"Have you been walking?"
A search for rehabilitation

by

Pamela Ann McLoughlin, BA, Litt.B, GDSE.

A dissertation submitted in fulfilment of the requirements for the degree of Master of Science (Honours) in Social Ecology in the University of Western Sydney - Hawkesbury.

October 1994.
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
DEDICATION

This thesis is dedicated to the memory of my father, Vincent, my sister, Helen, my nephew, Andrew and to other friends who lived but short lives. It is also dedicated, with appreciation, to my past life - my life before ME/CFS.

ACKNOWLEDGMENTS

My thanks are due to Frances Parker and the staff and researchers in the School of Social Ecology in the University of Western Sydney, Hawkesbury. And to Denis Wakefield, my external consultant and physician, for his support and encouragement.

Special thanks are due to Diane Speed, my external consultant, who helped me get deeper into the philosophical aspects; and to Marianne Wiseman, a rehabilitation counsellor, who engaged with me on my inner dialogue and who commented generously on earlier drafts.

I am grateful for the friendship and listening ears of my ME/CFS friends, Carolyn, Hелеnе, Jenny, Marion, Peggy; and my fellow volunteer telephone counsellors at the ME/CFS Society of NSW, Inc.

And to my family, particularly my mother, Mary; my sister, Kate; my brother, Bill; and my cousin, Margaret.
"HAVE YOU BEEN WALKING?"
A Search for Rehabilitation

by

Pamela Ann McLoughlin

ABSTRACT

This thesis explores, through critical dialogue and personal experience, various aspects of rehabilitation in the context of Myalgic Encephalomyelitis or Chronic Fatigue Syndrome. The journey visits broad, in principle, government policy reports. It touches on insurance and political aspects of health care; the separation between medical, convalescent and tertiary divisions of the rehabilitation professions; and, most importantly, it is concerned with the personal struggle to find some 'meaning' in the experience of a chronic illness for which there is, at this stage, no cure. From this arises the complexity of the inter-relationships between professionals and clients and the vexed question of ethics.

The writing or methodology, is first-person narrative. It has deep roots in natural philosophy. The dissertation can be read on several levels - for example, the substantive factual level; the political level; the psychological level. However, it is deeply personal and makes no claims for a definitive (truth). It can also be read as a meta-thesis, that is, as an illustration of the process of researching/writing in an experiential methodology.

Keywords: Social Ecology, meta-thesis, methodology, collaboration, participation, client-as-researcher, client/professional symbiosis and ethics, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), rehabilitation, grief, reflection, reflexivity, rite of passage, pilgrimage, liminality, experiential, public/private, objective/subjective rigor, new paradigm and trans-disciplinary research, feminist, spiritual, hermeneutics, critical discourse, Socratic dialogue, Jungian psychology, creative writing, metaphor, anecdote.
HAVE YOU BEEN WALKING?
A Search for Rehabilitation

CONTENTS

OVERVIEW THREE i
OVERVIEW TWO iii
OVERVIEW ONE v

PREFACE 1

INTRODUCTION 9

PREAMBLE ONE 26
Experiential approach to the writing

PART I 28
Once upon a time
  . With hindsight, how do/did I prepare
    for this journey
  . "The End" is where you find it
  . A pre-view of "The End"

PART II 46
Now, where to start?
  . A peek at rites and rituals

PART III 60
The Story
  . Rite of separation
  . A major irritation

PART IV 78
A return to the threshold
  . Change of focus
  . Disembodied voices

PART V 91
Getting Started - Untangling the Skein
  . Looking for the end marked
    'methodology'
  . Back to the story
  . Disembodied voices
  . Finding the Yellow Brick Road
PART VI
The Big Black Hole
  . Disembodied voices
  . Feeling my way
  . The threshold comes into view
  . Disembodied voices

PART VII
Confusion and Uncertainty
  . Disembodied voices
  . Back on track
  . Addiction and control
  . Disembodied voices
  . A coffee break
  . Disembodied voices
  . The Yellow Brick Road
  . Foreign countries and language difficulties
  . Disembodied voices

PART VIII
Symbols and jargon
  . Preamble two
  . Rite of liminality
  . Restricted entry

PART IX
A rather long detour
  . What is research and how do you do it?
  . The Woodhouse Report
  . The Sackville Report
  . Reflections

PART X
The Real World
  . Disembodied voices
  . Blossom trees, chirping birds ... and a pond
  . Disembodied voices
  . The reflecting pond
  . It still hurts
  . A quick spin around Health-(Medical)-Care Issues
  . The threshold

PART XI
Where shall we start today?
  . Destination: unclear
  . Ethics and the client
  . The validity of experience
  . Disembodied voices
PART XII
  Sections and segments
    . Preamble three
    . The story so far ...
    . Disembodied voices

PART XIII
  Pavane
    . The land of walking trees
    . Letting go and letting be
    . Other ways of being
    . Disembodied voices

PART XIV
  Honeysuckle time
    . Fine and warm
    . Disembodied voices
    . Learned pessimism
    . A Passion of this earth

CONCLUSION
  Easter
    . Preamble four
    . The end of the beginning

AFTERWORD
  What is change, and what is progress?

REFERENCES

APPENDIX
A. A Rehabilitation Programme for Chronic Fatigue Syndrome - Guidelines
B. The CFS Multidisciplinary Rehabilitation Program at CRS Darlinghurst - Brochure
C. Comcare Rehabilitation Program - Flow Chart
D. The Curly-Pyjama Letters:
   Letter from Vasco to Mr. Curly
   Letter from Mr. Curly to Vasco in reply
E. The "Good Grief" Worksheets
F. Communications:
   Letter from me to Clarissa Pinkola Estes
OVERVIEW THREE

"Have you been Walking?"
A Search for Rehabilitation

The title "Have you been walking?" is the question asked by a doctor in response to the patient's question "What do I do in the meantime?" - in the time between now and ... The context is the struggle to come to terms with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS).

This is a personal story. Taking Social Ecology as the experience of daily life, it explores the concepts of walking and rehabilitation, of collaboration and participation. The perspective is that of the client-as-researcher.

Several major themes emerge - the personal struggle to find integrity and authenticity; the ambivalent status of the client as a partner in the research process and the symbiotic relationship between clients and professionals; the lack of a model of chronicity in a health system based on acute care; the lack of understanding, and hence avoidance, of grief; and the exploration of the meaning of rehabilitation, initially in the narrow context of ME/CFS then, through reflection and reflexivity, the concepts become metaphors and the exploration becomes more deeply spiritual.

Conflicts arise between the standard, intellectual approach to the methodology of academic research and the experiential and experimental nature of the narrative. Intellectual and personal confusion converge at the interface between the public and the private, the objective and the subjective, the self and other. Feminist, literary and spiritual writings provide clarification on many of these conflicts from both a political and a personal standpoint.

The style of presentation, of creative writing, has deep roots: Plato's Socratic dialogues, Chaucer's pilgrim, Dante's inferno, Boethius' Lady Philosophy, Julian's revelations, St John of the Cross' dark night. The style finds more modern connections in the writings of T.S. Eliot and Robert Persig and the psychology of C.G. Jung. There are connections with concepts, such as critical discourse, used in new paradigm research, a transdisciplinary approach which visits many disciplines including science, philosophy, religion, language and art.

The structure of the thesis resembles an onion. The core - that section relating to the broad public policy issues surrounding 'rehabilitation' - is included as a flashback at Part IX (p.142). The 'real' beginning, that is the
factual, sequential narrative, can be found at Part III (p. 60). The beginning of the creative writing process, however, is a Preamble (p. 26). These elements — the sequential narrative and the creative writing process — begin to conclude with Part XIV (p. 250). Around this is wrapped the Introduction (p. 9), Conclusion (p. 269) and Afterword (p. 285).

Then in sequence comes the Preface (p. 1) and Overview One and Two. This Overview (Overview Three) is the outer layer. There are three additional Preambles (p. 135 and p. 206 and p. 273) within the body of the thesis which indicate significant changes in focus, or depth of exploration. While the Contents give a thumbnail sketch of the thesis or story, the structure of the ‘onion’ is not perceptible. This is because of the limitations of the two dimensional and linear text. The structure also reflects the psychological and philosophical depths which have been plumbed and which now must be exited. The Overviews represent three attempts to leave the writing. It would appear that the exiting (Overviews) is no less difficult that the entering (Preambles)!

The Appendix is intended to illustrate some of the different approaches and understandings about rehabilitation and, particularly, the lack of models which incorporate grief, chronicity and wholistic therapies as major components in the rehabilitation process.

The Reference section includes books and articles which relate directly to ME/CFS. These are marked with an asterisk (*). The vast medical literature is not included, however a comprehensive list may be obtained from the ME/CFS Society of NSW, Inc. whose address is included in the entry under this name.
OVERVIEW TWO

If Social Ecology is characterised by collaborative and participatory research, then this thesis is not Social Ecology. However, if one allows both the presence and the absence of these characteristics, then it may qualify. In fact, I believe that it is the struggle with the concepts (and experience) of collaboration and participation which gives rise to Social Ecology. And this struggle is caught up in the politics and ethics of power, personal integrity, coming and going and doing and being. It has all the hallmarks of a rite of passage which, once begun with the experience of separation, precludes a return to a former state. The journey does not guarantee the traveller approval, legitimacy or acceptance. The successful completion of the final phase of a ‘classic’ rite of passage, that of reintegration, depends almost exclusively on the community’s beliefs and practices around inclusivity.

Most research reports reflect the perspective of the ‘professional’, the legitimate, respected, funded and authoritative researcher. It is not coincidental that the literature is written and published by academics/professionals, for academics/professionals. The writings of non-academics/non-professionals, such as there are, are likely to be dismissed as ‘simply anecdotal’ ... ‘subjective’ ... ‘lacking intellectual rigor’ ... and the authors are unlikely to be heard or read.

From the perspective of the ‘client’ (or subject) the doors to collaboration and participation appear as a mirage, an invitation decorated with encouragement and hung with concepts of self-management, personal responsibility and choice. The invitation reveals itself as a mirage whenever the client dares to knock. Perhaps the fear is that the client or subject may actually want to be admitted as a partner into the research ... and who knows what damage, inconvenience and irritation that may cause?

In my ‘search for rehabilitation’ I travel through lands of double-speak - through lands of jargon about rehabilitation, group dynamics and ethics. About empowerment and creating my own reality. About strategic planning, mission statements, deconstruction, postmodernism, praxis and epistemology. This designer language could not be considered ‘user friendly’, except by ‘friends’ ... it is unintelligible to ‘users’ (clients) and strangers.

As if to counter this intellectual assault, metaphors and anecdotes arise spontaneously from my imagination. I gaze through the brightly lit windows at the displays of
tantalising goodies. But these are not for sale. They are, in legal terms, 'invitations to treat'. The storeholder may choose to ignore my offer. The storeholder may order me off the premises. So much for the concepts of collaboration and participation.

My 'research' finds itself in the form of one of Plato's Socratic dialogues, or an exercise in Jungian active imagination, or a narrative of deep personal reflection and reflexivity of the kind used by mystics and creative writers. Such an approach is exciting, entertaining, lonely and, at times, frightening. I discuss and debate, play Devil's advocate and alternate between fighting the good fight ... and withdrawing in despair. My contacts with others have been peripheral but, nonetheless, significant. These others have acted as touchstones and witnesses. The ethics of being a critical client researcher forces me to research my own hidden agendas ... am I acting out of concern for myself, or others, or the (truth), or from strong feelings of revenge and vindictiveness? My response to not having my needs met sets me off on a pilgrimage into uncertainty ... after all, I followed the signs which advertised "Needs met here" ... did I not understand the language? ... did I mistake the letter for the spirit? ... was there something wrong with my ritual? The use of spiritual metaphors marks a significant transition.

The thesis is a critical discourse with several of my many selves which reveals as much about my struggles to write a thesis as it does about my search for rehabilitation. This 'meta-thesis' (or 'metathesis'), is an experiential/experimental methodology: 'how to' 'do something' which 'feels right' for me. Question: Am I deconstructing, hermeneutically, an epistemology which is ontologically correct and hermeneutically satisfying? And then, what do I do with the construct of the dialectic? In a world of fuzzy boundaries and liminality and thresholds and transitions, who is to say which is which? In the end, perhaps it really doesn't matter! Perhaps it isn't even my business? Many things have to be left behind if one is a pilgrim. Pilgrims persevere with the walking. Pilgrims travel light. But, oh, for a five star hotel, or a suite on the Q.E.II!
OVERVIEW ONE

This is my story of my search for the meaning of rehabilitation in the context of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The story is as much a story about writing/researching a thesis as it is about anything else. The narrative style, reminiscent of a Socratic dialogue, is interspersed with interruptions from "unseen voices" of my own internal "wisdom".

I am not seeking causal connections, cures or management techniques within the medical model of acute care. Within an experiential framework I am confronted with the significant question of ethics from the point of view of the client-as-researcher.

Walking becomes a metaphor for exploring the relationship between the outer (political, formal) and inner (personal, unconscious) worlds of rehabilitation. Ultimately, my walking is a pilgrimage which is not facilitated by the formal system.

The title is both a Zen koan, or intellectual riddle, and a rite de passage. My experience is that the recognised stages in rites de passage (separation, liminality or isolation and reintegration or aggregation) are blurred. The stage of liminality (isolation or disconnectedness) is central to the thesis. However, the use of the label 'reintegration' is confusing, if not misleading. This stage is better understood through breaking down the concept into 'arrival' and 'new beginnings' and reflects more accurately the reality of significant/fundamental change.
PREFACE

I suffer from Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS).¹

Shortly after I received the diagnosis, I asked medical specialist, Denis Wakefield, Professor of Immunopathology at the University of New South Wales in The Prince Henry/Prince of Wales Hospitals ... "What do I do in the meantime?". What do I do in the space between now and when the medical fraternity finds a cause and a cure, or when I have a spontaneous remission, or I die?

It took some time before that question became real ... about two years, I suppose. It gradually led to my using this question as the basis for my Graduate Diploma in Social Ecology (McLoughlin, 1989). I approached the question through 'action research' (Dick, 1991), which is one of the ways one can explore the messiness of ordinary life.

Action research spirals around evaluating, discovering, planning, implementing and, above all, reflecting upon all phases of the process. And this reflecting necessarily involves not only the process and the outcome of the research, but also the effect that the researching has upon the researchers. I discovered that in most (all?) of the theories, models and methodologies, there was no explicit provision for waiting. However, it was clear to me from the frequency and intensity of my frustration and that which I also observed in most research students, that waiting was an essential, if implicit, part of any research process.

Now, several years along, I find myself reflecting upon Denis' often asked question, in a clinical setting ... "Have you been walking?"

¹Throughout this thesis I will use ME/CFS. In the USA it is also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).
It is ironic that in my previous life, as a social policy analyst in the Department of Social Security, my area of expertise was the broad policy area of compensation and rehabilitation. My focus then was on the income maintenance aspects of compensation. Here I was, years later, descending into my own personal rehabilitation. From this perspective, the broad policy experience was of little help - in fact I believe that the major part of my research involved my freeing myself from the pontifications from on high about what 'ought to be' and, therefore, 'is', and discovering what, in my personal experience, 'actually is'.

In the telling of my story I find there are many threads. The journey weaves its way through the spiral, affected significantly by events external ... and long periods of waiting.

It begins with my sitting with the keyboard and screen, waiting for something to appear. I was conscious that I was approaching this as I would my journal. When pain, confusion and restlessness appear, I often sit with my journal wanting and waiting to hear from the pain, confusion and restlessness - very much in the spirit of Jung's technique of 'active imagination'. (Johnson, 1986).

During these session, various 'voices' began to 'speak' - arguing with me, chiding me, challenging me to examine my underlying assumptions. I begin with whatever events and circumstances present themselves - such as the seasons, the view from my courtyard, the birds. I aim to return to first person, present tense whenever I find myself generalising into past tense and third person. A shift in person and tense is a sure sign of movement! And I trust the process.

My search is embodied in my story, in the wisdom of my inner voices. It is why it is written as a dialogue. I did not consciously structure my writing or style in this fashion. Bateson (1972, p.1) uses the term 'metalogue':

A metalogue is a conversation about some problematic subject. This conversation should be such that not only do the participants discuss the problem but the structure of the conversation as a whole is also relevant to the same subject.

I would quarrel with Bateson's use of the term 'problem'. The problematising of all manner of things in our society includes the assumption that if you can reduce anything to a 'problem', then that problem can be solved in a mathematical or geometric way. There is no space for a 'just so' story. I would prefer to use the term 'complexity'. Of course, many others before Bateson have delved into metalogue - Plato and Chaucer, for example - so Bateson is in good company.
Then there are the requirements of the University. Because I am a research student and because the School of Social Ecology operates on a transdisciplinary basis, I am required to have some external consultants who are familiar with the subject matter of my thesis and to whom I am able to turn for support.

Denis had indicated that he would be happy to help me in whatever way he could, in respect to my coping/living with ME/CFS. I am sure he did not imagine, nor did I at the time, that I would ask him to be an external consultant. I recall having curious conversations with myself about ‘should I?’ and ‘could I?’ and ‘would he?’ He was, after all, a doctor, steeped in the scientific method and operating out of a medical model. What would he think of storytelling, narratives, active imagination and anecdotal evidence?

By way of coincidence, my friend Helene Mackey, who also has ME/CFS, introduced me to Diane Speed. Diane lectures in English Language and Early English Literature at Sydney University. During our initial conversations we found common ground between my style of searching for rehabilitation, and my difficulties in understanding just what I meant by rehabilitation, and her interest in medieval literature.

However, I had an uneasy feeling that this was not sufficient. I needed some contact with the outside world. In a perfunctory gesture, I contacted the Commonwealth Rehabilitation Service (CRS), expecting to receive a sympathetic, yet negative, response to my request for assistance. As it happened the local Branch in my area had just received confirmation of funding to operate a pilot program of rehabilitation for people with ME/CFS (CRS, personal communication, 1992). Synchronicity and serendipity were at work.

Yet, surprising surprises were in store. I had imagined that since it was a ‘pilot program’, the CRS would be keen for participants, with first-hand experience of ME/CFS, to contribute to the design, research and evaluation of the program. I had to agree to be part of a research program, the results of which could be published. However, I could find no way to become involved in the design, research and evaluation of the program. I was a client. Repeatedly I spoke about my Master’s research. But I was not heard. What are the ethics here, I wondered? Do they already have their agenda? What kind of research are they conducting? Or is it simply a ‘treatment’ program, for which the relevant professional staff were recruited? For ten weeks I was a participant in what I experienced as a kind of theatre of the absurd.
Involvement in the pilot program proved to be a pivotal experience. It was also a vantage point from which I could view previous events and episodes. Yet it was critical that I meet a person who heard my story and was willing to come part of the way with me in my explorations. That person was Marianne Wiseman, the Rehabilitation Counsellor with the program. And although I am marked as a failure in the eyes of the CRS because I failed to re-enter employment at the end of the program, my interaction with the system, mediated by Marianne, allowed me to ask deep philosophical questions about the meaning and value of paid work. These questions had been arising in my journaling and my explorations of literature and spiritual writings, but I had no concrete connection with how these matters were being played out (Wiseman, personal communication, 1994).

As I put the finishing touches to my thesis, the CRS is releasing a new pamphlet, designed to market the program to people with ME/CFS (CRS, Darlinghurst, 1994. A copy is provided in the Appendix.) After a year the CRS feels able to say "we know what it is like to have ME/CFS". I am prompted to add that that kind of bald statement from people without first-hand experience incites rage within those privileged by the experience. Try telling a Vietnam veteran or family with a severely disabled child that you know what it is like! It is, in short, an insult ... softened somewhat by the good intentions of the providers.

The program is now explicitly directed to people under the age of 45 years who believe that after 10 weeks of 'rehabilitation' they will be ready to return to work. Herein lies the dilemma. In order to get funding, and to be certain of retaining that funding from the Commonwealth Government, one assumes that the CRS has to argue that its program is successful. The Commonwealth Government's policy is to get people back to work. What it means is that many people who really need the 'rehabilitation' program so that they will suffer no further physical deterioration, but who do not see themselves as being able to return to work, will not be admitted.

So for those people, among whom I include myself, 'rehabilitation' must mean something more complex. Something deeper and more radical.

I would like to include here some feedback from Marianne because of her personal involvement – as a counsellor, gifted with the art of listening; as a professional
Rehabilitation Counsellor, gifted with the insight to see that the parts are included in a more complex whole; and as a member of the CRS team. I also wanted to include her words because these are the words which will not appear in any official report of the research:

You speak of ME/CFS as 'systemic' – but all agencies/institutions have institutionalised fragmentation. In the CRS context, this means each client encounters the Medical Officer, Physiotherapist, Occupational Therapist, Clinical Psychologist, Rehabilitation Counsellor and perhaps even the JDO – the Job Development Officer. The client is thus perceived in at least 5 or 6 different ways according to the ideology of the profession, the status of the profession, not to mention the idiosyncrasies of the individual. One of the things that has become very clear to me recently is that we are all creating, living, expressing, sometimes even writing, our own stories. All of us. So an encounter with, for example, CRS, involves becoming embroiled in 5 or 6 different stories, a mini tower of Babel, and all in the context of two other stories, the official story, to be found in the documents and the hidden agenda story, which may be as unknown, in many respects, to the professionals as to the clients. And of course, in your CRS encounter, there was yet another story, the research story. It's still not clear to me who owns that story... Science is a story, academic research is a story – none of them are "the truth". Those stories are no less messy or subjective than yours, just officially validated.

Van Gennep talks about 'reintegration' – but how can one be integrated into something that is fragmented? Doesn't integration have to do with wholeness? Some of the ME/CFS clients I've listened to are concerned with how to live with ME/CFS – how can they create a life with it, what kind of life can they create? Others, if I understand them correctly, are trying to get back what they have lost, to get back on to the escalator, to get back to what they've been kicked out of. I find that the former are asking very radical, fundamental questions, questions which are the unreported questions of this culture – what/who are you if you don't have a job? Am I only allowed to eat in this culture if I have a job, (or I am kept by someone else, or I accept a socially constructed label (such as) 'disabled', 'old', etc. ME/CFS is subversive, especially if, like you, you want to talk about your experience, write about it, and horror of horrors, publish it [which I hope you can].

(Wiseman, 1994)
Denis says:

...people have a concept, or society indoctrinates in people, a concept that if you have a problem you go to a certain part of society, or to people in society whose job it is to rectify the problem. And what is never built into this structure is—Where do you go when those people can’t help you?

... and where do you go to structure a belief system? Where do you go for help if you say “I don’t believe in religion ... I’m hardly likely to go there for some philosophical help with a problem that I have.”

... If you go to the people that you expect to help you with a medical problem, namely, the medical fraternity, then the medical fraternity say, “Well, the only thing we can do is give you some rehabilitation and advise you to start walking, and all this...” then where do you go, and what processes do you go through? And are there any analogous situations that you can draw on to give you some further help and enlightenment?

... You know, somebody else who is a very religious sort of person could have written this whole concept and instead of saying “Have you been Walking” they could have called it “Have you been Praying?” ... and they could have said “I went to the priest but he didn’t have the answers and he just told me to pray.”

(Wakefield, 1994)

And both Denis and Marianne are right!

Diane (Speed, personal communication, 1994) has commented that “this fine thread called liminality” — the limbo, nowhere-land, the eye of the cyclone, the threshold, the experience of disconnection — is fine and thin ... and deep. It connects many disparate areas. At base it is a philosophical, religious and spiritual connecting thread. Medieval literature is awash with explicit references. In our modern twentieth-soon-to-be-twentyfirst-century there is a profound need to reclaim and ‘rehabilitate’ the sense of the sacred and to acknowledge that no matter how far we push the frontiers of knowledge there is always the mysterious ‘beyond’.

............

6
I would like to end this beginning with two stories.

At the recent residential I attended at Hawkesbury I went for a walk with John Cameron, a staff member at Hawkesbury, and some students who appreciate the art of 'Zen walking'. In the quiet reflective time following 'walking with the senses', I wandered over towards a grove of trees. Suddenly, my path was blocked by a freshly fallen tree. It looked as if it had been knocked over to thin out the grove. It was green and alive and lying prostrate. Its tap root was still deep in the earth. I walked around this tree and came to another. This one had been chopped down with an axe some time ago and had been dragged to this place. It was pink and lavender and mauve and grey in the fading light. I walked around it. I was about to pass between two saplings when the sun caught the movements of a tiny spider spinning its web between the trunks. I walked around. Then I looked down and saw that my socks were covered with grass seeds. When I returned to my room I opened a small book. The words read:

The Zen 'fact', whatever it may be, always lands across our road like a fallen tree beyond which we cannot pass.

(Thomas Merton, 1993, p.108)

The second story, also from the same residential, concerns the art of hang-gliding. I hung, enthralled, as Michael Boike, one of the research students, explained with great enthusiasm, passion and animation what it is like. When looking for a thermal one waits for the tip of the wing to lift. With that lift you lean out in order to steer into the thermal. If you are good enough, if you are a flyer, you will be able to sense the thermal. You’ll be able to read it. If not, you may shoot out the other side, encountering a fair bit of 'roughness', and you will have to try again. Once inside, the rising will be effortless.

I asked "But how do you get down?" Well ... you never take off unless you can see where it is you will be able to land ... and ... five-hundred feet from the ground you may encounter 'roughness' as you hit more thermals. It is not uncommon for beginners to be unable to land because of the flurry of little thermals close to the ground which whisk you up again.

---

The University of Western Sydney, Hawkesbury Campus. The residential for research students, was held at Kurrajong, in the foothills of the Blue Mountains not far from the main campus, in May 1994.
"So how do you get down?"

Well, you may have to make a wide circuit and come in on a long, low approach and ... watch for the lethal power lines! ... and come in under the thermals. Then, he explained, with grand gestures, arms pushing forward on an imaginary brake bar, you flare!³

I am encountering the thermals at five-hundred feet!

Am I constructing the onion from the inside, or am I peeling it from the outside?

A Small Voice yells from the sidelines, "Yes! Yes! Now, you flare!"

³I believe this term refers to deflating the canopy or sails of the hang-glider - and gravity does the rest.
INTRODUCTION

"Have you been walking?"

A simple enough question ... but it leads to further questions such as: who has the authority, temerity or concern to ask the question? As the interrogator, my unspoken imperative is that 'you' ought to be walking! As the accused, I react with my own set of questions: why should I be walking; how, and how much; when should I be walking; what will happen if I don't do it?

... and why walking?

Why not talking or running or praying or painting?

In other words, what is the context of the question?

The larger context is: rehabilitation. A search for rehabilitation. More questions arise: What is a search, what does it mean and how do you do it? And what is rehabilitation? What does it mean? Why is it necessary? How will I know when I have it? Do I need it? Who says so?

And where do I get it?

My Master's thesis started off with a simple enough idea. I have for many years been diagnosed with Chronic Fatigue Syndrome (CFS, also known as Myalgic Encephalomyelitis or ME), that much maligned, mysterious and devastating disease, and dis-ease.

I have listened to all manner of advice - from conservative, liberal and radical doctors, some more compassionate than others, within the medical fraternity; to alternative/ traditional professionals in the natural therapies; to so-called new-age gurus who psychologise all manner of disease and illness and who sometimes operate within a 'blame the victim' syndrome; to a wide range of spiritual healers, some of whom are wise, some of whom are misguided and some of whom are simply entrepreneurs.

At the broad sociological or philosophical level, our society does not have a category for 'can't-be-fixed'.
As a society, we believe that everything is fixable or, at least, controllable or manageable. In the era of experts, the challenge is to find the 'right' expert. In the era of experts, the co-ordinator becomes indispensable. Yet, even if a co-ordinator did exist, the very term 'co-ordinator' assumes some semblance of equality between what is to be co-ordinated - and in the health and medical system, in particular, equality of role or status does not exist.

So why am I doing a Master's thesis? And who am I writing this for?

First, of course, for myself, personally - to try to work out what has been happening and how I have been responding and what am I learning about myself and my worlds.

Second, in some sense, on behalf of the thousands of people with ME/CFS not, I might add, as a cookbook approach to fixing things, but as encouragement to those who would dare to do their own thing as the only possible way of moving around, or accommodating, an immovable object. An encouragement to jump into the abyss of no-thing-ness ... to fly with the imagination ... to live in the is-ness.

Third, as an attempt to find a voice which will be heard by the 'professionals' to whom people in distress turn for help. Unless they hear our needs, they cannot hope to help.

Fourth, to satisfy the requirements of the University. This fourth reason is significant. It is the only means I can find at this point whereby I can legitimise myself and receive some recognition that I have not been bludging on the taxpayer during my enforced separation from the common herd.

I am aware that this statement, while listed in fourth place, is more important than I am prepared to allow. It receives sudden shocks every now and then. My belief is that as a marginal person, that is somebody who is defined by society as dis-abled or in-valid, my ease of living will be directly related to my level of confidence about my own validity. Part of the grief of a chronic illness is the loss of social and intellectual validation - the loss of status and standing. It is a humbling experience to find oneself in a begging position - begging to be accepted as offering something worthwhile to a society which, by and large, would rather not hear.

So where do I find myself?
I find myself hanging on the end of a question posed by a concerned and compassionate physician.

Have you been walking? The context? It is a well-known fact that long periods, and not-so-long periods, of complete bed rest result in wastage of muscle and general and increasing physical deterioration. In their paper "Diagnosing CFS: Principles and Pitfalls for the Patient, Physician, and Researcher", Hickie and Wakefield (1992, p.16) note:

In all cases we recommend a structured program of graded physical exercise and psychosocial rehabilitation to reduce ongoing disability. We seek to create a treatment framework within which both the doctor and the patient can facilitate recovery.

So the question is simple, and specific. I can easily answer. Yes. I have been walking. Walking is one of my favourite occupations. I do it as often as I can, even when, on occasions, I am restricted to the forty measured steps between my front and back doors. (As I write this I am struck by the significance of the number ‘forty’.)

I puzzle over the question for months. What does it mean?

In one sense it means that I undertake a graded program of walking. In strict scientific fashion I am to record the distances walked, over given periods of time, and correlate that with some objective measure of my wellbeing (a reality more complex than well-being). Ideally, increasing distances and speeds should correlate with increasing physical fitness and wellbeing.

I already know that there is a correlation between distance/speed and fitness/wellbeing ... they are often inversely related!

I already know that as creative writers must leave the housework for the writing, I must leave the clerical note-taking and recording if I am to undertake the walking.

I already know that in the context of a system which believes in positive outcomes, my failure to achieve the anticipated positive result has been/will be attributed either to poor attitude or poor performance, or both. 'Blame the victim' goes without saying.
So, initially I began my own program. Increasingly it became obvious that although I probably did more walking than most people I know, I was not able to increase my distance or intensity without relapsing. These relapses lasted a minimum of several days. More severe relapses set me back for months. I noticed that when my program focused on walking I tended to find the requirements of daily living overwhelming. Often I chose shopping/cooking/eating as the primary focus for my limited energy! Walking would have to wait.

It occurred to me that I should seek professional help. Obviously, walking was not working. I would need to investigate the world of rehabilitation. And I asked about professional help – but none of the professionals referred me gave me a phone number or pointed me in the direction of rehabilitation. To them it seemed to be as simple as a direction to ‘eat more/less meat’, as if ‘rehabilitation’ was available at the corner store.

Without any referrals, I began to re-examine the rehabilitation and compensation systems in Australia.

In my former life as a policy analyst in the Commonwealth Department of Social Security, I considered myself somewhat of an expert in this area ... well, at least in the area of the income maintenance aspects of compensation, if not rehabilitation.

And it seems important to add that my experience was at the broad policy level, not at the administrative level or program delivery level. It has become increasingly clear to me, in the process of talking to people not so familiar with levels of policy making, that the distinctions between these three areas are not usually experienced or appreciated. It is, therefore, no wonder that we are, none of us, talking about the same thing.

Browsing through two of the many commissioned reports (Woodhouse Report, 1974; Sackville Report, 1983) into the compensation and rehabilitation systems in Australia and New Zealand which had travelled with me from my work desk to the top shelf of my bookcase, I began to understand, from personal experience, why it was that the world of rehabilitation resolutely refused to open its doors to me.

In short, the rehabilitation and compensation system is insurance based. Access to the system is based on legal rights and responsibilities, enforced through legislation and the payment of premiums. Access is limited to those who
are covered by such legislation, and emphasis is primarily on return-to-work and only secondarily concerned with issues of quality-of-life. Domestic rehabilitation, what is more, is skewed towards injured women who have to satisfy the quality-of-life demands of husbands and families.

My situation fell outside the guidelines. I had no insurance coverage and no guilty third party on whom to settle blame. And my primary concern was for an improved quality-of-life.

The significance of this realisation set me to untangling just what 'walking', 'searching' and 'rehabilitation' meant for me. How were these words and concepts used? Had I been caught up in the literal meaning and missed the metaphor?

At this point I will not discuss the structure of the rehabilitation systems. To do so would give the impression that I was aware, at the outset, of the significance of such distinctions as primary or medical rehabilitation, secondary or convalescent rehabilitation or tertiary or return-to-work rehabilitation. My understanding developed gradually as I walked. For the time being I will state, as succinctly as possible, the framework in which I found myself. The details will be expanded as the story unfolds.

Within the Commonwealth Department of Health and Community Services (the name of the Department changes quite regularly) is located the Commonwealth Rehabilitation Service (CRS).

I was aware of the existence of the CRS. I believed that it existed primarily to assist people injured in work and traffic accidents, and who had recovered sufficiently to return to work. However, as part of my search for rehabilitation (and turning over every stone which seemed to be carefully laid - by me and by others - along my path) I decided to approach them. I 'self-referred', as it is termed. I assumed that I would get a reply along the lines of "We'd like to help, but no, there is nothing we can offer."

As it transpired my local CRS office had just received Commonwealth funding to run a pilot program for people with ME/CFS (CRS, Darlinghurst, personal communication, 1992). As far as I know, no other CRS office in Australia has such a program and my further reading of policy issues within the health system (Bates and Linder-Pelz, 1990) threw some light
on the significance of individual initiatives in program design and availability. It was my luck to live within the geographical area serviced by this CRS office. The pilot program appears to have resulted from collaboration between the Departments of Social Security, Employment and Health, in an attempt to get people with ME/CFS off social security benefits and pensions following the 1990 Budget Disability Reform Package (Department of Social Security, 1994, pp.10-12; Human Rights Australia, Privacy Commissioner, 1992, pp.28-29).¹

So delighted was I that, at this point, I lost my 'presence of mind'.

[I can hear that wonderful British comedy monologue by Hoffnungh about the brickie who is claiming compensation for an accident on a building site! The story loses its hysterical element on paper because the humour comes from the timing of the delivery.

In short, the brickie, having finished the job, had some spare bricks on the top floor of the building. He goes down to the ground and sets up a pulley, secures the rope and returns to the top to load the bricks. Then he returns to the ground, unfastens the rope and ... the bricks are heavier than he is ...

At this point he loses his presence of mind and maintains his hold of the rope ... and on his way up ... he meets the bricks on their way down ... he gets his fingers caught in the pulley ... some of the bricks spill out on the ground ... now he is heavier than the bricks ... he meets the bricks on his way down ... he lands on his back, the remnants of the bricks now at the top of the building ... "At that point I again lost my presence of mind, and I let go of the rope" ...]

With very little effort I slipped into believing that the CRS actually offered facilities and services which would be helpful for me in improving my physical fitness and well-

¹The continuing difficulties surrounding diagnosis and legitimacy which people with ME/CFS face are dealt with at length in the latest issue of M.E. and You, September 1994, under the heading "Problems for doctors and patients in new legislation" which refers to July 1994 amendments to the Health Insurance Act by the Health Insurance (Professional Services) Act.
being. I did not expect, nor did they suggest to me, that the program would be curative. I often remind myself of this experience to reassure myself of my usual positive and accepting approach to things especially at times when I have been critical and I have accused myself of being cynical.

In the end, the reality is that the CRS is offering a program in which the client may be eligible to participate. The CRS is not offering to design a program around the needs of the client. Neither is it in the business of providing treatment or facilities. These, it is expected, are not required in tertiary rehabilitation and are more appropriate to the primary (medical) and secondary (convalescent) stages. In effect it is an educative program directed to the client’s perceived ‘wrong attitudes’ and designed to ‘work harden’ the client. The punitive aspects (regular and punctual attendance and a willingness to participate in all elements of the program are mandatory) reflect the underlying bias (CRS, 1993. A copy of the "Guidelines" is in the Appendix).

What emerges is the lack of a model of chronic illness/disability where services are available on an ‘as required’ basis. It would appear that the medical model of acute care is also the model adopted by the CRS within which to operate a range of return-to-work strategies. The patient/client comes in the door, is treated to the program, gets a better attitude and goes to work, never to return. As far as I know, I am not eligible to re-enter or participate in another program. (See, for example, Flow Chart for CRS Program and Flow Chart from Comcare Annual Report (Ballard, 1991) in the Appendix.)

However, my involvement in the program helped me put into perspective my earlier experiences.

It raised ethical issues.

For instance, what is the ethical position of client as researcher? How can the client/researcher become a full participant with the professional/researcher? How can the client have any input to the programs she (or he) will be participating in? What right does the client have to publish her results or anecdotal evidence when there is no mechanism for her to obtain ethical clearance from the professionals with whom she feels she is a co-researcher? And do the professionals regard her as a co-researcher? How does a client exercise her judgement in using information she gleaned and which may cause distress, or worse, to others? Distance, in time, from the writing often resolves the dilemma, but that may not always be the case. In short, does the client have ‘standing’? No!
A major part of my research, and that which has been most useful, is my interaction with the people I have met along the way.

Had it not been for my research I would not have approached Denis Wakefield (Professor of Immunopathology at the Prince of Wales and Prince Henry Hospitals) and risked the role change from patient to researcher. I am sure it feels as strange and as difficult for him as it does for me (present tense intentional).

I would not have had many fruitful discussions with Marianne Wiseman, both within and outside her role as Rehabilitation Counsellor with the pilot program at the CRS, and I am indeed grateful for her support and courage in asking these questions with me and exploring the difficulties which professionals face when they may wish to critique the system which pays their wages.

I would not have discovered/created the concept of the "limen", an extremely complex context/experience of thresholding, thrashing, threshold and thoroughfare, nor enjoyed so much my journeys into philosophy and literature without the help of Diane Speed (Senior Lecturer English Language and Early English Literature, at Sydney University).

Nor would I be standing on this very unsteady spot, sharing the panic of uncertainty with those at the University of Western Sydney, Hawkesbury campus, as the University launches itself into transdisciplinary abseiling.

Having written that last sentence I am aware that I am deluding myself. The reality of the situation is that I am not sharing in the experience of the staff at the University. I have been greatly disappointed in this respect. It seems curious that while I am struggling with the experience of isolation, invisibility and lack of acknowledgement in my living with a chronic illness, I should find myself experiencing this in yet another arena. For more than six months I found myself without a supervisor. Had I been more aware I would have followed good business practice and asked for confirmation of our telephone conversation in writing, and an explanation about the likely impact on me. As it was, my "quiet acceptance" (I didn't, at the time, understand exactly what PEP leave was) seems to have been mistaken for "informed agreement".

This single event proved to be extremely productive in my learning, forcing me to dig deep into areas of fear. I am grateful to Frances Parker who, unknowingly I'm sure, left me wandering in the darkness long enough for me to gain some deeper understanding. Almost in chronological sequence the thoughts/feelings arose as follows:
My experience raises issues concerning the ability of
disabled students, those who are less able in any
number of ways, to confront institutions. Many
institutions pay lip service to access for disabled
students. This is often narrowly understood in terms
of wheelchairs and ramps and facilities for the
visually and hearing impaired. Specific positions are
created to deal with issues of equality and access
which in effect fragment the policy and enable the
institution to claim 'concern'. However, the policy is
not systemic. It does not permeate the workings of all
Departments and Faculties. Institutions are
essentially pragmatic. Like anything else, the success
of the policy relies on the goodwill of individuals.

I mention my disappointment in regard to my sense of
exclusion from the atmosphere and life of the
university because I am challenging myself to be
authentic. I am trying to tell the (truth) as I
experience it. I also mention it because one of the
concerns of social ecology is the reality of the
messiness of the research process. This process is to
be acknowledged, not sanitised or trimmed off in order
to fit some ideal framework.

This experience is sobering. "By your age Pam, all of
your illusions ought to have been shattered!" said a
friend. Perhaps my illusions about caring and sharing
are what keep me from falling off the edge into
depression and total cynicism?

However, further reflection reveals an even deeper
concern. Yes. I did experience a need for support and
a sense of isolation. But I also connected with the
distressing physical and neurological symptoms of
ME/CFS - overwhelming fatigue, pain, mental confusion
and short term memory loss. And I had to face up to
being 'different' and unable to participate as fully as
I wished. I have often failed to disclose the extent
of this distress for fear of being labelled neurotic,
and this would play into the hands of those wishing to
label ME/CFS as simply psychological. I have often
wished that appropriate psychological help had been
available. However outside the hospital/medical/
psychiatric setting, psychology is not considered a
central medical concern - services are not covered by
the universal health (medical) care system in
Australia, Medicare, and neither is another essential
element in physical wellbeing, physiotherapy.
I have found help and friendship with Veronica Green, a 
Mercy nun living in the wider community, in our exploration 
of spirituality, and the importance of passion, commitment 
and justice in connecting science, art and mysticism; 
evolution and growth and the wonder of creation itself.

And then there is my family - our Telecom bills attest to 
the need we have to keep in touch.

Weaving some kind of thread through these cobwebs is the 
image of a cello.

It has been said that writing serves at least two purposes - 
the writer is concerned with what it is she (or he) has to 
say, and whether she can say it well. The writer is also 
transformed by the process and surprised, bewildered and 
delighted when difficult feelings and ideas finally find 
their way into words on the page.

In this respect it could be said that my thesis is as much a 
thesis about writing a thesis, a 'meta-thesis', as it is a 
thesis about a search for rehabilitation. It is, most 
definitely, an experiential approach to research and 
writing. I'm not sure, either, whether it is an 'anti-
thesis' - perhaps it is all of the above, struggling for 
'syn-thesis'?

Much of the writing of this thesis has been extremely 
painful. It has been emotionally painful in revisiting the 
sites of grief. It has been physically, intellectually, 
psychologically and spiritually painful, as parts of myself 
resist and impede the flow of images and words. And then 
there is simply the physical pain and mental confusion. I 
cannot believe that such creative force is necessary in the 
birthing process - a strange remark for a woman to make. 
For whether she has had many or no children, a woman must 
intuitively have this knowledge.

It is not surprising that the sources I have found to help 
me clarify my ideas and intuitions come from diverse areas. 
I struggled in the early part of my writing to be academic. 
I wanted to ground my work securely in the body of theory of 
social ecology. At some point, something in me became 
impatient with this structured, controlling self.
Perhaps I would not have felt this so keenly had it not been for my lack of stamina and mobility. I had great difficulty in actually writing the words that gave voice to the fact that I was physically not able to frequent libraries. I found myself justifying, rationalising and apologising for not undertaking the classic literature search in order to get across the discipline.

Sometimes I became so confused that I had to leave the sentence unfinished for weeks. Sometimes I needed to persist in my struggle with the image. On other occasions only the gentlest approach permitted the ideas to emerge. Yet again, aspects of myself chimed in to present different points of view, to challenge or support my writing. Shifts in person and tense (third to first person and from past to present tense in the text) also signify changes in perspective. Most of this was not contrived in the sense of having a framework from which to work. It simply happened in the writing, and I became increasingly aware as these shifts were taking place. And I found that I could either walk or write or wait or wrest — one activity excluded the others — and I was left with balancing the tensions, fully immersed in liminality or disconnectedness.

In these areas of difficulty, and in the spirit of social ecology, I have left a good deal of the writing unedited. Hopefully, I have been explicit so that the reader will be able to stay with the confusion and uncertainty and appreciate the birthing process.

There is a need here to say that much of the emotional work has been deleted in keeping with an academic work. However I have allowed some emotional outburst to remain, even if these are likely to attract criticism from the academic reader. These represent the tip of the iceberg reminding the reader of the hidden dangers and deeper currents. To omit these 'outbursts' would be to deny the wholistic nature of experiential writing/research, to generalise from the particular and to deny my personal (truth) in arguing for a wider (truth).

Hence, the sources I have drawn upon have, for the most part, presented themselves to me in context. I have found companions and lighthouses, street lights and directions, in all manner of things. Most of all I have found literature the greatest help. And I am grateful that Diane has reminded me of Chaucer's (1961) Canterbury Tales, as an example of storytelling, experience and journeying. She introduced me to Boethius (1943), writing from prison in the sixth century, in which he dialogues with Lady Philosophy, in The Consolation of Philosophy. And T.S. Eliot's (1972) Selected Essays.
Great literature goes without fear or favour, without guidelines or formal methodologies, into the unknown. Writers of literature have risked madness to venture into the void and bring back the insights we so badly need. There seems to be a growing body of literature about literature as methodology - and I find this quite interesting. I can only speculate that this is very much after-the-fact and that writers are guided more by unconscious inner processes than ego control ... allowing, of course, that one can also write to a formula in order to satisfy commercial, academic or political needs.

The anecdote, analogy and allegory are well known literary devices. But they are much more than that. This is the way people tell their stories, tell their truths and try to share their experience. In this respect the anecdote is as 'true' as any scientific 'fact'. In fact, on a recent radio broadcast I heard Terry Stokes (1994) speak about his anthropological research with a team of medical researchers at the Walter and Eliza Hall Institute. He said that the anthropology model of research (a model of participant observation under the tutelage of an appointed person or group, which is used to study foreign cultures where one does not even know the language)

is basically a literary device by which we can study our own society and aspects of it which we usually take for granted.

Others, such as Carol Gilligan (1982) and Hugh Mackay (1993), would say that we need the courage to state the obvious. In that way, nothing is taken for granted. The fact that what is obvious to one person may not be obvious to another seems to demand that we speak out our individual truths. And in order to speak out, to state the obvious that, for example, "The emperor has no clothes", it seems essential that one has experienced a liminality born of 'shame'. Susan Dickman (1984) writing of "Margery Kempe and the Continental Tradition of the Pious Woman" comments:

(Shame) was a way to punish (while simultaneously gratifying) a particular kind of social pride and desire for attention. But for Margery, shame also became a substitute for poverty ... shame assumed another important role in her spiritual life as well. [Margery had the embarrassing habit of bursting into floods of tears, and it is not surprising that she was labelled a neurotic.] We have already had occasion to mention that in the late medieval period pious women were what Victor and Edith Turner call 'liminal' to men. They were perceived as a moment of reversal of worldly standards, as an alternative and corrective to
male power. To some degree Margery regarded her own femaleness as liminal in this way ... But far more than gender it was shame on which Margery depended for the experience of liminality. To her shame was a guarantee of purity and it became the basis of her particular critique of the male clergy. In her shame ... Margery felt free to speak out against the worldliness of the clergy. (pp.164-65).

Shame in this context is not ashamed. It is a social function where one feels society's attribution of shame for being 'different'. Bernard of Clairvaux writes that Christ suffered viltas et asperitas, the shame or vilification and the pain. Diane Speed elaborated this point for me (personal communication, 1994). In all societies and in all ages the need to vilify and scapegoat selected groups points to the centrality of fear and power in basic human/social interactions.

The concepts of the limen and liminality have proven to be both a help and a hindrance. Many a time I have found myself in a void (perhaps just another aspect of liminality) which is explained by neither the threshold, nor the journey, nor the experience - the experience of threshold, the experience of the journey, and the emotional experience of a past/present/future confusion.

The research process has, to a large degree, provided candle-power of uncertain wattage to help illuminate the limens or thresholds I have encountered, both as invisible force fields and recognisable crossing points. In retrospect I can see that this has been for me a rite de passage. And Van Gennep (1960) uses the term liminality to indicate the dangerous phase between separation and reintegration... the phase of not belonging, of isolation, of vilification, of shame ...

Two important realisations have emerged through the process of my writing.

First, my experience tells me that one cannot see a threshold in advance. This helps me understand why it is that I have difficulty in planning and executing the many significant shifts I have had to make in my perception, my values and the way I search for meaning, the way I searched for rehabilitation. This has been my walking.

I was fascinated the other night by a television program on horse jumping. I was unaware that horses cannot see the
obstacles they are about to jump. So it is essential that both horse and rider are ‘as one’. Unless the horse trusts the rider’s directions, it will balk at the obstacle because over the last few meters the obstacle is out of the range of the horse’s vision.

What became clear was that thresholds are visible only after some significant shift has been made. The whole area of the threshold is out of range of normal vision. It is an amorphous area, draped in mist. Sensory deprivation, or lack of feedback from the environment, sets up uncertainty and contradiction, and potential madness.

The second point concerns the value of being a witness to other people’s crossings. There is a separate and different quality attaching to experiencing first-hand, and being witness to other people’s experience. By being a witness we can become aware that there are new areas of experience, we can gain an insight or a glimpse into another world. In sharing our own experience, we can open up the window for somebody else. This is not the same experience as actually moving into that other world, but at least there can be an inkling that this other world exists.

My initial exploration of the world of rehabilitation and compensation, for example, has brought that world into the awareness of those who have read my musings. My experience of the CRS rehabilitation program helped clarify for me that the aims and objects of the program did not necessarily match the expectations and needs of the clients. The system operates within a set of rules and regulations, aims and objectives, which have been arrived at and decided upon before the first client or sessional therapist has entered the building.

I cannot resist the temptation to say that the clients satisfy an essential need of researchers – they are the fodder. Without them there would be no career path for the researchers. Kate Healey (personal communication, 1993), related anecdotes about ‘fodder’ which circulated at an inaugural National Community Development Conference presented by The Centre for Australian Community Organisations and Management (CACOM) and organised by the University of Technology, Sydney (Power, Politics and Performance, 1993). The practitioners were fearful that they could become ready fodder, as research material and as gateways to clients, for the academics. In turn, the academics were fearful that their theories could be blown out of the water by the practitioners. Boundaries had to be drawn and defended!

Many people would join the unemployment queues if patients/clients/subjects/gatekeepers refused to cooperate, either directly or indirectly. And I have, on occasions,
been tempted by anger, disappointment, frustration or revenge, to exercise this power myself. In reading research findings I sometimes wonder whether subjects have exercised their (lesser) power to subvert the process and thus helped to produce a false (truth). This exercise of (lesser) power is different to that exercised in deliberate fraud. Compare, for example, the experience of anthropologist Margaret Mead in Tonga who was misled by her Tongan informants (Freeman 1983) and the academic hoax (let’s not call it a fraud!) surrounding the prehistoric remains of Piltdown Man in the United Kingdom (Miller, 1974; Johanson and Edey, 1981). And I will leave the other disciplines to cite their own examples.

However, the relationship between researchers and clients is often symbiotic. Patients and clients have a vested interest – they have a need which they hope will be filled by the researchers. I assume that we rely on this relationship to keep the subjects reasonably obedient and truthful and the researchers reasonably ethical. I am also aware of the interface between activist and researcher, although the boundaries are blurred even with heightened awareness of assumptions and hidden agendas. This liminality is called ethics!

But, frankly, I just wish the researchers would examine the questions they ask! "Garbage in! Garbage out!" say the computer programmers. Too often I have wanted to respond to questions with "None of the above" or "How long is a piece of string!" Sometimes I wonder whether there is a paranoid fear about departing from the measuring instrument. To the comment, "We have to use the same questionnaires, otherwise the research does not satisfy the criteria of replication", I would comment that it may satisfy the criteria of replication, but it replicates irrelevancies!

Overall, my learning has been that peoples’ stories fall into a category which also contains fairytales and myths. Therefore, my story will be in the category of fairytales and myths for other people. This is not to disparage any of these. I have arrived at the understanding that only I can live my life. I can look to the experience of others for comfort and encouragement. But that encouragement is in terms of continuing to walk my own narrow ledge beyond which is uncertainty.

We all have to find our own ledges, there are no cookbook solutions or maps of the territory. All I know is that there are maps and there are territories, in principle. How the country looks to any person depends upon whether they are in, say, Australia or Ethiopia, the Moon or circling the outer planets and beyond ... or trying to find their way out of a shopping centre.
When I had finished my first draft of this thesis I came to the curious realisation that during this process I felt no need to mention self-help organisations. I have pondered upon this and it seems to me that my earlier observation of the ‘as required’ needs of chronic disability plays a part here.

The ME/CFS Society of NSW was extremely important to me in the days/months/years following my diagnosis. It was a great source of information, newsletters (M.E. and You) and personal contacts. Self-help groups are formed by people who are trying to help themselves because what they need is not available through the normal channels.

Although I continue to belong to the Society, and to undertake volunteer telephone counselling, it is clear to me now that we, as a group, have nothing to offer in the way of rehabilitation services. Most of the members are ill! They are not well enough to organise their own support networks. Information, of itself, does not provide transport, organise meals, look after children or help relatives understand the mysterious. Neither does it help pay for massage, physiotherapy or psychotherapy, even if these services are accessible.

Basically, the Society is operating within the medical model. In addition to providing information for the members, the main emphasis is on fund raising to attract and support medical researchers. This is necessary because it seems that significant government funding for medical research is only available for ‘end’ research, that is, for research which can confidently predict an outcome and is in line with conservative AMA (Australian Medical Association) received wisdom. Exploratory and discovery procedures do not rate highly in the competitive world of public funding.

Moreover, it is ridiculous to expect a voluntary agency, run by a handful of committee members, staffed by a few paid workers who are funded by a small grant from the NSW Department of Health, to provide a range of services on a voluntary and non-professional basis by sick people. These services are considered too costly and difficult for the huge resources of the combined federal, state, local government, public and private health systems.

At present there is no medical pill, no magic bullet, to put things right within the week.

The scientists continue to explore, as they always have, learning a bit more about this and a bit more about that. They too experience the threshold, the loss of vision, the pregnant moment before the leap into the unknown and the shame of being wrong. This marks a qualitative shift from technician to creative scientist. A spiritual teacher would
say that there is no distinction, no division, there is only
the living and the void. It is all the same. In the very
mundaneness of the ordinary day-to-day things lies the
mystical answer, the breakthrough point, the breakthrough
into a broader understanding.

..........

For myself I have discovered the excitement in finding the
words to say what it is I want to say. I find my life
enlivened and beautified by the poets and philosophers and
spiritual writers ... the garden and the sunshine.

I am also faced with decisions about what is my business and
what is not. I will have crossed another threshold when
there are only two possible answers to any question: "Yes"
and "It doesn't matter."

I will be much relieved when I understand just what is meant
by "Ask and you shall receive; Knock and the door will be
have asked and knocked for so long and have not understood,
these phrases take on the quality of a Zen koan, joining in
with the title of my thesis.

My next step seems to be guided by the image and sound of a
cello. And here, dear reader, we must part company.

But for now, let us begin.
PREAMBLE ONE

Expectations - Experiential approach to the writing.

As I approach the writing, I become aware that I am trying to weave four, at least four, themes into the story. The four seem to be: The Substantive (the facts, an objective finding of the 'truth' about walking and rehabilitation): The Theoretical (the ideas underlying the facts - the underlying assumptions about walking and rehabilitation): The Research Method (the search - why I am writing this, the way I am writing it, and who says it's okay to do it this way): and, all of the above.

The container for this is The Vehicle, my unique story, my way of telling it. This is the context of my research. And my research is in the context of Chronic Fatigue Syndrome. It is also in the context of an exploration of the world of rehabilitation, from the perspective of the client. It is my account of my walking.

My story is made from the impact of my searching - of things sought and not sought - of my response to these happenings, and my reflection on what is/has happened; it may include discussions about solutions and resolutions. Over and above all this will be the experience of discovering exactly what it is I have to say. I am aware that in anticipating the writing my thoughts and feelings are changing. I will be changed even further as I commit myself to the writing.

I see concepts of solution, dissolution and resolution floating before me. Little signs reading postmodernism and deconstruction and reconstruction drift by. Echoes of creation, conversion, constitution, choice, explanation and clarity sing in my ears. Already I am alert to the possibility of needing to find a helpful, relevant explanation of rehabilitation. Words, labels, jargon ... these are artifacts and pseudo-statistics.

I do not expect a conclusion or a solution. I expect that when I have finished writing I will have discovered the space into which I have moved ... some will say that I have created the space. Perhaps that is what a search for rehabilitation is about. Walking is both a physical activity and a metaphor: a metaphor alluding to a process rather than a specific destination or outcome. Any outcome, wherever sought along the continuum, may be merely a moment of arrested movement.
I would like the reader to keep in mind that this dissertation tries to remain faithful to the process or, more precisely, the cyclical nature of the process. Hence, I expect there will be ideas raised and often left unremarked, to reappear at a later date, in a different context in which comment flows more naturally. The spiral of enquiry seems to move with the depth of feeling – moving this way, and that, from past fact to future speculation, from ego voice to subliminal thoughts. Most of the time there is a competition for centre stage.

Already I anticipate that changes in focus will mark transition points or thresholds in my thinking, experience or understanding. The threshold is both process and evidence. The process: the threshing, the sorting of the grain. The manifestation: the stone, or plank, the keystone – underfoot and overhead. In the process lies the uncertainty, the doubts, the lostness, the messiness, the frustration, the loss of control, the pride, the fearfulness of staying with the situation and learning to engage, fully, with what is. That timeless space of being uncomfortable, of not knowing, of being wrong.

Where my articulation is successful I am closest to mySelf.
PART I

ONCE UPON A TIME

Once upon a time, many years ago ... yesterday ..... tomorrow ... This is the opening of a fiction, a story, a departure from the rational. It signals the presence of a limen, a threshold.

*Relinquish all hope, ye who enter here.* (Dante's "Inferno", Canto III:8)

Hope, as it is usually construed in the external, rational world of dictionary definitions, is a combination of expectation and desire mingled with trust ... very subjective ...

But hope ...

Small voice: ... how strange the shape of the word when repeated - try writing the word *eighth* several times and experience the dissolution of boundaries, the certainty that you know what *eighth* means, sounds like, even looks like! ...

... but hope is a strange word, a strange concept, a construction.

Small voice: Hope was the one bright thing that came out of Pandora's Box, and if you can't remember the story, Joseph Campbell (1988) and Liz Greene (1985) examine the Prometheus myth in great detail.

Tell me more.

Small voice: Well, Prometheus was one of the Titans, the earth gods who are the original children of Ouranos. Prometheus notices that humankind is struggling in the dark and so he steals some divine fire or inspiration from Zeus, and gives it to humankind. Zeus is not amused. Despite good intentions, Prometheus has committed a cardinal sin. He is a thief. He did not ask permission. And he is unrepentant. He displays arrogant pride. Zeus has him chained to a rock at the ends of the earth. Every day an eagle eats away his liver. By night the liver grows again. This torture is ended when Herakles breaks the chains.

However, Zeus is still out to get revenge, not just against Prometheus, but against humankind who now has access to the divine fire and, therefore, capable of Prometheus's sin of hubris. He designs a perfect woman, Pandora, complete with an unopened box of devastation, and offers her to Prometheus. Prometheus
(which means 'foresight') is not fooled, so Zeus offers Pandora to his brother, Epimetheus (which means 'hindsight'). Epimetheus can’t believe his luck. He jumps at the chance and Pandora is able to open her treasure chest, full of death, war, sickness and loneliness and, thus, these evil and vile elements are unleashed upon the earth. But because Pandora is 'perfect', she also brings with her the one redeeming thing – hope.

Thanks for the story. I get the impression that you are telling me that good and evil come together in one package – you can’t get one without the other.

Small voice: You are bright! And I would remind you that when setting off on a journey, especially one where you are looking for the positive, it is guaranteed that you will be confronted with the negative aspect of things.

Which is probably why people are loath to begin. Intuitively we know that all is not going to be plain sailing.

_I said to my soul, be still ... and wait without hope ... for it would be hope for the wrong thing._

_(T.S. Eliot (1974), "Four Quartets - East Coker")

 ..........

It would seem that the hope which must be abandoned is the hope that the ego (the conscious, worldly self) will be able to stay in control. It is only by suspending belief in control, in the ordinary, rational and literal meaning of things that one is able to approach and step through the threshold, into the subliminal. Thus, to undertake a journey past this undefined, invisible and terrifying point, one must abandon hope ... one must become hopeless regarding one’s personal expectations and desires, and hopeful in trusting the unknown.

_Boundaries ... exist to be transgressed, they are there to facilitate crossings, not to frustrate them ... It is not ... in those places whose exact frontiers have already been defined for us, but in the regions of uncertainty where definitions have yet to be located, that we must find our place._

_(Alex Miller, 1992, p.194)
Small voice: Already you are indicating that this search for rehabilitation is a search for both the rational and irrational. Did you know that the negative prefix seems to have gained a higher currency in the eighteenth century which was a time marked by concepts of order and classification? The use of negative prefixes

betrays the pejorative bias towards the speech of the soul, whose expressions are simply imaginative, symbolic, fantastic, mythic - all words standing on their own, requiring no prior terms that are rational, conscious, and sane.

(James Hillman, 1992, p.130)

Thus all journeys begin...

but before the beginning...

Small voice: Silly person - you began many years ago. This is just another example of the truism 'back to square one'. It is a device for finding a place to break into the timeless circle.

 Interruption - disembodied voices:

["We'll have to give her time to notice the difference between circles, cycles and spirals!""]

Silence:

Thank you! There are so many loose ends and strands ... I don't know which one to start with.

...........

This morning I joined a few friends, as I do each Friday morning, for our mediation session. We listened to a tape of a talk given by a monk, Dom Laurence Freeman (1993), about the distinction between a discipline and a technique. He pointed out that, when used as a technique to achieve any number of logical, rational goals, meditation is ego-centered. It is a technique for control when one is clear about the goal. The goal is immediate and considered to be achievable. However, if the technique becomes too difficult or does not appear to be achieving its desired outcomes, then the technique can be dropped, and replaced by another, and hopefully more successful, one.

Small voice: There is that hope again!
Perhaps we are talking about wishful thinking?

By contrast, meditation as a discipline transcends the ego. It involves learning what one cannot at present perceive. The goal, if it can be imagined, can only be conceived in very broad terms, "as through a glass, darkly." (Paul's Letter to the Corinthians, 1:13.) In The Jerusalem Bible, the translation is "Now we are seeing a dim reflection in a mirror."

Small voice: The purpose seems to be to discover the goal and, more importantly, to experience the discovering.

A technique, method or methodology is a means to an end with the end clearly in view, whereas a discipline is a daily activity. A discipline is a process ... and there is an intimate bond between the disciple and the discipline. Techniques are disposable.

**Interruption:**

"You've just started and already you are into dualism! I wonder how long it will take you to discover it?"

"Who ARE these people?"

"Better keep an eye on them, they look as if they are coming our way!"

"I wonder who they're looking for?"

"Certainly not you!"

"Why not?"

"Dork!"

**Interruption subsides:**

Small voice: Can I ask what all this is about. What are you trying to say?

I'm noticing leads and ideas and things that have some bearing on what it is I want to say, but I can't work out how they fit together, at the moment. Would you mind if I continue to thrash around for a while.

**Pause:**

Small voice: I suppose you know what you are doing. All right. Let's see where this leads.
Pause:

Thanks.

...........

It is interesting that where something is used as a technique, and the goal is not reached, the exercise is considered a failure. On the other hand when one pays attention to the process, failure loses its meaning.

Small voice (with more volume): It is interesting to note that my Concise Oxford suggests that a disciple is a follower in a religious or philosophical context whereas discipline is a system of rules.

As I read it, discipline is most definitely ... punitive. And there is a qualitative difference between the 'practice' and the 'doctrine'. Or the experience and the dogma. Or the practice and the theory. Or process and outcome.

So, if I am to continue with notions of outcome and process, of 'end-gaining' and 'means-whereby', to use Alexander (Huxley, 1978; Barlow, 1978) and Feldenkrais (Feldenkrais, 1977 and Alon, 1990) terminology; of ego control and transcendence of ego; of known and unknown; then I will need to enter through the limen or threshold and leave behind the Concise Oxford definitions.

Small voice: Who were Feldenkrais and Alexander?

Mmmm. Yes, I'm racing ahead. It's a bit like asking who were Derrida and Garfinkel! (Latour, 1988, p.166-68)


Pay no attention. It's an in-joke (shared by sociologists in the camps flying the flags of postmodern/deconstruction and ethnomethodology and the literary critics)! Latour (p.166) says:

"The stylistic goal is similar in both cases; render the text unreadable so that the usual two-way link between the account [the text] and the referent [the object in the real world] be interrupted and suspended."

But I digress!

Pause;

32
Both Alexander and Feldenkrais were interested in the relationship between mind and body, muscles and nervous system, and the dynamics of movement and self-image. They each came to their philosophies through personal injuries for which there was no orthodox cure. They found it necessary to concentrate on small movements, at the point just short of resistance, and to explore the body’s willingness to allow other parts of the body to 'help' to accommodate the injury. Often, this careful attention to the process, relieved stress on the injured part, thus allowing healing and/or a strengthening of other parts of the body. Alexander concentrated on the carriage of the head while Feldenkrais was more into spines and ribs and kneecaps.

But that’s a very simple explanation.

Disturbed air:

Where are you?

Small voice: I’m here. I’ve been pondering ...

About what?

Small voice: I’ve lost it! I can’t remember what it was I was going to say!!!

Perhaps you ought to see a doctor!

Small voice: Oh, I know. It was something to do with this region, the region which is yet undefined, it has no boundaries. It has the feeling of horses milling around behind the stalls prior to the race. Funny! The image has gone.

Perhaps we can catch it at another time.

...........

With hindsight, how do/did I prepare for this journey?

Given the difficulties, not to mention disorientation, which emerge when all, or many, definitions are up for grabs, one would need a very good reason for stepping across the limen.

My title, Have you been walking?, presented itself to me through a medical specialist, Denis Wakefield (personal
communication, and Hickie and Wakefield, 1992). Initially, the question was a straightforward inquiry about my level of physical activity. Over time, it has assumed the quality of a Zen koan.

Small voice: Zen? koan?

Pause:

"Have you been walking?" At some point this question began to irritate me. Yes, of course, I’ve been walking! What does he mean by ‘walking’? What do I mean? Confusion exists between quantity and quality, being and doing. Monsters called Coersion and Imperative appear on the scene. What don’t I know about walking? Who will tell me? My intellect can go no further – a koan has been born. According to Christmas Humphreys (1990), in his book Buddhism. An introduction and guide:

the process of Zen is a leap from thinking to knowing, from second-hand to direct experience. For those unable to make the leap for themselves a bridge must be built which, however rickety, being built for the occasion before being flung away, will land the traveller on the “other side” of enlightenment ... (p.182). There are two devices — the *mondo*, a form of rapid question and answer ... and the *koan*, a word or phrase insoluble by the intellect. (pp.182-83)

The aim of these techniques or devices is to break through some mental constructs. When the intellect becomes frustrated and gives up, then the intuitive ‘knowing’ may be experienced — Zen begins. Humphreys says

all systems of thought and philosophy, all ‘isms’, including Buddhism, all these are means to the end of KNOWING, and easily become obstacles in the way. (p.185)

When there is no way out, one must make the leap into the abyss. Ultimately, there is no walking and no goals!


Small voice: Interesting ...
Pause:

Means and processes and outcomes. For me this search is both chosen and forced upon me. Walking and rehabilitation are both literal and metaphorical. And trying to juggle all of these ‘boths’ is by turns and circles, cycles and spirals, frightening, exciting, frustrating, hopeless and enlightening.

Small voice: I believe it is absolutely essential to examine all of these apprehensions. I anticipate, too, that you will come to some understanding of the limen, or threshold, by staying with the confusion and allowing the issues to resolve.

Silence:

Thanks for that confirmation. I’ll take a few deep breaths and take a few tentative steps.

Small voice: Good!

Walking meditation is ... the Way of the Visionary ...

The purpose of walking meditation is to honour sacred time. This is a time set aside for introspection, contemplation, discovery and honouring the sacred or divine.

(Angeles Arien, 1993, p.100 – given to me by Marianne Wiseman, personal communication.)

 ..........

I was ushered to this threshold by Chronic Fatigue Syndrome and I will speak of this at length shortly. While this syndrome has some specific and particular hurdles, I believe that people who are marginalised through interruptions to health, relationships, employment or comfort, or by a variety of happenstances, find themselves in this strange place – of interruptions, of mist, of cloud and unknowing.

And an almost automatic response to such an occurrence focuses on cause, blame, fault and guilt. The questions begin to rise. How did I get here? Did I jump or was I pushed? How can I get out ... fast!

Pause:
Small voice: And I don’t think this response is well understood. People write about it, but do they understand it?

How do you mean?

Small voice: Somebody who did was Erika Schuchardt and I think you should say something about her work.

Thanks for the reminder.

Pause:

Erika Schuchardt (1989), a German educator and winner of the German Protestant Literature Prize, examined the life stories of 500 people.

She finds that when she looks at "Coping with Crisis as a Learning Process" (Chapter 2) there is a close connection between "the ability to be aggressive and the capacity for acceptance". (p.40) She believes that the role of aggression (phase three of her eight-phase spiral) may be replaced by faith. (p.42) Her final phase, which she labels 'solidarity' with the broader community, is not dissimilar to Van Gennep’s (1960) ‘reaggregation’ third phase in his The Rites of Passage.

However, Schuchardt concludes that this final stage "is reached by only a small number of disabled people and only rarely by people without disabilities." (p.37).

Small voice: You might have to come back to this, so you’d better include a copy of her diagram in the Appendix.

I will.

Pause:

Small voice: What was it that Karen Blixen wrote?

I learned the strange learning that things can happen which we ourselves cannot possibly imagine, either beforehand, or at the time when they are taking place, or afterwards when we look back at them ... (Blixen, 1986, p.269)

Hamlet (Shakespeare, 1980, Hamlet, Act 1, Scene 5) came to the same conclusion!
Small voice: And how does that fit in with the notions of the interrelatedness of everything which Lesley White (1992, p.7) canvasses?

...the [researcher] is actually constructing that knowledge which s/he considers to have discovered ... and, she asks, ... how is it that our research - the questions we ask, the experiments we are involved in etc. - constructs the particular realities, rationalities and scientific or natural laws that we consider we have 'discovered'?

Lesley White draws on biologists Maturana and Varela (1992), philosopher Suzanne Langer (1942), and the constructs and cognition of 'rationality'.

Physicist, Brian Swimme (1990), in a series of taped lectures, Canticle to the Cosmos, talks about 'time' as being a discovery of the past and a measure of the depth of change in perspective. He suggests that in the tension between meaning and chaos (empiricism and entropy), the organism/person chooses 'a world' and is then shaped by the environment of that world - the choice, however, is at the intuitive level rather than at an ego-conscious level. This intuitive level he locates in the DNA.

Small voice: At what point do people become conscious that they HAVE made a choice? Perhaps, only when consequences begin to manifest?

Interruption:

["That's it! They measure consequences and call them causes of themselves!"

["Quiet!"]

Silence:

If the truth be known, most people probably visit this 'place of interruptions' often, or at least pass by, quickly, not wishing to remain or venture too close.

Michelle Cliff (1979), in her paper, "The Resonance of Interruption", explores how women artists and writers, over the years, have been interrupted in their creative work by expectations that they will give priority to relationships, that is, they will give priority to the needs of others. Out of these expectations arise silences which blanket the despair, ridicule, isolation and unfinished work.
For myself, I found this place of interruptions to be a
blinding focus. When nothing else seemed to be achievable,
I began paying attention to the interruptions. Not only
from the point of view of being 'stopped', but also with the
intuitive realisation that the interruptions were
'messengers of the gods'. These interruptions initially
presented themselves to me in the form of telephone calls
which although infrequent seemed to come when I was about to
do something else. And in the acute phases of ME/CFS I am
restricted to doing one thing at a time. I had the
strongest 'feeling' that the telephone call was what I
needed to attend to, rather than the activity which I had
usually planned well in advance.

This is not to say that I disagree with Michelle Cliff. But
I wish to point out that words carry a wonderful array of
meanings and it is wise to inquire into the particular
meaning the author is trying to communicate.

Small voice: I'm sure you are right. There are times
and places - and, as always, there is the context.

Yes! Most people, most of the time, are able to pick up
speed, take a deep breath, divert the gaze and move on.

Small voice: Ego control has the upper hand, eh?

And I wonder about the processes of negative and positive
choices; and who defines negative and positive in any case?

Irritation:

Small voice: Hold on! Don't run away. There is an
issue here around happenings, creating your own reality
and control. You haven't said where you stand on this
sort of thing. For instance, look back at our discuss-
ion, or was it a discussion? about techniques and
disciplines....

Pause:

... mmmmm, yes. Distinctions between being in control and
allowing things to happen; between hope and wishful think-
ing; between ... between Jung's 'active imagination' and
Gawain's 'creative visualisation'...

Small voice: Hang about! Please explain!

...between techniques and disciplines?

Perhaps I could say that the distinction between the two
techniques seems to be one of ego control. For example, in
Hannah, 1981), the ego allows the unconscious (and thus unknown or unfelt) feelings and images to arise through imagination. The ego then speaks with the images. In creative visualization (Gawain, 1982), the ego directs the imagination to produce desired images.

Robert Johnson (1986, p.161) notes that inner dialogue should be written or typed, or one might use art or dance, but there must be some kind of active expression. Otherwise it is likely to turn into passive fantasy. He also counsels against acting out. Rather, he suggests ritual as a way of honouring and containing the contents of the unconscious.

On the other hand, creative visualisation encourages one to act out. David Feinstein and Peg Elliot May (1990, p.135) say that:

Creative visualization is one of our most powerful tools for directing our energies to positive ends. It is not, however, ‘magic’... without action, creative visualization can degenerate into the pleasant but fruitless exercise of wishful thinking.

Robert Johnson would say that creative visualization can also be dangerous, psychically and emotionally.

Small voice: Just what does ‘action’ mean to the people who are advocating it? Zen would have ‘action’ and ‘non-action’ as a simple paradox within the world of opposites. Both are one!

Pause:

I do seem to be wandering all over the place don’t I? I can’t quite work out what it is I’m trying to say.

Small voice: Well, anyway, this control, or being in control, or making things happen ... is this always possible?

I really don’t know.

Pause:

But that brings to mind the work of Anne Wilson Schaef (1992, p.190):

Many New Age and/or ‘holistic’ approaches [of health and business organization professionals], for example, have changed the content of their thinking. They talk about holism, spirituality, the environment, and many concerns that seem to
encompass a post modern paradigm. Yet, when they actually work with people, I find that their behavior and their techniques continue to come out of a mechanistic cause-and-effect paradigm that is subtly based on the illusion of control. [original emphasis]

Small voice: Exactly! What about earthquakes? How come you weren't born an Ethiopian? Or were you? And aren't these positive statements made from a stable base. For instance, I can see a mountain in the centre of an island, millions of years old, being able to speak authoritatively about stability. I can't so easily imagine a few grains of sand at the edge of a wild ocean being so sure!

Interruption:

["... is the mountain aware that it is really a stream of moulten lava? A volcano? ..." dazu]

["Isn't this fascinating? She's actually blurring the boundaries. She's talking about creating from context and then she jumps into identity itself!""]

["I am most impressed by this!""]

["But what has this to do with her walking and her rehabilitation and her thesis?""]

["I agree! She needs to refocus and get back into control - otherwise ...""]

Silence:

Well, I am trying to avoid this duality by taking a middle position where BOTH are right and appropriate in given situations.

Pause:

Small voice: Hold on! Duality doesn't necessarily impose a hierarchy of values - although I have to admit that our compulsive tendency is to classify! On the basis of some supposed (objective) merit!

True!

Interruption:
"She isn’t taking the bait!"

"Shut up!"

Silence:

So, to get back to the original question ...

Small voice: ... about 'happenings' and 'creating your own reality' ...

... if I have to make a choice, I am closer to Karen Blixen (that things happen) than to Lesley White (that we construct reality), on an ego-conscious level. On a deeper psychic level I am in agreement with Lesley White. Brian Swimme suggests that physics shows us that the cosmos is becoming aware or conscious of its own existence, and that this evolutionary step is within the human domain. It is humankind’s destiny! The birth of consciousness is an incredibly awesome process which requires the re-entering of chaos. And I found some profound reading in Hayward and Varela’s (1992), Gentle Bridges: Conversations with the Dalai Lama on the Sciences of Mind.

But anyway, this is just the beginning and by flagging this point you have perhaps indicated the area where most of the action is likely to occur!

Small voice: You mean, that just as the goldfish believes that the bowl is the whole universe, we humans tend to believe that the universe consists entirely of what we are able to rationally perceive (split infinitive intended)!

Perhaps not so much ‘rationally’ but ‘sensibly’? And don’t forget, there are at least six senses! And time zones and dimensions of consciousness ...

Pause:

That reminds me that there are several issues/concepts which I will need to take up. These include the medicalization of social and political ills; followed by the psychologization of the medicalization; followed, no doubt, by the ... the ... the ... spiritualization of the psychologization.

Sighing:

Small voice: In my day that was called scapegoating.
Pause:

I have already mentioned the work of Anne Wilson Schaef (1988, 1992) who suggests that one of the core issues that we must resolve is that of addiction. As a society, we are addicted to control, thinking, analysis and interpretation (head stuff) — individually, corporately and institutionally — and have lost our body/heart wisdom and our way in the cosmos or universe.

Small voice: Enough! I’m happy with that for the moment. Maybe concepts of margin and threshold could hold the key for your thesis? The key stone in the arch! Yet I suspect that your confusion lies in that area where process and boundary are indistinguishable — and where the limen is to be found in the threshing and the threshold and the connection between.

Pause:

"The End" is where you find it.

Now I hate books that insist that you have to read every word, in strict linear fashion, before you find out that the butler did it ... so I will let you know the end. If it interests you, may want to come with me on my journey.

While I am going to tell you the end, it is not an end. It is a clearing. A point I have come to. It is far enough away from the beginning to give me some sense of having been on the path and long enough, in time and space, to convince me that there is a path. So I am just looking backwards, a little way, to show you that by looking backwards we can see that we have been travelling. It is somewhat different from setting goals and gazing forever into the future, ever in pursuit of THE GOAL.

Small voice: That reminds me of Ariadne’s thread (see, for example, Campbell, 1988, pp.23-24). In the Greek myth, Ariadne gives Theseus a skein of linen thread to unwind as he goes into the labyrinth so that he can find his way out after he has killed the Minotaur. And it also reminds me of your earlier dream (Mcloughlin, 1989) where you could tell how far you’d come by tracing back the silk thread you had laid.

Actually it could be helpful to reflect on the heuristic method (Moustakas, 1981) of research or problem solving.
which is, according to The Fontana Dictionary of Modern Thought (Fontana, 1988), "a procedure for searching out an unknown goal by incremental exploration, according to some [known] guiding principle which reduces the amount of searching required".

Small voice: I'm not too sure about the notion of reducing the amount of searching required!

As Moustakas (1981, p.207) says about his own research:

Rather than listing a series of research concepts and abstractions which would be fragmented, mechanical effort, and which I would approach unenthusiastically, I have decided to explore an actual research experience which distinguishes the discovery process from that of verification and corroboration ... Because of its recent significance and its impact on my own awareness and way of life, I have chosen my study of loneliness ... to express and illustrate the nature and meaning of hermeneutic research.

Actually, the notion of starting from your own experience, from wherever you are and with whatever you already have, seems like common sense!

Small voice: Which 'common' sense? And, of course, that doesn't rule out the possibility of quantum leaps...

... nor the possibility of incorporating new learnings. Which means that we are always working from the 'known' to the 'unknown', from an ego perspective! It is, however, a different way from assuming that experts know better and that all knowledge is bound up in volumes on the shelves of august institutions. It is also quite terrifying to face my own vulnerabilities and authenticity, rather than making pronouncements on somebody else's experience.

Small voice: True! The road ahead is always under construction. And, there is no square two!

A pre-view of "The End"

After crossing the threshold ...

Sounds of movement. A voice whispers:
"She is having difficulty in describing the experience of intuitively knowing that she must actually crossover, or cross-sover, or cross-over, or cross over, or what is a cross what is an over ... (I aa cross') ... from her perception of her being a well and healthy person capable of doing anything that her ego willed, to a new but more honest perception of herself. Brian Swimme (1990) would say that having (chosen) (entered) (discovered) (created) a new world of chronic illness, this new world will, from this point on, impress itself upon her consciousness. She is not aware of having made this choice. She struggles between her attachment to her old image of herself and an emerging different reality. And this faintly indicates the presence of the limen."

Pause:

...and it took some time before I realised that there was a threshold - I had many adventures.

One day I found that I was gradually emerging into a world I did not recognise. My first (and recurring and frustrating) impulse was/is to try to find my way back from whence I’d come. And, besides, that is the expectation of society and of people who consider themselves members of that society. "You’ll soon be your old self, again!" If a cure is not imminent, then the search for rehabilitation is on! At least that is the hope.

By degrees, and with much heartache, I come to the realisation that this return is not possible. Rehabilitation is not a re-entry or a return, which is a required outcome from any rehabilitation program. For me, it is an imperative to continue. The search and research, pro-search or proto-search, deconstruction or construction requires a telescopic periscope.

I find myself struggling with labels or constructs or concepts which I know or know of to help me to identify the world which comes into existence, that is, a world that I become aware of. Of course, until I actually cross the threshold I cannot become aware. One might say that if I sense in some way that I will not like or want this world, AND if I have the ability in a god-like way, then I can create another world.

This construct might lie behind the emphatic psychological statement that people with a chronic illness or disability or unemployment MUST be getting 'secondary gains', otherwise why would they choose to create such a world. If I am getting secondary gains, who is getting 'primary gains'?
And how do I move from secondary to primary? That’s a bit difficult, because from where I sit, those getting primary gains are the professionals who owe their livelihood to my deviant behaviour!

Small voice: That was a nice piece of deconstruction!

Thank you!

Pause:

The task now facing me involves: charting and defining, venturing out and withdrawing, testing and relapsing, making sense and finding meaning — learning to ask not "Why?", but "What for? What now?".

"Have you been walking?" echoes in my mind, my body and my psyche. It asks, "What are you learning?". It encourages me to reflect. It presses on me the necessity to consolidate my 'knowing'.

In brief, it inquires into my dedication to the discipline of living. It says "Do you know who you are, yet?"

Pause:

Small voice: HEAVY!!!!
PART II

NOW, WHERE TO START?

I was going to start historically, with some context of Chronic Fatigue Syndrome, ME/CFS, but since I have mentioned time several times, let us start there, at the threshold. Perhaps there will be some stage directions for ME/CFS in the script?

But before I begin I want to emphasise that this is a fiction — even though I also believe it to be fact. It is my interpretation of my experiences. Others involved in my story may well have different interpretations — from their perspective. And who is to say which is the ‘correct’ interpretation? Each and every interpretation is true, in its context. As Maturana and Varela (1992, p.26) would say,

Everything said is said by somebody ... all knowing is doing; all doing is knowing ... Every act of knowing brings forth a world.

Small voice (mockingly): Now how are you going to explore this issue of fact and fiction? No doubt it will be largely theoretical, encompassing construction and deconstruction and the importance of context/text. And the equal value of ‘feminine’ ways — the domestic, day-to-day, subjective, life skills — and ‘masculine’ ways — the industrial, artificial, scientific and objective skills.

Well, I’ve got a whole swag of references which are jumping up and down, hands in the air, wanting to be included.

Small voice: What? Right now, this minute?

Yes!

Small voice: Could you let them know that we’ve seen them and will get to them, one at a time?


Over here we have: Vince Taylor (1979), Bob Dick (1991), Egon A. Guba and Yvonna S. Lincoln (1990) ...
and Bruno Latour (1988), Yolanda Wadsworth (1993), Jim Cheney (1987), and ...

and ... and Angela Brew’s and Hilary Traylen’s individual work reported by Peter Reason (1988, pp.14,26,28; and 1989) ... and ...

Small voice: Pleased to meet you all!

Well, actually, I’m not sure whether I’ll need to talk to these ‘references’ separately, or whether I will find a way to weave them into ‘the story’. Can we mark this out for further discussion and pick up the idea of *limen*?

*Pause:*

Small voice (miffed): Yes, the *limen*! My *Concise Oxford* says:

*Limæn: (psych) Limit below which given stimulus ceases to be perceptible, minimum of nerve-excitation required to produce sensation. Liminal: threshold.*

Logically then,

*Subliminal: (psych) Below the threshold of consciousness, (of sensations) so faint that subject is not conscious of them: the *subliminal self*: the subconscious mind as a distinct part of the individual’s personality.*

... Freudian, perhaps?

I can find in my copy of *Fontana* some other explanations: *Limæn: see threshold. Liminality: see under rites of passage. Now this is looking promising.*

*Threshold (or *limen*). In the measurement of sensation, the statistical point at which (1) two stimuli resemble each other so closely as to be confusable (the *differential* threshold) or (2) a stimulus so weak that its presence cannot be detected except by chance (the *absolute* threshold).*

Ah ha. The *Concise Oxford* has focused on (2), the *absolute* threshold. Yet the *Fontana* definition has alerted us to another statistical element – confusion. One of chance and one of confusion. Most appropriate wouldn’t you say?
Silence:

In any case, both Oxford and Fontana are concerned with the detection of a stimulus. A measurable stimulus, perturbation or intrusion. It seems important that the stimulus is defined in terms of measurability. The crossover point, the threshold, marks the line which divides what can and cannot be measured (absolutely), and includes the concept of difficulty in assigning 'cause' to any one stimulus (differential). So far, so good.

Small voice: Are we simply measuring measurability? Isn’t that pretty tautological and circular? Great stuff! We line up a whole mess of data for the sole purpose of exploring the concept of measurement?!? We could use any data, it wouldn’t matter! Guns, butter, frogs, stars ... even ... even ... GOD FORBID! ... people?

A peek at rites and rituals

Fontana, however, also connects liminality with rite de passage. Let me quote the entry in full:

Rites of transition, a term developed by Van Gennep [1960] to describe the movement of an individual from one state to another. The transition is marked by ritual and involves initiation. In this way society recognizes and legitimates change. Examples of rite de passage include marriage, circumcision, coronation and mortuary rituals.

Van Gennep identified three elements in rite de passage. (1) Rite of separation, temporary removal of an individual from society while preparing for the change. (2) Rite of marginality/liminality, moment of transition, initiation. (3) Rite of aggregation, new status affirmed and the individual is reincorporated into society. The middle element or liminal phase is potentially dangerous as the individual is between social roles. In this phase the initiate is subject to restrictions and taboo."

Small voice: I might add here that this three-way split into ‘elements’, is not real, inasmuch as it is a device, a framework, which helps to contain and gives structure to the discussion. Musical composer, Christopher Willcock (1994), has used four stages - the departure, the journey, the arrival and new beginnings - in his "New Song in an Ancient Land".
For the moment, can we stay with Van Gennep's trinity.

Small voice: Good point.

Pause:

So, let that lie for a moment while I continue with Fontana's entry following:

Ritual: Formalized behaviour or activity in accordance with rules and procedures specified by society. The 'peculiarly' or 'altering' quality of ritual sets it apart from other social activity. Ritual may be individual or private ... or social and public... The clarity of the boundary between ritual and non-ritual varies. Certain rituals are very clearly marked off from the rest of social activity. Ritual may have an elaborate internal structure (beginning, middle and an end) and this may be seen in rites de passage ...  

... Ritual has both instrumental and expressive aspects: it is an activity (it does something) and it is a statement (it says something).

Flurry of activity.

Argumentative voices:

["As if "saying" something is not also "doing" something. Anyway, doesn't Maturana (Maturana and Varela, 1992, p.27) say that "all knowing is doing"?"]

["Feldenkrais (1977, pp.46-47) insists that "doing does not mean knowing", "awareness is not essential to life" but is a "new stage of evolution".]

["Picky, picky! Be fair, this is in context, in the context of anthropological theory! Obviously, activity and statement are significant distinctions which anthropologists make."]

["It may be significant to them, it isn't so obvious to me."]

["Good point!"]

49
"What's this about context? I see context as an essential dimension of any discussion. And it is related to 'focus' and 'boundary' and other analytical concepts. It is also a symbolic 'container' in the Jungian sense which makes the container and the contained inseparable . . ."

["Yes . . . container and contained define/create each other. Shulamit Reinharz (1991, p. 205) notes in her chapter on "The Stress of Detached Fieldwork":

Some of this contextual work was irrelevant to the research but valuable for my . . . therapist . . . role. Since the contexts of the two responsibilities differed, their merger was not convenient."

["And what has this to do with the rituals of early retirement or applying for Social Security Disability Support (Invalid) Pension?"]

["Right on!"

["Dork! Applying for social security benefits is an empty ritual. It gets you money - if you're lucky; but it doesn't guarantee legitimacy."]

["Exactly! It guarantees a marginal existence."]

The atmosphere settles:

To continue with Fontana's definition:

Anthropologists working in the functionalist tradition (Malinowski, Radcliffe Brown, Gluckman) have attempted to understand the function of ritual by situating it within a specific social context. Others have focused upon the content of ritual and pursued its meaning rather than its function. These anthropologists are usually sub-divided into 'intellectualists' and 'symbolists'. An intellectualist approach (ritual concerned with providing an explanation of the world) may be seen in the work of Stephen Hugh-Jones. The symbolists have highlighted the expressive or emotional content of ritual (Turner)."

Another interruption:

50
"Okay. Is activity equivalent to function/explanation, as statement is to expressive/emotional? And does that mean that if I make a statement in order to explain something, that that explanation is necessarily emotional? And that the only non-emotional explanation, by definition, is not a statement but an activity?"

Heavy breathing:

"No wonder our ‘world’ is so caught up with activity - all the time trying to avoid the statement. And, to extend this diatribe further, if I engage in ‘activities’ does that make me an ‘intellectualist; if I indulge in making ‘statements’ does that make me a ‘symbolist?’"

"Then we all join hands and play with the postmodernists and ethnomethodologists?"

Cyclonic winds:

Enough! Enough! Where is all this coming from? You’ve got yourself further into the mire, predictably, with ‘value-free’ engaging and ‘value-laden’ indulge. Maybe the point is that activity is perceived in a social context, with a generally agreed upon meaning; whereas statement is perceived as expressing an individual and personal meaning? Neither is actually true. It’s just that for the sake of argument, in a specific and specialised context, we act as if they were true.

See - we’ve got caught up in a circular argument. The only BIG mistake we make, is that we forget about the as if. And as soon as we want to move out of our defined context we run into the trouble of translation.

We break the container and the contained is no longer!

Irritation subsides:

There are two points I want to make here.

Small voice: Go ahead.

First, listen, threshold and rite de passage have in common a point which differentiates one form of behaviour or stimulus from another ...
Small voice: Wait a minute, isn't behaviour supposed to be the result of a stimulus? Perhaps it is by measuring the behaviour that the stimulus is imputed? Sometimes, maybe, there is no stimulus? Merely behaviour? Merely movement? Is this what Maturana and Varela (1992) were playing with? Weren't they saying in Chapter 7, which deals with "The Nervous System and Cognition", that the central question in behavior, differentiation, structural change and development, is "What is movement?"

Pause:

... in a measurable, observable, objective manner, even if allowance must be made for a 'fuzzy' area of indefinability. And, by the way, Oxford doesn't admit to such 'fuzzy' areas for their definition of subliminal self.

Small voice: Okay, okay.

Rite de passage introduces the social context which brings with it rules and regulations. Notions of permissible and non-permissible behaviour overlay the notions of observation and measurement which are overlayed by notions of public and private which are overlayed yet again by notions of function and meaning.

Rite de passage is indeed a fine metaphor for my walking.

Small voice: In literal and metaphoric terms?

Yep. Van Gennep's first phase, the rite of separation, parallels a temporary removal from the mainstream of society through, in my case, illness. The third phase, rite of aggregation (I find myself using the term 'reintegration') is suggestive (but only suggestive) of the rehabilitation aspect of my thesis. It is through the rite de passage that society legitimates change. The second or transition phase, the liminal phase, is marked by restrictions and taboo.

Small voice: ... and problems of translation? And what happens if society doesn't legitimate the change? Do you get stuck with the restrictions and taboos? Is this where the trinity fails? Is this where we need to create more complex descriptions?

Pause:

Small voice: I wonder whether this is why Schuchardt (1989, p.37 and discussed at p.36 above) finds that few people reach "appropriate social integration"?
Small voice: Obviously if one strives to be included success depends equally on one's individual efforts and the willingness of the larger society to open a door in their exclusiveness. I begin to like Christopher Willcock's (1994) labelling of 'arrival' and 'new beginnings'.

I'm not sure of the equalness in the above equation. And maybe the door one knocks on may not be the appropriate door? The second point...

Small Voice: Enough. One point is enough. And besides, that's what Maturana and Varela (1992, pp. 211 and 231) are on about:

We make descriptions of the descriptions that we make (as this sentence is doing) ... What we say - unless we are lying - reflects what we live, not what happens from the perspective of an independent observer.

True. And Brian Swimme (1990) says that change, especially significant or evolutionary change, seems to require a splitting off from the crowd, isolation, deep reflection and the company of a few like-minded people? After all, the environment presses in on one's consciousness - the status quo is never friendly to new ideas, new turnings, new worlds.

Small voice: I was interested to read that Dorothy Rowe, in her book Beyond Fear (1987, pp. 282f.) considers such behaviour, of isolation and deep reflection, as symptomatic of 'depression'. Obviously Swimme and Rowe might disagree as to the experience and meaning of depression. I must make a mental note to question the questioners about what they mean when they use the word 'depression'.

Pause:

Small voice: But for now, I find this a suitable place to stop. Your second point can wait, because I know you are going off on a tangent!

You are right. It is off on a tangent and it belongs somewhere else. But I just want to emphasise the point that seems to have been lost, that unless society legitimises changes, then restrictions and taboos remain in place and those in the throes of that change are still in limbo.

Small voice: That's why it's so difficult! Being medically retired or on disability support is always il-legitimate or in-valid.
Long silence:

Well, Small Voice, where to from here?

Another long silence:

Small Voice: Let me think for a minute ... we started out with meditation, disciple and discipline, dictionary definitions, control, measurement, ego ... it's beginning to look like a dog's breakfast!

I think we ought to stay with the exploration of why threshold is so important, before we get to whatever it is we are measuring and whether or not it can, or even should, be measured!

Thanks. I thought I'd done that in referring to *rite de passage* and Van Gennep's ... 

Small voice: Well, yes, you did refer but you didn't explain, least wise not so that I understood.

This is a problem - just where does one enter a circle?

Small voice: I don't know. Ask a sperm!

So we are into seminal jokes, are we? How come significant insights are always 'seminal'? His work is 'seminal' - her work is 'ovumal'? Could we just as well have 'ovumars' as well as 'seminars'? Marianne Wiseman (1994) tells me that at the University of New England, the word 'ovumars' had coinage in the 1980s!

Brief interruption:

["Just another example of the exclusively masculine languaged world of hard science!"]

Small voice: Ha, ha! We haven't got all day. You begin, simply, by saying that you are now entering a circle. You are entering into a play which has already begun. The audience will have to take some time to acquaint themselves with the dark and the characters.

Silence. Deep contemplation:
Small voice: So perhaps we could have something like "The story thus far..."

Pause:

Small voice: In fact, right at the beginning you started off with Once upon a time, so why not start again?

Longer pause:

Small voice: By the way, don’t you think you ought to say something about ‘the dialectic’?

Sudden confusion:

Later, later!

Small voice: No, now!

Now?

Small voice: Yes.

Resigned sighing, obvious effort:

Very well. John Rowan (1981, p.104) says that dialectic questions are about the philosophical assumptions of the research.

Does it assume that there is one right answer?  
Does it assume that the relationships are linear?  
Does it have room for change and transformation?  
Is it looking for the major contradiction?  
What does it take for granted?

Egon Guba and Yvonna Lincoln (1990, pp.146-47) have also argued for a hermeneutic/dialectic methodology where the hermeneutic aspect seeks to examine each individual construction as accurately as possible in order to increase the amount of information and level of sophistication. In such a context, generalization cannot be an aim. The dialectic aspect insists upon confronting the constructions
of others in the hope that consensus may emerge. They go on to say that:

Constructivism aims neither to control nor to dominate the ‘real’ world. … it is a struggle, but rather to reconstruct the world at the only point at which it exists: in the minds of constructors, human beings. It is the mind that is to be transformed, not the ‘real world’. (p.147).

Of course, hermeneutics has always been a hotbed of opinion in biblical studies and the debate is fueled through the writings of feminists Elizabeth Schussler Fiorenza (1984, 1992), T Doreah Setel (1985), Rosemary Ruethe (1983) and Anne Carr (1988), to name but a few.

Pause:

What made you think of that now?

Pause:

Small voice: Well, Peter Reason draws attention to the need to get out of the philosophy and into the reality of the research. In his introduction to Human Inquiry, Reason (1981, p.xviii) says that the book

is not a record of people trying to apply philosophical purities to intractable daily-life problems. Much more it is a record of people being forced by the logic of what works and what does not work with human beings, further and further in these directions... So although we can call on distinguished philosophical traditions if we wish, this work is really much more practical than theoretical... [However], you may find that you need the philosophical ideas to illuminate and inform your own actual experience, as you discover [others might say create] them for yourself. That is what human inquiry is all about.

Silence:

Can I take it that all this pussyfooting around has to do with the fact that I ought to get out of this theoretical and generalised stuff and try to ‘tell the story’?

Small voice: Exactly! But tell me a little about ‘telling the story’.
Let me think.

Pause:

Peter Reason and Peter Hawkins (1993, pp.79ff.) explore "Storytelling as Inquiry" and find that this creates a culture which values both explanation and expression. It deepens inquiry, can move from individual stories to collective patterns and changes the way we collect information.

...as many writers are pointing out ... all theories rely on root metaphors and images ...
Story telling, and in particular the method of story response ... [replies, echoes, recreations, and reflections], is one way in which root metaphors may be discovered and given form... Stories are a powerful way of communicating the findings of inquiry to other people. The outcome of a cooperative inquiry is often deeply personal and practical, as well as theoretical. The theory and the practice can often be well grounded and expressed in the personal or collective story...
Thus science can learn to tell good stories, and then explanation and expression become married, and the progeny are theories born of story, and stories born of theory. (pp.100-101)

Bruno Latour, (1988) in his paper "The Politics of Explanation: An Alternative", says that there is an assumption that:

Providing an explanation (in either natural or social sciences) is inherently good; thus accusing someone of providing no explanation puts an end to the dispute; the opponent is just story-telling and may be stopped by a simple question like 'so what?'; to answer the 'so what?' question entails proving that he or she is doing more than just telling stories, that he or she is really also offering some explanation. (p.156).

Pause:

Latour continues:

No explanation, no matter how abstract the science, no matter how powerful the regime, has ever consisted of anything more than a disproportionate amount of heterogeneous, historical, contingent elements. (p.163).
He argues for "throw away causes and for one-off explanations".

The stylistic conclusion is that we have to write stories that do not start with a framework but that end up with local and provisional variations of scale. The achievement of such stories is a new relationship between historical detail and the grand picture. Since the latter is produced by the former, the reader will always want more details, not less, and will never wish to leave details in favour of getting at the general trend. (Latour, 1988, p.174).

He believes that we should avoid using meta-language or jargon so that we can acquire "the ability to get out of academic circles and to tie our work to the many current struggles to resist being known, explained, studied, mobilized or represented." (p.175).

**Disturbance. Turbulent air:**

["In other words, you are relying on Reason, Hawkins and Latour to validate your methodology."]

**Hey! What’s this all about?**

Small voice: Don’t be so crude! She’d be just as happy to ‘tell the story’, but this being academia, there are rules to follow ...

["... like justification, rationalisation, validation and all those other -ations?"]

I’m picking up all this irritation ... with which I agree, to a point ... and I also have to admit to a degree of insecurity ... because I don’t feel like such a dork when other luminaries ...

Small voice: **published** luminaries?

... okay, published luminaries, legitimate what I am doing!

Small voice: I’m only teasing!

**Sounds of ruffled feathers:**

I was unaware that I was feeling such ambivalence! I must be getting too close to the liminality - the process of getting ready to make the leap into the void. There is a sense of resistance and coldness and the mists and fogs are swirling all around.
Pause:

I also wanted to mention an article by Jim Cheney (1987) "Eco-Feminism and Deep Ecology" in which he explores why feminism does not necessarily fit comfortably with deep ecology, which purports to support 'the feminine'. He draws heavily on the significant work of Carol Gilligan (1982), In a Different Voice. Cheney notes:

To contextualize ethical deliberation is, in some sense, to provide a narrative, or story. (p.144).

He goes on to quote Holmes Rolston, III:

Ethics must be written in theory with universal intent, but the theory must permit and require ethics to be lived in practice in the first person singular...The logic of the home, the ecology, is finally narrative, and human life will not be disembodied reason but a person organic in history... The theory can provide a skeleton but not the flesh. (cited in Cheney, 1987, p.145)

Small voice: Finished?

I think that's enough for present ...

Pause:

So, are we sitting comfortably? Yes?
PART III

THE STORY

Rite of Separation

An empty stage. Enter a Greek Chorus. Players strum on lutes and harps. A voice intones:

Once upon a time, a long time ago, yesterday ... she was a successful functional person in the world of work and society, but as fate would have it, she was struck down with a virus. She did not recover as expected.

Three years went by, then four.

She struggled to remain in the workforce. At the same time she visited many doctors who were unable to come up with anything other than glandular fever and atypical bits and pieces. She came to believe that she must have been doing something wrong, although she couldn't fathom what.

So she tried massage, acupuncture, homeopathy, herbs, meditation, yoga, walking, a Pritikin Diet and positive thinking. Finally she came to suspect that she was probably in the wrong place, in the wrong job, although she couldn't quite accept that, either.

Lights up. Spot on centre stage:

Nevertheless, I took steps to change my lifestyle, radically. I put my house on the market, arranged to move from Canberra to Sydney and to move out of policy work into administrative work. I applied for extended unpaid leave. I applied for admission to the Masters of Business Administration at the University of New South Wales.

This is 1985.

Lights down:

Things then went from bad to worse.
She could not fill in the application form when it arrived. She could not even find where to put her name and address. Only days after leaving work she deteriorated further. Surely, she reasoned, if work was the problem she ought to be feeling brighter and better by the hour!

She wasn’t.

Lights up:

Finally, my brother suggested, not for the first time, that I visit his doctor. Within 15 minutes of arrival at the doctor’s surgery I was told that I had Myalgic Encephalomyelitis (now known as ME/CFS). I had never heard of such a thing.

Small voice: You could tell the story differently. You could say that you chose to experience a dislocation from the workforce and ...

You may very well say that, I don’t intend to comment! As I said at the outset, this is my experience, my story. If it felt like I was struck down, then that is how it felt. If the energy runs out of the soles of my feet, then that’s how it feels. Can we get into this creating your own reality later?

Small voice: Of course! I was only teasing!

Grey matter. Flashing lights. Busyness:

Since 1985, and even before that, the name has changed ... often. Myalgic Encephalomyelitis gave way to:

Post Viral Syndrome (because there was no detectable inflammation of the brain); which gave way to:

Post Viral Infection Syndrome (because some people did not have a confirmed viral onset). At some point it became:

Post Viral Infection Fatigue Syndrome (because fatigue seemed to be emerging as a major symptom); and currently it is called:

Chronic Fatigue Syndrome or CFS.
In the United States, patient support groups call it Chronic Fatigue Immune Dysfunction Syndrome or CFIDS. They insist on the inclusion of ‘immune dysfunction’ because at the current rate of reductionism the illness could be defined out of existence and it will be increasingly difficult to encourage research into causes and treatments. In Britain, Australia and New Zealand, M.E. and CFS seem to be used interchangeably (by the sufferers, if not by the medical fraternity) and I will use the abbreviation ME/CFS.

The media grabs headlines with ‘Yuppie Flu’ and ‘Mystery Illness’ and the ‘ME disease’ (hence the use of M.E.). The Centres for Disease Control (CDC) in Atlanta, Georgia have proposed a set of criteria for clinical diagnosis known, predictably, as the CDC criteria. In the light of research studies, these criteria are subject to amendment.

Small voice: Careful! Aliens at 12 o’clock are wanting to break into the narrative. They want references!

Thank you! Will they be satisfied if I acknowledge that I’ll asterisk the references in the bibliography? As a starting point I’ll refer you to ME/CFS in the 90s, proceedings of the First National Conference on ME/CFS held in Canberra in October 1991, and to Dwyer (1991, 1993), Hickie and Wakefield (1992) and Bell (1991).

Pause:

Small voice: That will be fine.

Now, to continue...

The arguments rage backwards and forwards ... is it primarily an organic disease or is it psychological in origin? Is it the result of stress or is it an inherited predisposition? Is the site of the pathology (if there is a pathology) in the muscles or the brain? And what of the unexplained tissue inflammation? And how do we identify cytokines? What is the role of neurotransmitters and hormones? Are sufferers just work-shy, bludging off the taxpayer, a burden on society? In brief, are these people just looking for a way to opt out of life?

Are these people living proof that only the ‘fittest’ survive, in any context you wish to construct? Perhaps all life on the planet is part of a huge laboratory, experimenting and testing out new evolutions in preparation for deep space colonisation or simply for living on an increasingly polluted Earth? In which case, are we the ‘fittest’, likely to be ‘crippled’ by the experiment, but strong enough not to be killed? And besides, what is FATIGUE anyway?
Small voice: I don't know! And isn't 'fittest' here used to mean 'fit in'? Like a foot into a shoe? Like finding an ecological niche? I'm sure it doesn't mean 'fit' as in 'strong as a bull'! Although it could mean that, too!

That was a rhetorical question!

Small voice: Point taken.

There are at least four broad sources of information about ME/CFS:

First: the formal medical literature. There are numerous reports of research published in medical journals throughout the world. These journals are not available at the corner newsagent. As would be expected, reports of technical medical research are not easily understood by the general public. However, if one wants to know the parameters of research findings, it is essential to become familiar with the debates which are generated by the release of such findings.

Small voice: Of course, research findings are not necessarily 'facts', yet the political reality of the battle for research funding, academic jealousies and the appetite of the media often leaves the patient or potential recipient in a quandary. One hopes/believes that the expert has enough interest and/or experience to cry "Hold on! Is that REALLY what the report says! And is it good science?"

The research findings most often have the status of 'facts' or 'cures' amongst people without first-hand experience of the situation who find themselves bombarded by media hype and for whom the 'real' facts are not important. By that I mean, that they are not personally affected by them.

And, I might add, for the purposes of your thesis, there is very little by way of detailed discussion or exploration of the methods or experience of recovery or rehabilitation.

Second: the popular medical literature. There is a handful of books, published by general publishers, written by medical doctors and researchers and professionals in
alternative therapies. Often the aim of these books is to educate doctors, their patients and their carers.

Small voice: I am not sure whether much of this gets into general medical text books. And some of it is suspect anyway, isn't it? Most of these books make recommendations about coping skills, because, as we know, modern society makes a virtue of making your own informed decisions. And this places the responsibility (some say blame) on the individual.

Yes ... I remember my recent surgery.

Pause:

Small voice: What was it the eminent surgeon wrote to your referring doctor? "You will recall that she chose the more definitive procedure of the options available..." ... as if you had more knowledge than the eminent surgeon ... and as if you weren't influenced by his unspoken imperatives!!!!

Pause:

Small voice: Who was he kidding? And what real choice did you have when the words which rang in your ears were "Whatever decision you make, I want you to remember that we have had this conversation!"

Pause:

... Third: the voices of edited experience. Various books and articles pop up in a variety of ways. These are written by people living with ME/CFS or who claim to have improved, if not recovered, through lifestyle changes and the help of alternative practitioners and therapies. The authors share, in various degrees, their experience of the illness and the ways they have coped.

Small voice: ... or died! Diana Longden's story is told by her husband. Deric Longden (1989) is an English comedy writer, so the book is extremely funny. Perhaps it is only through humour that death can be approached?

Often times these books are published by small health magazines and specialised publishers or by the authors themselves for limited circulation. And popular magazines like happy endings.

Small voice: Unlike the medical literature, which emphasises the need for objective, double-blind, placebo controlled research, this literature is 'purely
subjective' and lacks research, comparability, and examination. Claims of 'cure' go undefined and unchallenged. Much of it is simply anecdotal - the bain of all good 'scientists'. Anecdotes, opinions, debates and research were buzz words at the ME/CFS in the 90s Conference in Canberra in October, 1991. I'm beginning to sound like you!

Actually, you have made a good point. The claim of 'simply anecdotal' can be a way of devaluing a person's experience and observation. It signals that not only am I not in agreement with the 'evidence', but that I will make no effort to investigate it. It is a demand made by me, the powerful, of you, the less powerful, to prove the point within my frame of reference.

Small voice: Interesting, eh!

Yes. I might need to come back to this discussion later.

Pause:

Many people with ME/CFS have come up against the legal system, through claims for insurance based disability benefits or for Social Security income maintenance payments, because ME/CFS is 'invisible' and because there is no clear prognosis. Even if ME/CFS exists, do you really have it? These issues were discussed in workshops at the ME/CFS in the 90s National Conference in Canberra, 1991, pp.130-31 and 163-66, specifically.

In fact, so contentious is the subject that the Commonwealth Government needed to be taken to the Administrative Appeals Tribunal to decide the issue of medical evidence. [Walker and Coicare, cited in Ballard, 1991, pp.24-25]. The debate continues (M.E. and You, September 1994).

In my own personal case, I required the help of the Public Interest Advocacy Centre (1988) to break the circle of 'medical examination and deferred decision' in my claim for superannuation entitlements. I have also heard the stories of self-employed people who face a similar brick wall when claiming on very expensive private disability insurance.

Pause:

...Fourth: the interviews or 'captured' biographies (to use Matthew's (1981) term). One finds a rash, every now and then, of personal and human interest stories appearing in television programs, newspapers and magazines.

Small voice: Some of this is really good ... other stuff is, well, less than useless! And quite
misleading, if not damaging. It all depends on the reporter and editor.

... and lastly: the self-help associations’ newsletters. Running alongside all of this and trying to connect these various sources of information, are the Newsletters published by the ME/CFS/CFIDS self-help groups around the world.

Small voice: And didn’t the Canadian historian, Professor Shorter (1992), use this source well ... well, very selectively and with great aim. But you can talk about that later ...

I have included a wide, if not complete, list of books, articles and newsletters, in the Reference section and have marked them with an asterisk (*).

Small voice: Perhaps later on you might want to talk about the role of fiction, poetry, art, as sources not only of inspiration, but processes which are essential companions on the journey across the limen.

Yes. But you’re getting ahead of me. And I need a break.

..........

A major irritation

For an oyster to create a pearl, there first of all has to be a grain of sand ...

A fascinating, recent book, written by Professor Shorter (1992), a Canadian historian, concludes that ME/CFS is the late-twentieth-century version of women’s hysteria and paralysis. He claims that fatigue, hysteria and paralysis, where the diagnoses are based primarily on clinical presentation of symptoms, are basically physical and psychiatric responses to difficult social and personal situations.

An equally interesting book ...

Small voice: Heavens! Don’t you want to say more? I would have thought you could fill a page!!

Perhaps you would like to say something?

Small voice: My oath! What I was livid about, perhaps because I’ve not be trained in the discipline of history, is his use of ‘primary sources’. Even the simplest economic rationalist knows that you don’t compare apples with oranges – or is it oranges and
lemons? - and there is always a trade-off between guns and butter.

What do you mean?

Small voice: I mean, you have to compare like with like. Shorter sets up his arguments on the basis of psychiatric case studies, historical-medical literature, and his belief that doctors and patients manipulate each other. Then in order to confirm his findings, that people with ME/CFS are a sub-culture of manipulative drop-outs, he cites 'diary dates' in ME/CFS self-help newsletters. He cites notices that advise members of fundraising and picnic events! He gives much space to emotive and one-sided media outbursts, attributing general acceptance (by the ME/CFS sub-culture) to minority opinion. He cites such outbursts as evidence of psychiatric disturbance and misses the personal and political import of these outbursts. (See, for example, Shorter, 1992, Chapters 9, 10 and 11 and pp.265-67, 307, 314-20.)

Do I hear you saying that to 'prove' his theoretical and scholarly findings he calls on anecdotal evidence? Tut, tut!

Small voice (continuing): He labels doctors, especially immunologists who suspect that there is an underlying organic component in ME/CFS, as 'medical enthusiasts' (p.312). Those who support a psychiatric cause are called 'scholars'(pp.314-15).

Pause:

Small voice: ... and he doesn't have a bibliography for ease of reference. Instead you have to wade through 75, yes, 75 pages of footnotes.

Interruption:

["And, besides, he tells us that his wife is a doctor! (p. xi)."]

["This needs examining sociologically. Is it conceivable that prior to organ transplants and HIV/AIDS, immunologists were viewed as allergists and obscure researchers?"]

["And I would want to know where he sits on 'moral' issues. For instance, where does he sit on issues of equality and social justice?"]

Pause:
Do you think the feminists might make a meal of this book?

Small voice: Not only the feminists ... Shorter notes that:

Patients' groups and physician-enthusiasts of CFS have seized with glee a trickle of inchoate immunological findings. Since the 1960s immunology has become the queen bee of the medical sciences ... quite naturally, psychosomatic patients who want their symptoms to keep abreast of scientific progress wish to see the underlying source of the problems as immunological in nature. Yet the standard-bearers of immunology themselves have displayed little interest in the diseases of fashion. (pp. 314-15).

He provides no footnote to support this opinion.

 Interruption:

["Because he hasn't looked at the immunological literature?"]

Pause:

Yes, yes! I hear the tone of voice! But what of his findings?

Small voice: You mean that everybody with ME/CFS is an oppressed woman looking for a good .... looking for a way out of her oppression?

In short, I think Shorter believes that the cause of eighteenth-century paralysis in women and the modern phenomenon of chronic fatigue syndrome (although I don't believe that he differentiates between 'chronic fatigue' and 'the Chronic Fatigue Syndrome') lies in the structure of the family, which, incidentally, is his primary interest and the subject of another of his publications.

Small voice: Well, as for the oyster, it takes a grain of sand to begin a pearl! Aren't ALL families, like society, dysfunctional? (Schaef and Fassel, The Addictive Organization, 1988). And I note that Shorter off-loads undiagnosed 'real' illnesses as his historical bandwagon rolls on. If I remember correctly he doesn't make much of 'real' organic illnesses which were diagnosed as 'simply' psychosomatic symptoms because, at the time, medical science had not yet found an organic pathology.

Is this your main gripe?
Long pause:

Small voice: Actually, yes! I was thinking, particularly, of TB (tuberculosis). I have an image of the ‘good women’ who suffer ‘consumption’ (metaphorically, consumed by some psychological illness, preoccupied with themselves) and are allowed to languish in expensive sanatoriums so that their (necessarily wealthy) families will not be embarrassed by their abnormal illness behaviour.

And it wasn’t only women ... think of the recent British televised series of Thomas Mann’s (1965) book *The Magic Mountain*, written in the 1920s about the inmates of a sanitarium in Switzerland....

Pause:


Small voice: Of course, if you aren’t cured physically, then you die a happier death?

Shlain (cited in Capra, 1988, p.295) says that

*when I see a patient today who happens to be so unfortunate as to have tuberculosis, and if I treat him with drugs, he gets better. Whereas, if I send him to a sanitarium and give him the right diet and clean air and the whole number, the chances are that this isn’t going to make him better.*

In an article "Blaming the Victim" Susan Ince (1992, p.16) quotes Ken Wilber, a transpersonal psychologist, as saying

*If he accidentally inhales plutonium, there’s a 99.9 percent chance that even Bernie Siegel [American surgeon and author] is going to get lung cancer. That’s not a spiritual lesson; it’s a practical fact.*

Bernie Siegel doesn’t need me to defend him but I do have one of his books *Peace, Love & Healing*, (Siegel, 1989). While what he preaches can be interpreted as choosing life or death, he concedes, grudgingly, that:
We must all confront the reality that no one lives forever. Illness and death are not signs of failure; what is a failure is not living. Our goal is learning to live — joyously and lovingly. Disease can often teach us to do that... When I discuss survivors I am interested in how they embrace life, not how they avoid death. Those who have learned to take on the challenge of their illness and share responsibility for their treatment have chosen the path that leads to peace of mind and healing on a spiritual level... There is no denying that not every physical illness can be cured. We can, however, make use of an illness to help us redirect our lives. (pp.3-5)

Small voice: Getting back to the Simontons ... I think the main point of the discussion in Capra's book was that the Simontons were very good people. They had the quality of 'healers' and they were combining both modern medical treatment and emotional and spiritual healing. (Capra, 1988, pp.304ff.)

In other words, the placebo effect? Or a spontaneous remission? A faith healing? The 'cure' may have had nothing to do with 'the treatment' or with 'the disease' as such.

Small voice: Shlain is concerned that statistics from the group of people in the Simonston study don't take into account the personalities of doctors and patients, the strict selection criteria (which insists on a high positive attitude/belief and motivation and an eagerness — and financial wherewithal — to undergo intensive psychoanalytic therapy), and the total immersion of the patient and family in holistic treatment.

 Interruption:

["Or the fact that you die when it is the right time for you to die!"]

["It's all karma, anyway. I don't know why people get into a blue funk over all this!"]

["They get into a blue funk because they feel as if they are going mad — because nobody believes what they say. Dubbo!"]

Pause:
In short, the statistics may be misleading. Most people will not examine the details of the total, and very expensive, package. The simplistic understanding is that 'the treatment' is available to all, and that it leads in most cases to 'a cure' based essentially on the concept of 'positive thinking'.

This 'appeal to simplistic scientism' was discussed on a recent Radio National current affairs program (Australian Broadcasting Corporation, 1993). The discussion related to the outcome of the November 1993 New Zealand elections with particular reference to economic rationalists who believe that a country 'chooses' its level of unemployment by 'choosing' the level of wages. This is the simplistic argument which ignores the multitude of other factors impacting on the level of unemployment. It is an argument used, primarily, to rationalise and justify wage cutting. A prime example of blaming the victim ... "If you would accept lower and lower wages you would not be unemployed!"

Small voice: Thank you!

Pause:

Small voice: And isn't the bottom line here the issue of wishful thinking? Of trying to live with false hope? And avoidance of grief?

Yes. I believe that where there is false hope there is hidden, unspeakable despair.

Small voice: The paradox is that once you dare to experience the despair, therein lies the real hope.

It is Pandora's Box.

Pause:

This is certainly a time for a long break.

Silence.

..........  

An equally interesting book, Good and Mad Women, written by an Australian historian, Jill Matthews (1984), looks at the clinical records from a psychiatric hospital in Adelaide. Matthews (especially pp.9-29) raises interesting questions about the kinds of 'factual' data recorded and the assumptions of the examining doctors. She examines her own
research methodology, the purposes (which changed with the focus) of her research, and concludes that all women have similar experiences - differentiated by both degree of severity and their ability to respond appropriately. Luck seems to play a significant role in whether women come away with a psychiatric label or not. And this hinges, to a significant degree, on societal norms of what it is to be a 'good woman'.

Small voice: I think it would be helpful to quote some of her findings.

All right!

Matthews found that:

... there are no objectively definable criteria for the existence [of madness]; there are no objectively established social norms whose transgression leads to the label of mad being applied. ... Even in the case of the medical profession, which alone can legitimately and conclusively diagnose or define a person as mad, each doctor's judgement is subjective, inevitably biased according to her or his age, sex, class position, etc.; and in so far as the judgement is made of behaviour alone, it is inevitably a moral judgement about what ought to be. (pp.21-22)

Of her own research she says:

By the time I had decided to embark afresh on my pursuit of the history of the good woman through analysis of the gender order ...

... her initial project was a mixture of social history and women's history, and she went through many twists and turns, rationalisations and justifications before she arrived at her final thesis ...

... I had at hand 60 such captured biographies [her description of case notes]. These I proceeded to sort out and categorise in terms of the information they contained about family, sexuality and work. It was a tedious and horrific task. The psychiatric record laid out in stark detail the extremes of unhappiness and hopelessness of these women's lives, because that was where the psychiatrists sought to find the clues to their present condition. Eventually, I was able to see that the horror was partly produced by the method of recording. I learned how to recount the traumas of my own and my friends' lives in such a way as to leave out everything else, and so
create the semblance of a psychiatric record, and wondered why we weren't in hospital too... The lives of mad women are certainly not ordinary, but there is no one who can say how much out of the ordinary they are. (pp.25-26) [emphasis added.]

Pause:

Small voice: It is interesting that Shorter's subtitle is "A history of psychosomatic illness in the modern era" whereas Matthews' subtitle is "The Historical Construction of Femininity in Twentieth-Century Australia".

Now isn't this a coincidence!

Small Voice: What do you mean?

Well, at the outset I said that my thesis is a fiction, a fantasy, it is my interpretation of my experience. Here we have two books written by historians about madness, illness, women and social pressure written in different ways, from different perspectives and leaving the reader with quite different appreciations!

Small voice: How true! And I have never met a person, man or woman, who does not at times find life difficult and oppressive, who does not wonder about their sanity (jokingly, of course!).

Shorter obviously takes his cue (as do Capra, Simonot and Matthews) from the concept of 'medicalization' of social ills. The entry in Fontana alerts me to this concept which is described as:

the tendency, increasingly marked in the U.S. but also shown elsewhere, as in the Soviet Union [sic] to treat all socially undesirable or deviant behaviour as the fit object of medical science and medical treatment.

Small voice: Could you say a bit more about that?

Now?

Small voice: Sure!

Okay. Well, where do I start. It seems as if when a 'new' concept emerges there is a rush to get on board - rather like people rushing from one side of the ship to the other to get a look at the view. The difficulty arises in the moments of unbalance, the moments when everybody wants to claim the concept. They rush to one side. The entry in Fontana is succinct and will save me scrambling around.
Continuing on: Drugs are invented to treat children diagnosed as 'hyperactive'. Mental patients and prison inmates with particularly intractable problems of behaviour are diagnosed as suffering from constitutional conditions of insanity or aggression, and given the appropriate drug therapy. Political dissidents are seen as temperamentally disturbed and in need of medical 'correction'. The view is that most if not all social problems - violent crime, vandalism, alcoholism homosexuality, political or moral dissidence - are the result of clinically identifiable 'diseases', which can be cured provided the medical profession is given the care of them. Critics ... of the medicalization of social problems not unnaturally see in it an unwarranted extension of the power of the medical profession. More seriously, they see danger in the extension of the 'medical model' to problems with complex social causes, for which drugs appear a high unsuitable form of treatment.

Fontana cites Conrad and Schneider (1980) and Illich (1977) as references.

Pause:

And the more I read that entry the more complex it becomes. It is a fine example of the negative side of the practice of generalisation, the bundling of concepts which encourages the reader to accept all manner of truisms simply because they are subsumed under the one heading.

Matthews (1983, p.20) says:

The two major institutional systems dealing with deviance in twentieth-century Australia are the judiciary-police and the medical profession.

 Interruption:

["Medicos also control income. It is on their say-so that people qualify for sick leave, sickness benefits and pensions and medical retirement!"]

["I wonder whether doctors really understand how they use their power?"]

["I'm sure some do. But I suspect that doctors are no better citizens than any other member of society!"]

Mumbling and grumblings:
Small voice: So you are saying that Shorter puts ME/CFS into the basket of 'social deviance'?

It would seem that way.

Pause:

Small voice: And where would you put Matthews?

I'd say that Matthews is more openly political - less blaming than Shorter tends to be. For instance, she says that:

*Psychiatry is an institution very strongly implicated in the maintenance of the gender order in so far as it is concerned with curing deviation and restoring normality. This normality is gender-specific; normal individuals but normal women (and men) is the hoped-for goal, and normal women, by definition, pursue the ideal of becoming good women.* (p.24).

Matthews comments on the process of her research and the eventual writing of her book:

*The captured biographies play a less significant part than they did in its making. But the process of struggling to make sense of them as social documents has been crucial to my understanding of feminist history. As well, the continuing uneasy tension that they introduce, the play of social forces and the lives of individuals, is a vital corrective. It what would otherwise be a straight-forward history that makes coherent pattern of social experience, they are a constant reminder of the anomalies, the gaps, the untidiness of real social life. History is only made coherent after the event by omission of what does not quite fit.* (p.26)

Anyhow, it strikes me that significant illness and disease can be overlooked when symptoms are dismissed as 'simply deviant behaviour'. Ellen Goudsmit and Robin Gadd (1992, pp. 14-15) argue that:

*... misdiagnoses of some gravity are occurring far more often than is generally recognised (except by the victims?!) and organic illnesses are too often put down to nerves and stress, especially in women.* [original parenthesis]

* Interruption:
"And that is why the self-help groups in the United States insist on including 'immune dysfunction' in their nomenclature – Chronic Fatigue Immune Dysfunction Syndrome or CFIDS."

Pause:

Small Voice: Do I take it that you are connecting with Matthews in the value of struggling for something more than concrete 'facts' in your research?

Pause:

I believe you are right!

Small voice: I feel better now. I also have a sneaking suspicion that there is another element here – that of the litigation practices in the USA. If too many (however defined) diseases fall into the 'medical' category, then the insurance companies don't like it. Could it be that this current fashionable concept of 'choice' is fuelled by the insurance companies in order to limit liability?

The whole thing is extremely complex and complicated, but I recall hearing an argument calling for the de-medicalization of pregnancy and childbirth based on the cost of insurance! Although the argument started out with the warm fuzzies of 'women's power', midwives and cuddley mums and bubs, the underlying motivation soon became apparent! Perhaps that's a long bow?

Small voice: I'll think on it! But I can't help noticing that all this really does have to do with women. I've never heard the same argument about AIDS – and let's face it, we hear lots and lots and lots about AIDS. For AIDS Day 1989, Fran Peavey (1989) spoke on the Australian Broadcasting Corporation's "The Coming Out Show". At the time she was trying to form support groups for women in the United States who are HIV positive. Apparently the medical profession was almost exclusively concerned with men, and excluded women from research programs, on the basis that they might pollute the statistics, even though Fran says there are more than 40,000 women in the States who are HIV positive. Perhaps things have changed since 1989?

Sounds of shuffling:

"Women have been seen through history, as polluting."
"There's tons of stuff around on this at the moment. Goudsmit and Gadd (1992), Matthews (1983), Walker (1985) have all had heaps to say about the need to clarify the role of gender as a source of bias."

"Only a few months ago, the ABC's (1993) "The Coming Out Show" devoted a whole program to "Sex as a Variable"."

 Interruption subsides:

But, can we continue?

Small voice: To be sure! But first I think we'd better take a break so you can find your way back from this garden path!

Thanks.

Small voice: Just to finish up ... I believe you are saying that an 'all or nothing' approach to the cause and treatment of illness, such as is evident in theories of social and/or psychological deviance or the slavish adherence to the medical model, actually blocks appropriate treatment and relief and leaves the patient 'expendable' between the warring parties.

Funny. I have been tempted to request a psychological/psychiatric referral (it has never been suggested to me by any doctor that this would be appropriate). However, as a telephone counsellor for the ME/CFS Society I have heard too many stories of what happens to people who receive a psychiatric diagnosis to take the chance.

Pause:

Here ... look ...

Amazing!
PART IV

A RETURN TO THE THRESHOLD

There is a sharp divide between researchers interested in ME/CFS. Reports of research in psychiatric journals, lean towards a psychiatric etiology. Other journals report research in the fields of infectious diseases, rheumatology, immunology, and virology.

Whether the neuropsychiatric features are primary or secondary in ME/CFS, there is no doubt that they occur. Headaches, confusion, loss of concentration, searching for words, blurred vision and perceptual and spatial problems go hand in hand with muscle and joint pain and debilitating fatigue.

Small voice: Thank you. That covers it nicely. Now what about your thesis? And besides, I’ve had enough of this howling wind and salty seas!

Right! Back to base. But before we move on ...

Small voice: Are you aware how often you say that?

Say what?

Small voice: But before we move on ... But before we begin ... But before ... 

 Interruption:

["Mmmm. Interesting! That requires some discussion about text and context!""]

["At a later date, perhaps?"]

["For the time being, can I just mention the work of Carol Gilligan (1982), Fonow and Cook’s (1992) volume of papers by feminist scholars, Shulamit Reinharz’s (1991) ‘retrospective’ of her research and teaching. And Anne Wilson Schaef’s (1992) critique of her own practice."]

["That’s a good idea!"]

["Yes. They all point out how important context is, at least for women!"]

Silence:
... I just want to say that this discussion about the organic/psychiatric nature of the illness is important from the point of view of people living on the margins and those seeking direction. During the journey many garden paths are waiting to be explored. These garden paths sometimes lead into psychiatric territory.

Pause:

Small voice: I would venture to say that without a trip to psychiatric territory no journey is possible.

Pause:

This is not to say that the cause of the problem is psychiatric and therefore can be relegated to the too hard basket. The closer to the centre and the further from the margins, the easier it is to be more certain of causes. Conversely, the closer to the margins the less certain the cause and the less attractive it is to core disciplines!

Interruption:

["Now that was a comment not to be glossed-over. This is the difficulty that transdisciplinary research has to contend with."]

["Do you mean that it can’t find a home?"]

["True. And if it can’t find a home, it cannot claim legitimacy!"]

["Mmmm...."]

Silence:

Small voice: So, how does this fit in with thresholds and rites of passage? You have wandered far!

Mea culpa. I wander only to return! This IS my ‘walking’.

............

For a rite de passage to be undertaken and fully experienced, a departure from the rational is essential. Otherwise why is it necessary for any rites or rituals? As the anthropological literature suggests, such societal behaviour is not necessarily psychotic, deviant or deficient, it is an age-old part of every-day, and not so
every-day, life. "In this way, society recognizes and legitimates change." says my Fontana.

And it seems to me that when one is dislocated from the common view of what it is to be an acceptable member of society, either through illness, disability, unemployment, chosen or unchosen difficult situations, then our emotional and psychic lives are standing next in line and demand our attention. No longer can we busy ourselves with doingsness. We enter the world of becoming. In her book The Crone, Barbara Walker (1985, p.33) comments:

For good reason the religions of the Goddess viewed existence as becoming, not being ... That which seemed lifeless would sooner or later become part of something alive. That which lived was, by degrees, becoming dead ...

...........

Cosy drawing room. Warm fire.

Early on in the illness there is an expectation that recovery will follow, if not sooner, then later. Both 'sooner' and 'later' are defined very loosely - they range somewhere between six months and infinity (depending on your spiritual viewpoint). Recovery, too, is loosely defined. Full recovery? Perhaps. Partial recovery? More than likely. But what is 'partial'. And what is 'full'?

My general feeling around this issue relates to our inability, as individuals and as a society, to confront death and ageing. Either we are Olympian youths (usually male), or we have died an honorable death (in an heroic manner). Barbara Walker (1985, p.33) notes:

... [the Goddess] represented the kind of death that our culture wished to conceal, making it invisible as old women are made invisible: the common garden-variety kind of death; death in old age, death from wasting disease, death after slow degeneration of body and mind. Our civilization tries not to acknowledge such death. The kind we are invited to contemplate instead, as 'entertainment', is the sudden, violent, bloody kind, in keeping with patriarchal ideals of conflict and aggression. As spectacle, violent death is safe ...
Small voice (musing): Coming back to notions of 'full' and 'partial' recovery ... try telling all this to the Department of Society Security!

You are right. This is indeed a problem. And I've already mentioned this in Part III, above, and John Ballard's (1991) Annotated Commonwealth Employees' Rehabilitation and Compensation Act 1988, is helpful in providing examples. For those interested in the fine details, these could be obtained from cases in Administrative Law, in the cases which have come before the Social Security Appeals Tribunal and the Administrative Appeals Tribunal.

Pause:

Because many people require income maintenance, they apply to the Department of Social Security. Others may have claims for workers' compensation or private disability superannuation or pensions. Social Security has a set of criteria which they apply to determine eligibility for payments. Apart from an income/assets test, Social Security requires medical reports. The small print in private insurance policies is also aligned with Social Security determinations on medical matters.

Small voice: That's what you were talking about earlier in relation to Matthews' work? (pp.71 ff. above).

Exactly! Given the confusion within the medical profession about illness and deviance, temporary and permanent incapacity - and, of course, the view that deviant behaviour is not be to socially sanctioned - it is not surprising that many, many people with ME/CFS ...

 Interruption: ["And other chronic illnesses!"]

 Interruption subsides: ...

... and other chronic illnesses, feel persecuted by the system which promotes itself as offering support. The insurance industry and governments, quite naturally, wish to minimise payouts.

Pause:

And what happens when one is caught in a time warp. What if 10 years has elapsed? Memories of wellness relate to a time 10 years distant. How does one cope with the jump in age from 40 to 50 years? From plans for parenthood to menopause? And what of adolescents who completely 'miss'
their teenage years? Of young parents who are dependant for care upon their young children?

Small voice: It's simple. If things could return to 'normal', then 'normal people' in 'normal times' are no longer there. They are 10 years further along the track. "There" no longer exists!

Pause:

Yes. In conversations with several of my friends with ME/CFS, they say things like:

_We've come too far down the track even to return._

and

_You can't go back, because it (back) no longer exists._

and

_I don't recognise where I am._

Attempts to come to terms with a chronic illness with no certain outcome are often thwarted by attitudes and philosophies of well-meaning friends and relatives, and professional health workers. And as one is a member of the society, these expectations and attitudes are deeply ingrained in the individual. To accept things as they are is seen as 'giving up' and 'giving in', especially with regards hope.

Small voice: How often have I heard the phrase *This thing isn't going to beat me*. We have all been conditioned to 'soldier on', as the ad exhorts us!

That particular advertisement for a cold and flu tablet has always struck me as totally alien to my concept of 'commonsense'.

One is caught in a Catch-22 situation. To continue to 'soldier on' attracts comments such as "You'll never improve until you learn to accept things". To learn to accept things as they are attracts comments such as "You're obviously getting 'secondary gain' by continuing this abnormal illness behaviour."

_Hot, blustery conditions:

Small voice: The solution seems clear to me. Forget about what other people say, think, believe, do, etc.
Cooler breeze:

Not so easy. Carol Gilligan states the obvious – that women make moral judgments with an ‘ethic of care’ which is not included in the dominant theories of an ‘ethic of rights’.

Small voice: Would you say some more about these ‘ethics’?

Pause:

In her book, In a Different Voice, Carol Gilligan (1982) reviews psychological theory and women’s development. She says:

I began to notice the recurrent problems in interpreting women’s development and to connect these problems to the repeated exclusion of women from the critical theory-building studies of psychological research. (p.1)

She believes that:

the failure to see the different reality of women’s lives and to hear the differences in their voices stems in part from the assumption that there is a single mode of social experience and interpretation. (p.173)

She continues:

My research [of how people make moral judgments] suggests that men and women may speak different languages that they assume are the same, using similar words to encode disparate experience of self and social relationships ... Just as the language of responsibilities provides a weblike imagery of relationships to replace a hierarchical ordering that dissolves with the coming of equality, so the language of rights underlines the importance of including in the network of care not only the other but also the self. (p.173)

In essence, Gilligan is stating the obvious: that women basically operate out of an ethic of care and concern for ‘the other’; whereas men tend to operate out of an ethic of rights and concern for ‘self’. Therefore, the accusing tone which accompanies exhortations to women to an exercise of individual rights is extremely irritating, if not hurtful, when the hidden agenda and expectation is that they will ignore the ‘rights’ and continue on with their ‘cares’!

Small voice: I’m not sure what you mean by that. It seems that we are a contrary society – exhorting those
who operate out of an ethics of care to exercise more care. And those who operate out of an ethic of rights to insist on more rights.

Pause:

Right! It is contrary for women to suddenly shift from an ethic of care (for others) to an ethic of rights (for oneself). If a woman does shift she is, by definition NOT a good woman! She is selfish and morally and socially deviant.

From the perspective of ME/CFS, it seems that the convergence of these two ethics, of care and of rights, gives rise to the Catch-22 situation I have just described. To be unaffected by what others say, to focus attention on 'self' - and to hell with the rest - runs counter to an ethic of care. An ethic of justice or rights rests on the premise of equality; an ethic of care rests on the premise of nonviolence. "The convergence of the two marks times of crisis and change." (Gilligan, 1982, p.2)

Small voice: I think this is really important ... but it's getting messier and messier. Could we just get back to the mundane for a moment, and summarise some images of ME/CFS.

Pause:

Change of focus.

That would probably be helpful. And in the context of Carol Gilligan's work, this summary is presented in logical and focussed point-form.

ME/CFS is diagnosed by exclusion of other diseases

- sufferers experience exclusion

ME/CFS is controversial. Many doctors believe that it doesn't exist

- sufferers are controversial or don't exist

ME/CFS is a mystery and the cause is unknown

- sufferers feel they are invisible
ME/CFS is simply a collection of symptoms
- sufferers feel they are treated as a collection of symptoms

ME/CFS has no status as an independent diagnostic category
- sufferers have no status

ME/CFS is A disease of a thousand names (Bell, 1991)
- sufferers are called "names".

Silence:

That feels like a plate of cold porridge!
Small voice: It doesn’t look much better.

Pause.

Small voice: Knock. Knock. What’s red and hot and sure to pressure a peer?

I don’t know! What’s red and hot and sure to pressure a peer?

Small Voice: The Department of Social Security’s (1993) "Dob in a Dole Cheat" hot line.

Pause:

You are rambling. For what purpose?

Small voice: I’m trying to grab hold of something that is just floating out of reach. Indulge me for a moment or two, please.

Okay. Back to the knock-knock joke.

Small voice: I want you to remember something!

What?

Small voice: I don’t know ... just remember ... please?
Okay. I remember ... I remember ... For the Newcastle/Hunter Region (in NSW) it is 008-62 11 44.

Small voice: Good! Keep going!

On Sydney Radio 2GB, 2 August 1993, the announcer was selling the product with such enthusiasm you would think that it was the greatest thing since sliced bread. He was exhorting his listeners to use the hotline, or even to phone him at the Station and he would happily pass on information.

Small voice: This feeds nicely into the notion of marginalisation and thresholds ...

Yes, but it also has me asking: for what purpose would groups of people, and individuals in far-flung places, unknown to each other, find themselves, or seek to place themselves, in a category with such negative connotations?

Small voice: Beats me! Just keep making connections.

The recently released Burdekin Report on Human Rights and the Mentally Ill (Human Rights and Equal Opportunity Commission, 1993), draws attention to the sorry treatment meted out to people suffering from mental illness. It highlights the social stigma and the lack of funding, services and co-ordination.

Small voice: This is touching on something un ... un ... uncomfortable ...

I would not voluntarily choose such experience! And I've never met anyone who does! No wonder people are terrified by suggested referrals to psychiatrists.

I know of people with ME/CFS who are trying to have their medical records amended or annotated because of referrals to psychiatrists. The patients have, in their ignorance, disclosed such referrals to other medical specialists - only to be patronized, at best, or to have their physical symptoms dismissed as the delusions of a mentally ill person!

Small voice: So what? Can you try to be more precise! This is important!
It doesn't do much for feelings of security and self-esteem. In short, it undermines the strong secure foundations necessary to encourage sufferers to find new ways of living, especially when that challenge must be faced with pain, fatigue and confusion.

Small voice: And what constitutes encouragement? Is it a word, stuck in the middle of a sentence, spoken once? Or does it require something more than the pronunciation: "I encourage you!" ... That's no encouragement, it's an imperative! Do it, or else! Surely encouragement has to do with courage, and heart, and support? But encouragement to do what? Be what? Become what/who?

It is a daunting enough task for the well and healthy who, being self-supporting and in control, can consciously choose to strike off into the unknown with buoyant feelings of excitement and confidence in their ability to face the tasks ... not to mention social approval.

Small voice: True. It is an entirely different matter when buoyant feelings of confidence are replaced by fear and dread. When the physical energy is depleted and the usual resilient body is racked with pain. Then the REAL letting go begins...

*Interruption:*

["She's getting close to a really sensitive area here. No wonder she's prattling on."]

["Verbal diarrhoea!"]

Silence:

Exactly. A timely reminder.

Small voice: How?

This delay, a delay which assumes that things will be back to normal before too much longer, lengthens into denial of the reality, and this lengthens into an inability to recognise that one has crossed the line.

Small voice: Of course, we all live in the hope that medical research will find a cause/cure. But where is that fine line between staying with that hope (long term) and giving up that hope (short term) and getting on with the reality of everyday life?
**Interuption:**

"How long is a piece of string?"

"If she doesn't finish up shortly, I'm going to fall off my perch!"

"Yawn ... yawn ... ZZZ ... zzz ... "

**Pause:**

It is not surprising, therefore, that perceptual problems, a symptom of the illness itself, are compounded by a blurring of the line between reality, as we wish it to be and as it, inexorably drags us into another world.

We are encouraged to accept the socially sanctioned reality, "Don't give up hope. We can beat this." ... and to deny our own reality, which is otherwise.

And we are wise not to speak of this other reality if we wish to maintain social relationships.

However, the reality is that often we cannot maintain social and work relationships.

But by not speaking of it, by not acknowledging it, we live a lie.

We confuse ourselves and delay the joy of return.
Disembodied Voices

Blackness:

"I don’t know. She looks like a rag doll!"

"How long do we have, do you think?"

"Who asked that question?"

"I did."

"Who are you?"

"Who me?"

"Come on youse guys. How many of us are there?"

"For chrisakes. We only have a few hours before light. Let’s not waste it. Now what is it we have to do?"

"As far as I can, so far, at this point in time..."

"Get on with it..."

"... it seems that she needs some help with footnoting. I think we act as a review committee. We can check what she’s done, fill in the gaps and plant some seeds for her next effort. Does that sound okay to you?"

Sounds of shuffling:

"Okay?"

"Rhubarb. Rhubarb. Okay!!!!"

"Right: From what I see she needs a source for "Abandon Hope..."

"Wasn’t that written over somebody’s doorway?"

"Yes. But which doorway?"

"Hell, surely! Dante?"

"At this speed we’ll travel far!"

"Please. Can somebody make a list of things to be done at the library?"

"You’re on!"
"Good."

"Next?"

"Pandora’s Box"

"That’s the Amor/Eros and Psyche myth."

"No! That’s the jar of ointment for Aphrodite!"

"Didn’t it turn up with Prometheus?"

"No! She married his brother, Epimetheus."

"Put it on the list."

"Next!"

"Can I interrupt? I don’t think this is working. We’ve made some big assumptions that we know more than she does. We might know what she’s talking about, but in all this blackness we’re in no better position that she is."

"Okay. What do you suggest?"

"Why don’t we keep our noses out of it and let her get on with the story. When it is over, then we can offer our help. But basically, from where I sit, at this point...er. Anyway, let’s check with her whether she wants our help?"

"Now why didn’t I think of that."

"Can you ask her next time you’re talking to her?"

"Sure!"

"Let’s have an early night."

Sounds of shuffling.
PART V

GETTING STARTED - UNTANGLING THE SKEIN

Looking for the end marked 'methodology':

Cold light of dawn:

.........T

he se

c o n d point refers
to my use of materials.

Small voice: Hang on a minute. You're not awake yet.
What?

Small voice: Coffee?

Thanks!

Now what was that 'second point' about? Oh yes. I'd briefly talked about thresholds, my encounter with ME/CFS. Then you suggested I talk about my thesis. And I was anxious to talk about my research methodology.

Small voice: I don't think you are aware of how important it is to be very clear about where you are coming from and exactly why and how you are researching. What is research anyway? Tell me, why are you doing a Masters?

Oh God! Can't I get on with it?

Small voice: In a word...NO! How is anyone going to understand what you are about if you aren't explicit about how you got to this point and why you are doing things this way?

You mean I have to define the problem?

Small voice (irritated): No, I don't. I mean I want to know why it is important for you to do this...the passion, for chrisakes!

Hang on! You're getting a little hot under the collar.
Small voice: Well, I wouldn’t have to it you would loosen up, slow up and stop trying to race ahead. Time is of no importance. Remember the luxury of having time to think and ponder?

Point taken. Okay, let’s recap and then find the next piece of string.

Long pause:

But, please, please, PLEASE let me say this!!!

Puzzled silence:

The reason for ‘point two’ is that I wanted to be explicit about using secondary and tertiary sources, quoting from The Fontana Dictionary of Modern Thought and not following up with specific references to the various schools of anthropological, or any other ‘school’ of theory.

Small voice: That’s clearer. So if anyone wants to delve into those areas, then they are alerted to their existence!

Lights up:

Okay. I want to be explicit that as part of my contract with myself I consciously decided to observe and acknowledge the limitations under which I am working.

As a person with ME/CFS with limited energy, I make no apology for not hunting out primary sources if secondary or even tertiary materials are useful in explicating issues and ideas. Indeed, in our world which is swamped by information, citing sources for the sake of having an impressive bibliography may not be at all helpful.

And besides, this dissertation is not a hermeneutic treatment of some specific body of theory.

Small voice. You’ve lost me!

What do you mean?

Small voice: What’s this hermeneutic stuff?

Pause:

Oh, right! I did touch on that earlier, but I suppose you’re right in wanting a bit more clarify.
Rowan and Reason (1981), in their article "On making sense", suggest that the 'making sense' is an integral part of the research itself.

... traditional scientific thinking says nothing about this issue of meaning — it is quite simply not accounted for, and indeed, science gained its power as an inquiry process when it ceased to try to discover the meaning of phenomena in the physical world, and started to explore phenomena empirically. But we cannot ignore the issue of meaning in a human science ... Hermeneutics is an ancient discipline which was originally concerned with the interpretation of ancient religious texts; it was primarily a method for discovering the correct interpretation from several different versions of the same text. Modern hermeneutics has been developed by Heidegger and Gadamer as a general philosophy of human understanding and interpretation. (p.132)

They then go on to explore the major implications of such a philosophy by drawing on Kockelmanns' (1975) article "Towards an interpretive or hermeneutic social science".

In essence, Kockelmanns proposes 'canons' of an interpretive social science which "have no other function than to help us make explicit systematically what implicitly was already there before us." (cited in Rowan and Reason, 1981, p.133).

The first cannon is that of the autonomy of the object. This means that we do not try to fit data into theories and ideas derived from other sources. The second cannon is that the interpretation should make the phenomenon maximally reasonable in human terms, and requires a high level of consciousness-raising on the part of the researcher to uncover, explore and articulate the complexity and historical roots. The third cannon is that the interpreter must achieve the greatest possible familiarity with the phenomenon ... it involves knowing with as well as knowing about. The interpreter must also show the meaning of the phenomenon for his (or her) own situation, (pp.133-34)

The most important cannon is the hermeneutic circle.

Understanding thus consists of circular and spiral relationships between whole and parts, between what is known and what is unknown, between the phenomenon itself and its wider context, between the knower and that which is known. This is a dialectical process which is in theory infinite, although we may rest, for a time, at some acceptable point of intersubjective validity ... there is a perpetual oscillation of
interpretations; we have, as it were, to leap into the circle of understanding before we can start. (p.135)

Small voice: Thank you very much. That helps me a lot.

You’re welcome! I could go, but this isn’t the place to take on the philosophical debate within hermeneutics, especially from a feminist perspective (Fiorenza, 1992).

Small voice: Prego!

Da nada!

Small voice: You COULD talk about the other side of the coin.

What?

Small voice: Postmodernism, Derrida and all that jazz – where Nothing Mat(t)ers (Brodribb, 1992).

Right. Derrida and Foucault pop up in the most unlikely places, don’t they – like late night radio talk programs. Their names drop off the lips of the initiated. Only recently did I come across a book which contained copious references to these magical names: Somer Brodribb’s (1992) Nothing Mat(t)ers: A Feminist Critique of Postmodernism. It promises to advance my education in feminist, sociological, psychological and literary theory ... and take me back to Paris in the 60s! If you remember the 60s, then you weren’t there, as the saying goes!

Small voice: I’m glad you remembered to mention this.

Pause:

I also wanted to confirm that university libraries and specialised, elite and scholarly texts were not the only source of wisdom (wisdom, here, being different to information). Other people, similarly limited, may take heart that local libraries and bookshops, radio and television programs, even unsolicited junk mail are sources of great inspiration and stimulus.

Small voice: Even if one might query the usefulness of the information!

Well, one can use one’s intellect and experience to critique even the junk mail! And even if it is of no use, intellectually, it can make a great addition to the compost!

Pause:
Small voice: I think what you’re trying to say is that one can develop one’s ability to ‘notice’?

Long pause:

Thank you Small Voice. Actually that is exactly what I am trying to say - the importance of ‘noticing’ I would call this ‘a capacity for enjoyment’. Thomas Hardy’s poem (1975, p.89) "Finale - Afterwards" says it well:

If, when hearing that I have been stilled at last, they stand at the door,
Watching the full-starred heavens that winter sees,
Will this thought rise on those who will meet my face no more,
"He was one who had an eye for such mysteries?"
..."He was a man who used to notice such things."
..."To him this must have been a familiar sight".

Pause:

This is not to say that pure science and other hi-tech-driven research can be done from the comfort of the lounge room. However, thinking, musing, considering, and reflecting upon lived experience does not need a high degree of technology.

I will admit, nevertheless, to the pleasure of having a (non-compatible) five-year-old word-processor! And a telephone at the end of which are several very good and fascinating friends. I cannot afford to upgrade my system or to graduate to telephone answering machines, faxes, desktop publishing, laser printers - or e-mail and bulletin boards. And I don’t think I want to. I have difficulty in absorbing information as it is. To be deluged with more and more information, delivered more and more quickly, could only increase my anxiety levels. And, besides, surely I have a store of information and experience of everyday life that can be dusted off, reflected upon and evaluated.

Small voice: What have other people had to say about this? This ‘research’? I sense a fair degree of antagonism here. I also sense that that you haven’t quite got a handle on what it is you are trying to do.

Irritation:
Well, as you may or may not know, the usual and typical method of academic research looks clean and neat and straightforward ...

Small voice: I'm sure you don't mean the actual experience of doing academic research? Perhaps you mean the text book version of methodology?

... and the writing style emphasises the objective nature of the inquiry.

Small voice: What do you mean?

Irritated whispers:

"She hasn't recognised, yet, that her problem is with 'scientism' not 'science'!"

"For heaven's sake. Let her get on with the discovery - that's what it's all about!"

Irritation subsides:

Well, for instance (let me get my tongue firmly in my cheek), a text book approach goes something like this:

The problem or task is defined succinctly, and narrowly, usually after an exhaustive search of published literature. This search often suggests a particular area of inquiry. Old conclusions might need to be revisited in the light of more recent experience. The search may also suggest a particular method of inquiry depending upon the discipline in which the enquiry is to be conducted. There are many methods ... for example, 'scientific', 'sociological' 'historical' or 'anthropological'.

The methods acceptable to particular disciplines gain this acceptability because of ... tradition.

Small voice: We are creatures of habit, aren't we!
And do I hear the rumblings of measurability again?

Once the data is

Irritated voice:

"Never forget that data are plural!"

collected - specified data in the specified manner - that data is (it doesn't have an -s on the end, so it's singular as far as I'm concerned! In English it's grammatically singular, even if it is Latinly collective!) analysed, again using a specified methodology, and conclusions are reached. The result is a 'scholarly' paper or thesis arguing the
validity of the findings, the merits of the methodology ... with a sound and swift decapitation of your opponents.

And, the assumption is that the analysis of the data reveals a (truth) which is independent of the data. That is, the (truth) can be tested by accumulating a fresh set of data or observations. Maturana (1985, p.43) said, in an interview published in The Family Therapy Networker:

... if you put objectivity in parentheses, other views become legitimate verses in a multi-verse. It is not that one is mistaken and the other is not, one has the truth and the other does not. Different ideologies become different ways of being, different ways of looking and listening, in which each person is responsible for the way of being which he becomes.

Proponents of ‘grounded theory’ advocated by Glaser and Strauss (1967) say that the theory is grounded in the data - that is, the data generates the theory. Grounded theory does not take account of the constructivists’ view that the assumptions we make about the questions we wish to ask influences (or creates) the data we decide to collect in the first place. So far from the theory coming out of the data, the data comes out of our assumptions! In short, we make up the whole thing; we create (or look for) the data to fit our assumptions! This is implicit in the questions we ask and the structure of the questionnaire and the sampling technique. It takes a great deal of (personal, emotional) work to hunt out the unconscious assumptions and hidden agendas.

The claim for the superiority of grounded theory in qualitative sociological theory is the emphasis on ‘rigor’ in the examination of the data which is collected in a three-tiered approach: questionnaires, personal interviews and focus group discussions. Reason and Rowan (1981, p.xxx) and Reason and Hawkins (1988, p.79) offer some critique of these claims. Reason (1988, pp.34-35) cites how the research of Lyn Goswell successfully used the grounded theory approach in exploring the experiences of Western Buddhist monks and nuns. She was able to present to them a descriptive model with which they agreed.

Hugh Mackay, (1993) Reinventing Australia: The mind and mood of Australia in the 90s notes that:

In social research, it is critically important to find a method which is compatible with the kind of thing we are trying to investigate. (p.300).

He goes on to explain his approach to the ‘non-directive group discussion’, which, he admits, has its limitations.
In order to be successful as a method for social research, the group discussion technique must have three features: the group must be a real group (that is, people who are well-known to each other and who are used to interacting with each other); the discussion must be conducted on the home ground of the group - a place where it is natural for them to be, and where they feel most comfortable; the discussion must proceed freely and spontaneously, without any interference or any structure being imposed upon it by the researcher. ... The unstructured (or 'non-directive') personal interview also takes place on the 'home ground' of the respondent. (pp.304-06)

Small voice: So what is your problem with this? Sounds fine to me - except for your tone of voice!

The 'problem' is not so much a 'problem' as it is a conundrum...

Small voice: You mean it is a riddle?

Pause:

Well yes, it is that. It concerns the notion that most things are comparable to a greater degree than perhaps they really are. There is a passion for generalisation at the expense of uniqueness. And it raises the issues of appropriateness and fairness and accessibility.

Small voice: Really? Do I need to get ready for a long diatribe on fairness, equity and other such matters? And just what has this got to do with your research? I sense that rigor mortis is about to set in!

I'm sorry to hear that tone of voice. But if you stay tuned you might just learn something.

Small voice: Whoops! Actually we were talking last night, a group of us. We thought you could use some help and we started off by trying to fill in the blanks you left ... you know, for the footnotes. Anyway we soon got lost and they asked me to ask you whether you wanted us to help. Do you?

Pause:

Actually, you are very helpful, extremely helpful, with your naive comments and I would be grateful if you would continue to interrupt me. During the night you could talk with your
friends. Who knows, this could turn out to be a great way to work.

Small voice (excitedly) Do you really think so?

Sure do!

Small voice: All right. What were you going to say about fairness and equity? But don’t forget to come back to ‘data’ and ‘truths’. I am rather fascinated by the implications.

............

Back to the story:

One of the things about having ME/CFS is that because of physical and mental symptoms ...

Small voice: ... of fatigue and confusion and short concentration spans?

... yes ... it is difficult to take on a full research or study load. It is often difficult to travel far. It is difficult to keep up with healthy students. Many adults have to leave work altogether because they cannot satisfy the legitimate demands of employers and clients. Often teenagers at school have to transfer to distance education or correspondence for a time just to keep in touch with studies.

Small voice: So this means they sometimes can’t get to libraries to do ‘proper’ research? Or out into the field?

Yes, that’s right. And even if they can physically get to the library, their concentration span is such that they tire quickly. But it is more than just libraries. It impacts on all areas of social interaction - even the notion of ‘doing research’ with other people with ME/CFS is impossible.

Small voice: Like, where are my subjects? Where is my research group? Can I be a research group on my own? N=1? Where is the precedent for doing this kind of autobiographical research? Is it really academic? Is it rigorous? Is it merely subjective?

Exactly!

Lights down:
Small voice: That must make them uncertain and fearful!

True. How true! This business about being able to do whatever you like, or creating your own reality, starts to make inroads. Questions loom in the darkness.

A voice intones:

It sets up all kinds of dilemmas about personal worth and ability. It taxes their egos and self-esteem. They see themselves falling further and further behind. Running like mad trying to catch up with the last relapse. And all the time they are encouraged to

Chorus:

"Keep at it! Don't give up!"

Lone voice continues:

Of course, at this early stage, it has not yet occurred to them that they don't have to keep up. It hasn't occurred to them that there are alternatives, different paths, new directions. It is a time of fear and guilt and anger. It is not yet time to discover that all these feelings are symptoms of deep grief. Of loss. Loss of friends, esteem, direction, expectations, future. Loss of self. Loss of hope.

Pause:

This is the time just before the beginning. The time before they are able to whisper, ever so quietly, the word

Chorus (whisper):

"Can't" "Can't" "Can't" "Can't"

.......... 

Lights up:

Small voice: I'm feeling very uncomfortable.
Yes, it is uncomfortable. So let's leave this for a while while I think a bit about re:

sea

rch .

-----

Disembodied Voices

Blackness:

"She's dropped off again."

"What do you think all this 'uncomfortableness' is about?"

"It must have something to do with not being able to keep up with everybody else."

"Good heavens! Why would that be a problem?"

"It's easy to see why you wouldn't see it! You've never felt the need to keep up with anybody!"

"Why would I?"

"Come on. Let's get on with it."

"No, wait a minute. I think this needs following up. Perhaps she needs somebody who's always done exactly as they've wanted to help her sort out why she has a problem."

"How can a real drop-out have anything to contribute?"

"Look we're all talking at once. Small Voice seems to be getting on with her quite well. Do you think you could take this concern back to her. Maybe our noticing will help her?"

"Fine."

..........

101
Finding the Yellow Brick Road

Drawing room. The embers of the overnight fire begin to flame under some fresh logs:

A second part of this concerns an examination of what it is to do ‘research’.

And what is it one wants to research.

Pause:

Small voice: Are you saying there is a method in your madness?

How clever of you!

I’ve just been thinking that I want to talk at some length about methodology. Particularly feminist methodology (Reinharz, 1991; Matthews, 1984; Fonow and Cook, 1991) and Peter Reason’s (1981, 1988) work on Human Inquiry and ‘new paradigm’ research. And I wanted to refer to research by/with non-academic experts (Yoland Wadsworth, 1993) and others, too. I will need to locate this ‘social ecology’ theory by reference to sociological, anthropological, psychological and scientific theory and methodology.

Small voice: I thought you weren’t going to do that? I’m not sure what you have in mind.

 Interruption:

["She’s not aware that that is exactly what she’s been doing."]

["Let her stay with this confusion. It is productive."]

["Okay. If you think so. For myself, I can’t see the point!"]

["You never do. Dork!"]

["Please? A little quiet?"]

 Interruption subsides:
Now, I am not sure exactly how this will fit in, or whether a separate ‘book’ on the theoretical aspects would work better. My feeling is that the better I can weave the theory into the experience, the closer will be the example, anecdote, practicality or praxis, and hence the more persuasive the argument ...

Small voice: Do you think of it as an argument?

Well, no! It is NOT an argument, it is an explication! — and hence the better chance of getting my meaning clear.

Small voice: A Freudian slip. Sounds like you’re spoiling for a fight!

Actually, as I think on it, it would definitely be better to combine ‘the story’ with ‘the theory’ because in that way I can catch myself before I wander too far up the wrong garden path. On the other hand, there are no ‘wrong’ paths!

Small voice: Do you want to leave this for the moment?

Yes, I think so.

Small voice: You know last night we were chatting about the sense of discomfort you were feeling just before you dropped off. We weren’t clear what this discomfort stems from. Do you think you could explore that?

Do you think it’s important?

Small voice: Well, it FEELS important!

Perhaps!

Pause:

One of the consequences of ME/CFS is isolation and solitude. The opportunity for time to reflect and think in an unfocused and wide ranging way, is a precious gift. The loss of companionship through excessive fatigue, pain and mental confusion forces one to confront oneself. This loss enables one to follow long and laborious arguments, to ponder the ‘what ifs’ to amazing conclusions.

I suppose it is a compensation, if I’m looking for the ‘benefits’ I get from exhibiting such abnormal illness behaviour!

Small voice: Beats me why you just don’t accept that YOU ARE ILL! Your behaviour is absolutely normal!

You don’t understand!
Small voice: Well, why not try to tell me?

Pause:

When patients don’t get well, as expected, they are accused of falling into ‘abnormal illness behaviour’. There are two elements here – a rationalisation for the failure of treatment (perhaps you weren’t really ill in the first place); and a justification for withdrawing support (abnormal illness behaviour is not supportable). ‘Normal illness behaviour’ is when a patient, legitimately diagnosed, becomes dependent upon doctors and carers, takes to her bed, sleeps, takes medication, undergoes surgery or whatever, and allows the day-to-day cares to slip away (hopefully into the hands of some carer) while she concentrates on directing her energy into healing her body.

Pause:

Not all ill people have carers into whose hands such day-to-day worries are consigned.

Pause:

Most women don’t. But that’s the assumption. Much of the feminist literature struggles with these assumptions, as do Bates and Linder-Pelz, in Health Care Issues, (1990, pp.71-72).

Small voice: What’s this about acute and chronic?

What do you mean? I didn’t mention anything about acute and chronic?

Small voice: Well, no. No you didn’t. But you were thinking about it. Isn’t that part of the concern of Bates and Linder-Pelz?

Yes. Of course. I’m sorry, I’m making leaps here without filling in the gaps.

Pause:

Put simply, the medical model envisages a linear, unidirectional system. Sick person enters through door, sick person is treated, sick person gets better/dies, sick/dead person leaves. A chronic model would require a rotating or revolving door where treatment and services are available on an ‘as required’ basis.

Small voice: I see.
Can we take this up at a later stage?

Small voice: Fine.

For the moment I want to make the point that after long, or sometimes, short, forays into this twilight world of chronic ill health, it is necessary to connect again with functioning human beings in the ordinary, everyday, rational world; to bring back the insights and fascinations; to share the experiences.

Pause:

To reassure myself that I'm not mad! Or maybe I am - and that's alright, too.

Pause:

And to take up all of those offers "Get back to me when you're feeling better!".

It is at these times that the 'abnormal illness behaviour' accusations begin to fly. Just when you thought it was safe to come out of the water ...

Small voice: Hold on. You are running on at the mouth! Can we step back and unpack that?

Watch it! You're beginning to use all that nasty psychological jargon.

But yes.

Here I could refer to psychological theories within the medical model - deviance and deficit models of behaviour - and try to find the threshold that flags the line between pathology and growth. I could refer here to, for example, Feldenkrais (1977) and Maturana and Varela's (1992) work on 'movement', cognitive behaviour therapy which, according to Dorothy Rowe (1987), declines to explore deeper levels of consciousness, and the simplistic 'cure yourself' industry which I've already alluded to.

Small voice: You're evading the issue. What is this discomfort? (And do leave the cognitive behaviour stuff to the behaviourists!)

Long silence:
Grief!

Pause:

Small voice: Thank you.

.......... 

I'm not at all sure how to bring this in, except that it is central to the journey. The letting go of past expectations, hopes and dreams is a painful part of the process. Yet, it is the first step, without which there can be no second or third steps.

Pause:

Small voice: So why not try to begin here with grief? Actually, it occurs to me that the difficulties you're having with 'standard' ideas of research are tied in with the whole notion of letting go of 'standardised' anything and the fearful, dreadful nothingness which may exist if one dares to let go?

Exactly! And what might help bridge the gap?

Small voice: Why ... storytelling, fairy stories, metaphor and art!

Well done, Small Voice!

Sounds of singing laughter:

"Follow the yellow brick,
follow the yellow brick,
follow the yellow brick road!!!!".

"Weee’rree ... orff to see the Wizard, ...the wonderful Wizard of Oz...."

Much singing and dancing ... and stupidity.

106
PART VI

THE BIG BLACK HOLE

Disembodied Voices

Darkness:

"She really is going around in circles. Can we help her out?"

"Hum! There seems to be some confusion about research methodology and substantive matters."

"Good. I agree. She needs to be alerted to this fact. I think it would be easier for her to get the methodological question out of the way because the substantive work of 'grief' is central to moving into 'rehabilitation'..."

"...because the grief is too dense. If things are taken off, layer by layer, this will let the light in."

"True. Can we recall exactly what she's been saying?"

"Well, I think she's been revising the earlier parts, so I don't think we need worry about the footnoting/editing - she'll obviously pick that up."

"And I think she handled the details of ME/CFS well enough. Now the research..."

"...Perhaps she might go back and fit in the feminist methodology earlier..."

"...No, I don’t believe so. It’s important to let the reader see that this process of writing, sorting out, fitting in, isn’t all that straightforward."

"Isn’t that part of her thesis - the explication?"

"Perhaps if she goes back again she’ll notice?"

"Yes. She’s getting caught up in emotions. Different things seem to push her buttons. The would be valuable points to explore."

"Grief seems to be very important. I sense that she is often on the verge of anger. Can we try to spark that anger?"
"Just how do you plan to do that?"

"Temper, temper!"

"Good! Excellent!"

"Who said that!"

"Let's work on the anger. If she gets wound up enough she'll generate enough energy to tackle it."

.......... 

Feeling my way

Mid-morning:

I was beginning to wonder just how I was going to get myself out of that play.

Small voice: Actually, you aren't 'out' of the play. We had a meeting last night.

What do you mean?

Small voice: We could sense that things are in a bit of a muddle and felt that if you could unload a bit of the 'research methodology' it might be easier to get to the central issue.

Well, did you just?

Small voice: Yes. We thought that you might find the energy through anger ...

I don't know what you mean?

Pause:

Small voice: I don't exactly know how you might do that, but perhaps if you could find something to REALLY get your teeth into it could catapult you right into the middle of GRIEF.

Why do you think anger might be the best vehicle?
Small voice: That's what everybody says, don't they... that anger is energy. Destructive and constructive.

I suppose they do. I'm not sure I agree.

Small voice: Could you try to tell me?

Pause:

I'll try.

Pause:

It seems to me that anger uses energy - energy which is floating around, without a focus or anchor. For instance, it all ties in with the idea of CAN'T.

Imagine the situation, if you will, where the body can't respond, and it is used to responding; where the brain or intellect can't respond, and it is used to responding. Confusion reigns. You search for 'meaning' or direction. You look for mirrors which can present a 'reality' you can recognise.

Society has many mirrors, most of which are of the material, economic, physical variety.

Small voice: How do you mean?

Parents want healthy, happy children. When they go to school it is nice if they have lots of friends, are seen as friendly and helpful, graceful, athletic, good at sports, and in the top ten percent of the academic grades. This is one of the mirrors.

You look into the mirror and hope to find yourself there. If you do, then all is well.

As years go by, different mirrors are held up. But they really aren't different, they just have different frames. Still there is the emphasis on the young, the beautiful, the successful... and the successful mirror has a very narrow frame.

Pause:

Also, as years go by, you develop the knack of applying filters to the mirror, filtering out this and that, things you have found which don't apply to you and which can be erased, adding in things which sit comfortably with you. This process leaves you with a mirror which reflects a congruent image which you recognise.
But what if, at some point, the filters and frames dissolve? Before your very eyes? Maybe it occurs to you to get busy and construct new ones. This process requires a safe place in which to complete the work.

But no!

THIS IS NOT ALLOWED.

Instead people who notice that you are slipping behind, looking for a safe place to re-group, keep shining their mirrors in your face, urging you onward.

Dogs and cats don’t have this problem. When they are ill, they find some dark quiet place and lie down. They don’t eat, they just lie down until they are well. Of course, they don’t have to pay bills, cook meals, satisfy employers and deal with difficult or demanding relationships! Perhaps dogs and cats just don’t have unrealistic expectations ... they are happy to be who and what they are!

Bright reflected light is painful – and useless. The voices get louder and more insistent. And you keep falling further behind.

And you are kept from this ‘necessary work’, this necessary withdrawal in order to construct new mirrors and frames which, according to Dorothy Rowe, (1987, pp.282ff.) is a definition of ‘depression’. Seen in this light, any treatment to alleviate depression may simply prevent ‘recovery’. There are few things so painful as having to watch a relative or friend struggle with their grief. Helplessness is a state from which we flee.

Pause:

Now this is my scenario for anger to emerge. It is two-pronged, and it is barbed.

On the one hand, well meaning people don’t want to hear that the help they are insisting you receive is not welcome or even appropriate. There are two responses: One, "I don’t want it!" Two, "You ought to be grateful!"

On the other hand, a well developed ego WANTS help. It wants to get back there, in with the rest of society. There are two responses: One, "You/I ought to be able to recognise and accept this help." Two, "Why can’t I/You?"

It is two-pronged – towards others and self. And the definition between self and others begins to blur.
It is barbed. There are baited hooks from helpers: "It's your own fault if you don't get well because you won't accept my help!" (this is usually just personal opinion) and (implied) "If you won't do as I say I will withdraw my support." If you do bow to the pressure, and don't get well, then, of course "It's your own fault. You didn't try hard enough ... your belief wasn't strong enough..."

Small voice: Sounds something like primitive 'magical thinking'? Was there something wrong with your 'ritual'? 

So one struggles to free oneself from conditioning that says society's norms and values are to be desired. One struggles to have the courage and strength to go it alone. "I have to make some life and death decisions here and I can't do it unless you leave me alone." On the other hand "I need you to support me even if I seem to making decisions which do not meet with your approval." The barbs are well embedded! Carol Gilligan's *In a Different Voice, (1982)* is extremely enlightening in respect of the crises which arise when an 'ethics of care (for the other)' conflicts with an 'ethics of rights (for self)'. For Gilligan, the crises for women revolves around the need to include 'self' within the 'ethics of care'.

Pause:

Small voice: So that's your experience of anger?

Pause:

Feels like it. It isn't possible to say exactly what it is. It seems only possible to indicate that there is conflict. An invisible conflict that only you can feel. And when the 'thinking' and 'sensation' functions are impaired, the 'feeling' and 'intuitive' functions must take the full load.

This connects with Jung's "Psychological Types" (Jung, 1976, pp.178-269) and my earlier (p.73 above) analogy to the unbalanced boat in the medicalization debate, the narrow focus of the medical model, the dismissive effect of the psychological approach – and the inevitable standoff in the either/or paradigm.

In a society which recognises and applauds the rational and sensate, any appeal to felt and intuitive experiences is ridiculed or bound to fall on deaf ears and blind eyes.

Pause:
Perhaps, in this context the cry for recognition, visibility, or to be left alone is labelled 'anger'; to muffle the cry is labelled 'depression'; to act out this clash of realities, is to be labelled 'mad'.

It appears that in our society there is no model to help its members to construct meaning when there is nothing the 'experts' can do to help - individual efforts are simply anecdotal, subjective and not to be trusted.

In the context of a chronic illness to be told that "It'll soon pass." "You'll get better, someday!" feels like "You should forget about it. I have!" "I don't want to know about it!" "Go away!" "Forget it!"

Small voice: And you've been guilty of that cruel, tired and bored tone of voice yourself!

True. One of the advantages of doing telephone counselling is that we learn to catch ourselves sliding from interest and compassion into disinterest and boredom.

Pause:

Small voice: But, of course you can't forget it!

A bit like telling a man to forget that he's a man?

Small voice: Exactly! When something affects you to the core, you can't forget it.

............... 

The threshold comes into view

And this struggle to get free of internalised societal norms - to get free of the expectations of others, and of yourself - is the first experience of crossing the threshold. It is no wonder that people's immediate reaction is to retrace their steps, quickly.

Small voice: And most of us do that, very quickly.

Long pause:

Until one day, perhaps, the door has already been slammed shut and retreat is no longer possible!
In his paper on "Eco-feminism and Deep Ecology" Cheney (1987) draws on feminist theory about women’s ‘ways of being’. He queries why the deep ecology movement does not attract women in larger numbers given that it claims a feminist sensibility to care for the earth. He refers to anthropological literature and, extensively, to Carol Gilligan’s (1982) *In a Different Voice*. He notes the differences between a ‘gift’ economy and a ‘market’ economy. The economy is, basically, a patriarchal construct, despite its root in ‘home’. Our economy values ‘market’ over ‘gift’ and ties value up with the commodity rather than with the relationships established by the exchange. Matthews (1984) picks up this emphasis in her *Good and Mad Women*.

From my perspective, any attempt by women to deviate from an emphasis on gift and relationship will be viewed as deviant behaviour by both women and men. I have heard many a career woman explode with indignation that "What I need is a wife!" - to take care of the relationships while she gets on with the abstract analytical concerns of her career in the patriarchal world which does not value relationship.

**Small voice:** I’m not sure what you mean?

**Pause:**

I mean somebody to take care of HER, to do the family and domestic chores and to ‘worry’ about these things!"

**Small voice:** Right.

**Pause:**

ME/CFS requires relationship with Self - and this, in terms of the gift/market dichotomy, is a contradiction, a paradox - chaos!

**Silence:**

**Small voice:** I’m sorry. I didn’t understand. Funny, isn’t it that we all have ideas about how things are. These ideas don’t often hold up when put to the test.

**How do you mean?**

**Small voice:** Well, I suppose we all thought that all we had to do was to needle you, push your buttons...

You mean, confront me with your view of the world?
Small voice: Yes ... and you would react - and that reaction we would label as anger. And as we thought of anger as energy, we assumed that if we could get you angry you would somehow tap into a source of physical and intellectual energy.

And then what?

Small voice: Then you'd see that you had just misplaced your energy. It would then be a simple step, with the help of a cognitive behaviour approach, to channel the energy into positive things ... like wellness and paid employment!

Pause:

I thank you for being so patient with me.

Pause:

Actually, I feel a lot clearer myself - and not at all angry, if by that you mean fumin'n'fightin'. Perhaps that is just because you listened. I no longer feel invisible!

Nevertheless, there is a lot more to say about anger - or behaviour which is labelled anger - but I don't feel up to the effort at the moment.

Pause:

Do you think I should push on with a chat about methodology?

Small voice: Possibly! I'm still just sitting! I have a feeling that this would lead quite comfortably into grief. Can I venture a thought?

Sure! What's that?

Small voice: Tell me if I've got it wrong, but it seems that grief is a process of unknotting ...

...and it is also an expression or evidence of the fact that a person is in the process of unknotting. But I wish you'd get off the anger bandwagon. Anger isn't an analytical concept. And it isn't behaviour. It's an emotion. A feeling. It has no sharp boundaries. It is not easily dissected and defined. It is a basic human experience.

And yet:

That is not what I meant at all. That is not it at all. It is impossible to say just what I mean. (T.S. Eliot, "The Love Song of J. Alfred Prufrock", 1963.)
Small voice: Well, what do you mean. Is there no point where anger is finished with?

Exactly! No more than you can finish with the sun or the rain!

Small voice: I’ll bet you are about to say that this is a cyclical process and therefore infinite, more or less?

True! True!

Pause:

Actually it isn’t even anger. It is grief. Where is the energy to be angry? It is grief. And that is why grief-stricken people say “I’m not depressed. I’m not angry.” The lesson is to accept what the person having the experience has to say about it! Even in the midst of their confession that they don’t know how they feel! I’ve included some worksheets in the appendix (Appendix F) which I have found helpful in understanding the grieving process.

Silence:

Small voice: I suppose this isn’t the right place to talk about methodology. If you don’t mind, I’m feeling rather tired and drained. Could we take a

break?

............

Disembodied Voices

Darkness:

“Well, what did you make of that?”

“I feel rather humbled - and a bit of a fool.”

“Yes. Here we are wondering how to tidy up the script, with footnotes, making all kinds of assumptions …”

“… and we couldn’t have been further from the centre of things. Makes you wonder, doesn’t it!”

115
"Tell you, though. I'm feeling a lot more comfortable, and not so hurried."

"You? You? Not so hurried? Tell me the last time you broke into a trot?"

"So, I'm one of the quieter types! Not so you, eh?"

"Somebody has to keep the engine revved and the furnace stoked. We'd never get anywhere if we relied on you."

"Come on now, be fair. We had to get this sorted out simply because all your revving and stoking was merely making a lot of obfuscating steam."

"Obfu-what?"

"Forget it! No, don't forget it. I think we might be needing your particular kind of help shortly."

"Gee. Thanks!"

"Can we go now?"

"You have, haven't you?"

"Actually ... it would be a good idea for her to drag out those notes she made following the grief workshop."

"She could put them in the Appendix!"

"Let's see what happens, eh?"
PART VII

CONFUSION AND UNCERTAINTY

**Disembodied Voices**

*Blackness:*

"So here we are in another place."

"True. So what do we do now?"

"A little bit of twiddling our thumbs."

"Dancing! Singing!"

"A hum here, a hum there! A little soft shoe!"

"A whistle?"

"Now, there's an interesting thought!"

"What?"

"A whistle!"

"Whistle while you work ... "

"Whistle down the wind!"

"Some joke - after you've just lost five pages of inspired crap!"

"Now then! We all thought we'd done it right. It was just a little slip. We just forgot which window we were in and deleted the lot!"

"I think it was a good thing, because it was crap! Let it go and start again."

"So where do you suggest."

"I don't think it's up to us. She's trying to move from one place to another."

"Remember the Sufi story of the cabbages?"

**Pause:**
[I interrupt to give the reference, Shah, 1971, pp.2-15, retold in Maturana and Varela, 1992, pp.249-50.]

Pause:

"What was that?"

"Well, briefly, this is my version:

... over the eons the people who lived on an island had forgotten how to swim. As is the way with stories, one or two people remembered. And secretly they began to re-learn this ancient skill. Soon they were able to come and go from the island and bring back stories of the outside world.

Gradually some of the more adventurous inhabitants became fascinated, and one day they approached the swimmers, asking if they, too, could learn the art of swimming. Most arrived for their lessons with bundles of cabbages on their backs. When asked why they wanted to carry cabbages, they said that they wanted to make sure they had food when they landed on the distant shore. The teacher tried to explain to them that they would have great difficulty. It is impossible to swim with such a load ... and besides, they would have to trust that they would find food when they arrived in that distant place. Most of the would-be swimmers returned to their fields to plant more cabbages.

Pause:

"So, the moral is: if you want to move on and out, to explore new territory, you have to leave the cabbages behind?"

"True! You don’t get out of a hole by digging the same hole deeper!"

"So is this what she was doing when she lost the next five pages?"

"I don’t know! You’d better ask her!"

"Let’s go back to whistle for a moment."

"It’s a musical instrument..."

"... and a signal you make by blowing through pursed lips ..."

"... just pucker up, and blow! ...

"... and a tune ..."
"... it's a sign of happiness ..."

"... or command ..."

"I've an image of a train - a whistle-stop tour - the train blows its whistle as it comes into the station - and blows it again as it leaves..."

"...Silly - the train doesn't actually blow! The driver or the engineer pulls the chord to let the steam escape into the whistle - sound of the steam rushing through the opening causes a noise which we perceive as a whistle."

"How do we always end up in semantics?"

"It's not just semantics. It's an exploration. Trying to find the end of a ball of wool."

"Well, whistle, doesn't seem to be helping."

"Exactly! It's a vain hope!"

"Oh, shit! Here we are back again with hope."

"Thank you! I rest my case."

.......... 

Back on track

Small voice: Are you there?

Yes.

Small voice: You don't sound too confident.

No, I'm not.

Small voice: Did our confused conversation help any?

Well, yes, it did. But I'm not sure where to go from here. I thought it interesting that you came back to hope. And I'm still sitting with the story about the cabbages. In fact, I have a strong feeling, a cabbagey type of feeling, that while I am trying to go with the momentum of this story I feel a strong pull to drop into the academic mould ... and having trouble deciding just how to drop the academic cabbages and dive into the water.
Small voice: I know this may sound trite - but it is very simple to let go - you just do it! Let go!

Oh yes! Of course! Fold my wings and learn how to plummet!

Small voice: Wonderful story, wasn’t it?

Pause:

Leslie Devereaux (1992). Yes! She tells the story of her experience with ME/CFS and what happened to her. Among other things, she watched seagulls... how they fold their wings and plummet, totally unaware of the watcher on the cliffs. Did it matter whether they caught a fish every time? Leslie identified with the FLAP FLAP FLAP as the gulls struggle to become airborne again. To that point she hadn’t experienced the freedom of just plummeting.

Small voice: And neither do many of us. So where can we go from here if we stay with the plummeting?

Actually - I have been plummeting - diving into this and that...

Small voice: ... but you haven’t been doing it unaware of the watcher on the cliffs and neither have you been doing it without concern for the catching of the fish...

True! At least not until a few weeks ago when I reminded myself that I had to write this thesis from my own situation, from my perspective, from my own authenticity.

Small voice: That’s a very scary thought...

...yes, like the faith needed if one is going to leave the cabbages behind - and that’s the hope; it’s not wishful thinking, but faith that all shall be well and all manner of thing shall be well (Julian of Norwich, 1966, Chapter 27; and T.S. Eliot, 1963, “Little Gidding”).

So having got to this point, perhaps I can now go back and look at how I got into binds, and contortions, and struggles to control not only myself, but everything around me, in my search for rehabilitation.

At the risk of boring you to tears I want to quote, at length, from Anne Wilson Schaef (1992) because her thoughts give a frame of reference to my struggles.

Small voice: I know it is early in the day, but could we break here?

Sure. What’s up?
Small voice: I don't know, but it has something to do with Julian of Norwich.

Pause:

Mmmmm?

Small voice: Julian lived part of her life as an anchoress, or hermit, in Norwich, England in the fourteenth-century. Following what seems to have been a serious illness, she experienced 'shewings'. She initially wrote down these 'shewings' and later reflected and expanded her writings into *Revelations of Divine Love* (translated and introduced by Clifton Wolters, 1966). Her book has become a classic in the English spiritual tradition.

So?

Small voice: Hold on. Give me some time. I'm trying to grab onto what I want to say ...

Pause:

Small voice: It has to do with not worrying because things will turn out all right in the end.

Can I suggest that you stop struggling and go put your hand on the relevant article?

Small voice: I'm doing the thinking ... you are the one capable of putting your hand on the relevant article!

Amazing! We are getting our roles mixed up. I'll get it straight away!!!!

............

Right ... here it is. J. Ruud (or Rudd, I'm not sure) wrote an article titled "Nature and Grace in Julian of Norwich". It was published in *Mystics Quarterly*. I don't have a date. Yes I do - 1993, pp.71-81.

Small voice (excitedly): That's it!

Pause:  

121
What?

Small voice: Nature and Grace. The mask of Janus. There is much discussion in Christian scriptures, especially in Paul's Letters, about 'nature and grace' and 'good works and faith', just as there are discussions in psychology about 'nature and nurture' and 'fate and free choice'. We don't need to go into deep discussion about Julian other than to note that her emphasis, as in St. Paul's Letter to the Corinthians (1 Cor.13), is on 'love'.

This is the 'natural law' of love which binds the universe in harmony, which is a commonplace in medieval writers from Boethius to Aquinas and through Chaucer. (Ruud/Rudd, 1993, p.74)

Indeed

...Julian's emphasis on the love of God leads her to posit that God's wrath and his damnation of those who are not among the elect is inconsistent with his nature, and that at the end of time he will create some special miracle which will make everything 'all right' (Ch.27). (Ruud/Rudd, 1993, pp.79-80)

Pause:

Am I right in assuming that you are trying to tell me that we human beings have a Prometheus tendency towards hubris which leads us to believe that we can control ourselves and our world? No matter how far we push the frontiers of rational knowledge, at some point we have to face the fact that we are mortal and will die?

Small voice: Yes. But more than that. In the end it will come out 'all right' - whether you call it God or love or grace or nature or the cosmos or creator ... or chaos. There is something bigger than us. We are part of something mysterious and we are called upon to approach the mysterious with trust. And this trust, or faith, or salvation, or peace of mind, is in fact something we are graced with (Paul's Letter to the Romans). There seems to be no rational way in which we can plan to achieve it. It just happens.

In this way would you see hope as tied in with a trust in 'universal forces' for want of a better word, rather than with thinking, wishfully, that we can stay in control?

Small voice: Exactly! And while we can't manufacture this hope, we can at least make room for it.
Pause:

And now it really is time for a break.

.........

Addiction and control

Schaef (1992) believes that our (modern, scientific) world is built upon addictive processes - addiction to thinking, to control, to wellness, to work, to money, to status, to explanations and interpretations etc.

Small voice: Those scholars pushing a hermeneutical or interpretative approach probably don't think of themselves as addicts!?

Nor would the systems thinkers or the scientific pragmatists - or any of us, come to think of it. But in my own struggles I have come to her point of view and I would like to quote her at length (Schaef, 1992, pp.286-88, original emphasis).

I see two main groups actively struggling with the extensive implications of a new paradigm. Those two groups are theoretical scientists (mostly physicists) and people in recovery [from addictions].

... Scientists are changing theories and thinking and the recovering people are changing attitudes, feelings and behaviour in themselves.

... In my experience, the new paradigm cannot be approached theoretically. The very nature of the paradigm is that it is a participatory paradigm. One can have ideas and assumptions about the theory and the way it should operate. This is very different from living it, and living it is the only way to really know it.

... Often the ideas about a new paradigm are not tempered by experience or even science. It is important not to make the same political and emotional mistakes of the old mechanistic paradigm and force ourselves to accept a new paradigm because of an emotional, political or theoretical attachment when it does not seem congruent with our experience. This very process of disembodied or nonexperiential figuring things out is, itself, the old paradigm. Often, those operating in old
paradigms have changed the content of which is said and have clung to processes and procedures that are incongruent with that belief system.

... When we Live in Process, we are open to wherever that process takes us. Often, that is different from where we thought we were going or what we planned. It is interesting that every major religious leader has spoken in these terms, but a mechanistic, deterministic worldview introduced the illusion of control, and the subtlety of this illusion permeates even our thinking about the new paradigm. If the new paradigm comes out of our recovery and experience, the illusion of control must be dealt with early on (and again and again)...

Pause:

Diane Speed (1994) reminds me that other than the nuns, the only woman on pilgrimage, in Chaucer's Canterbury Tales, was the Wife of Bath. She begins by stating that even if there were no quotable authority ('authoris',) experience would be good enough to enable her to speak of marriage (Chaucer, 1961, p.114, the Wife of Bath's Prologue).

Small voice: Perhaps you could say how the belief in control and planning and achieving lost its footing on the slippery rocks ... at the threshold of solid earth and powerful, surging seas ...

...and how things which are true in one context, are not true in another.

Pause:

Small voice: Could you talk a bit about how this confusion and uncertainty, the 'getting lost' and 'getting stuck', is part of the research process?

And, it is also a research methodology ...

Small voice: ... when compared with, say, the literature search as being part of the methodology, or the designing of questionnaires to collect data, and examining the data collected in the light of the questions asked. For instance, what questions are you asking? Today? This very moment?
At this very moment? ... well, I'm wondering how do I know whether I'm improving, rehabilitating, changing ... in myself ... and how do I communicate that to others, so that they understand.

A second question, of course, is: Does it matter whether people understand or not? Has the real question to do with simply plummeting? Or has it to do with the need for me to place markers at significant points? A kind of drawing the map, tracing Ariadne's thread? If I can be confident, and satisfied, with drawing the map, then the rest doesn't matter?

Small voice: Question: Are you paying too much attention to the observer on the cliff?

Answer: Probably!

Small voice: Most definitely!

You're right!

Small voice: Drop the cabbages!

Okay.

Small voice: And be satisfied!

...........

_Disembodied Voices_

_Darkness:_

"Now what was all that about?"

"Who knows? Sounds like lots of indecision."

"What does she need to do to get past this impasse?"

"As far as I'm concerned, she ought to get on with the job and stop of this shilly-shallying about!"

"And, pray tell, what is the job?"

"Well, writing the bloody thing!"
"And what do you think she ought to be writing?"

"The facts!"

"What facts?"

"Well, she's got to move the story on. Get into the stuff she has done - you know, like the literature searches she did do, not the stuff she hasn't done. Like, the experiences she has had, not the experiences she can't get! Like, the way the world is, not the way she hopes it would be!"

"Easy now, that's a bit rough!"

"It's not rough. For some reason she is skirting round all the issues and not facing them squarely."

"Wait a minute. It is very difficult to face something squarely if one can't actually see what it is, AND it keeps dancing around you. This notion of squarely comes in a long, long way from the dawning of understanding, when what it is becomes square as it slowly consolidates into something observable."

"That reminds me of the 's quarling of the circle' - these two abstract figures, the square and the circle, which form the mandala ground plan."

"And what's this all about?"

"It's ... well ... it's one of the ancient mysteries ... in art, architecture, geometry ... in matters secular and sacred."

**Interruption:**

[I interrupt to provide the reference: Carl Jung (1978, pp.266ff) in *Man and his symbols.*]

**Pause:**

"I can identify with that."

"With what?"

"With trying to face something squarely when it is dancing around you."

"Oh."

"Actually her thesis is about crossing thresholds, from being productive to non-productive, in common every day terms. About living in a sort of twilight zone where things aren't as they seem."
"... and I feel that it is absolutely proper, right, appropriate, whatever word you want to use, to dance around in this twilight zone, to grope and struggle ... otherwise, where is the ..."

"... the what ..."

"... the ... the ... authenticity?"

"Actually, I think that the notion of rehabilitation - what is it, how do you get it - is getting closer to the surface. Surely, it is some clear expectation about 'rehabilitation' which is being challenged?"

"I get the feeling that she doesn't know whether she is being rehabilitated, or rehabilitating herself, or whatever ..."

"... exactly ... and she needs to get down to some concrete facts ...

"... or, at least, start with what she believes are concrete facts ..."

"... maybe that way she'll put up something she can challenge and that will provide the catapult."

"Okay. Can we agree that Small Voice take this back to her and see what eventuates?"

Grumbles and shuffles:

"Well, if nobody has a better idea, we'll leave it at this for the moment. Thank you for coming!"

...........

A Coffee Break

Late afternoon:

That was very interesting, and I thank you for bringing it back to me.

Small voice: My pleasure!
You are right, of course! I am getting deeper and deeper into the mire - which is the way things are. But I can see that if I broaden out for a while and 'set up' the facts, then I can/might get a different perspective.

Small voice: Perhaps, at this point, it could be helpful to look, in some depth, at the 'rehabilitation system' at least for the benefit of the readers who, no doubt, are in need of a real meal. And this will give them some clearer background and definition in which to locate your story.

Strange! I don't know why I have such resistance?

Small voice: Well, you'll never know, unless you start!

Do you think I could call on the Greek Chorus to help in the telling of the tale?

Small voice: It worked well before and I'm sure they'd be delighted to be able to perform again.

Noise and confusion. Interruptions and disruptions:

Disembodied Voices

Darkness:

"Wait a minute ...
wait

MINUTE ... This is taking the easy way out ... didn't she say she wanted to fold her wings and plummet - this is getting stuck in a framework."

"I agree! Can we encourage her to let that bit go and continue on with the journey?"

"Actually, I was becoming quite intrigued with her methodology ... and I think I would be very disappointed, and frankly, bored, if she gets stuck with the Greek Chorus."

"I thought you wanted 'facts'?"

"Well ... yes ... but ..."

"No buts about it - you were screaming for blood!"
"I say, what an exciting turn of events?"

"Where's the costume mistress?"

"Coming!"

Movement ... quickening.

A second cup of coffee

A strong gust of wind:

Small voice: Good heavens! What was all that about?

I see, I see. Right!

Small voice: What do you mean? You've lost me.

It's time to connect with Dorothy, the yellow brick road and the wizard.

...........

The Yellow Brick Road

Evening:

A little girl called Dorothy lived a grey life in the grey landscape of Kansas, in the mid-west of the United States of America, as the nineteenth century was becoming the twentieth century ... a land subject to drought, and fierce wind storms, and dust. The light of her life was her little dog, Toto. She lived with her Aunt and Uncle.

Lights up:

One day, at the height of a fierce wind, Dorothy finds herself, and her little dog, Toto, swept up into the sky and deposited in the land of the little people, the Munchkins. She also finds that her house has landed on the Wicked
Witch, squashing her. Happily, this event liberates the Munchkins who had been under the spell of the Wicked Witch. Dorothy becomes a hero, and inherits the shoes of the Wicked Witch. "Toto," says Dorothy, "I have a feeling we aren't in Kansas anymore."

Now in the book version (Baum, 1979, pp.29-32), these shoes are silver. They were known to be magic shoes, and in the land of the Munchkins the magic number was 'three' ... but the Munchkins had no idea how to activate the magic embedded in the shoes. But in any event, they are now Dorothy's.

In the Hollywood version, the shoes were ruby (no doubt for cinematic effect), but if I remember correctly, there was some indication that they would protect the wearer from the powers of other Wicked Witches.

So whether for protection or for other magic powers, these shoes were significant. In fairy stories, shoes and colour (and most other things, too) are symbolic and important. (Marie-Louise von Franz, 1972, 1980; and Clarissa Pinkoles Estes, 1992.) For example, shoes provide protection for the feet and make social statements about status and power and tie in with metaphors in language about the feet - standing, walking, understanding. And because we are in the world of fairytales, shoes have meaning in both our inner and outer lives. The colour red is used, metaphorically, to express intensity of ... anything!

Interestingly, silver is usually associated with things feminine. I wonder whether The Wizard of Oz is really a story about a man's search for his femininity? The book was written by a man!

Pause:

Small voice: Alice in Wonderland was also written by a man - and both heroines are pre-pubescent?!

Please, don't go getting literal on me. This is a metaphor.

Small voice: Alright. Let's get on with the story.

Pause:

Dorothy has but one wish - to return home to Kansas, a place unheard of in Munchkin-land. But then nobody knows of Munchkin-land in Kansas, either! The Good Fairy suggests she might find help with the Wizard who lives in the Land of Oz, some ways distant. When Dorothy asks how she can get
there, the Good Fairy asks, "Do you have a broomstick?" ... Dorothy is surprised by the question. "Well, then, you'll have to walk?" "But which way will I go?", asks Dorothy. "Just follow the Yellow Brick Road!"

Full of optimism and cheerfulness, Dorothy sets out along the Yellow Brick Road, wearing her newly acquired silverruby shoes, with Toto running alongside.

In the next little while, Dorothy happens across three interesting characters - a Strawman, who wants a brain; a Tin Woodsman, who wants a heart; and a timid Lion, who wants courage. Since Dorothy is in search of the Wizard, because she wants to get home, it seems only fair and reasonable that the Strawman, the Tin Woodsman and the Lion should travel with her, in search of their wants. And if the Wizard is as great as the Good Fairy says, then they might all find their hearts' desires. Besides, the company of strange people is obligatory when one is making a solitary pilgrimage ... just ask Mr. Chaucer!

They travel for miles across rainbow coloured lands, until they arrive at the Land of Oz, where everything is coloured Green. And then the fun really begins! The closer they get to the Wizard, the harder it seems to make any progress - and the forces of the Wicked Witch of the North become more potent.

Dorothy’s want has been multiplied three times by the Strawman, the Tin Woodsman and the Lion. And yet, Dorothy’s wanting to get home to Kansas cannot not be granted until the other three wants have been attended to. They need the brains of the Strawman, the heartfelt emotion of the Tin Woodsman and the courage of the Lion - not to mention the instincts of little Toto - in order to press for Dorothy’s return.

Pause:

Small voice: Are you saying that Dorothy didn’t know that she needed to acquire three helpers ... or new skills ... ?

Silence:

Well, I suppose she found herself on a one-way street - she just couldn’t turn around and exit through the door through which she’d arrived.

Small voice: And because she was in a strange land, her own intelligence, compassion and courage were not sufficient, or appropriate, to the task. Hence her meeting up with the three characters who needed to develop these very characteristics?
How smart you are! I hadn’t thought of that before – but it is very apt.

Small voice: And what about Toto?

I’ve wondered about Toto. Because, after all, Toto was the light of her life in that grey town in Kansas.

Small voice: in toto ...? Wholeness?

I’ll think on that.

...........

Foreign countries and language difficulties

Small voice: Now if you will allow me ...

It seems that your struggles for 'rehabilitation' are tied to the notion of rehabilitation. Are you trying to get Kansas-style rehabilitation in a Munchkin-type situation? Or are you trying to define it, or locate it?

How true! This is a confusing state and I continue to fall into the same trap.

Small voice: And that’s not surprising! You are using one set of vocabulary, one language, in at least two situations and you forget to prefix for Kansas or Munchkin-land. And you also forget to say whether you are looking for rehabilitation, for yourself, or whether you are writing about it!

So, what you’re saying is that once across the threshold, I need to develop new skills which, co-incidentally, bear identical labels to old skills?

Small voice: Right!

Right!

Pause:

So, what does all this mean?
Small voice: Well, you have to distinguish between hope and hope, between intelligence and intelligence, between feeling and feeling, between courage and courage ...

... between rehabilitation and rehabilitation!

Small voice: ... and between the experience and the telling ...

If there is one – I'm beginning to wonder!

Small voice: Exactly! You had no difficulty in distinguishing walking as a physical activity and as a metaphor – now you have to make use of this distinguishing skill.

Just so! Then I can more easily talk about rehabilitation, as it is generally understood, Kansas-style, and contrast it with rehabilitation, Munchkin-style.

Small voice: I can see that the whole exercise is similar to positive and negative photographic prints ... they are not opposites of each other. The positive has gone through an additional process!

... so my additional process will provide me with a Munchkin appreciation of rehabilitation, ...

Small voice: ... in addition to the Kansas understanding!

You know, most of the stuff I was going to talk about in relation to rehabilitation seems rather ... irrelevant!

Small voice: It may seem irrelevant to you ... now ... but others may not see the relevancy, one way or the other ... when you started out you needed to sort out 'primary' and 'secondary' rehabilitation from 'tertiary' rehabilitation. You needed to find the barriers between compensable and non-compensable injuries ... and the politics behind the system ... and then, from the grieving process came the 'emotional' rehabilitation ...

Only to find it all irrelevant!

Long silence:

Small voice: Not so!
Well it feels that way now.

Small voice: Do you mean to say that somebody with ME/CFS has to expend a lot of energy trying to understand a system, such as 'rehabilitation', which they will then find irrelevant?

Yes ... and no.

Small voice: You go through the motions, quite sincerely and seriously, only to find there is no job for someone who experiences extreme fatigue in an unpredictable, uncontrollable way.

Actually, I think this affects all those involved in the 'rehabilitation' system. The client could 'work' if there were 'jobs' enabling them to choose when and how long to work. In reality, this 'work' and these 'jobs' don't exist!

Small voice: Really?

But more than that, on a personal level, the idea of 'jobs' and 'returning to work' turns out to be irrelevant when one is dealing with deep spiritual matters which find no place in the 'rehabilitation' model.

Long silence:

Time out!

...........

Disembodied Voices

Blackness:

"Well, what do you know!"

"Amazing!"

"Let's leave her for a while ... she looks plum tuckered out!"
PART VIII

SYMBOLS, SIGNS AND JARGON

Preamble Two:

Today is 20 September, just a day short of the Spring Equinox - ten days since I was stung by a bee.

[As I edit this, it is the Autumn Equinox!]

[As I edit, again, it is Mid-Winter!]

[As I edit, finally, it is Spring!]

In the past month or so I have had many dreams, involving two old Jewish men, Adam and Aaron; a youth orchestra; a young Jewish boy with a cello; and small four-wheeled vehicles similar to dodgem cars! And a Madonna and a young girl, both with candles, framed by a window.

Cellos figure regularly in my dreams and waking fantasies. For example, I have seen a young girl carrying a cello along my street; a young woman with a cello has stood in front of me on Town Hall Station; most recently, a middle-aged man with a cello boarded the 380 bus in Paddington, along with a girls’ hockey team. At peak hour, a large man with a cello on the 380 bus is remarkable! School sports groups go unremarked.

I notice cellos - and cello music. I am not a musician, except in my on-going self appointed role of becoming the best possible audience for the Sydney Symphony Orchestra.

Recently I spoke with a woman who found herself similarly involved with a harp. She encouraged me to stay with the unfolding of this interesting relationship. The cello is a symbol - that is, it points to something as yet unknown. It is also an integral part of this unknown thing, place, idea or truth. A symbol is not something to be taken literally, necessarily. To become literal would be to reduce the symbol to a sign, and thus I would lose the numinosity and the entry into something deeper and more mysterious. The patient attention to the unfolding process is not attractive to the rational intellect!

Pause:

Herein lies my dilemma.

Pause:
A tug-o-war between the irrational and rational ... and a reluctance to speak of matters spiritual...

... for, to speak of rehabilitation necessarily leads me to speak of reconciliation and redemption ...

... and the recognition of these connections is at the heart of my difficulty in beginning to speak of rehabilitation at all.

I am acutely aware of the spiritual dimension of my journey. And I am afraid both of the intensity, awe and magnitude of my blossoming awareness; and of the unacceptability in (scientific) academic circles of such subjective, emotional and spiritual research.

Oodgeroo of the Noonuccal died last Thursday. Her poem, "We are Going" somehow captures my own dilemma, and the haunting unreality of this in-between space. The space between what we know to have passed, our being and our going which is the present. We are gone, and we are going, yet we are here. I, too, sit and am confused, I cannot say my thoughts:

"They came in to the little town
A semi-naked band subdued and silent,
All that remained of their tribe.
...
They sit and are confused, they cannot say their thoughts:
'Ve are the corroboree and the bora ground,
We are the old sacred ceremonies, the laws of the elders
We are the wonder tales of Dream Time, the tribal legends told.
We are the past, the hunts and the laughing games, the wandering camp fires.
We are the lightning-bolt over Gaphembah Hill
Quick and terrible,
And the Thunderer after him, that loud fellow.
We are the quiet daybreak paling the dark lagoon.
We are the shadow-ghosts creeping back as the camp fires burn low.
We are nature and the past, all the old ways
Gone now and scattered.
...
The bora ring is gone.
The corroboree is gone.
And we are going."

"We are Going"
For Grannie Coolwell by Oodgeroo Noonuccal
(Kath Walker 1920–1993)
Rite of liminality

One of the first facts I learned about rehabilitation is that, among other things, it is a trinity. That is, it has three aspects. The first is, of course, primary ... or medical - the sort of rehabilitation which is involved in stabilising an injury so that the injury is not compounded by secondary complications.

Following that is a reconstruction phase where medical and surgical techniques are applied. Plaster casts, pins, grafts, transfusions and medications ... "calling on the patient's will to live".

As the patient comes out of the acute phase, she enters the secondary phase. Most often this is still connected to the medical or primary phase. Diverse therapies are available to assist the patient to work through the injury, to achieve the best possible medical outcome and to come to terms with any residual physical impairments. This is the convalescent stage. This stage also involves psychological counselling ... "pushing passed the pain barrier".

The next, or tertiary, step involves a return to the community - learning how to function as a productive member of the community. This has usually been defined in terms of full-time paid employment for men, and coping with the demands of husband and family for women. There is an expectation that the injured person will have learned inappropriate illness behaviour and will need to be encouraged to adopt a can-do approach to overcome fears of inadequacy ... "pushing passed the fear barrier".

Some background to this process can be found in Hooker, 1983, Penington and Burry, 1990, Bates and Linder-Pelz, 1990 and Herschberg, Lewis and Vaughan, 1976.

Oh, that it were so simple!

Pause:

It is immediately obvious that failure to achieve optimum recovery, or life itself, is either a failure of the patient, who didn't try hard enough, or a failure of the professional, who believes she or he ought to have made a better diagnosis, given better treatment or referred the patient to somebody else.

In very few places is there an acceptance of a 'just so' situation. And there is very good explanation for this.

In our society we believe that we can achieve virtually anything provided we take control, plan our goals and apply ourselves.
The most overused word in the Australian vocabulary - the vocabulary of Western society - is 'choice'. We hear it daily - in every context. In short, whatever happens to us is our choice. We choose to do or accept. We chose not to do or accept. In the event, it is our fault. We made our beds and we have to lie in them. We are not to go looking for sympathy, understanding ... or help! Lest we forget ... user pays!

Dr. Dennis S. Smith, President of the Australian College of Rehabilitation Medicine, says in the Foreword to Penington and Burry's, *Introduction to Medical Rehabilitation: An Australian Perspective*, (1990, p.vi):

_Criticism of rehabilitation methods in the past has often been based upon the suspicion that success has been claimed for what is in reality the passage of time. Clinical trials of rehabilitation in such disorders as severe stroke illness have demonstrated that natural recovery of function is often a pious hope. The use of rehabilitation methods as an acceptable but expensive placebo is equally to be avoided in those who cannot benefit; in these circumstances it is a cruel deception. Selection of patients for whom the rehabilitation process is relevant is an important skill and, when properly used, avoids both waste and frustration._

For whom? This neatly draws the line and defines this book as a text book.

Susan Hooker (1983, p.57) comments:

_Rehabilitation must continue until the best possible results have been achieved. Usually that will mean the return to full use and normal life, but for some people that is not possible, and they may have to come to terms with some degree of disability._

Injecting a little humanity into the text book style are the cautionary words of Herschberg, Lewis and Vaughan (1976, p.166):

_To have a patient achieve ambulation with great effort, only to have his disability force him back into a wheelchair within two months may satisfy professional vanity but does not render a service to the patient._

_Pause:
So. What happens to the patient who is now relieved of this "deception, waste and frustration"? It is obviously no longer a medical concern. But what happens next? Where is this unrehabilitative human being to be deposited — if he or she hasn’t got the good grace to die? And one may ask who decides what is "deception, waste and frustration"?

But let us return to the beginning of the road marked 'rehabilitation' because I have assumed that one can simply jump into 'system' without satisfying specific eligibility criteria. And we begin with an overview of the planet — at the broad policy level.

Restricted Entry

It is not the first thing I noticed because I was not expecting it, and I might have, but it is the first unmarked detour which I recognised only after I had lost my way ... and that is: the world of rehabilitation has special entry requirements. It is not a world with unrestricted entry.

There are two distinct, yet invisible, signs at the entry point. Under one sign, marked 'compensible', are collected all those for whom rehabilitation is a legislated and legal requirement, with both negative and positive aspects.

Small voice: A bit like 'counselling'? or 'discipline'?

Under the other sign, marked 'non-compensible', are collected all those for whom rehabilitation is a restricted, and expensive, optional extra ... in small print are the words 'conditions apply'. Unfortunately, most of us aren’t aware of the invisible signs, or of the conditions. Some people aren’t aware that such a country exists.

Small voice: And, outside of the hospital system, many of the rehabilitation services aren’t covered by Medicare (the universal health coverage for Australians). You might get some physiotherapy extra coverage through private insurance. But psychology doesn’t seem to be classified as a health concern!

Pause:

Hold on, you’re getting ahead of me. You’re getting into the politics of the hospital and medical and health and community systems. I’ll talk about Erica Bates and Susie Linder-Pelz, 1990, work on Health Care Issues later on.
Small voice: True! The politics of the medical and hospital systems may be way ahead, but the impact of those policies on the patient/client/user/customer is massive! And immediate!!

Yes. You remind me of just how connected everything is. But for the present, let's take a little detour, behind those invisible signs, to get a little flavour, a little history, of the current situation.

Small voice: But tell me. Why 'might' you have noticed the restricted entry?

Irritation:

But before we begin ... injury and illness are treated separately and differently. Injury and illness which can be legally attributed to a lack of care on the part of a third party may be 'compensible'. Illness and injury which cannot be legally attributed to a lack of care on the part of a third party is usually 'non-compensible'.

Increasing irritation:

Small voice: Excuse me, please! Can we stop here? I sense you are resisting something.

What?

Small voice: The task of unpacking concepts?!?

Pause:

Somehow I'm trying to avoid ... well, not actually avoid ...

Small voice: ... avoid ...

... okay ... I am avoiding ...

Small voice: Avoiding what?

I'm trying to take a short cut ... and it isn't working.

Small voice: Great! Can we start again?

Pause:

Thanks for your vigilance.

Small voice: May I make a point?
Go ahead.

Pause:

Small voice: It has just occurred to me that when you say 'But before I begin ...' you are in fact trying to preface the beginning with a neat and tidy statement about the end. Surely it would be easier to just start at the beginning?

Pause:

Are you suggesting that I should adopt a storytelling approach?

Small voice: That's probably what I mean. But then again, maybe I don't. Can I refer you to your difficulty in just this area earlier in your research? Do go and hunt it up. That's a good girl!

Quit the patronising!

Small voice: Well, get a cup of coffee ... and then consider including some of those difficulties? Please?

Silence.
A RATHER LONG DETOUR

What is research and how do you do it?

Earlier in my research I wrote at length about my struggles to get into the research, and it seems appropriate to include those searchings here.

At the time my writing had not fallen into the framework of a conversation. Neither had I noticed, sufficiently, the different tones of voice which alerted me to different points of view. However, as associated and/or peripheral ideas came to me, I began to indent paragraphs.

I now wonder whether to reframe these musings, giving Small Voice and the Disembodied Voices clearer directions and a sense of identity. However, in the interests of watching the process unfold, I will leave the writing more or less in tact.

These are my ponderings during January, 1993:

I have been having a less than successful time of trying to do research! First of all, I believe I ought to be doing a literature search to find out what has gone before and so that I can locate my research within a body of research.

I don’t need to be dogmatic about this, but no matter the jargon I use, it has to be done! But how?

A textbook approach doesn’t seem to be working. I find myself at the library with no idea of why I am there, or vaguely aware but unable to summon up the necessary mental energy to direct my enquiry. Other times I sit looking at a page for what seems like hours (but in fact is only minutes) unable to retain what I am reading. And I return home, dissatisfied and disappointed.

I have been reading Robert Pirsig’s (1992) Lila and found myself hanging on every word he said/wrote about research. His method (actually his character, Phaedrus’, passion) is to collect pieces of (philosophical) information, gleaned from reading or conversations or chance remarks, and to record them on cards which he then classifies, re-classifies, removes, re-sorts or throws out as the years go by.
His shoe boxes of cards reminded me of a linguistics lecturer who said that he wrote his PhD thesis straight off his cards, once he had sorted them to his satisfaction. There was no need for drafts and re-drafts, he only had to carry his boxes with him, shuffle the cards and sort them back into the boxes!

Phaedrus’ attention to this painstaking work seems to just happen when the spirit moves him.

I decided to take a leaf out of his book and try to incorporate this note-taking into the framework of an ordinary day. I did not, however, assume that my way was to put all this on pieces of paper, or 5x8 cards (my hand-eye coordination is not reliable and I don’t carry 5x8 cards with me). Pirsig reminded me that I needed to find a way that is natural to me. I’d try to watch myself.

I found that I had brought home two books from the library, one of which I had browsed through before and which was there again on the shelf (Bates and Linder-Pelz (1990) Health Care Issues) – obviously it was meant for me to bring home. But when I got home I could find no direction.

Then I remembered my own area of expertise. I ask myself: “Is this a definition of ‘re-search’?”

I really didn’t need to start with a literature search at the library because I already have at least two books on my bookshelf which could provide as good a starting point as I needed, and could accommodate, at this very moment.

The aim? To get an idea of the availability of and attitude towards the concept and practice of rehabilitation. If I was going to talk about rehabilitation I had to be aware of how other people had tackled the issue and to check out whether we were all speaking about the same thing.


...........

So I took these two reports and sat looking out onto my courtyard, cup of tea in hand and the antics of the bulbulls and silver-eyes to distract me.
In the course of an hour or so, I had turned over the corners of several pages of the first book - not a nice thing to do to books, but I had tried to write a few notes and my hand would not cooperate.

Ah ha!! This is why I have difficulty in taking notes; and I could not bring myself to dog-ear the library books! I satisfied myself with having located several pages of import and relaxed with the beating of wings over the bird bath.

Now, several days later, I feel together enough to try to collect the wisdom from the dog-eared pages.

As I begin, I find myself connecting, with great affection and nostalgia, to my days in Social Security and the Great National Compensation and Rehabilitation Debates. Echoes of "Com-pen-sation, Com-pen-sation" sung to the strains of the "Alleluja Chorus" (an in-joke!). Then, my concern was with the impact of the proposed National Scheme (and later debates on no-fault accident schemes) on Social Security provisions, and specifically in the area of compensation and income maintenance, not with the rehabilitation aspects.

Further back: passionate debates at family meal times about politics, justice and ethics.

Even further back: Me, aged 3. Dad, early home, opens the door ... a shock of bright red on the white turban.

.............

I try to keep the horse before the cart. I want to extract these pieces of information in order to find a place for them in my own research for rehabilitation.

My immediate joy, however, was in discovering my own limitations and finding a way to do one thing at a time. More importantly, I had found a way of not losing that one thing that I had managed to do! The day of dog-earedness had arrived!

I have to stay in the moment, one piece of information at a time, and not jump ahead into analysis and synthesis! Here goes! In the context of how I got to this point, I can record these scraps in my computer, the latter day version of the shoe box full of 5x8 cards!

.............

144
The Woodhouse Report

The Report of the National Committee of Inquiry [The Woodhouse Report] into Compensation and Rehabilitation in Australia, in three volumes. The publication date is 1974.

The Hon Mr Justice A O Woodhouse, was a Judge of the Court of Appeal of New Zealand. New Zealand had introduced a National Compensation Scheme following a Royal Commission of Inquiry in the 1960s.

The Woodhouse Report, commissioned by the then newly elected Whitlam Government in 1972 ...


... was originally concerned only with injury. The terms of reference were later expanded to include sickness. (Vol.1, paras 22 and 23) The Inquiry "is concerned with the responsibility of society for the injured and the sick." (Vol.1, para.1)

The Committee took as its starting point:

. the magnitude of death and personal injury due to road and work related injuries;

. significant advances in medical science and technology which results in the survival of seriously and permanently injured people;

. the 'justice' of the concept of 'fault' in today's fast moving and mechanised society; and

. the 'lottery' of the legal negligence action in providing adequate care and compensation.

...........

A quick once-around-the-table survey will reveal deep philosophical differences in attitude to the concepts of 'fault' and 'responsibility'.

...........

Let us begin to explore what Woodhouse found concerning, in particular, injury, illness and rehabilitation.
"In terms of social conscience, it is remarkable that the community has not insisted long ago that at the very least the losses of the injured should be borne by the community as a whole. This has not been done." (Vol. I, para. 2)

"The needs of the sick are even more neglected . . . The needs of men and women are not mitigated by the chance visitation of sickness rather than injury . . . In terms of equity, therefore, and as a matter of logic, there should be equal treatment for equal losses . . . Accordingly, the wider scheme outlined in the Report embraces incapacities arising congenitally, or from injury or from sickness. It has been constructed, however, so that it can be implemented by stages should decisions be taken to that effect." (Vol. I, para. 3)

"It is self-evident that the problem of incapacity, whether arising from injury or from sickness, demands an attack on three fronts. The most important is obviously prevention. Next in importance is the obligation to rehabilitate the injured and the sick. Finally, there is the need to provide economic assistance in the form of compensation for their losses. The priorities need to be emphasised and particularly it is necessary to ensure that the objective of compensation does not bear down upon the far more important need for the restoration of health and physical well-being." (Vol. I, para. 8)

"To promote the purpose of rehabilitation it is proposed that organisation and administration be concentrated as a single division of a social welfare policy and planning department; and that rehabilitation in all its aspects — medical, vocational, education and social — be encouraged as a total concept by the injection of sufficient funds and the provision of adequate manpower, together with all necessary facilities." (Vol. I, para. 8)

"A definition of rehabilitation is ‘the restoration of the handicapped to the fullest physical, mental, social, vocational and economic usefulness of which they are capable.’ It is therefore a total process. Adequate and appropriate rehabilitation services should be readily available from the time the disability is recognised, and should continue to be made available in a completely co-ordinated and uninterrupted fashion until optimum recovery has been achieved." (Vol. I, para. 449)

Volume 2 provides a detailed explanation of the then current system together with recommendations for improvement.
"The aim should be to provide rehabilitation services for Australia that are -

- Universal, and so available to every Australian in need of the services, irrespective of the cause or nature of the handicap;
- Accessible, and within reach of all members of the population;
- Comprehensive, so that all aspects of rehabilitation will be embraced and the services effectively co-ordinated and directed;
- Continuous, and thus without interruption from the onset of the handicap; and
- Complete, so that the process is not withdrawn from any handicapped person until everything possible has been achieved.

... It is of the first importance that the Australian Government should accept over-all administrative and financial responsibility for implementing, developing and co-ordinating a national plan, based on those principles, that will provide fully comprehensive rehabilitation services in Australia." (Vol.1, para.452)

..........

A friend, somewhat connected with this Inquiry, remarked sadly that these brave and innovative beginnings (or, more accurately, another beginning) were 'over-taken by events' (a euphemism for 'nothing was done'). These 'events' continued through the 1980s with the concepts of user pays and maximise profit/minimise tax and into the 90s with the concepts of effectiveness and efficiency, and productivity which is measured almost exclusively in terms of redundancies or reduced anythings (people, costs, services).

[My oh my! With any luck, we will be able effectively and efficiently to achieve maximum productivity by eliminating the entire population in a radical restructure which will be full of career pathways!]

Now, that wasn’t too bad - time for a break and please, Pam, try to refrain from editorial comment!

..........

147
Much later ...

I am now up to Volume 2, "Rehabilitation and Safety". The Report notes:

"Medical rehabilitation is the process of medical care aiming at developing the functional and psychological abilities of the individual, and, if necessary, his compensatory mechanisms, so as to enable him to attain self-dependence and lead an active life." (Vol.2, para.50)

"We define vocational rehabilitation as the provision of those vocational services, such as vocational guidance, vocational training and selective placement, designed to enable a disabled person to secure and retain suitable employment." (Vol.2, para.51)

"By social rehabilitation we mean that part of the rehabilitation process aimed at the integration or re-integration of a disabled person into society by helping him to adjust to the demands of family, community, and occupation, while reducing any economic and social burden that may impede the total rehabilitation process." (Vol.2, para.52)

These definitions were formulated by Judge A.T. Conybeare, Q.C., and adapted from submissions made to his Inquiry, see Report on Inquiry into Feasibility of Establishing a System for the Rehabilitation of Injured Workers in New South Wales, (December, 1970, pp.15-16).

..........  

Woodhouse identifies the many and various types of rehabilitation units, centres and teams. The Australian Council for Rehabilitation of Disabled (ACROD) submitted a report on Recreation for the Handicapped. Woodhouse comments (Vol.2, paras 206-209):

"Recreation is an essential aspect of rehabilitation. It embraces -

- Physical recreation activities - outdoor sports, other outdoor activities such as camping, and indoor activities such as gymnastics, table tennis, dancing, fencing;

- Cultural activities - such as music, drama, art, handicrafts, literature; and

148
Social recreation activities – public and private social evenings and entertainment, barbecues, picnics and excursions.

Recreation is an important aspect of living for the able-bodied, but it can be even more important for those whose many opportunities for living have been limited as a result of mental or physical handicap. It can save the handicapped from a life of soul-destroying dullness." (Vol.2, para.207)

"Some present day rehabilitation programmes place an over-emphasis on employment and an under-emphasis on the enjoyment of leisure hours." (Vol.2, para.208)

"Rehabilitation counselling and follow-up work should be concerned not only with the employment objective but with placement of the handicapped person into suitable community recreational situations." (Vol.2, para.208)

With regard to (rehabilitation) staff training:

"The Committee has received much convincing information concerning the serious shortage of specialised rehabilitation personnel and it seems that this problem is not improving although some measures are being taken to overcome it (e.g. Lidcombe Campus of the then NSW College of Paramedical Studies)." (Vol.2, para.210)

"...Substantial additional facilities will be necessary and unless they are established as a matter of high priority the rehabilitation plan will be frustrated for many years. The Committee recommends that this whole question be regarded as an issue for urgent attention by the Rehabilitation Division." (Vol.2, para.211)

Woodhouse quotes from Judge A.T. Conybeare's (1970) Report:

"It is clear that many patients, who could benefit from rehabilitation, are not referred, whether in due time or at all, either because the treating doctor is unaware of the existence of suitable facilities and/or of the benefits of rehabilitation in the particular case, or because of the attitude of the treating doctor towards rehabilitation.

... generations of medical graduates have gone into practice with no real exposure to the ideas and techniques of rehabilitation; the result of this is reflected, according to most of the witnesses before me in a striking lack of awareness, on the part of many doctors, of what rehabilitation is and what it can achieve." (cited in Woodhouse, Vol.2, para.212)
Woodhouse continues:

"Those areas in which there are first class medical rehabilitation facilities (both in this country and elsewhere) are often due to the initiative and leadership and enthusiasm of an individual doctor. Unfortunately, with few exceptions, medical schools do not include any worthwhile period of training in physical and rehabilitation medicine. This, we believe, is wrong." (Vol.2, para.214)

"The clinical speciality of Physical and Rehabilitation Medicine has been defined by the International Federation of Physical Medicine and Rehabilitation [in 1973] as 'The diagnosis and management of the medical disorders of the locomotor system and an understanding of the principles of rehabilitation including prevention through the whole range of injury and disease.'" (Vol.2, para.215)

[For wider discussion see Penington and Burry, Medical Rehabilitation, 1990.]

[It is interesting to speculate on the historical beginnings of rehabilitation in warfare. Both the military and medical models have similar hierarchical organisational structures, authority, uniform, rank, spirit, etc. Such beginnings would echo when the rehabilitation services are extended to a civilian population.]

Woodhouse used definitions current in 1972-4 prior to the United Nations International Year of the Disabled Person (IYDP) in 1981 when a more rigorous use of the terms 'impairment', 'disability' and 'handicap' was adopted. 'Impairment' refers to the medical condition, 'disability' relates to the physical effect of the 'impairment' and 'handicap' is applied to the social effects of the impairment and disability. Before then, these terms had often been used interchangeably. It remains to be seen whether these improvements were more cosmetic than substantive.

The Sackville Report


In November 1981, the NSW Law Reform Commission, with Professor Ron Sackville as Chair, was requested by the
then Attorney General and Minister for Justice, the Hon F J Walker, "to inquire into and make recommendations concerning the circumstances in which compensation should be payable in respect of death or personal injury caused by accident." (Working Paper 1 - A Transport Accidents Scheme for NSW, 1983, p.v).

[It is worth noting that the financial strains of meeting the costs of third-party compensation claims, and the recent (1970s early 1980s) collapse of several large insurance companies, were raising serious problems for the main carrier of this type of insurance business, the (State) Government Insurance Office (GIO).]

Given the fact that the NSW Law Reform Commission was charged with responsibility for this Inquiry, it is to be expected that the legal aspects of the compensation system would receive full attention. Chapter 3 of the Working Paper addresses these legal issues, pointing out the delays, costs, resources and deficiencies in the system. Sackville emphasises that about one-third of road accident victims cannot claim compensation. For example, drivers in one-car accidents, will fail in their claims if they are unable to find 'fault' in a third party. (para. 3.10)

In respect of submissions made to the Inquiry regarding Health Care and Rehabilitation Services, Sackville noted:

"Many of the case studies emphasised the importance of health and rehabilitation services to accident victims. Very often the absence of these services or the cost of obtaining them has been crippling in both a financial and personal sense. A number of victims criticised the lack of support given to them and the absence of any clear information as to the services which were available. Some victims claimed that the lack of suitable support services forced them into institutional care or marred their independence and limited their opportunities for rehabilitation. It was clear to them, as it has become clear to us, that the provision of health and rehabilitation services is poorly co-ordinated and fragmented and that information concerning services is difficult to obtain. In addition, health insurance and health care funding are in a state of flux as a result of changes at Commonwealth level proposed under the newly announced Health Plan." (para.11.2)

[This referred to (Federal) Labor’s Health Plan, January 1983, for the Medibank Scheme funded by a 1% levy on income, the provision of free hospital and 85% medical expenses, and specific purpose block Health Grants to the States].
So, in 1983 the NSW Law Reform Commission was saying:

"Rehabilitation and other supporting services are presently supplied through a mixture of public and private health and welfare services, and also through families and friends. Because of the complexity of these arrangements we do not attempt to outline their availability, or the manner in which they are provided or funded. We do, however, regard the provision of such services as essential to the well being of accident victims, and these will be further examined in the course of our reference." (para 11.15)

Sackville mentions, often, the complexity of rehabilitation arrangements.

"Rehabilitation is an essential objective of an accident compensation scheme, and, arguably it is not adequately provided for by the existing common law and workers' compensation system. This was emphasised in a number of submissions. Clearly the provision of effective rehabilitation services benefits both the injured victim and the community. The victim benefits by developing skills which equip him or her for the maximum degree of independence in daily life and for possible entry or re-entry into the paid workforce. The community gains financially through reduced [social security] benefits and increased tax revenue, if the person is able to return to the paid workforce. More importantly, perhaps, the quality of life of the community is enhanced by the increased participation of disabled people within society generally. Rehabilitation is a proper supplement to compensation for lost earning capacity and it may be the most effective form of compensating non-earners, or those whose potential earning capacity has been impaired." (para 11.42) [emphasis added]

[These comments stand in stark contrast to the opinion of Dr. Smith, President of the Australian College of Rehabilitation Medicine, who presents the medical viewpoint in Penington and Burry, 1990, p.vi:

"The use of rehabilitation methods as an acceptable but expensive placebo is equally to be avoided in those who cannot benefit."

The term 'rehabilitation' has technical and specific meaning depending on the context in which it is used. There is often no common ground in medical, psychological, social, legal, equity, economic and policy (broad, administrative,
program) discussions as each 'discipline' narrowly defines its area of responsibility and lobbys for the best possible deal.

Sackville points out that the current [1983] arrangements are complex and fragmented and that

...[Commonwealth Rehabilitation Service (CRS)]
“services are generally confined to people with long-term and severe disability, who are within the working age group, and in practice they have been focused on vocational rehabilitation...

...It is virtually impossible to determine the extent of the use of the existing rehabilitation services or their costs, because of the fragmentation of such services." (para.11.43)

Sackville claimed that:

"...no-fault accident schemes, administered by a compensation authority able to provide or pay for services as and when they are appropriate should be able to provide more effective rehabilitation services. This appears to have been the experience under the New Zealand scheme where the recent trend has been for the authority to participate more extensively in rehabilitation services. Considerable attention is also being given to this aspect by the Victorian Motor Accidents Board. Amendments to the governing legislation in Victoria, which came into force in late 1981, created an obligation to introduce 'a programme designed to secure the early and effective medical and vocational rehabilitation of persons injured' as a result of motor vehicle accidents." (para.11.44)

[The philosophical debate about 'fault' and 'responsibility' continued at several interstate seminars in 1984-85 following the release of the Working Paper. I attended two of these seminars which were organised, in the main, by Law Societies and insurance companies. At these seminars there was strong lobbying for the abolition of the recently introduced Medibank/ Medicare, especially by the doctors. My impression of the underlying agenda was that if Medicare actually did provide universal health care it would help the no-fault concept to spread - an outcome not desired by lawyers and insurance companies who are philosophically opposed to government 'intervention' and in favour of 'peer review' (personal notes).]
[Update: In July 1994, amendments were made to the Health Insurance Act by the Health Insurance (Professional Services) Act, introducing a new definition of "inappropriate practice" (overservicing) which will effectively limit medical treatments to existing, accepted forms of therapy and impose severe penalties on doctors who use new diagnostic and therapeutic measures. ("A legal analysis of the Health Insurance (Professional Services) Act 1994", in ME and You, September 1994, pp.17f)]


Back to Sackville.

Again, Sackville remarked:

"It has not been possible at this stage of our inquiry to undertake a detailed examination of the issues raised by rehabilitation. It is a matter of great importance to a transport accidents scheme and is of considerable complexity. We would welcome detailed assistance by way of submissions from interested parties." (para.11.48)

Given his brief, there is no discussion of illness, as such.

[At the same time as all this was going on, there were inquiries into workers' compensation in all States (Workers' Compensation being a State responsibility), including the Commonwealth Employees' Compensation Scheme, which was later reformed into Comcare, see Ballard, 1991.]


Needless to say, things have been 'overtaken by events'. The current NSW State Government has solved its road traffic insurance problems by parcelling out the third-party business, and then selling off the GIO, which had a monopoly of the third-party insurance business, once again pushing the problems of compensation and rehabilitation into the future and leaving the social security system to pick up the pieces. The concept of 'fault' has been retained.
[And here I am asking rhetorical questions, nostalgic for my past life in policy analysis. Is it time for another national or state-wide inquiry into the provision of these services? Regardless of the political will to have such plans implemented, the strength of the lobby/interest groups cannot be overestimated. Perhaps it is a little early. Most States have made some reforms/revisions to their compensable injury provisions. It remains to see how successful these revisions are.]

...........

The introduction of Medibank, now Medicare, was a first step in providing universal health care (actually it is restricted to 'medical' care) to all Australians. Over time, these advances have been whittled away, principally through the extensive lobbying of the various interest groups and by the obvious difficulties of large scale administration.

This lobbying coincided with the manifestations of privatisation, corporatisation, Reaganism (USA) and Thatcherism (UK), Rogernomics (NZ) and Economic Rationalism and rampant inflation, and the subsequent collapse of those systems, for example, the rise and fall of WA Inc, the fall-out following the deregulation of the banks, the Homefund debacle (in NSW) and the (hoped-for) sell-off of public assets by governments of all political persuasions.

But I am getting ahead of myself, and indulging in editorial comment.

Since this is not a treatise on the insurance industry or the provision of risk underwriting, nor is it a treatise on the funding of health and rehabilitation services, I have no intention of following this train of thought any further (but I probably will!). Those interested can be no better advised than to read above, below, along and between the lines of both of these Reports, in the light of economic and political events, and to marvel at the number of pages of submissions and other literature that is generated by these debates.

But before I leave this, I have found a dog-eared page which alerts me to the path my rehabilitation seems to be taking, away from the insurance based compensation claims, into the world of chronic illness. Woodhouse reminds us (Vol.2, para 208), that "some present day rehabilitation programmes place an over-emphasis on employment and an under-emphasis on the
enjoyment of leisure hours." If in the early 1970s there was such emphasis, how much more emphasis will be placed on economic productivity in the 1990s?


And Yahweh said, "Where were you when I created the world?" and Job covered his mouth with his hand and said no more ... (The Book of Job, Ch.38.)


Several days later:

How does this fit in with Maturana’s ‘structural determinism’ in the biological roots of cognition, The Tree of Knowledge (Maturana and Varela, 1992)? Am I working in a way which is determined by my own internal structure. The text book approach requires a particular type of rigor. ME/CFS seems to put this approach out of action.

Reflection

Following the text book approach to a literature search is non-productive for me. So I looked for something that was productive. I had remembered what Pirsig wrote. In fact, I love his books. It didn’t matter, for the present, why I should find Pirsig easy to read. For the present it was enough that I did. Pirsig was on my wave length. He connected me with warm fuzzy feelings (an apology to the ‘rationalists’ for the use of such language!) and the excitement of discovery. He put me into a receptive mood. He led me to drop the text book approach and to connect with the feeling of discovery, and lo:

I became aware of my way of marking interesting information, within my limitations. 'The dog-eared day'. I did not have to locate, read, digest and understand all at the same time. If I could be satisfied with locating the information,
and then hold on to that, I could follow with another step at another time.

Yes. The quality, and the duration, of time had changed.

This is quite a tactile method – using hands to physically mark the book, which has the added advantage of being visible when the book is closed and the page can be accessed by fanning the pages.

I had to actually fan the pages of a book to find the word "fan".

I have thought about using coloured bookmarks (even torn up scraps of paper) for use in the library, but that doesn’t help with the need to ‘put it aside’ for several hours days weeks.

...........

I have made regular excursions during this exercise into the feeling realm, connecting with past experiences. It is not a simple

"one step forward ..."

... "back step one

... e n i t u o r

It is multi-dimensional ... as if ... when my cognitive pattern begins to scatter I can re-enter the cognitive domain via the feeling domain. But I have to make the detour spontaneously for it to work well. I can handle it better if I am aware of the scattering and allow the feeling level to take over. I feel this could be reflected in my comment about doing one thing at a time.

157
In the note-taking sections I initially put on my clerical hat and attended to copy typing – even there I have inserted some editorial comment, connecting with past memories or grabbing new information which drifts by.

As I write this I notice that these remembrances are comfortable and confident! I am tempted to edit out these editorials for fear of revealing where I am coming from!!!

Then I could feel it all disintegrating.

A kind of anxiety that this work-in-progress should be complete

and tidied up.
PART X

THE REAL WORLD

Small voice: Can we resume?

Okay. I'd like to thank you for your insistence that I go back and reclaim some of this earlier angst. For one thing, it connects me again with the source of my grief—the inability to do easily what I once took for granted; and the sense of belonging to a vital, passionate and committed group of policy people. I am clearly more able to move forward ... in fact, I marvel at how far I have come.

Small voice: You also needed to provide this background to the reader who may not have come out of such an environment. But now, can we leave this behind and get on with it?!?!?

Of course.

Pause:

Small voice: An added dimension to the search for rehabilitation is the notion of visibility. A physical injury is most often visible, it is immediate, it is acute. An illness or disease, by contrast, is often invisible, it is cumulative and it may be chronic. We can overlay these perceptions with notions of objective and subjective, legitimacy and illegitimacy, deserving and undeserving, believable and non-believable.

Right! As we overlay these templates, it becomes clear that in our rational, concrete, visible, demonstrable, observable and controlable society, we are more at ease dealing with injury than with illness.

Small voice: Are you saying, perhaps, that it is easier to deal with an injury, specific, definable, manageable, than it is to deal with an indeterminate, tentative, internal medical diagnosis?

As a society? Yes! Which one of the disciples needed to see and touch before he would believe? Thomas?

Pause:

Small voice: We haven't come far in 2,000 years!

Pause:
So injury (which is often visible and compensable) and illness (which is usually invisible and non-compensable) tend to fall into separate categories. However, as with any insurance matter, it pays to read the fine print! The personable and helpful marketing people who design an affordable policy are of a different species to the impersonal and legalistic claims people who point out the restricted nature of that affordable policy.

Small voice: And an added template - or should I say, groundplate - is the historical beginning of the rehabilitation system. And that is: rehabilitation has its origins in the injuries of warfare, such as blindness and shattered limbs. It had to do with re-habilitating service men back into civilian life. And with the provision of prostheses and appliances. Moreover, it had to do with a sense of moral obligation towards those whom the government and generals of the day sent out to do their bidding.

* Interruption: *

"["I sense that you are procrastinating. Please get on with the simple first steps. Be assured that you are nowhere near the dangerous ground of spirituality. I and my friends will be close at hand to help you negotiate the passage. So press on with confidence!""]

Who Are You? Thank you, whoever is offering this advice. I need to collect my bits and pieces, first.

* Disembodied voices *

Blackness:

"She is really scared of this stuff, isn’t she!"

"Why do you always attribute a careful and studious approach to fear?"

"Why are you preempting Small Voice? I thought we agreed that we would do our discussing here and leave it to Small Voice to speak with her."
"You're right! All this psychologising! This is a process thesis and as such she needs to be explicit about the way certain things are approached. That is the methodology. A thoroughness of method. Being explicit means acknowledging the hesitations, false steps, trying this and trying that, to-ing and fro-ing, testing the ice ... a certain tentativeness."

"What's this got to do with rehabilitation?"

"Ho hum! Rehabilitation is the substance; process is the context."

"Silly! It's the other way round! They both work together. Sometimes there is more emphasis on one, than on the other."

"You walk, one step at a time! Otherwise you'd be jumping!"

"Is she in walking mode, not jumping mode?"

"When does she get into jumping? That's what I want to know!"

"All this circling is driving me crazy!"

"Surely this is as valid a way to progress as any other? We circle around the issue, see it from all sides, getting closer and honing our perceptions, pulling back and amending our attitude."

"Okay. Okay. But it is still driving me crazy!"

"Well, how would you do it?"

"I'd just DO it! Heavens above! There can't be many ways to talk about rehabilitation - it's either there, or it's not. And if it's not, then what are we squabbling about?"

"That's just it! It isn't either this or that ... and that's the difficulty ... it's a bit of this and a bit of that. It's not all weft or weave - nothing would hold together if it were."

"Can I suggest that we get off her back - you know, that's what we've been doing. Pretending to support her, but all the while with strings attached. Could we see what happens if we really support her?"

"Have we been that manipulative?"

"You have!"

"Be fair. This isn't malicious manipulation. It's manipulation in the sense of trying to move things."
"Okay. I accept that. But it isn’t necessarily helpful. You’re assuming you know more than she does. And that isn’t right!"

"You’re all just too precious about things. Sometimes you just have to take a deep breath and jump ... that’s all I’m saying!"

"Well, where do we go from here?"

"Perhaps ... we could send her some messages about frogs, and that might do the trick?"

"In the absence of anything 'better' ..."

"C’mon ... that’s quitting ..."

"So what? You said that she knew more about things that I do!"

Small voice: Can I suggest that I take this back with me. Then she can decide whether or not our discussions have been helpful. Surely that is our task?

"Are we agreed?"

"Agreed!"

**Blossom trees, chirping birds ... and a pond**

**Humming bees:**

I’m trying to find a way to bring in a discussion about the background to rehabilitation and all I can see is to cut and paste from the notes I’ve made. And that doesn’t flow – it will look like a cut and paste job.

And I am struck by the force of the work of Bates and Linder-Pelz (1990, pp.1-12) – from a sociological perspective of conflict/consensus – and their explication of the acute/chronic division in the treatment of illness ... and since our medical system is set up, and funded, from an acute philosophical base, it is exceedingly difficult for that model to accommodate chronicity. And that throws me back to Barbara Walker’s (1985, p.33) book, *The Crone*, especially my earlier references to death and ageing – our culture wishes to conceal death from wasting disease after
slow degeneration of body and mind while it enjoys the spectacle of violence (p.80 above).

It all feels very messy, full of holes, dangerous and not at all 'friendly'.

Silence.

Small voice: We had quite a heated discussion last night.

Really? What about?

Small voice: About the intrusion, about procrastination, about process and content, about walking and jumping ...

Like a frog?

Small voice: Exactly! Can you see how you could jump in? For example, you have helped us understand how difficult it is to start something that you KNOW is going to lead into deep waters ...

Yes, just the KNOWING acts as a barrier.

Small voice: Perhaps you could tell me about this KNOWING?

How?

Small voice: For instance ... what does it feel like, look like ... what colour is it ... physically?

I see what you mean. Well, it is large and cloud-like. It takes the edge off things and makes them indistinct. It isn't frightening, in the usual sense of frightening...

Small voice: How do you mean 'usual sense'... 

... a kind of foreboding, nasty, gut-wrenching, nauseating, cold and freezing kind of thing ...

Small voice: Right ...

... it's more like a softness, mushiness - I don't know which way is up. I KNOW that I am moving, unlike the fear which stops me moving. I KNOW that I am moving, taking step after step.

Small voice: So what is it that is different?
It's the not being able to recognise, to label, to speak about...

Small voice: About what?

Well, if I knew that I'd know what to say! But the confusion arises when I use everyday language in a metaphoric way, and even I get confused at the going in and coming out point.

Pause:

Small voice: So you're saying that the difficulty you have with starting is exactly that huge difficulty of 'going in'?

Yes. Perhaps our interruption that led on to your discussion about jumping in is indeed apt and appropriate.

Small voice: Could you try to be a bit more precise about that?

Right! I had said earlier about the use of everyday terms...

Small voice: Like hope and hope...

... and the Wizard of Oz, and learning new skills, and crossing thresholds... all of that... oh, what am I trying to say...

Small voice: Take your time! Slow down. You are at the threshold, changing over from one reality to another. You are trying to deal with rehabilitation and rehabilitation. But you have now identified that with a new concept of...

... redemption and reconciliation...

Small voice: ... so how does that help?

I realise that I can't just take one step after another. At this point I have to jump. I can't straddle the line - either what I am talking about is prior to the threshold, or after the threshold. Then I have two distinct contexts in which to work. This crossing backwards and forwards is necessarily messy and imprecise.

Small voice: Does that mean you have to abandon your ideas of weaving the past and future?
I'm not sure. Perhaps I'm trying to grab hold of ideas and force them into some template I have...

Small voice: ...and are not aware of?

Perhaps? What might that be?

Small voice: I don't know! Would you like me to take it back to the group, next time?

Yes please! Even if there is a lot of squabbling, it certainly shakes things up.

Pause:

Small voice: Can I leave you here to make some sense of this?

That would be appreciated. I think I'll just watch the bees and the blossoms. Who knows, maybe a frog will come by. Thanks!

Silence.

...........

So, I wonder, is it not possible to live in two worlds? Or is it? It is, but only if I admit the spiritual dimension into my everyday pragmatic day-to-day life. There is no hedging about. Maybe I need to say where I am now and then trace the journey as to how I got here. Didn't I do something like that at the beginning. I'll tell you the end first, and then,

a
   n
d   t
   h
   e
   n.

...........

165
Disembodied voices

Blackness:

"That was a heavy session. Thanks Small Voice."

"What did we learn from that?"

"I didn’t realise that there is an invisible barrier at the threshold ... I was only joking about the frog...still..."

Small voice: Actually, I think that helped.

"What about this invisible barrier?"

"It certainly feels powerful."

"I don’t understand what she means about language, using the same language for different things and then finding other words, like redemption ... "

"You’re right! I’m sure she’ll now be able to get onto the psychological and physical realities ..."

"...and speak about them because of the third, fourth, fifth dimension, the spiritual ..."

"Hold on! You’re just getting into jargon!"

"You’re a fine one to talk about jargon!"

"And, therefore, I’m just the one to talk about jargon, since I know it so well!"

"Didn’t she want to avoid the jargon?"

"Exactly! And that is why I am so helpful! Jargon is not only helpful to exclude people, it is also helpful to use BEFORE you know what you are talking about. Afterwards you can dispense with the jargon. But it is like a symbol, it is helpful to indicate the presence of something you don’t yet fully understand."

"Right! So what sort of jargon do you think would be helpful?"

"Already she is talking about spirituality - she needs to think about that, and directly connect that to rehabilitation. She has mentioned redemption and the likes, but what does that mean in spiritual terms?"

"Perhaps, if she could jump into spirituality for a while?"
"Actually, I think she needs to make a whole-hearted attempt to get back into the pragmatic. What’s happened is that she is caught between the two and therefore can’t speak about either without confusion."

"Is that really what’s going on?....I’m not so sure?"

"There is something really important about this break, being about to use different words ... go back to the last bit, she was talking about hope and hope, intelligence and intelligence, rehabilitation and rehabilitation ..... now she has got to saying rehabilitation and redemption, reconciliation.

Small voice: You keep forgetting that word reconciliation.

 Interruption: 

Yes, I wonder what that’s about ...

 Interruption subsides: 

"Hang on! She’s getting involved in our conversations."

"On this point I move that we adjourn for some reflection and refreshment. Things are complicated enough without her finding her way in here."

"I think that’s a marvellous idea!"

"Scones?"

"Lovely!"

...........

The reflecting pond

Off to the side of the courtyard is a small pond. Not really a pond, more a slight indentation. It is surrounded by iris, blue and white, and a clump of bluebells.
What is really interesting about this pond is that it doesn't really exist, except as a bird bath atop a piece of sandstone. But if one could imagine this ... a deep pond, the quiet end of a rushing waterfall. Quiet and still and reflecting ... reflecting bluebells, irises - blue and white, and a strange face. Two eyes and arcing brows reminiscent of the birds which come to bathe several times a day - bulbul, a blue wren and two jennies, several lime silver-eyes. Yesterday, a magpie ventured into the plum tree to have a look.

Maggies are curious birds. Curious about ... reconciliation?

Small voice: Wow! Do I get to look up dictionary definitions again, please?

Go to it. I can't be bothered!

Sounds of activity:

Small voice: reconcile The Concise Oxford says: 1. Make friendly after estrangement; 2. purify (consecrated place) by special service after desecration; 3. Make resigned or contentedly submission (to disagreeables); 4. heal, compose (quarrel); 5. harmonize, make compatible, show compatibility of by argument or in practice - with and/or rarely to another.

conciliate: gain (esteem, goodwill); pacify; win over (to one's side); reconcile (discrepant theories).

How about rehabilitation?

Small voice: rehabilitation. Fontana says: 1. Rehabilitation is the combined and co-ordinated use of medical, social, educational and vocational measures for training and retraining the individual to the highest possible level of functional ability. The main aim is maximum restoration of physical, mental and social capabilities. Good rehabilitation ...

Obviously there is such a thing as 'bad rehabilitation'?

Interruption:

["What about training and re-training. Animal images vs education vs journeying and growth."]
Interruption subsides:

...requires a team approach involving the patient, family doctor, consultant, appropriate paramedical therapists, social worker, the family and employer. Rehabilitation of the physical disabled will involve the services of many paramedical and other support groups, for example, physiotherapists, occupational therapists.

Interruption:

["This computer wants to hyphenate therapists to the-rapists!"]

Interruption subsides:

speech therapists, social workers, also the voluntary agencies."

Pause:

This ties in nicely with Penington and Burry's (1990) Chapter 3, on "The Therapy Team" seen from the perspective of the "Team". Question: Can the patient identify him or herself? Is this how it is seen by the patient?

The patient must be seen [by the Therapy Team?] as an active member of the team, agreeing to all goals and plans, if not actively participating in their development. It is the patient's life that has been changed by the impairment, after all. [Oh, thank you for the acknowledgement.] It is essential that the patient's views are represented [not necessarily heard or acted upon?] at the team meeting, if the patient is not present [perhaps it is easier if he or she isn't?], and that [the Therapy Team's?] decisions are fed back to, and discussed with [told to? explained? open to appeal?], the patient. [emphasis added]

Small voice: Need I go on to say that it is also a political term, in the former USSR?

Oh do!

I think it is interesting to see the underlying attitudes in the use of a word which make it so useable in other contexts.

Small voice: Okay. Back to Fontana...
"Rehabilitation: (2) In politics, a term used particularly of the posthumous acquittal and restoral to Party favour of communists executed during the purges in Russia and in Eastern Europe in the Stalin epoch. In Russia, it is applied largely to political leaders executed in secret, to Army leaders, and to certain writers. Of those accused in the public Moscow Trials only half a dozen have been publicly rehabilitated, though statements have been made which are incompatible with the guilt of any of the others. Rehabilitation on criminal charges does not always imply complete political rehabilitation as well. A further process, sometimes known as derehabilitation, has also been noted, by which certain Party officials (e.g. F. Raskolnikov) restored to Party favour in the early 1960s have been denounced as traitors once again."

Now does this sound like an underlying concern with the health and happiness of people, or a kind and caring approach? One does not need much convincing that coercion is a significant element of rehabilitation. Just look at the prison system!

Interuption:

["And the discipline of the Commonwealth Rehabilitation Service (CRS) Program!"

["What do you mean?"]

["She means the bit about having to be punctual and regular as a condition of entry into the program."]

["Actually, the words are:

In order to benefit the most from the programme, it is important that participants attend all sessions. It is therefore not possible to attend some parts of the programme (i.e. physiotherapy) without the others.

1I have only recently heard, anecdotally, via an independent source, that hands-on physiotherapy is viewed within rehabilitation circles as 'soft' and likely to 'encourage dependency', and as such it should not be easily available. Besides, it costs too much!"
You will be expected to attend 70% of all sessions. If you are unable to meet these requirements your continuation in the programme will be discussed with you. (CRS 1993, p.1)"

Interruption subsides:

Small voice: So where does this take us?

Not so fast. We have yet to look at redemption.

Small voice: Right! Let’s start with redeem: The Concise Oxford says:

"1. buy back, recover by expenditure of effort or by stipulated payment; compound for, buy off, by payment: 2. perform (promise): 3. purchase the freedom of, save by ransom: 4. save, rescue, reclaim; (of God or Christ) deliver from sin and damnation: 5. make amends for, compensate, counterbalance; save from a defect."

However, I find redemption might offer some insight: something that is beyond redemption is considered hopeless! Of even more interest is deem: "believe, consider, judge, count".

Can we try to put this altogether to see if it helps with our concern here with rehabilitation which in my simple sense means, a situation in which one is able again to ... whatever. This notion of return, to do again what one was formerly able to do, habitually, is not appropriate where one must learn anew, new and different abilities - or new and different ways to use old skills. There is no re- in this habilitation. Interestingly, habilitate is used to mean ‘to furnish a mine with working capital’ and ‘to qualify for office (in a German University!)’ Habilitate has none of the coercive qualities attached to rehabilitate.

Small voice: Okay! So how does this fit in with redeem and reconcile? I can see the connection between redeem and compensate!

Somehow one can redeem and reconcile oneself. Rehabilitation is something that requires the input, if not authority, of others. If, however, I choose to rehabilitate myself then I undertake to perform the task normally undertaken by the various experts ...

Small voice: You become your own expert?

In relation to myself, in my own unique situation? Yes!

Small voice: And your own punisher or disciplinarian?
Most definitely not! Carer, perhaps ... yes.

Small voice: I’ve just connected with your earlier discussions about the difference between a discipline and a technique which is, at bottom, an ethical issue of control!

Of course ... the discipline was in relation to meditation (pp.30 ff. above) ... and Anne Wilson Schaef’s exploration of the addiction of control (pp.39, 68 and 123 ff. above).

Pause:

Small voice: So what is the connection with the notion of compensable and non-compensible?

You just want to look up more definitions, don’t you?

Small voice: True!

Okay.

Small voice: compensate: The Concise Oxford says: 1. counterbalance; make amends (for thing, to person, with, by, another thing) compensation: thing given as recompense.

Pause:

That’s not much help. It is only in the area of the law, where blame can be apportioned that compensation can be enforced.

 Interruption:

"She’s yet to make the connection with compensating in her own personal life for the loss caused by ME/CFS."

"Leave her alone. She has to get this off her chest before ..."

"Well, of course she’s got to do that ... but can’t somebody give her a shove?"

"I didn’t mean to start an argument ... I was simply making a comment!"

"You and your bloody comments!"

 Interruption subsides:
Small voice: And, of course, that means that in order to limit the liability of the insurer, the successful claimant can be required to undertake rehabilitation ... it is mandatory. For example, this is spelled out in the Comcare Act (Ballard, 1991, pp.79-88.)

But that means that the responsible party who accepts the liability (usually the insurance company) is the one with the power to set up and maintain a system of rehabilitation for purposes other than, or in addition to, the wellbeing of the injured party!

Small voice: I don’t see what you’re getting at.

Irritation:

What I’m getting at is that UNLESS the injury can be attributed to a guilty party (person, manufacturer, employer, etc.), and an insurance company accepts liability on behalf of that guilty party, there is no access for an injured party to the rehabilitation system! The system itself is set up to look after only one class of person. The system is not designed with access for the general public. (Refer to Part IX, "A Rather Long Detour" (pp.142 ff. above), on the public debates surrounding the various compensation and rehabilitation schemes.)

Small voice: But didn’t you ‘self-refer’ to the CRS?

That I did.

Pause:

But the CRS can decide if, in their opinion, I am a suitable candidate. Depending on their aims and objectives it could be decided that such rehabilitation as they are offering is inappropriate – in line with Dr. Smith’s comments: "The use of rehabilitation methods as an acceptable but expensive placebo is ... to be avoided in those who cannot benefit."

(Smith, in Penington and Burry, 1990, p.vi, and referred to in Part IX above.)

Pause:

Small voice: And what about the insurer?

The insurer? The insurer takes the legal responsibility by virtue of being paid, via a premium, to provide either the service itself or the money to pay for such service.

Small voice: So it is the insurer who has the biggest slice of the action – the most to lose – because of the nature of the role of insurer?
Right! So am I saying that unless I am likely to make a claim on an insurer (and that means that I, or somebody on my behalf, have paid a premium) then the insurer doesn’t know I exist?

Small voice: And if you don’t exist, then there is no need to provide services.

So, even if I am prepared to pay, privately and individually, I cannot access the services, because I don’t exist.

Small voice (softly): Oh dear. I sense that we are getting into an area of deep personal hurt.

Pause:

There is despair and confusion. Simple medical rehabilitation is only at the level of medical intervention. Once the medical situation has been stabilised, one moves through to the convalescent stage. In the acute care model both these stages are seen as of limited duration. Once an optimum (if less than satisfactory) outcome has been achieved, that is, there is no ongoing treatment which is likely to be offered, the books are closed and the person with a chronic disability is left to fend for him or herself.

At this point they sometimes stumble across a self-help group which has received some media coverage. I have no evidence of people being referred to self-help groups by medical or paramedical practitioners. See Bates and Linder-Pelz (1990) *Health Care Issues*, for an illuminating discussion surrounding the activities of self-help groups and the ambivalent attitude of the professions towards these groups.

Small voice: You mean the attitude that people join self help groups in order to become dependent and to wallow in their affliction?

Much huffing and puffing.

Yes.

Silence.
It still hurts

Small voice: Remember the time you went to the local community health centre?

I certainly do. Early in the piece, I went to ask for psychological counselling to help me deal with my loss of life(style). This followed the diagnosis of ME/CFS in Canberra in 1985. A doctor suggested that hypnosis/deep relaxation might be beneficial in coming to terms with the impact of ME/CFS on my life. He suggested I seek out some services when I moved to Sydney. At the time I was in receipt of Department of Social Security (DSS) Sickness Benefit and was unable to afford private counselling. After an interesting chat with a counsellor at a community health centre, I was told that I was not in crisis and they were being funded to deal with people in crisis. (I was embarrassed when I realised that Community Health Centres in NSW deal principally with community care of psychiatric patients and drug and alcohol counselling.)

Small voice: But she did direct you to the work of C. G. Jung, the Adyar Bookshop in Sydney and the existence of (then) Hawkesbury Agricultural College.

A puff of cool air:

Thanks for reminding me. I’d forgotten. Yes. The counsellor told me that she had recently completed a Graduate Diploma in Social Communication at Hawkesbury and during our friendly chat she suggested that when I had more energy I might well find some kindred spirits at Hawkesbury. However, it took almost three years before I was well enough to make the initial contact. In the meantime I felt I had found a friend in C.G. Jung.

Small voice: And the bereavement counselling after Helen died?

True! My sister, Helen, and her four-year-old son were killed in an inexplicable car accident at Christmas 1989. Her husband and nine-year-old son were seriously injured.

Silence:

It was really quite strange how that came about.

Small voice: What do you mean?

Well, I’d been having abnormal pap smears (before Helen’s death) and was feeling very confused by the advice I was getting from a gynaecologist. A friend suggested I talk to the Women’s Health Advisor. The chat was really helpful and
informative (it didn’t stave off a hysterectomy almost three years later!). During our conversation I mentioned that my sister had died almost a year ago. It was the Women’s Health Advisor who not only told me that there was a bereavement counsellor available, and encouraged me to see her, but she also organised our initial appointment.

Small voice: That surprised you, didn’t it?

Certainly. I found the sessions extremely helpful.

Pause:

But when I wanted to talk about the effect of ME/CFS on my life, I was led back to discussions about Helen. When I continued to talk about ME/CFS, the bereavement sessions were terminated.

 Interruption:

["Clients shouldn’t have two experiences at the same time, such as a loss and a chronic illness."]

["Surely she’s aware that this would require greater skill and empathy of professionals?"]

["It’d make the statistics difficult!"]

["Maybe grief is not considered ‘clinical’?"]

Silence:

Small voice: And referrals to a physiotherapist?

Again, I referred myself after years and months of physical pain ... and it was only because I had finally received my superannuation that I could pay for the sessions ...

Small voice: Am I correct in saying that there is no co-ordination of treatment or referrals to the various paramedical services?

No!

Small voice: And why is that?

Now that sounds just like a Dorothy Dixer!!!!!
Small voice: Well, I wouldn’t have to come at things so indirectly if you weren’t so ... in ... infuriating!

Am I?

Small voice: Sometimes. Yes!

Silence:

I don’t think you realise just how painful it is to write about all of this.

Silence:

Small voice: I know you don’t want to do it, but please make the effort to put the health system in some kind of context.

Sighing.

A Quick Spin Around Health—(Medical)—Care Issues

Erica Bates and Susie Linder-Pelz (1990) point out that often the patient gets lost between the various agencies. Politics is primary.

And the source of funding reflects the politics involved.

In an ever-changing world, where economic rationalism reigns, and the bottom line is the only line to toe, I put forward a crude outline of the current system. Of course, as I speak, there are experts beavering away, endeavouring to cut costs.

Irritation:

Small voice: Beats me! Now matter what it costs, it costs. Playing with the deck chairs on the Titanic doesn’t reduce costs – it simply relocates them for a time, until the weight of the relocation results in
another move, on the part of the sub-system/holder, to relocate ...

Stiff breeze springs up:

The medical system gets its funding primarily through the Federal government, and patients are covered for the bulk of medical costs through the Medicare system, financed through a universal, but limited, levy on taxable income.

The hospital system is partly, and indirectly, funded by the Federal government (through the income tax system and State government yearly grants) and directly controlled and funded by individual State governments.

Small voice: At one time it used to be funded, in part, by the NSW State Lotteries.

 Interruption:

['"Until they became privatised!"

['"You’ve got it wrong! It all went into consolidated revenue!"

Irritation:

Small voice: Shut up! You lot. She’s a hostile witness and this is very stressful, not least because she isn’t up to the substantive research necessary to cover all of the issues, chapter and verse.

Irritation subsides:

With the exception of Social Security recipients, who receive free medical and hospital treatment, and those who are in the low-income category and who have enough self-esteem to beg, all other people are encouraged to carry private health insurance.

Small voice: I hope you aren’t going to get into poverty traps, universal and selective coverage, regressive taxation, equity and fairness, and the like.

Not at the moment, but I think public debates about the merits of different ways of funding essential services would be less acrimonious if the underlying ethics were made explicit.
Stiff breezes, cross currents:

The enormous complexity of the organisation of public finances and their philosophical unpinnings is beyond the scope of this research. However, I would refer the reader to some excellent sources ... And a good place to start is the Newsletter from the Social Policy Research Centre at the University of New South Wales. Or the Institute for Family Studies, in Melbourne. Or the Brotherhood of St. Lawrence. Or the Catholic Commission for Justice and Peace. Or the Australian Council of Social Services (ACOSS) and its various State counterparts. Or the Commonwealth Departments of Social Security and Health, the State Departments of Health and Community Services and the Local Government provisions for health and welfare services.

Then there are the numerous industry lobby groups - doctors, lawyers, farmers, miners, trade unions, etc. ... all of whom argue strongly for their particular interests. At the international level is the enormous output of the various committees of the United Nations and the Organisation for Economic Cooperation and Development (OECD).

Small voice: Or you could try your local member of Parliament ... and the relevant faculties at the local University ... current affairs programs and feature articles in reputable newspapers ... and the older members of the community who have a lifetime of experience.

Pause:

But ... to continue.

Patients without private insurance are treated as ‘public’ patients and are ‘paid for’ through the Medicare system. Hospitals and doctors can charge additional fees which are, again, only partly covered for those ‘private’ patients who are privately insured.

Outside of these two ‘big’ systems (medical and hospital), are a multitude of other private systems which directly charge patients for services. There is no general rule regarding which, if any, of these services are covered by health insurers (I think this is called the benefits of competition and privatisation!). In addition, only those expenses in excess of $1,000 (currently) attract a small taxation rebate, and then only if these services were ordered by a medical practitioner. In reality, very few are. And Bates and Linder-Pelz (1990, p.175) make the point that:
General practitioners in private practice do not generally refer patients to health centre staff such as social workers, psychologists and community nurses. Nor do people generally refer themselves [because they don’t know of the existence of services or because they don’t know how to access the system, or even that it is possible to refer themselves].

Squeezed out from between the ‘universal’ medical/hospital system and the confused overlapping of the scattered ‘private’ system is The Community System. This is another scattered system, and the structures and functions reflect the underlying philosophies of the various State governments which regulate ‘the community’. There is no uniformity across States on the type and level of service permitted or available.

What emerges is a distinct hierarchy, with doctors at the apex and the community system at the base. There seems to be very little communication between the various levels of service providers, and a seeming inability of those on the lower levels to question the decisions of those on the higher levels. There also seems little chance that those on the lower levels could influence anything of a larger policy nature in any level above them.

I have heard professionals argue that they are not concerned with politics, they are only interested in people. Perhaps if more were politically aware, the people they minister to would get a better deal? But, the systems appear to operate as if there were unaware of each others’ existence!

*Interruption:*

"Sounds like a well-functioning bureaucracy to me! Be fair! If you had to work with an awareness of ’the big picture’ you’d find it hard to farm your own patch! Watching for marauders! Making sure you didn’t lose your edge! Ensuring that you weren’t the one to suffer the cold steel of the razor! The inevitable down-sizing!"

"Leave her alone! This is really hard slog."

"I don’t know why she has to *contextualise* everything."

"And what would you know?"

*Pause:*
Small voice: For heavens sake! Let her get on with it. You’ll have plenty of time afterwards to have your say.

Irritation subsides:

Of course, alongside the bureaucracy are the counselling services run by religious groups and voluntary agencies. The growth in self-help organisations can be seen from at least two perspectives. On the one hand, self-help

emphasises the [society’s?] need for people to be self-reliant, both in relation to particular illnesses and in maintaining their health in general.

On the other hand,

most self-care has grown around chronic, disabling and stigmatised conditions for which conventional professionals have no cures and no means of alleviating the pain and discomfort of the patients and their families.

(Bates and Linder-Pelz, 1990, pp.108-109)

Pause:

Small voice: Can we get back to rehabilitation?

Pause:

So unless you can get into the rehabilitation system through the hospital-provided services, provided generally for in-patients, or for out-patients who have previously been in-patients; or through the privately-provided services which respond to the needs of insurance companies ... then, as Bates and Linder-Pelz (1990, pp.71-72) point out, the patient gets caught in the void. "A lot depends on the patient’s ability to find existing services and/or experts."

Moreover, disability is seen as deviance and ...

Small voice: I though you weren’t going to get caught up in all this angst?

Pause:
As you are well aware, I have been trying my darnest to avoid it, and it was you, if you remember, that pushed me onto this nasty piece of thin ice.

Small voice: Well, you were spending so much time avoiding it I thought you may as well venture on to it, express your angst and then be free to move on to greener pastures.

Pause:

Okay. It’s a mess. It shouldn’t be like that. Something ought to be done. And I feel powerless to do anything about it, other than describe it.

Small voice: And that’s all that’s required.

No! That’s not all that’s required. What’s required is to get some straight talk going. All this window dressing. All these impressions and perceptions and underlying assumptions about ‘availability’ ... all WRONG! And the easy talk...

Small voice: From whom?

From ... from ... from insurance companies, in their glib marketing of their product;

from well-meaning professionals who insist (because they believe it to be fact) that things are available when they are not;

from well-meaning people who had the luck to fall into the right stream of traffic, and presume that everybody is that lucky;

from those who have the financial resources to afford what fragmented services are available in the private sector, and assume that if you can’t afford it, then you don’t really want/deserve it;

from those who have financial and emotional and social support, who look pityingly at those who don’t, and then assume that, perhaps, they like it that way!

Much steaming and hissing:
Thank you for letting me say all this!

Small voice: No need to thank me, it's your thesis!
But, basically, people just don't want to know!

Why would they? Disability is deviance! Even with the
greatest self esteem in the world, months or years of being
treated like a deviant takes it toll...

Small voice: and then?

... and then when you do finally find professional help, you
still hear: "Why do you think you chose to be ill in the
first place?"

Small voice: Life's a bitch...

["...and then you don't die!"]

The disappointments congeal.

The sheer number of disappointments, tolerable in their
singularity, compound. Every little disappointment ever
encountered finds its way to this congealing mass.

 Interruption:

["This is not illness behaviour. It is stress cause by
interacting with the system."]

["It is being invalidated."]

 Pause:

It is all too much.

Much too much.

There is nothing I can do about it.

 Silence:
The threshold

It is at this point, this standing on the edge of a cliff, that all notions of going back reveal themselves to be pious hopes, wishful thinking.

A parting of the ways is inevitable. The realisation strikes sharp and clear that the end of the road has been reached ... no going back.

In future, any trip back there will have to be undertaken wearing a space suit - for protection.

In future, any reference to common-garden-variety things will need to be wrapped up in the knowledge that I am here as a foreigner, an outsider. I might be using the language of the locals, I may even have lived here at some stage, but it is no longer my place, it is no longer friendly.

I have to get what I’ve come for and get out quickly, before the barbs of control, choice, productivity, achievement, success, ambition, community, goals begin to pierce my, as yet, crude and makeshift armour.

Time to withdraw, to interiorise, to work on my suit of armour so that I may pay longer visits to this foreign land, without being mortally wounded.

Time for inner work. Inner growth. Tuning into the cosmos. Into the bigger world which has its starting point deep in me. Awareness of suffering, of pain, of heat and cold, darkness and light, of solitude and connection with something other.

Time to meet the infinite, the essence, to learn of my special task, to find out who I am - stripped of all these outer trappings.

Time to bathe the wounds and nourish the emerging self.

Silence.
PART XI

WHERE SHALL WE START TODAY?

Destination: Unclear

Small voice: Where shall we start today?

First up, I just want to say that I wrote to Clarissa Pinkola Estes (1992) yesterday to tell her that when reading her book, Women who run with the Wolves, I could hear the voice of Colleen Dewhurst.

Small voice: The actress who died recently?

The very same!

Small voice: Really? And why did you do that?

I heard her speaking with Margaret Throsby on Radio National (Australian Broadcasting Corporation, "Life Matters" program, 28 September 1993) but didn’t think to phone ...

Small voice: You? Phoning a talk-back radio program?

Silly idea, isn’t it! But after the program had finished I had a flash that I wanted to tell her about Colleen Dewhurst. So I wrote a letter, in care of her publishers.

Small voice: And you posted it?

Yes, I did. Without thinking about it, without sleeping on it. I just wrote it, put a stamp on the envelope and popped it in the post box (see Appendix G).

Small voice: Funny person! So where are we going to start today?

Pause:

I wanted to pull out a couple of quotes from a book by Shulamit Reinharz ...

Small voice: Great name, eh?

Interruption:

["What’s names got to do with it?"]

Pause:
... well...yes.... The book is called *On Becoming a Social Scientist*. She quotes from a paper by Friedlander (1967) on "Researcher-Subject Alienation in Behavioral Research".

The determination of who is researcher and who is subject in behavioral research is somewhat arbitrary since it depends entirely upon one’s point of view ... Similarly, the designation of just what are research results and what are irrelevant background data is arbitrary. The researcher, however, assigns the role of who will play researcher and who will play subject, and he also determines what will be considered as research results. These decisions, in part, are predetermiined in accordance with his interests and hypotheses. The subject, however, may choose not to accept the roles which the researcher has assigned. He may decide, unknown to the researcher, to play a research role himself, thus placing the researcher in the role of subject ...

... In this sense the research process and research results are completely embedded in and confounded with a set of ongoing research-subject relationships. (Reinharz, 1991, p.322)

She goes on to say that:

Researchers should explore and then bracket their attitudes toward their subjects so they can differentiate what was brought to the encounter from what was brought away.

Advances in knowledge about psychosocial realities require the assistance of subjects who feel ready and willing to be partners in the enterprise. There must be room for subject involvement in the research... Relationships devoid of these qualities ...

[Reinharz here draws on the concepts of 'participation' and 'parity' in an article by M L Wax (1972)]

... seem inappropriate for the study of significant human concerns ... [Further more], researchers must possess personal security and maturity to overcome their ego boundaries. (Reinharz, 1991, p.323)

One assumes she is stating some 'ideal'.
Ethics and the client

This is foremost in my mind this morning because a few days ago I wrote my doctor a brief report of my experience, as a client of a pilot rehabilitation program. This pilot program was advertised as being designed specifically for people with ME/CFS (Commonwealth Rehabilitation Service (CRS), 1993). In this report I indicated what I found of benefit and what was disappointing. I also included some comments made to me in one-to-one sessions. I felt able to do this because I was sending this to my doctor and what I said would be covered by the ethics of the doctor/patient relationship.

Small voice: What's the problem?

The problem is an ethical one. For instance, there are at least two agendas. One is that I was informing my doctor of my state of health. But it also felt as if I was 'telling tales out of school' ... gossiping, so to speak.

Small voice: I don't see.

Pause:

While I was a client in the program I tried to introduce my involvement in my Master's research. I sought in various ways to alert the professionals running the program that I wanted this to be part of my research, too. I somehow wanted their acknowledgement that they were aware that I was a researcher as well as a client. However, I could not strike up any relationship other than as 'client'.

Small voice: Maybe you went about it the wrong way?

I know I didn't do it well. In fact, that is what I learned. That I didn't do it well ... and I didn't learn how to do it any better.

Pause:

I had tried before, when I had been in a group (at Prince Henry Hospital, in Sydney in 1992), as part of a controlled evaluative trial on the efficacy of a Cognitive Behaviour Therapy approach in coping with ME/CFS. The trial was announced by Ian Hickie (1992) in an article "Assessment of Psychological Treatments in Patients with Chronic Fatigue Syndrome. (Why should patients with CFS cooperate with psychiatric research?)".

The studies planned for 1992 represent our current attempts to dispel the many myths that surround
this disorder and to continue to demonstrate to others that we do not make statements about the likely 'cures' for CFS until we have conducted adequate scientific trials.

We hope that patients with CFS will continue to support our efforts to evaluate proposed treatment strategies, be they immunological, psychological or anti-infective. (Hickie, 1992, pp.8-9).

Small voice: How did you handle it then?

I disclosed, during one of our group discussion sessions, that I was doing my Master's on rehabilitation and that I was interested in the underlying philosophy of this particular method/therapy (cognitive behaviour therapy). The response of "Oh, yes?", was followed by obvious disinterest.

Small voice: A sort of ... "So that's what you're doing, eh? How interesting/boring/irrelevant!"

I then approach the psychologist, personally, and told her what I was doing. At the end of the trial period I wrote a report to her about how I had experienced the program. She phoned and suggested we meet and I was delighted.

However, it turned out that she was concerned that I hadn't 'understood the therapy' and that I probably needed some personal one-to-one counselling. When I tried to put the meeting onto a more 'we-are-researchers-together' basis, and explore the assumptions underlying this particular approach, she did not step out of the role of therapist. Rather she explained, again, how cognitive behaviour therapy is supposed to work.

Pause:

Small voice: What happened this time?

Pause:

Well, to a large degree ... exactly the same!

Small voice: You mean indifference?

Yes.

Small voice: It seems to me that you are up to your old tricks!

Pause:

What do you mean?
Pause:

Small voice: Going to the butcher shop to ask for milk! You have to keep in mind that 'they' are offering the program. 'They' have designed it. And when you sign up, you are signing up for what 'they' have in mind. The CRS would be operating from a very traditional basis. They would have pre-arranged protocol. They would have their own agenda.

Of course! At the back of my mind I was hopeful that they would be interested in what it was I had to say, out of my experience of ME/CFS.

Small voice: So what was the difference, this time?

Pause:

The problem that I was now grappling with seemed to come to me in the following question: How was I going to be able to use the information I gleaned if I hadn't got an ethical clearance from them (professionals and fellow clients). As a client, of course, it was made clear that I agreed to the results of the pilot program being used for research purposes ... a less formal version of the medical 'informed consent' protocol. There is no reciprocal consent, from the point of view of the client.

Small voice: Actually, there was no need for the formal consent because it is a government program, funded by the government, and all such programs would be evaluated. And that, necessarily, results in analysis — both qualitative and quantitative.

Irritation:

["Evaluated in terms of their objectives and agendas ... and based on the statistics of eligibility criteria!""]

["She's missed the point ... publication!!!"]

["Does she know just how many records about her are taking up valuable space in computer storage?"]

["Actually, I think she does! And she also knows that after the fact, the computer/written/professional record is 'god'!"]

["Scare-rey!"]
"Hang about guys! I think what she is grappling with is not so much the Freedom of Information type of information, although that is important, but the underlying ethics of the situation."

Long pause:

Now this leaves me in a dilemma. On the one hand, 'they' can use anything I said or did in their research because I have 'consented'. I was required to consent in order to be accepted into the program. On the other hand, what 'right' do I have to use/publish what I learned?

Small voice: Well if you are making a personal comment about your impressions and feelings and thoughts ...

No, that's not the point. The point is that ...

Small voice: You're getting yourself into knots here. Surely it is the same dilemma facing journalists who get 'off the record' comments ...

Journalists are professionals! What they do is in the public domain. People know, or at least it is assumed that they know, that a journalist is out looking for a story and the interviewee is 'fair game' and should be aware of that.

Small voice: Another one of the myths!

I, in my capacity as 'client', am assumed to have no power. Anything can be said to me, and if I repeat what I have heard, and somebody wants to take exception to what I say, then I can be dismissed as ... as ... 'insignificant', 'deviant'...

Small voice: "She has a problem, that one!" A sort of, "my word against yours"? Master/slave ... actually, think about The Royals and their servants or, more dangerously, their ex-members!

Interruption:

"Not only that. What is learned about the people in the group can be used to end the program."

"Yes! What if she cruels it for others?"

Pause:
Yes, that... and I want to pass on what I have learned, but feel constrained.

Small voice: Isn't that just a normal day-to-day dilemma?

No. In a normal day-to-day living, it is generally assumed (perhaps incorrectly) that friends and relatives are in a special relationship of equality and trust.

Interruption:

["She means that it's not nice to dob in a mate!"]

["What about the Social Security hot line?"]

["What about it?"]

Irritation:

Small voice: Get off the line! The Department of Social Security's (1993) hot line is irrelevant at this point!

Breeze rustles the orange tree:

In this case I am a 'client'—supposedly satisfying the eligibility criteria but at the same time dependent on the goodwill of the 'professional' to allow me to enter the program... and if I seem to be a threat, or disruptive, then a comment is made about my 'behaviour'—not as an 'equal' researcher legitimately critiquing the research...

Small voice: After all, you didn't have a say in the design of the program, did you?

... well, no... but as a 'client' demonstrating some deviance and ingratitude.

Small voice: So are you saying that your comments as 'client' can be challenged on a personal level, whereas comments about a 'researcher', while they may be personal, are more likely to be critical of the method used or conclusions drawn?

Absolutely! Comments about professional undertakings, if they reflect negatively upon the person's character, are subject to defamation laws (if you are a public figure with access to the expensive legal profession and can organise to be defamed by somebody similarly situated).
"Like the jokes about politicians who manage to get themselves defamed ..."

"... just before they bow out of politics..."

"... and end up with a very nice lump sum, thank you very much!"

"Ah! Feeling a bit bitchy, are we?"

"My oath!"

Small voice: Is that how it feels?

Yes. My feeling is that my comments can be dismissed as the ramblings of a deviant person (illness IS deviant unless condoned by a higher authority - and if it is not deviant, then I have no power to be anything but passive and dependent). My person can be attacked simply because I have no standing as a researcher...

Small voice: And all this can be done behind your back?

True! And I'm not talking here about legally enforceable rights. I'm talking about the informal network. I mean the sort of thing that leaves you with the label 'trouble maker', or comments like, 'she's a manipulator' or 'a difficult patient/person'. Most often ambiguous language, while innocuous to the outsider, is quite meaningful to an insider.

Pause:

Small voice: Correct me if I'm wrong, but can't you get some sort of back-up from the other participants?

Pause:

I've thought about that.

Pause:

The dilemma is that it is my research. Let me see if I can tease this out.

Pause:
The researchers are bound together through the very structure that makes it possible for such a pilot program to exist in the first place.

Pause:

My understanding is that the Department of Social Security (DSS) enlisted the support of the Commonwealth Employment Service (CES) and the Commonwealth Rehabilitation Service (CRS) to see if they could do something about getting people off social security benefits and back into the workforce. (Department of Social Security, 1994, pp.10-12; Human Rights Australia, Privacy Commissioner, 1992, pp.28-29).

Small voice: You could be wrong about that — about the researchers being ‘bound together’. You don’t know how the program was set up. You can’t even give an outline to the reader of the aims and objectives, the number of participants, the methodology, the time frame ... or any of those things that would need to have in order to assess the outcomes.

Pause:

Small voice: For a start, we are dealing with the David/Goliath archetype!

Well, anyway, let me tell the story from my perspective.

A doctor (we are in the medical model, don’t forget) makes a submission for funding to run the program.

Small voice: I recall that Woodhouse (see earlier discussion, pp.145 ff. above) made the comment that where medical rehabilitation facilities were available this was often due to “the initiative and leadership and enthusiasm of an individual doctor.” (Woodhouse Report, Vol.2, para.214; and p.150 above).

Pause:

This includes recruiting therapists to make up the team. Part of her/his responsibility is to assess potential clients, obviously with a view to guaranteeing, as best she or he can, a positive outcome in line with what has been set out in the submission. In the case of the CRS, this would be in line with a return to work.

Small voice: You don’t mean to say that the research program is stacked? Biased? Gerrymandered! Dear me — and all in the name of science?
When the potential clients arrive, individually, they may be unaware of the background to all of this...

Small voice: Were you?

Yes ... to a point ... but I wondered whether the individual therapists were being employed in a research capacity (and hence aware of the agenda) or whether they were employed on a sessional/program/day-labourer basis.

Small voice: Well, this marks the point where you have to accept your role as client. It is not client-like behaviour to start asking questions about agendas and roles and politics and methodology ... as well you know, or at least should know, by now!

Silence:

I had not been referred by either Social Security (DSS) or the Commonwealth Employment Service (CES), but had quite independently referred myself to the Commonwealth Rehabilitation Service (CRS). In my own mind I was both client and researcher.

Pause:

I knew of the existence of the CRS and its role in preparing people to return to the workforce after an injury ... from my policy research experience with DSS. I was hopeful, but not expectant, that the CRS might be able to help me search for or design my own rehabilitation in a wider context. I was looking for 'quality' and 'alternatives'.

Small voice: As it turned out they offered you a place on their newly funded pilot program for ME/CFS.

 Interruption:

["She’s off wandering again!"

["Well, why don’t you let her go, she’s obviously trying to make some very difficult point. Maybe it is just out of her reach.”]

["Just a few minutes more, and then I’m going to insist that she either get to the point, or drop the whole thing.”]

["How generous of you!"

 Interruption subsides:
...As I was saying... generally, when the clients arrive they are strangers to the background, to the system, to the range of professionals, to the building ... and they are not well ... they are feeling ambivalent, vulnerable ...

Small voice: I take it you are talking about your own experience?

Yes.

Pause:

Small voice: So, this is not a good beginning, at least not for 'bonding' or forming a 'participative egalitarian group' ...

And why would the group be even thinking of this? They have come for treatment, set up within the medical model where doctor/patient (or in this case, client/therapist) relationships prevail.

Small voice: While the therapists already have a 'group' formed, or at least are working on a collaborative basis (or so you assume) - individual clients have no such structure.

Pause:

Exactly, for the therapists/researchers the structure is already in place. Not only is it is place but it is legitimate. It has authority. It has provision for private case study meetings.

Small voice: It can exclude clients if they do not meet minimum non-disclosed 'standards'.

For the clients, unknown to each other, a structure has barely begun to emerge before the program has finished.

Small voice: I see more clearly now. So how does this tie in with the researcher/client situation?

A little turbulence is apparent:

Well, as I was saying there is no way I can go back to get other clients to validate what I am saying because there was no relationship established in the first place and each client went their own way after the program finished, and since I was in the first intake of only four, this hardly seems representative. After the program, the 'ethics' of the situation prohibits the divulging of names of clients. Besides, much of what I learned was not learned in the company of other participants.
Small voice: Wasn't that one of the 'fears' of the professionals?

What was that?

Small voice: A 'fear' that you, as clients, could become 'dependent' on them and their facilities and they didn't want to do anything which would encourage that?

Yes. And keep in mind that the medical model operates from an 'acute' not a 'chronic' base. Actually, we suggested, as a group and individually, that we would like to have access to the premises after the program had finished. We felt this would help us continue to explore our own individual programs and monitor our progress. 'Noises' were made, but nothing eventuated!

Small voice: Of course, you don't know what discussions were held within the professional ranks. After all, it is a new program, so its status is uncertain. No doubt, this would encourage a conservative approach. And don't forget that if they can't prove this work within the official guidelines, then the program will be dropped.

*Interruption:*

"She's lost track of the need for professional and public indemnity insurance."

"What on earth does that mean?"

"It means, dork, that you can't let clients prance around in premises, operating equipment, without supervision."

"Right! They might trash equipment!"

"They might fall over and hurt themselves - and then where would we be - up to our ears in paper work and insurance claims and explanations to the hierarchy!"

*Pause:*

Yes. I take your point. But that is asking me to put on a 'professional' hat over the top of my 'client' hat. Believe me, I can appreciate the dilemma of the professionals, but at the same time, I am trying to get my needs met!
Small voice: Your problem of getting the professionals to see you as a researcher is simply a projection of your conflict of interests!

Pause:

The point I'm trying to make is that I can't discuss the program in a textbook fashion, nor can I write from the perspective of the legitimate professionals. For them, the program is (hopefully) on-going. After ten weeks, another group is formed. After another ten weeks, another group. The perspective of the professionals includes the experience of several/many groups, and even changes in personnel. My experience is a one-off affair. My concerns are whether my needs are being met ... and those needs include my personal rehabilitation needs as well as my needs to contribute to the research.

Small voice: Right! Back to your dilemma about revealing what you heard, 'off the record'.

Pause:

Actually, it no longer seems to be a problem.

Small voice: What do you mean?

Pause:

I mean that I've suddenly found some boundaries to contain the dilemma! You alerted me to my conflict of interests!

Pause:

I passed on my experience, quite comfortably within the medical model of doctor/patient relationship. The details hardly seem to matter. My doctor can read the generalised results of the CRS research, if published. She or he can also assess and re-assess me in the light of my personal experience of the research program and the generalised results.

Pause:

Small voice: You aren't really happy with that, are you?

On one level, I'm quite happy with that.

Small voice: But what about the politics?

Pause:
Yes, on that level it struck me as being most unsatisfactory. But when I think on it, I realise that I have done my bit. I sow some seeds, when I can; I act as a conduit, where I can; I run my leg of the relay and pass the baton to the next person. And I was most fortunate in coming across some really helpful people at the CRS.

Small voice: Waxing lyrical?

Actually, this little exchange has been most helpful to me. I realise that I was rushing around, taking on the whole world, trying to put things right; when, in fact, I just have to do my little bit, and be satisfied with that.

Small voice: Keep going, there’s something else to be said here!

Extreme agitation:

Okay. Okay. Quit pushing.

Pause:

I didn’t trust other people to do it.

Pause:

Small voice: Do you want to spell that out?

Silence:

My hidden agenda in joining the program was to take the opportunity to contribute my experience to the research. From my experience of the cognitive behaviour therapy model in the Prince Henry Hospital trials (Hickie, 1992), I wanted to emphasise the need for more ‘quality’ grief work. This aspect of rehabilitation is, in my opinion, too quickly swept into two piles, one marked ‘anger’, the other marked ‘depression’. The mention of the word ‘grief’ seems to send many psychologists into a panic!

I wanted some acknowledgment from the professionals that they had heard what I was saying.

I did not get any feedback.

Pause:

Small voice: Thank you!

Pause:
That reminds me ... I have prepared some worksheets from the notes I made at a Loss and Grief Seminar conducted by Anne Mulheron from the Bereavement Care Centre in April 1993. Her discussion was by far the best I have heard on the subject. I have included the worksheets at Appendix F.

Long pause:

Small voice: But it still doesn't answer the broader problem, the political problem. The difficulty of having the experience of a marginal group validated by the larger, and more powerful, group who may not wish to change their views of things ... and who, always, have their own agenda.

 Interruption:

["And of the marginal not having access to the findings and thoughts of the powerful group.""]

["It is easy to become paranoid - with good reason!""]

["I can't remember her, or any of her friends, ever having the opportunity to comment on the design of the research or any research findings, prior to the findings being published!"]

["Yes! The best they can do is grumble about the stupidity of things while the research in on-going!"]

["This is simply the effect of aggregation and generalisation and objectification.""]

["Meaning?""]

["Meaning that we are looking for some general scientific (truth) in which the personal details will be buried and trimmed off. Something that bears no relationship to the individuals from whom this (truth) was extracted."]

["Come on you guys - we all know that what the client or patient or subject tells us is likely to be subjective, coloured, biased and whatever, so we have to trick them into telling the (truth). We just can't accept what they say. What would they know, anyway. They are ignorant. We are the professionals."]

199
** Interruption ceases:**

Maybe not. But I can just do what I can do and trust that if we all do our little bit, things will change ... in the long run.

Small voice: In the long run we'll all be dead!

** Pause:**

Rome wasn't built in a day.

** Silence:**

Now, before we leave this behind I wanted to make a comment about Reinharz's (1991) book. And it concerns the validity of experience¹.

Small voice: Hold on! I need a break.

You're right. A wander around the courtyard would be nice.

...........

** The validity of experience**

Sociologist Shulamit Reinharz talks about her 'distain' for the work of an anthropologist, Laura Bohannan who wrote, under the pseudonym of Elenore Smith Bowen, (1964) Return to Laughter. The book is an autobiographical novel based on Bohannan's experience of field work. Reinharz, trained in the discipline of sociology, reveals her indoctrination in the scientific method:

> Because I had already adopted the notion that social scientists could achieve nearly perfect control of their activities with participant observation or other methods, I was unaware of the differences between experiential and abstract learning. The only impediment to the pure appli-

¹Chapter 9 "Responding to Consumer Needs in Organisations" in Jones and May (1993) has come to my attention too late for me to include a detailed discussion of their work. However, it confirms my subjective experiences in interacting with 'the system'.
cation of method, was, I believed, personal inadequacies or unpredictable and overwhelming external constraints. My understanding of methodology was coated from the start with a veneer of moralism. When a social scientist such as Bohanan [sic] explained the shortcomings and actual processes of her research, I assumed it was a confession of wrongdoing, of wandering from the path of methodological righteousness. (Reinharz, 1991, p.53)

I recall reading Return to Laughter myself, and having a totally different appreciation. It was clear to me that Bohanan needed to write the book under a pseudonym because of academic ‘rules’. It was also clear to me that she felt very strongly that in some way she needed to ‘tell the truth’. I also had the benefit of reading David Riesman’s Foreword (in the 1964, Doubleday edition) and of being in the anthropology rather than in the sociology camp.

In contrast to Reinharz’s experience, I was not the wide-eyed, eager (young) student ready to be indoctrinated, when I read/studied anthropology, but I do remember the great divide that existed, on campus, between the ‘participant observers’ of the anthropology camp and the ‘clip-board toting, number-crunching, busy-bodies’ of the sociology department.

Pause:

I thank Shulamit Reinharz for her honesty. In her new introduction to the Transaction publication in 1991 she explains how her thinking has continued to evolve. She says:

In the past five years two developments led me to place this book in new frameworks. First is the overlap between the ideas expressed here and feminist concerns with method in the social sciences: second is the similarity between my efforts to defend an experiential method and the efforts of others in disparate fields to do the same. (p.v.)

I can recall that it was not easy being a mature student, full of first-hand experience and short on theory, in an environment where theory was king and experience was ... well, it was considered inferior and merely anecdotal and subjective!

Interruption:

["Mind you, the Wife of Bath (in Chaucer’s Canterbury Tales, 1961, p.112) had no such qualms!"]

201
"Exactly!"

"Experience", she says, "though noon auctoritee
Were in this world, is right ynoth for me
To speke of wo that is in marriage:"

"In English, please!"

"Put simply: even if there were no quotable authority, experience would be good enough to enable me to speak of marriage."

"She'd had a few husbands!"

"Thank you, Diane, for the translation!"

**Merrymaking subsides:**

Small voice: Perhaps these accusations and dismissals of things 'merely anecdotal' have something to do with your passion for defending the validity of 'experience'?

I have no doubt of it.

Theories, about how human beings feel and why they act the way they do, can become an intellectual game - great fun, but dangerous if it is assumed that the theory is experiential 'fact'. The great gulf between broad, in principle, policy proposals and the reality of how they operate on the ground is proof enough for that. After all, statistics and generalities are derived. They are artifacts, not facts. At best they are probabilities, when used for prediction. When used as explanation, the raggedy edges are simply trimmed off in the pursuit of elegance.

Small voice: Whether you are affected by these mind games depends on whether you are making pastry - or whether you are making pie crusts! Perhaps you care for neither pastry nor crusts?

Perhaps, it is the use of the facts or artifacts, the imposition of these (truths) by the powerful upon the less powerful which I find difficult. You can choose not to submit to such powerplay, if you are not in need of the services offered. You may, however, find yourself 'trimmed off' yet in need of the services covered by the pie crust. But you are not 'of the crust'.

Small voice: I suppose that's where you are?

What do you mean?
Small voice: I mean that you are in the 'trimmed off' pieces ...

True. But more to the point, treated 'as if' we (the marginalised) were included in the pie crust proper, simply because we, too, are pastry!

Small voice: Perhaps we would say that although you are 'pastry', you are not subject to the laws relating to pie crusts because you do not belong to the class of 'crusts'!

Beautifully said. And speaking of things edible ... how about it?

Picnic hamper. Clear blue skies. ... and a cushion on the back step.

Disembodied voices

Blackness:

"Now, that's what I've been waiting for, a quantum leap."

"Well, bully for you!"

"What you you make of all this?"

"How do you mean?"

"I mean how is this moving the thesis along? - the search for rehabilitation?"

"I think it's picking up the difficulty of interaction with the professionals you meet along the way ..."

"... and whose help you need, from time to time."

"And fancy it bring up all that stuff about being stung by smart-arsed criticism ..."

"... and that coming from people without personal experience but who rely on hearsay evidence, generalities and theories!"

"Are you talking to me?"
"Oh no. We're just talking about you!"

"You know, you're piss weak. Why don't you come out and say what you think? C'mon! Spit it out!"

"Quit the agro. You don't have to get into violence when you disagree."

"And who says so? You've never had to fight for anything. You landed on your feet from day one and never fell over - not once!"

"That's how much you know!"

"How am I to know otherwise. Shit! You prance around the place, spreading sweetness and light, syrupy sludge. Why don't you say what you mean, for once?"

"And what is it you want me to say?"

"There you go again. I don't WANT you to say anything. I just to hear how you think and feel - unedited, uncensored, pure!"

"Pure, eh? That's what you call pure?"

"Give me a better definition."

"Cool it! This isn't getting us anywhere!"

"NO! It's always time to cool it. This time let's see where it leads."

"It's lead us to here, this spot, this time ... that's WHERE."

"Right. We are here."

"Can we consider for a minute that she's put down quite a bit of good stuff and give her some support, instead of squabbling among ourselves?"

"Actually, I'd quite lost track of all that. Remind me. Just what did she do?"

"Are you for real? Have you really not been paying attention?"

"Good heavens...I can't be everywhere at once ..."

"And just where have you been?"

"I've been to London to see the Queen!"
"And, pray, for what purpose?"

"Silly person! That's a joke, Joyce! ... Actually, I've been thinking about the letter she wrote to Clarissa Pinkola Estes."

"Really?!?!"

"Really. She spoke about the re-learning, or learning anew, different skills which carry the same label as other skills."

"Explain, please."

"Well, perhaps we can get her to pick this up when she gets back. I find that aspect quite intriguing. She's already spoken a bit about "The Wizard of Oz" story, and Dorothy and Strawman and Tinman and Lion ..."

"...and she hasn't talked much, or even at all, about Toto."

"Right!"

"Toto? in toto? Wholeness?"

Long pause:

"Are we all feeling okay, now? Anger and rage subsided? Cleared? Clarified?"

"Good. Let's leave it there."

"How about putting a copy of that letter to Estes in her Appendix (Appendix G). What do you think?"

"I think she's going to have a burst appendix!"

Sounds of various and unconnected conversations

... and the tinkling of glasses.
PART XII

SECTIONS AND SEGMENTS

Preamble Three

I’ve been reading a bit of this and a bit of that trying to find some way to start this section.

Small voice: So you think of this as a section?

I suppose so. That’s what I said.

Small voice: Is that what you meant?

I don’t know.

Small voice: Think on it. Why a section?

A section is a part of something, like a segment in an orange.

Small voice: And that is what this part is about?

Part? Parting of the ways?

Small voice: Participation, particle.

Section, sectionalism, sect, sector ...

Small voice: Why is there a need for sections? There is no need to start a new section. Why not just continue on — things flow into one another.

I suppose because I’m just standing here waiting for something to take my attention ... like the parting and the participation ... 

Small voice: Good! Good! Good! Except, of course, you are sitting!

Literalist!

Small voice: Well, how about a re-cap, a survey of the territory and that will then allow you to fill in a few gaps, or notice something peripheral just waiting to be included!

Pause:

Okay.
**Interruption:**

["Like part and part-ing and part-icip-ation and part-ition!"]

**Pause:**

I've just noticed ... preamble ... a sort of practice prior to actually walking? And I wondered at the distinction. It's a kind of before I begin walking. Why is the practice — the trying out — excluded from walking proper? It is an attempt to section off what later may be considered false starts, errors in perception ... a sort of limbering up ... an assumption that these exploratory movements are not for public display? Something to be done in the privacy of one's own home — not good enough!

Small voice: Sounds like it. Tell me more. It's good to know where there words come from — what history they bring with them.

You just want to get back to dictionary definitions!

Small voice: Well ... Did you know that 'amble' relates to horses (lifting two feet on one side together). And, for example, a person who moves at the same pace as the ambling horse, is said to be 'ambling'. So perhaps we could say that in writing, the 'preamble' is a slow start, a warm up before we break into a trot (diagonal feet off the ground) or a gallop (all feet off the ground).

**Interruption:**

["The neurological and physical complexity (and difficulty) of these movements can be discovered, experientially, by doing some classes in Awareness Through Movement (Feldenkrais 1977)."]

["Is that so?"]

["Would I lie to you? Do you really want an answer?"]
"And wouldn’t Feldenkrais be a new learning, not a re-learning? Therefore, it wouldn’t count as re-habilitation?"

"Good thought, Moriarty."

"Don’t mention it!"

Flurry subsides:

So there is an assumption that ambling is not good enough?

Small voice: Hold on! There is nothing wrong with an easy pace and a gentle swaying from side to side.

But it doesn’t win races!

Small voice: And who wants to win races? There are many reasons for breaking into a trot or a gallop. In order to win a competitive race is but one! A simple change in pace from boredom! Tiredness! Avoidance of obstacles! Sudden speed may be essential to survival! Or the overuse of particular sets of muscles!! You’re making an assumption, again, that the ultimate is to win races – very anthropocentric! But there are horses for courses and appropriate actions in appropriate circumstances.

Well, let’s leave the horses for the moment.

Pause:

I really don’t know what to tell. It’s just a feeling ...

Small voice: ... ‘just’???

Thank you! I have a strong feeling that these exploratory movements are pre-verbal. It isn’t until I have some bodily knowledge of what these movements feel like that I can find the words to describe them ...

Small voice: And is that what makes it difficult to ‘tell’?

I’m sure you are right.

Small voice: So could you review what you have been ‘telling’? It would help us enormously to see what aspects you understand well, and which aspects are cloudy, misty and unformed and, perhaps, which aspects you might not be aware of.
Long pause:

The Story so far ...

What I have been trying to do is to retrace my footsteps ... to find out, to describe, the journey from there to here. And particularly to help me see, more clearly, just what the here is.

I started off with thresholds, hope and discipline ... and thresholds were really difficult to see. For instance, because of the confusion which exists at the borders, it is easier to recognise a threshold only after it has been crossed. And I spent a lot of time ruminating.

Small voice: We are into animal metaphors today!

I found myself becoming involved in the feelings around the threshold - because, after all, one feels one's way in the dark and visual descriptions of concrete facts are not possible simply because there are no concrete facts.

Am I saying that the threshold is an artifact rather than a fact? A sort of 'thing' that is created in the process of travelling.

Small voice: That's it!

A threshold is a marker I put up when I can 'see' that I have gathered some hard won understanding. At the point I can say 'ah ha', now I see, I actually create the threshold as a symbol of the quantum leap I have made in understanding. Only after having made the leap AND landing somewhere else (metaphorically) does a threshold materialise out of the fog from which I've come! It CANNOT be seen beforehand, because it does not yet exist. Therefore, a threshold has the quality of infinite depth and dimension. Which, of course, is why it is perceived as impenetrable, inscrutable and unfathomable.

In trying to set up a framework for the story which had to be created in the telling, I thrashed around, grabbing at the wafting whisps of feelings and memories, unwilling (or unable for reason of not knowing how) to make that quantum leap across what I assumed was an abyss. The story which I thought I would be telling was left behind as I engaged in a whole new story which I intuitively knew would involve a discovery, in a conscious sense, of the journey I had already undertaken, unconsciously ... there was sense of terror. The abyss is an imagined space which doesn't exist? The leaping and the landing are synchronised? Each implied in the other?
In the early part of my writing I needed the artifice of the Greek play and chorus to provide the container, the frame-work. I didn’t ‘invent’ this artifice on a conscious level. It was as if these images suggested themselves to me as companions in the taking of a step.

Pause:

This step involved a recitation of my presenting complaint ... the early stages of ME/CFS and my 'fight' to find meaning.

Pause:

I find it interesting that at other junctions where I was insecure and fearful I tried to employ the same tactic, consciously, only to be ‘told’ that I needed different companions. This was confirmed in a dream showing the need to change batons, as in a relay race. I initially thought that I, the dreamer, was carrying the baton. Later it occurred to me that I was in fact the baton, and had to allow myself to be 'passed on' to other runners.

There are other parts where I obviously want to ditch the effort and appeal to 'straight' academic authorities. It also shows me where I lose the plot, so to speak, and regress to standard ways of dealing with the vacuum. And this vacuum seems to exist at points of resistance to facing the painful raw emotions of grief and anger.

Pause:

These resistances are not simply that.

What emerges - loosened, dug up and activitated - in the unseen dialogue between disembodied voices, is a need to differentiate between my felt emotions and the verbal generalisations which have been externalised. These generalisations are just that - generalisations. I found that I had to struggle with the fact that the generalisations were not my 'fit'. And I had to explore where they did not 'fit'. In so doing, I found that I had to lift the veil...

Pause:

Small voice: May I be so bold as to intrude. I am impressed. But may I point out that you have fallen into the habit of generalisation yourself - you give yourself away with your language ...

Thank you! No wonder I was struggling to say what I want to say. Basically, because I had to really struggle, and with your help, Small Voice, I learned a lot about my grief and anger.
Small voice: And I’m sure we could work further on that, if you like.

What did you have in mind?

Small voice: I don’t know. I felt you were prodding, avoiding, circling around the area.

Pause:

I have just flipped back to previous pages and I notice that it was at this point that I began to talk about Dorothy and The Wizard of Oz (pp.129 ff. above). And the notion of being confused by the feelings I was feeling and the words or labels I was using to describe, to designate, these feelings.

Small voice: A sort of feeling that you were aware of having made some kind of leap but had not yet landed?

Right! And a dawning awareness that there were subtle, and not so subtle differences in meaning, depending on whether I was more there than here. And that perhaps the leap and the landing were one and the same.

Small voice: And a growing awareness of the need to learn new skills?

The story of the cabbages, too! And learning how to plummet! And paying less attention to the observer on the cliff!

Small voice: How difficult that is!

And then, wham! Back to the everyday reality, and disappointment and grief - the interaction between agencies, people, patients, clients, institutional generalisations!

Small voice: And knocking on the wrong doors!

 Interruption:

["To what extent was her involvement in the CRS program a ‘back track’?"]

["Yes. Wasn’t she already on her own rehabilitation road when she decided to go in search of standard rehabilitation?"]

["But then was it part of her ‘research’ or her ‘search’?"]
"Research for me suggests the academy, and finding what is already known.""

"Isn’t ... everything ... already known?"

Pause:

But this is also an important part of the research. Naming, identifying, speaking out about the parts of the system which do not deliver services which according to the generalisations and mission statements are presumed to be facts and truisms.

And in the desire to name comes ... ethics.

Small voice: And isn’t ethics a power issue? And doesn’t it come with it’s own set of rules?

True. It has raised for me my own set of rules, my wanting to play the game, of wanting to part of ‘it’ – whatever ‘it’ may be. It also tells me that I must be sure of my standing, in time and space.

I jokingly ask "What’s in it for me?" ... in a sense of wants, desires, even greed ... but also as a way to remind me to ask myself what it is that is important, at this moment, for me. I ask myself whether ‘this’, whatever ‘this’ may be, is really my business. Am I being acquisitive, overly curious – in short: am I greedy for power, knowledge, revenge, status, belonging.

... And so each venture
Is a new beginning, a raid on the inarticulate
With shabby equipment always deteriorating
In the general mess of imprecision of feeling,
Undisciplined squads of emotion. And what there is to conquer
By strength and submission, has already been discovered
Once or twice, or several times, by men whom one cannot hope
To emulate – but there is no competition –
There is only the fight to recover what has been lost
And found and lost again and again; and now, under conditions
That seem unpropitious. But perhaps neither gain nor loss.

For us, there is only the trying. The rest is not our business.

T.S. Eliot (1974) "East Coker"

Pause:
It is amazing that just when I think I have arrived at some half-formed, uncomfortable position I find myself thumbing through Eliot’s poems — and it has all been said before. This time I understand ... I think.

Pause:

And I feel that this might be a working definition of ethics.

Small voice: Do you mean a sort of why am I doing or wanting to do this, or that, or whatever?

Yes. What is my agenda, especially, what is my hidden agenda.

And when I can be honest with myself, the question of ethics is no longer a problem.

Small voice: God! That’s asking yourself to be perfect!

You misunderstand! I don’t mean that, although in the past (and hopefully less often in the future) I acted that way.

Small voice: Really? I would have thought that you have just said that you were unaware in the past and that is why any discussion of ethics raises your blood pressure!

Alright already! You’ve got me! I confess!

Small voice: So perhaps you could say again.

Pause:

If I am being really honest, and authentic, then I am acting ethically. If, however, I am not being authentic in myself, then I have to struggle with ethical questions until I identify my hidden agenda. That isn’t to say that I can’t be greedy, envious, vengeful — it just means that when I am, I am operating in a difficult ethical situation! And if I am seeking to satisfy a hidden agenda, then I’ll have to wear the consequences which will inevitably present themselves, as unexpected or unintended.

Small voice: That’s a painful way to learn lessons!

I know! It is especially difficult not to ‘shoot the messenger’ when it is the message that is unpalatable.
Small voice: You should pay attention to your own words. Being a 'messenger' is a dangerous occupation, you have to learn to duck! And you may not win too many friends! People don’t like having their institutions questioned.

And I think, having ME/CFS has provided me with some valuable lessons.

Small voice: Que?

The lessons? Well, perhaps one is that being disappointed is not reason enough to want to dismantle things. Being 'enraged' is!

Small voice: How do you know the difference?

Rage is like spontaneous combustion. Disappointment is a slow burn.

Small voice: Can’t disappointment become rage?

Yes. But somehow disappointment feels like rage with myself for not dealing with the disappointments. Outrage by definition is in a wider context, and has to do with absolutes rather than relativities.

Small voice: What if you can’t change things with your rage?

Well, that requires that I admit I’m not God, I am not in control of the world. And I have to recognise that. I have to recognise that, perhaps, is not my domain of activity and I have to leave it to others.

Small voice: You mean, you walk away?

Exactly! But not in a defeated or defiant manner. The I Ching, (1985) the Chinese Oracle which has stood for around five-thousand years, reminds the seeker of wisdom that there is a time for everything. "There is a season for everything, a time for every occupation under heaven" is the oft-quoted Chapter 3 from Ecclesiastes in the Christian tradition.

I mean, I walk away from something that, as it turns out, is not my business. It doesn’t matter how I try to make it my business, if it is not my business, it is not my business, and if I find myself holding the baton, I have to pass it on.

Pause:
No doubt, learning to walk away is another aspect of my search for rehabilitation. Have you been walking? I must remind myself of this more often!

Pause:

Small voice: What about all this hype in society that says you 'ought' to do this, or that. That you 'ought' to be concerned, involved, active. That you 'ought' to ... whatever ...

Well, that comes back to whether I am my own person, as they say. Whether I know what is my business and what is not. If I KNOW what is my business, then I will get on with it, without coercion. It is only when I DON'T KNOW that I am open to exploitation.

Small voice: That's a bit hard, isn't it?

I used to think so, too. But I am learning how to plummet, to stop worrying about what the observer on the cliff might be thinking ... and you know, it leads on to being less judgmental about other people.

Pause:

Some time ago I realised that "I always do the right thing, given the circumstances". When I shared this with one of my friends, she said (in typically New Age parlance) "I have a problem with that!"

Small voice: ... meaning that this attitude was a cop-out and a denial of responsibility?

Exactly. I explained that it was an acknowledgment that even if I acted with malice aforethought, I was acting to the best of my ability (intellectual, emotional, physical and spiritual) in the circumstances. If what I did looked 'bad' that simply reflected my current abilities and circumstances. That didn't mean that as circumstances changed - and, of course, my (in)action contributed to those changing circumstances - that I was not required to act or to refrain from acting, again, and again, and again, in accordance with these changing circumstances and my fluctuating abilities.

Pause:

I played with this for some time and gradually I added "...and I assume that other people do, too". This addition raised more resistance than the original statement, because what do you say, for instance, about murderers, rapists, etc. etc.
Pause:

I sat with this for some time, too, until I realised that by making no judgments about others, I freed myself from making judgments about myself (and my failure to overcome ME/CFS). That doesn’t mean that I condone violent, hurtful or spiteful actions, or fail to identify with the pain suffered by the recipients of those actions. It doesn’t mean that I don’t engage in such behaviour. It does mean that I withhold judgment. I still get angry that such violent things should happen, but I wonder what circumstances and with what abilities the participants found themselves in.

Small voice: It is, indeed, a mystery.

Pause:

Small voice: Does this account for your understanding of outrage?

Pause:

Perhaps.

Pause:

If I find myself in difficult circumstances, I can only act as best I can. Hindsight is a wonderful thing. In the light of day I may find myself thinking, "Why didn’t I do this ... or that ...", but that is with hindsight. At the time I did the best I could. And now, in the light of that, I have other decisions to make. The circumstances have changed!

Small voice: You seem to have the idea that if you make a ‘right’ decision, you don’t have to make another. I wonder where you got that idea? And if you have to make another decision, you had obviously made a ‘wrong’ decision in the first place?

Somewhere in the dim distant past, no doubt. Strange, isn’t it!

Small voice: I’m sure it’s got something to do with general principles which are bandied about as cure-alls when in fact they have to be carefully selected for their appropriateness in any given situation.
Silence:

Small voice: As your Mr. Eliot’s Prufrock says "In a minute there is time for decisions and revisions which a minute will reverse". (T.S. Eliot (1974) "The Love Song of J Alfred Prufrock").

Silence:

This led me on to thinking about anxiety ... the anxiety which precedes, attends or follows painful and difficult situations... especially those situations where I find myself thinking "What if...", "When I am well...", those situations which I have come to call 'living too far into the future'.

Small voice: Very Zen! Avoiding 'The Eternal Now'?

 Interruption:

["Living with a chronic illness means living with uncertainty."]

["Excuse me! ALL living is living with uncertainty - chronic illness or no. You could fall off your perch in the next ten seconds!"]

Sudden breeze:

Exactly! The goal of having goals, achieving them, projecting our successful selves into the future, can lead to a minefield of anxiety. But then, how could we operate in our mechanistic, material world unless we assume that there is a certain future? What would happen to government and business and house renovations?

Small voice: You are moving in and out of the personal and the political. Of course there is a future - but it is present or past for those with different time scales!

Nevertheless, struggling to identify the goals, with the help of well-meaning healthy people is, for the less-than-well, a destructive exercise in the short term. In the long term it leads to exhaustion and enlightenment. It can also lead to suicide. And who knows which is which.
Pause:

It is not so much that having 'goals' is a problem. The problem lies in the examples cited to illustrate the concept. The problem lies in literalism. The confusion lies between 'doing what I say', and 'doing what I do', and 'being who I am'.

Small voice: Reminds me of biblical sayings and exhortations to 'goodness'.

Actually, that is where I began to get some insight into this problem.

Small voice: How do you mean?

Well, how could anybody believe that Christians were required to "Do as Jesus did", literally. Surely the Bible tells us that he did what he did so that others would not have to, in some metaphysical sense? My current understanding is that this concept means that Jesus lived his life according to his times and who he was. And we are to do likewise, that is, to live our lives according to our time and who we are.

Small voice: I think you are going to have to come back to this.

Pause:

To continue. The confusion and uncertainty are magnified when somebody says, 'that is not a (good enough) goal'. Goals in our society are defined by healthy people, full of optimism.

Small voice: Some might say 'naivete'?

Pause:

Now if one is not healthy, the first thing you have to do is to cross off the list all the examples of goals which have to do with activities accessible to healthy people, or wealthy people, or people with special, high profile, acceptable 'gifts'. Having done that, you can substitute 'realistic' goals, in line with your own limitations and gifts.

 Interruption:

["Of course, one must not look for approval from the wider society if these goals do not appear on the all-time 'top 40'."]
Giggles:

Unfortunately, most of us don’t know what our own special talents are because we have been brainwashed by society (and you can name any segment of society that is relevant to you) that only certain things are desirable and permissible goals.

Small voice: If we did, then we wouldn’t have to cross anything off any list because we’d only be concerned with what is appropriate to us. We wouldn’t even know what a ‘list’ was! And we wouldn’t be lusting after impossibilities! The seven deadly sins have a lot to teach us!

Blustery conditions:

It’s my turn to remind you that maybe the task of the human being is to find out who we are and, as a human, perhaps that can only be done by finding out who we are not? But I am getting ahead of myself and circling back to Mr. Eliot’s "East Coker":

In order to arrive at what you are not
You must go through the way in which you are not.
And what you do not know is the only thing you know
And what you own is what you do not own
And where you are is where you are not.

Pause:

Some years ago I was indeed fortunate to meet a wise, older woman, with years of wide experience. Aileen Beaver assured me that it was quite legitimate to have a goal of ‘not having a goal’, and this was a good starting point for me to begin my de-programming exercise. She also reminded me that for the most part, people simply wanted to complain. They needed somebody to hear their complaints, their pain. What they didn’t want was to hear a litany of simplistic ‘easy fixes’ (all of which they had already tried), because the ground of their complaint was the very complexity of their situation. In her opinion, the lack of understanding of the ‘complex ground’ contributed immeasurably to the pain of the complainant.

Pause:
Small voice: But where does this fit in with programs and services (and research projects) which, in order to be funded, must have goals and objectives and measurable outcomes?

Interrupt:

["That reminds me of having to leave behind the cabbages if one wants to learn to swim."]

["What's that got to do with 'grounds'?"]

["I haven't got a clue what she's on about!"]

["To put it simply, she's saying that people become overwhelmed by the complexity of their lives - overwhelmed by circumstances that they do not control. At some point the only thing to do is to 'drop the cabbages'. Leave the cabbages to somebody else (whose job it is to look after cabbages) and to give full attention to the ordinary, common, day-to-day concerns of keeping body and soul together ... like eating, drinking, sleeping, caring for each other ."]

["What happens if you are an Ethiopian?"]

["Then, keeping body and soul together, and the ordinary things of life are embedded in those extremely difficult circumstances. And I don't know about that, from the point of view of a starving Ethiopian - except, perhaps, for the 'caring for each other'."]

["Do you mean that we are all caged in our own set of experiences?"]

["Exactly! And we have to honour each other in our own set of circumstances. Sometimes just 'noticing' is all that we can do, on a personal level."]

["Oftentimes that is enough."]

Strong breeze gusts through the courtyard:

I am pleased to see that you are taking an interest in this discussion.

Pause:
I didn’t realise just how hard a goal that was, particularly if one wanted to ‘belong’ in the wide society. Of course, if I don’t accept that I can’t participate fully because of physical, intellectual, economic or for any of a range of reasons, then I have set myself up for failure.

While I accepted the need for ‘not having a goal’ on an intellectual level, I WANTED to have a goal which was more than ‘not having a goal’. How was I to measure how far I’d come? How could I gauge success? Moreover, how could I get confirmation and validation from others, especially when I had selected (from what seemed to be a forced choice) a goal which did not meet with their approval?

Pause:

Small voice: Do I hear you say that you were looking for approval?

Yes. Of course, I didn’t quite realise that at the beginning, but the de-programming had begun. And it is not the simplistic approval-seeking type of approval. It is the necessary approval which affirms that one is indeed a member of the human race and is therefore not (entirely) mad; and the reassurance that one is not a cognitive minority of one!

Long pause:

And now, when I look back on it, I can see the beginning ... I can’t see the end. It’s like peeling an onion. What I have learned is that when you take a risk in a relationship, the risk is that the relationship will not survive the challenge. With ME/CFS, it is a common experience that many, many contacts with ‘society’ at large are broken. How often have we heard the words “Let’s hear from you when you’re feeling better and we’ll do lunch, or something!” So we take our cue, and try desperately, to ‘feel better’.

It is no wonder that people are fearful of crossing the threshold because of the fear of isolation, occasioned by alienation, rejection, abandonment, loss. So we try, for the longest time, to hang on to the aims, goal, aspirations of society at large. Our addiction to belonging, to avoiding loneliness, paralyses us.

Pause:

And like the three-toed sloth, even when we have secured a foothold in another place, we are fearful of relinquishing the remnant of a grip in the known world.
Pause:

Small voice: I can see now why it is so difficult to describe the crossing of the threshold. It isn’t a simple ‘let go and move on’ is it?

And there are times and rhythms ... Yes, we forget, or at least I forgot, that intellectual, emotional, psychological and spiritual spheres have different cycles and rhythms ...

Small voice: ... and like Javanese music, the gongs of different cycles coincide infrequently ... almost like waiting for all of the cycles to converge before the ‘crossing’ is possible?

Interruption:

["The I Ching often remarks that the timing is crucial to any action."]

["Right! Move at the wrong time and you will come to grief!"

["Well, maybe not grief, exactly. Half-cooked potatoes are difficult to digest! And the human gestation period is nine months."]

Interruption subsides:

Right - and I also became confused as to which ‘cycle’ I was responding to - in that confusion one is likely to attribute clarity to the wrong sphere!

Small voice: Hence the confusion about using words like hope and hope and rehabilitation and rehabilitation ...?

Pause:

Mmmmmmm.

Small voice: Seems like a good place to rest.

Mmmmmmm.

I’ve just had a thought on the limen and liminality.

Small voice: Yes?

I’ve mentioned the ideas of thresholds, and threshing, and bridges and keystones, and both sides of the crossing, and the relationships between all of this...
Small voice: And?

And I hadn't made the connection between the power and authority which attaches to the experience.

Small voice: Which is?

The power and freedom to actually say "The Emperor Has No Clothes".

Small voice: Really? And what is essential about this experience? Of being split off and disconnected?

Pause:

Shame.

Silence.

_Disembodied voices_

_Blackness:_

"How do we all feel about that?"

"I was interested in her mention of 'telling'. It's an interesting word."

"How do you mean, interesting?"

"Well, it's more than just a description. It sort of an account, as in counting up, measuring, accounting for ..."

"... revealing, confessional type of stuff?"

"Yes."

"I've still got my eye on all the footnoting she's going to have to do!"
"You are a worry-wort. But keep it in mind, I'm sure she'll be appreciative — sooner or later."

"Don't be so dismissive! Just because it doesn't involve quantum leaps, whizz-bang excitement, doesn't mean it isn't as important as any other part."

"Sorry! It was just a joke!"

"Well, jokes sometimes hurt! And besides what do you do that's so valuable!"

"Me? I push things along. She gets stuck quite a bit you know and she needs me to push things along."

"Sheer brute force, eh?"

"Now who's doing the de-valuing?"

"True enough!"

"What's next on the agenda? Any suggestions, complaints, ideas?"

"I'm concerned she isn't paying enough attention to the academic literature."

"Yes, I feel that's something that needs attention, too."

"Does anybody have any suggestions as to how that might be rectified?"

"Can I suggest that she continues on with the story first. I sense she is getting close to a kind of finishing place."

"And then what?"

"Well, once it is down, then she can move into an editing mode, you know, expanding on half-formed thoughts, referring to the academic literature, that sort of thing."

"Yes, I feel things have freed up quite a bit and we should let it flow to a natural conclusion."

"Some way down the track I'd like her to spend some time on the difficult middle sections around the 'threshold'."

"Good. We can put that in a later agenda. Thanks."

"I thought she'd already that!? You couldn't have been listening!"

"And I'd like her to be a more specific about the spiritual aspect."
"Yes, that’s been swept aside somewhat. Perhaps that might come to the fore in the next section."

"Perhaps that’s enough for the present. We don’t want to push her into information overload."

"Or deflect some emerging insight."

"Can we finish here?"

"Okay with everybody?"

"Let’s do lunch!"
PART XIII

PAVANE

The Land of Walking Trees

This morning I am listening to Ravel's "Pavane for a Dead Princess" on my radio. It is early and the spring sparkles in my courtyard.

I muse over the word 'pavane' - a dance.

More than that - a dance where the dancers are elaborately dressed.

It is slow and stately ... and melodic ...

... and very beautiful ...

and ... I wonder how Ravel came to write such music.

Funereal - yet not at all gloomy. Aching, yearning, yes - but not gloomy. Visceral!

Small voice: So how does that set the scene for today's episode?

Michael Hansen (1993) has written a beautiful book, The Land of Walking Trees: Meditations for the seriously ill. I was dipping into it yesterday and opened the page at a meditation called 'Prayer', a meditation on Luke's (11:5-13) "knock and the door will be opened to you." Michael, who is also on the ME/CFS path, has written so poignantly that I will simply quote his words:

I woke in the middle of the night. Wrestling with demons, running with legs that would not carry me. My dreams exhaust me, Lord. Again I prayed to you. Again you did not answer.

My life is a landscape of endless mountains. I climb. I fall. I regather energy. I climb again. I fall again. I cry to you for healing. You do not answer. I persist and climb again. I fall again. Why do you not answer? I have knocked on the door of your heart till my hands are bloody. That door has not opened. Will you make a mockery of your promises? Am I so worthless? Am I to be thrown aside from your sight?

In the early days of my illness I trusted you. In time, I told my heart, in God's own time I will find healing. I prayed each day and told myself

226
tomorrow would be better. But it was not better. I swallowed frustration, thanked you for my faith and hid my desperation. Next month would see me right. Not so. Then it came to be. Perhaps if I stopped climbing mountains you would rescue me. Yes, I was at peace. I waited. I trusted for another month. No word from you, Lord, no healing. Each day my teeth clench a little tighter and each day my anger grows.

When I seek to reassure my heart in the early hours of the morning, my anger strides about my room wanting to break and smash. It grows and feeds on your silence. Are you listening? Ask, you say, and I will receive! I have asked, damn you, till my voice grows dry. I have pleased, begged, cried, shouted and banged on your door. Are you a liar as well as deaf? I have been faithful for months. What more do you want? There has been not a crumb of bread from your almighty hands. Your words are ashes in my mouth. If you stood before me now I would smash your face open. You are nothing but a dealer in scorpions and snakes. Come. Answer me. (pp.122-23)

Pause:

And Michael’s imagined reply from The Lord?

Be still, and know that I am God. (p.124)

Long silence:

And I am reminded of the biblical story, The Book of Job.

Pause:

Job is an Old Testament, historical figure known for his virtue. In the story, Satan suggests to God that Job’s virtue is an easy virtue because he has been so well treated by God. But what if God/Yahweh allowed Satan to strip Job of his fortunes, his family, his health? What then? Would Job turn upon God? God agrees to the challenge.
Small voice: I suspect that this very act, of God agreeing to Satan’s tormenting Job, has provided many a theologian with a career path! Jung (1976, pp.540f. and 562) suggests that Yahweh is more concerned with his battle with Satan than with the cries of his creation, Job, for justice and mercy — and that, perhaps, through the transformation of rage, jealousy and violence in 'knowledge', we bring consciousness to God and divinity to ourselves.

You can’t leave it there without some explanation. Jung was concerned to point out the dangers of raising religious questions:

*Whoever talks of such matters inevitably runs the risk of being torn to pieces by two parties who are in mortal conflict about those very things. This conflict is due to the strange supposition that a thing is true only if it presents itself as a physical fact. Thus some people believe it to be physically true that Christ was born as the son of a virgin, while others deny this as a physical impossibility. Everyone can see that there is no logical solution to this conflict and that one would do better not to get involved in such sterile disputes. Both are right and both are wrong. Yet they could easily reach agreement if only they dropped the word 'physical'. 'Physical' is not the only criterion of truth: there are also psychic truths which can neither be explained nor proved nor contested in any physical way ... The psyche is an autonomous factor, and religious statements are psychic confessions which in the last resort are based on unconscious, i.e., on transcendental, processes. (pp.522-23) [original emphasis]*

*Flurry of noise and irritation:*

*["Sounds like idle speculation to me!"]

*["True! And isn’t Jung putting forward just another 'what if' story?"]

*["I think you missed the preface in which Jung says: The book does not pretend to be anything but the voice or question of a single individual who hopes or expects to meet with thoughtfulness in the public. (p.521)]
["Oh? Right!"]

Silence:

So, having put this in context, let's continue with the story of Job.

Expectant silence:

As Job's fortunes, family and health are taken from him, his friends offer all kinds of advice, giving him the 'answers' to his problems. Job pleads with God for relief, for justice, for mercy and for answers. Yahweh finally answers:

> Who is this obscuring my designs with his empty words? Brace yourself like a fighter: now it is my turn to ask questions and yours to inform me. Where were you when I laid the earth's foundations? Tell me, since you are so well-informed! (Job 38:1-4)

Yahweh goes on (for 3 pages!) to ask (rhetorical) questions about the mysteries of creation. These mysteries are thrown at Job, in a kind of psychological torture/interrogation, and there seems no end to the diatribe.

And what can Job say?

> My words have been frivolous: what can I reply? I had better lay my finger on my lips. I have spoken once ... I will not speak again; more than once ... I will add nothing. (Job 40:3-5)

Pause:

Yahweh continues (for another 3 pages!) asking Job to compare his strength and power to that of Behemoth (a gigantic hippopotamus) and Leviathan (a whale-like monster from the depths of the ocean) — after all, Job would need such size and strength if he would wish to put God in the wrong.
Small voice: You can see that God is playing to the crowd! "Intoxicated with the tremendous power and grandeur of his creation," says Jung (1976, p.570). Maybe it was a crowd of one, since it is with Satan he has wagered Job's fidelity.

Job gives up. His final answer to Yahweh is:

I know that you are all-powerful; what you conceive, you can perform ... I have been holding forth on matters I cannot understand, on marvels beyond me and my knowledge ... I retract all I have said... (Job Ch. 42)

Pause:

Having humiliated and crushed Job's spirit, God/Yahweh is happy! And so we have a 'happy ending' ... 

Small voice: Sounds more like a domestic violence scene to me...

... but one which leaves much for thought. God takes Job's friends to task for not speaking truthfully, as Job has done! According to Yahweh, Job's friends should have realised that mere human beings cannot possibly know the answers to these mysteries. Job's fortunes are then restored, double!

Small voice: Job must been a singular person because he went on to live till age 140, and gave inheritance rights to his daughters, as well as his sons! Such even-handedness in inheritance rights during the historical period in which the story is told?

Interrupting:

"That's a pathetic story!"

Pause:

Jung's (1976) reflections are indeed fascinating. Job, the oppressed, stands morally higher than Yahweh.

Yahweh comes up against a man who stands firm, who clings to his rights until he is compelled to give way to brute force. He has seen God's face and the unconscious split in his nature. God was now known, and this knowledge went on working not only in Yahweh but in man too. (Jung, 1976, p.562)
In this respect, the creature has surpassed the creator. As always when an external event touches on some unconscious knowledge, this knowledge can reach consciousness ... Hence a situation arises in which real reflection is needed. That is why Sophia steps in. (Jung, 1976, p.572)

Jung comments:

The lack of Eros, of relationship to values, is painfully apparent in the Book of Job: this paragon of all creation is not a man but a monster! Yahweh has no Eros, no relationship to man, but only to a purpose man must help him fulfill ... One misses Sophia's 'love of mankind' more than ever. Even Job longs for the Wisdom which is nowhere to be found. (pp.561-62)

 Interruption:

["All of our institutions - even the apparently caring - are based on Yahweh. Where is Sophia?"

["Yeah! Where is Sophia in rehabilitation?"]

Silence:

She reinforces the much needed self-reflection and this makes possible Yahweh's decision to become man. It is a decision fraught with consequences: he raises himself above his early primitive level of consciousness by indirectly acknowledging that the man Job is morally superior to him and therefore he has to catch up with and become human himself - precisely because he has done man a wrong. (pp.572-73)

Small voice: So what's this got to do with the price of fish?

Pause:

Well, if you take it in a literal sense, then nothing much. But as a metaphor I find great comfort in it.

Small voice: How come?

Well, at some point I have to admit that I can go no further ... I can make no plans, and even if I do I cannot carry them out. No matter how well intentioned I am in my actions, they are quite likely to have unintended consequences. At bottom, I just have to leave things alone ... I have to mind my own business.
Small voice: What about the anger?

The anger comes from my wishing, wanting, assuming—whatever—that I have control. And when I find out that I haven’t, and I find myself helpless, I just have to... to...

Small voice: And your belief system says it is wrong to surrender, to give up, to admit that you can’t control...

Exactly! Especially since it is not only my personal belief system, it is the belief system propagated, proselytised, advertised—and insisted upon—by the society in which I live... strange, so many ME/CFS people remember, vividly, the television ad for a cold and flu remedy which shows sick people ‘soldiering on’ in the midst of their misery...

Pause:

Matthew Fox (1983, p.162) says:

The strength called for... is not a... strength of gritting the teeth nor a macho strength of controlling the situation; it is a vulnerable strength, the strength to absorb, to receive the dark with the light, the pain with the pleasure, a strength to keep on falling. It is a strength born of sensitivity, a refusal to live with insensitivity, with coldness of heart, with the god of protection, the idol of invulnerability... The strength of emptiness, nothingness, the zero point. This strength shatters our very definitions and projections of what it means to be strong.

Small voice: And if you give up this attachment to control you are ostracised, scapegoated, excluded, isolated and shamed?

Fox (1983, p.101) notes that

As science has made clear, humanity represents the most laborious and lengthy effort of the cosmos... to grow ever more beautiful. In humanity for the first time in twenty billion years, the cosmos can reflect on itself...

It seems sad to me that this is how humanity/cosmos sees itself—in a power vice of controlling or being controlled...

Pause:

232
... which leads to fear of annihilation, to no longer exist (for the extrovert) or of chaos, lack of meaning (for the introvert) (Rowe, 1987).

Pause:

The secret seems to be that all of this doesn't matter. If I can get to the stage where the answer to every question is either a simple "Yes" or "It doesn't matter" then all will be well with the world, and all manner of things will be well.

Small voice: But doesn't that mean that you ignore the mores of society?

Of course not! Remember the dictate that we "give unto Caesar what is Caesar's and to God, what is God's" ... the Taxman cometh ...

Small voice: And what about justice?

Temperature rises:

Wonderful - justice! That's at the heart of this, isn't it!

Well, there is no such thing as justice - which is why societies legislate for it ...

Small voice: To give themselves a cover under which to practice injustice! Like Yahweh and Satan!

Now who's being cynical?

A creation-centered belief system would say that justice is no more, and no less, than compassion - a combination of passion, rights and relationships - and an ability to recover feeling. Says Fox (1983, p.264):

The spiraling journey ... finds its fulfillment in persons responding to their prophetic vocations ... the prophet [from the Greek 'to speak out', to be an advocate or a spokesperson] interferes with pessimism, cynicism, and despair, and channels moral outrage into rebirth.

Small voice: Does that mean that you have no prophetic vocation, in this sense?

Pause:

What do you mean?
Small voice: Well, if you are having to come face to face with pessimism, cynicism and despair — that is, you are actually experiencing it, it is rather difficult to speak out against it at the same time, isn’t it?

Herein lies the paradox. On the one hand, the interference and on the other hand, the channelling. But why not have both together? The interference or speaking out can simply be seen as naming the experience, for yourself and for others ...

Small voice: And who is more appropriate to do the naming than the person with the experience?

Exactly. And at the same time channelling or forging the experience into something new.

Long silence:

Small voice: This contrasts with the attitude of much of the legal profession which claims expertise in the field of justice, doesn’t it!

Yes. I remember — what was his name? — a litigation solicitor I worked with in Canada? He used to say: "Never sue on principle, only ever sue for money ... and make sure the person you are suing has the money to pay." Another lawyer I came across used to say, "Never pay the bill till you get the summons." Yet another confronted a distressed woman with, "You pay for my time, not for my advice."

Small voice: To balance the scales, somewhat, you owe a debt of gratitude to the Public Interest Advocacy Centre (1988) who came to your aid with care, compassion and expertise when you’d almost lost the battle for your superannuation.

That I do.

Pause:

Perhaps we could say that we give ourselves such camouflages, and indulge in meaningless rhetoric and jargon, to relieve ourselves of the terrifying truth that we can’t control things! Infantile temper tantrums — I want and I intend to get! It’s mine! And grabbing this and that, refusing to let go.

Pause:

Small voice: And this is what you are learning from ME/CFS?
Yes, I believe this is the learning, or at least a major learning.

Learning the difference between hope and hope between rehabilitation and rehabilitation.

Pause:

ME/CFS forces one to face uncertainty, chaos, fear, death (if not literally in the body in a short space of time, as in terminal illnesses, then metaphorically - a practice for physical death) - in short, you face your own mortality, your helplessness, your lack of control...

I experience the lack of eros, wisdom, mercy, gentleness - the lack of Sophia ... in myself ... and in society in general ...

Small voice: This is beginning to sound morose ...

... not meant to be - that's only because you are in your Pollyanna - positive thinking, all singing, all dancing, life will never end - mode. The other side of the coin is an incredible freedom, a letting go of inappropriate responsibility...

Small voice: Yes. Your friend, Dina, used to ask "Who do you think you are? God?!?"

... and a willingness, more often, to allow other people to live their lives without judgment from me about how they are doing it. And perhaps that's just another way of allowing Wisdom in?

Small voice: How does that fit in with the broader aspects of justice - social justice, poverty and the like?

Pause:

Letting go and letting be

I've thought long and hard about that ... and I am concluding that I am where I am for a reason (my fear of chaos revealing itself!) and if I am to 'interfere' in whatever, I will find myself in the the appropriate place, with the appropriate energy, to make a contribution.
Small voice: Yes. Why not allow other people to practice their gifts? Why would you want to rush in and deprive other people of the opportunity to make a better fist of it than you are capable of? Why would you want to be able to do EVERYTHING that every other person on this earth is good at. Let the Olympic athletes perform — that is their gift; let the musicians play — enjoy; and do not feel envy or jealousy. Jealousy and envy exist where you do not rejoice in another’s gifts. And that is because you are not practicing your own gifts. When you are living your gifts, you are then delighted to see other people living out their gifts.

Pause:

Wow! I knew the seven deadly sins would reappear! So where does that leave me?

Small voice: I would have thought it leaves you to ensure that you are using our gifts, whatever they may be — that way you forget that there might be an observer on the cliff.

So that’s where the observer comes from?

Small voice: I suspect there are (at least) two types of observers. One is the audience which delights in the expression, the manifestation of gift. The other is the critic who looks only to find fault, never to enjoy or to interact with the writer.

Pause:

Small voice: Your Mr. Eliot has things to say about "Tradition and the Individual Talent" and "The Function of Criticism", two essays which he wrote in the early part of this century (Eliot, 1972). I mention this simply because it is floating around in my head and ...

... and the finding of fault is, in itself, an expression of isolation from one’s own path? A grabbing of whatever is there and by defining it as ‘not mine’ ...

Small voice: ... by denigrating things ‘other’ ...

... I am hopeful of finding what ‘is mine’.

Small voice: It is a pretty destructive way to go about things, isn’t it?

Pause:
In one way, yes, if the ‘creator’ of the thing which is being criticised is looking for external validation.

Small voice: Perhaps that what Yahweh is doing with Job? Expecting Job to validate His creation? Being no better than humans who desperately want confirmation and validation?

Pause:

Of course, if the creator is centred in him or herself, then such criticism does not mean much. The ‘creation’ serves many purposes – one to provide joy to both creator/created and witness; another to provide joy to the creator/created and to challenge to witness. Yet another provides challenges to both creator and created. And another provides joy to the witness and utter despair to the creator. And another ...

Small voice: And so if goes on, and on ... just how are we to distinguish between ‘the creation’ meaning the mystery of our existence ... and the way people display their gifts, be they of a personal, interior nature, or public, external nature?

I don’t think there is a distinction. Isn’t it always a mystery – wondering about who people, myself included, are, what they do, why they do it. I know that when I start thinking, pondering, on myself, I come up with the answer that ‘it’s all a mystery’ in the end!

Small voice: So, surely, this leads to incredible anxiety?

You mean ‘angst’ and ‘free floating anxiety’ and such?

Small voice: That doesn’t do justice to the intensity or the depth of the emotion. I mean, just calling something ‘existential angst’ or whatever, is simply a way of sweeping it under the carpet. It’s a way of saying that this is just too much and I don’t want to engage in any way with this.

 Interruption:

["Like anecdotal evidence?"]

Pause:

And this, actually, is one of the hardest things about having ME/CFS – and no doubt, any other number of chronic illnesses ... the unwillingness to engage in the struggle to understand.

Silence:

237
The questions that are raised and which need to be pondered, meditated, examined, tasted, are questions which we have to address in a spiritual or existential or ontological context. And this is simply because these questions question our hubris, our certainty and our smugness. We assume that what we don’t understand at this present time is either fanciful, non-existent or unimportant.

Pause:

Small voice: Many people busying themselves with the outer-world have no time for such indulgence, labelling this behaviour as ‘deviant’, appropriate or inappropriate ‘illness behaviour’ and the like. Others, such as Maturana (Maturana and Varela, 1992) would perhaps speak of this ‘behaviour’ as ‘growth’.

Pause:

Small voice: And at one level, you could say that this freedom to explore existential questions is what you are ‘getting’ from being ill?

Certainly, outside the discipline of philosophy, it is difficult to raise such issues in the everyday, pragmatic world of economic and scientific rationalism. On the other hand, the pragmatic world demands our attention if for no other reason than we need to eat in order to remain alive in order to ask the questions!

And even philosophy/theology has fragmented into various departments with their own territory to defend. Joseph Campbell (1984, p.7) calls this ‘dicta of authority’ the “holding to the shells of forms produced and left behind by lives once lived.”

Pause:

Small voice: But isn’t that just what Job and Michael Hanson are talking about? The futility of asking such questions?

But how do you know (whether and if) they are futile unless and until you dare to ask them? Listen again to Michael Hanson (1993, pp.125-26):

I mistook silence and stillness for emptiness. In that silence, a little way apart from my anger and suffering, I found you waiting. You have not asked me to feel any different. You only ask me to join you in the stillness. I am speechless. It is well. There are no words, just you and me, as I am and as you are.
Interruption:

["I could have used Michael's words to describe the experience of joy."

["Thanks."]

["Ah. The paradox. Different sides of the coin - love/hate; fear/joy!"]

Joyful, happy silence:

From that I understand that unless I ask these questions, I cannot, simply cannot, come near the silence. I do not learn the difference between 'silence' and 'emptiness'. Perhaps if I am a person of simple faith, I may enter into this silence, simply and quietly, and I would never need to ask the questions - and I would never experience in the silence in the same way.

Small voice: This must help tremendously with fear and anxiety?

Actually, following my 'discovery' that "I always make the right decisions, given the circumstances" and the later addition of "and I assume that other people do, too"; the 'answer' became apparent.

Small voice: What 'answer' ... and what 'question'?

Sorry, I'm being cryptic again.

Pause:

What I mean is that it doesn't matter what the question is, there are only two possible answers: "Yes!" and "It doesn't matter!"

Small voice: So?

So ... what? I've lost the thread of what I wanted to say.

Small voice: You are trying to handle too many concepts at once.

Pause:

Right!

Pause:
Right! If I trust other people to 'make the right decision, given the circumstances' that means that I trust others to live their lives. Then why would I be anxious? Surely the emotion is joy?

Pause:

I am only anxious if I seek to relieve them of their responsibility ... if I try to make their responsibility my business.

Pause:

Small voice: You mean you just don't care about them?

On the contrary! If I assume the responsibility for being myself, I can relinquish the responsibility to become something that I am not. Hence, all (or most) anxiety evaporates (most of the time).

Small voice: So ... you allow them to 'do their own thing'? ... And support them in the doing?

Yes. But I think this 'support' is a kind of spiritual support. The New Agers speak in terms of 'sending white light'. This sounds pretty sentimental, but it is no different from earlier periods when groups of contemplatives accepted their vocation to 'pray' for the world.

Pause:

When I am wavering, finding the anxiety creeping up again, I remind myself that I was not around when the foundations of creation were laid, nor am I called to do anything more than I am doing.

Thomas Merton, in New Seeds of Contemplation, (1972 p.100) says this:

But the greatest humility can be learned from the anguish of keeping your balance in such a position [between honesty and pride]; of continuing to be yourself without getting tough about it and without asserting your false self against the false selves of other people.

And if I am not anxious, then I remove from the world some of that anxiety which infects others, particularly those who are near and dear. I take up what is my business and in so doing I am an example to others.

Pause:
Some eighteen years ago, when my father was dying, I became aware of my desire to die his death for him. My anxiety revolved around my fear that he would not be able to handle it himself! How arrogant! He showed me that it was his life and his death and that he, and he alone, was capable of living and dying it to the full. It was my fear, not his dying, that caused me anxiety.

Small voice: And anticipating his loss, and the hole which would be left in your life.

And at that point I call upon Sophia, not Yahweh!

Pause:

And that was his gift to me. His example. He died with the same passion and commitment that he had to life. His dignity lay in his doing what he had to do, attending to his business.

Small voice: So now you carry this treasure?

Yes ... and no. "There is no need to carry it ... You only have to hold it." These powerful words came to me through Felicity Bowak, the Bereavement Counsellor at Waverley Community Health Centre early in 1991.

Pause:

Small voice: So, if you were meant to be doing something different, you would be somewhere else, you would find yourself doing something different. (Merton, 1972, p.273)

I suppose the 'create your own reality' people would say that I 'create' my life (or meaning) as I go, and that is true, too. I suppose, at a deeper level, I'm asking why I find myself with the specific options which I have.

Small voice: What are you trying to say?

At bottom I wonder how come I was not born an Ethiopian.

Small voice: The new age people would say that you chose your parents, and place and time of birth ... or that you are reaping your karma as a result of past lives ...
Small voice: ... and after all, the insights we gain from other cultures and belief systems are passed on through translations and coloured by our own indigenous knowledge and 'mother' culture.

_**Interruption:**_

"Exactly. Taken out of context, selectively!"

"The deeper (truths) are obscured by focusing on individual elements."

"While at the same time the culture in which we are born becomes fossilised. It is in the very nature of human beings to want to build structures and deify those structures ..."

"... at the expense of the (truths)"

_**Interruption subsides:**_

All right. I accept all of this, in context. It's a belief system. It's a system of meaning which is embedded in the context of what it is trying to explain. No doubt an Ethiopian would have different explanations - and after all, these are 'just' explanations, not facts, in the concrete sense. What 'questions' does a dying Ethiopian ask? Did she choose to be born into such a culture in order to work through her karma?

Small voice: Does all this matter?

Yes, I think it does, because until I can be comfortable, in myself, with my belief system, I am at the 'mercy' of competing explanations.

Small voice: But didn't we already say that having to deal with competing explanations helps one discover who one really is by the negative route, the way of discovering what one isn't?

Yes.

Small voice: And why are you quarrelling with this? Why can't you really accept it?

_Pause:_

Perhaps ... because I have some sense that there ought to be 'an answer'? I think I've found it, then a gust of wind disturbs the dust. Perhaps I'm wrong?
Small voice: Couldn't you see this as a way to broaden and deepen your understanding by showing you a different perspective?

Pause:

The Indian Medicine Wheel? I'd forgotten.

Pause:

Of course, I have to realise that other people may not feel the need to find meaning - at least not in the way I do. What about agnostics, atheists and humanists, for example?

Small voice: It is such an individual thing. The best example is to 'follow your own bliss', as Joseph Campbell says. There is no cookbook recipe. No ONE way of doing things. It is simply a matter of becoming aware! And, besides, great thinkers and feelers have struggled with this... God and Yahweh, Adam, Buddha, Allah, the Rainbow Serpent, Luke Skywalker and every member of the Sceptics Club.

Thanks... a lot!

...........

Other ways of being

The Indian Medicine Wheel is another culture's explanation of the inexplicable (Storm, 1973). A way of explaining not only the circumstances of one's birth, but of the many and varied experiences which come through external circumstances and natural maturation. The explanation is that we are required to see the world from many and varied perspectives and that we voluntarily look for these different perspectives, or/and circumstances force them upon us.

Thomas Merton (cited in Fox, 1983, p.324 and 1989, p.231), a modern-day Christian contemplative and mystic who died in the 1960s, said that he was led to his own tradition by Suzuki, the great Zen Master. Suzuki knew well the writings of the Dominican Christian mystic, Meister Eckhart, whom he considered to be 'an enlightened one' (Suzuki, 1988). Fox (1983, pp.16-17) points out how many Christians do not know their own traditions. How strange that a Zen Buddhist Master would be the one to find lost treasure for a Christian.
Small voice: I think you should be explicit that you are talking about cultural roots of spiritual traditions and that the dogma and the institutions of these traditions are often achieved at the expense of the ‘spirit’.

I thought I’d already said that?

Small voice: Maybe I didn’t hear it.

Pause:

Small voice: It occurs to me that the Christian message of loving yourself, your neighbour and your enemy is perhaps better understood and practised by the Australian Aboriginal culture, than by the Judeo/Christian culture which spawned it.

Silence:

Small voice: May I also venture a comment, that you run into difficulty when you try to explain the irrational, the mysterious, the deep feeling currents, in the context of rational, pragmatic and superficial day-to-day living?

And that’s exactly my point – about hope and hope and rehabilitation and rehabilitation. Somewhere along the way it is essential for me, and maybe for others as well, to try to forge links between the deeper currents and the surface movements. The surface movements seem to be at the mercy of the wind, blown about, willy-nilly, ever changing, fascinating. The deeper currents sound a timeless, throbbing, insistent, rhythm ... but we use the same vocabulary for both.

 Interruption:

["Oh, dear! She needs to be reminded. Because this is ‘new’ it can’t be done in the places of surface movements, i.e. the official world."]

["Right!? What do you mean?"]

["Well, for example, you can go into the CRS and come away with new awareness, but at present you can’t take this awareness back to the CRS."]
"Why not?"

"Because the energy there is in protecting the surface currents. If one begins to listen to the rhythm, one can’t stay there."

"Why not?"

"Because this is the limen, the threshold. You have to make choices either to defend the institution or surface currents, or you begin to ask questions about first principles."

"Oh."

"And when loyalty to the surface currents actually pays your bills, then ...?"

"Are you saying that this marrying of the surface and deeper currents is an ideal."

"You could very well say that."

"And that only those who have been ousted have the opportunity to be a ... prophet?"

 INTERRUPTION SUBSIDES:

Small voice: Hence your interest in the cello?

...I hadn’t made that connection before, but now that you mention it Pablo Casals (cited in Fox, 1983, p.206) says

There is of course no substitute for work ... I have been told that I play the cello with the ease of a bird flying. I do not know with how much effort a bird learns to fly, but I do know what effort has gone into my cello.

Small voice: Is this what your cello represents?

What do you mean?

Small voice: Could your cello represent the work you are required to do - marrying the surface and deeper currents?

Silence:
Ah! My radio is delivering Tchaikovsky's 5th Symphony ... it is time to leave these mind games.

Art is the basic form of meditation ... with art as meditation we truly listen to the cosmos within us and around us and give birth to the ongoing cosmogenesis of our world and worlds. With art as meditation creation as blessing is rediscovered and our trust in letting go is affirmed. (Fox, 1983, p.198)

............

Disembodied voices

Blackness:

"I feel quite shaken by all this talk. Not my cup of tea at all."

"I don't see what you mean."

"Well, I'm feeling very vulnerable. She trying to come in and take over our territory."

"I don't see why you would be complaining - you never take any responsibility for your territory at the best of times. Why start to get worried now?"

"Well, it's just that she's getting too close. And I don't like it!"

"I didn't realise you felt like that? Why didn't you say anything before this? Want to talk about it?"

"No!"

"Oh, well, if you find you want to say something later ... "

Pause:

"How do the rest of you feel about it?"

"Isn't she getting a bit too precious about things? I mean, it's a bit tacky to be talking about ..."

"About what?"
"You know!"

"No, I don't. What do you mean?"

"Scorpions and snakes and all that stuff about 'crying out to the Lord'."

"Ah ha. Hit a nerve, did she?"

"Don't be so smart!"

"What's wrong with crying out to the Lord?"

"Well, it's sort of a bit childish."

"So you'd rather she talked about putting up proposals and negotiated agreements, and 'win-win' situations, standing your ground, playing the ball and ..."

"... jargon words like, 'empowerment' and 'owning your own emotions' and 'refusing to limit yourself' ..."

"Yuk!"

"So, what's wrong with 'crying out to the Lord'? What if I say you can substitute anything you like for the word 'Lord'?"

"I'd say ..."

"What?"

"I'd say ... that's the wrong question!"

"Really?"

Pause:

"Yes. The wrong question because you've got stuck on the language - that's all it is words, language, designed to hide at least as much as it reveals."

"I agree. She's making an effort to get these experiences 'across the threshold'. Is she telling us something about ourselves which we don't like?"

"What could that be?"

"That perhaps we have been identifying ourselves too closely with 'the spiritual' ... and ..."

"... and, after all, she's noticed that this allmighty, algood, spiritual dimension may be somewhat lacking?"
"Shit! Do you mean that we could be next on her agenda. Next to undergo her incessant questioning? I don’t like the sound of that at all!"

"Well, you’ve got good reason to be worried. Perhaps you’d better get to and tidy up your act before she gets to you!"

"What’s happened to all this ‘care and concern’ we purport to have for each other ... we talk about it often enough, in the abstract."

"It’s alright for you, goodytwoshoes. She’s goin’ t’get ya right where it hurts. Mark my words!"

"Well, are we going to present a united front, or are we all going to sink or swim, individually. Perhaps we’d better make some contingency plans. Any ideas?"

Pause:

"I don’t know whether we need to get into a panic. We’ve got Small Voice to act as a lookout, a mediator."

"What a good idea! She’s done really well with Small Voice, perhaps we could ask Small Voice to help us out. What about it?"

"That’s the best idea you’ve come up with for ages ... and ages!"

"Does everybody agree?"

"Oh my god!!!! If you must, you must! This is going to be interminable!"

Pause:

Small voice: If I am permitted to speak? It won’t necessarily be a interminable process. You have all had the experience of her experience and process. Perhaps the issues can be identified in a reasonably short time.

Pause:

"What do you think?"

Grumbles and shuffling, snorting and coughing:
"Nobody wants to speak?"

"Then I'll take it that we will ask Small Voice to sit with us."

"Perhaps this is a good time for a break. It would be helpful if you could do a bit of thinking on your own. See you back here next time."

*Sounds of hurried exits.*
PART XIV

HONEY SUCKLE TIME

Fine and Warm

Yesterday I received my quarterly Newsletter (M.E. and You, September 1993) from the ME/CFS Society. In it was a questionnaire designed to collect information for a submission to the Medicare Working Party, within the Commonwealth Department of Health, asking for details of members' experience of diagnosis and treatment of ME/CFS. And what is and is not covered by Medicare. This, indeed, is a welcome sight - and, of course, I have responded generously.

Also in the Newsletter was an article reprinted from Interaction: the Journal of M.E. Action, a support group from the United Kingdom. In that article, "M.E. An Alternative View" Jock Millenson (1992) writes:

My own experience with over three years of this illness tells me that the more I struggled to gain control, the worse the illness became. It was only when I gave up and began to just wait that gradually in the fullness of time, nature's own (not mine) good time, I was one of those graced by forces beyond myself to be granted some recovery. (p.25)

He now considers himself to be "about 90% normal and almost ready to view the long nightmare as a gift" (p.25).

I was also interested in his exploration of traditional/complementary medicine. Millenson (1992, pp.23-24) writes that the holistic model is based on the principles that

an illness (a) is originally induced by prolonged stress; and (b) represents a form of energy imbalance or disharmony.

Since allopathic (orthodox) medicine has so far come up with very little in the way of effective treatment, M.E. sufferers everywhere will be interested in what complementary medicine might have to offer. Unfortunately the suggestions made, which are likely to be representative of the view of many complementary medicine practitioners, seem to me, speaking as a psychologist, medical herbalist and M.E. sufferer, to be seriously misguided.

It is one thing for us to say that improving diet, reducing stress, and learning to relax all work to
strengthen the immune system, and something quite different to presume that they therefore must promote recovery from M.E. This kind of logical error opens the way for an easy discredit of alternative treatments; for by implying that certain treatments are effective but may take a very long time, we invite exactly the criticism made by the medical establishment: i.e., that alternative practitioners are exploiting sufferers who are desperate to try anything.

Milleson concludes that ME/CFS fits neither the orthodox nor naturopathic framework of 'disease'.

... we can either force it into the mould by ignoring the disparities (as those who are not intimately familiar with M.E. all too often do); or alternatively, we shall have to develop another model (p.24).

He suggests (p.25):

1. using holistic research models to identify precisely what kinds of lifestyles are predisposing [he emphasises 'predisposing' not 'causing'] towards ME/CFS.

   It is not enough to parrot the truisms that mind and body are inextricably intertwined. We need to know what particular patterns of stress behaviours and predisposing circumstances are correlated with M.E. onset.

2. validating 'viral depression' as a sign and symptom of the illness.

   ... hope, understanding and empathy ... are more useful than exhorting sufferers to try to gain control of an imaginary energy switch.

3. listening to, and obeying, the body at the first sign of recovery.

   This is crucial for reducing the likelihood of relapses, and thus for ensuring that the duration of the illness, long as it is, remains as short as possible.

4. engaging in two-pronged research programs into predisposing factors.

   To the extent that the complementary approaches, by their holistic focus, can identify pathological factors in lifestyle and environment, they can indeed complement the virologists, immunologists,
neurophysiologists, and microbiologists who are seeking to specify the body malfunctions that underlie the symptomology we call M.E.

Pause:

Small voice: Well, all that is very confirming, isn’t it?

My word! Except, of course, that the conservative medical establishment (for example in Australia, the Australian Medical Association) doesn’t have the same viewpoint. (ME and You, September 1994).

Pause:

Small voice: So what did you have in mind for today?

I was thinking of leaving behind all that angst, all the struggle of modifying, justifying and rationalising things ...

Small voice: Is that because you’ve filled in the questionnaire for the Minister for Health?

Sighing:

Yes ... that ... and because I had an interesting session yesterday – a Feldenkrais Functional Integration session ...

Small voice: And what about it?

Well, I came away quite disoriented. I still have difficulty with my breathing.

Small voice: And what did she say?

About my body?

Small voice: Yes, your body – what else???

You’re getting irritable!

Small voice: Well, if you won’t get irritable, then I have to get irritable for you!

Pause:

Okay, okay.

Small voice: Well, well. What is it? Spit it out!

My bloody body hurts!
Small voice: I'm sorry.

Silence:

Ho hum! Just another day. Actually, it really does hurt. ... must have activated some areas around my middle back and ribs ... yes, the rib cage and diaphragm ... and she did say, as I left: "You know you have stand like that and defiantly say 'I'm coping' ... or you can stand like this and quietly say 'I'm coping'..." ... but the muscles keep spasming and I get cramps in my feet ... and ... and ...

Small voice: So - life's a shit ...

... and then you don't die!

Small voice: Best to say how it is, really, and then let it go. Stop denying the pain. But isn't it also to do with a sense of despair that the 'scientists' and the 'alternatives' will ever get it together?

Pause:

Perhaps. I suppose I'm thinking of the energy I have put into filling out questionnaires which have come to nothing - those hundreds of sheets of paper that fill up an untold number of filing cabinets. I'm seriously considering that next time I might exercise my options to not cooperate or to throw a handful of subversive spanners into the works!

But what good would that do? The processors of the questionnaires would accept my subversive answers as 'correct' and come up with authoritative, but totally incorrect and potentially dangerous, findings.

Small voice: Would that matter?

How do you mean?

Small voice: Well, haven't you said that they ask the wrong questions so that the answers will be wrong, anyway?

Yes.

Pause:

Small voice: And what of your experience of what 'working parties' are really designed to do?

True! True! When all else fails and the natives seem to be getting restless, propose a working party ... and that will shut them up - for a while! That way we look as if we are
doing something - It doesn't cost much money and it can buy us time, politically speaking!!!

Silence:

Small voice: We are feeling out of sorts today!

Stop patronising!

Small voice: You're right - I was patronising, but only because I don't know what to say.

You don't have to say anything.

Silence:

It's not time to write ...

.......... 

Many days later:

Disembodied voices

Blackness:

"Now that was a fine example of pushing when there is no energy to push."

"And of not letting go of an idea ..."

"An idea?"

"Let me finish ... an idea ... the idea that she was going to sit down and cover some more of the thesis."

"Yes. There was no doubt that she was committed to writing when she started, but very quickly the energy drained. Funny."

'A year later ... no response from the Minister or the Department (M.E. and You, September 1994).
"My reading of this is that the combination of 'questionnaire filling', yet another opening of the wound, and the confirmation of Millenson's article, and the body work, brought about a despair (dare I say, 'depression')."

"No doubt about the feeling. But I don't know whether I would call it 'depression' either."

Pause:

"Anybody else with any ideas?"

"Surely it is simply the pain of recognising the reality of the situation ... the reality of the hostility ..."

"And, let's face it ... the drain on her energy of simply doing things, like form filling, facing physical, emotional and spiritual pain, and the body work."

"Too much in too short a time - for anybody, I would think!"

"My feeling is that the truth of Millenson's article threw a bright light on the 'struggling to gain control', 'the fullness of time' and 'waiting' ..."

"... which, of course, was her thesis for her Graduate Diploma dissertation ..."

"... she has not yet been 'graced for forces beyond myself to be granted some recovery'."

"Hold on. We're getting everything mixed up!"

"That's the way it is."

"I don't mean that. I mean that there are several things here which are important."

"Like what?"

"Like ... she's already said all these things that Millenson is saying ... and ... but ..."

"... but she isn't recognising that she has been granted 'some recovery', because if she hadn't she wouldn't be writing this!"

"And while she accepts these things intellectually, she hasn't really given up the struggle for control."

"Do you think that's why she reacts so strongly to the questionnaires?"

"Perhaps!"
"I’d say more than perhaps. I’d say that even the sight of a questionnaire which relates to policy decisions is a Technicolour, CinemaScope, Stereophonic reminder of her powerlessness."

"Hey, that’s a bit strong!"

Pause:

"I don’t think it is. I think that despite all of her rhetoric, ‘giving up, giving in and letting go’ is extremely difficult for her. Her struggle to hang on to the positive inhibits the pessimism necessary for resigning and waiting."

"So, how can we help her to make this quantum leap."

"It seems to me that everytime she gets close to the abyss there are too many reminders in the environment which exhorte her to ‘try, try again’, to ‘keep sodering on’...

"We’re back to this crossing of thresholds again! This area of liminality – of chaos, confusion, fogginess ...

"My feeling is that she has already crossed many thresholds."

"It ocurs to me that there are no thresholds – just a continuous walking into, through, around..."

"Why should that disturb you? After all, isn’t that what her thesis is about?

"True! And wasn’t it Leslie Devereaux (1992) who spoke about ‘one breath mu’, focusing on what is really important, and learning how to plummet?"

"I know that’s what she really wants to do ... so how can we help her just let go?"

Pause:

"Look at Millenson’s article again ..."

Pause:

"... in it he says that he is now "about 90% normal and almost ready to view the long nightmare as a gift." She is nowhere near 90% normal. She is not nearly as ready as Millenson to view the long nightmare as a gift!"

Southerly change blows through:
"Well done! I think that is the crux of the matter. She is expecting too much of herself. He is writing after the fact—after the fact of getting to firm territory, on the other side. By comparison . . ."

Irritation:

"Comparisons are odious! And, besides, who says he hasn’t had a relapse since he wrote the article?!?!"

"... she is still in limbo, trying to describe it. At some point she needs to give up trying, and give in to the pessimism . . ."

"Exactly what did Millenson say?"

"The article says

[In 1987] . . . after spending six months trying several dozen treatments (orthodox and complementary) he gave up, moved in a wheelchair to a warm climate, and with considerable pessimism resigned himself to wait a few years to see what might happen. In February 1990 he began spontaneously to recover both his energy and his spirits . . . (Millenson, 1992, p.25)

"Thanks. Millenson is not writing about what happened between 1987 and 1990. He is talking about ‘coming out’, on the other side, so to speak."

"Right! Her struggle is in trying to capture the turn around point, before coming out on the other side. That is why she is agitated! Millenson has already moved through that invisible point and she is disappointed that he is writing after the fact and can provide no guidelines for her, except for the key with considerable pessimism he resigned himself to wait."

"And already she has been waiting for bloody years!"

"Well, she just has to wait some more . . . perhaps this time with less optimism and a good bit more pessimism."

Pause:
"Do you think that depression in this case may be helpful in providing the vehicle for this necessary pessimism?"

"Perhaps the depression is the physical sign that 'letting go' is occurring."

Pause:

"In that case, could you say that any attempt to deal with the depression by, for example, drugs or cognitive behaviour therapy WITHOUT the deep spiritual or philosophical searching is 'strictly tap-dancing'? What do you think?"

"I think that because the things/ideas that people are attached to are personal and numerous, any of the generalisations used will be less than useful."

"Actually, I believe it is the underlying societal addiction to positivism which inhibits the letting go."

"I think you're right. Not only are we not encouraged to let go, give up, drop out ... we are actively persecuted, humiliated, ridiculed ..."

"... and we also persecute, humiliate and ridicule others ..."

Long pause:

"Isn't that the disappointment with the Commonwealth Rehabilitation Service (CRS) Program? The fact is there is no permission to 'let go' whatever it is. The whole aim of tertiary rehabilitation is to 'toughen up' the participant and encourage and enforce 'good' work attitudes and values! ... And that's the very thing one must relinquish in order to move from the 'doing' to the 'becoming'.."

"Wouldn't it be nice if the CRS had a drop-in centre where you could have access to physiotherapists, who could help when the body spasms into knots, and counsellors who were comfortable with 'process', and ..."

Pause:

"In your dreams!"

Pause:
"We are back to the terrifying prospect of having to go it alone."

"Right, right. I get the picture!"

"Okay. If this is where we are at, how do we now give her permission to drop out, give up, let go?"

Pause:

"You just have!"

"Does that mean she’s finished her thesis?"

"Sounds like it!"

Pause:

"Well! I’m ready for a break, my little neurons are spinning in all directions. Can we leave it up to her to sort out what she wants to do and how to go about doing it?"

"Of course we can leave it up to her! It’s her thesis!"

"God! Some of you people are precious!!!"

.......... 

Learned Pessimism

Small voice: How are things today?

Softly, softly. Actually I feel quite calm. Bodily I feel as if I have been belted around - bruised and battered - after a fight! And I don’t have the energy to get out of my own way. But that’s okay, today.

Small voice: Did our discussions help any?

Sure did! I’m beginning to read the environment better. I’m getting used to the mists rolling in and obscuring things. They are rolling in less often these days. I found Millenson’s article quite enlightening.

Small voice: Really? How?

Well - I recognised that he is one of those people who are blessed with a ‘spontaneous remission’. I can recognise,
now, that my recovery is not one of those. Instead it is a slow climb, a long walk, an incremental recovery. Slow and steady (or not so steady).

Small voice: Where does the disappointment come in?

It comes in with the realisation that we are each alone in the journey. It is helpful to know of other people on the path.

Small voice: Yet it is disappointing to read such accounts of ‘recovery’. Usually because there is no detail of the process – only that one day they felt better ...

Mind you, given the relapsing/remitting nature of ME/CFS, who’s to say that Millenson hasn’t had a relapse since writing that article?

Pause:

It throws me back to the article by Bruno Latour (1988, p. 174):

The reader will always want more details, not less, and will never wish to leave details in favour of getting at the general trend.

 Interruption:

["The ‘client’ reader might want more details. The professional wants generalisations ... it’s easier!"]

["And sharp, focused, introductions ..."]

["...which are so sharp and brief that the reader doesn’t even have to skim through the body of the text..."]

["In fact, one wonders why you need to bother with the body – just write an introduction!"]

["You’ve missed the point."]

["So what is the point."]

["The point is that we want a definitive answer, in no more than one page – we want outcomes, quantifiable outcomes – we don’t have time for the process."]

260
Interruption subsides:

Small voice: And the underlying message is 'if I could get better, then so can you.'

This might be encouraging at the beginning, but as the years go by and the euphoric spontaneous remission fails to materialise ... well ...

Pause:

Small voice: And what would be helpful?

Pause:

For me, it would be helpful to provide some 'keys'.

Small voice: What do you mean by 'keys'?

Sort of pegs ... issues, concepts, truisms, paradoxes ... even Zen koans ... 

Small voice: Perhaps, especially Zen koans?

Pause:

So far, the only 'keys' I've found are in spiritual literature. Many of these 'keys' are used in personal growth courses. They are appropriated, and twisted, to fit into the door of 'control' when in fact these 'keys' come out of areas over which we have no control.

Long pause:

In fact, I was disappointed when I finally got hold of a book Life after Loss, by Francis Macnab (1989) because it came highly recommended. By the time I got to page 8, I knew we were on different paths:

Sometimes the human being when dealing with the stresses of life stays downstream and drifts onward to the ocean. At other times the human being can be like the salmon. As if responding to some greater call of nature he will turn upstream and, negotiating a course through stressful events and difficult odds, will continue to leap. Drawn toward a destination upstream, the human being there fulfils one part of destiny and there also begins another.

Pause:

261
The paradox of this story is that the salmon only turns upstream in order to spawn and die. By far the greatest part of its life is in the ocean.

Macnab has many useful things to say, but his book suffers from his trying to draw generalisations from the multitude of experiences. I have difficulty with his continual references to ‘control’ and ‘regaining control’, and his habit of including himself in his clients’ grief. Some of it reads like a cut-and-paste job from his case notes — in which he confuses his clients’ actual stories, his interpretations and his self-congratulatory style.

Small voice: Do I detect a little judgemental criticism here?

You do!

Pause:

But to return:

Small voice: Then it is no wonder that confusion reigns.

Right! In my normal state, I would be able to sort the wheat from the chaff. I would be able to differentiate the means and ends. But in the ME/CFS state, this cog slips. I lose focus. My perceptions — physical and emotional — become confused. What is up? What is down? What is coming? What is going?

Small voice: And when you go looking for help, all you find is more confusion because the people offering the help are really offering to help you stay stuck, rather than helping you to let go.

Yes! And to make it more confusing they are saying that they are offering to help you let go … but there are strings attached … they have their idea of what it is you ought to let go of!

Small voice: Is it a matter of morals or ethics?

Exactly. The help that is available is socially sanctioned. That is, it is only the dominant societal values of controlling, producing, acquiring, succeeding that are encouraged. It is assumed that one does not have these values. For one to value pessimism over optimism, letting go over getting and keeping, withdrawal over commitment, being over doing …

Small voice: ... as essential to maintaining life ...
... one must turn away from professionally offered help. One must turn away from previously firmly held beliefs ...

**Interruption:**

"It always has its price, this going it alone ... and the price is not necessarily upfront."

"Yes. It's a hard lesson for her to learn."

"In going your own way, you pay a price! How much are you willing to pay?"

"It's the strangest feeling to find a price tag many miles away from the point of sale, so to speak!"

"Yeah! Like getting your Bankcard statement!"

**Interruption subsides:**

Small voice: ... and venture into the land of verbs, not nouns ...

... away from ...

Small voice: ... away from static nominalisation!

Right! Concepts! Away from concepts. Concepts ... concepting? From outcome to process. And while Millenson's (1992) article had some of the process, it was nevertheless, written in an 'outcome' style.

**Pause:**

And Macnab (1989, p.57) would insist on your doing it his way:

*I set out for grieving people what is required for their emotional rehabilitation. When it is expressed sensitively and empathically they quickly see it as the necessary and urgent course of action ... The basic anxiety is so difficult to cope with because it threatens our established sense of control, it threatens our accepted view and meaning of things and it threatens to be so diffuse that it eludes attempts to convert it into manageable problems and challenges.*

Under Macnab's tutoring I would not have been allowed to undertake my journey.
A Passion for this Earth

Several weeks have passed.

Soft air:

The time must be right because while putting away some books I found one particular book which had been 'lost'. It is a lovely book written by Valerie Andrews (1990). It had been 'remaindered' — excess to demand. And I am happy to have found it, twice.

On the sleeve notes, Valerie says that

humain illness is rooted in the illness of the land and there can be no separation of the wound within and the wound without.

Robert Johnson comments

I have a consuming hunger for a new mythology that will be loyal to the past but rise above the one-sided patriarchy that has occupied humanity for several millennia ... Valerie Andrews ... writes with the grace and insight on this subject that only a woman could provide. So much of our mythology has been masculine ... now it is good to hear a reconciling female voice.

Pause:

I would like to quote Valerie Andrews (1990, pp.5-8 and 104-108) at length because it is so rare to find space given to the process — what we usually get is a set of data, a methodology, a measurement and an outcome (in no more than one page, please!).

And since this is a story, one must enter through the limen, purified and accepting, willing to receive. Willing to be challenged and to challenge, willing to be shamed.

Pause:

And I wonder whether the 'prize' is the revelation of some meaning which may be defined as 'a threshold', if one wishes to find a category under which to file the experience.

Silence:
Let us begin: Valerie Andrews tells her story:

Once upon a time ...

"... I learned about this correspondence between the human body and the larger cycles of this planet first hand when a series of infections paralyzed my immune system for a period of four years. As a journalist, I pushed myself well beyond my limits, putting in fourteen hours a day with no time out for renewal. Finally, I had to pay the price for ignoring one of nature's basic laws.

My healing came, slowly, as I became a chronicler of wildlife on the Rondout Creek.

At dawn I watched sixteen white-tailed deer cross the Rondout in a shroud of morning fog.

Then I would sit on the banks with my tea as the great blue heron flew above me.

Later I walked to a nearby meadow to gather chicory and Queen Anne's lace.

On the days I felt strong, I rowed out into the middle of the creek to watch the muskrats build their sandy burrows near the shore.

In winter, I saw ice floes form like giant vertebrae along the white spine of the river.

And in the spring, I witnessed the wavelike migrations of the shad and carp.

As I lived through the changing of the seasons, I began to see myself in a different context.

I no longer worried about the demands of a job or a corporation.

Instead, I was absorbed in the life cycle of an estuary.

In the quiet time so necessary for my recovery, I began to read about early matriarchal cultures that worshipped the earth as a goddess, 'the Great Mother,' who gives birth to all creation ... the stories of Inanna and Persephone ...

"we must make our descent into the darkness then wait for some new kind of wisdom to take root."
The story continues...

"... At first, I approached my healing the wrong way, making
detailed lists of how to change my diet and my schedule and
trying to jam too many ‘therapies’ into a single day.

Then another dream spoke about my need to slow down and
relax...

I began to feel more in touch with the feminine
the more time I spent in nature.

My husband and I had moved to an old farmhouse on an estuary
in upstate New York, and every day I sat on a glass-enclosed
porch, watching the world unfold around me.

In the early morning fog, I saw the deer walk across
the mudflats; then the heron and the egret came down to
explore the black bottom of the riverbed.

By midafternoon, the tide had changed and the
water was deep enough to swim across. The banks
were inhabited by muskrat and beaver and the creek
was filled with carp...

I set up a ritual to honor my connection to the animals and
the landscape.

In a spare room that overlooked the garden and creek I
laid out a sacred circle, some five feet in diameter,
composed of heron feathers, stones, a bird’s nest and a
heart-shaped bone I found in the woods.

I sat in the middle of the circle and called on
the deer and the heron, the beaver and the
muskrat, the shad and the carp.

I then asked them to teach me about their
ways of being in the world.

The deer spoke to me of trust; the
heron, of purity of heart. From the
beaver and the muskrat, I learned
tenacity, and I receive a lesson in
surrender from the shad and carp. A
short time after this I had a dream that
offered me a blueprint for my healing:

‘Just sit and pray. There is
nothing more that we can do ... the
wind will blow through your house,
but do not be afraid.’"

The End
Small voice: Does that mean that you are going to leave the thesis here?

Pause:

Funny. I am trying to reconcile Valerie Andrew's experience with what Jock Millenson had to say about 'pessimism' - and it doesn't compute!

Strange. Is it because Jock is a man who speaks of an outcome but not of the process; and Valerie is a woman who delights in the detail?

Pause:

And I feel an obligation to myself and to the reader to emphasise that these 'tales' are not to be taken literally. Who among us has a caring and wealthy husband able to take us off to the delights of upper New York State? And who looked after Jock Millenson during his two-to-three years in a wheelchair in the sun? Who paid his bills and did his washing, shopping, cooking and cleaning? Who cared for Michael or Leslie?

These stories are really no different to Dorothy and the Strawman, the Tin Woodsman and the Lion. I can't be a Dorothy; nor can I do as Valerie or Jock or Michael or Leslie have done. These are analogies, metaphors, ideas.

As I read it, these stories are snippets of what other people have done. They are not a prescription for what I should do. These are stories of their lives, not mine.

Pause:

Small voice: So where to from here?

Pause:

It seems that my task now is to click my heels together, three times, and return to Kansas ...

... Perhaps I am already in Kansas.

Silence:
It has been helpful to stay with the disorientation, the confusion, to explore the coming up to the threshold - and a little of the venturing into limbo. The next step I take alone. There are no words.

Small voice: Like the journey into NgoroNgoro Crater?²

Yes!

We returned to the rim.

We smiled at each other.

We sang "We have talked to the animals.

We have been to Bangui³, but we didn't see the Queen."

And we smiled some more.

Some people thought we were mad.

A few understood.

Silence.

²In Tanzania, East Africa, on the eastern edge of the Great Rift Valley. In 1974/5 a small group of friends travelled overland through Africa, north to south, for six months.

³Capital of the Central African Republic.
CONCLUSION

Easter

Easter is a moveable feast. It is early this year¹.

In the Christian calendar it marks a new beginning. A resurrection, like the phoenix from the ashes. In the Jewish calendar it marks Passover ... a celebration of the escaping, or passing over, of the plagues, the delivery from slavery and the journey out of Egypt. Ahead lay the wilderness. (Exodus).

In the northern hemisphere it coincides with the first full moon after the spring equinox ... following Ground Hog Day and, hopefully, the last of the winter storms on St Patrick's Day. A time of bluebells, snowdrops and crocus ... followed by daffodils ... followed by tulips.

But in the southern hemisphere, it coincides with the decline of the year ... with the autumn equinox. That time when humidity drops, the air becomes cool ... and the sun, still hot, shadows across the Sydney Show Ground. The oranges are ripening, the water is warm, the earth smells sweet ... and the tides come roaring across the Pacific.

Small voice: Well, you only notice the tides if you live on the east coast!

Point taken!

Pause:

So it is at this point that I have to come to some kind of conclusion about my re-searching.

I can truly say that I have come out into a new space.

I am a failure in the eyes of the Commonwealth Rehabilitation Service program — and yet the CRS program was pivotal in my rehabilitation.

Small voice: How was that?

It gave me a formal structure, within the normal societal values, against which to measure my journey. It gave me a focus. It ...
Small voice: Hang on. You don't know what it is you want to say.

True. I don't know what it is I want to say... except...

Small voice: Except...?

...except... that it doesn't seem to matter...

Small voice: I can sense that just as you found it difficult to start, it is just as difficult to finish?

Yes. It is this business of drawing boundaries - like where to start and what to include - and where to finish and what to leave out...

Small voice: Perhaps you need to recap or highlight some of the significant points in the journey...?

Pause:

Like what?

Pause:

Small voice: Like the issue of ethics... or the point of discovering the difference between rehabilitation and rehabilitation... or the interaction with Denis, Diane, Marianne and Frances... or the actual writing...

Pause:

Yes - all of that... but there is something else or more or instead... something just hanging around the corner...

Small voice: Would that be the concept of liminality?

Yes - that too... but not that...

 Interruption:

"Here we go again. Just when she ought to be getting focused and pointing out in succinct fashion just what she has achieved and learned, she's still hanging around that bloody corner...""

"She's got a few squares in her chart, hasn't she!"

"And Neptune on the Ascendent!"
"Okay. Smarty pants! Why don’t you step in and help her out, since you seem to know everything."

"Well ... well, I didn’t really mean ..."

"Of course you didn’t really mean ... you just like being judgemental."

"Maybe not? Maybe you really do have something to say?"

Pause:

"Do you think she would listen?"

"I’m sure she would, if you would be less defensive and aggressive."

"How can I do that?"

"Well, you could ask her direct!"

"Oh, no. I couldn’t do that."

"Why not?"

"Well, she’d think I was ... she might think I don’t know what I’m talking about."

"And do you? Would she be right?"

"I don’t know! I don’t think I’m game!"

"Could you try something simple, first?"

"Yes! Like you could offer to help her with the straight up-and-down stuff — the pragmatics."

Pause:

Small Voice: I’ve got a suggestion. Why don’t I step aside and let you step in. Besides, I think I’ve done all that I can, for the moment.

"I’m rather scared of that."

Small voice: I could introduce you first, if you like.

"Okay. But if it doesn’t work, you’ll have to come back."
Small voice: I’ll be here if you need me, but I suspect that once you get talking you’ll do just fine.

["Oh, I don’t know."]

Small voice: Will you just stay here for a minute and I’ll introduce you. Then you can see what happens after that?

["All right. I’ll try."]

Interruption subsides:

Small voice: I’d like to introduce Little Afraid. He’d like to get involved in this finishing up. He’s a little afraid because he’s been sitting in the background, but I can vouch for him. He may be a little abrupt, now and then, but now that you are needing to draw some boundaries, I believe his help will be invaluable.

Thank you, Small Voice. I’m sure you need a well-deserved rest and I’m grateful for your help.

Pause:

So Little Afraid, you’d like to step into the light ...

Little Afraid: Nooooo. No, I don’t want to step into the light, but I’m happy to prompt you from the wings.

That sounds great to me.

Pause:

So, where do we start?

Little Afraid: Can I suggest that you go away for a little time—wander in the garden, do some meditation, or whatever—I need to settle myself and get my thoughts in order.

Okay. I’ll do that.

Little Afraid: Be back in 15 minutes—sharp!
I think this is going to work well. Already I am feeling more confident just knowing that you will be close by.

Little Afraid: Don’t be late!

Thanks ... I won’t.

...........

Preamble Four

Little Afraid: You’re late!

Whoops!

Little Afraid: Now if we are going to tackle this properly you’ll need to go back to your first preamble.

You mean, get back into that leisurely ambling.

Little Afraid: Yes. In that frame of mind you won’t be rushing around trying to do a dozen things at a time.


Pause:

Little Afraid: Don’t rely so heavily - I’m new at this.

Pause:

Well, what do you suggest?

Little Afraid: Perhaps you could say how things are now ... how you are seeing things ...

I’m not at all enthused about doing this. I feel as if I’ve ‘done’ it and want to tidy up and put things away.

Little Afraid: Perhaps you could say something about Eliot’s ‘objective correlative’?

Thank you.
Silence:

Little Afraid: Small voice, could you please come over here?

Small voice: Certainly.

Little Afraid: I'm afraid this isn't working too well.

Small voice: How's that?

Little Afraid: Well, it just isn't working too well.

Small voice: You've already said that.

Little Afraid: Hh ee 11 pp!

Pause:

Small voice: I have a suggestion. Why don't we two do it, eh?

Little Afraid: You mean we could tell her how we see it ...

Small voice: Yes. She's too tied up with it ... and besides if we give her our version that might confirm or challenge her.

Little Afraid: What a good idea ... and I'd feel much better doing it with you than with her.

Small voice: Okay, let me take it back to her.

Pause:

Small voice: Well, what do you think of that?

I suppose I have to let go of it at some point, so why not start now - besides, it doesn't really matter.

Small voice: Really?

Pause:

I didn't mean it to sound like that. I really mean that it doesn't really matter. This isn't sour grapes or anything like that ... I really mean that it doesn't really matter ...
Pause:

... in fact, I would be grateful if you and Little Afraid would let me have feedback.

Small voice: Good! Done!

Little Afraid: I've got a better idea. Why don't we all hop into the same body and just get the bloody thing done!

The end of the beginning

Now what's all this about an 'objective correlative'?

T.S. Eliot wrote a short essay on "Hamlet" (Eliot, 1972, pp.141-46) raising questions about Hamlet's failure to 'act', the motive of revenge, Hamlet's 'madness' and the guilt of his mother. Eliot (p.145) says:

The only way of expressing emotion in the form of art is by finding an 'objective correlative'; in other words, a set of objects, a situation, a chain of events which shall be the formula of that particular emotion; such that when the external facts, which must terminate in sensory experience, are given, the emotion is immediately evoked.

Eliot (p.146), by the way, concludes that "Shakespeare tackled a problem which proved too much for him. ... The experience exceeded the facts" and that he couldn't find an 'objective correlative'.

Small voice: I would say that ...

Little Afraid: Tut. Tut. We are not doing a hatchet job on Hamlet or Shakespeare ... or Eliot!

The reason for raising this 'objective correlative' is that it provides a convenient label. We don't want to get into a debate about how Eliot used it or whether what he said is considered brilliant or simply idle speculation by the academics.

What she has done throughout the thesis is to search for 'objective corollaries', analogies, metaphors. And what she has found is that often the 'objective correlative' bears the same label as the 'subjective experience', that is, in terms of hope and hope, of rehabilitation and rehabilitation.

275
Ken Wilber (1983, p.17) uses the term external corrective, and he uses it in the context of a discussion of Habermas (1971). Habermas, Wilber says, explicitly recognises the hierarchic paradigm as a corrective to historical-hermeneutic inquiry ... a corrective to the hermeneutic circle. It is a scheme of developmental levels of narrative competence.

Small voice: Right. He moves out of a circle into a spiral?

Pause:

Little Afraid: Sort of. Roger Walsh, in his Foreword to Wilber’s (1983, p.xi) A sociable God points out:

The fact that sensory, intellectual and contemplative modes yield different realms or categories of knowledge that are not wholly equivalent or reducible one to another is often forgotten. Conceptual symbolic knowledge cannot wholly be reduced to the objective sensory dimension, nor the contemplative to the conceptual, without resulting in what is called category error. Thus the method for establishing the validity of each realm’s knowledge is specific: analytic-empirical for objective data, hermeneutics for symbolic communication, and direct gnostic apprehension for the contemplative.

Small voice: Meaning?

Little Afraid: Meaning, that Wilber was attempting to place religion in a modern sociological context - in a transpersonal way. He was at pains to point out that he was looking for a critical discipline in a developing field which, nevertheless, has a very old and very honourable history in perennial or natural philosophy.

Small voice: Well, we don’t want to get into all of this.

Little Afraid: No, I agree. It was just that the term external corrective seemed to fit nicely with objective correlative.

Small voice: Come to think of it - it’s only a mess of words and while we seem to need external correctives and objective correlates to validate something else we end up confusing our categories!!
Little Afraid: Yes! And all this is necessary if we are searching for generalisations!

Pause:

She has also alluded to the different qualities of nouns and verbs. That is, nouns (and nominalisation) define things, give concrete form, and lead to fossilisation. On the other hand, verbs describe processes, suggest fluidity and can be downright subversive.

We could say that both nouns and verbs have gender. And here I am not talking about the formal grammar of any particular language where gender is usually a grammatical category of nouns. I am speaking metaphorically.

Nouns are masculine, and verbs are feminine. Nouns name things, classify things, focus awareness. Verbs insist on movement. They destabilise categories, diffuse focus and awareness and take you somewhere else.

Pause:

Small voice: Perhaps we could say that verbs are always looking for nouns - for signposts - on their journeying ...

Little Afraid: ... and nouns are ever fearful that verbs will rush in like a torrent and wash away the hard won ground.

And more than that. Verbs show scant regard for the nouns they claim to be looking for!

Pause:

So there seems to be a need to tarry at the crossroads. At least at that point verbs and nouns are facing their nemesis - the Goddess of Retribution. At this point, verbs actually scan the signposts, looking for a clue ... and nouns wait expectantly for the verbs who may, with a good story and first hand experience, help them modify their stance.

And this is the limen. The territory, the crossroad, the insecurity, the expectancy, the authority of experience, the signposts and the travellers, the naming and the journeying.

Pause:
Thank you both very much for helping me over this style.

Pause:

Now, in concrete terms, let me say how all of this naming and journeying has assisted me.

I revisited the land of rehabilitation ... that may be seen as a backward step. And it would be if one thought in terms of vicious circles. However, if one thinks of a spiral, the revisiting marks not so much as a return (for that is never possible, even in the imagination) but of a new perspective.

The revisiting allowed me to approach my sense of loss and distance from the world of work ... from career ... from status. My shame. And it is only out of shame, the experience of liminality, that one can speak authoratively.

Pause:

Perhaps 'authority' is not the word? Perhaps the word is 'authenticity'?

It highlighted for me, in sharp relief, the ethical dilemma which faces the client as researcher. I cannot set out briefly and succinctly how the research (of the professionals) was organised and funded. I have no direct access to that. I cannot describe their methodology, their measurements, their aims and objectives in terms of their research. I can only describe how I came to the program, as a client, responding to a public announcement, or as they quaintly say 'self-referred'. I only know from personal feedback that I am likely to be considered a failure - because in narrow terms, I did not return to paid employment at the end of the program.

However, with the assistance of the Rehabilitation Counsellor who allowed me to see something of her world, I was able to see more clearly that we were at cross-purposes. I experience the conflicts associated with trying to find a role ... knocking, asking to be allowed to contribute. But of course, that was not part of their research. Neither has there been any follow-up. There is no feedback. There is no re-entry.

I was part of the first small group. Other groups follow.

There is no re-entry.
The process continues, but with a new set of participants.

Small voice: ... or objective correlatives?

Long pause:

This experience allowed me to see first hand that there is no structure for 'chronicity'. There is no structure to allow clients to participate in the design, methodology, aims, objectives and evaluation of the program on an ongoing basis. I am simply a 'patient' client. Despite all of the rhetoric about 'patients' being involved in their treatment, and taking responsibility for their treatment, they are involved only in as much as they are obedient.

This is not to say that the professionals are not interested in what the clients have to contribute - some are, some are not. The dilemma lies in conflicting objectives which cannot be reconciled unless the client is allowed to be involved in the design and implementation and evaluation of the program. In the rehabilitation system, the professionals are the experts. They advertise themselves as a kind of multidisciplinary supermarket. But they only sell meat.

I took what meat was on sale but found that I also needed bread. I had entered a meat-market, not Aladdin's Cave. Having discovered that, the onus was on me to withdraw, and look elsewhere. However, I came away with a sense of being 'had'. This adds to the shame because I had been labouring under the impression that I could have become an active participant in their research.

But they, too, are labouring under a heavy burden. They are funded to offer a restricted program and to strive for specific, and narrow outcomes. They are testing their theories (and in traditional research, you can't let the subjects know too much because that might prejudice the outcome. There is no reference to how not informing the subjects might prejudice the outcome!). Each professional is employed to provide a specific service, not to explore with the clients what might be appropriate or needed.

Moreover, they operate within strict legislative requirements. Things such as limited facilities and equipment, workers' compensation and client supervision, mean that individual access for clients to the facilities may not be possible.

Small voice: They are testing theories, not, necessarily, responding or listening to clients.
Little Afraid: And don't forget that they, too, are on a steep learning curve - treading a fine line between what is required and what is possible and what might be needed.

Small voice: All in all there is a lot of dross from which one may pan a few specks of gold.

Silence:

Little Afraid: Tell us about the gold.

Pause:

Well, there was one nugget, in the form of the Rehabilitation Counsellor who, personally, gave me a lot of space in which to work on issues of control, status and alternatives. The speck of gold lies in the physical program, which, although I no longer follow the routine suggested and which caused me significant physical pain, sent me scurrying for something which was more appropriate, if outside the CRS.

In my earlier struggles for rehabilitation, I had begun Feldenkrais, Awareness Through Movement, classes. Whether I over-extended myself or whether there were other things happening, I had had several relapses and had to discontinue. My experience with the CRS directed me back to the Feldenkrais classes.

Many of us have been raised with the dictum that life is about serious obligations, and that we must accept the toll, as if our moral honesty depends upon our readiness to do our utmost - 'utmost' meaning more power, more involvement, more in quantity. We weren't raised to value our utmost in terms of quality, of sensitivity, of loyalty to our inner selves. It is only when we mobilise ourselves to do something energetically that we believe we have done our share; we do not even take notice of the penalty we pay with our body. To be patient and attentive in the graceful and harmonious way does not seem legitimate to us, as if sensitivity were egocentric, and desire for refinement in movement were a luxury.

Perhaps we need to re-define the meaning of achievement and begin to evaluate our performance not only quantitatively, in terms of distance, but
also in terms of our inner experience, assessed by our own feelings. Once we come to understand that achievement that is going against the inner sensations of our organism is actually false, we can begin a process of healing.


I approach them differently these days - with much more care, less effort and no demand or expectation that this will make me well. These days, I am less controlling. Now after almost a year of faithful and enjoyable attendance, I am having less physical pain, and I find that my visits to a regular physiotherapist for acute treatment are less frequent. This may be due to Feldenkrais, or it may simply be the natural course of the disease.

**Interruption:**

"I interrupt here to tell you that she has slipped again and is, unfortunately, at this very moment in need of the physiotherapist."

"Just as she thought it was safe to go back into the water! Back comes the muscle spasms, joint pain and tissue inflammation!"

**Interruption subsides:**

Shortly after becoming ill, and without a diagnosis, I chased around after every therapy that was on offer - from meditation, yoga, Pritikin diet, homeopathy, acupuncture, etc. etc. This was not going to beat me! I was encouraged in this by my (then) general practitioner and an assortment of specialists to whom I had been referred. In my opinion, this activity and attitude simply exacerbated the symptoms, maximised tissue damage and brought me to a physical collapse some five years down the track. By the time I had a diagnosis, and a legitimate (medical) instruction to 'rest', and I do not mean total hospital bed-rest, the damage had been done.

From my vantage point, some nine years after diagnosis, I can see that behind everything I did was an expectation - of myself and any therapy I undertook - that I would get well ... and I worked hard at it. I was good at setting goals, and achieving them.

My search for rehabilitation has taken me far down another path where control and expectation are not part of my vocabulary. This path, down the yellow brick road, speaks of enjoyment and simplicity. A realisation that some things
are just the way they are and that I must be creative in finding ways to move in and out. I must live in the 'eternal now'. And I have to remove 'control' and 'expectation' from my relationships with other people - relatives, friends and professionals I meet along the way.

*Interruption:*

"Did you hear what she just said?"

"What?"

"I have to remove 'control'!"

"She'll always be looking for control and she's having herself on it she thinks otherwise!"

"And after all these thousands of words..."

"Oh dear!"

*Interruption subsides:*

Little Afraid: I can see why you froth at the mouth when the first thing a psychologist says is that you need to set goals! Without enquiring into your usual operating style!

Small voice: Yet, you have done better with 'control' than you have with 'expectation'.

Little Afraid: Yes. I can see that in your difficulty with the word 'hope'. There is that expectation that programs will deliver what they promise ...

Small voice: ... and even if they don't promise specific things, there is that expectation that they are flexible enough to modify programs in the light of the input from clients ...

*Silence:*
I have found my Friday meditation to be of great help here. One of my first forays out into the world included a Saturday afternoon class on Tarot cards. I cannot begin to tell you how liberating and enjoyable that class was. I had no intellectual interest in it at all. I didn’t go to learn ‘how to do it’. I didn’t go because I had a belief system compatible with esoteric matters. Although both turned out to be true. I simply thought, "This sounds like a good way to reactivate my imagination." It was held in the afternoon. It was local.

My next, some would say ‘logical’, step was to attend several religious courses – on spirituality – run by David Walker (Walker, 1979; Boud, Keogh and Walker, 1985), a Catholic priest and theologian. Again I was delighted to be in the company of gentle people as we peered into the the lives of those who had had a spiritual rather than a pragmatic or secular focus for their lives.

Pause:

It was during that time that I met my neighbour, Margaret McGee. For more than four years now we have met each Friday morning at her home, for a half-hour of meditation. For the longest time there were just the two of us. Nowadays we sometimes count three or five.

One day in late 1985 I visited a local Community Health Centre, seeking hypnotherapy and deep relaxation. I sought, but I did not find. Instead I met psychologist, Lois Downing, who mentioned three little words to me – Adyar (a Sydney bookshop), Jung (the work of C.G. Jung and the Sydney Jung Society), Hawkesbury (the then Hawkesbury Agricultural College). She smiled a knowing smile. All she said was that she felt that here I might find what I was looking for. When I asked her for more details, she simply told me that I would find the numbers in the telephone book. Three long years passed before I was well enough to contact Hawkesbury. In the meantime, I found Adyar and Jung.

Pause:

So it is true, in a way, that my involvement in the Commonwealth Rehabilitation Service (CRS) pilot rehabilitation program for people with ME/CFS was a return to the past. I had already gone many miles down the track. The CRS program assumed that people were at the beginning of the road – but at the same time, at the end. Again, a linear approach.
There is no structure in our society which provides for "What do you do when the experts can't help" - well, at least not in the compartmentalised, pragmatic, secular sense. At all times, the client is a consumer. Unlike the secular consumer, responding to an avalanche of propaganda advertising any number of paths for sale, the spiritual consumer, must lay the path in walking it. The client needs to design and manufacture his or her own paths.

The spiritual traveller is the one who erects the signs for him or herself because nobody else can. She will see signposts erected by others. They are not to be followed. They are to be studied for she needs to understand that she too must erect her own signs. Symbols of her journeying.

Silence:

I may find myself 'well' again one day. I may not. But whatever the outcome, there is only the living.

Nouns and verbs.

Hope and hope.

Rehabilitation and rehabilitation.

Walking and walking.

Pause:

Small voice: And "Have you been walking?"

Yes. I am.

............

284
AFTERWORD

What is change, and what is progress?

When I had completed my Graduate Diploma in Social Ecology in 1989, I rested comfortably with the image of Waiting, from the Chinese I Ching1 (Hexagram 5).

The question at that time was "What do I do in the meantime?" — between now and a cure, or death. One of my last memories of my sister, Helen, was of her standing at her kitchen bench, a month before her death, reading that I Ching quotation from the copy of my document:

...When the clouds rise in the sky, it is a sign that it will rain. There is nothing to do but to wait until the rain falls. It is the same in life when destiny is at work. We should not worry and seek to shape the future by interfering in things before the time is ripe. We should quietly fortify the body with food and drink and the mind with gladness and good cheer. Fate comes when it will, and thus we are ready.

Recently my brother told me that he had that quotation above his desk at work.

.......... 

In the years following I have regularly consulted my I Ching — posing whatever question seemed to be of concern on the day. Often I was surprised by the answer I got. On reflection I always found that the answer related to the real underlying concern, rather than the question I had consciously formulated.

1The I Ching (Book of Changes) which comes out of the history and system of Chinese thought is at least 5,000 years old. It can be read as a book of 'wisdom', an ancient text and oracle of divination. The Oracle can be consulted with the help of 49 yarrow stalks, or by throwing three coins six times. There are 64 hexagrams which can be 'read' many ways, i.e. line by line (six lines), as a whole, as part of a sequence.
Today, I again consulted my I Ching. If Waiting was the answer to "What do I do in the Meantime?", what was the answer to "Have you been walking?".

Not content with the first two answers, I threw the coins a third time.

The first answer was, suprisingly, Waiting (Hexagram 5). The second was Before Completion (Hexagram 64), and the third was Following/The Unexpected (Hexagrams 17 and 25). Both second and third answers were variations on the theme of 'waiting'.

There is something wrong here.

Of course! The question needed to be rephrased: "Have I been walking?"

However, when I threw the coins, the question I found myself asking was "Have I been waiting?"

Regardless of the question, the answer was the same as the answer to my third throw.

Hexagram 17 - Following:

In the autumn electricity withdraws into the earth again and rests. Here it is the thunder in the middle of the lake that serves as the image - thunder in its winter rest, not thunder in motion. The idea of following in the sense of adaptation to the demands of the time grows out of this image. Thunder in the middle of the lake indicates times of darkness and rest. Similarly, a superior (wo)man, after being tirelessly active all day, allows (her)self rest and recuperation at night. No situation can become favorable until one is able to adapt to it and does not wear (her)self out with mistaken resistance.

With a moving line²,

This refers to a (person), an exalted sage, who had already put the turmoil of the world behind him/her. But a follower appears who understands

²When three coins are thrown there are four possibilities, three heads, three tails, two heads/one tail, two tails/one head. The coins are thrown six times. When a throw results in three-of-a-kind, this is interpreted as a moving line - from yin to yang, or yang to yin, depending on whether the coins show heads (yang) or tails (yin).
him/her and is not to be put off. So the sage comes back into the world and aids the other in (her) work. Thus there develops an eternal tie between the two.

I was directed to

Hexagram 25 - Innocence (The Unexpected)

In springtime when thunder, life energy, begins to move again under the heavens, everything sprouts and grows, and all beings receive from the creative activity of nature the childlike innocence of their original state. So it is with the good rulers of (hu)mankind: drawing on the spiritual wealth at their command, they take care of all forms of life and all forms of culture and do everything to further them, and at the proper time.

...........

And so I consulted the Oracle a final time, asking "What do I do while I am waiting?"

The answer:

Hexagram 9 - The Taming Power of the Small

The hexagram presents a configuration of circumstances in which a strong element is temporarily held in leash by a weak element. It is only through gentleness that this can have a successful outcome.

The wind can indeed drive the clouds together in the sky; yet, being nothing but air, without solid body, it does not produce great or lasting effects. So also an individual, in times when (s)he can produce no great effect in the outer world, can do nothing except refine the expression of (her) nature in small ways.

Hence, my walking, my journeying, my pilgrimage is in search of this refinement.

And now I am really intrigued by the appearance of ‘the sage’!

...........

287
CHRONIC FATIGUE SYNDROME

Q: DOES ANYONE KNOW WHAT C.F.S. IS LIKE?

A: YES!

CRS AT DARLINGHURST KNOW AND OFFER

A MULTIDISCIPLINARY REHABILITATION PROGRAM

The CFS Multidisciplinary Rehabilitation Program at CRS Darlinghurst
(02) 360 2411

CRS Darlinghurst 1994
Darlinghurst CRS have been running a program

Duration: 10 weeks

Time: 9.00 am to 12.00pm
Monday/Wednesday/Friday
(Morning tea provided)

Cost: Nil

Requirements: Leisure wear
Comfortable covered footwear
- flat shoes, joggers or sand shoes

Referral Method: By
- Self
- Local Doctor
- Specialist
- Community Service Organisation
- Employer

Contact: Debbie Porges-Program Co-ordinator
(02) 360 2411

Venue: Darlinghurst Regional Unit
Unit 5
32A Oxford Street
Darlinghurst NSW 2010
A REHABILITATION PROGRAMME FOR CHRONIC FATIGUE SYNDROME

INTRODUCTION

CRS is offering a programme for individuals who have been diagnosed as suffering from Chronic Fatigue Syndrome and who are interested in undergoing rehabilitation, with a view to returning to the workforce or seeking vocational retraining.

The information contained in this guide is based on work carried out at the Prince of Wales and Prince Henry Hospitals.

THE PROGRAMME

The programme is of 10 weeks duration, 3 days a week (Mondays, Wednesdays and Fridays from 9 to 12 noon and includes Physiotherapy, Occupational Therapy and Psychology. In addition, individual sessions are held with a Rehabilitation Counsellor.

In order to benefit the most from the programme, it is important that participants attend all sessions. It is therefore not possible to attend some parts of the programme (i.e. physiotherapy) without the others.

You will be expected to attend 70% of all sessions. If you are unable to meet these requirements your continuation in the programme will be discussed with you.

WHY A REHABILITATION PROGRAMME?

Studies into Chronic Fatigue and other chronic illnesses have shown that individuals with long-standing illnesses develop other "secondary" problems such as:

1. Loss of muscle size and strength
2. Loss of muscle endurance
3. Loss of heart and lung fitness
4. Increased postural hypotension (low blood pressure - giving feeling of dizziness and light-headedness when you go from lying or sitting down, to standing up).
5. Loss of calcium from bones, which makes them weaker
6. Loss of flexibility in the soft tissues
7. Psychological difficulties (mainly worries and depression) due to the loss of: employment, social activities, educational activities and forced withdrawal from normal social engagements.
Chronic illness, and Chronic Fatigue, is felt to lead to the following:

CHRONIC ILLNESS

↓

Physical Activity

Depressive feelings, anxiety, loss of control

Withdrawal (Social, Work Personal, etc.)

↓

Enjoyment

Even less Activity, deconditioning

It is important to stress that chronic illnesses are different from acute illnesses, where the treatment may be to stay in bed for a few days or weeks, not go to work or school and not go out socially until recovery occurs.

WHY SHOULD REHABILITATION HELP?

The aim of the CRS programme is not to "cure" you of CFS, but to make the most of your abilities. It also aims to help overcome some of the "secondary" problems mentioned above.

Just as people who have had strokes, heart attacks or accidents to their arms or legs need physical exercise programmes to recover their maximum strength, so people with CFS require exercise retraining. The same is also true of psychological and mental activity.
ISN'T REST THE BEST TREATMENT FOR THIS DISORDER?

There are three main reasons why an exercise programme is important to rehabilitation:

1. **Physical degeneration secondary to inactivity**
   If you are ill longer than a week or two, your body’s capacity for exercise degenerates rapidly. Full physical recovery depends, therefore, on not only treating the illness directly (e.g. through transfer factor) but restoring the muscles’, the lungs’ and the heart’s capacity for exercise.

2. **Exercise as a treatment**
   The advantages of rest versus exercise have never been adequately tested in patients with CFS. It may be that exercise improves not only cardio-respiratory capacity (heart and lung fitness), but also immunological and psychological functioning. For example, in patients with Rheumatoid arthritis, some patients are known to respond very well to increased, rather than decreased, physical activity (probably through improved immune function).

   Increased physical exercise has been shown similarly to be of benefit to some people with anxiety and depression.

3. **Retraining your nervous system**
   When people are well, they will normally exercise until they have completed an activity. When people are ill or have a problem like CFS, they attempt to continue with their NORMAL activities, but stop due to pain or fatigue.

   ie. in well people ...

   Exercise ----> Task completion ----> rest

   in sick people ...

   Exercise ----> fatigue ----> rest without task completion

   This changed pattern has two important implications:

a) Loss of the physical and psychological benefit of completing things

b) The imbalance between periods of normal activity and rest may be worsened and thus lead to worse cardio-respiratory function.

We know from "biofeedback" studies that humans are able to regulate their heart rate, their blood pressure and many other aspects of their body’s functioning and "remain" their nervous system.
In this programme, exercise will be structured so that it ends at the completion of a task, that is, BEFORE YOU FEEL TIRED OUT and it will be slowly increased as muscle and cardiovascular tone is increased. Rest will follow completion of the activity.

The activity will be designed so that rest occurs BEFORE the onset of, or any worsening of, your underlying fatigue.

while ill ..

exercise ----> fatigue ----> rest
STOPPING ONLY WHEN YOU ARE TIRED IS TOO LATE!

retraining:

restricted ---> task completion ----> rest
exercise

What is different is that the task will be specifically designed according to what you can do NOW, not what you used to be able to do when you were well. They will then be VERY SLOWLY increased so that you do not fall into the habit of only resting AFTER you are tired out.

Some people with CFS report that they can carry out normal activities but are so tired the next day that they can’t go on, ie.

while ill ...

exercise ----> task completion ----> severe fatigue
(normal intensity)

The problem here is that ...

exercise ----> task completion ----> severe fatigue

failure to complete tomorrow's task

In this situation the plan would be:

exercise ----> earlier termination ----> less "rebound
(reduced) of activity fatigue"

ABLE TO COMPLETE tomorrow’s tasks

In the same way then exercise will be gradually increased as cardio-respiratory tone increases, but never to the point where it produces severe "rebound" fatigue.
WHY PSYCHOLOGICAL REHABILITATION?

Research into most chronic illnesses has found that individuals who have been sick for long periods experience at least some of the following:

1. Feelings of sadness, frustration and a marked sense of loss

2. Feelings of worry or anxiety about the future and about their capacity to return to normal

3. Disruption of their work/social/family life which results in difficulties with inter-personal relationships

4. Anger about the disruption of one's life-style, loss of income, etc.

5. A sense of "loss of control" over one's life

It is important that rehabilitation occurs at a psychological as well as a physical level. However, it is important to stress that it is not believed that CFS is "in the mind", or "psychosomatic", or caused by 'depression'.

The Psychological component of the programme offers SYMPTOMATIC treatment for these problems, in a similar way to taking aspirin for a headache. The aspirin may relieve the headache, but it does not mean that a lack of aspirin was the CAUSE of the headache.

Once people become severely depressed, their body literally slows down and metabolic rates and hormonal pathways change and they become physically ill. Immunological functioning is disturbed in depressed people and psychological treatments can help restore normal immune functioning.

Severe depression causes cortisol to behave abnormally in the body and this can interfere with one's immune response to CFS. Some people say "of course I'm depressed - wouldn't you be if you were in my situation!!" Our answer is yes, it is very understandable, but it is important to treat the depression. In the same way it is known that people after heart attacks or strokes do worse if they are depressed, it is important to treat depression in CFS. This can be done by taking appropriate medication and/or psychological techniques.

Anxiety is another important psychological symptom that can interfere with one's physical functioning by affecting heart and breathing rate, and thereby producing severe fatigue. Further anxiety increases adrenalin and cortisol levels, and these may impair immune response.

Relaxation and anxiety management techniques help to minimise the effect of these symptoms on fatigue.
WHAT IS EXPECTED OF YOU

*Attendance at each session of the programme and a phone call if you are unable to come.

*A commitment and "open mind" to try the methods suggested.

*A willingness to practice the techniques shown between sessions.

The programme is designed to teach you new ways of dealing with physical activity and exertion, and new ways of thinking. To get the most out of the programme, these techniques have to be used regularly - not just in the sessions - and ideally become a part of your life-style. It is not enough to come to the sessions, do what is expected but return to your usual life-style in between.

The techniques require some effort and an ongoing commitment to apply them, during and after the programme finishes. It is a programme designed to teach you new ways of exerting physical energy, carrying out activities and thinking. If you do not apply them on an ongoing basis, you will not benefit from the programme as much as you could.

REHABILITATION PROGRAM

Injury

Contact by Case Manager

Or { Off work or likely to be off 28 days? Soft tissue, back, overuse injury?

- No rehab action

Rehab Assessment ($36) & Case Manager to develop Case Management Plan in consultation with Injured Worker

- Supervisor
- Treating Doctor

Injured Worker satisfied with proposed Program

- Revocation
- Request Review by Comcare

Case Manager
- Contract with Provider
- Negotiate with Supervisor
- Monitor process

Implement Rehab Program ($37)
- in the workplace if return to previous job
- involving retraining if need to return to new job
- negotiate placements and arrange training and work trials to return to new workplace

Return to work

- No Revise CMP
- Invalidity Retirement

Case Closure

Source: Ballard, 1991
Fig. V: Crisis Management as a Learning Process in Eight Spiral Phases

I Initial Stage
Cognitive dimension
- "head" dimension - externally directed reaction

II Transit Stage
Dimension of emotion
- "heart" dimension - non-directed reaction

III Target Stage
Dimension of activity
- "hand" dimension - considered interaction

1. What is really going on?
2. Yes, but is it still can't be true?
3. Aggression
   - Why me...
4. Negotiation
   - But if..., then...
5. Depression
   - What for..., it's all pointless...
6. Acceptance
   - Now I begin to realize...
7. Activity
   - I'll handle it!
8. Solidarity
   - We're handling it together!

Source: Schuchardt, 1989
Dear Mr. Curly, I am writing to report a great and wonderful discovery. It is the discovery of my own stupidity and what a marvellous and enjoyable thing it is for me.

As my journey has become lonelier I have somehow grown more stupid in what I feel is a natural and comfortable way. Perhaps it is the fine example set by the duck or perhaps it is because there is nobody to chastise me with strictures or an intelligent gaze – the clever world can be so unforgiving, don’t you think; so cruel and oppressive to the stupid part of our nature. Stupidity is like love in this respect Curly, that it will find a way and if it is suppressed or thwarted too much it will become a demon and enter surreptitiously into the world as cruelty, coldness or misery. The need to be clever and excellent and brilliant eventually brings a particular kind of weariness and the time comes to let dear old stupidity play its wonky hand. That time has come for me and I think the duck is relieved, as indeed I am.

So I feel Curly, that I am leaving the vast continent of solitude and entering the land of stupidity: my promised land and sanctuary of freedom: my country of new life and good sleep and forgiveness: my poor, long suffering, beautiful stupidity - friend of my childhood, I have found you at last and I am coming home.

That’s how it seems to me Mr. Curly and I find that I have quite a capacity for slow-wittedness and dumb silliness which seems to suit me down to the ground. I like it. There’s almost a spiritual quality in it...! Come to think of it, the paintings I always liked the most were always a bit on the stupid side. Do you know what I mean Curly? I’m sure you do.

Your happily, 

Vasco Pyjama

P.S. I’m still quite clever too.

Leunig

Source: The Age, 7 May 1994
Dear Vasco, I was delighted to receive your letter this morning and read the joyous news that you have finally embraced your stupidity and found such blessed relief. How very good for your heart Vasco. How marvellous! What a momentous achievement this embrace has been; and what a splendid liberation awaits you. What glorious songs the birds will now sing for you — great fugues of rapture, just you wait, as the miracle of your beautiful stupidity comes wobbling and clanking into your life and sets you free. My most extravagant congratulations Vasco and a warm welcome to the fold.

After I had read your letter I straight away seized my tin whistle and went up to the top field where I did a celebratory dance in your honor — a sort of weird jig. This was quite a stupid thing to do because the ground was slippery and muddy from the rain which was pelting down and I kept falling over and made quite a mess of my new corduroy trousers.

Still, I had a lovely bowl of soup for dinner this evening which was all the more delicious for me having fallen in the mud and I've never enjoyed a bowl of soup so much in all my life. It goes to show you doesn't it. I'd better hop into bed now because I'm feeling very pleasantly sleepy. The day is done. Goodnight Vasco;

yours truly,

Mr. Curly.

***

Source: The Age, 14 May 1994
THE EXPERIENCE OF GRIEF

DEPRESSION = INTENSE SORROW

"I want to be out of this painful body/situation." "I want to be with the same as they were, "I want things as they were, "I want a suicidal phase.

- an extremely important phase.
- BUILT confusion precursor to loving-kindness towards myself.
- use anti-depressants as a last resort.

ANGER = IT ISN'T FAIR!

"If you can take my anger, perhaps I can trust you with my sorrow." "This anger may be essential for survival, for what has to be done.

"It isn't right; it isn't fair!"

PAIN

FINDING KEEPSAKES

"Once was his, or hers, or mine!" "I invest this relic with a "connection"

- I use this as a "focus" for grieving and as a "focus" for grieving.

DON'T NEGATE

DENIAL = I AM STILL ALIVE.

- A necessary survival mechanism
- Limits what I can handle at this moment

- "If only I had...

BODILY DISTRESS

"I hurt;

PHYSICAL SOURCES OF HURT:

- stroke, legs, arms, heart, lungs, etc.

- site of injury, brain, etc.

I am hopeless, my "survival," my "life" is so great!

- acceptance, this experience

LESS IS SO GREAT!

Source: Personal notes taken at a workshop run by Anne Mulheron from the Bereavement Care Centre, April 1993.
The Experience of Grief

Denial
- "This hasn't happened. I am still alive."

Anger
- "If you can take my anger, perhaps I can trust you with my sorrow."
- "This anger is not aggression, the energy may be essential for survival, for what has to be done."

Intense Sorrow
- "I want to be out of this painful situation."
- "I want to be with the same as they were, an extremely important phase."
- "I use anti-depressants as a last resort."

Depression
- "I want to be with the same as they were."
- "I often appear as the 'sullen' phase."
- "I try to express the grief of body distress."

Despair
- "I am hopeless, the loss is so great!"

Depression
- "I am hopeless, the loss is so great!"

Rejection
- "I am a reject, stroke, abdominal, lung, brain injury, heart attack, death or 'loss' - grief is the way of expression of grief."

Physical expression of grief
- "In my pain, I lovingly turned towards myself."
- "If only I could turn the pages of my preoccupation with my illness and all my problems."
- "This has not happened, I am still alive."

- "It's not right, it isn't fair!"
- "Precursor to Sorrow."

Connection
- "I can use this as a 'focus' for grieving, as a 'tool' for grieving, as a 'substitute' for grieving."

Experiences
- "This once was my 'talent with others'."
- "I can use this as a 'tool' for grieving, as a 'substitute' for grieving."

Sorrow
- "I invent this, this as a 'tool' for grieving, as a 'substitute' for grieving."

 sourced from the Bereavement Care Centre, April 1991.

Dear Clarissa,

I heard you speak with Margaret Throsby on Sydney radio this morning, but did not think to phone!!

After the program had finished I remembered what it was I wanted to tell you ... as I began your book, the voice of Colleen Dewhurst began reading to me, quietly at first, and then very powerfully. I know very little about Colleen Dewhurst, other than she was an actress who died recently. I’ve seen several of the films she made and, of course, her last appearance as Murphy Brown’s mother ... but it is her voice I heard, so clearly, as if we had spoken on a daily basis.

At present I am working on my Master’s thesis - obviously I need to take time out to write this to you. My thesis, by the way, is entitled "Have you Been Walking? - A search for rehabilitation", and comes out of my experience of Chronic Fatigue Syndrome. It is quite a challenge to be authentic in what I write, knowing that the style and content (especially coming from the point of view of 'the client' or 'the patient') may not find favour in academic circles. Nevertheless, the University of Western Sydney - Hawkesbury Campus, has a School of Social Ecology which is exploring 'new paradigm' research, and here I find some kindred spirits.

I have been reading Jung, and post-Jungian writing, and a whole swag of spiritual literature, for about 7 years now, and have had 18 months analysis. Since I became ill my life has taken me into areas - emotional, intellectual and spiritual - which I never imagined I would ever visit. My surprise is that I am still not well (physically), and am writing from my 'weakness'. It would appear that this is where I am meant to be ... still walking, and discovering new things, new territory.

In fact, I have just been writing about thresholds, and the difficulty in crossing them, getting caught with language which while understood in Kansas does not mean the same thing in Munchkin-land (Dorothy in "The Wizard of Oz"). It occurred to me that my skills - compassion, intellect and courage - sufficient in Kansas (the outer world), have to be re-learned en route to Oz (the inner world - and, no doubt, a synchronistic connection with Australia), and that is why Dorothy takes along Strawman, Tinman and Lion when they cross her path: they are symbols of her learning, too. Only after these have been learned can Dorothy find the means of returning 'home' to Kansas. And so it is with me, perhaps?

Source: Extract from letter to Clarissa Pinkola Estés.
REFERENCES

References marked with an asterick (*) relate directly to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). I do not necessarily agree with the opinions expressed therein. They are included, however, in the spirit of storytelling - each tells a story from the point of view of the individual authors.

...........


Australian Broadcasting Corporation (ABC), "Radio National" programming, including 'The Search for Meaning', 'Life Matters' and 'The Coming Out Show', in particular. Audio tapes (and videotapes of television programs) of many of their programs are available from the ABC, PO Box 9994, Sydney, 2000.


Burdekin Report (see under "Human Rights and Equal Opportunity Commission").


*Commonwealth Rehabilitation Service (1991) "Work Training Scheme", brochure, DHHCS.*

(n.d.) "What you should know about", brochure, DHHCS.


(1993) "Chronic Fatigue Syndrome Rehabilitation Programme", a guide to the programme, Darlinghurst Regional Unit.


Cliff, Michelle (1979) "The Resonance of Interruption", in Chrysalis, No. 8, Summer 1979, pp. 29-37.


Freeman, Laurence. (1993) Audio tapes are available from Christian Meditation Network, 30 Canterbury Street, Flemington, Victoria, 3131. A quarterly newsletter is also available. The network has its roots in the work of Dom John Main, a Benedictine monk. It encompasses the teaching of Dom Bede Griffiths who recently died (May 1993) and whose life work concerned the marriage of eastern and western spirituality.


Gilligan, Carol (1982) *In a Different Voice*, Harvard UP.


Healey, Kate (1993) personal communication. Anecdotes from the *Power, Politics and Performance* Conference, held in Sydney, 13-16 April 1993. An inaugural national conference organised by the University of Technology, Sydney and presented by The Centre for Australian Community Organisations and Management (CACOM).


Kockelmans, J (1975) "Towards an interpretative or hermeneutic social science" in Graduate Faculty Philosophy Journal, 5(1), 73-96 (cited in Reason and Rowan, 1981).


Mackay, Hugh (1993) Reinventing Australia: The mind and mood of Australia in the 90s, Sydney:Angus & Robertson.


*M.E. and You*, Quarterly Newsletter of the ME/CFS Society of NSW, Inc. available to members from PO Box 449, Crows Nest, NSW, 2065.


National Committee of Inquiry into Compensation and Rehabilitation in Australia, Canberra: AGPS, 1974. [Known at the Woodhouse Report.]


(1992) "30 things you should know about the chronic fatigue syndrome epidemic". New York: That New Magazine.


296


Riesman, David (1964) "Foreword" to Bowen (1964) Return to Laughter.


Sackville Report. See under "NSW Law Reform Commission".


297
Simonton, O Carl and Stephanie Matthews-Simonton and James L Creighton (1980) Getting Well Again, Toronto: Bantam Books


Storm, Hyemeyohsts (1973) Seven Arrows, New York: Ballantine.


Symes, Mary (1987) Grief & Dreams, North Balwyn, Victoria, Australia: Rene Gordon Pty Ltd.


*Wakefield, Denis, personal communication, 10 January 1994.


Walker, Kath (Oodgeroo Noonuccal) (1964) *We are Going*, Brisbane:Jacaranda Press.


(1992) quoted in Susan Ince's (1992) article "Blaming the Victim".


Wiseman, Marianne, personal communication, 8 May 1994.
Woodhouse Report. See under "National Committee of Inquiry"
