only three participants present for Sessions 15 and 16. It is obvious from the change scores that Leanne's absence in the last session may have meant the omission of a high score on the CEAA, since her mood had improved on the GDS by -1 at T2.
c) What effect will this programme have on language retrieval and cognition over the 16 weeks in the group undertaking voluntary dramatherapy sessions using the Boston Naming Test short version (SBV-15) (Kaplan et al., 2001)?

Since the greater part of the dramatherapy programme was conducted using games, movement and song, it is understandable that the language of the participants did not improve in comparison to those watching films, according to the SBV-15. The group change score of 1.25 (deterioration) for the Dramatherapy group compared with .89 (improvement) for the Film group may have been due to the constant emphasis on speech that occurs in films, which had been overlooked in the research design. Except for the initial checking-in times and later reflection times in the Dramatherapy group, much of the involvement was through the body. In Merleau-Ponty's view, "all latent knowledge of itself that (our) body possesses" (1962, p. 233) can assist our conscious intentionality, and the qualitative research has shown that movement acts as an important stimulus for purposeful awareness for people with dementia. Mirror neurons appear to operate through body experience rather than language (Berrol, 2006), and neuroscientist Greenfield believes that the book, rather than the screen, more successfully engages feelings because stories are the means by which we form our own pictures, engaging the imagination (Greenfield, 2007). This could be a reason why people in nursing homes who have dementia and sit in front of televisions often have no idea what they have seen.

Christine Roelle (2010) puts the opposite view, that films simultaneously address different senses and cognitive channels, language being supported by visuals that make the content easier to understand. However, since emotions and feelings are more likely to trigger learning in people with dementia as documented earlier in this thesis, this is an argument for human to human (in this case, dramatherapeutic) rather than filmic interaction.

The question of cognition is an interesting one. The group trendline on the CEAA scores actually improved from just over 2 (rarely observed) to almost 3 (sometimes observed) in the combined qualities of problem solving and decision-making, which both represent frontal lobe skills (Chapter 10). This
was contra-indicated by the SBV-15 trendline which was downwards, as stated. Ben's cognition actually deteriorated in terms of the SBV-15, and yet, as is shown in Chapter 10, his individual problem-solving ability improved at times during the programme and his decision-making ability improved overall on the CEAA scores. This is counter-intuitive, and indicates that SBV-15 may have been the wrong scale to use.

d) Will the quality of life of participants improve after 16 weekly sessions when measured against the control group with the Quality of Life Alzheimer's Disease (QoL-AD) (Logsdon, et al., 1999)?

In the search for validation of this hypothesis, the QoL-AD scale has shown a small quantitative improvement which, although not statistically significant, demonstrates that the results align with those of the CEAA and with the qualitative research generally. The results show that in the area of positivist research, there is a need for further investigation in this area. As presented in Chapter 10, CEAA trendlines in almost all areas rose from the early to the late stages of the Dramatherapy group. Early group scores in each section were in the twos (rarely observed) and later group scores in the threes (sometimes observed), moving towards four ([almost] always observed).

Qualitatively, there are many reasons for this improvement in the social, psychosocial, confidence, decision-making and grieving areas. Socialisation was a significant factor in the improvement of QoL, and this can be perceived in the mounting ease with which the participants interacted and spoke together. There was also clearly a greater connection with their carers as the weeks went by. Psychosocial improvements can be seen in the sharing of feelings and meaning, either through metaphor, as in Leanne’s description of the beauty of her rock, sparkling on top and earthy underneath, or through plain speaking, as in the witty exchange about the nature of short-term memory (“Gone, gone, gone”). Group humour seemed to become more witty and subtle as time went on. The opportunity to grieve over losses and bereavements showed a steady increase, as did greater honesty about difficult relationships with others. Confidence improved as participants became more willing to tease one another and recognise their common
difficulties with dementia. The decision-making process climbed well into the 3-4 area of the CEAA, and this can be seen clearly in the dramatic role decisions that were made, to play roles such as “Country Squire” or more personally, the self as a “Year 10 student”.

e) Will improvements according to the qualitative assessments: CEAA (Gottlieb-Tanaka et al., 2008) and Jones' (2006) dramatherapeutic adaptation of the Sutton-Smith-Lazier Scale of Dramatic Involvement (1981) be transferable to other areas of participants' lives in future?

This is not a longitudinal study; however, it is likely that certain improvements will be transferable to other areas of the participants' lives and others will not. In the community, where these participants are living, there are likely to be some changes, and these have been reported anecdotally by carers. After more than twelve months, Leanne's husband/carer was able to attest to the fact of her omission of any reference to the troubled issue of Mrs. Lackey, a memory which had been referred to as "obsessive". He also reported a new enjoyable playfulness in his interactions with his wife, especially at bedtimes, which had previously been more problematic. We saw a cross-fertilisation of interests and a depth of immersion in art works and drama that showed what could be achieved if participants continued with this work. There was also a camaraderie which assisted with the loneliness that arises from receiving the diagnosis. They took most of the art works home, enabling others to realise that people with dementia do not just "eat the paint" (McAdam, 2012, p. 381)!

f) What can this research distinguish from the experience and body language of the participants which will provide insight into the journey of dementia and possibilities for improvement of the QoL of those with the diagnosis?

The research shows that the metaphorical communication and creative experience of participants in the Dramatherapy group, as well as the information they gave through their body language was instrumental in changing their own way of relating to their lives as well as their manner of relating to others. This was as true of their relationships with care staff in the Dramatherapy experience as with each other. Participants showed they had hidden talents for drama, as well as demonstrating their intelligent presence, as documented in the dementia drama when they sculpted one another and
named the sculptures (Session 11). The phenomenological insights provided in this thesis as a result of my research into dramatherapy have far-reaching implications for the area of person-centred care in the community and in aged care facilities, and are essential for real connection by staff and carers with the person with dementia.

In 1997, Kitwood wrote that 2,000 people were needed in the UK in order to train others in person-centred skills (p. 143). Chenoweth and her Bradford colleagues (including Professor Brodaty from Sydney) have found that person-centred care mapping (Kitwood & Bredin, 1992)\(^\text{40}\) is marginally more successful than simply training staff in the area (Chenoweth, King, Jeon, Brodaty, Stein-Parbury, Norman, et al., 2009).\(^\text{41}\) Both are more effective in controlling agitation in people and more cost-effective than what is termed "usual care". Some training of this type is happening now in Australia and the research insights offered in this thesis regarding communication are significant in view of this extra professional development of care staff. Unfortunately, "usual care" often means that control of agitation is brought about through anti-psychotic medication rather than safe, creative and trustful interpersonal communication. I have suggested elsewhere that dramatherapy can, in certain circumstances, obviate the necessity for such medication (Jaaniste, 2013c, in press) in the late afternoon “sundowning” periods, for example: a restless time of day for people when anti-psychotics are generally administered.

Since the engendering of trust and therapeutic communication are essential roles of the arts therapist or dramatherapist, it would in the future be helpful to have at least one such professional on the staff of the facility, rather than as an "add-on" to diversional therapy, which tends to happen in care homes. Such a position would provide an effective means of demonstrating an enjoyable and cost-effective means of improving QoL as well as calming agitation.

\(^{40}\) Dementia care mapping is a method of detailed feedback on the wellbeing of people with dementia within a facility where person-centred care is in operation; it is labour-intensive, requiring expert training (Chenoweth et al., 2009).

\(^{41}\) Professors Chenoweth, Brodaty and others have just completed a study of a combination of person-centred and environment centred care in an RCT of 40 nursing homes in Australia and the results are at present being analysed (Ham, 2012). These are soon to be published (Brodaty, personal communication, May 14, 2013).
g) What can this thesis reveal with regard to the consciousness of participants with dementia by providing sixteen sessions of group drama psychotherapy?

This question has been partially answered by f) above, although it has not yet been pointed out here that the consciousness of the "feeling intelligence" became ever more apparent as the sixteen sessions progressed. It was evident that participants need to be approached on their levels, in other words, when there was an awareness of the possible or probable meaning behind their words, in order to engage their consciousness. An awareness of their intelligence of feeling needs to be present in this kind of work, and as Verity and Lee suggest, when "appreciat(ing) another person, it is necessary to engage both heart and mind for the experience to make a real difference" (2011, p. 28). As the Woman from Dementia says in *For Love of the World* in Chapter 6:

\[
\begin{align*}
I \text{ still have my intelligence, the intelligence of feeling} \\
It \text{ helps me understand and love my fellow human friends} \\
But if only you could picture now my clearest golden moments \\
You never would confuse me with demented people, no! (Chapter 6).
\end{align*}
\]

It is evident from much of the metaphor initiated by participants, such as Leanne bringing water for Paul's broken tree and Ben describing the domestic ambience of his adolescence with the expression "shameful kitchen", that they knew very well what they were about. Cheston (1996) indicates that metaphor is used by people with dementia to express feeling experience, and says that often they use a past experience to express what they are undergoing in the present. I agree with Cheston, and believe that the research findings through metaphor demonstrate each participant's wealth of experience brought to bear on the present moment and being-in-the-world, justifying the improvement in QoL which is the main aim of this thesis.

This is, however, not the only compelling aspect of use of metaphor by people with dementia. As Sardello points out:

\[
\text{the phenomena of soul life are available to consciousness and can be described...it becomes necessary to be able to speak from within what one is observing; that is to say, the observer is inevitably an aspect of}
\]

313
what one observes when working from a soul perspective (2008, pp. 7-8).

I submit that I was indeed working from a soul perspective, as a facilitator. Kitwood writes about the attention and "readiness to respond to the gesture which a person with dementia makes; not forcing meaning upon it, but sharing in the creation of meaning" (1997, p. 120). This powerful soul work, salient throughout the qualitative description in this thesis, allows the invisible to become visible and more than justifies the improvement in participants’ QoL.

The present research has made visible the golden moments of the participants. It has shown that, when people with dementia are offered creative experiential games, exercises and dramatic engagement, they expose an aspect of themselves which may be unseen at most other times. It extends their conscious and metaphorical ability to self-advocate, their ability to have a voice in the world and their astonishing ability to self-heal. It enables them to express difficult feelings in a way that it would be totally inappropriate to describe as "restlessness" or "aggression" (Jaaniste, 2013c, p.3).

It is evident from the qualitative research that a gradual acceptance of others’ points of view took place among participants, pointing to improved harmonious social aspects of QoL. There are manifold examples of a more compassionate attitude towards other group members as time went on. Neil's views of the other participants as "strange" faded away. All participants' vocal and active support of Leanne in her issue with Mrs. Lackey rose to a crescendo over the period. Paul was honoured as a wise elder, and Ben ceased to speak harshly to Tanya, eventually telling her she was "OK".

h) How does this study provide information for researchers in the area, on the basis of this researcher’s experience?

This description of the study’s process can assist researchers in understanding that the investigator’s own challenges and learning experience assisted significantly in the interpersonal structure of the dramatherapy
sessions. The description reveals a stepwise structure enabling mutual trust, showing the early challenges and difficulties with the contract. Such issues as Tanya's displays of grief and Neil's initial unwillingness to be present gradually evolved into more harmonious dance of mutual endeavour. The rich description reveals a strong emphasis on the value of metaphor in any such enquiry. The methodology offers a very potent "way in" for researchers who wish to provide an original yet replicable\textsuperscript{42} means of connecting with people with dementia on a level of unspoken mutual understanding. A traditional "deficit model" of assessment can often result in the neglect of a person's identity, culture and history, and this study presents a viable alternative to such models.

The study demonstrates also that the QoL-AD is a robust measure to use alongside the CEAA and JASDI. Since it is suggested the former is used in conjunction with two additional measures, I would recommend that a further search be made for a more sensitive mood scale than the GDS. It is also suggested that the CEAA be assessed by funded outside assessors using the video of sessional activity.

**Limitations in this study**

A literature search for the best scales to use in a study of this sort, inspired by the Rusted et al. (2006) RCT researching art therapy, eventually focused on measures for a two-arm study instead. The research began with an exploration of mixed method research using biomarkers; the approach was abandoned in favour of a mixed method thesis where the evidence-based enquiry would involve assessment using neuropsychological scales. Funding was not available for the administration of biomarkers. This meant that in lieu of the biomedical approach, assessment scales were used which did not necessarily suit the dramatherapy approach. There is still some way to go in finding the optimum measures for this purpose.

\textsuperscript{42} Since all session plans are available in Appendix 16, the sessions can be replicated if desired.
The lack of available funding was also a limiting factor in the triangulation of the data. It would have been possible with further funding to have addressed the same research question twice, thus being able to address data findings that did not accord with one another (Morgan, 2006). Consensus assessments on the CEAA amongst a multi-disciplinary team of four or five could also have been improved upon if each professional had individually viewed the video after the session and the results had been collated later by a non-associated recorder. This latter means of data-gathering would have been a "time and resource-intensive technique" (Morgan, 2006, p. 1449) and was therefore not considered in the study design.

It was my initial intention only to invite volunteers who had a diagnosis of AD, as this would have prevented the diagnosis variables present in both parts of the two-arm study, and especially the dramatherapy group where there were three other variables at T1 and one at T2. This drawback is associated with the difficulty in accessing volunteers for the project which was probably the major limitation of this study, since it hampered the breadth of statistical enquiry and the potential for outcome generalisability.

Further limitations with regard to the quantitative analysis were firstly, my lack of experience in this realm, although I received help from many sources which I have mentioned in the acknowledgements at the beginning of this thesis. Secondly, the time constraints applied to the PhD proved to be a significant limitation.

**Recommendations for future research**

There is a well-defined case here for engaging the arts therapies in general, and dramatherapy in particular, to improve the QoL of people with dementia. Arts therapies are still fairly new to the aged care sector and I would recommend using mixed methods again, but with a larger population. The quantitative results are needed to assist the biomedical gerontologists to discover that there are arts therapists who can speak their language. The qualitative approaches used in this study reveal that there is far more to people with dementia than their deteriorating frontal lobes! Without these
epistemologies of heuristic phenomenology, narrative and metaphor, the fine and specific detail of the lived experience and conscious expression of the participants can be missed altogether.

The findings of this study, that dramatherapy is indeed a promising means of improving the QoL, suggest that although rewarding, further research needs to be carried out, using the QoL-AD as well as the CEAA, RPE and JASDI. Additional research as well as more funding is needed to build on the findings of this thesis; other, more sensitive measures could be found and used to demonstrate changes in mood and cognition.

Although I agree with Holmes (2005) that it is clear from the literature that measurement of QoL shows how happy and satisfied people are with their lives, there is little acknowledgement of more subtle elements of QoL improvement that contribute to researchers' views. This lack of clarity can be addressed in future by asking participants to give their own views on what constitutes QoL, as the authors of the Alzheimer's Society Report (2010a) have done. For example, the request that the theme of "Who I am" be one of their chosen six elements of QoL speaks volumes about the importance of recognition of identity among people with dementia (p.27).

The experience of the Society's research, facilitated with the use of talking mats and picture cards carried out by the Alzheimer's Society (2010a) show that even people with severe dementia can understand concepts which relate to stigma. Ideas about their human rights and social inclusion were forthcoming, as were their views on the right to practise their faith or religion (Jaaniste, 2013c). I would recommend that further research involve participants from more varied cultural backgrounds and personal circumstances than has been the case in this study.

**Discussion**

As far as the qualitative design is concerned, it has been helpful to have the opportunity to write a play about some of the researcher's questions and fears in the light of statistical analysis and the enquiry of seeking an evidence base, triangulated with qualitative methods. This ethnographic release of
personal experience has been beneficial for me, just as the dramatic release of personal issues can help a participant in the group. As a person who has always engaged with poetry and drama, the combined expression of these two literary areas has been very satisfying. The phenomenological approach, and particularly holding in tension the ideas of Merleau-Ponty and Steiner, have been key in opening my mind to the area of body consciousness and being-in-the-world as well as the life of the spirit. How powerful this tenuous combination of epistemologies can be in striving to understand the meaning and intentions of people with dementia!

Since two of the measures used produced a null result, much has been learned through the lived experience of the researcher as facilitator, and the documentation of phenomena through metaphor, narrative, use of particular group interventions, video, and performance. The CEAA has helped to “quantify the qualitative” in innovatory and unexpected ways and the JASDI has offered an alternative means of documenting changes in the embodiment process. RPE has proved to be extremely helpful in working with the various levels of dementia severity. As in the case of the study by Rusted et al. (2006), observer ratings were used, a fact which could be seen as a potential source of bias. However, I agree with Rusted and her colleagues (2006) that such practices are often used with this elderly group for reasons of frequently impaired communication and cognition.

In the case of the QoL-AD, carers rated the participants lower than they did themselves. This has been found to be the case with other QoL scales as well, which is why the scoring is weighted in favour of the person with dementia: “Quality of life is generally rated as being lower by carers than by the person with dementia themselves” (Alzheimer’s Society, 2010a, p. 44).

There was no behavioural disturbance of an aggressive or inappropriate nature during the programme and it is clear that dramatherapy can help in this area, and in some cases may be an effective substitute for psychiatric and other medication such as Aricept, with its potentially disconcerting side effects. Of course, there were also no participants with very severe dementia. Wendy Moyle et al. (2007) found in their study of residents in care that
cognitive decline could constitute a reason for disturbing behaviour, but that aggression usually settles down after a change of lifestyle has been made. The research showed that people who were new to the facility had lower QoL on the scale. They agree with researchers who have carried out QoL studies and found that higher QoL is associated with meaningful activities (Raphael, 1996; Renwick, Brown, & Raphael, 2000; Renwick et al., 2003; Wilcock, 1993). They say this is also the case for people with dementia, and their research using the QoL-AD shows that the transition from home to a residential care setting will take people away from their normal routine and give them opportunities for engaging in behaviours that have meaning. This research demonstrates that dramatherapy can flourish and would surely be high on any spectrum of meaningful activities in residential care, assisting in the improvement of QoL.

**Conclusion**

This study has provided a valuable and justifiable contribution to research in dramatherapy with people who have dementia. Readers of this thesis have pointed out to me that I have provided my own “model” of dramatherapy, not justifiable by others’ approaches. Doing this research has made me aware that I have my own approach to dramatherapy as a practitioner, and whilst it has not been the focus of this thesis, I plan to elaborate on this aspect further in a future publication. In my data collection I have used mixed methods, which is a methodology rarely employed in the field.

In 2009, I heard Dahlia Gottlieb-Tanaka, co-author of the CEAA (Gottlieb-Tanaka et al., 2008) talk about how she had been compiling long lists of articles, for a paper on creative therapies with people with dementia, from relevant databases, researching any creative modalities represented there. In a later conference paper she gave in 2011 with Peter Graf, they presented findings where many of the authors had failed to give details of the efficacy of the programmes they ran, the methodologies behind them or the qualifications of the people who had run them.
It is essential that our programmes document the methodologies we use, the intentions behind the research, and above all, our results. I believe I have done this. It is without question from an anecdotal and practitioner point of view that people with dementia benefit from the arts, and from the arts therapies in particular. Since medications may not generally be the answer for improved QoL except in a prophylactic sense, it is essential that results are available and replicable, as with the present thesis.\footnote{Session plans, with explanations of activities and resource references where they are available, can be found in Appendix16.}

Additionally, as stated in Chapter 4, it has been very important to me in the research to be triangulating across both sides of the methodological divide. The quantitative findings, especially the promising QoL-AD results, even though not statistically significant, give researchers and others a measurable signpost as to the type of future work needed in this essential area of QoL. The thesis has triangulated the quantitative measurements of QoL with the qualitative results of the phenomenological journey of witnessing and documenting the embodied and voiced expression of participants' lives. The meta-analysis of the data, in a spirit of openness and enquiry, has revealed a disarming willingness on the part of members of the dramatherapy group to reveal their lived experience.

Because of the high calibre of the qualitative findings, a surprising conscious appreciation by the participants of their situation has emerged. Most valuable also to this and future research is the discovery that these people with mild and moderate dementia were willing and able to put their trust in group psychotherapy using drama. They shared their stories in a way that clarified issues, problems and joys they had carried with them through life, contributing in the showing and telling of these to qualitative evidence for the improvement of QoL and justifying the aims of the research.

I have learned that their capacity to celebrate their present state of being with humour, compassion for themselves and others and a healthy attitude to grieving losses has much to teach the rest of us – those of us who have not (yet) succumbed to the disease. They were open and trusting, and showed
that perhaps the rest of us could remove some of our protective armour and like them, be willing to reveal more private aspects of who we really are.

The inspiration of Kitwood and others who use person-centred therapy – such as, Dahlia Gottlieb Tanaka, Hilary Lee, Jane Verity and Wendy Moyle – has enabled me to explore the combined areas of creativity and person-centred therapy using dramatherapy. The inspiration of my trainers, teachers and colleagues in dramatherapy around the world has enabled me to find dramatic connections with this area of dementia research.

Because of the "feeling intelligence" that shows itself even in the severest forms of dementia, it is essential to introduce programmes in day centres and residential facilities that assist people to express their feelings in satisfying and creative ways. Dramatherapy helps people to do this. There are staff shortages in many retirement and nursing home institutions, and family members and those who work in carer positions often do not have the time to sit and talk with people with dementia. The results of this study indicate strongly that where there is an organisation such as AlzA which is genuinely interested in providing a space where such a group can meet and be supported by staff, there is a willingness on the part of participants to share their creativity and express their joys and woes through the artistic medium of drama.

The spirituality of people with dementia is alive and well, and very connected to conscious feeling intelligence. The dramatherapist's containment of therapeutic understanding and time-and-place-boundaries serves as a warm enfolding of the spiritual life of these elderly people. Life stage strengths, such as strong memories of past pain and pleasure, a closeness to the presence of loved ones who have died, and questions about their own mortality have been responded to creatively in this study (Jaaniste, 2011b). As the population ages, and more of us fall prey to dementia, it is ever more important to bring I-and-thou communication and meaningful rituals to these individuals, and to treat them as treasured elders of our community. This thesis explains and validates how improvement in QoL has been successfully achieved through these and other conscious approaches.
We are not measured by our exalted moments, by our exalted thoughts and beliefs, but by deeds, only by deeds, of love or otherwise. The limits to art are our human limits. But to say this is to leave much unsaid: the serious speech, the exalted thoughts are not made meaningless by life, by deeds, by human failure. (Stockholm Slender, 2010).

Steiner predicted, in a group of lectures he gave in 1919, something that the neuroscientists are telling us now in a different language when they advise us to be creative, to follow a new interest and to exercise our neurocognitive faculties. This is something that dramatherapy can assist with:

We must be quite clear that in old age, [humans] become wise and spiritual ... in the case of people who, right into their old age, can preserve elasticity and life power for their spirit, we must recognise the beginnings of spiritual qualities. For there are such possibilities (Steiner, 1975, pp. 99-100).

I am very glad that I chose a mixed methods approach to the research, and that this thesis has found triangulated evidence that is significant in the broader sense, to build on in the future for the QoL of people with dementia. My qualitative research, using phenomenological method as well as narrative, ethnography and metaphor emphatically produced significance in what would otherwise be regarded quantitatively as a non-significant change.

There are some surprising results, just as Robert Sardello described in his reference to Jung's own triangulation of systems: "something new will emerge" (Wehr, 2002, p. 9). The "new" is the removal of the veil, revealing what was formerly invisible and showing that the Quality of Life of elders with dementia needs nurturing through safe, meaningful and enjoyable therapy. The dramatherapy which is at the centre of this research has allowed this to become apparent, with the help of the conscious engagement of the participants and their goodwill and honesty about being-in-the-world. I believe my research is an opening for the future where further mixed-methods, evidence-based work can be done on dramatherapy and QoL, where the soul and spirit of people with dementia can flourish and their QoL can be measured.

Mary Smail (2012), one of the directors of the Sesame Institute for Drama and Movement Therapy, London, wrote the following poem about the soul –
not wanting to be "shown" and therefore immeasurable – the often invisible, yet trustworthy, element in this study:

You can feel me, You can touch me
You can hold me, You can need me
But you can’t prove me - I am Soul

You can paint me, You can dance me
You can sing me, You can play me
But you can’t prove me - I am Soul

Do not take me to a place I cannot go
Do not try to make me something that will show
A research lab consigns me to the tomb
I am Mother of the Darkness – I am Womb.

You may weigh me, Or assess me
Try to measure. Verify me
But you won’t prove me - I am Soul

Why not trust me? Journey with me?
Learn to free me. Come to love me
Let me prove to you - I am Soul.
I am Soul, I am Soul

Mary Smail

(Sesame Institute for Drama and Movement Therapy, 2012)
References


Forming, Storming, Norming. [Figure]. Retrieved April 19, 2013, from www.infed.org


Macadam, J. G. (2012, 3rd September). In a system where drugs replace staff, no one can hear you. *Sydney Morning Herald*, p.11.


*Sydney Magazine*, Fairfax Newspapers Ltd. (publication date withheld).


356


Appendices

Appendix 1: Letter of Support from Alzheimer's Australia (NSW)

Dear ,

Date:

Re: Invitation to Participate in a Dramatherapy Research Project

This letter introduces Joanna Jaaniste, who is undertaking a project in partnership with Alzheimer’s Australia (NSW), as part of the requirements of a PhD study with the University of Western Sydney. She is a dramatherapist doing research in the School of Social Science, College of Arts, and her principal supervisor is Dr. Sheridan Linnell. The research will be partially funded by the University and also by Rotary, CBD, Sydney. Joanna’s research project has been approved by the University’s Ethics Committee, and we at Alzheimer’s Australia (NSW) are in support of her research, as it will contribute to new knowledge about programs that enhance quality of life for people living with dementia.

Joanna is conducting a study to identify how dramatherapy can improve the quality of life of people with mild to moderate dementia. We have identified potential participants, such as yourself and/or your family member who have previously attended a ‘Living with Memory Loss’ programme. The study will consist of 2 activities: one being 2 x eight-week sessions of dramatherapy in North Ryde, and the other activity being a film group of similar duration in Newcastle, with a two-week rest period in between. The films shown in Newcastle will be of a musical nature.

The aims of the project are set out in Joanna’s letter, as well as an explanation of dramatherapy. We endorse the research project’s expected outcomes of improved relationships, language and cognitive skills leading to enhanced mood and quality of life. We are confident that any potential risks involved with the dramatherapy group have been foreseen, and that Joanna, in cooperation with our staff and art therapy students on placement with us, will be able to lessen or ameliorate any risks to participants. In each of our facilities there will be staff that are aware of the research program and will be available for confidential one-to-one discussions with anyone who has any concerns that may arise for them during the program.

Participation in this research project is voluntary. If you decide to take part and later change your mind, you are free to withdraw from the project at any
time. Your decision on participation will not affect your relationship with the researcher or Alzheimer’s Australia NSW and our services.

Joanna will be telephoning participants who have accepted the invitation and their carers early in February, so that she can meet with them at Ryde and at Newcastle for explanation and assessment purposes, and to answer any questions you may have concerning the project. Meanwhile, the enclosed letter of invitation from Joanna, endorsed by the University, will answer your initial queries.

Yours sincerely,

Ms Heidi Miller
Manager Support Services
Appendix 2: Letter of Invitation to Join the Dramatherapy Group to the Carer of Person with Dementia

To: Date:

Dear ,

This letter is an invitation for your family member or client to join a project in partnership with the University of Western Sydney, as part of the requirements of a PhD study. I am a dramatherapist doing research in the School of Social Science, College of Arts, and her principal supervisor is Dr. Sheridan Linnell. The research will be partially funded by the University and there will be additional funding provided by Rotary, CBD, Sydney.

Your family member or client has already shown a commitment to the 'Living with Memory Loss' programme, and is invited to take part in two eight-week sessions of dramatherapy, with a two-week rest period in between. The aims of the project are the improvement of relationships between clients, carers and relatives and improvements in language skills leading to better communication. These outcomes should result in enhanced wellbeing. As participants experience movement, it is likely that critical incidents such as falls, and symptoms of depression and anxiety will decrease as a result of greater bodily flexibility and increased confidence, as a result of enjoyment and creativity. The sessions will also present an opportunity to deal with any grief and sense of loss associated with your early stage dementia.

Description of Research

The study will follow a two arm approach. Quantitative measures will be taken from participants in both groups.

Participants at Alzheimer's Australia, NSW (Ryde) will be required to undertake 16 sessions of dramatherapy, consisting of two iterations of 8 weeks (one session per week), with a break of 2 weeks between the 8 week periods. Carers will be asked to complete measures where this is not possible for participants to do so. Qualitative (observational) measures will be taken informing the researcher on memory, attention, language/body language, psychosocial, problem solving, emotions, culture and spirituality, and use of space in the dramatherapy sessions.

Assessments with cognitive, language, quality of life and mood measures will be taken at baseline (during the six weeks before the group starts) and after the cessation of dramatherapy. The control group at AlzA, Newcastle will undertake 4 mornings or afternoons at which a film is shown during the period.

The study aims, through creative and enjoyable warm-ups and exercises, to achieve a possible reduction in psychiatric medications, and to promote acceptance of disabilities and connection with others. It aims to enhance spoken language and body language and quality of life. Acknowledgement of past achievements, rehearsal of social skills and ability to communicate are paramount. Roleplaying emotions and communicative expressions and
experiencing these in a safe environment can lead to new ways of everyday living, increased self-esteem and opening to new experiences.

The results of the research will be valuable to other arts therapists, as there is a gap in the research literature about the efficacy of dramatherapy with people with dementia. Through conference presentations and journal papers associated with my PhD, organisations which play a role in dementia care and could be prospective employers of dramatherapists can be alerted to the role that dramatherapy could play in this area.

I, Joanna, will be working with Ms. ____, Coordinator, Social and Therapeutic Activities, whom you may know, and with an Art Therapy student or students. A Psychologist will be assisting her to evaluate and assess the projects. Any potential inconvenience such as falls will be obviated to the best of our ability by providing this team of helpers.

You and your client or family member will be asked to come for an interview of 1-1.5 hours in February or March. You will be asked to fill out assessment forms at the interview. You carer will also be asked to complete a carer ticksheet which gives information about your perceived wellbeing each week that the participant takes part in the sessions. The groups will take place on a Friday between 10 and 12, and there will be a break for morning tea. The groups will run from Friday, 1st April until Friday 27th May with a break on April 22nd for Good Friday, and then a break of two weeks in which you will be asked to fill out assessment forms again. The next group of sessions will run from Friday, June 17th until Friday 5th August. You and your family member or client will then once more be asked to fill out assessment forms at the end of the project.

Confidentiality of your information will be respected, as all information provided by you both will be anonymous. The work will be videoed and a consent form will be provided at the assessment interview which will assure you of all aspects of collection, storage and use of data which you will generously provide for the project. You will also be informed of specific results of the study once it has been assessed and validated.

It is important to emphasise that participation is voluntary for the programme, and your client or family member will not be asked to give a reason if he or she chooses not to participate. They are also free to withdraw your consent at any time during the project, or to withdraw data that has already been collected during the project.

The results of the study will be sent to you by mail towards the end of 2011. The results will also be disseminated in a journal article and a book.

If you have any questions or require any further information about the research project, please contact Joanna on (02)95186519. If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Human Research Executive Officer
University of Western Sydney
Locked Bag 1797
Penrith, NSW, 2751.

I am very much looking forward to meeting with you, and will be in touch with you by telephone shortly.

Yours sincerely,

Joanna Jaaniste, PhD Candidate
Appendix 3: Letter of Invitation to the Dramatherapy Group to the Person with Dementia

To: Date:

Dear,

This letter is an invitation for you to join a project in partnership with the University of Western Sydney, as part of the requirements of a PhD study. I, Joanna, am a dramatherapist doing research in the School of Social Science, College of Arts, and my principal supervisor is Dr. Sheridan Linnell. The research will be partially funded by the University and also by Rotary, CBD, Sydney.

As a participant who has already shown a commitment to the ‘Living with Memory Loss’ programme, you are invited to take part in two eight-week sessions of dramatherapy, with a two-week rest period in between. The aims of the project are the improvement of relationships between clients, carers and relatives and improvements in language skills leading to better communication.

These outcomes should result in enhanced wellbeing for you. As you experience movement, it is envisaged that any potential physical risks, as well as symptoms of depression and anxiety will decrease as a result of greater bodily flexibility and increased confidence, as a result of enjoyment and creativity. The sessions will also present you with an opportunity to deal with any grief or sense of loss associated with your early stage dementia.

**Description of Research**

The study will follow a two arm approach. Quantitative measures will be taken from participants in both groups.

As a participant at Alzheimer’s Australia, (NSW) Ryde, you will be required to undertake 16 sessions of dramatherapy, consisting of two iterations of 8 weeks (one session per week), with a break of 2 weeks between the 8 week periods. Carers will be asked to complete measures where this is not possible for you to do so. Qualitative (observational) measures will be taken informing the researcher on memory, attention, language/body language, psychosocial, problem solving, emotions, culture and spirituality, and use of space in the dramatherapy sessions.

The second arm of the study will involve a group at Alzheimer’s Australia (NSW), Newcastle which will undertake 16 afternoon sessions at which a film is shown during the period.

The study aims, through creative and enjoyable warm-ups and exercises, to achieve a possible reduction in psychiatric medications, and to promote acceptance of disabilities and connection with others. It aims to enhance spoken language and body language and quality of life. Acknowledgement of past achievements, rehearsal of social skills and ability to communicate are paramount. Roleplaying emotions and communicative expressions and
experiencing these in a safe environment can lead to new ways of everyday living, increased self-esteem and opening to new experiences.

The results of the research will be valuable to other arts therapists, as there is a gap in the research literature about the efficacy of dramatherapy with people with dementia. Through conference presentations and journal papers associated with my PhD, organisations which play a role in dementia care and could be prospective employers of dramatherapists can be alerted to the role that dramatherapy could play in this area.

I will be working with Ms. _____, Coordinator, Social and Therapeutic Activities, whom you may know, and with an Art Therapy student or students. A Psychologist will be assisting me to evaluate and assess the projects. Any potential inconvenience such as falls will be obviated to the best of our ability by providing this team of helpers.

You will be asked to come for an interview of 1-1.5 hours in February or March at 120 Coxs Road, North Ryde, along with your carer. You will be asked to fill out assessment forms at the interview. The groups will take place on a Friday between 10 and 12, and there will be a break for morning tea. The groups will run from Friday, 1st April until Friday 27th May with a break on April 22nd for Good Friday, and then a break of two weeks. The next group of sessions will run from Friday, June 17th until Friday 5th August. Assessments of cognitive and language ability, quality of life and mood measures will take place at baseline, mid-term and at the end.

Confidentiality of your information will be respected, as all information provided by you will be anonymous. The work will be videoed and a consent form will be provided at the assessment interview which will assure selected participants of all aspects of collection, storage and use of data which you will generously provide for the project. You will also be informed of specific results of the study once it has been assessed and validated.

It is important to emphasise that your participation is voluntary, and you will not be asked to give a reason if you choose not to participate. You are also free to withdraw your consent at any time during the project, or to withdraw data that has already been collected during the project.

The results of the study will be sent to you by mail towards the end of 2011. The results will also be disseminated in a journal article and a book.

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Human Ethics Officer, nominated as Complaint Officer (phone (02) 4736 0883 or email humanethics@uws.edu.au). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

I am very much looking forward to meeting with you, and will be in touch with you by telephone shortly. My telephone number in case you need to contact
me is (mobile) 0408956070, and my supervisor, Dr. Linnell’s is (02) 47 360605.

Yours sincerely,
Joanna Jaaniste, PhD Candidate
Appendix 4: Letter of Invitation to Join the Film Group to the Carer of Person with Dementia

Dear [Name],

Date:

This letter is an invitation for your family member or client to join a project in partnership with the University of Western Sydney, as part of the requirements of a PhD study. I, Joanna, am a dramatherapist doing research in the School of Social Science, College of Arts, and her principal supervisor is Dr. Sheridan Linnell. The research will be partially funded by the University and there will be additional funding provided by Rotary, CBD, Sydney.

Your family member or client has already shown a commitment to the ‘Living with Memory Loss’ programme, and is invited to take part in sixteen film sessions of musicals, providing popcorn and a cinematic atmosphere. The parallel group in Sydney, at Alzheimer’s Australia (NSW), North Ryde, will undertake sixteen sessions of dramatherapy during this period. The aims of the project are the improvement of relationships between clients, carers and relatives and improvements in language skills leading to better communication. These outcomes should result in enhanced wellbeing.

**Description of Research**

The study will follow a two arm approach. Quantitative measures will be taken from participants in both groups.

Participants at Alzheimer’s Australia, NSW (Newcastle) will be required to attend sixteen film sessions, where they will experience musical movies on sixteen separate occasions during the period beginning 4th April 2011 up to 8th August 2011. Carers will be asked to complete measures where this is not possible for participants to do so.

The results of the research will be valuable to other arts therapists, as there is a gap in the research literature about the efficacy of dramatherapy with people with dementia. Through conference presentations and journal papers associated with my PhD, organisations which play a role in dementia care and could be prospective employers of dramatherapists can be alerted to the role that dramatherapy could play in this area.

I will be working with Sally O’Loughlin, Regional Coordinator, Hunter/Central Coast whom you may know, and with an Art Therapy student. A Psychologist in Sydney will be assisting her to evaluate and assess the projects. Any potential physical risks will be obviated to the best of our ability by providing this team of helpers.

You and your client or family member will be invited to come for an interview of 1-1.5 hours in February or March at the Hunter Dementia and Memory Resource Centre, Hamilton. You will be asked to fill out assessment forms at the interview. The assessments measure language and cognitive skills, mood and quality of life.

Confidentiality of your information will be respected, as all information provided by you both will be anonymous for all participants selected. A
consent form will be provided at the interview which will assure you of all aspects of collection, storage and use of data which you will generously provide for the project. You will also be informed of specific results of the study once it has been assessed and validated.

It is important to emphasise that participation is voluntary for the programme, and your client or family member will not be asked to give a reason if he or she chooses not to participate. They are also free to withdraw your consent at any time during the project, or to withdraw data that has already been collected during the project.

The results of the study will be sent to you by mail towards the end of 2011. The results will also be disseminated in a journal article and a book.

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Human Ethics Officer, nominated as Complaint Officer (phone (02) 4736 0883 or email humanethics@uws.edu.au). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Joanna is very much looking forward to meeting with you, and will be in touch with you by telephone shortly. Her telephone number in case you need to contact her is (m) 0408956070, and her supervisor, Dr. Linnell’s is (02) 4736 0605.

Yours sincerely,

Joanna Jaaniste, PhD Candidate
Appendix 5: Letter of Invitation to join the Film Group to the Person with Dementia

Dear ,

Date:

This letter is an invitation for you to join a project in partnership with the University of Western Sydney, as part of the requirements of a PhD study. I, Joanna, am a dramatherapist doing research in the School of Social Science, College of Arts, and her principal supervisor is Dr. Sheridan Linnell. The research will be partially funded by the University and additional funding will be provided by Rotary CBD, Sydney.

As a participant who has already shown a commitment to the ‘Living with Memory Loss’ programme, you are invited to take part in sixteen film sessions of musicals, providing popcorn and a cinematic atmosphere. The parallel group in Sydney, at Alzheimer’s Australia (NSW), North Ryde, will undertake sixteen sessions of dramatherapy during this period. The aims of the project are the improvement of relationships between clients, carers and relatives and improvements in language skills leading to better communication. These outcomes should result in enhanced wellbeing.

Description of Research

The study will follow a two arm approach. Quantitative measures will be taken from participants in both groups.

Participants at Alzheimer’s Australia, NSW (Newcastle) will be required to attend 16 film sessions, where they will experience musical movies on sixteen separate occasions during the period beginning 4th April 2011 up to 8th August 2011. Family members or carers will be asked to complete measures where this is not possible for participants to do so.

Assessments with cognitive, language, quality of life and mood measures will be taken at baseline in order to participate in the research project.

I will be working with Sally O’Loughlin, Regional Coordinator, Hunter/Central Coast, whom you may know, and with an Art Therapy student. A Psychologist in Sydney will be assisting her to evaluate and assess the projects. Any potential physical risks will be obviated to the best of our ability by providing this team of helpers.

The results of the research will be valuable to other arts therapists, as there is a gap in the research literature about the efficacy of dramatherapy with people with dementia. Through conference presentations and journal papers associated with my PhD, organisations which play a role in dementia care and could be prospective employers of dramatherapists can be alerted to the role that dramatherapy could play in this area.

You and your carer or family member will be invited to come for an interview of 1-1.5 hours in February or March at the Hunter Dementia and Memory Resource Centre, Hamilton. You and your carer or family member will be asked to fill out assessment forms at the interview.

A consent form will be provided at the assessment interview which will assure you of all aspects of collection, storage and use of data which you will
generously provide for the project. Confidentiality of your information will be respected, as all information provided by you will be anonymous. You will also be informed of specific results of the study once it has been assessed and validated.

It is important to emphasise that your participation is voluntary, and neither you or your carer or family member will be asked to give a reason if you choose not to participate. You are also free to withdraw your consent at any time during the project, or to withdraw data that has already been collected during the project.

The results of the study will be sent to you by mail towards the end of 2011. The results will also be disseminated in a journal article and a book.

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Human Ethics Officer, nominated as Complaint Officer (phone (02) 4736 0883 or email humanethics@uws.edu.au). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

I am very much looking forward to meeting with you, and will be in touch with you by telephone shortly. Her telephone number in case you need to contact her is (m) 0408956070, and her supervisor, Dr. Linnell’s is (02) 47 360605.

Yours sincerely,

Joanna Jaaniste, PhD Candidate
Appendix 6: Consent by Carers/Family Members for Participants in Dramatherapy Research

Alzheimer’s Australia NSW in partnership with the University of Western Sydney (UWS) is committed to supporting and advocating with and for people living with dementia and their families/carers to raise awareness of dementia in our community. One way to achieve this is to actively involve people with dementia and their family members/carers in publications, media and research activities that will help to reduce stigma surrounding dementia.

- I hereby authorise Alzheimer’s Australia NSW and Joanna Jaaniste, who is undertaking a PhD at UWS on the efficacy of dramatherapy to improve the quality of life of people with dementia to undertake the following activities:
  - Recording and retention of images of the participant on film and/or video tape for visual reproduction, to be viewed by the researcher and a psychologist involved in the research, Adrian Lania. They will monitor the footage for the purposes of verifying research outcomes.
  - Publication in a journal article or book and presenting at conferences the participant’s biographic and other information concerning the participant including the dementia diagnosis of them, without using their name or other identifying information. This includes creative works produced by them.
  - I entitle Alzheimer’s Australia and Joanna Jaaniste the right to confirm your client/family member’s diagnosis with the participant’s medical officer or general practitioner.
  - I understand that any data that refers to my client/family member will be stored safely by the researcher in a locked cabinet and destroyed after five years.

Name..........................................................................................................................

Signature........................................................................................................Date.............

Name of the person for whom you are giving consent:

..........................................................................................................................

I have discussed this with the person involved and gained their consent

Signature........................................................................................................Date.............

Signed........................................Date: ....... (Joanna Jaaniste)

Signed............................ .......Date: ....... (on behalf of Alzheimer’s Australia NSW)
Appendix 7: Consent for Participants in Dramatherapy Group Research

Alzheimer’s Australia NSW in partnership with the University of Western Sydney (UWS) is committed to supporting and advocating with and for people living with dementia and their families/carers to raise awareness of dementia in our community. One way to achieve this is to actively involve people with dementia and their family members/carers in publications, media and research activities that will help to reduce stigma surrounding dementia.

I hereby authorise Alzheimer’s Australia NSW and Joanna Jaaniste, who is undertaking a PhD at UWS on the efficacy of dramatherapy to improve the quality of life of people with dementia to undertake the following activities:-

- Recording and retention of images of myself on film and/or video tape for visual reproduction, to be viewed by the researcher and a psychologist involved in the research, Adrian Lania. They will monitor the footage for the purposes of verifying research outcomes.

- Publication in a journal article or book the participant’s biographic and other information concerning me including the dementia diagnosis of myself, without using my name or other identifying information. This includes creative works produced by me.

- I entitle Alzheimer’s Australia and Joanna Jaaniste the right to confirm my diagnosis with your medical officer or general practitioner.

- I understand that any data that refers to me will be stored safely by the researcher in a locked cabinet and destroyed after five years.

Name..............................................................................................................

Signature........................................................................................................Date.........................

Signed................................................................................Date:............ (Joanna Jaaniste)

Signed................................................................................Date:...........

(on behalf of Alzheimer’s Australia NSW)
Appendix 8: Consent by Carers/Family Members for Participants in Dramatherapy Research (Alzheimer’s Australia NSW, Newcastle)

Alzheimer’s Australia NSW in partnership with the University of Western Sydney (UWS) is committed to supporting and advocating with and for people living with dementia and their families/carers to raise awareness of dementia in our community. One way to achieve this is to actively involve people with dementia and their family members/carers in publications, media and research activities that will help to reduce stigma surrounding dementia.

- I hereby authorise Alzheimer’s Australia NSW and Joanna Jaaniste, who is undertaking a PhD at UWS on the efficacy of dramatherapy to improve the quality of life of people with dementia to undertake the following activities:

  - Publication in a journal article or book and presenting at conferences the participant’s biographic and other information concerning the participant including the dementia diagnosis of them, without using their name or other identifying information. This includes creative works produced by them.

  - I entitle Alzheimer’s Australia and Joanna Jaaniste the right to confirm my client/family member’s diagnosis with the participant’s medical officer or general practitioner.

  - I understand that any data that refers to my client/family member will be stored safely by the researcher in a locked cabinet and destroyed after five years.

Name

.................................................................................................................................

Signature............................................................................................................Date.................

Name of the person for whom you are giving consent:

.................................................................................................................................

I have discussed this with the person involved and gained their consent

Signature............................................................................................................Date.................

Signed........................................Date:........... (Joanna Jaaniste)

Signed........................................Date:........... (On behalf of Alzheimer’s Australia NSW)
Appendix 9: Consent for Participants in Dramatherapy Research
Alzheimer’s Australia (NSW), Newcastle

Alzheimer’s Australia NSW in partnership with the University of Western Sydney (UWS) is committed to supporting and advocating with and for people living with dementia and their families/carers to raise awareness of dementia in our community. One way to achieve this is to actively involve people with dementia and their family members/carers in publications, media and research activities that will help to reduce stigma surrounding dementia.

I hereby authorise Alzheimer’s Australia NSW and Joanna Jaaniste, who is undertaking a PhD at UWS on the efficacy of dramatherapy to improve the quality of life of people with dementia to undertake the following activities:-

- Publication in a journal article or book the participant’s biographic and other information concerning me including the dementia diagnosis of myself, without using my name or other identifying information. This includes creative works produced by me.

- I understand that any data that refers to me will be stored safely by the researcher in a locked cabinet and destroyed after five years.

- I entitle Alzheimer’s Australia and Joanna Jaaniste the right to confirm my diagnosis with your medical officer or general practitioner.

Name..............................................................................................................

Signature......................................................................................................Date..............

Signed........................................Date:......... (Joanna Jaaniste)

Signed........................................Date:.........

(on behalf of Alzheimer’s Australia NSW)
Appendix 10: Consent for Participants in Dramatherapy Research (Staff and Students)

Alzheimer’s Australia NSW in partnership with the University of Western Sydney (UWS) is committed to supporting and advocating with and for people living with dementia and their families/carers to raise awareness of dementia in our community. One way to achieve this is to actively involve people with dementia and their family members/carers in publications, media and research activities that will help to reduce stigma surrounding dementia.

I hereby authorise Alzheimer’s Australia NSW and Joanna Jaaniste, who is undertaking a PhD at UWS on the efficacy of dramatherapy to improve the quality of life of people with dementia to undertake the following activities:-

- Recording and retention of images of myself on film and/or video tape for visual reproduction, to be viewed by the researcher and a psychologist involved in the research, Adrian Lania. They will monitor the footage for the purposes of verifying research outcomes.

- Publication in a journal article or book information concerning myself and my activity in the dramatherapy group without using my name or other identifying information. This includes creative works produced by me.

- I understand that any data that refers to me will be stored safely by the researcher in a locked cabinet and destroyed after five years.

Name..........................................................................................................................

Signature........................................................................................................Date........

Signed........................................Date:......

Signed........................................Date:......

(on behalf of Alzheimer’s Australia NSW)  (Joanna Jaaniste)
Appendix 11: Ethics Final Report

Variations to Ethics Protocol Research Procedures (sample size)

1.2.1 My original ethics application designated 8 participants at Newcastle Alzheimer’s Australia (NSW) (AlzA) to watch movies and 8 participants in AlzA Ryde to take part in dramatherapy sessions. I was unable to achieve this, and instead, began with 11 participants in Newcastle and 6 in Ryde.

Source and Method of Recruitment

6.5.1 The source and method of recruitment as designated in the Ethics Application was not satisfactory. Although I took all the steps outlined in my ethics application, AlzA did not make sure that all participants in their ‘Living with Memory Loss’ programme had given them a signed consent form to say that other individuals such as group facilitators or researchers could get in touch with them, as they told me they had. Thus there was a complaint from a carer to the Ethics Committee who had been telephoned by the researcher on a private number without permission. This is all recorded in my report to Jane Hudson, by email, on 2nd March 2011.

2. Number of participants recruited Fewer than expected

In Ryde, the dramatherapy group had only 6 participants, and in Newcastle the film group had 11. The implications for my statistical analysis are not serious. As it is, the small numbers prefigure results that are not quantitatively/statistically significant. I am at present addressing the statistics by including all participants in my analysis and working with variables such as age, diagnosis and gender, and these are producing indications and tendencies which align with my hypothesis. Descriptive significance for quantitative analysis in my thesis will also be necessary to show comparative trends. See item 4 for details of actions put in place to remedy this situation.

3. Adverse Effects

The complaint that was made by a carer was that no expression of interest had been given to AlzA on behalf of the carer or the person with dementia, and therefore the telephone number of these persons should never have been passed on to the researcher. Because of this, the research ceased until the Manager, Support Services at AlzA, Heidi Miller, had also received a complaint from the carer concerned. She then assured the Ethics Committee that the protocol for expressions of interest would be changed.

The researcher then designed a pro forma to be used by AlzA staff, so that contact could be made with clients by their organisation and the date and time, as well as the expression of interest could be recorded, ensuring that consent had been given for contact to be made by the researcher. Each contact had to be signed by the staff member making or taking the telephone call concerning the research. The researcher made sure that she viewed the signed pro forma before she make contact with the potential participant. A copy of this pro forma is attached to this report.
Appendix 12: Phone Contact Register

**PHONE CONTACT REGISTER - Expressions of Interest**

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Date called</th>
<th>Time called</th>
<th>Client agrees to be contacted by letter (yes/no)</th>
<th>Joanna or Alz NSW to call after receipt of letter? (yes/no)</th>
<th>Initials of caller</th>
<th>Address &amp; Phone No. if client expresses interest</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 13: Quality of Life in Alzheimer’s Disease: Participant Report

ID No:______ Assessment No:______ Interview Date: ________

- Administer according to Instruction sheet:
- Circle Participant responses.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Living situation</td>
<td>Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Marriage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Self as a whole</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Ability to do chores around the house</td>
<td>Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Ability to do things for fun</td>
<td>Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Money</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Life as a whole</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 14: Quality of Life in Alzheimer’s Disease: Family Version

ID No:______ Assessment No:_____ Interview Date: ________

Instructions: Please rate your relative’s current situation, as you see it

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.</td>
<td>Physical Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Mood</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Living situation</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>18.</td>
<td>Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Marriage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Self as a whole</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Ability to do chores around the house</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Ability to do things for fun</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>25.</td>
<td>Money</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Life as a whole</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 15: Geriatric Depression Scale

**Geriatric Depression Scale (GDS-15)**
This scale was developed as a basic screening measure for depression in older adults. Created in the early 1980s by Yesage & Brink, the original scale is in the public domain.

**Mood Scale**
Choose the best answer for how you have felt over the past week.

1. Are you basically satisfied with your life? YES/NO
2. Have you dropped many of your activities and interests? YES/NO
3. Do you feel that your life is empty? YES/NO
4. Do you often get bored? YES/NO
5. Are you in good spirits most of the time? YES/NO
6. Are you afraid that something bad is going to happen to you? YES/NO
7. Do you feel happy most of the time? YES/NO
8. Do you often feel helpless? YES/NO
9. Do you prefer to stay at home, rather than going out and doing new things? YES/NO
10. Do you feel that you have more problems with memory than most? YES/NO
11. Do you think it is wonderful to be alive now? YES/NO
12. Do you feel pretty worthless the way you are now? YES/NO
13. Do you feel full of energy? YES/NO
14. Do you feel that your situation is hopeless? YES/NO
15. Do you think that most people are better off than you are? YES/NO

Answers in **bold** score 1 point.

(The GDS is a screening tool and not a diagnosis. Although differing sensitivities and specificities have been obtained across studies, for clinical purposes a score of 6 points or more is suggestive of depression and should warrant a thorough assessment.)
Appendix 16: Dramatherapy Themes, Aims and Session Plans

Dramatherapy Sessions at Alzheimer's Australia (NSW), 120 Coxs Road, North Ryde.

Overall Aims:
Alzheimer’s Australia (NSW)’s Vision:
A society committed to the prevention of dementia, while valuing and supporting people living with dementia.

Alzheimer’s Australia (NSW)’s Mission:
Providing leadership in dementia advocacy, awareness and understanding.

Dramatherapy Aims:
- Improve the quality of life of participants
- Improve the language ability of participants
- Achieve enhanced communication, especially with carers
- Reduce depressive symptoms
- Stabilise cognitive function
- Encourage creativity and expression

Session Themes:
Session 1 1.4.11 Getting to know you/personal aims
Session 2 8.4.11 Weather and the Seasons
Session 3 15.4.11 Finding Treasure
Easter Break (2 weeks)
Session 4 29.4.11 Colour
Session 5 6.5.11 Planting seeds
Session 6 13.5.11 The Joys and Woes of Memory
Session 7 20.5.11 Grief and Loss
Session 8 27.5.11 Celebrating Ourselves
Break (3 weeks)
Session 9 17.6.11 Animal Kingdom with art therapy
Session 10 24.6.11 Magic Shop
Session 11 1.7.11 Dealing with Difficult People
Session 12 8.7.11 In the Land of Forgetfulness
Session 13 15.7.11 The joys and woes of Memory
Session 14 22.7.11 Future Wants and Needs
Session 15 29.7.11 Grief and Loss
Session 16 5.8.11 Celebrating Ourselves
Session 1  Dramatherapy at Alzheimer’s Australia (NSW)
1.4.11  Getting to know you

Objectives:

- Make a joint contract
- Participants demonstrate early cohesion by introductions and interaction
- Participants list their personal aims for the group
- Group members demonstrate understanding of warmup activities
- Participants choose and reflect on photos, connecting with selves/group aims
- Participants assist in choice of ending ritual

10.30  Contract and housekeeping
10.40  Introductions in pairs
11.00  Warmups in circle:
   Name game – balls
   Name game – gestures
   Heads up: heads down - Participants stand in a circle. The facilitator or designated group member asks them to look down to start. When he calls 'heads up', everyone gives eye contact to someone anywhere in the circle. If two people are looking straight at each other, they change places. Then he calls out 'heads down'.
11.20  Choose a photograph from those laid out on the floor and discuss pictures in pairs. (Photolanguage Australia (1986).
11.35  Come into larger group and share aims, perceptions, memories
11.55  Song: Getting to know you (Rodgers & Hammerstein, 1951).
12.00  Ending ritual - nod to the participants on either side of you.

Resources: large poster-sized cardboard for contract, ipod, balls, photographs.

Session 2  Dramatherapy at Alzheimer’s Australia (NSW)
8.4.11  Seasons and Weather

Objectives:

- Remind about contract
- Participants demonstrate early cohesion by further interaction
- Participants list any other personal aims for the group
- Participants express in drawing, speech and movement how they feel about weather
Participants sing and assist in choice of ending ritual
10.30 Reflection on last week’s work
10.40 Introductions (brief)
10.50 Warmups in circle:

Catch my Name (Farmer, 2007, p. 6).

Ball pattern - Participants try to remember who threw to whom by repetition

Clapping numbers - Participants clap once, twice up to 5. The 5 claps are repeated, and then down the scale back to 1. Then exercise repeated.

Participants walk around in various weathers - Walk around space and facilitator names various types of weather. Pretend we are walking in that weather. Participants choose their favourite kind of weather. They sit with it for a moment, and then draw a picture of self in the weather. Facilitator comes around and taps each one on the shoulder, and they make a sound that goes with the weather if they can, and then a word or sentence.

11.10 Participants come into the middle if they can and make a shape of their body that connects with what they have just done – say what they see.

11.20 Participants find a partner and talk about their week in turn. Then they draw a line on a second piece of paper – straight or wiggly or whatever your week was like. Draw weather for each part of their week. (This exercise was too difficult for only the 2nd session.)

11.25 Participants come into the circle and talk about what they have drawn.

11.50 Listen to and sing Just walking in the rain (Bragg & Riley, 1952) and then sing Getting to know you (Rodgers & Hammerstein, 1951).

12.00 Participants choose ending.

Resources: ipod, contract, large poster-sized cardboard for aims, balls, dry art materials, paper.

Session 3          Dramatherapy at Alzheimer’s Australia (NSW)
15.4.11          *Finding Treasure

Objectives:
• Remind about contract and aims
• Participants demonstrate early cohesion by further interaction
• Participants list varied names for feelings
• Group members demonstrate quicker uptake of warmup activities
• Participants use objects as projective techniques to engage in storytelling
• Participants sing and receive Easter eggs.
10.30 Reflection on last week’s work

10.40 Warmups in circle:

- **Ball pattern**
- **Clapping numbers**

*Shoo, fin, bounce* - Playback theatre game (Adrian Lania, September 6, 2006, personal communication). Participants learn first stage of the game: they sweep their right arm across their body towards the person next to them and say ‘Shoo’. This takes place a few times around the circle.

*Emotional Statues* - Participants walk around the room. Whenever a feeling is called out, they make a shape or sculpt with their body that corresponds with the feeling. They make a sound that goes with the feeling. (Emunah, 1994, p. 157).

*Group mood* Someone goes out of the room and the rest choose a mood - e.g. shy, anxious, etc. The others try to act that mood and see if the person coming in from outside can guess what it is (Emunah, 1994, pp. 148-150).

11.10 Participants take an object from the lucky dip treasure box. Take your object and talk to a partner about it. Does it remind them of any happening, person, story in particular?

11.30 Participants share their objects with the whole group.

11.25 Participants join group and talk or put into action a story it reminded them of.

11.50 Everyone sing *Getting to know you* (Rodgers & Hammerstein, 1951).

12.00 Ending with Easter Eggs for each person.

**Resources:** ipod, contract, list of aims, balls, treasure box of objects.

*(This session also incorporated a train ride in 1938 from Vienna to Holland, as Tanya needed her support in her memory of this frightening episode).*

---

**Session 4**

**Dramatherapy at Alzheimer’s Australia (NSW)**

29.4.11

**Colour**

**Objectives:**

- Remind about contract and aims
- Participants demonstrate early cohesion by further interaction
- Participants say how they are feeling
- Group members demonstrate attitudes to colour
- Participants choose a colour and stay with it to paint and perform
- Participants sing and assist in choice of ending ritual

10.15 Reflection on how people feel
10.20 Participants talk about colour – one sentence each

10.30 Warmups in circle:

Ball pattern

Clapping numbers

Using cloth for impro - A cloth is passed around the circle, giving each member an opportunity to use it in improvised form - either as a piece of clothing, a picnic rug, a flag, etc. Each person shows it to the next one in the circle who mirrors their action with the cloth and then finds their own way of using it to show to the next person.

10.45 Pick up a silk cloth of your favourite colour, paint a picture with the same colour and show painting. Use the paintings to create an improvisation.

11.15 Perform from paintings.

11.45 Reflect on performance

11.55 Everyone sing Getting to know you (Rodgers & Hammerstein, 1951).

12.00 Ending – group choice

Resources: ipod, contract, list of aims, balls, silk cloths, paints, water, paper

Session 5 Dramatherapy at Alzheimer's Australia (NSW) 29.4.11 Planting Seeds

Objectives:

- Remind about contract
- Participants demonstrate embodiment and voice expression
- Participants say how they are feeling
- Group members tell us about their own experience of planting seeds
- Participants mime their story
- Participants sing and assist in choice of ending ritual

10.15 Reflection on how people feel

10.20 Talk growth – one sentence each

10.30 Warmups in circle:

Walking round and leading with different parts of the body

Make the shape of your favourite tree

Movement to music

11.00 Pick up cards – talk in pairs about planting seeds in your life

11.15 Sculpt in pairs, sharing your movements with one another.

11.25 Join into fours and perform for the other participants with sound and movement.
11.35 Plant crocus bulbs, giving them a message
11.45 Reflect on work
11.55 Everyone sing *Getting to know you* (Rodgers & Hammerstein, 1951).
12.00 Ending - group choice.

**Resources:** ipod, contract, aims, cards with words about planting seeds (*let go*, *grow tall*, etc.) crocus bulbs, pots of soil.

**Session 6**  
**Dramatherapy at Alzheimer’s Australia (NSW)**

13.5.11  
**The Joys and Woes of Memory**

**Objectives:**
- Remind about contract
- Participants demonstrate storytelling about their lives
- Participants say how they are feeling
- Group members walk through their life story remembering happenings
- Participants walk back, harvesting the gifts of those memories
- Participants freeze moments from the memories
- Participants sing *Thanks for the Memory*, (Robin & Rainger, 1938).

10.15 Reflection on how people feel
10.20 Memory – one sentence each
10.30 Warmups in circle:

  *Shoo, fin, bounce* (See Session 3) An extra movement is added. Any participant can change direction by using the other hand from the ‘shoo’ hand, making a shark’s fin with it, and saying ‘fin’. This action can be used by anyone in the circle to change direction after a ‘shoo’ or a ‘fin’.

*Developmental Transformations* (See Chapters 2 and 9)

**Do you remember?**
10.50 Go and visit each part of the room which represents an age – Childhood, Adolescence, 20-30, 30-50, 50-60+
11.15 Walk back through the stages, picking up pictures, cloths and objects
11.40 Reflect on these memories and freeze the actions if time
11.55 Everyone sing *Thanks for the Memory* (Robin & Rainger, 1938).
12.00 Ending

**Resources:** ipod, contract, aims, objects representing life stages, small baskets for collecting objects, cloths.

**Session 7**  
**Dramatherapy at Alzheimer’s Australia (NSW)**
20.5.11  Grief and Loss

Objectives:

- Remind about contract
- Participants demonstrate storytelling about their lives
- Participants say how they are feeling
- Group members remember losses and grieves
- Participants improvise/draw memories of these losses
- Participants freeze moments from the memories
- Participants sing *We’ll meet again* (Parker, 1943).

10.15 Reflection on how people feel

10.20 Grief and loss memories – introduction to grief table (see Chin, 1996).

10.30 Warmups in circle:

*Ball throwing with one word about grief and loss*


10.50 Tell story of *Ulu and the Breadfruit Tree* (Gersie & King, 1990, p. 237).

11.15 Participants improvise the story

11.40 Reflect on story and what it reminds us of. Place a flower on the grief table for someone you have lost.

11.55 Everyone sing *We’ll meet again* (Parker, 1943).

12.00 Ending - Group Whooooosh on behalf of the divorced and separated fathers who cannot get access to their children.

Resources: ipod, contract, aims, balls, blindfolds, dressups, cloths, flowers, grief table.

---

**Session 8  Dramatherapy at Alzheimer’s Australia (NSW)**

20.5.11  Celebrating ourselves

Objectives:

- Remind about contract
- Participants demonstrate storytelling about their lives
- Participants say how they are feeling
- Group members celebrate each other
- Participants improvise/draw memories of past group activities
- Participants freeze moments from the sessions
- Participants sing

10.15 Reflection on how people feel
10.20 Introduction to celebrating ourselves
10.30 Warmups in circle:
   *Balloon game* - Pass the balloon tucked under the chin of the first participant, around the circle in the same manner (see *Pass the Orange*, Jennings, 1986, p. 82).
   *Cat and Mouse* (Farmer, 2012, p. 12).
   *Grandmother's Footsteps* - A participant takes on the role of Grandmother, and stands at one end of the room, while all the others line up on the opposite wall and when given the instruction, they walk slowly and carefully towards 'her'. She has her back to the others, but can turn around at any time and send anyone whom she sees moving back to the wall again. The person who arrives first, undetected, has the honour of becoming the next Grandmother (Farmer, 2007, p. 55).
   *Cat and Dog in pairs* - Partner game where one plays a cat and the other a dog, and they communicate with one another in cat and dog language - caterwauling and 'dogawauling' (Howe, 2010).
10.50 Developmental Transformations
11.15 Hats improvisation or *Pick a Hat* (Scher & Verrall, 1975, pp. 75-76).
11.40 Reflection

**Resources:** ipod, contract, aims, balloon, silk cloths, hats.

---

**Session 9**
**Dramatherapy at Alzheimer's Australia (NSW)**
**17.06.11**
**Animal Kingdom**

**Objectives:**
- Remind about contract
- Participants demonstrate storytelling about their lives
- Participants say how they are feeling
- Group members show improvisational skills
- Participants use games, impro and pictures as stimulus material for clay modelling
- Participants sing *Tie me kangaroo down, sport* (Harris, 1960).
10.15 Reflection on how people feel

10.20 Introduction to animals in our lives
10.30 Warmups in circle:
   *Ball game*
Cat and Mouse (Scher & Verrall, 1975, p. 20)

Guess the animal - Each participant takes a turn at miming a certain animal in the centre of the circle. The others try to guess the animal.

10.50 Find your partner from impros – pick a card (marked with an animal name: monkey, lion, etc. There are two of each animal. Participants find their partner by checking each of their cards are marked with the same animal).

11.15 Take some clay and model an animal, looking at pictures

11.40 Reflection

11.55 Everyone sing Tie me Kangaroo Down, Sport (Harris, 1960).

12.00 Ending

Resources: ipod, contract, aims, clay, clay boards, animal pictures, balls, cards

Session 10 Dramatherapy at Alzheimer's Australia (NSW)
17.06.11 Magic Shop

Objectives:

- Remembering last week
- Participants demonstrate spontaneity
- Participants express what they are looking for in life
- Group members disclose what they are willing to give up in exchange
- Participants sing We'll meet again (Parker, 1943).

10.15 Reflection on how people feel and remembering last week

10.25 Warmups in circle:

Who am I? (Farmer, 2007, p. 31).

Diamonds - Participants make groups of four and stand all looking in the same direction, in a diamond shape. The person at the apex of the diamond is the leader and makes movements with head, limbs, etc. All other participants copy his movements until he requests a 'change', looking at another member of the four. Then that person becomes the leader, and the other three stand behind him, facing his back, and copy his movements. The changes continue until all four have had a turn at leading.

Balloon under chin game (see Session 8).

Emotional machines (Scher & Verrall, 1975, p. 57).


11.10 Take turns in the Magic Shop

11.40 Reflection

11.55 Everyone sing We'll meet again (Parker, 1943).
12.00 Ending - choice by participants.

Resources: ipod, contract, aims, balloon.

Session 11  
Dramatherapy at Alzheimer‘s Australia (NSW)  
1.7.11  
Dealing with Difficult People

Objectives:

- Remembering last week
- Participants demonstrate openness about difficult people in their lives
- Participants improvise difficult people in their lives
- Group members role reverse with the difficult person
- Participants sing

10.15 Reflection on how people feel and remembering last week – cards with feelings

10.25 Warmups in circle:

Silly walks in movement (Scher & Verrall, 1975, pp. 45-46).
Sculptor and Statue (Emunah, 1994, pp. 157-158).

11.00 Improvisations emanating from the sculptures, using hats, cloths and dressups.

11.40 Reflection on work.

11.55 Everyone sing Tie me Kangaroo Down, Sport (Harris, 1960). (A different song had been planned, but now that Leanne could play this one, everyone wanted to sing it again).

12.00 Ending - choice of ritual

Resources: ipod, contract, aims, circular table, dressups, cloths, hats.

Session 12  
Dramatherapy at Alzheimer’s Australia (NSW)  
8.7.11  
The Land of Forgetfulness

Objectives:

- Remembering last week
- Participants demonstrate awareness about memory being difficult for all
- Participants demonstrate spontaneity in the play space (DvT)
- Group members show they can transform fear, anger, tears and emptiness
- Participants sing Near friends, dear friends (Watts, 2006).
- Leanne to play tune on piano, if she can (prepare before group)
10.15 Reflection on how people feel and remembering last week – cards with feelings

10.25 Warmups in circle:

*Fruit Bowl* - Choose someone to stand in the centre of the circle and have enough chairs for everyone minus one. Give each person, including the one in the centre, one of the names of three fruits: apple, orange and banana, around the circle. The person in the middle calls out the name of a fruit, and those (oranges, for example) have to change places, while the middle person finds a space. The one without a chair then becomes the middle person. 'Fruit Bowl' can be called out, which means that everyone has to move (Farmer, 2012, p. 3).

*Adam and Eve* (Scher & Verrall, 1975, p. 24).

*Blindfold with feeling* - One participant is blindfolded and has to identify others in the circle by feel. The facilitator helps with safety, and hands, feet and heads can be designated as the boundaried feeling areas.

11.00 DvT playspace: the Land of Forgetfulness – finding anger, fear, emptiness & tears (see Chapter 7, Session 12).

11.20 Bringing back gifts from the Land – Reflection on transformation of objects

11.50 Everyone sing *Near Friends, Dear Friends* (Watts, 2006).

12.00 Ending ritual - there was no other ending ritual apart from the song, as the ritual with objects seemed to be enough.

**Resources:** ipod, contract, aims, blindfolds, stones, sticks, leaves, petals, bowls; silk cloths. (Session adapted from *The Truth Mandala*, Macy & Young Brown (1998), pp. 101-104).

---

**Session 13**

**Dramatherapy at Alzheimer’s Australia (NSW)**

**15.7.11**

**Joys and Woes of Memory**

**Objectives:**

- Remembering last week
- Participants demonstrate awareness about memory being difficult for all
- Participants demonstrate awareness of olfactory memory
- Group members show they can create vignettes from memories of scent
- Participants sing *Thanks for the memory* (Robin & Rainger, 1938).
- Leanne to play tune on piano, if she can (prepare before group)

10.15 Reflection on how people feel and remembering last week
10.25 Warmups in circle:

* Dance movement cloth exercise (all participants hold a stretchy cloth. Music is played while they pull, stretch, dance and crawl under the cloth).

* Who started the motion? (Emunah, 1994, p.181)

* Emotion machine (Scher & Verrall, 1975, p. 50).

*I remember when...* (A player finishes this sentence and the others have to quickly form the scene the person remembers – group sculpt, then coming alive).

11.00 With a partner. Each person has a pen and chart. Pick up the smelling bags off the cloth, one by one, guessing what is in the bags and filling in the spaces below the number that coincides with the numbers on the bags.

11.20 Bring back to group, and share the memories the scents brought up.

11.50 Sing: *Thanks for the Memory* (Robin & Rainger, 1938).


12.00 Ending ritual - Leanne played and accompanied the above song on piano.

**Resources:** ipod, contract, aims, stretchy cloth, smelling bags, blindfolds, cloths, charts to complete, pens.

---

**Session 14**

**Dramatherapy at Alzheimer’s Australia (NSW)**

**22.7.11**

**Past, Present and Future**

**Objectives:**

- Remembering last week
- Participants collaborate with others’ memories
- *Participants think about what they would like for the future
- *Participants sing *Thanks for the memory*, (Robin & Rainger, 1938).
- Leanne to play tune on piano, if she can (prepare before group)

10.15 Reflection on how people feel and remembering last week

10.25 Warmups in circle:

* Fruit Bowl (see Session 12)

* Finding your strength in partners - In pairs, feet hip width apart, partners place their palms flat against their partner’s palms, testing strength against one another. (This is not an exercise to push each other over, but to be strongly flexible in partnership.)

* Tug of war (Scher & Verrall, 1975, p. 43).

* Cat and mouse (Farmer, 2012, p. 12)).
10.55 Scenarios brought forward from last week: Neil being in the kitchen while his mother is cooking – he is 6.

Leanne had a memory of Christmas.

David had a memory of the orchard and being in trouble.

11.30 What do people want for the future? Throw ball with wishes for future. Facilitator write them on cards. Walk around to see them on cards. Draw your wish for the future and share. (*These wishes for the future were not made - only the past was considered).

11.55 Sing: *Near Friends, Dear Friends*, (Watts, 2006). (*We had no time to sing the memory song, and Leanne was happy to accompany this one).

12.00 Ending

**Resources:** ipod, contract, cards, balls.

---

**Session 15**

**Dramatherapy at Alzheimer's Australia (NSW)**

**29.7.11**

**Grief and Loss 2**

**Objectives:**

- Remembering last week
- Participants say how they are feeling
- Group members remember losses and griefs
- Participants improvise memories of these losses
- Participants sing *We'll meet again* (Robin & Rainger, 1938).

10.15 Reflection on how people feel

10.20 Grief and loss memories – losses

10.30 Warmups in circle:


10.40 Pick up a twig and do a brief drawing of the tree that it came from – place near grief table

10.55 Write on a card something about a promise that has been made – perhaps broken – or a loss that has occurred in your life and place the card near a drawing that you like.

11.05 Talk about a loss that you have experienced or a promise that has been broken

11.15 Opportunity for dramatherapy work with someone’s loss (It was Leanne’s turn to work with her issue with Mrs. Lackey for the last time - see Chapter 7, Session 15).

11.45 Sing *We’ll meet again* (Robin & Rainger, 1938).

11.55 Sing *Near Friends, Dear Friends* (Watts, 2006).

12.00 Ending - the songs were repeated.
**Session 16**

**Dramatherapy at Alzheimer’s Australia (NSW).**

**5.8.11**

**Bringing Gifts to the Feast**

**Objectives:**

- Opportunity to express appreciation of each other
- Participants choose gestures or words, remembering what we have done together
- Opportunity to engage with memories of the group
- A closure is made, followed by a special morning tea

10.15 Reflection on how people feel and last week’s work
10.20 Grief and loss memories – losses
10.30 Warmups in circle:
  
  *Ballthrowing with one word about our ending*
  
  *Gestures with silk cloths*

10.40 Developmental Transformations - Magic Box

10.55 Talk about *Bringing Gifts to the Feast*. Pick up a fruit or flower and place it on the celebratory table, saying something about your experience in this group

11.15 Sing *We'll meet again* (Robin & Rainger, 1938).

11.20 Sing *Near Friends, Dear Friends* (Watts, 2006).

11.25 Say goodbye to one another in your own way to each person.

11.30 Morning tea celebration.

**Resources:** ipod, contract, aims, silk cloths, ball, celebration table, fruit and flowers.
Appendix 17: Dementia Diagnoses

Vascular Dementia and Lewy Bodies Dementia

290.4x Vascular Dementia (formerly Multi-Infarct Dementia)

Diagnostic criteria for 290.4x Vascular Dementia

- The development of multiple cognitive deficits manifested by both
  - memory impairment (impaired ability to learn new information or to recall previously learned information)
  - one (or more) of the following cognitive disturbances:
    - aphasia (language disturbance)
    - apraxia (impaired ability to carry out motor activities despite intact motor function)
    - agnosia (failure to recognize or identify objects despite intact sensory function)
    - disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)
- The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.
- Focal neurological signs and symptoms (e.g., exaggeration of deep tendon reflexes, extensor plantar response, pseudobulbar palsy, gait abnormalities, weakness of an extremity) or laboratory evidence indicative of cerebrovascular disease (e.g., multiple infarctions involving cortex and underlying white matter) that are judged to be etiologically related to the disturbance.
- The deficits do not occur exclusively during the course of a delirium.

Code based on predominant features:

- 290.41 With Delirium: if delirium is superimposed on the dementia
- 290.42 With Delusions: if delusions are the predominant feature
- 290.43 With Depressed Mood: if depressed mood (including presentations that meet full symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.
- 290.40 Uncomplicated: if none of the above predominates in the current clinical presentation

Specify if:

- With Behavioral Disturbance

Coding note: Also code cerebrovascular condition on Axis III.

Diagnostic Features

The cognitive deficits (Criterion A) and the required impairment (Criterion B) in Vascular Dementia are discussed in Dementia. There must be evidence of cerebrovascular disease (i.e., focal neurological signs and symptoms or laboratory evidence) that is judged to be etiologically related to the dementia
(Criterion C). The focal neurological signs and symptoms include extensor plantar response, pseudobulbar palsy, gait abnormalities, exaggeration of deep tendon reflexes, or weakness of an extremity. Computed tomography (CT) of the head and magnetic resonance imaging (MRI) usually demonstrate multiple vascular lesions of the cerebral cortex and subcortical structures. Vascular Dementia is not diagnosed if the symptoms occur exclusively during delirium (Criterion D). However, delirium may be superimposed on a preexisting Vascular Dementia, in which case the subtype ‘With Delirium’ should be indicated.

Subtypes
By ICD-9-CM convention, Vascular Dementia is the only type of dementia that employs subtypes to indicate the presence of significant associated symptoms. The following subtypes (each of which has its own separate code) must be used to indicate the predominant feature of the current clinical presentation:

- **With Delirium.** This subtype is used if delirium is superimposed on the dementia.
- **With Delusions.** This subtype is used if delusions are the predominant feature.
- **With Depressed Mood.** This subtype is used if depressed mood (including presentations that meet symptom criteria for a Major Depressive Episode) is the predominant feature. A separate diagnosis of Mood Disorder Due to a General Medical Condition is not given.
- **Uncomplicated.** This subtype is used if none of the above predominates in the current clinical presentation.

The specifier **With Behavioral Disturbance** (which cannot be coded) can also be used to indicate clinically significant behavioral disturbances (e.g., wandering).

Recording Procedures
By ICD-9-CM convention, only Vascular Dementia has codable subtypes. The diagnostic codes for Vascular Dementia depend on the subtype for predominant features: 290.41 for With Delirium, 290.42 for With Delusions, 290.43 for With Depressed Mood, 290.40 for Uncomplicated. The specifier With Behavioral Disturbance is uncoded and can be applied to each of the above subtypes (e.g., 290.43 Vascular Dementia, With Depressed Mood, With Behavioral Disturbance). In addition, the cerebrovascular condition (e.g., 436 stroke) should be coded on Axis III.

Associated laboratory findings
The extent of central nervous system lesions detected by CT and MRI in Vascular Dementia typically exceeds the extent of changes detected in the brains of healthy elderly persons (e.g., periventricular and white matter hyperintensities noted on MRI scans). Lesions often appear in both white matter and gray matter structures, including subcortical regions and nuclei.
Evidence of old infarctions (e.g., focal atrophy) may be detected, as well as findings of more recent disease. EEG findings may reflect focal lesions in the brain. In addition, there may be laboratory evidence of associated cardiac and systemic vascular conditions (e.g., ECG abnormalities, laboratory evidence of renal failure).

**Associated physical examination findings and general medical conditions**

Common neurological signs (e.g., abnormal reflexes, weakness of an extremity, gait disturbance) are discussed in the "Diagnostic Features" section. There is often evidence of long-standing arterial hypertension (e.g., funduscopic abnormalities, enlarged heart), valvular heart disease (e.g., abnormal heart sounds), or extracranial vascular disease that may be sources of cerebral emboli. A single stroke may cause a relatively circumscribed change in mental state (e.g., an aphasia following damage to the left hemisphere, or an amnestic disorder from infarction in the distribution of the posterior cerebral arteries), but generally does not cause Vascular Dementia, which typically results from the occurrence of multiple strokes, usually at different times.

**Specific Culture, Age, and Gender Features**

The onset of Vascular Dementia is typically earlier than that of Dementia of the Alzheimer's Type. The disorder is apparently more common in males than in females.

**Prevalence**

Vascular Dementia is reportedly much less common than Dementia of the Alzheimer's Type.

**Course**

The onset of Vascular Dementia is typically abrupt, followed by a stepwise and fluctuating course that is characterized by rapid changes in functioning rather than slow progression. The course, however, may be highly variable, and an insidious onset with gradual decline is also encountered. Usually the pattern of deficits is "patchy," depending on which regions of the brain have been destroyed. Certain cognitive functions may be affected early, whereas others remain relatively unimpaired. Early treatment of hypertension and vascular disease may prevent further progression.

**Lewy Bodies Dementia 294.1x**

Dementia Due to Parkinson's Disease

The essential feature of Dementia Due to Parkinson's Disease is the presence of a dementia that is judged to be the direct pathophysiological consequence of Parkinson's disease. Parkinson's disease is a slowly progressive neurological condition, characterized by tremor, rigidity, bradykinesia, and postural instability. Dementia has been reported to occur in approximately 20%–60% of individuals with Parkinson's disease and is more likely to be present in older individuals or those with more severe or advanced disease. The dementia associated with Parkinson's disease is characterized by cognitive and motoric slowing, executive dysfunction, and impairment in memory retrieval. Declining
cognitive performance in individuals with Parkinson's disease is frequently exacerbated by depression. Findings on physical examination include the characteristic abnormal motor signs of resting tremor, evidence of slowness and poverty of movement (such as micrographia), or muscular rigidity and loss of associated movements. At autopsy, neuronal loss and Lewy bodies are evident in the substantia nigra. There are a number of syndromes that may manifest with dementia, parkinsonian movement disorders, and additional neurological features (e.g., progressive supranuclear palsy, olivopontocerebellar degeneration, and Vascular Dementia). Some individuals with Parkinson's disease and dementia are found at autopsy to have coexisting neuropathology indicative of Alzheimer's disease or of diffuse Lewy body disease. Dementia due to Lewy Body Disease in the absence of evidence of Parkinson's (such as tremor and cogwheel rigidity) should be diagnosed as Dementia Due to Lewy body disease, one of the dementias due to other general medical conditions.

Recording Procedures
In recording the diagnosis of Delirium Due to a General Medical Condition, the clinician should note both the delirium and the identified general medical condition judged to be causing the disturbance on Axis I (e.g., 293.0 Delirium Due to Hypoglycemia). The ICD-9-CM code for the general medical condition should also be noted on Axis III (e.g., 251.2 hypoglycemia.) When the delirium is superimposed on a preexisting dementia, both diagnoses should be made (e.g., 294.11 Dementia of the Alzheimer's Type, With Behavioral Disturbance, and 293.0 Delirium Due to Hyponatremia). Since Alzheimer's disease is not an established etiology for delirium but only a risk factor, the etiology of any delirium superimposed on Alzheimer's disease must be determined. Because of ICD-9-CM coding requirements, delirium superimposed on Vascular Dementia is noted by coding the appropriate subtype of the dementia (e.g., 290.41 Vascular Dementia, With Delirium). In situations in which it is unclear whether the cognitive deficits are due to delirium or to dementia, it may be useful to make a provisional diagnosis of delirium and observe the person carefully while continuing efforts to identify the nature of the disturbance.

Appendix 18: Jones' Adaptation of Scale of Dramatic Involvement

1 Focus
(a) Within the dramatic activity as a whole
Focused Occasionally focused Often distracted Distracted
(b) in engaging with 'as if' behaviours
Focused Occasionally focused Often distracted Distracted

2 Completion
The degree to which the client completes tasks
Completes all tasks Completes some tasks Completes no tasks

3 Use of imaginary objects
The capacity for creating and sustaining the use of pretended objects in a manner convincing to self and others
(a) Can create and sustain pretended objects
(b) Can disengage from object at the end of activity
(c) Can engage with others' created objects
Until end of activity During part of activity Momentarily Not at all

4 Elaboration
Demonstrating the capacity to develop and initiate ideas within improvisation or play
No elaboration Useful elaboration Too much elaboration*
Useful engagement with others' elaborations No engagement with elaborations

*(detracts from enactment)

5 Use of space
Use of space within dramatic activity: movement in improvisation, games or character-based work

Uses available Uses space well Confines self to space easily in relation to others small space

6 Facial expression
Use of face to depict appropriate emotions or responses in pretend or improvised activity
Appropriate and constant Some attempts No use of face use of face to use face

7 Body movement
Using body effectively and appropriately to dramatic activity or character, communicating information or messages appropriately
Appropriate and effective Some use of body No use of body use of body

Understanding information or messages communicated by others’ bodies within dramatic work
Constant For some of the work Not at all

8 Vocal Expression
Emotional relevance and projection within activities
Constant For some of the work Not at all

9 Social relationships
Awareness and response to others within the activities
Constant For some of the work Not at all

(Jones, 2006, pp. 273-4).
Appendix 19: From The Hare with Amber Eyes

Edmund de Waal, in his moving account of his family history (de Waal, 2011, p.301) writes of his visit to Vienna many years after the war, to look up members of his family in the archive:-

It is on this visit that I go to the Jewish archive in Vienna, the one seized by Eichmann, to check up on the details of a marriage. I look through the ledger to find Viktor, and there is an official red stamp across his first name. It reads "Israel". An edict decreed that all Jews had to take new names. Someone has gone through every single name in the lists of Viennese Jews and stamped them: "Israel" for the men, "Sara" for the women.

I am wrong. The family is not erased, but written over. And, finally, it is this that makes me cry.

He writes of the treatment of Viennese Jews in the early months of 1938:

They are beaten, of course; but they are also forbidden to shave or wash so that they look even more degenerate. This is because it is important to address the old affront of not looking like Jews. This process of stripping away your respectability, taking away your watch chain, or your shoes or your belt, so that you stumble to hold up your trousers with one hand, is a way of returning everyone to the shtetl, stripping you back to your essential character - wandering, unshaven, bowed with your possessions on your back. You are supposed to end up looking like a cartoon from Der Stuermer, Streicher's tabloid that is now sold on the streets of Vienna. They take away your reading glasses.

Is it any wonder that Tanya had endless memories of Hitler's troops marching into Vienna, when she must already have known the fate of some of those they left behind when their family escaped to Holland?