

Stories of Care

AT END-OF-LIFE

*Listening to Aboriginal and Culturally
Diverse Communities in Western Sydney*

قصص عن تقديم الرعاية في مرحلة نهاية الحياة

الإصغاء إلى مجتمعات السكان الأصليين والمجتمعات المتنوعة ثقافياً في غرب

जीवन के अंत समय में देखभाल की कहानियाँ

पश्चिमी सिडनी में आदिवासी और सांस्कृतिक रूप से विविध समुदायों को सुनना

临终关怀故事

倾听悉尼西部原住民和文化多样性社区的声音

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JULY 2023

WARNING ABOUT IMAGES

Aboriginal and Torres Strait Islander people are warned that this publication contains images of people who are deceased.

Image, front cover: Vanessa (photovoice participant)

Image, back cover: Marine (photovoice participant)

Stories of Care

AT END-OF-LIFE

Listening to Aboriginal and culturally diverse communities in Western Sydney

ACKNOWLEDGEMENT OF COUNTRY

With respect for Aboriginal cultural protocol and out of recognition that its campuses occupy their traditional lands, Western Sydney University acknowledges the Darug, Eora, Dharawal (also referred to as Tharawal) and Wiradjuri peoples and thanks them for their support of its work in their lands (Western Sydney and beyond).

ABOUT THE RESEARCH

This report (*Stories of Care*) and its partner publication (*What Matters in the End*) document findings from the research project *Investigating the End-of-Life Needs of CALD and Aboriginal Communities in Western Sydney Local Health District*. The research was funded by the NSW Ministry of Health and undertaken by researchers from Western Sydney University in consultation with the Advisory Team from Western Sydney Local Health District. Both reports are available online at the following links:

Stories of Care at End-of-Life: <https://doi.org/10.26183/w66h-qn16>

What Matters in the End: <https://doi.org/10.26183/cnxj-nw28>

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REFERENCING GUIDE

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Joy Paton, Helen Psychogios, Rosemary Leonard

Western Sydney University

شكر وتقدير

نودّ أن نعبر عن جزييل شكرنا لكل من شارك في البحث الخاص بطريقة التعبير بالصور (فوتو فويس) ومن ساهم في كتاب "قصص عن تقديم الرعاية في مرحلة نهاية الحياة"، كما نودّ أن نعترف بقصصهم النابعة من القلب والتي شاطرونا إيها في كتاب المجتمع هذا. لم يبخل المشاركون بوقتهم ولا بتجاربهم عندما تحدثوا معنا بمحض إرادتهم عن تجاربهم الشخصية والتي كانت في معظم الأحيان عاطفية أيضاً. علاوة على ذلك، قدّموا صورهم وقصصهم بشجاعة كي يتم عرضها في هذا الكتاب لربما يستفيد آخرون في المجتمع من مشاركتهم في البحث. ونأمل أن يكون قد استمدّ المشاركون قوة من تجاربهم في هذا المشروع وإن كانت صعبة في مراحل ما من دون شك، ونحن ممتنون للغاية لمساهماتهم.

جوي بايتن، هيلين سايكوجيوس، روزماري لينارد

आभार

हम उन सभी फोटोवॉइस अनुसंधान प्रतिभागियों को तहे दिल से धन्यवाद देना चाहते हैं जिन्होंने *जीवन के अंत समय में देखभाल की कहानियाँ (स्टोरीज़ ऑफ़ केयर एट एण्ड ऑफ़ लाइफ़)* में योगदान दिया है और इस सामुदायिक पुस्तक में उनके द्वारा दिल से साझा की गई कहानियों के लिए आभारी हैं। अपने समय और अनुभवों दोनों के प्रति उदार होकर, प्रतिभागियों ने स्वेच्छा से अपने व्यक्तिगत और प्रायः भावनात्मक अनुभवों के बारे में हमसे बात की। इसके अलावा, उन्होंने साहसपूर्वक इस पुस्तक में शामिल करने के लिए अपनी तस्वीरें और कहानियाँ साझा की हैं ताकि समुदाय के अन्य लोग अनुसंधान में उनकी भागीदारी से लाभान्वित हो सकें। हालाँकि कई बार यह बेशक कठिन होता है, हमें आशा है कि प्रतिभागियों ने इस परियोजना में अपने अनुभव से स्वयं को सशक्त महसूस किया है। हम उनके योगदान के लिए उनके बहुत आभारी हैं।

जॉय पैटन, हेलेन साइकोगियोस, रोज़मेरी लियोनार्ड

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乔伊·帕顿、海伦·心理吉奥斯、罗斯玛丽·伦纳德

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Introduction

The Research Project and Reports

At the end of 2019, representatives from Western Sydney Local Health District (WSLHD) Supportive and Palliative Care, Aboriginal Health and Multicultural Health, came together as an Advisory Panel for research to be conducted by Western Sydney University's Caring at End-of-Life Research Program. The three-year research project was titled *Understanding the End-of-Life Needs of CALD and Aboriginal Communities in Western Sydney Local Health District (2020-2022)*. It investigated palliative care needs and bereavement models of care in four cultural groups. The researchers worked with people from Aboriginal communities, and people from Arabic, Mandarin and Hindi speaking backgrounds; as well as people working in the end-of-life space who had experience working with diverse communities (some were members of the specific communities). Multiple methods of data collection were used for the research, including an online Death Literacy Survey, Community Focus Groups, Key Informant Interviews and Photovoice Interviews. All phases of the research were undertaken by Western Sydney University with funding from the NSW Ministry of Health. There are two reports stemming from this research. *What Matters in the End* documents the three-year project and includes the overall research findings and recommendations. *Stories of Care at End-of-Life* documents and presents findings from the project's photovoice component wherein the researchers worked directly with people who had personal experience of caring at end-of-life.

A Community Resource

The *Stories of Care at End-of-life* report is the culmination of a unique collaboration between researchers and photovoice participants within the broader multi-method research initiative investigating end-of-life needs in culturally diverse communities. Using the photovoice method, we asked participants what they found helpful and supportive in their caring at end-of-life journey. This uncovered stories about what works (and doesn't) in the service system and wider community to support culturally diverse people and their families at end-of life. The arts-based research (photovoice) disseminated in *Stories of Care* reports on culturally diverse people's experiences of end-of-life care, including their experiences with service providers where they are often positioned at the margins in terms of their specific cultural needs. This risks undermining the high quality supportive and palliative care that "should be accessible to all Australians" (Department of Health, 2018). In contrast to the other methods deployed in the research project, the photovoice research was undertaken with the express aim to hear *directly from individuals* about their cultural needs and the ways services can provide more culturally safe end-of-life care. This is a sensitive area of research where recruitment can be challenging, yet crucial to give voice to marginalised and/or vulnerable populations in order to "identify and begin addressing their needs" (Alexander et al, 2018 p85). Participants in this project have been generous in their engagement, thereby contributing to our deeper appreciation of the relationships, values and practices that can sustain and be significant for people at end-of life.

The photovoice interviews provided a rich data-set for analysis and, in collaboration with the research participants (Springham & Xenophontes, 2021), were also used to distill the cultural stories included in this report. These co-produced narratives in each participant's voice, take the reader inside an experience of what helps and does not help when caring at end-of-life. They demonstrate how a participatory creative methodology like photovoice can overcome barriers often present in such a sensitive research context (Paton et al, 2018; Copes et al, 2018), helping to elicit deeper understandings of the issues and phenomena that are significant for people caring at the end-of-life. In turn, *Stories of Care* provides an in-depth and ongoing presence in the public domain of relevant cultural knowledge about needs at end-of-life that would otherwise remain marginalised and rendered invisible. The research findings presented here expand our knowledge of the traditions, beliefs, practices and needs of culturally diverse communities and show that culture and connection are pivotal to care at end-of-life. The report contributes to our understanding of what works (and doesn't) in the service system and wider community to support culturally diverse people and their families caring for someone living with a life-limiting condition or facing a life-limiting illness. It gives voice and visibility to their experiences and needs, amplifying these in both scholarly and public domains. This provides a tangible contribution to participants' communities and broader society; but it also resources people working in the health sector. Crucially, the findings show the capacity of service providers to build trust and connection is foundational to the delivery of culturally appropriate and safe end-of-life care.

في نهاية عام 2019، قام ممثلون عن "الرعاية الداعمة والتلطيفية التابعة للمنطقة الصحية المحلية في غرب سيدني" وممثلون عن "مركز صحة السكان الأصليين" وعن "خدمة صحة الجاليات متعددة الثقافات" بتكوين مجلس استشاري للبحث الذي سوف يقوم به أعضاء "برنامج البحث في تقديم الرعاية في مرحلة نهاية الحياة" في جامعة غرب سيدني. وقد قام مشروع البحث الذي استمر لمدة ثلاث سنوات تحت عنوان "فهم احتياجات مرحلة نهاية الحياة لدى المجتمعات المتنوعة ثقافياً ولغوياً ومجتمعات السكان الأصليين في المنطقة الصحية المحلية في غرب سيدني (2020-2022)"، باستقصاء احتياجات الرعاية التلطيفية وأشكال المواساة عند وقوع فاجعة لدى أربع مجموعات ثقافية. وعمل الباحثون مع أشخاص من مجتمعات السكان الأصليين وأشخاص من الجاليات المتحدثة باللغات العربية والصينية والهندية؛ كما قاموا بالعمل مع أشخاص يقومون بتقديم الرعاية في مرحلة نهاية الحياة ممن لديهم الخبرة في العمل مع مجتمعات متنوعة (وكان بعضهم ينتمون إلى هذه المجتمعات المعينة). وتم استخدام عدة طرق لجمع بيانات البحث، بما في ذلك "استطلاع رأي عبر الإنترنت عن المعلومات المتعلقة بالموت"، و"مجموعات تركيز لجمع المعلومات من أفراد المجتمع"، ومقابلات مع أصحاب خبرة ومعرفة رئيسيين" و"مقابلات فوتو فويس". وقامت جامعة غرب سيدني بجميع مراحل البحث بتمويل من المنطقة الصحية المحلية في غرب سيدني. ويوثق تقرير البحث الذي يحمل عنوان "ما يهم في النهاية" كامل المشروع الذي استغرق ثلاث سنوات ويتضمن استنتاجات البحث والتوصيات. والتقريب متاح على الرابط التالي: <https://doi.org/10.26183/cnxj-nw28>

كتاب المجتمع

يعد كتاب المجتمع "قصص عن تقديم الرعاية في مرحلة نهاية الحياة" نتاج تعاون فريد بين باحثين ومشاركين بواسطة التعبير بالصور (فوتو فويس) في مبادرة بحث متعددة الأساليب تستقصي احتياجات مرحلة نهاية الحياة لدى أشخاص من ثقافات متنوعة يسكنون في غرب سيدني. وقد أجري البحث من ضمن "برنامج البحث في تقديم الرعاية في مرحلة نهاية الحياة" التابع لجامعة غرب سيدني بالتعاون مع المنطقة الصحية المحلية في غرب سيدني. وفيما يتعلق بإجراءات فوتو فويس، عملنا مع مشاركين من مجتمعات السكان الأصليين وأشخاص من خلفيات متنوعة يتحدثون اللغات العربية والصينية والهندية ممن قدموا الرعاية لشخص ما في مرحلة نهاية الحياة. وطرحنا عليهم أسئلة حول ما وجدوه مفيداً وداعماً خلال مسيرة تقديم الرعاية. وهذا ما كشف النقاب عن قصص تتعلق بما يصلح ولا يصلح في نظام الخدمة وفي المجتمع على نطاق أوسع من أجل دعم الأشخاص والعائلات من خلفيات متنوعة ثقافياً في مرحلة نهاية الحياة. ويعرض كتاب المجتمع صور المشاركين وقصصهم، مما يتيح الفرصة لسماع تجاربهم واحتياجاتهم ورؤيتهم. وقد ساهم المشاركون من خلال التزامهم السخي، بتوطيد امتناننا للعلاقات والقيم والممارسات التي من شأنها أن توازر الأشخاص في نهاية حياتهم وتكون مهمة لهم. وقامت كل من الدكتورة جوي بايتن والسيدة هيلين سايكوجيوس بتنسيق كتاب المجتمع "قصص عن تقديم الرعاية" بالتعاون مع المشاركين في البحث. والكتاب متاح على الرابط التالي: <https://doi.org/10.26183/w66h-qn16>

परिचय

अनुसंधान परियोजना और रिपोर्ट

2019 के अंत में, पश्चिमी सिडनी स्थानीय स्वास्थ्य जिला सहायक और उपशामक देखभाल (Western Sydney Local Health District Supportive and Palliative Care), आदिवासी स्वास्थ्य और बहुसांस्कृतिक स्वास्थ्य (Aboriginal Health and Multicultural Health) के प्रतिनिधि पश्चिमी सिडनी विश्वविद्यालय (Western Sydney University) के केयरिंग एट एंड-ऑफ-लाइफ रिसर्च प्रोग्राम के सदस्यों द्वारा किए जाने वाले शोध के लिए एक सलाहकार पैनल के रूप में एक साथ आए। तीन साल की अनुसंधान परियोजना - पश्चिमी सिडनी स्थानीय स्वास्थ्य जिले में CALD और आदिवासी समुदायों की जीवन के अंत समय की आवश्यकताओं को समझना (2020-2022) - चार सांस्कृतिक समूहों में उपशामक (palliative) देखभाल आवश्यकताओं और देखभाल के समय शोक के तरीकों की जाँच की गई। शोधकर्ताओं ने आदिवासी समुदायों के लोगों और अरबी, मैडेरिन और हिंदी भाषी पृष्ठभूमि के लोगों के साथ काम किया; साथ ही जीवन के अंत में समय काम करने वाले लोगों के साथ जिनके पास विविध

समुदायों के साथ काम करने का अनुभव था (इनमें से कुछ विशिष्ट समुदायों के सदस्य थे)। अनुसंधान के लिए डेटा संग्रह के कई तरीकों का उपयोग किया गया, जिसमें ऑनलाइन मृत्यु साक्षरता सर्वेक्षण, सामुदायिक फोकस समूह, प्रमुख सूचना देनेवालों के साक्षात्कार और फोटोवॉइस साक्षात्कार शामिल हैं। शोध के सभी चरण पश्चिमी सिडनी विश्वविद्यालय द्वारा पश्चिमी सिडनी स्थानीय स्वास्थ्य जिले से वित्त पोषण के साथ किए गए थे। *व्हाट मैटर्स इन द एंड रिसर्च (What Matters in the End)* रिपोर्ट पूरे तीन साल के प्रोजेक्ट का एक लिखित रूप है और इसमें शोध के निष्कर्ष और सिफारिशें शामिल हैं। रिपोर्ट यहां उपलब्ध है: <https://doi.org/10.26183/cnxj-nw28>

सामुदायिक पुस्तक

जीवन के अंत समय में देखभाल की *कहानियाँ सामुदायिक पुस्तक* पश्चिमी सिडनी में रहने वाले सांस्कृतिक रूप से विविध लोगों की जीवन के अंत समय की आवश्यकताओं के बारे में पता लगाने वाली एक बहु-विधि अनुसंधान पहल के अंतर्गत शोधकर्ताओं और फोटोवॉइस प्रतिभागियों के बीच एक अद्वितीय सहयोग की परिणति है। यह शोध वेस्टर्न सिडनी यूनिवर्सिटी केयरिंग एट एंड-ऑफ-लाइफ रिसर्च प्रोग्राम द्वारा वेस्टर्न सिडनी लोकल हेल्थ डिस्ट्रिक्ट के सहयोग से किया गया था। फोटोवॉइस प्रक्रिया में, हमने आदिवासी समुदाय और अरबी, मेंडेरिन और हिंदी भाषी पृष्ठभूमि के प्रतिभागियों के साथ काम किया, जिन्होंने जीवन के अंत समय में किसी की देखभाल की थी। हमने उनसे पूछा कि उन्हें अपनी देखभाल के दौरान क्या उपयोगी और मददगार लगा। इसने जीवन के अंत समय में सांस्कृतिक रूप से विविध लोगों और उनके परिवारों की सहायता करने के लिए सेवा प्रणाली और व्यापक समुदाय में क्या बातें काम करती हैं (और क्या नहीं) उन बातों के बारे में कहानियों को उजागर किया। सामुदायिक पुस्तक प्रतिभागियों की तस्वीरों और कहानियों को प्रदर्शित करती है, जो उनके अनुभवों और आवश्यकताओं को एक आवाज़ और दृश्यता प्रदान करती है। अपने उदार जुड़ाव के माध्यम से, प्रतिभागियों ने उन रिश्तों, मूल्यों और प्रथाओं की हमारी हार्दिक सराहना में योगदान दिया है जो जीवन के अंत समय में लोगों के लिए सहायक और महत्वपूर्ण हो सकती हैं। *देखभाल की कहानियाँ* सामुदायिक पुस्तक को अनुसंधान प्रतिभागियों के सहयोग से डॉ. जॉय पैटन और सुश्री हेलेन साइकोगियोस (Dr Joy Paton and Ms Helen Psychogios) द्वारा रुचि पूर्वक संग्रहीत किया गया था। पुस्तक यहाँ उपलब्ध है: <https://doi.org/10.26183/w66h-qn16>

संक्षेप

संक्षेप और रिपोर्ट

संक्षेप में, 2019 के अंत में, वेस्टर्न सिडनी स्थानीय स्वास्थ्य जिले की सहायता से, पश्चिमी सिडनी विश्वविद्यालय के अनुसंधानकर्ताओं और फोटोवॉइस प्रतिभागियों के सहयोग से, *व्हाट मैटर्स इन द एंड रिसर्च (What Matters in the End)* रिपोर्ट पूरे तीन साल के प्रोजेक्ट का एक लिखित रूप है और इसमें शोध के निष्कर्ष और सिफारिशें शामिल हैं। रिपोर्ट यहां उपलब्ध है: <https://doi.org/10.26183/cnxj-nw28>

संक्षेप

व्हाट मैटर्स इन द एंड रिसर्च (What Matters in the End) रिपोर्ट पूरे तीन साल के प्रोजेक्ट का एक लिखित रूप है और इसमें शोध के निष्कर्ष और सिफारिशें शामिल हैं। रिपोर्ट यहां उपलब्ध है: <https://doi.org/10.26183/cnxj-nw28>

Research Design

Ethics

The *Stories of Care* research design put the voice of participants at the centre of the project, acknowledging people as the ‘experts’ of their own experience. However, affording epistemic privilege meant more than hearing their voices as expert research ‘subjects’ (Paton et al 2018). Within the photovoice process (Wang & Burris 1997), we sought to foster an ethical relationship with participants based on equality and participation as co-researchers (Kwaymullina 2016). This, together with WSLHD Advisory Panel consultations, ensured the research goals were achieved in ways that were simultaneously ethical and culturally sensitive. Ethics approval for this research was granted by: Western Sydney University Ref: H13743; Aboriginal Health & Medical Research Council of NSW Ref: 1657/20; and Western Sydney Local Health District Ref: 6530 – 2020/ETH00559.

Aims, Methods, and Procedures

The research aimed to understand the culturally specific end-of-life needs of the Aboriginal community, and those from an Arabic, Hindi and Mandarin-speaking background living within Western Sydney Local Health District (WSLHD). In the photovoice process, which was adapted for online participation due to COVID lockdowns, participants with an experience of caring at end-of-life took photographs that illustrated what was useful, helpful, or meaningful for them, their family and/or community during that caring time. Over a period of two or three weeks, participants were contacted by a researcher to see how they were going with the ‘photo assignment’ and to offer support if needed. Sometimes taking the photographs was challenging, especially under COVID mobility constraints, so we suggested people could also use existing photographs. Participants subsequently engaged in a semi-structured two-hour Zoom interview where they were invited to talk about their photographs and to discuss:

1. The supports and services they found useful, or believe could have been useful, and how that would have been different to what was already available;
2. Any other supports or services they needed and who would be best suited to provide these supports and/or services;
3. The ways existing services and supports need to change in order to be culturally appropriate.

The photovoice interviews enabled us to understand what was helpful and supportive (or not) in the participants’ caring journeys. They were conducted by a researcher speaking English with Multicultural Health Education officers attending some interviews to assist with translation as needed. The interview conversations were recorded and transcribed, providing a rich dataset for analysis and, in collaboration with the research participants, the transcripts were also used to distil the cultural stories included in this report. These co-produced narratives (Springham & Xenophontes, 2021) take the reader inside an experience of what helps and does not help when caring at end-of-life. They demonstrate how a creative methodology can overcome barriers often present in such a sensitive research context, eliciting a deeper understanding of the relationships and practices that can sustain and be significant for people caring at the end-of-life.

Participants and Recruitment

Eligible participants for this research were from the Aboriginal or Torres Strait Islander community, or from an Arabic, Hindi or Mandarin-speaking background. They were required to have cared for someone at the end-of-life, but more than 6 months ago; be living in Western Sydney LHD; and be over 18 years of age. The initial recruitment for 16 participants (4 from each cultural group) was conducted through the online Death Literacy survey (Leonard et al, 2012) which invited interested respondents to leave contact details. Further recruitment was conducted by word of mouth and distribution of translated electronic and print flyers through partner networks alongside digital campaigns on the Western Sydney University Facebook page and online local newspapers. WSLHD Aboriginal Health Unit and Multicultural Health Education teams provided each participant with an in-depth explanation of the project (in their preferred language) and assurance their participation would be voluntary and anonymous. As shown in Table 1 below, our recruitment aim was almost fully met. The majority of participants identified as female, which is consistent with the historically gendered character of caring roles (Craig & Churchill 2021).

Table 1. Distribution of photovoice participants by gender and cultural group

Participants	Aboriginal	Arabic	Hindi	Mandarin	Other	Total
Number of participants	4	4	3	4		15
Gender	4F	4F	2F 1M	3F 1M		13F 2M

Research Findings

Data Analysis

The raw qualitative data for this project comprised transcriptions of the two-hour photovoice interviews. Each photovoice transcript was analysed independently by two members of the research team following the principles of thematic analysis (Braun & Clarke, 2021; Crowe, Inder & Porter, 2015). Analyzing the transcripts was an interpretative, qualitative, and data-driven inductive process that focused on emergent themes as well as the specific research questions. This process identified common and recurring themes (discussed below) that contribute to the broader project findings about people's needs at end-of-life. In collaboration with participants, the analysis of transcripts was also used to develop the one-page narratives that accompany participant photographs in this report. Developing the stories was an iterative co-production process (Springham & Xenophontes, 2021). Researchers distilled key elements from the transcripts into each one-page story using the participant's own words; participants reviewed and made changes if required to ensure the integrity of their story.

Key Themes and Implications for Service Delivery

1. Connection and Trust

The data showed familial and social connections are important to people and their wellbeing, with community connections being especially pronounced at end-of-life for participants from Aboriginal and Culturally and Linguistically Diverse (CaLD) communities. These trusted relationships support both carers and the person facing end-of-life. However, the capacity of service providers to build connections based on relationships of trust and cultural safety for patients and families is also crucial, indeed foundational to the delivery of culturally appropriate end-of-life care (Broom et al 2013). While connections to service providers are central, the data produced mixed results. On the one hand, there was evidence of strong relationships with supportive services: *they did heaps for our family...and they're still a great support, even now* (Shanna); *the people who carry the services...they've all got a good attitude. I was very touched and moved in all of what they do* (Alice); *the whole palliative care team, everyone that was involved with him did so much, they couldn't have done anything different or better. They treated him very well* (Vanessa). However, there were evident disconnections on the other: *don't dismiss family members. It's not between just you and the patient...that's someone they love. Allow the family to be near them, it's very important* (Marine); *once my daughter reached 18, I found the specialists not talking to me, as if I'm invisible in the room. Include us in delivering the information or giving her advice or suggestion...I know she's adult enough to understand but don't exclude the parents* (Amira).

The need for more sensitive communication by service provider staff (in multiple contexts) was a strong theme: *Be a person first...have the right attitude towards to others. Respect to the person who is passing... who is suffering, in pain. You need to understand rather than discriminate. Ask them what they want. Everything you do, be friendly, be kind. Kindness. Human respect. Very important* (David); *It was very hard for us, very, very hard...just be patient* (Lilian); *I think it's important when they employ people for these kinds of places, they check the person's character, their heart – ask social questions, not just academic. To see someone compassionate makes a lot of difference* (Marine). Taking the time to build relational trust and rapport is important and appreciated: *they always talked with us, shared with us the stories. I remember this [nurse], she tried to speak Arabic for her to feel supported* (Lilian). Continuity of relationships between service providers, patients, families, and communities is needed to provide quality supportive care from diagnosis, through treatment and into palliative care and bereavement. There is a need for support through all these stages: *there should be somebody there to make that contact. Someone with compassion, wisdom and experience who understands the transition to the end of life, to support the person, as well as the family* (Ann); *she was in tears all the time. They didn't send any social worker or a psychologist. They didn't offer help. Another doctor comes - 'we will do the scan; we will do the stress test' - all these worries they're putting on her without offering any comfort* (Amira).

2. Cultural Traditions and Practices

Although generational change in some families can mean cultural or religious traditions may be adapted or abandoned, the data showed that cultural practices and rituals related to end-of-life are important, sometimes crucial: *their religious belief – that's also very important. That gives someone strength to continue, and it helps them accept separation and death* (Marine). Here again, our research produced mixed results. Some people's experience of service providers was positive: *the hospital, the nurses were beautiful. They offered their condolences. They didn't tell us to go 'cos we were taking up the waiting room. We were taking up the room and we were taking up the corridor. They allowed us to gather for that time* (Rouba). However, other experiences were less positive: *one of the biggest things for us is food...we would pack some food from home and ask the nurses to warm it up for the following day, but we just knew they weren't. I'm not saying there was specific staff that wasn't helping out, it was just the facility and the system was not...it wasn't a positive experience at all* (Aish). The data also indicated there was rarely options for cultural practices in service contexts: *he didn't have a proper place to pray...so that stopped him. Culturally...he felt...isolated* (Khwaja); *I don't remember there ever [being] a chaplain or a spiritual person in the hospital to recite any words over the dead* (Rouba). Not being able to perform cultural rituals at death can be very distressing, even harmful: *one thing that always still bothers me, that in hospital at the very end after he passed, they put him into the hospital clothes. In Chinese cultural traditions, when the body's still really warm, we need to put on the formal best clothes for them to go. They didn't give us the opportunity to do all of that. No-one asked, no-one helped, no-one gave the opportunity to do it* (Alice). *Elderly people when they go, they must have these special clothes...the Holy Clothes* (Mary).

Sometimes the respect for patient autonomy in Western contexts is in tension with alternative decision-making practices that may be collective or collaborative in nature: *no one took that initiative to learn about the family dynamics. For us, family is really important. Each of us has a specific role and responsibility. When we make any decision in the family, it involves the entire family - Uncles and Aunts, too - making that decision together, especially the big decisions* (Aish). Cultural beliefs and practices bring complexity to the responses required of service providers, not least because of the diversity between and within different cultural groups. On the one hand, implications for space availability may mean longer term capital investments to create suitable and sufficient areas to accommodate extended families or kinship groups. Relationally, taking a position of cultural humility is a way forward for service provider staff to address diversity and the attendant power imbalances often present in the context of cultural needs at end-of-life. The concept of cultural humility suggests supportive interactions are based on attributes of openness and reflexive self-awareness (Forondo et al 2016) where people are asked about their cultural needs rather than having these assumed or ignored. Its practice is “relationship-based” in contrast to the presumptions of ‘knowledge’ embedded in the “models of cultural competence” shaping much diversity training (Loue 2022, p.105). Cultural humility offers a way to move beyond “cultural stereotyping and predicting need” (Broom et al 2013, p.1043) toward creating respectful, inclusive environments with “optimal care” (Forondo et al 2016, p.210).

3. Grief and Bereavement

A range of connections are central to a person’s cultural identity and sense of trust and belonging and when these connections are lost at end-of-life, people can become isolated and the need for community and service provider connections are amplified. Isolation is a key factor in the development of mental health issues (Neilson et al 2015) and can exacerbate grief leading to protracted periods of complex grief. This further isolates people from their community and/or the services that could help. The need for grief support starts with the beginning of the palliative care journey, not just at the point of bereavement. There is ‘loss’ long before death. Loss begins from the moment of diagnosis, through phases of treatment and again when treatment can no longer assist. Access to counselling with a suitably trained person *who understands the transition to the end of life* (Ann) is needed through all these stages: *I understand the grief takes time to heal. I felt at that time that I need somebody just to listen to me. I felt I want just to talk and somebody just to listen* (Amira). Sometimes it helps to talk with a person outside the grieving family: *having someone to talk to...maybe that’s my best experience – talking to someone that wasn’t family about losing her or potentially losing her at the time* (Rouba). The data showed knowledge about the availability of counselling was not consistent across the participant cohorts, indicating a need for dissemination of existing service availability through culturally appropriate means: *no support services were made available to help Mum with coping, or to help her process everything going on...we weren’t advised of services available to us, such as a bereavement counsellor* (Aish).

For some people from CaLD and Aboriginal communities, the experience of grief and bereavement is heightened when family or community connections are broken by distance. The family of people who have migrated may live overseas with contact limited to phone calls: *we only had strong communication with our family back home, over here we didn’t have much community support. It was a very isolating time* (Aish). Similarly, the extended family of Aboriginal people may not be able to travel from Country or, conversely, the dying person may not be able to return to Country, as is the preference for many Aboriginal people: *he really wanted to go home to Country, but we just couldn’t leave at the time given it was COVID then. There were a lot of restrictions*, (Vanessa). These situations can heighten distress for carers before and after their loved-one’s death. Connecting with nature emerged in the findings in a variety of ways, including as a cultural anchor: *the bottlebrush. I picked that as my symbol because it will take me back into my history - I’m Mununjali, Beaudesert mob. When I look at it, I remember. I can tell you my whole story, my whole family background, where I come from...that’s the connection I have to my family* (Ann); or symbolic of something positive, such as a sunrise: *every day is a new day and hopefully things will get better* (Urvashi); or life affirming, such as new growth on an old tree: *I was very down. I lost hope. I was walking and suddenly I saw this tree. I said, ‘Maybe this is your hope... it’s green’. Life, it should grow* (Amira). From pets at home to special places in the natural world, connections to nature may provide solace, be central to cultural practice, or contribute to self-care.

4. Caring and Self-care

Attending to self-care is an important aspect of caring for someone at the end of life. Self-care practices are crucial to the compassionate delivery of services at end-of-life (Mills et al 2018) and work to support the attributes of cultural humility in the people employed by service providers. Self-care is also vital for family carers: *I had to make sure I had time for me during that time* (Anon). Our findings showed a variety of self-care practices supported people in their caring role. Connecting to nature was a recurrent theme, with this often representing a space to unwind or connect spirituality: *I found the beach really therapeutic, it was just a bit of a space - getting into nature where I could unwind* (Shanna); *trees represent culture, roots into the ground, connection to the land* (Vanessa); *a love heart in a gumtree at palliative care. It was my happy place out in the courtyard. I used to go out there, I used to be upset then I’d turn and look at that love heart and I’d be like, ‘OK I’m right again now. I can go back inside’* (Anon). Creative endeavours were also a common self-care activity. Artmaking, photography, dance, music and singing, for example, were all undertaken either personally or with their loved one or social group. Creative practices provide a means of self-expression and self-care, helping at distressing times. Creative activity has benefits for wellbeing, including increased focus, relaxation, and the easing of stress, depression and anxiety (Hass-Cohen & Carr 2008, p.15): *that’s helped me a lot to come out of the emotional sadness, bring my life back to normal...we prepare many performances so we can concentrate on the rehearsals...my time has been occupied by the busy schedule and it makes me feel better* (Mary). Participating in the creative arts can also be a

way of building relationships and social connections: *a choir; Tai-chi; dancing; fashion parade – a lot of different activities - it's medicine, but it's even better than medicine!* (Anna). This can be an important way of offsetting the isolating tendencies of overwhelming sadness and grief (Neilson et al 2015, p.1): participating in this dancing group and the art group has really helped me to get out of [the depression] (Alice).

The key findings articulated here have been corroborated by, and contribute to, the findings of the companion report, *What matters in the End*, which provides a comprehensive set of recommendations for improving the quality of care at end-of-life.

In the Caring – Culture and Connection At End Of Life

They treated us all very well. A lot of it had to do with connection and culture and just the care that they gave...it was the respect of it all...it was mutual (Vanessa).

They did a good job but some things weren't good about the connection. If [they] could talk with her – just talk – not translate – it would make her feel safe (Lilian)

That the care one gives or receives during the end-of-life should be based on compassion, love and/or mutual respect seems self-evident. For people from diverse communities, culture can provide the basis for the connection and belonging that underpins care from families and communities. Yet, culturally diverse people's experience of end-of-life services is often one that positions them at the margins in terms of their specific cultural needs. As a result, the quality of care at end-of-life risks being undermined. Yet, high quality supportive and palliative care "should be accessible to all Australians" (Department of Health, 2018). At the same time, there is inconsistency in the collection and reporting of palliative care data (Productivity Commission, 2017). We therefore need to hear directly from culturally diverse communities about their needs and the ways services can provide more culturally safe end-of-life care.

Exploring Cultural Needs

There is much to be learned and understood about the traditions, beliefs, practices and needs of culturally diverse communities. With its focus on Western Sydney, our research was undertaken in collaboration with the Aboriginal community and Arabic, Mandarin and Hindi-speaking communities, which represent three of the largest language groups in the Western Sydney Local Health District. Our generous participants have taken us inside an experience of caring for someone living with a life-limiting condition or during a time of life-limiting illness. This period may span a number of years, months or just a few short weeks. Participant contributions to the research presented in this report reveals what is important to people from diverse cultural communities, what helped them and how culture can sustain and be sustained in the face of grief and loss. Importantly, their stories contribute to our understanding of people's end-of-life needs and what service providers might do to better deliver culturally safe and appropriate services.

The experience of many people from Aboriginal or migrant communities is one of social marginalisation and invisibility. Their specific needs at end-of-life are rarely accommodated. This can have serious impacts, including re-traumatisation, at a time when people may be especially vulnerable. In this research, we used participant generated photographs as a starting point to learn more about what works in the health service system and wider community to support people caring for someone at the end of life. Visual imagery can be a helpful method in sensitive enquiry (Paton et al 2018), providing a gentle basis for entering into conversations that are difficult due to their very personal nature. To understand more about cultural needs at end-of-life, we turned to the research method known as photovoice (Wang & Burris 1997). This method exploits the power of photographic imagery to communicate when matters are difficult to speak about and can be an empowering means for people to represent their experience in a meaningful way (Booth and Booth 2003).

Photovoice uses photography to give visibility to the stories and experiences of research participants. It amplifies marginalised voices in both scholarly and public domains, providing participants with a tangible opportunity to contribute to their communities and broader society. Photovoice projects typically aim to influence policy or service delivery for vulnerable or marginalised groups. It often disseminates findings in the form of photographic exhibitions and/or publications which can have a positive impact on community building and contribute to social and cultural capital. The *Stories of Care* report provides an opportunity for participants to project their stories in a public forum and contribute socially to developing understandings associated with end-of-life needs in diverse communities. Their photographs and written narratives provide us with a cultural lens through which to view and understand what is helpful and supportive to the experience of care at end-of-life.

To meet the aims and goals of our research, we modified the use of photovoice within a context where Covid 19 lockdowns prevented us from meeting people face-to-face. Participants recruited for this part of the project used their own cameras or devices to take photographs that represented what was helpful or meaningful to them during the time of caring for someone at end-of-life. Sometimes taking the photographs was challenging and the Covid 19 context added to this when people's mobility, and therefore choices for photographic subjects, was limited. We suggested that people could also consider choosing existing

photographs for the photovoice interviews. In the process of taking new photographs or choosing existing ones, participants were able to revisit life memories and make or remake connections, visually expressing what was meaningful and important to them. This established the basis for interviews about each participant's end-of-life caring, including previously unexplored aspects of that experience (McIntyre 2003).

The semi-structured interviews with individual participants took place online using Zoom. Five of the fifteen photovoice participants had a support person attend their interview for translation, as needed. The discussions focussed on the participant's experience of caring at end-of-life prompted by a selection of the photographs they had taken or chosen for the interview. These conversations were also guided by a series of prompts based on the project information previously given to participants. This process enabled us to understand what was helpful and supportive (or not) in the participant's caring journey from their point of view. Participants were then invited to choose photographs for inclusion in the *Stories of Care* report and to add anything further they specifically wanted to be reflected in their one-page narrative. With permission, the individual interviews were audio recorded and later transcribed. These transcriptions provided a rich basis for data analysis as well as developing the one-page stories in collaboration with each participant.

Stories that Matter

The images given to this project bring into focus the experiences of people who are marginalised and often 'voiceless' as a consequence. The photographs and narratives in the *Stories of Care* report provide a resource for members of the community who may, now or in the future, care for someone at the end-of-life. They tell us what matters to people at such a time, and they bring attention to some of the challenges people may experience. The report also offers stories of resilience and resourcefulness that are inspiring, especially in contexts where cultural needs at end-of-life have been overlooked or dismissed. The report is a resource for people working in the health sector who care (or should care) about culturally safe service provision. The capacity of service providers to build trust and connection is foundational to the delivery of culturally appropriate end-of-life care. Themes of culture, connection and belonging - all necessary to the development of trust - are strongly reflected in the findings and, unsurprisingly, feature in the stories and photographs included in the report.

Familial, social and community connections are all shown to be important to people and their wellbeing. Connections to service providers are also central with stories reflecting strong relationships with supportive services: *they did heaps for our family...and they're still a great support, even now* (Shanna). Sadly, there are also stories of disappointment: *don't dismiss family members. It's not between just you and the patient...that's someone they love. Allow the family to be near them, it's very important* (Marine). Connection to nature is a recurrent theme, with this often representing a space to unwind or as symbolic of something positive, such as a sunrise: *every day is a new day and hopefully things will get better* (Urvashi); or new growth on an old tree: *it's green. Life, it should grow. This photo is still life-giving* (Amira). There are also stories indicating the significance of spirituality or faith, as well as cultural traditions and practices. Although central to people's identity, there was not always space for these in service contexts: *he didn't have a proper place to pray...So that stopped him. Culturally...he felt...isolated* (Khwaja).

A wide variety of connections are evidently central to a person's cultural identity and sense of belonging and acceptance. When these connections are lost at end-of-life, people can become isolated and the need for community and service provider connections are amplified. Isolation can exacerbate grief leading to protracted periods of complex grief and further isolating people from their community and/or the services that could help. Social isolation is a key factor in the development of mental health issues (Neilson et al 2015:1). The need for grief support starts with the beginning of the palliative care journey, not just at the point of bereavement. There is 'loss' long before death. Loss begins from the moment of diagnosis, through phases of treatment and again when treatment can no longer assist. There is a need for support and access to counselling through all these stages: *...there should be somebody there to make that contact. Someone with compassion, wisdom and experience who understands the transition to the end of life, to support the person, as well as the family* (Ann).

In caring for someone at the end of life, care and self-care sit alongside each other. Self-care practices are crucial to the compassionate delivery of services at end-of-life (Mills et al 2018) and are no less vital for family carers: *I had to make sure I had time for me during that time* (Anon). Creative endeavours were a common thread between many participants' self-care activities. Artmaking, photography, dance, music and singing, for example, were all undertaken either personally or with their loved one or social group. Such practices provide a means of self-expression and self-care, helping at distressing times. Engaging in the creative arts can provide benefits for wellbeing, including increased focus, relaxation, and the easing of stress, depression and anxiety (Hass-Cohen & Carr 2008:15). Creative activity can also be a way of building relationships and social connections, offsetting the isolating tendencies of overwhelming sadness and grief (Neilson et al 2015:1): *it's medicine, but it's even better than medicine!* (Anna)

Much like the social role of artists, the research participants in this report have made "the objects of...common life...poignant and momentous" (Dewey 1934:118). The photographs are "saturated with story" connected to people and the rhythm of their lives (Dewey 1934:344). Each image has the potential to bridge different worlds, opening up new areas of experience or revealing fresh qualities in familiar scenes (Dewey 1934:144). Collectively, the photographs and stories generate an increased awareness in the

Western Sydney region and beyond of how people are experiencing end-of-life issues from different cultural perspectives. In so doing, they create the potential for greater social and institutional understanding, giving participants the hope that their stories will make a difference in the future delivery of services for their communities. They have displayed bravery and resilience in circumstances that do not always, perhaps rarely, fully accommodate the specific cultural needs of their communities and traditions.

The contributors to *Stories of Care* have been generous in their sharing of personal and often emotive material. The stories held within these pages come from the heart and soul. They also hold the hope of system change for people with specific cultural needs at the end-of-life. In giving voice and visibility to the participants, this report provides them with a very tangible opportunity to make a significant statement about their caring experiences. In turn, their willingness to portray those experiences in such a public forum takes great courage. Their photographs and stories are serving to enrich our understanding of cultural needs at the end-of-life. Through their engagement in the research project and report, participants are helping to build knowledge of the relationships, values and practices that can sustain people, and the families who care for them, at the end-of-life. Most importantly, they have given us all the opportunity to enter into their everyday stories, to reflect on what we see, and to be changed by that encounter.

تحت الرعاية: الثقافة والتواصل في مرحلة نهاية الحياة

لقد عاملونا جميعاً بطريقة جيدة جداً، ويعود ذلك بمعظمه إلى تواصلهم معنا ومراعاة ثقافتنا ولمجرد الرعاية التي قدموها لنا... واحترام كل شي ... وكان الاحترام متبادلاً (فانيسا).

لقد قاموا بعمل جيد ولكن لم تكن بعض الأمور المتعلقة بالتواصل جيدة. لو كان بإمكانهم التحدث معها - التحدث فقط - وليس الترجمة - لكانت شعرت بالأمان (ليليان).

قد يبدو أنه من المسلّم به أن تكون الرعاية التي يقدمها شخص ما أو يتلقاها في مرحلة نهاية الحياة مبنية على الرأفة والحب و/أو الاحترام المتبادل. وبالنسبة للأشخاص من مجتمعات متنوعة، يمكن أن تشكل الثقافة ركيزة للتواصل والانتماء التي تستند إليها الرعاية التي تقدمها العائلات والمجتمعات. لكنّ تجربة الأشخاص من خلفيات متنوعة ثقافياً مع خدمات الرعاية في مرحلة نهاية الحياة غالباً ما تجعلهم يشعرون بأنهم مهمشون من ناحية احتياجاتهم الثقافية المحددة. ونتيجة لذلك، تتعرض جودة الرعاية في مرحلة نهاية الحياة لخطر التقليل من شأنها. بيد أنّ الرعاية الداعمة والتلطيفية رفيعة المستوى "يجب أن تكون متاحة لجميع الأستراليين" (دائرة الصحة، 2018)؛ وفي نفس الوقت، هناك تباين في جمع المعلومات عن الرعاية التلطيفية والإبلاغ عنها (هيئة الإنتاجية، 2017). لذا علينا الاطلاع مباشرة من المجتمعات المتنوعة ثقافياً عن احتياجاتهم والأساليب التي بموجبها يمكن أن تقدم الخدمات رعاية أكثر أماناً وملاءمة من الناحية الثقافية في مرحلة نهاية الحياة.

استكشاف الاحتياجات الثقافية

هناك المزيد لتتعلمه وندرکه عن تقاليد المجتمعات المتنوعة ثقافياً ومعتقداتها وممارساتها واحتياجاتها. وركز بحثنا على منطقة غرب سيدني وأجري بالتعاون مع مجتمع السكان الأصليين والمجتمعات المتحدثة باللغات العربية والصينية والهندية، التي تمثّل ثلاثاً من أكبر المجموعات اللغوية في المنطقة الصحية المحلية في غرب سيدني. وقد أخذنا المشاركون الكرام في مسيرة الرعاية التي تُقدّم لشخص يعاني من حالة صحية تحدّ حياته أو خلال فترة مرض يحدّ حياته. وقد تمتدّ هذه الفترة إلى عدد من السنوات أو الأشهر أو حتى بضعة أسابيع قصيرة. وتكشف مساهمة المشاركين في هذا الكتاب المجتمعي عما هو مهم للأشخاص من مجتمعات متنوعة ثقافياً، وعما ساعدتهم وكيف يمكن للثقافة أن تدعمهم وأن تستمر في وجه الحزن لفقدان عزيز. والمهم هو أنّ قصصهم تساهم في فهمنا لاحتياجات الأشخاص في مرحلة نهاية الحياة، وفهم ما يمكن لمقدمي الخدمات القيام به من أجل توفير خدمات آمنة ومناسبة ثقافياً بشكل أفضل.

تعدّ تجربة العديد من الأشخاص من مجتمعات السكان الأصليين أو المهاجرين تهميشاً اجتماعياً وإقصاءً لهم؛ ونادراً ما يتم استيعاب احتياجاتهم الخاصة في مرحلة نهاية الحياة. وقد يترتب عن ذلك تأثيرات خطيرة منها استرجاع الصدمة، في وقت قد يكون فيه الأشخاص ضعيفي الحيلة بشكل خاص. وفي هذا البحث، استخدمنا كنقطة انطلاقاً صورياً قام المشاركون بالتقاطها لنعرف أكثر عما يصلح في نظام الخدمة الصحية وفي المجتمع الأوسع من أجل دعم الأشخاص الذين يقدمون الرعاية لأحد في مرحلة نهاية الحياة. وقد تكون الصور المرئية وسيلة تساعد في استقصاء المواضيع الحساسة (Paton et al 2018) وتشكل أساساً جيداً لفتح حوارات صعبة نظراً لطبيعتها الشخصية جداً. ولمساعدتنا في فهم الاحتياجات الثقافية في مرحلة نهاية الحياة، لجأنا إلى طريقة البحث المعروفة باسم فوتو فويس (Wang & Burris 1997). تستغلّ هذه الطريقة قدرة الصور الفوتوغرافية على توفير التواصل عندما يصعب التحدّث في مواضيع ما، كما يمكن أن تكون وسيلة تمكّن المشاركين من تجسيد تجاربهم بطريقة معتبرة (Booth and Booth 2003).

تُستخدم في وسيلة فوتو فويس الصور من أجل عرض قصص المشاركين في البحث وتجاربهم؛ كما تزيد من أهمية الأصوات المهمشة في كل من المجالين العلمي والعام، ما يتيح فرصة ملموسة للمشاركين في المساهمة بمجتمعاتهم وبالمجتمع العريض. وتهدف مشاريع فوتو فويس عادةً إلى التأثير على السياسة أو تقديم الخدمة للفتات الضعيفة أو المهمشة. وغالباً ما يتم نشر النتائج إما من خلال معارض صورية و/أو منشورات ويكون لذلك تأثيراً إيجابياً على بناء المجتمع والمساهمة في رأس المال الاجتماعي والثقافي. ويوفر كتاب المجتمع "قصص عن تقديم الرعاية" الفرصة للمشاركين لعرض قصصهم في منتدى عام وللمساهمة اجتماعياً في تطوير المفاهيم المرتبطة باحتياجات الأشخاص من مجتمعات متنوعة في مرحلة نهاية الحياة. كذلك توفر لنا صورهم وقصصهم المكتوبة عدسة ثقافية نرى من خلالها ونفهم ما هو مفيد وداعم لتجربة تقديم الرعاية في مرحلة نهاية الحياة.

ومن أجل تحقيق أهداف بحثنا، قمنا بتعديل استخدام طريقة فوتو فويس لكي تتماشى مع مجريات فترات الإغلاق بسبب فيروس Covid-19 التي منعتنا من مقابلة الأشخاص وجهاً لوجه. واستخدم المشاركون في هذا الجزء من المشروع كاميراتهم وأجهزتهم الخاصة لالتقاط الصور التي تمثل ما كان مهمماً وذا مغزى بالنسبة لهم خلال فترة تقديم الرعاية لشخص في مرحلة نهاية الحياة. وفي بعض الأحيان كان التقاط الصور صعباً وخاصةً في ظل ظروف Covid-19 حيث كانت تنقلات الأشخاص، وبالتالي خيارات مواضيع التصوير، محدودة. وبناءً عليه، اقترحنا أن يختار المشاركون صوراً موجودة لمقابلات فوتو فويس. وعند التقاط الصور الجديدة أو اختيار القديمة منها استطاع المشاركون استحضار ذكريات مرت في حياتهم وإنشاء روابط أو إعادة تكوينها، معبرين عما كان مهمماً وذا مغزى لهم بطريقة بصرية. وقد كان هذا الأمر ركيزة للمقابلات الخاصة بمشاركين يقدمون الرعاية لأشخاص في مرحلة نهاية الحياة، بما في ذلك جوانب غير مستكشفة سابقاً من تلك التجربة (McIntyre 2003).

وأجريت المقابلات شبه المنظمة مع المشاركين بصورة فردية عبر الإنترنت باستخدام تطبيق Zoom. وقد احتاج خمسة مشاركين في فوتو فويس من أصل خمسة عشر مشارك إلى شخص دائم يحضر المقابلة معهم لمساعدتهم في الترجمة عند الحاجة. وقد ركزت المناقشات على تجربة المشارك في تقديم الرعاية لشخص ما في مرحلة نهاية الحياة من وحي مجموعة صور كان قد التقطها أو اختارها للمقابلة. كذلك تم الاسترشاد في هذه الحوارات بمجموعة من المواضيع المحفزة المتعلقة بمعلومات المشروع أعطيت سابقاً إلى المشاركين. مكنتنا هذه العملية من فهم ما كان مفيداً وداعماً لمسيرة المشارك في تقديم الرعاية وما لم يكن كذلك. وبعد ذلك تمت دعوة المشاركين لاختيار الصور التي يودون إدراجها في كتاب المجتمع وإضافة أية معلومات يريدون على وجه التحديد ذكرها في الموجز المكوّن من صفحة واحدة الخاص بهم. وتم تسجيل المقابلات الفردية صوتياً بموافقة المشاركين ومن ثم تم استنساخها. وشكّلت هذه المدوّنات أرضية غنية لقصص كتاب المجتمع التي تمت صياغتها بالتعاون مع كل مشارك.

قصص ذات أهمية

تسلط الصور المقدمة في هذا المشروع الضوء على تجارب أشخاص مهمشين وغالباً ما يكون "لا صوت لهم" نتيجة لذلك. وتعتبر الصور والقصص الموجودة في كتاب "قصص عن تقديم الرعاية" مرجعاً لأفراد المجتمع الذين قد يقدمون الرعاية لشخص في مرحلة نهاية الحياة، أكان ذلك في الحاضر أم في المستقبل. وتخبّرنا بما يهمّ الناس في مثل هذا الوقت، كما تلفت الانتباه إلى بعض الصعوبات التي قد يواجهها الشخص. ويقدم هذا الكتاب قصصاً ملهمة عن القدرة على التكيف وسعة الحيلة، وخاصةً في السياقات التي تمّ فيها التفاوض عن الاحتياجات الثقافية في نهاية الحياة أو تجاهلها. كذلك يعتبر هذا الكتاب مرجعاً للأشخاص العاملين في قطاع الصحة الذين يهتمون (أو يتعيّن أن يهتموا) بتقديم خدمة آمنة ثقافياً. وتعدّ قدرة مقدّم الخدمة على بناء الثقة والتواصل أمراً أساسياً في تقديم رعاية مناسبة ثقافياً في مرحلة نهاية الحياة. وتعكس الصور والقصص التي يتضمّنهما الكتاب مواضيع الثقافة والتواصل والانتماء التي تعتبر كلها ضرورية لبناء الثقة.

ويبين الكتاب أن أشكال التواصل العائلية والاجتماعية والمجتمعية مهمة لجميعها للمشاركين وللحفاظ على رفاهيتهم. كذلك يعتبر التواصل مع مقدمي الخدمة أساسياً إذ تعكس القصص أن وجود خدمات داعمة يؤدي إلى بناء علاقات متينة، كما عبرت شانا بقولها: "لقد فعلوا الكثير من أجل عائلتنا... وما يزالون يقدمون دعماً كبيراً لنا، حتى الآن". لكن للأسف هناك أيضاً قصص مخيبة للأمل كما ذكرت مارين على سبيل المثال: "لا تتجاهلوا أفراد الأسرة. ليس الأمر بينكم وبين المريض فقط... أن أفراد الأسرة يحبون هذا الشخص. أتيجوا لهم الفرصة للتواجد بقربه، فهذا مهم جداً". هذا ويعتبر التواصل بالطبيعة موضوعاً متكرراً إذ غالباً ما يمثل مساحةً للترويح عن النفس ورمزاً من الرموز الإيجابية، مثل شروق الشمس كما تقول يورفاشي: "كل يوم هو يوم جديد ونأمل أن تتحسن الأمور؛ أو عودة الحياة إلى شجرة قديمة بحسب أميرة: إن الحياة كالشجرة، يجب أن تنمو. ما تزال هذه الصورة ترمز إلى انبعاث الحياة". كذلك هناك قصص ترمز إلى الأهمية الروحانية أو الإيمان، بالإضافة إلى التقاليد والممارسات الثقافية. وعلى الرغم من أن هذه الأمور هي جوهر هوية الأشخاص، إلا أنه لم تتوفر دائماً الفرصة لهذه الممارسات والتقاليد في سياقات الخدمة كما يقول خواجه: "لم يكن لديه مكان مناسب للصلاة... ما جعله يتوقّف عن ذلك. لقد شعر... بالعزلة... ثقافياً".

من الواضح أنّ مجموعة متنوّعة من الروابط تشكّل أساس هوية الشخص الثقافية وشعوره بالانتماء والقبول. وعند فقدان هذه الروابط في مرحلة نهاية الحياة، يمكن أن يصبح الأشخاص معزولين فتزداد حاجتهم للروابط المجتمعية والتواصل مع مقدّم الرعاية. من هنا فإن العزلة يمكن أن تؤدي إلى تفاقم الحزن وإلى فترات طويلة من الحزن المعقد وتزيد من انعزال الأشخاص عن مجتمعاتهم وأو الخدمات التي يمكن أن تساعدهم. وتعتبر العزلة الاجتماعية سبباً رئيسياً في تطوّر مشاكل الصحة العقلية (Neilson et al 2015:1). وتبدأ الحاجة إلى الدعم للتغلب على الحزن مع بداية مسيرة الرعاية التلطيفية وليس فقط عند وقوع الفاجعة. إذ هناك "خسارة" قبل الوصول إلى الموت بوقت طويل، إذ تبدأ الخسارة من لحظة تشخيص المرض وصولاً إلى مراحل العلاج ومرّة أخرى حين يصبح العلاج غير مجدٍ. لذلك هناك حاجة للدعم والحصول على المشورة في جميع المراحل كما قالت آن، إحدى المشاركات: "... يجب أن يكون هناك شخص يقدم هذا الدعم. شخص يتمتع بالرفقة والحكمة والخبرة ويفهم الانتقال إلى مرحلة نهاية الحياة، من أجل تقديم الدعم للشخص وللعائلة على السواء.

أثناء تقديم الرعاية لشخص في مرحلة نهاية الحياة، تتماشى رعاية الآخر مع الرعاية الذاتية، إذ تعتبر ممارسات الرعاية الذاتية في غاية الأهمية من أجل تقديم الخدمات برأفة وتعاطف في مرحلة نهاية الحياة (Mills et al 2018) ولا تقل شأنًا بالنسبة لمقدّم الرعاية لأحد أفراد العائلة كما يقول أحد المشاركين، آنون: "كان عليّ التأكد من تخصيص وقت للاهتمام بنفسى أثناء تلك المرحلة". ومن نشاطات الرعاية الذاتية كانت الفنون الإبداعية القاسم المشترك بين المشاركين، على سبيل المثال ممارسة التعبير بالأعمال الفنية والتصوير والرقص والموسيقى والغناء، والقيام بذلك إما على بصورة ذاتية أو مع الأحباء الذين تتم رعايتهم أو ضمن مجموعة اجتماعية. ومثل هذه الممارسات يوفر وسيلة للتعبير عن الذات وللرعاية الذاتية معاً مما يساعد في الأوقات العصيبة. ويمكن أن يوفر الانخراط في الفنون الإبداعية فوائد للصحة والعافية، بما في ذلك زيادة القدرة على التركيز والاسترخاء وتخفيف التوتر والكتئاب والقلق (Hass-Cohen & Carr 2008:15). كذلك يمكن أن يشكل النشاط الإبداعي وسيلة لبناء العلاقات والروابط الاجتماعية ولمقاومة الميول للعزلة الناجمة عن الشعور الغامر بالحزن والأسى (Neilson et al 2015:1) ووصفته أنا بقولها: "إنه دواء، إنه أفضل حتى من الدواء!"

وتماماً كدور الفنانين الاجتماعي، جعل المساهمون في كتاب المجتمع هذا "الأشياء المتعلقة... بالحياة العادية... مؤثرة وبالغة الأهمية" (Dewey 1934:118)، فالصور الفوتوغرافية "مثقلة بقصص" ترتبط بأشخاص وبوتيرة حياتهم (Dewey 1934:344). ولكل صورة القدرة على ربط عوالم مختلفة وفتح مجالات جديدة من التجارب أو الكشف عن صفات جديدة في مشاهد مألوفة (Dewey 1934:144). وبصورة عامة، تولّد الصور والقصص وعياً متزايداً في منطقة غرب سيدني وفي مناطق أخرى حول طريقة مواجهة الأشخاص لقضايا مرحلة نهاية الحياة من وجهات نظر ثقافية مختلفة. وبذلك فإنهم يمهّدون الطريق لفهم هذه القضايا بشكل أكبر على صعيد

المجتمع والمؤسسات، ما يعطي المشاركين الأمل بحصول تغيير نحو الأفضل في تقديم الخدمات لمجتمعاتهم في المستقبل. وقد أظهر المشاركون شجاعة وقدرة على التكيف في ظروف لا تلي دائماً، وربما نادراً ما تلي، الاحتياجات الثقافية الخاصة بمجتمعاتهم وتقاليدهم.

لقد زدنا المساهمون بسخاء في "قصص عن تقديم الرعاية" بمعلومات وصور شخصية وعاطفية في أغلبها. وفي طيات هذا الكتاب قصص نابغة من القلب والروح، وتحمل الأمل في تغيير النظام للأشخاص ذوي الاحتياجات الثقافية الخاصة في مرحلة نهاية الحياة. ويمنح هذا الكتاب المجتمعي صوتاً وظهوراً للمشاركين، ما يتيح لهم فرصة ملموسة جداً للتعبير بشكل ملحوظ عن تجاربهم في تقديم الرعاية. ومن ناحية أخرى، إن استعدادهم لوصف هذه التجارب في مثل هذا المنتدى العام يتطلب شجاعة كبيرة، وصورهم وقصصهم تثير فهمنا للاحتياجات الثقافية عند مرحلة نهاية الحياة. ويساعد المشاركون من خلال مساهمتهم في مشروع البحث وفي كتاب المجتمع هذا، في بناء المعرفة بالعلاقات والقيم والممارسات التي يمكن أن تدعم الأشخاص وعائلاتهم في مرحلة نهاية الحياة. والأهم من ذلك أنهم منحونا جميعاً الفرصة للولوج في قصصهم اليومية والتفكير ملياً في ما نراه وتغيير نظرتنا إلى الأمور.

देखभाल में - जीवन के अंत में संस्कृति और संबंध

उन्होंने हम सभी के साथ बहुत अच्छा व्यवहार किया। इसका एक बड़ा भाग संबंधों और संस्कृति से जुड़ा हुआ था और बस वह देखभाल जो उन्होंने प्रदान की... इस सब के आदर और सम्मान के बारे में था... यह पारस्परिक था (Vanessa)

उन्होंने अच्छा काम किया लेकिन जुड़ाव को लेकर कुछ चीज़ें अच्छी नहीं थीं। अगर [वे] उससे बात कर सकें - तो केवल बात करें - अनुवाद नहीं - इससे उसे सुरक्षित महसूस होगा (Lilian)

यह स्वतः ही स्पष्ट प्रतीत होता है कि जीवन के अंत के समय व्यक्ति जो देखभाल देता है या प्राप्त करता है वह करुणा, प्रेम और/या पारस्परिक सम्मान पर आधारित होनी चाहिए। विविध समुदायों के लोगों के लिए, संस्कृति उन संबंधों और अपनेपन का आधार प्रदान कर सकती है जो परिवारों और समुदायों की देखभाल को सुदृढ़ बनाती है। फिर भी, सांस्कृतिक रूप से विविध लोगों का जीवन के अंत समय की सेवाओं का अनुभव प्रायः ऐसा होता है जो उनकी विशिष्ट सांस्कृतिक आवश्यकताओं के संदर्भ में उन्हें समाज के हाशिये पर रखता है। परिणामस्वरूप, जीवन के अंत समय में देखभाल की गुणवत्ता में कमी होने का जोखिम रहता है। फिर भी, उच्च गुणवत्ता वाली सहायक और उपशामक देखभाल "सभी ऑस्ट्रेलियाई लोगों के लिए सुलभ होनी चाहिए" (स्वास्थ्य विभाग, 2018 - Department of Health, 2018)। इसके साथ ही, उपशामक देखभाल डेटा (उत्पादकता आयोग, 2017 - Productivity Commission, 2017) के संग्रह और रिपोर्टिंग में भिन्नता है। इसलिए हमें सांस्कृतिक रूप से विविध समुदायों से उनकी आवश्यकताओं और उन तरीकों के बारे में सीधे जानने की आवश्यकता है जिनसे सेवाएँ जीवन के अंत में सांस्कृतिक रूप से अधिक सुरक्षित देखभाल प्रदान कर सकती हैं।

सांस्कृतिक आवश्यकताओं का पता लगाना

सांस्कृतिक रूप से विविध समुदायों की परंपराओं, विश्वासों, प्रथाओं और आवश्यकताओं के बारे में सीखने और समझने के लिए अभी बहुत कुछ है। पश्चिमी सिडनी पर ध्यान केंद्रित करते हुए, हमारा शोध आदिवासी समुदाय और अरबी, मेंडेरिन और हिंदी भाषी समुदायों के सहयोग से किया गया था, जो पश्चिमी सिडनी स्थानीय स्वास्थ्य जिले में तीन सबसे बड़े भाषा समूहों का प्रतिनिधित्व करते हैं। हमारे उदार प्रतिभागियों ने हमें जीवन को सीमित करने वाली स्थिति के दौरान या जीवन को सीमित करने वाली किसी बीमारी का सामना कर रहे किसी व्यक्ति की देखभाल करने के अनुभव में शामिल कर लिया है। यह अवधि कई वर्षों, महीनों या कुछ छोटे सप्ताहों की हो सकती है। इस सामुदायिक पुस्तक में प्रतिभागियों के योगदान से पता चलता है कि विविध सांस्कृतिक समुदायों के लोगों के लिए क्या महत्वपूर्ण है, किस बात ने उनकी मदद की और दुःख और किसी को खोने की स्थिति में संस्कृति कैसे बनी रह सकती है और इसे कैसे बनाए रखा जा सकता है। महत्वपूर्ण रूप से, उनकी कहानियाँ लोगों की जीवन के अंत समय की आवश्यकताओं के बारे में हमारी समझ और यह समझने में योगदान देती हैं कि सेवा प्रदाता सांस्कृतिक रूप से सुरक्षित और उचित सेवाओं को बेहतर ढंग से प्रदान करने के लिए क्या कर सकते हैं।

आदिवासी या प्रवासी समुदायों के कई लोगों का अनुभव सामाजिक हाशिए पर रहने और अनदेखा किए जाने का होता है। जीवन के अंत समय की उनकी विशिष्ट आवश्यकताओं को शायद ही कभी पूरा किया जाता है। ऐसे समय में जब लोग विशेष रूप से अति संवेदनशील हो सकते हैं, इसके गंभीर प्रभाव हो सकते हैं जिनमें पुनः सदमा लगना भी शामिल है, । इस शोध में, हमने प्रतिभागियों द्वारा तैयार की गई तस्वीरों का उपयोग एक प्रारंभिक बिंदु के रूप में किया, और अधिक सीखने के लिए कि स्वास्थ्य सेवा प्रणाली और व्यापक समुदाय में क्या बातें काम करती हैं, जिससे जीवन के अंत समय में किसी की देखभाल करने वाले लोगों की सहायता की जा सके। संवेदनशील पूछताछ में चित्रों या तस्वीरों का उपयोग एक सहायक विधि हो सकती है (Paton et al 2018), जो उन्हें उन वार्तालापों को आरंभ करने के लिए एक सौम्य आधार प्रदान करती है जो कि उनके व्यक्तिगत स्वभाव के कारण उनके लिए कठिन हैं। जीवन के अंत समय में सांस्कृतिक आवश्यकताओं के बारे में अधिक समझने के लिए, हमने फोटोवॉयस (Wang & Burris 1997) नामक शोध पद्धति की ओर रुख किया। जब किसी मामले के बारे में बोलना मुश्किल हो तो

यह विधि संवाद करने के लिए चित्रों या तस्वीरों की शक्ति का उपयोग करती है और लोगों के लिए अपने अनुभव को सार्थक तरीके से प्रस्तुत करने के एक सशक्त साधन के रूप में सामने आ सकती है (Booth and Booth 2003)।

फोटोवॉयस अनुसंधान प्रतिभागियों की कहानियों और अनुभवों को दिखाने के लिए फोटोग्राफी का उपयोग करता है। यह विद्वानों और सार्वजनिक दोनों क्षेत्रों में हाशिये पर पड़ी आवाजों को बढ़ावा देता है, जिससे प्रतिभागियों को अपने समुदायों और व्यापक समाज में योगदान करने का एक ठोस अवसर मिलता है। फोटोवॉइस परियोजनाओं का लक्ष्य आमतौर पर निर्बल या हाशिए पर रहने वाले समूहों के लिए नीति या सेवा की पहुँच को प्रभावित करना है। यह निष्कर्षों का प्रसार, अक्सर फोटोग्राफिक प्रदर्शनों और/या प्रकाशनों के रूप में करता है जो सामुदायिक निर्माण पर सकारात्मक प्रभाव डाल सकते हैं और सामाजिक और सांस्कृतिक धरोहर में योगदान कर सकते हैं। *स्टोरीज़ ऑफ़ केयर (Stories of care)* सामुदायिक पुस्तक प्रतिभागियों को अपनी कहानियों को सार्वजनिक मंच पर पेश करने और विविध समुदायों में जीवन के अंत समय की आवश्यकताओं से जुड़ी समझ को विकसित करने में सामाजिक रूप से योगदान करने का अवसर प्रदान करती है। उनकी तस्वीरें और लिखित वर्णन हमें एक सांस्कृतिक लेंस प्रदान करते हैं जिसके माध्यम से हम देख और समझ सकते हैं कि जीवन के अंत समय में देखभाल के अनुभव में क्या बातें उपयोगी और सहायक हैं।

अपने शोध के उद्देश्यों और लक्ष्यों को पूरा करने के लिए, हमने फोटोवॉइस के उपयोग को उस संदर्भ में परिवर्तित किया जहाँ कोविड 19 लॉकडाउन ने हमें लोगों से आमने-सामने मिलने से रोक दिया था। परियोजना के इस भाग में सम्मिलित किए गए प्रतिभागियों ने तस्वीरें लेने के लिए अपने स्वयं के कैमरे या उपकरणों का उपयोग किया, जो दर्शाता था कि किसी व्यक्ति की जीवन के अंत समय वाली देखभाल के दौरान उनके लिए क्या बातें उपयोगी या सार्थक थीं। कभी-कभी तस्वीरें लेना चुनौतीपूर्ण होता था और जब लोगों के चलने फिरने का सामर्थ्य सीमित था और इस कारण से फोटोग्राफिक विषयों के विकल्प भी सीमित थे, तो इसमें कोविड 19 का संदर्भ भी जुड़ गया। हमने सुझाव दिया कि लोग फोटोवॉइस साक्षात्कार के लिए मौजूदा तस्वीरों को चुनने पर भी विचार कर सकते हैं। नई तस्वीरें लेने या मौजूदा तस्वीरों को चुनने की प्रक्रिया में, प्रतिभागी के जीवन की यादों को एक बार फिर से देखने और रिश्ते-नाते बनाने या उसे पुनर्स्थापित करने में सक्षम हो सके, दृष्टिगत रूप से यह व्यक्त कर सके कि उनके लिए क्या सार्थक था और क्या महत्वपूर्ण था। इसने प्रतिभागियों के द्वारा की गई जीवन के अंत समय की देखभाल के बारे में साक्षात्कार के लिए आधार स्थापित किया, जिसमें उस अनुभव के पहले से अनछुए पहलू भी शामिल थे (McIntyre 2003)।

कुछ विशिष्ट प्रतिभागियों के साथ अर्ध-संरचित साक्षात्कार जूम (Zoom) का उपयोग करके ऑनलाइन किए गए। आवश्यकतानुसार, पंद्रह फोटोवॉइस प्रतिभागियों में से पाँच के अनुवाद के लिए एक सहायक व्यक्ति उनके साक्षात्कार में शामिल हुआ। चर्चा प्रतिभागियों द्वारा के जीवन के अंत समय में की जाने वाली देखभाल के समय हुए उनके अनुभव पर केंद्रित थी, जो उनके द्वारा ली गई या साक्षात्कार के लिए उनके द्वारा चुनी गई तस्वीरों के चयन पर आधारित थी। इन वार्तालापों को, प्रतिभागियों को परियोजना से संबन्धित जो जानकारी पहले से दी गई थी उसके आधार पर बनाए गए बहुत सारे संकेतों के माध्यम से निर्देशित किया गया था। इस प्रक्रिया ने हमें यह समझने में सक्षम बनाया कि प्रतिभागियों की देखभाल की यात्रा में उनके दृष्टिकोण से क्या बातें सहायक थीं (या नहीं थीं)। फिर प्रतिभागियों को सामुदायिक पुस्तक में शामिल करने के लिए तस्वीरें चुनने और कुछ और जोड़ने के लिए आमंत्रित किया गया जिसे वे विशेष रूप से अपने एक-पृष्ठ की सारांश कथा में प्रतिबिंबित करना चाहते थे। अनुमति के साथ, व्यक्तिगत साक्षात्कार का ऑडियो रिकॉर्ड किया गया और बाद में उसका प्रतिलेखन (transcribe) किया गया। इन प्रतिलेखनों ने सामुदायिक पुस्तक कहानियों के लिए एक समृद्ध आधार प्रदान किया, जिन्हें प्रत्येक प्रतिभागी के सहयोग तैयार किया गया था।

कहानियाँ जो मायने रखती हैं

इस परियोजना को दी गई तस्वीरें उन लोगों के अनुभवों को ध्यान में लाती हैं जो समाज के हाशिए पर हैं और परिणामस्वरूप अक्सर अपनी आवाज़ उठाने में सक्षम नहीं होते हैं। *स्टोरीज़ ऑफ़ केयर (Stories of Care)* पुस्तक में मौजूद तस्वीरें और कथाएँ समुदाय के उन सदस्यों के लिए एक संसाधन प्रदान करती हैं जो वर्तमान या शायद भविष्य में, जीवन के अंत समय में किसी की देखभाल करेंगे। वे हमें बताती हैं कि ऐसे समय में लोगों के लिए क्या बातें मायने रखती हैं, और वे लोगों द्वारा अनुभव की जा सकने वाली कुछ चुनौतियों की ओर ध्यान दिलाते हैं। यह पुस्तक उत्थान शक्ति और संसाधनपूर्ण होने की कहानियाँ भी पेश करती है जो प्रेरणादायक हैं, खासकर उन संदर्भों में जहाँ जीवन के अंत समय में सांस्कृतिक आवश्यकताओं को अनदेखा कर दिया गया है या खारिज कर दिया गया है। यह पुस्तक स्वास्थ्य क्षेत्र में काम करने वाले उन लोगों के लिए एक संसाधन है जो सांस्कृतिक रूप से सुरक्षित सेवा प्रदान करने की परवाह करते हैं (या उन्हें इसकी परवाह करना चाहिए)। सेवा प्रदाताओं की विश्वास और संबंध बनाने की क्षमता, जीवन के अंत समय की देखभाल को सांस्कृतिक रूप से उपयुक्त ढंग से किए जाने के लिए मूलभूत है। संस्कृति, संबंध और किसी से जुड़े होने, ये सभी विषय विश्वास उत्पन्न करने के लिए आवश्यक हैं, ये सभी पुस्तक में शामिल कहानियाँ और तस्वीरों में दृढ़ता से प्रतिबिंबित होते हैं।

पारिवारिक, सामाजिक और सामुदायिक संबंध सभी लोगों द्वारा और उनकी भलाई के लिए महत्वपूर्ण माने जाते हैं। सहायक सेवाओं के साथ दृढ़ संबंधों को दर्शाने वाली कहानियों में सेवा प्रदाताओं के साथ बनाई गई जान पहचान भी केंद्र बिंदु होते हैं: *उन्होंने हमारे परिवार के लिए बहुत कुछ किया... और वे अभी भी एक बड़ा सहारा हैं, यहाँ तक कि अब भी (Shanna)*। दुःख की बात है कि इनमें निराशा की भी कहानियाँ हैं: *परिवार*

के सदस्यों को अनदेखा न करें। यह सिर्फ आपके और मरीज़ के बीच की बात नहीं है...वह कोई ऐसा है जिसे वे प्यार करते हैं। परिवार को उनके पास रहने दें, यह बहुत महत्वपूर्ण है (Marine)। प्रकृति से जुड़ाव बार-बार सामने आने वाला एक विषय है, यह अक्सर आराम करने के लिए कोई जगह होती है या किसी सकारात्मक चीज़ का प्रतीक होता है, जैसे कि सूर्योदय: हर दिन एक नया दिन है और उम्मीद है कि चीज़ें बेहतर हो जाएंगी (Urvashi); या किसी पुराने पेड़ का नए सिरे से उगना: यह हरा है। जीवन, इसे बढ़ना चाहिए। यह फ़ोटो आज भी जीवनादायी है (Amira)। आध्यात्मिकता, आस्था के महत्व, सांस्कृतिक परंपराओं और प्रथाओं का संकेत देने वाली कहानियाँ भी हैं। यद्यपि ये बातें लोगों की पहचान का केंद्र बिंदु हैं पर सेवा के सन्दर्भ में हमेशा इनके लिए स्थान नहीं था: उसके पास प्रार्थना करने के लिए उचित स्थान नहीं था...इसलिए इस बात ने उसे रोक दिया। सांस्कृतिक रूप से...उसे...अलग-थलग महसूस हुआ (Khwaja)।

किसी व्यक्ति की सांस्कृतिक पहचान, जुड़े होने की और स्वीकृति की भावना के लिए विविध प्रकार के संपर्क प्रत्यक्ष रूप से महत्वपूर्ण होते हैं। जब ये संपर्क जीवन का अंत आते आते खो जाते हैं, तो लोग अलग-थलग पड़ सकते हैं और समुदाय और सेवा प्रदाताओं के बीच इन संपर्कों की आवश्यकता और भी बढ़ जाती है। अलगाव दुःख को बढ़ा सकता है, जो जटिल दुःख की अवधि को और लंबा कर सकता है और लोगों को अपने समुदाय और ऐसी सेवाओं से और भी दूर कर सकता है जो उनकी मदद कर सकते थे। मानसिक स्वास्थ्य समस्याओं के विकास में सामाजिक अलगाव एक प्रमुख कारण है (Neilson et al 2015:1)। गहरे दुःख में सहायता की आवश्यकता उपशामक देखभाल के सफ़र से ही शुरू हो जाती है, न कि केवल उस समय जब किसी को खो देने का दुःख हो। मृत्यु से बहुत पहले ही 'खो देने का अहसास' होने लगता है। खो देने का अहसास निदान के क्षण से ही शुरू हो जाता है, उपचार के विभिन्न चरणों में जारी रहता है और फिर से उस समय पर भी जब उपचार कोई सहायता नहीं कर सकता है। इन सभी चरणों के दौरान सहायता प्राप्त और परामर्श तक पहुँच होने की आवश्यकता होती है: ... वहाँ कोई होना चाहिए जो ऐसे संपर्क को स्थापित कर सके। करुणा, ज्ञान और अनुभव रखने वाला कोई व्यक्ति जो जीवन के अंत होने तक के परिवर्तन काल को समझ सके, उस व्यक्ति के साथ-साथ, उसके परिवार की भी सहायता करने के लिए। (Ann)।

जीवन के अंतकाल में किसी की देखभाल करते समय, उनकी और खुद की देखभाल दोनों एक-दूसरे के साथ-साथ चलते हैं। जीवन के अंत समय में सेवाओं के सहानुभूतिपूर्वक रूप से प्रदान करने के लिए स्व-देखभाल अभ्यास महत्वपूर्ण है (Mills et al 2018) और परिवार की देखभाल करने वालों के लिए भी कम महत्वपूर्ण नहीं हैं: मुझे यह सुनिश्चित करना था कि उस दौरान मेरे पास मेरे लिए समय हो (Anon)। रचनात्मक क्रियाएँ कई प्रतिभागियों की स्व-देखभाल गतिविधियों का एक सामान्य साधन थीं। उदाहरण के लिए, कला निर्माण, फ़ोटोग्राफी, नृत्य, संगीत और गायन, सभी व्यक्तिगत रूप से या अपने प्रियजन या सामाजिक समूह के साथ किए गए थे। इस तरह की क्रियाएँ आत्म-अभिव्यक्ति और आत्म-देखभाल का एक साधन प्रदान करती हैं, जिससे परेशानी के समय में मदद मिलती है। रचनात्मक कलाओं में संलग्न होना स्व-कल्याण के लिए लाभकारी हो सकता है, जिसमें ध्यान केन्द्रित करने की क्षमता में बढ़ोतरी, शिथिलता और तनाव, अवसाद और चिंता में कमी आना शामिल हैं (Hass-Cohen & Carr 2008:15)। रचनात्मक गतिविधि रिश्तों और सामाजिक संबंधों के निर्माण का एक तरीका भी हो सकती है, जो भारी दुख और व्यथा की अलग-थलग करने वाली प्रवृत्तियों को दूर करती है (Neilson et al 2015:1): यह दवा है, लेकिन दवा से भी बेहतर है! (Anna)

कलाकारों की सामाजिक भूमिका की ही तरह, इस सामुदायिक पुस्तक के योगदानकर्ताओं ने "आम जीवन की वस्तुओं को... मार्मिक और महत्वपूर्ण" बनाया है (Dewey 1934:118)। तस्वीरें लोगों और उनके जीवन की लय से जुड़ी "कहानी से भरपूर" हैं (Dewey 1934:344)। प्रत्येक तस्वीर में अलग-अलग दुनियाओं को जोड़ने, अनुभव के नए क्षेत्रों को खोलने या परिचित दृश्यों में नए गुणों को प्रकट करने की क्षमता है (Dewey 1934:144)। सामूहिक रूप से, तस्वीरें और कहानियाँ पश्चिमी सिडनी क्षेत्र में और उससे परे, इस बारे में जागरूकता पैदा करती हैं कि कैसे लोग विभिन्न सांस्कृतिक दृष्टिकोणों से जीवन के अंत समय की समस्याओं का अनुभव कर रहे हैं। ऐसा कर के, वे और अधिक सामाजिक और संस्थागत समझ की संभावना को जन्म देते हैं, जिससे प्रतिभागियों को उम्मीद मिलती है कि उनकी कहानियाँ उनके समुदायों को भविष्य में मिलने वाली सेवाओं के वितरण में अंतर पैदा करेंगी। उन्होंने उन परिस्थितियों में बहादुरी और उत्थान शक्ति प्रदर्शित की है जो हमेशा भी नहीं, शायद दुर्लभ ही, उनके समुदायों और परंपराओं की विशिष्ट सांस्कृतिक आवश्यकताओं को पूरा करती है।

स्टोरीज़ ऑफ़ केयर (Stories of Care) के योगदानकर्ताओं ने व्यक्तिगत और अक्सर भावनात्मक बातें साझा करने में उदारता दिखाई है। इन पन्नों में दर्ज की गई कहानियाँ दिल और आत्मा से आती हैं। वे जीवन के अंत समय में विशिष्ट सांस्कृतिक आवश्यकताओं वाले लोगों के लिए व्यवस्था परिवर्तन की आशा भी रखती हैं। यह सामुदायिक पुस्तक, प्रतिभागियों को आवाज़ और प्रत्यक्षता प्रदान करते हुए, उन्हें देखभाल के अपने अनुभवों के बारे में बड़े रूप से बयान देने का एक बहुत ही ठोस अवसर प्रदान करती है। इसके बाद, ऐसे सार्वजनिक मंच पर उन अनुभवों को चित्रित करने की इच्छा रखना एक बहुत ही साहसपूर्वक बात है। उनकी तस्वीरें और कहानियाँ जीवन के अंत समय में सांस्कृतिक आवश्यकताओं के बारे में हमारी समझ को समृद्ध करने का काम कर रही हैं। अनुसंधान परियोजना और सामुदायिक पुस्तक में अपनी भागीदारी के माध्यम से, प्रतिभागी उन रिश्तों, मूल्यों और प्रथाओं के बारे में ज्ञान स्थापित करने में मदद कर रहे हैं जो जीवन के अंत में लोगों और उनकी देखभाल करने

वाले परिवारों की संभाल करते हैं। सबसे महत्वपूर्ण बात यह है कि उन्होंने हमें अपनी रोज़मर्रा की कहानियों में प्रवेश करने, हम जो देखते हैं उस पर विचार करने और उस अनुभव से खुद को बदलने का अवसर दिया है।

在关怀中：临终关怀的文化与联系

“他们对我们都非常好。很大一部分与联系、文化以及他们给予的关怀有关……彼此互相尊重” (Vanessa)。

“他们做得很好，但在联系上有一些不好的地方。如果[他们]能够与她交谈 – 只是交谈 – 而不是翻译，这会让她感到安全” (Lilian)。

在临终关怀过程中，给予或接受的关怀应该以同情、爱和/或相互尊重为基础，这似乎是不言而喻的。对于来自不同社区的人来说，文化可以为联系和归属感提供基础，这是家庭和社区关怀的基础。然而，文化多样性群体对于临终关怀服务的经历往往使他们在满足其特定文化需求方面处于边缘位置。因此，临终关怀的质量面临被削弱的风险。然而，高质量的支持性与临终关怀“应该是所有澳大利亚人都可获得的”（卫生部，2018年）。与此同时，关于临终关怀数据的收集和报告存在不一致性（生产力委员会，2017年）。因此，我们需要直接听取来自文化多样性社区的声音，了解他们的需求，以及了解服务机构可以如何提供更具文化安全性的临终关怀服务。

探索文化需求

有关文化多样性社区的传统、信仰、习俗和需求，还有很多东西需要学习和了解。我们的研究侧重于悉尼西部地区，并与原住民社区以及阿拉伯语、普通话和印地语社区合作进行了研究，这些群体代表了西悉尼地方卫生区最大的三个语言群体。这些慷慨的参与者让我们深入了解了照顾患有使人寿命有限疾病的人，或患者在此期间的经历。这段时间可能跨越几年、几个月或只是短短几周。参与者在这本社区图书中的贡献揭示了来自不同文化社区的人们所关注的重点，对他们有所帮助的事物，以及在悲伤和丧亲时文化如何维系和被维系。重要的是，他们的故事有助于我们理解人们在临终阶段的需求，以及服务提供者可能采取什么措施来更好地提供具有文化安全性和适当的服务。

许多原住民或移民社区的人们的经历被社会边缘化和被忽视。他们在临终阶段的特定需求很少得到满足。这可能会产生严重的影响，包括人们在特别脆弱的时候再次遭受创伤。在这研究项目中，我们使用了参与者提供的照片作为出发点，以进一步了解医疗服务系统和广泛社区向提供临终关怀的人所提供的哪些支持服务对他们有帮助。视觉图像对于敏感议题的研究方面可能是个有用的研究方法 (Paton et al 2018)，为进入因非常个人化而难以进行的对话提供了温和的基础。为了更好地了解临终阶段的文化需求，我们采用了一种称为照片之声 (photovoice) 的研究方法 (Wang 和 Burris 1997)。这种方法利用摄影的力量，在事情难以开口用言语描述时进行沟通，可以成为人们以有意义的方式表达他们的经历的一种有效手段 (Booth 和 Booth 2003)。

照片之声利用摄影来展示研究参与者的故事和经历。照片之声在学术界和公众领域中让更多人听到了被边缘化的声音，为参与者提供了能为他们的社区和更广泛的社会做出具体贡献的机会。照片之声项目通常旨在影响针对弱势或边缘化群体的政策或服务供应。照片之声项目经常以摄影展览和/或出版物的形式传播研究结果，这对社区建设具有积极影响，并有助于社会和文化资本的积累。《关怀故事》这一社区图书为参与者提供了一个机会，在公共论坛中展示他们的故事，并在社会上为发展与多元社区的临终需求相关的理解做出贡献。他们的照片和文字叙述为我们提供了一个文化视角，通过这个视角我们可以看到和理解在临终关怀的经历中什么是有益和支持性的。

为了实现我们研究的目标和目的，COVID-19 的封锁限制使我们无法与人们面对面交流，因此我们对照片之声的使用进行了修改。为项目的这部分招募的参与者使用他们自己的相机或设备拍摄照片，这些照片代表了在照料临终人士期间对他们有帮助或有意义的事物。有时要拍摄照片相当不容易，COVID-19 的环境又使人们的行动受到限制，因此对摄影对象的选择也受到限制。我们建议人们也可以考虑选择现有的照片用于照片之声的访谈。在拍摄新照片或选择现有照片的过程中，参与者能够回顾生活中的片段，建立或重建联系，并通过视觉方式表达对他们来说有意义和重要的事物。这为关于参与者临终关怀的访谈奠定了基础，包括以前对临终关怀照顾未曾进行探索过的方面 (McIntyre 2003)。

与个别参与者进行的半结构化访谈是通过Zoom在线进行的。在15名照片之声参与者中，有五人在访谈时由支持人员陪同出席进行翻译。讨论的内容主要围绕着参与者在提供临终关怀方面的经历，由他们为访谈拍摄的或选择的照片作为讨论话题加以进行提示。此外，讨论的内容也根据之前向参与者提供的项目信息作为提示进行引导。这个过程使我们能够从参与者的角度了解在他们的关怀历程中哪些是有帮助和具有支持性的（或者哪些是没有帮助和不具支持性的）。然后，

参与者被邀请选择将要加入社区图书中的照片，并进一步补充任何他们特别希望刊登在一页总结叙述中的内容。每次访谈都在征求了参与者的同意后进行了录音，并随后转录成文本。这些转录文本为社区图书的故事提供了丰富的基础，这些故事是与每个参与者合作编写的。

重要的故事

这个项目中提供的图片聚焦于那些被边缘化并经常成为“无声”的人的经历。《关怀故事》一书中的照片和叙述为现在或将来可能照顾临终者的社区成员提供了资源。他们告诉我们，在这样的时刻，什么对人们来说是重要的，他们让我们注意到人们可能经历的一些挑战。该书还提供了一些坚韧不拔和智慧的故事以鼓舞人心，特别是临终阶段的文化需求往往都是被忽视或被拒绝考虑的。这本书对于关心（或应该关心）文化安全服务提供的医疗部门的工作人员来说是一项资源。服务提供者建立信任和连接的能力是提供符合文化需求的临终关怀的基础。文化、联系和归属感等主题对于信任的建立至关重要，而这些主题在书中包含的故事和照片中得到了很好的体现。

家庭、社交和社区联系对人们及其福祉都非常重要。与服务提供者的联系也是核心所在，故事反映了参与者与支持性服务建立了牢固的关系：“他们为我们的家庭做了很多事情...即使现在，他们仍然是巨大的支持”（Shanna）。不幸的是，也有一些令人失望的故事：“不要忽视家庭成员。这不仅仅是你和病人之间的问题...那是他们所爱的人。让家人靠近他们，这非常重要”（Marine）。与自然界的联系是一个反复出现的主题，参与者常常表示大自然是一个能让他们放松的空间，或者大自然也往往象征积极的事物，比如日出：“每一天都是新的一天，希望事情会变得更好”（Urvashi）；或者是在一棵老树上冒出的新芽：“它是绿色的。生命，它应该生长。这张照片仍然有生命力”（Amira）。还有一些故事表明了宗教信仰、文化传统和习俗的重要性。尽管这些对人们的身份认同至关重要，但在服务环境中并不总是有足够的空间容纳这些元素：“他没有一个适当的地方可以祈祷...所以这阻止了他。在文化上...他感到...被孤立”（Khwaja）。

各种各样的联系显然对一个人的文化身份以及归属感和接受度非常重要。当人在生命末期失去这些联系时，人们会变得孤立无援，对社区和服务提供者联系的需求也会加大。孤立会加剧悲痛，导致长期的复杂悲痛，并使人们进一步与他们的社区和/或可能提供帮助的服务机构隔离开来。社交孤立是心理健康问题发展的关键因素（Neilson et al 2015:1）。对悲伤支持的需求始于姑息治疗旅程的开始，而不仅仅是在丧亲之时。在亲人去世之前，早已有所“失去”了。“失去”从诊断的那一刻开始，在治疗的各个阶段仍持续发生，治疗不再有帮助时仍旧持续“失去”。在所有这些阶段都需要支持和获得咨询：“...应该有人在那里建立这种联系。应该有一个具有同情心、智慧和经验的人，一个了解过渡到生命终结的过程的人来支持患者和家人”（Ann）。

在照顾临终的人时，关怀和自我关怀是相互并存的。自我关怀的做法对于在临终阶段提供富有同情心的服务至关重要（Mills et al 2018），对于家庭照顾者同样至关重要：“在那段时间，我必须确保给自己留出时间”（Anon）。创意艺术活动是许多参与者自我关怀活动的一个共同点。例如：艺术创作、摄影、舞蹈、音乐和唱歌，都是他们个人或与所爱之人或社会团体一起进行的活动。这种做法提供了一种自我表达和自我关怀的方式，在痛苦的时候会有所帮助。参与创意艺术活动可以为心理健康提供好处，包括提高注意力、放松身心、缓解压力、抑郁和焦虑（Hass-Cohen & Carr 2008:15）。创意活动还可以成为建立人际关系和社交联系的方式，抵消压倒性的悲伤和悲痛带来的孤立倾向（Neilson et al 2015:1）：“这是一种药物，但它比药物更好！”（Anna）

就像艺术家在社会中的角色一样，这本社区图书的作者们使“普通生活的对象...变得凄美而重要”（Dewey 1934:118）。这些照片“充满了故事”，与人们和他们生活的节奏相关（Dewey 1934:344）。每张图片都有可能连接不同的世界，开辟新的体验领域，或者在熟悉的场景中展现新的特质（Dewey 1934:144）。总的来说，这些照片和故事在西悉尼地区和其他地区引起了人们对人们如何从不同的文化角度来体验临终阶段问题的认识。在这个过程中，他们为社会和机构间的理解创造了更大的潜力，使参与者对于他们的故事能够对未来为他们的社区提供服务产生影响带来了希望。他们在并不总是（或许很少）完全满足他们的社区和传统的特定文化需求的环境中，表现了勇敢和坚韧。

《关怀故事》的作者们慷慨地分享了他们个人的、往往是带有情感的材料。这些故事都是发自内心，触及灵魂的。他们也为在临终阶段有特殊文化需求的人带来了系统变革的希望。这本社区图书让参与者有了发言权和可见性，为他们提供了一个非常切实的机会，让他们对自己的关怀经历做出重要的陈述。而他们愿意在这样一个公共论坛上展示这些经历，也需要极大的勇气。他们的照片和故事丰富了我们对于临终时文化需求的理解。通过参与研究项目和社区图书，参与者正在帮助建立有关关系、价值和做法的知识，这些关系、价值和做法可以在生命末期支持人们和照顾他们的家庭。最重要的是，他们给予我们所有人进入他们日常故事的机会，反思我们所看到的，并因此而改变。

Aboriginal, Arabic, Hindi and Mandarin Cultural Stories

(Alias chosen by research participants)

القصة الثقافية

(أسماء مستعارة اختارها المشاركون بالبحث)

सांस्कृतिक कहानियाँ

(कल्पित नाम अनुसंधान प्रतिभागियों द्वारा चुने गए हैं)

文化故事

(别名均由研究参与者自己选定)



Going to another place

Ann's Story
Cultural identity: Aboriginal

I'd like to start with the bottlebrush. I picked that as my symbol because it will take me back into my history - I'm Mununjali - Beaudesert mob. I can tell you my whole story, my whole family background, where I come from. When I look at it, I remember. I remember the way things are. I've got two of those bottlebrush trees in my backyard...so when I look at them...that's the connection I have to my family. Some people have photographs and things like that. Not me because we never owned a camera.

When I was going there...at palliative care...the garden was nice but there could be other things to brighten up the place, you know - the flowers. I'm mad about flowers. It could be a symbol - it could be a red bottlebrush that an Aboriginal person can recognise. Or somebody from overseas like my husband, he was Maltese, came here to Australia when he was seven. I think maybe an olive tree or something like that. To look out - like a sanctuary garden. If they go out the back on that back verandah - they can sit down and they can see things.

That photo represents when you feel like everything is on you - like there's a storm coming. Like things are pressing in on you. Yes, that time wasn't easy. I think my husband was going into denial - he couldn't believe it was happening to him. He didn't like talking about his emotions...he used to go out in the front porch and sit down. He wasn't a man for his emotion, he was a very private man. It wasn't easy. For me, I think that I withdrew inside myself. I think I went into shock. I went into shock in those days - not withdrawal, how would you put it, I just sort of coped with it. You cope with it, but you're in a daze.

That's when I think everybody needs support - during that transition period, there should be somebody there to make that contact. Someone with compassion, wisdom and experience who understands the transition to the end of life, to support the person, as well as the family. Not give them a card and say, 'If you need anything ring me'. No. I think it's very important that they form that relationship with the person. Be with that person all the way through their stages, because this is a big thing for somebody to go through: 'Oh you're going to pass over'. You've got to look at their spiritual wellbeing to help them too.

If they could have come in from the beginning when he was diagnosed, made contact, even now and again ring up and say, 'Oh Auntie I'll come around to have a cup of tea with you' or something like that - then that would be good. Go through the stages until he passed away - stage by stage leading up to that. Yes, yes. It's very, very important.

That's the moon - I like that because the moon is spiritual for me. The photo of the moon brings up the bible verse that says, 'Be still and know that I am God'. I like that. I look at the moon and say prayers for people, many times. Sometimes you get lonely, and I find that's very comforting. Yes, I like that very much.

I think for my husband, because he was Catholic, a priest or somebody could have come along and said prayers with him. Come along and talked to him and said, 'I'll say a prayer for you'. I prayed for him for the end. I prayed, 'Our Father, Hail Mary and Glory be', and that was comforting for him. That was comforting - that was to help him on his end-of-life journey. And I would like to hear that for myself when I'm passing.

That's where my husband's ashes were scattered [beach]. And it's peaceful. It was important to him because he came by boat - and I asked him, and he said he wanted to be cremated and his ashes scattered. He came by boat so that would be a nice place to scatter his ashes. The red geraniums I've got growing in the garden. And that was his favourite - he liked the geraniums. I like a bible verse to that one, too: 'Blessed are those who mourn because they shall be comforted'.

Sunrise is a special beautiful time for me as it reminds me to keep on moving forward. Every day you're moving forward, you move forward. You can't look back on some things - you've got to keep moving forward.

It's a new day.



No regrets... The story of mine and my Dad's journey

Anonymous
Cultural identity: Aboriginal

We were told in the February that Dad wasn't going to last for more than three to six months. A few years before that he had had bowel surgery. After that he never gained weight, never sort of got back to 100%. I used to say, 'I still think you've got cancer Dad'. And then when COVID started, he kept on saying, 'No I've just got COVID. Yeah, I've got COVID.' But when they finally did run a heap of tests...cancer was through his whole body.

It was a long journey, but the palliative care place is awesome. They sort of became family. I was there every day. I was just a regular. They were welcoming – they'd share how he was. Even if I was there to do things for him, they were still happy to do things for him, too. I always knew in the night-time Nicole (Aboriginal Palliative worker) would be there. 'Cos I'd been there most of the day, so I knew she always went to check on him before she went home. It was really nice.

I was happy that Dad went to palliative care because he wanted to die at home but Mum wasn't able to give him the care he needed. When it was getting close and he was in that delirious stage...he said, 'Come on! You've got to take me home. You've got to take me to your house. I just want to die on your lounge'. I said, 'Sorry Dad the dog's there. The dog'll jump all over you'. He said, 'I don't care, I like the dog', but he didn't, he hated the dog.

It was probably only a week before he passed away. It was in the middle of the night and I thought, I really don't know that much about my Dad. Just general things like, what's his favourite colour, his favourite food. So that was it. I sat up in bed and I just started writing lists of his favourite music, his favourite plants, everything that I could. And then I got there the next morning, ready for breakfast with him and I said, 'Right. We're doing an activity today'. And he was like, 'What the hell?' I said, 'I need to know some of your favourite things'. I found out one of his favourite smells is fresh compost! He worked on the council. Maybe that's where he got the compost smell from. So, it's all little things. Like his favourite plant was a hibiscus, so at Christmas time I was given a hibiscus as a gift – my Dad's plant. And things like the compost – I've got a compost maker now.

My chiminea. That was my happy place. I would just sit in front of the fire, drink my coffee, try and ignore the dog 'cos she'd be trying to get me to come back inside – and just keep putting more wood on the fire. My own little getaway. It could be three o'clock in the afternoon and I'd already have a fire cranking. It just takes your mind off things...gave me something else to think about. I had to make sure I had time for me during that period.

That was a love heart in a gumtree at palliative care. It's beautiful. I'd say when the tree was little somebody just carved it in there. It was my happy place out in the courtyard. I used to go out there, I used to be upset then I'd turn and look at that love heart and I'd be like, 'OK I'm right again now. I can go back inside'. Even though you can't see it very well, but when somebody's sick sometimes you've just got to look for other things that make you happy. And it might be the tiniest little thing.

That's my Dad. From the first day he went into palliative care, it became my screensaver on my phone. And just every time I looked at him when he was looking quite sickly or very thin, I'd always look at my phone and remember what he used to look like. That's the photo that we put on his coffin too. And the photo I've got in my house. As soon as I walk in the front door, I see him and there's a salt lamp behind it so it sort of glows. Looks like a bit of an angel. Every morning I wake up and I turn the salt lamp on and I say, 'Good morning Dad'. At night I hear my partner turn it off, and he says 'Goodnight'.

[Nicole] had been there through basically the whole time. It was just like another family member was there really. The nurses they're doing their nursing part you know...whereas just having Nicole there for that support, I think it would have been very different if we didn't have her. You just feel you're not doing it alone...it's just nice to know that you've got somebody there on your side. It's not **just** the fact she's Aboriginal – you know what I mean...it's not all about doing that *tick-a-box I'm here, I've done my part*. It's more Nicole's brought herself into our family – she was there.

If I can give one piece of advice it's no regrets, say and do what you need to do so that when the end comes you have no regrets.



An amazing gift

Shanna's Story
Cultural identity: Aboriginal

During Dolly's life I went and I lived in Coffs Harbour...right near the beach. I found the beach really therapeutic – it was just a bit of a space – getting into nature where I could unwind.

I took her and I put her feet in the sand, and I put her legs in the water. For me, that photo actually represents her footprints in our lives. There's a saying, you know, that some people come into our lives and leave quickly, and some people come and leave footprints across our hearts. And that's it. That was definitely it for Doll. The dragonflies represent Dolly's condition that she had. The back of her brain was actually the shape of a dragonfly. So, it's a symbol for her condition. Pontocerebellar hypoplasia.

Bear Cottage were fabulous – they did heaps for our family. For Dolly and her siblings as well and they're still a great support, even now. I think things could have been very different without them to be honest. And then Westmead Children's Hospital cared for Dolly...they were fantastic through her life. I was very fortunate to have some great consultants work with her. They were just very down to earth, and they were very good doctors, and they were genuine.

I started studying biomedical subjects...when Dolly was about three. I started studying things that she was impacted by...I wanted to be able to hold conversations with her specialists because there was a lot of people that I felt were making decisions and I was unaware of what those decisions actually were – so I wanted to be a part of that decision making. I got into Medical School this year. I feel like my journey's part of her legacy. So, kind of wanting to honour her in how I live my life, and this is my way of doing that. Knowing that it doesn't heal or take away my grief or my loss, but it gives me the capacity to help others.

The picture there of two little Aboriginal dolls was to represent the culture. I didn't know how else to do it but they're Dolly's dolls. I called them Sun and Moon because there's a story about the sun and moon I've always heard – that they're two lovers that never meet...they only ever meet when there's an eclipse. Our culture was very important to me – and it still is very important. The photo was to speak to the community as well – the dolls represent something bigger.

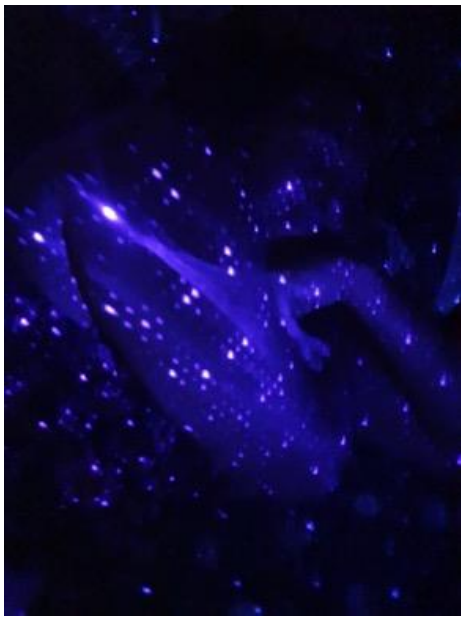
Myself and Dolly's Dad are both Aboriginal and were both community workers at the time. We were known and Dolly was known in the community, and I did feel that the community tried to support us where they could – which was nice because it was obviously a really difficult and challenging time for our family. And Dolly deserved that too. She deserved to be acknowledged and our community did that so well.

So, part of what was done was like a bit of a bucket list...just knowing that we didn't have a long time. Something that was on Dolly's bucket list was to do a sunrise with her. I got Dolly and I put her in the pram and if you haven't been to Bear Cottage, there's a really big f'ing hill! And I'm running down the hill, poor Dolly – she'd just had surgery: 'Got to go see a sunrise Doll!' She just put up with anything – God bless her. She was such a tolerant little girl. She was amazing. So, I rush her down to the beach and me and Doll did our first sunrise together. So, sunrises are very special, even now.

I also took her home to Country – I took her to Lightning Ridge and her Dad took her to Brewarrina, and I was meant to take her to Manilla just outside of Tamworth. But we were never able to make it there. I was going to take her to my Grandmother's grave too because she was named after my Grandmother, but funnily enough she died on the same day as my nan – nine years later. I just think Nan came and got her. We're very spiritual people – Aboriginal people – so those things are significant and do mean something more.

But I think I always knew to be honest. Even when she was little. Because I always knew I'd lose a child – I had a feeling. When she was born, I knew that she was that child. Strange but that's true. Sometimes you know.

Dolly was an amazing gift to me and to my family. I'm forever grateful for her. She's a beautiful, beautiful chapter of my life that I got to have. I'm proud to be her Mum. She was amazing. Special needs kids – there's something about them – they just love completely. They bring an amazing, amazing gift to the world. And she got to be ours.



He's up there watching over us

Vanessa's Story
Cultural identity: Aboriginal

My Grandchildren - they talk about their Pop and yeah...we let them know he's up there watching over us. He was always Pop. The kids took the photo of the moon - we stood out here and they took it - that was on my verandah. They've always known they've had a connection with their Pop. Even now when they go out at night, they all look up in the sky 'cos the moon is on the other side now, it's not off the verandah. Just to keep the Dreamtime alive, you know.

This one is like the flag - the sun and the ocean - the Aboriginal flag. I didn't take that one, but I chose it. My husband was very big on culture, so we wanted to have this one, given that it looks like the flag.

Water was always a part of our culture. He was always trying to teach the kids, you know, that water is important. He would say, 'Don't throw anything in there - things that weren't meant to be in there'. He would tell the kids to always cherish the water. Always respect the land. Preserve everything - preserve what we've got left. Yeah, that's right. He's made a mark. He has. He did a lot of culture and heritage stuff in the community. I've always - well both of us - always kept our culture. Told the kids about the culture. My language is Gamilaroi.

One night, we were laying in the room and the boys had a laser light. One is nine and the other one is turning eight soon. They were shining it up there [on the ceiling] and then they said, 'Oh look there's the stars Nan, what Pop always talked about at home'. That was because we've got a lot of stars in the sky back in Walgett. He always talked about back home with all the stars in the sky - to the kids. So, with that photo - the stars - we can remember Pop by that...it's about the Dreaming.

That was in the morning. Early morning when we were up getting ready for school. The kids were like, 'Let's take a photo of all that fog. Would Pop walk through the fog?' He'd always talk about trees to them; talk about the land and everything. Yep. The trees and grass when we were driving with the boys in the back. Yeah, the connection to the land. So yes, trees - represents culture again - the root style - roots into the ground, connection to the land.

He really wanted to go home to Country, but we just couldn't leave at the time given it was COVID then. There were a lot of restrictions, and he really didn't want to pass away at that time. He kept saying, 'I can't pass away because there wouldn't be many people coming to my funeral'. And I said, 'Don't worry about who's going to come to your funeral. You don't really need to be worried about any of that'.

I think he really wanted to go home. Well, he was a very strong person so he would have tried to get home. Like he really wanted to come back and live there but like at the time I said to him, 'Look we can get another bed put in. We'll bring you home'. Aboriginal people prefer to die out [on country] ...but he knew that we couldn't make it home. He had to be in palliative care, given his condition at the time.

The [team] did what they could, and they made his end-of-life really good for him. The whole care that they gave him - it was genuine, yeah - definitely. That's important for so many Aboriginal families. The doctors were like family to us. Family is very important to Aboriginal people - well it could be important to other cultures too. We've always had extended families that we take in and care for. The doctors were like family. There was the respect of it all. It was mutual. It's always mutual - respect that comes from our culture and the people we meet, you know.

They couldn't have done any more for him. So pretty much, you know, he loved all the doctors there. The whole palliative care team, everyone that was involved with him - did so much. He was a very grateful person. He loved everyone, respected everybody. They did so much - they couldn't have done anything different or better. They treated him very well.

We had all the support we needed through all of that. Yeah. They treated us all very well. A lot of it had to do with connection and culture and just the care that they gave, like the whole care of everything. So, to sum it all up I guess just respect and yeah... a lot of it - it's respect.



Angel of faith

Amira's Story
Cultural identity: Iranian
Arabic speaking

My daughter was 26 when she passed away – very young to go. She was in and out of the hospital all the time. The relationship between me and my daughter was very, very strong. Two weeks before she passed away – a condition with her heart, but believe me, during those two weeks she was a very, very happy girl – she told me, 'I love everyone'. She used to tell me, 'Just act like what God told us. Serve everyone regardless – gender, religion, whatever. Just support everyone – as long as you're still alive, support everyone'. She was a very successful social worker.

This tree actually near my house and after my daughter gone, I was very, very stressed. I was very down. I lost hope. I was walking and suddenly I saw this tree. Very old tree but towards the end of the tree I found this green leaves. I said, 'Maybe this is your hope. Maybe this is a message from God to comfort me. It's green'. Life, it should grow. This photo is still life-giving.

I understand the grief takes time to heal. I got support from my daughter, from my son...from my church – it is my extended family, so they support – they call from time to time, every occasion they call. I have no family here. Only my husband and me and my kids. Yes. So, I wish I have anyone [from] my family – my sister, my brother – just to tap on my shoulder when I cried, but this is the life here. I felt at that time that I need somebody just to listen to me. I felt I want just to talk and somebody just to listen – don't give me any suggestion. Just to give me a glass of water and say, 'I'm here to listen to you. I'm here to hear you. I understand your feelings'.

This is my daughter's violin - electric one. She used to perform for her school. She used to perform for her church. She used to play violin for me. She loved playing music. The violin was her friend. When she was sad, she used to play violin. When she was happy, she used to play violin.

She loves the red colour. My daughter bought [this] when she went to Singapore. She went by herself. She booked the plane, she booked the accommodation, she did everything and she bought this from Singapore. She sent me a photo, 'Mum do you like it?' I said, 'Yes, I like it'. And when she came back, she said, 'Mum, thank you very, very much, you allowed me to go by myself to explore'.

This is the Angel of Faith. My daughter, she was an angel in the house. I remember once I was very sick – I couldn't move. I saw my daughter standing next to me praying. I said, 'Oh my gosh, your faith...you have that strong faith'. And believe me, I think God listen to her. I got some strength...the moment my daughter was standing next to me praying, I survived. We kept talking about this story and on one of the Mother's Days – I think she was in Year 9 or Year 10 – she bought me this statue. I told her, 'This statue, it's not for me, that's yours'. She said, 'No Mum. Maybe I'm angel because you are the big angel. Because of you Mum'.

When my daughter was young all the communication is with the parents. But once my daughter reached 18, I found the specialists not talking to me, as if I'm invisible in the room. All the talk is with the patient. I totally understand – she was an adult, she is responsible for herself – but I'm still her Mum. Especially as she has a special condition – I'm also responsible for my daughter's condition. Include us in delivering the information or giving her advice or suggestion...I know she's adult enough to understand but don't exclude the parents.

All her life – in and out in the hospitals. I experienced so many hospitals. Each hospital is different. I was looking for just a social worker to be with her. I can provide the support, but I need external support as well, because the support Mum provides is different from the outsider. Don't wait for the parents or the person to ask for a social worker or somebody to talk to. She was in tears all the time. They didn't send any social worker or a psychologist. They didn't offer help. Another doctor comes – 'We will do the scan; we will do the stress test' – all these worries. Worries, worries they're putting on her without offering any comfort.

Emotional support is really, really important. Unconditional care. Not too much talk during difficult time like that. Don't give lectures. Just be there. Bring a tissue box with you. If they cry, cry with them. If they laugh, laugh with them. Don't ask questions. Just listen. Just tell them, 'I'm here. I'm available when you need me'. That's it.

My culture, the Arabic Coptic Orthodox people – try to understand their culture...their traditions. They are very close to God. So, when you serve them and when you want to develop anything for them, it should be based on their faith.



ملاك الإيمان

قصة بقلم أميرة
الهوية الثقافية: إيرانية
ناطقة بالعربية

كانت ابنتي تبلغ من العمر 26 عامًا عندما توفيت. كانت صغيرة جدًا على الرحيل. كانت تدخل وتخرج من المستشفى طوال الوقت. كانت العلاقة بيني وبين ابنتي قوية جدًا. قبل أسبوعين من وفاتها، كانت مصابة بحالة مرضية في قلبها. لكن صدقوني، خلال هذين الأسبوعين كانت فتاة سعيدة للغاية. قالت لي: "أنا أحب الجميع". كانت معتادة أن تقول لي: "لنتصرف مثلما علمنا الله. لنخدم الجميع بغض النظر عن جنسهم أو دينهم أو مهنا يكن وضعهم. المهم أن نساعد الجميع، وندعم الجميع ما دمنا على قيد الحياة. لقد كانت موظفة خدمات اجتماعية ناجحة للغاية.

هذه الشجرة في الواقع بالقرب من منزلي وبعد وفاة ابنتي، كنت أشعر بضغط نفسي كبير. كنت محبطة جدًا. فقدت الأمل. كنت أسير وفجأة رأيت هذه الشجرة. شجرة قديمة جدًا، ولكن قرب نهاية الشجرة وجدت هذه الأوراق الخضراء. قلت: "ربما هذا هو أمني. ربما تكون هذه رسالة من الله تعزيني. إنها خضراء". الحياة يجب أن تستمر. هذه الصورة لا تزال مفعمة بالحياة .

أتفهم أن الحزن يستغرق وقتًا للتعافي منه. لقد حصلت على دعم من ابنتي، من ابني ... من كنيسي، وهي امتداد لعائلي، لذا فهم يدعمونني، يتصلون بي من وقت لآخر، في كل مناسبة يتصلون بي. ليس لدي عائلة ممتدة هنا. أنا وزوجي وأولادي فقط. نعم. لذا، أتمنى لو كان لدي أي شخص من عائلي، أخي، أخي، لمجرد مواساتي عندما أبكي، ولكن هذه هي الحياة هنا. شعرت في ذلك الوقت أنني بحاجة إلى شخص ما ليستمع إلي. شعرت أنني أريد مجرد التحدث إلى شخص ما يصغي إلي، لا يقدم لي أي اقتراح. شعرت بحاجة لشخص يقدم لي مجرد كوب من الماء ويقول: "أنا هنا لأصغي إليك. أنا هنا لأسمعك. وأنا أتفهم مشاعرك".

هذه آلة الكمان الكهربائي الخاصة بابنتي. كانت تعزف عليه في مدرستها. كانت تعزف عليه في كنيستها. كانت تعزف لي بهذا الكمان. كانت تحب عزف الموسيقى. كان الكمان صديقها، كانت تعزف على الكمان عندما تكون حزينة، كانت تعزف على الكمان عندما تكون سعيدة.

كانت تحب اللون الأحمر. اشترت ابنتي [هذا] عندما ذهبت إلى سنغافورة. ذهبت لوحدها. حجزت بطاقة الطائرة، وحجزت مكان الإقامة، وفعلت كل شيء بنفسها واشترت هذا من سنغافورة. أرسلت لي صورة وكتبت عليها: "ماما، هل يعجبك هذا؟" قلت: "نعم، يعجبني". وعندما عادت، قالت: "ماما، شكرًا جزيلاً لك لأنك سمحت لي بالذهاب لوحدي لاستكشاف بلد آخر".

هذا هو ملاك الإيمان. ابنتي كانت ملاكًا في المنزل. أتذكر مرة كنت مريضة جدًا، لم أكن قادرة على الحركة. رأيت ابنتي تقف بجانبني تصلي. قلت: "يا إلهي، إيمانك ... لديك هذا الإيمان القوي". صدقوني أعتقد أن الله كان يصغي إليها. منحتني ابنتي القوة ... في اللحظة التي كانت فيها تقف بجوارني تصلي، لقد نجوت من تلك المحنة. تكررت هذه القصة في أحداثنا لاحقًا وفي إحدى مناسبات عيد الأم، أعتقد أنها كانت في الصف التاسع أو العاشر في المدرسة، اشترت لي هذا التمثال. قلت لها: "هذا التمثال ليس لي، إنه لك". قالت: "لا يا أمي. ربما أنا ملاك لأنك أنتِ الملاك الكبير. بفضلك أنتِ يا أمي".

عندما كانت ابنتي صغيرة، كان كل التواصل يتم مع الوالدين. لكن بمجرد أن بلغت 18 عامًا من العمر، أصبح الأطباء الأخصائيون لا يتحدثون معي بشأنها، كما لو كانت غير موجودة في الغرفة. كل الكلام كان يتم مع الممرض مباشرة. أنا أتفهم تمامًا أنها كانت بالغة ومسؤولة عن نفسها وحياتها، لكنني ما زلت أمها؛ خاصة وأن لديها حالة مرضية خاصة أنا أيضًا مسؤولة عن حالة ابنتي. من حقنا أن يتم اطلاعنا على المعلومات وأية نصيحة أو معالجة مقترحة تُقدّم لها... أعلم أنها بالغة بما يكفي لتفهم وتقرر، ولكن يجب عدم استبعاد الوالدين.

كل حياتها قضتها وهي تدخل إلى المستشفى وتخرج من المستشفى. لقد اختبرت الكثير من المستشفيات. كل مستشفى كان يختلف عن غيره. كنت أبحث عن موظف خدمات اجتماعية فقط ليكون معها. كان بإمكانني تقديم المساعدة لها، لكنني أحتاج أيضًا إلى دعم خارجي، لأنه مهما كان الدعم الذي تقدمه الأم للمريض فهو يختلف عن الدعم الذي يقدمه شخص حيادي. لا تنتظروا حتى يطلب الوالدان أو المريض التحدث إلى موظف خدمات اجتماعية أو شخص ما. لقد كانت تبكي طوال الوقت. لم يرسلوا أي موظف خدمات اجتماعية أو أخصائي نفسي. لم يعرضوا المساعدة. كان يأتي طبيب بعد آخر ويقول: "سنقوم بإجراء التصوير المسحي؛ سنجري اختبار الجهد". كانوا يحملونها كل هذه الهموم والتوجسات من دون تقديم أي مواساة أو راحة نفسية لها.

الدعم العاطفي مهم للغاية، والرعاية غير المشروطة مهمة جدًا. لا داع لكثرة الكلام خلال الأوقات الصعبة مثل هذه. لا تعظوا الناس. تواجدوا لدعم المريض نفسياً فقط، أحضروا معكم علبه مناديل. وإذا بكى، ابكوا معه. إذا ضحك، اضحكوا معه، لا تطرحوا الكثير من الأسئلة، اصغوا فقط، قولوا له فقط: "نحن هنا، موجودون عندما تحتاج إلينا"، هذا كل ما هو مطلوب.

ثقافتني هي الثقافة القبطية الأرثوذكسية العربية، فحاولوا فهم ثقافة الأقباط، تقاليدهم، عاداتهم. إنهم قريبون جدًا من الله، لذلك عندما تقدمون خدمة لهم أو تريدون بناء علاقة معهم، ينبغي مراعاة إيمانهم.



Story of my dear Mother-in-Law Elien

Lilian's Story
Cultural identity: Egyptian
Arabic speaking

I cared for my Mother-in-law for 10 years in Egypt when she was sick. Not in the same apartment but the one building. In Australia I cared for her full-time, she lived with me for around 20 years because when she came, she was 70 years old. She passed away at 92. She was like my Mum.

She had depression – severe depression. Sometimes she was good, sometimes she was bad. She had the seasons – like three months very bad, two months good, three months bad. Her health was good but when she had depression everything stopped and she was very upset, always sleeping. When the depression was gone, she changed completely. When she was good, everything was very good. She wanted to go out, she wanted to go to church, to visit people. Then when the depression came to her, nothing. Nothing. That was her life, it was hard. It was hard for us and for her too because she was very active.

[I received support] from my church, from the community, from my family – my family supported me because I did a lot of things for her. My husband supported me a lot. In 2016 we went to Egypt for around two months and after we came back, we found a change, a big change – in her life and her body, she was very weak. She went to the hospital for five months and did not come back again. She moved to the nursing home, after just one month or one month and a half, she passed away.

Her situation [in hospital] was very bad and she needed special care and treatment. Special bed and special equipment to get her up. They did a lot of things for her. The people were very nice. She was in a lot of pain – very, very painful – and they did a lot for her. Thank God for Australia! They always talked with us, shared with us the stories. I remember this [nurse], she tried to speak Arabic for her to feel supported. They were very good, very good, because she [Mother-in-law] didn't know any words of English just 'thank you'! All the time we wanted to be with her to translate what we would do. If someone spoke Arabic it would be easier for people. When they bring a doctor or a specialist – they bring an interpreter. But during the day, there's nothing, no-one [speaking the language]. Sometimes nothing happened for her. When we would come the next day, they would try to explain for us what they wanted and [we] explained for her. Sometimes someone spoke one word, two words – like this nurse – but the Arabic for Egyptian is different Arabic from Lebanon and different from Iraq. Sometimes when translating they brought to her an interpreter from Lebanon and she didn't know the accent, she didn't understand. Some words are different, and the accent is different.

They did a good job but some things weren't good about the *connection*. If anyone could talk with her – just talk – not translate – it would make her feel safe – because all the time she stayed in hospital, she didn't talk. When we went, we went for one hour, two hours, three hours but how about the 20 hours she stays with herself without any talk? An [Arabic] pastor always visited her [in hospital] and prayed with her. And another one from the hospital, I think he was Australian. But she loved anyone to pray for her like that. When this pastor came, my husband always translated for her what he said. And the elders from our church, they visited her too. She liked psalms – this is psalms in Arabic. From when I first knew her, she was reading the bible. Especially when she was feeling good, she read the bible every day. In hospital when the pastor came, he read a little bit from the bible and prayed for her.

The church was very, very important for her and she liked church. Every Sunday when she was feeling good, she woke up very early – like four o'clock – and she prepared herself. I took a photo for it – like her watch, she wore it when she went to church. The black dress is a special dress, just for occasions, she wore this one when she took Holy Communion. She liked to hear spiritual songs and this [tape recorder] was especially for her. She would sit there and listen all the time to Arabic spiritual songs. She loved to stay with herself in her room and she listened, and she tried to sing along with who was singing. And she prayed – sometimes she prayed with the spiritual song, singing and praying.

[It would be good to have] more support for the family because it's hard for some people to take loved ones to the nursing home. The social worker told us, 'You can't take her home...' She sent her to the nursing home. We tried, we tried many times with them, but they refused, and they told us it was 'Very, very big care you have to do'. Her treatment needed nurses to do it, not just anyone. We were in a hard situation to agree with the social worker, but we had to. It was very hard for us, very, very hard. [My advice is] just be patient because it was hard for us to leave her, because she loved to stay with us, but we couldn't. We couldn't do [what was needed for her].

She was a special lady. We feel like she still lives with us.



قصة حياة جاتالي غالي: إيلين

قصة بقلم ليليان
الهوية الثقافية:مصرية
ناطقة بالعربية

لقد قدمت الرعاية لحماتي لمدة 10 سنوات في مصر عندما كانت مريضة. ليس في نفس الشقة، ولكن في نفس المبنى. في أستراليا، كنت أقدم لها الرعاية بها بدوام كامل، وعاشت معي حوالي 20 عامًا لأنها عندما قدمت إلى أستراليا، كانت تبلغ من العمر 70 عامًا. توفيت عن عمر يناهز 92 عامًا. كانت مثل أمي.

كانت تعاني من الاكتئاب، اكتئاب حاد. كانت حالتها أحيانًا جيدة، وأحيانًا أخرى سيئة. كان تمرّ بما يشبه الفصول الأربعة: ثلاثة أشهر سيئة للغاية، شهران جيدان، ثلاثة أشهر سيئة. كانت صحتها الجسدية جيدة، لكن عندما كانت تعاني من الاكتئاب يتوقف كل شيء وتصبح مستاءة للغاية، وتنام معظم الوقت. وعندما يتلاشى الاكتئاب، تتغير تمامًا. عندما تكون جيدة، يكون كل شيء جيدًا جدًا. ترغب بالخروج، وتريد الذهاب إلى الكنيسة، وزيارة الناس. لكن عندما كان الاكتئاب يصيبها ثانية، يتوقف كل شيء، كل شيء. هكذا كانت حياتها، كانت صعبة. كان الأمر صعبًا علينا وعليها أيضًا لأنها كانت نشطة للغاية.

تلقيت دعمًا من كنيستي، ومن الجالية، ومن عائلتي. دعمتني عائلتي لأنني فعلت الكثير من الأشياء لها. دعمني زوجي كثيرًا. في العام 2016 ذهبنا إلى مصر لمدة شهرين تقريبًا وبعد عودتنا وجدنا تغييرًا كبيرًا، في حياتها وحالتها الجسدية، كانت ضعيفة جدًا. ذهبت إلى المستشفى لمدة خمسة أشهر ولم تعد إلى البيت ثانية. انتقلت إلى دار المسنين، ولكن بعد شهر واحد أو شهر ونصف فقط، توفيت.

كان وضعها في المستشفى سيئًا للغاية وكانت بحاجة إلى رعاية خاصة وعلاج محدد، وسرير خاص ومعدات خاصة لمساعدتها على الوقوف. لقد فعلوا الكثير من الأشياء لها. كانوا لطفاءً جدًا. كانت تعاني من أوجاع شديدة ومؤلمة للغاية، وقاموا بالكثير من أجلها. الحمد لله على وجودنا بأستراليا! كانوا يتحدثون معنا دائمًا ويشاركونا القصص. أتذكر تلك الممرضة التي حاولت التحدث بالعربية معها حتى لا تشعر بالوحدة وبأنها محاطة بالدعم. لقد كانوا جيدين جدًا، بالفعل، لأن حماتي لم تكن تعرف أية كلمة باللغة الإنجليزية سوى "شكرًا"! أردنا أن نكون معها طوال الوقت لترجمة ما سنفعله. عند وجود شخص يتكلم بالعربية تصبح الأمور أسهل. عند حضور طبيب أو أخصائي كان يؤمنون بوجود مترجم. لكن خلال أوقات النهار، لم يكن يتواجد مترجم ولا أحد يتحدث اللغة العربية. أحيانًا لم يكن يحدث شيء لها. حين كنا نأتي في اليوم التالي، كانوا يحاولون أن يشرحوا لنا ما يريدون ونحن نشرح لها بالعربية. وأحيانًا كان هناك شخص يتكلم معها كلمة أو كلمتين بالعربية. مثل هذه الممرضة، لكن اللهجة المصرية تختلف عن اللهجة اللبنانية أو العراقية. أحيانًا كانوا يحضرون مترجمًا لبنانيًا لكنها لم تكن تفهم اللهجة، فبعض الكلمات مختلفة واللهجة مختلفة.

لقد قدموا لها خدمة جيدة، ولكن بعض الأشياء لم تكن جيدة فيما يتعلق بالترابط، لو قام أي شخص بالتحدث معها، مجرد التحدث معها، بدون ترجمة، فهذا كان سيجعلها تشعر بالأمان. لأنها طوال الوقت الذي كانت فيه بالمستشفى لم تكن تتكلم. عندما كنا نزرورها، كنا نمكث لمدة ساعة، ساعتين، ثلاث ساعات، ولكن ماذا عن الـ 20 ساعة التي كانت تقضيها لوحدها دون أن تتحدث أحدًا؟ كان هناك قس عربي يزورها دائمًا في المستشفى ويصلي معها، وكذلك قس آخر من المستشفى، أعتقد أنه كان أستراليًا. لكنها أحببت أي شخص يدعو ويصلي لها هكذا. عندما كان يأتي القس الأسترالي، كان زوجي يترجم لها دائمًا ما يقوله. وزارها كبار السن من كنيستنا أيضًا. كانت تحب المزامير، أي مزامير الكتاب المقدس بالعربية. منذ أن تعرّفت عليها لأول مرة كانت تقرأ الكتاب المقدس. وخاصة عندما كانت تشعر أنها على ما يرام، كانت تقرأ الكتاب المقدس كل يوم. عندما كان القس يزورها في المستشفى كان يقرأ لها بعض ما جاء في الكتاب المقدس ويصلي لها.

كانت الكنيسة مهمة جدًا جدًا لها وكانت تحب الذهاب إلى الكنيسة، كل يوم أحد عندما كانت تشعر بحالة جيدة، كانت تستيقظ باكراً جدًا، حوالي الساعة الرابعة صباحًا، وتحضر نفسها استعداداً للذهاب. التقطت صورة لساعتها التي كانت تحبها وترتديها عندما تذهب إلى الكنيسة. الفستان الأسود هو فستان خاص، فقط للمناسبات. كانت ترتدي هذا الفستان عندما تتناول القربان المقدس. كانت تحب سماع الترانيم الدينية وجهاز التسجيل هذا كان خاصًا بها. كانت تجلس هناك وتستمع طوال الوقت للتراتيل الدينية العربية. كانت تحب البقاء لوحدها في غرفتها تستمع للتراتيل الكنسية، وتحاول الترتيل مع من كان يرتل. وكانت تصلي، وأحيانًا كانت تصلي أثناء سماع الترانيم الروحية، ترنم وتصلي.

كان من المستحسن أن تحصل العائلة على المزيد من الدعم لأنه من الصعب على بعض الناس أن يأخذوا أحبائهم إلى دار المسنين. قالت لنا موظفة الخدمات الاجتماعية إنه "لا يمكننا اصطحابها إلى المنزل... فأرسلناها إلى دار المسنين. حاولنا، حاولنا عدة مرات معهم، لكنهم رفضوا، وقالوا لنا إنه "سيترتب علينا تقديم رعاية كبيرة للغاية لها تفوق طاقتنا". لقد كانت بحاجة لخبرة الممرضات للقيام بذلك العمل، وليس مجرد أي شخص. كنا في حالة صعبة تحتم علينا الموافقة على ما أشارت به موظفة الخدمات الاجتماعية، لكن لم يكن باليد حيلة. كان الأمر صعبًا جدًا بالنسبة لنا، صعبًا جدًا. نصيحتي هي التحلي بالصبر لأنه كان من الصعب علينا أن نتركها، لأنها كانت تحب البقاء معنا، لكننا لم نتمكن من ذلك. لم تكن قادرين على القيام بما كانت تحتاج إليه.

لقد كانت سيدة مميزة، ونشعر أنها ما تزال تعيش معنا.



Making the most of our time together

Marine's Story
Cultural identity: Lebanese
Arabic speaking

Their first approach was, 'She's too weak, she's too tired', like she may not last the day. But then when we dig through more, 'So why is she not going to make it?' 'Because she's dehydrated', 'Why don't you give her fluid?' 'Why is she not going to make it?' 'Because she has fluid on her lungs.' I had to literally beg for treatment. One doctor even said to me, 'it's like a dog chasing its tail'. I don't know if it's to do with her age, because she turned 90 – that's why they didn't want to treat her? Is that fair? I believe God decides if it's time for the person to go or not.

At that time also, they wanted to put her on comfort medicine [morphine] and she pulled through. She didn't need to go to hospital for another year or so. One time when she was to be discharged from hospital, they wanted to send her to a nursing home. I said, 'But why? We want to take care of her. She likes her independence and I'm not going to deprive her of that.'

After a few years, it was becoming difficult for her. I said, 'Mum, there is a place you can go. You can have help if you want but we will still come visit you.' I decorated her room just like home. We were heavily involved in her care and wellbeing. My sibling and I had a timetable to visit her. We would bring food from home, do her washing, and give her showers. Mum had physical problems, but her brain was very sharp – you would enjoy sitting with her. You make her laugh, she makes you laugh.

In COVID, Mum was in isolation for 10 weeks and that was a massive battle for me again, because I'm 100% confident that Mum was entitled for special visits. When she was in isolation I was on the telephone, on the internet – searching and researching. I contacted OPAN (Older Person Advocacy Network). I spoke to Aged Care Quality and Safety Commission and various other agencies. All of them confirmed that Mum was entitled for visits. According to the Industry Code of Practice for Visiting Aged Care Homes During Covid-19, principle 7-b clearly states that, *Residents who have a clearly established and regular pattern of involvement from visitors contributing to their care and support...must continue to have these visits facilitated.* But the manager was like a rock. She said to me, 'Only people in palliative care can have visitors.' I said, 'If she stays without us for two months, she's going to become a palliative care patient'. And you know what she said to me? 'Then you can visit her'. Is this the manager of a centre that claims to care for the elderly? I was shocked. How can you trust someone like that?

On the phone Mum says to me, 'I just stare at this door waiting for one of you to walk in'. We reached a brick wall with the manager. I took Mum out. I hired all the equipment needed for her. She was with me only two months – she had heart failure. She was 96 when she died. I did say that I'd rather she'd last with me three months than last with them six months without us, but she only lasted two months with me. I wish I took her out sooner but in my mind at that time, I was convinced the manager would finally let us. But there was no way. I'm grateful we took her out. I was with her 24 hours a day not a few hours a day.

I think it's important when they employ people for these kinds of places, they check the person's character, their heart – ask social questions, not just academic. To see someone compassionate makes a lot of difference. To see someone tapping Mum's back and see tears in her eyes, that makes me comfortable that Mum is in good hands when I go home, but if you see someone rushing and not caring and dismissive of your concern... Don't dismiss family members. It's not between just you and the patient. They're devastated – regardless of age because that's someone they love. Allow the family to be near them, it's very important. And their religious belief – that's also very important. That gives someone strength to continue. And it helps them accept separation and death.

I'm grateful for one thing – when the hospital tried to get rid of Mum eight years ago – that made me aware that the time will come she's going to leave, and I became proactive doing everything in my power to make her happy. I'd become a clown just to make her happy – to put a smile on her face. My motto became, *don't leave room for regrets, no regrets.* These [photos] reflect my feelings of what I did to try and make the most of whatever time I had left with her.

I'd taken her to Auburn Gardens 'cos she loved animals, we were feeding the ducks and the duck came right to her hand – it was so amazing! I wasn't embarrassed to ask people anything, so someone passing on the street, 'Oh can Mum pat your dog?' Look at her smile. She is beautiful. I'd arrange pictures on the wall of her room at the aged-care facility. Mum lost a son [my brother] in the civil war in Lebanon, 'cos we came from Lebanon, so that's his picture up there. And this is her chair she'd sit in when in my home, and the jacket she was wearing before she passed. The empty chair is a constant reminder of the void she left in my heart.

I miss her. I know it was better for her she went 'cos all the problems she had, but I still miss her. She is forever in my heart.



اغتنام الوقت المتاح لنا معاً

قصة بقلم مارين
الهوية الثقافية: لبنانية
ناطقة بالعربية

كان التوجه الأول للمعالجة هو: "إنها ضعيفة للغاية، متعبة للغاية"، وكأنها قد لا تعيش حتى نهاية اليوم. ولكن عندما استفسرنا أكثر وسألنا: "ولماذا تشارف على الموت؟" قالوا: "لأنها تعاني من التجفاف نتيجة فقد السوائل"، قلت: "لماذا لا تعطونها السوائل؟" لماذا تشارف على الموت؟ قالوا: "لأن لديها سوائل في رئتيها." اضطرت حرفياً إلى تسؤل العلاج. حتى أن أحد الأطباء قال لي: "إن حالتها ميؤوس منها". لا أعرف ما إذا كان الأمر يتعلق بعمرها، لأنها بلغت الـ 90 عاماً، ولهذا السبب لا يريدون معالجتها. هل هذا عدل وإنصاف؟ أو من أن الله يقرر ما إذا قد حان وقت رحيل الشخص عن هذا العالم أم لا.

وفي ذلك الوقت أيضاً، أرادوا وضعها على المعالجة المخففة للألم بالمورفين وتجاوزت هذا الوضع الصعب. لم تكن بحاجة للذهاب إلى المستشفى لعام آخر أو نحو ذلك. في إحدى المرات التي كان من المقرر أن يتم تخريجها من المستشفى، أرادوا إرسالها إلى دار لرعاية المسنين. فقلت: "ولكن لماذا؟" نحن نريد أن نقدّم لها الرعاية، إنها تحب استقلاليتها ولن أحرّمها من ذلك."

بعد بضعة سنوات، أصبح الأمر صعباً بالنسبة لها. قلت: "يا أمي، هناك مكان يمكنك الذهاب إليه. يمكنك الحصول على المساعدة إذا أردت لكننا سنظل نأتي لزيارتك." قمت بتزيين غرفتها مثل المنزل تماماً. كنا نشارك كثيراً في رعايتها وخدمتها. كنت أنا وشقيقتي نتناوب على زيارتها. كنا نحضر الطعام من المنزل، ونغسل حاجياتها، ونساعدنا بالاستحمام. كانت أمي تعاني من مشاكل جسدية، لكنها كانت حادة الذهن للغاية. الجميع كانوا يستمتعون بالجلوس معها. إذا جعلها أحدهم تضحك، تجعله يضحك.

في فترة انتشار فيروس كورونا، كانت أمي في عزلة لمدة 10 أسابيع وكان ذلك وقتاً عصيباً بالنسبة لي مرة أخرى، لأنني كنت واثقة مئة بالمائة أن أمي كان يحق لها استقبال زائرين خصوصيين. عندما كانت في عزلة، كنت اتصل على الهاتف، وأبحث على الإنترنت دون كلل لأستعلم عن موضوع الزيارات. اتصلت بـ OPAN (شبكة مناصرة كبار السن). تحدثت إلى لجنة جودة خدمات رعاية كبار السن وسلامتهم وإلى العديد من الوكالات الأخرى. أكدوا لي كلهم أن أمي كان يحق لها استقبال زائرين، ووفقاً للقواعد الناظمة للزيارات إلى دور رعاية المسنين خلال فترة Covid-19، فإن المبدأ b-7 ينص بوضوح على أنه "يجب متابعة تسهيل الزيارات... للمقيمين الذين يزورهم زائرون يساهمون في رعايتهم ودعمهم بشكل ثابت ومنظم." لكن مديرة دار الرعاية لم تحد عن رأيها. قالت لي: "مرضى الرعاية التلطيفية فقط يُسمح بالزيارات لهم." قلت لها: "إذا بقيت أمي بدوننا لمدة شهرين، فسوف تصبح مريضة في الرعاية التلطيفية". كان ردّها: "عندئذ يمكنك زيارتها". هل هذه مديرة مركز يدعي أنه يهتم بالمسنين؟ لقد ضُدمت. كيف يمكن الوثوق بشخص من هذا النوع؟

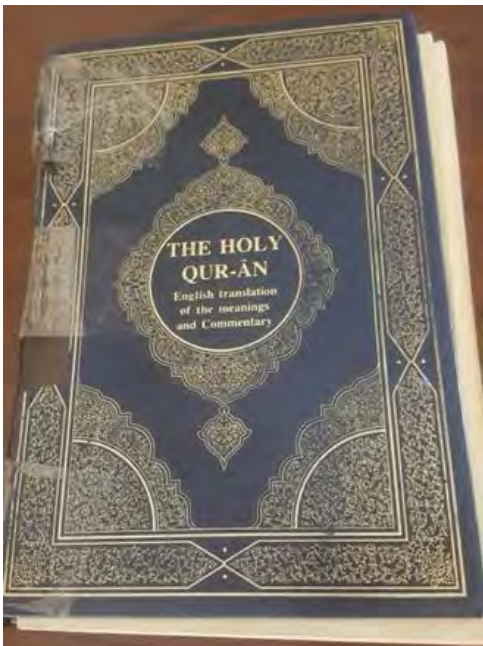
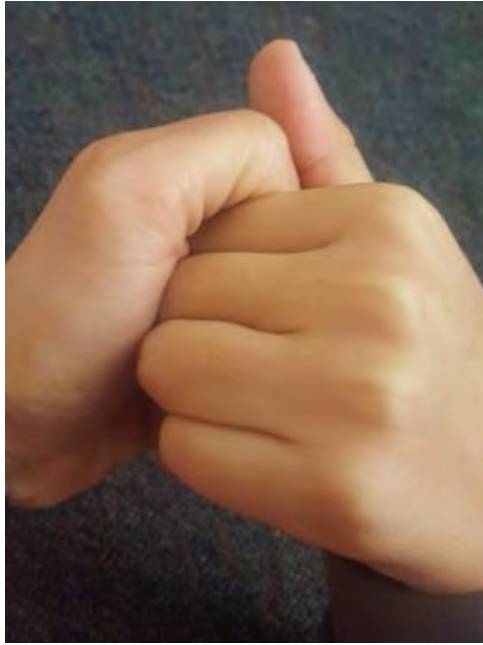
على الهاتف، تقول لي أمي: "أبقى أحقد في هذا الباب في انتظار أحدهم ليدخل منه". وصلنا إلى حائط مسدود في محاولاتنا مع المديرة. أخرجت أمي من الدار، واستأجرت جميع اللوازم التي تحتاجها. بقيت معي شهرين فقط - أصيبت بـ قصور القلب. كانت تبلغ من العمر 96 عاماً عندما توفيت. لقد كان من الأفضل أن تعيش ثلاثة أشهر معنا على أن تعيش ستة أشهر بدوننا، لكنها لم تعيش أكثر من شهرين فقط. أتمنى لو أنني أخرجتها في وقت أبكر، حيث كنت في وقتها مقتنعة بأن المديرة ستسمح لنا أخيراً بزيارتها. ولكن ذلك كان مستحيلاً. أنا ممتنة لأننا أخرجناها من دار المسنين، إذ بقيت معها على مدار الساعة وليس بضع ساعات في اليوم.

أعتقد أنه من المهم جداً عندما يختارون أشخاصاً لتعيينهم في مثل هذه الوظائف، أن يتم التحقق من شخصية طالب الوظيفة، والنواحي المعنوية لديه بما فيها طيبة قلبه، وأن يتم طرح أسئلة اجتماعية عليه وليس فقط الأسئلة الأكاديمية. إن رؤية شخص عطوف يحدث فارقاً كبيراً، ورؤية شخص يطيب خواطر والدتي ويلاحظ الدموع في عينيها يجعلني أشعر بالاطمئنان إلى أن أمي في أيد أمينة عندما أذهب إلى المنزل. ولكن عندما أرى شخصاً يتصرف بعجالة، ولا يهتم لمخاوفي أو يستخف بها فهذا أمر يدعو للاستهجان... لا تستخفوا بقلق أفراد الأسرة، فليست المسألة بينكم وبين المريض فقط. إن أفراد الأسرة مصدومون بوضع والدهم أو والدتهم بغض النظر عن عمره أو عمرها لأنهم يحبون هذا الشخص. اسمحوا لأفراد الأسرة أن يكونوا قريبين من والدهم أو والدتهم، إنه أمر مهم للغاية. هذا يعطيه أو يعطيها القوة للاستمرار والمتابعة، ويساعد المريض على تقبل الانفصال والموت.

أنا ممتنة لشيء واحد. عندما حاول المستشفى التخلص من أمي قبل ثماني سنوات، جعلني ذلك أدرك أن الوقت سيأتي لتغادر فينال حياة، وصرت أستيق الأمور وأفعل كل ما بوسعي لجعلها سعيدة. كنت مستعدة للتصرف كمهزج من أجل إسعادها، من أجل رسم ابتسامة على وجهها. أصبح شعاري، لا تترك مجالاً للندم، ولا تندم على شيء. تعكس هذه الصور مشاعري حول ما فعلته لمحاولة الاستفادة القصوى من الوقت الذي قضيته معها.

لقد أخذتها إلى أوبرن غاردنز - لأنها كانت تحب الحيوانات، كنا نطعم البط عندما سبحت إحدى البطات متوجهة مباشرة نحو يدها - كان الأمر رائعاً للغاية! لم أكن محرّجة من سؤال الناس عن أي شيء، لذا كنت إذا رأيت شخصاً يمر في الشارع مع كلبه أقول له "هل تستطيع أمي أن تروى على كلبك". انظر إلى ابتسامتها، إنها جميلة. كنت أرتب الصور على جدار غرفتها في دار رعاية المسنين. فقدت أمي ابناً [أخي] في الحرب الأهلية بلبنان، لأن أصلنا من لبنان، وهذه صورته هناك. وهذا هو كرسيها الذي كانت تجلس عليه عندما كانت تتواجد في منزلي، والسترة التي كانت ترتديها قبل وفاتها. الكرسي الفارغ هو تذكير دائم بالفراغ الذي تركته في قلبي.

أشعر بفقدانها. أعلم أن رحيلها كان راحة لها بسبب كل المشاكل الصحية التي واجهتها، لكنني ما زلت أشعر بفقدانها. سوف تبقى حية إلى الأبد في قلبي.



Goodbye my angel

Rouba's Story
Cultural identity: Lebanese
Arabic speaking

That photo, I took of me holding my son's hand. That was the only way I could visually represent that when you're losing a loved one, the most important thing that you need is your family. 'Cos my Grandmother was near and dear to all of us. Losing a mother – she's a Mother, she's a Grandmother. She helped in raising us. Saw us as babies. Going through those troubling years as teens. Then through marriage. And she got to see me give birth to a special needs child, get divorced as a result of that, and try to live a life as a single woman. Her support was everything at that time. So, losing her – the only thing that makes it bearable, is having family at the time. We were on the phone with the family in Lebanon pretty much every day. Yes, family's everything.

The phone...keeping in touch with everybody. We needed the communication, so there was *chat* and all that. When she passed away, the only way we can tell everyone was through messages. The only way they found out Grandma had a heart attack at night was through the messages in the morning.

She was in ICU. I can't recall the conversation clearly, but they decided to move her to a ward, and she said, 'Am I dying?' 'Grandma!' I don't know, maybe she was trying to prepare herself. I'm like, 'No! You're not dying! We're just taking you to a ward'. Maybe two days or three days later – that's when the palliative nurses came.

And so, this lovely woman walked in, and she introduced herself. I can't recall the name, but she says she's a palliative nurse. I didn't know what that was, but she explained that they're there to make the end-of-life more comfortable – 'cos death is a painful thing. She was lovely – I actually remember that – she was a lovely woman.

I don't remember there ever was a chaplain or a spiritual person in the hospital to recite any words over the dead. My Father grabbed his phone. He had the Koran – there's an app – and he read chapter Yaseen, which is what we recite over our dead. He made Dua – Dua is the supplication for the dead. It's for the soul for the one that's leaving – not only that – it's for those that are now having to deal with this new trial of losing somebody. We're all travellers, we're all going to leave. Someone's going to mourn us.

I think – if the family asks – if they want someone there that can recite the Koran, that can make Dua for them, possibly there should be that option there. 'Cos in a difficult situation like that, in an emotional situation like that, it might bring some comfort knowing at least they did that for their dead. My Mother and my aunt were the ones that washed my Grandmother – I couldn't do it. I was a mess. There was a woman guiding them how to wash the body, how to wrap her, make sure everything was clean and everything's covered. Ready for the family to say goodbye to her.

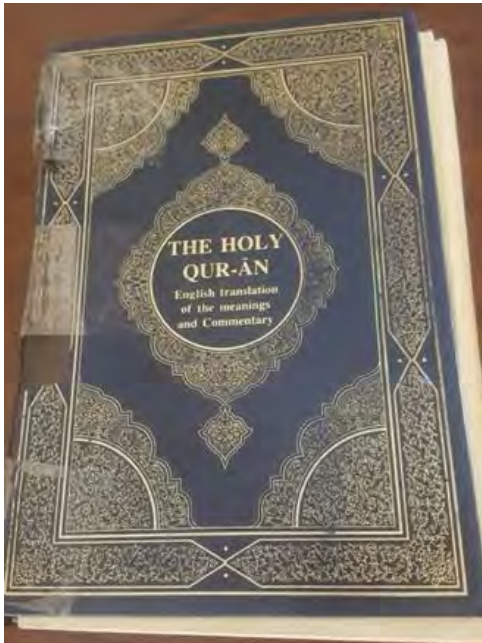
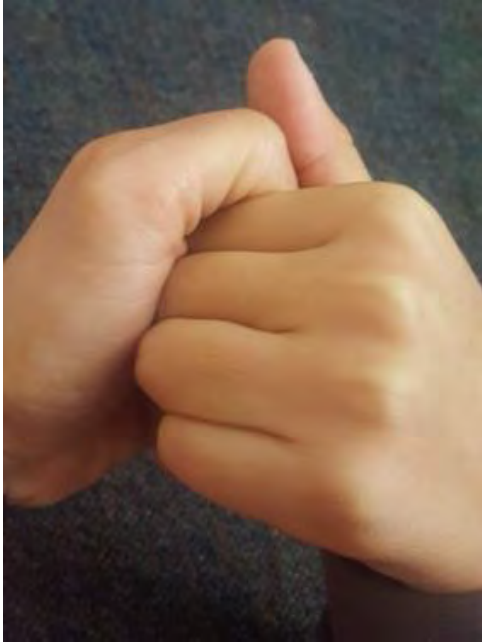
Mag'sal means to wash the body. A funeral home, it's where it's washed. They move the body. In an adjacent room we say goodbye to our loved one and then they put the body in the coffin, the men – only the men – hold the body. She's a woman, so she gets twirled seven times around and then she goes to the mag'sal. It was mid-afternoon prayer, which is Dhuhr. So, we had that prayer and then we did the Janazah prayer – the funeral prayer. Then they take the body, they say, 'There's only one God'.

The hospital – the nurses were beautiful. They offered their condolences. They didn't tell us to go – 'cos we were taking up the waiting room. We were taking up the room and we were taking up the corridor. They allowed us to gather for that time. We didn't gather all night. As silly as it sounds – maybe more chairs!

Oh. Maybe if the person is one that prays five times a day, for someone to come in and remind the person that's leaving, 'Oh it's time for this prayer'. My Grandmother was praying in her bed. She was lying down and she was praying. We would tell her, 'Grandmother this prayer has arrived. Do you want to pray?' And she would pray.

The palliative nurses were beautiful. Just their understanding of losing someone is not an easy thing. I suppose with experience – they've done this for a while – I'm just assuming they had, they were really understanding. The fact that they give you time. They give you that space. Yeah, they were lovely. And having someone to talk to even at that time when you're losing someone – that's not family. Maybe that's my best experience – talking to someone that wasn't family about losing her or potentially losing her at the time.

I know it's not easy but still remembering her in any way – you don't stop loving them even though they've left. They're with you till you leave.



وداعاً يا ملاكي

قصة بقلم ربي
ال هويثالي افية لبنان ليرة
ناطقة بالعربية

تلك الصورة، التقطتها لنفسني وأنا أمسك بيد ابني، كانت هي الطريقة الوحيدة التي يمكنني من خلالها أن أعبر بالصورة عن أن أهم شيء تحتاجه عندما تفقد أحد أفراد أسرتك هو عائلتك. "لقد كانت جدتي قريبة منا وعزيزة علينا جميعاً، وفقدانها هو فقدان أم - إنها أم، إنها جدة. ساعدت في تربيته، ورأينا ونحن أطفال نجتاز سنوات المراهقة المضطربة، ثم نمر بفترة الزواج. لقد كانت إلى جانبي عندما أنجبت طفلاً من ذوي الاحتياجات الخاصة، وطلاقي نتيجة لذلك، ثم حياتي كإمرأة عزباء، كان دعمها لي هو كل شيء في ذلك الوقت. إن الشيء الوحيد الذي خفف من ألم فقدانها هو وجود أسرة محيطة بنا في ذلك الوقت. كنا نتحدث على الهاتف مع العائلة في لبنان كل يوم تقريباً. نعم، إنها العائلة، إنها كل شيء.

الهاتف ... البقاء على اتصال مع الجميع بواسطة الهاتف كان ضرورة ملحة للحفاظ على التواصل مع الآخرين، لذلك كنا دائماً نتحدث وندرش بطرق ووسائل مختلفة. عندما توفيت جدتي، كانت الطريقة الوحيدة التي يمكننا بها إخبار الجميع برحليها هي من خلال الرسائل النصية على الهاتف النقال. الطريقة الوحيدة التي عرفوا بها أن جدتي أصيبت بنوبة قلبية في الليل كانت من خلال الرسائل النصية في الصباح.

كانت في وحدة العناية المركزة. لا أستطيع أن أتذكر تفاصيل المحادثة تماماً، لكنهم عندما قرروا نقلها إلى جناح في المستشفى، قالت لي: "هل أنا على وشك الموت؟" لا أدري، ربما كانت تحاول إعداد نفسها. أحببتها: "جدتي!" "لا! لن تموتي! نحن فقط نأخذك إلى جناح في المستشفى". وبعد يومين أو ثلاثة أيام، حضرت ممرضات الرعاية التلطيفية.

دخلت علينا تلك المرأة الجميلة، وعرفت عن نفسها. لا أتذكر اسمها، لكنها قالت إنها ممرضة مختصة بالرعاية الملطفة للألم، لم أكن أعرف ماذا يعني ذلك، لكنها أوضحت أن ممرضات الرعاية التلطيفية يساعدن على جعل نهاية الحياة أكثر راحة وأقل معاناة للمرضى لأن الموت مؤلم. كانت رائعة، أتذكر ذلك جيداً، كانت امرأة رائعة.

لا أتذكر رؤية أي قسيس أو رجل دين في المستشفى يتلو أي كلمات على الموتى. أمسك والدي بهاتفه. كان لديه القرآن في تطبيق على الهاتف النقال. تلا سورة ياسين (يس)، وهي ما نتلوه عادةً على موتانا، طلب الدعاء، وهو التضرع للميت. إنه لروح الشخص الذي يغادرننا، وليس هذا فحسب، بل إنه أيضاً لمن تمر عليهم هذه التجربة الجديدة وهي محنة فقدان شخص عزيز. نحن جميعاً سنفارق هذه الحياة، وسوف يحزن علينا شخص ما.

أعتقد - لو سألت الأسرة - إذا كانوا يريدون شخصاً متواجداً في المشفى بإمكانه أن يتلو القرآن، ويطلب الدعاء لهم، فربما يجب أن يكون هذا الخيار متوفراً. لأنه في موقف صعب مثل هذا، في موقف عاطفي كهذا، فإن معرفة أهل الميت أنهم فعلوا على الأقل ذلك من أجل موتاهم قد يجلب لهم بعض الراحة. كانت والديني وعمتي من غسل جدتي - لم أستطع فعل ذلك، كنت في حالة يرثى لها، كانت هناك امرأة ترشدهم إلى كيفية غسل الجسم، وكيفية لفها، والتأكد من أن كل شيء نظيف وأن كل شيء مغطى وعلى استعداد لتوديع العائلة لها.

كلمة مغسل تعني غسل الجسم، مكان تحضير الميت للدفن، حيث يتم غسل الميت. ينقلون الجثمان إلى غرفة مجاورة حيث نودع الفقيد ثم يضعون الجثمان في النعش. الرجال، الرجال فقط يحملون الجثمان. ولإنها امرأة، يتم تدويرها سبع مرات ثم نقلها إلى المغسل. كان فترة الظهر، قمنا بأداء صلاة الظهر، ثم صلاة الجنازة، أي صلاة الميت. ثم أخذوا الجثمان، مرددين "لا إله إلا الله".

في المستشفى - كانت الممرضات رائعات. فدمن تعازيهن، ولم يطلبن منا أن نذهب، لأننا كنا ننتقل غرفة الانتظار. كنا متواجدين في الغرفة وفي الممر. سمحوا لنا بالتجمع في ذلك الوقت. لم نتجمع طوال الليل، ربما لعدم وجود عدد كاف من الكراسي!

وربما من المناسب إذا كان الشخص الذي على فراش الموت يصلي خمس مرات في اليوم أن يأتي شخص ويذكره بأنه "حان وقت الصلاة". كانت جدتي تصلي في سريرها. كانت تصلي وهي مستلقية. كنا نقول لها، "لقد حان موعد الصلاة يا جدتي. أتريدن أن تصلي؟" فتصلي.

كانت ممرضات الرعاية التلطيفية رائعات. إن التعبير عن تفهمهن لفقدان عزيز ليس بالأمر السهل عليهن. أعتقد أنهن اكتسبن خبرة من خلال التجربة. أنا افترض ذلك، لأنهن كن متفهمات جداً لحالتنا، ومنحونا الوقت الكافي والمساحة الكافية. كن رائعات فعلاً. إن وجود شخص للتحدث معه في ذلك الوقت العصيب عندما تكون على وشك فقدان شخص عزيز يخفف من وقع القصاب. صحيح أن أولئك الممرضات لم يكن من العائلة، ولكن ربما كان ذلك أفضل تجربة لي في ذلك الوقت، أعني تجربة التحدث إلى شخص ليس من أفراد أسرتي بشأن فقدان جدتي أو احتمال فقدانها.

أعلم أن الأمر ليس سهلاً، ولكن ما زلت أتذكرها في كل الأحوال. إن حبها دائم في القلب ولو رحلت عن هذا العالم، وذكرها ستبقى حية حتى الممات.



A Grandfather's love

Aish's Story
Cultural identity: Indian
Hindi speaking

Those are my Grandparents when they were in their early 20's. They got married when they were 16 and 19 years old. My Grandmum passed away fairly young, early 50's, so my Granddad widowed quite early. Mum had a lot on her plate when my Grandmum passed away, having to care for me and my brother when we were literally one and two years old. So, her going through that when she was younger – with my Granddad a few years ago, she knew what she wanted, and she knew what my Granddad would want.

That's my Mum when she was maybe three or four years old. It was taken in a place in South India called Chennai. She was the last child for my Grandparents, and they adored her. This is one of my favourite photos, my Granddad played a big role in my life. He'd always take me for my singing classes, dancing classes, swimming and to school. He played the role of mum and dad in one, and then himself and my Grandmum in one person. Granddad loved to gift and give, he was a true role model and showed us so much love, generosity, and learning. Granddad loved to learn new things and always adapted to change really well, I vividly remember Granddad arguing with Siri at one stage.

Granddad had some pain come along his spine and that's when we took him to ED at Blacktown Hospital, at a later stage this developed into a paralysis on one side of my Granddad's body. We didn't have a positive experience with the health system. It was just not a very pleasant experience, in terms of clinicians not being very empathetic, or culturally sensitive with the way they interacted with us or in understanding the roles and responsibilities each of us play in my Granddad's life. We almost found the patient journey to have had some form of medical negligence in the duty of care for my Grandfather with the clinical misdiagnosis. No one took that initiative to learn about the family dynamics. For us, family is really important. Each of us has a specific role and responsibility. When we make any decision in the family, it involves the entire family – Uncles and Aunts, too – making that decision together, especially the big decisions.

In our culture, it's quite taboo for a family member to go to an aged care facility. It's almost like we can't care for our own. It's quite shameful. Especially for my Mum, she felt very ashamed that that was where my Granddad had to go. During the family meeting, it was sort of "this is what's gonna happen, that's the end of that. He's gonna have to go to an aged care facility." It wasn't like we had an option – or any ability to ask, or negotiate, or see what other options were available to us. No support services were made available to help Mum with coping, or to help her process everything going on. Even for me, knowing there was some young carer support service or someone for me to reach out to. We weren't advised of services available to us, such as a bereavement counsellor. I think it would just have been a little bit of a lighter process if we had someone to vent to or learn how to cope with this. Mum once sort of opened up with a GP and said that she wanted to speak to someone, but she found the entire interaction really insensitive. It was just sort of ticking boxes on an anxiety and depression checklist or some questionnaire, and my Mum just didn't feel comfortable. If there were support services or a community that we could have mixed with, if Mum could have worked with other carers, I think that would have helped her. We only had strong communication with our family back home, over here we didn't have much community support. It was a very isolating time.

Granddad struggled with depression after my Grandmum passed away and really appreciated how much my Mum had done for my him in terms of moral support and just companionship, someone to be there, even just cooking the traditional foods that he loves. One of the biggest things for us is food, eating good food. We've got a lot of festivals and religious days that we observe, and some days we're fasting and some days we're vegetarian for religious purposes. For example, my Granddad's passing date or my Grandmum's passing day, we would observe that day and we would be vegetarian. It's very typical and specific to every family. But the food in the [aged] facility was not for us, every time we went and saw our Granddad, we would pack some food from home and ask the nurses to warm it up for the following day but we just knew they weren't – I'm not saying there was specific staff that wasn't helping out – it was just the facility and the system was not – it wasn't a positive experience at all.

Our dog was one of the last things our Granddad gifted us. He sort of said, "Once I go, she'll be there in place of me" and we hold her very dear to us. My Granddad would always say that she reminds him of his Mum, it's funny how human animals can be. But she was so impactful in my Granddad's life for how short that time was they spent with each other to when my Granddad transitioned to aged care. I think I just realised the importance of family and treating them with respect and not knowing what could happen the next day and just being grateful for the small things. And I think that's what my dog really taught me.



एक दादाजी का प्यार

कहानीकार - ऐश
सांस्कृतिक पहचान: भारतीय
हिंदी भाषी

ये मेरे दादा-दादी हैं जब उनकी आयु 20 से थोड़ी सी अधिक थी। 16 और 19 साल की उम्र में उन्होंने शादी कर ली। मेरी दादी का देहांत काफी कम उम्र में हो गया था, उनकी 50वीं के बाद पहले कुछ सालों में, इसलिए मेरे दादाजी बहुत जल्दी विधुर हो गए। जब मेरी दादी का निधन हुआ, तब मेरी और मेरे भाई की देखभाल करने के लिए माँ के ऊपर बहुत बोझ था, जब हम सिर्फ एक और दो साल के थे। इसलिए, जब वह छोटी थी, तो वह उस दौर से गुजर रही थी - कुछ साल पहले मेरे दादाजी के साथ, वह जानती थी कि उन्हें क्या चाहिए, और वह जानती थी कि मेरे दादाजी क्या चाहते थे।

यह मेरी माँ है जब वह शायद तीन या चार साल की थी। यह दक्षिण भारत में चेन्नई नामक स्थान पर ली गई थी। वह मेरे दादा-दादी की आखिरी संतान थी, और वे उनसे बहुत प्यार करते थे। यह मेरी पसंदीदा तस्वीरों में से एक है, मेरे दादाजी ने मेरे जीवन में एक बड़ी भूमिका निभाई। वह मुझे हमेशा मेरी गायन कक्षाओं, नृत्य कक्षाओं, तैराकी और स्कूल के लिए ले जाते थे। उन्होंने अकेले ही माँ और पिता की भूमिकाएँ निभाईं, और फिर अकेले खुद मेरे दादा और मेरी दादी की भूमिकाएँ निभाईं। दादाजी को उपहार देना बहुत पसंद था, वह एक सच्चे आदर्श व्यक्ति थे और उन्होंने हमें बहुत अधिक प्यार, उदारता और बहुत कुछ सिखाया। दादाजी नई चीज़ें सीखना पसंद करते थे और उन्होंने हमेशा खुद को बदलते समय के साथ बड़ी खूबी से बदला, मुझे स्पष्ट रूप से याद है एक बार दादाजी सिरी के साथ बहस कर रहे थे।

दादाजी की रीढ़ की हड्डी में कुछ दर्द की शुरुआत हुई और तब हम उन्हें ब्लैकटाउन अस्पताल के ईडी (इमर्जन्सी विभाग) में ले गए, आगे चल के यह मेरे दादाजी के शरीर में एक तरफ से होने वाले लकवे में बदल गया। स्वास्थ्य प्रणाली के साथ हमारा अनुभव कुछ खास सकारात्मक नहीं था। कहें तो यह बहुत ज्यादा सुखद अनुभव नहीं था, चिकित्सक हमारे साथ बहुत सहानुभूति पूर्ण नहीं थे, या उनके हमसे बातचीत करने के तरीके में, या इस बात को समझने में कि हमारे दादाजी के जीवन में हम सभी की क्या भूमिकाएँ और जिम्मेदारियाँ हैं, वे हमारे साथ सांस्कृतिक रूप से संवेदनशील नहीं थे। हमने, रोगी के रूप में मेरे दादाजी की इस यात्रा में हमने पाया उनका निदान गलत हुआ था और उनकी देखभाल के सन्दर्भ में किसी न किसी प्रकार की चिकित्सीय लापरवाही दिखने में आई थी। एक परिवार के रूप में हम कैसे हैं, इसके बारे में जानने के लिए किसी ने भी पहल नहीं की। हमारे लिए परिवार बहुत ही महत्वपूर्ण है। हम में से प्रत्येक की एक विशिष्ट भूमिका और जिम्मेदारी है। जब हम परिवार में कोई निर्णय लेते हैं, तो उसमें पूरा परिवार शामिल होता है - अंकल और आंटियाँ भी - हम एक साथ निर्णय लेते हैं, विशेष रूप से बड़े निर्णय।

हमारी संस्कृति में, परिवार के किसी सदस्य का वृद्ध देखभाल केंद्र में जाना अच्छा नहीं माना जाता है। यह लगभग ऐसा है जैसे हम अपने लोगों की देखभाल नहीं कर सकते। यह काफी शर्मनाक होता है। विशेष रूप से मेरी माँ के लिए, उन्हें बहुत शर्म आती थी कि मेरे दादाजी को वहाँ जाना पड़ा। परिवार की बैठक के दौरान, यह कुछ ऐसे था "यही होने वाला है, बस यहीं बात खत्म होती है। उन्हें एक वृद्ध देखभाल सुविधा में जाना होगा।" ऐसा नहीं था कि हमारे पास कोई विकल्प था - या पूछने, या बातचीत करने की कोई क्षमता, या यह देखने का, कि हमारे पास कौन से अन्य विकल्प उपलब्ध थे। माँ को इस परिस्थिति का सामना करने में मदद करने के लिए, या जो सब कुछ चल रहा है उसे ठीक तरह से समझाने में मदद करने के लिए कोई सहायता सेवाएँ उपलब्ध नहीं कराई गईं। मेरे लिए भी, यह जानते हुए कि कोई युवा देखभाल कर्ता सहायता सेवा है या मेरे लिए कोई है जिससे संपर्क किया जा सकता है। हमें हमारे लिए उपलब्ध सेवाओं के बारे में नहीं बताया गया, जैसे कि एक शोक परामर्शदाता। मुझे लगता है कि यह कुछ प्रक्रिया थोड़ी सी आसान होती अगर हमारे पास कोई ऐसा व्यक्ति होता जिसके सामने हम अपने दिल की बात रख पाते या इनका सामना करने सम्बन्धी युक्तियाँ सीख सकते। माँ ने एक बार एक जीपी के साथ खुलकर बात की और कहा कि वह किसी से बात करना चाहती हैं, लेकिन उन्हें वह सारी बातचीत वास्तव में असंवेदनशील लगी। यह एक चिंता और अवसाद चेकलिस्ट या कुछ प्रश्नावली पर टिक बाँक्स लगाने जैसा था, और मेरी माँ बस सहज महसूस नहीं कर रही थीं। अगर वहाँ सहायता सेवाएँ या कोई समुदाय होता जिससे हम घुल-मिल सकते, यदि माँ अन्य देखभाल कर्ताओं के साथ काम कर सकती, तो मुझे लगता है कि इससे उन्हें मदद मिलती। हमारे पास केवल हमारे परिवार के साथ मजबूत बातचीत थी, यहाँ पर हमारे पास अधिक सामुदायिक सहारा नहीं था। यह बहुत ही अलग-थलग महसूस करवाने वाला समय था।

मेरी दादी के निधन के बाद दादाजी अवसाद से जूझ रहे थे और इस बात की बहुत सराहना करते थे कि नैतिक समर्थन और सिर्फ साथ देने के नाते, कि कोई वहाँ हो, मेरी माँ ने उनके लिए कितना कुछ किया है, यहाँ तक कि सिर्फ वे पारंपरिक व्यंजन पकाना जिन्हें वो पसंद करते थे। हमारे लिए सबसे बड़ी चीज़ों में से एक है खाना, अच्छा खाना खाना। हमारे बहुत सारे त्यौहार और धार्मिक दिन होते हैं जिनका हम पालन करते हैं, कुछ दिन हम उपवास करते हैं और कुछ दिन हम धार्मिक उद्देश्यों के लिए शाकाहारी रहते हैं। उदाहरण के लिए, मेरे दादाजी के गुजरने की तारीख या मेरी दादी का गुजरने वाला दिन, हम उस दिन शाकाहारी रह कर उन दिनों का पालन करते हैं। यह हर परिवार के लिए बहुत खास और अलग होता है। लेकिन [वृद्ध] सुविधा में खाना हमारे अनुकूल नहीं था, हर बार जब हम जाते और अपने दादाजी को देखते, हम घर से कुछ खाना पैक करते और नर्सों से अगले दिन इसे गर्म करने के लिए कहते लेकिन हमें पता था कि वे ऐसा नहीं करते थे - मैं यह नहीं कह रहा हूँ कि कुछ खास कर्मचारी थे जो मदद नहीं कर रहे थे - सिर्फ वह सुविधा और वहाँ की प्रणाली ही थी जो कि यह नहीं कर रही थी - यह बिल्कुल भी सकारात्मक अनुभव नहीं था।

हमारा कुत्ता उन आखिरी चीज़ों में से एक था जिसे हमारे दादाजी ने हमें उपहार में दिया था। एक तरह से उन्होंने कहा, "जब मैं चला गया, तो यह मेरे स्थान पर होगी" और वह हमारे लिए बहुत प्रिय है। मेरे दादाजी हमेशा कहते थे कि वह उन्हें अपनी माँ की याद दिलाती है, यह मज़ेदार है कि जानवर भी कितने मानव समान ही हो सकते हैं। लेकिन यह देखते हुए कि उन्होंने एक-दूसरे के साथ कितना कम समय बिताया जब मेरे दादाजी वृद्ध देखभाल में दाखिल हुए; वह मेरे दादाजी के जीवन में बहुत प्रभावशाली थी। मुझे लगता है कि मैंने सिर्फ परिवार और उनके साथ सम्मान के साथ व्यवहार करने के महत्व को महसूस किया और न जाने अगले दिन क्या हो जाए और मैं बस छोटी-छोटी चीज़ों के लिए आभारी हूँ। और मुझे लगता है कि मेरे कुत्ते ने वास्तव में मुझे यही सिखाया है।



Only one regret

Khwaja's Story
Cultural identity: Indian
Hindi speaking

My parents – we are from India. I came to Australia in 1990 because my brothers were already here and I was working in America. My family managed to bring our parents here to Australia in 1997. They really adjusted very nicely here.

In 2009, my Mother passed away. Mostly my Father stayed with me after that...he was quite old when he passed, 96, I think. He had a long and quiet, healthy life. He was quite mobile and active. And he was an avid reader. He kept himself busy in gardening and in reading. That was maybe when he was 90, I would say, when his health started deteriorating. He developed arthritis and then he had a mild heart attack, so they put a stent in his heart. His GP, after the operation, recommended that he live in a nursing home, but we didn't like that idea. He was quite happy with us, and we were happy too. So, we prolonged that. But one day, while I was at work, he had a fall. He didn't have any fractures but then the doctor insisted that it's time that he should be going to the nursing home now. He had had two falls by that time.

So, then we spoke to him. Initially he was not very happy – but he agreed in the end. We organised a nursing home for him very close to our house. All three brothers took turns to go and visit him daily. And the people there, they're very good – in the nursing home. He was happy there. They took good care of him. Every weekend I used to bring him home. Go Saturday to bring him home and he would stay all night with us and then I used to drop him off on Sunday evening.

There was a visiting doctor – he visited every week and just before his death, maybe a couple of months before, the doctor called me and said, 'Your Father's getting sick – his health's deteriorating. His kidney prolapsed so we don't expect him to live longer'. Like, he mentally prepared us. But he went suddenly. Just one day he was okay and then he passed.

That's my sister in his lap – he's holding her. He was around 48 at that time. In India, they call it, 'Sherwani'. I think it is originally from Iran, adapted in India. It's a kind of dress – you wear it on happy occasions. So that's what he's wearing in that photo. That is the Liberty Bell in Philadelphia. If you see where my Mother is standing, the bell is cracked...they'd just noticed the crack in the bell – I think it was due to some lightning or something. That's when the authorities brought the bell down to the ground. These are all my brothers and sister. It was just after our Mother passed away. Almost seven years, I would say. She passed away in 2009 and our Father passed away in 2016.

This one is very, very important. This is our family tree for many generations. He developed that. And I couldn't even open the whole thing. A huge, huge thing. He was afraid that we're forgetting all our generations...so he compiled all this. Some is in Urdu – but I can read it. I have to sit down and write it again – I don't get time to but I'm going to do it one day. When I retire.

This photo was taken in the nursing home. His last years here. What I regret now is that we shouldn't have sent him to the nursing home. He should have still stayed with us. I blame myself – not blame, but I could have taken a year's leave from work and then looked after him rather than sending him there. Especially his last year. Although he had no complaints about the nursing home – they were very good – but it's just a cultural thing that in his old age he should have been with us and not away from us. Even though his doctor was telling us to put him in the nursing home for a long time, but we delayed that, we did not do that – that's a cultural thing.

It was very difficult. The good thing we always took as a family decision. Not just one person but all discuss, and we decide on something. At home he used to pray. But in there – not that there was anyone stopping him from praying, but he wanted a clean corner to pray and the prayer mat – he didn't have a proper place to pray there. So that stopped him. Culturally...he felt a bit isolated because there was no-one to speak his language in that facility there. Although he could speak English but because of his accent, other people couldn't understand him, or he couldn't understand their accent. He was a writer – he'd read and write...and the lights used to go off at 8 o'clock at night so he couldn't read if he wanted to, so that's one more thing.

The only thing that happened good was he was able to come to our house every week for the weekend. That was good because here he could meet all his Grandchildren. That was good he did that.



केवल एक ही अफ़सोस

कहानीकार - ख्वाजा
सांस्कृतिक पहचान: भारतीय
हिंदी भाषी

मेरे माता-पिता - हम भारत से हैं। मैं 1990 में ऑस्ट्रेलिया आया था क्योंकि मेरे भाई पहले से ही यहाँ थे और मैं अमेरिका में काम कर रहा था। मेरा परिवार 1997 में हमारे माता-पिता को यहाँ ऑस्ट्रेलिया लाने में कामयाब रहा। वे वास्तव में यहाँ बहुत अच्छी तरह से हिल-मिल गए हैं।

2009 में मेरी माँ का देहांत हो गया। उसके बाद ज्यादातर मेरे पिता मेरे साथ रहे ... जब वे गुज़रे, तब वे काफी बूढ़े थे, मुझे लगता है 96 वर्ष के। उन्होंने लंबा, शांत और स्वस्थ जीवन व्यतीत किया। वह काफी गतिशील और सक्रिय थे। और वे एक उत्साही पाठक थे। वे अपने आप को बागवानी और पढ़ने में व्यस्त रखते थे। शायद जब वह 90 वर्ष के थे, मैं कहूँगा, तब उनका स्वास्थ्य बिगड़ने लगा। उन्हें गठिया हो गया और फिर उन्हें हल्का दिल का दौरा पड़ा, इसलिए उन्होंने उनके दिल में एक स्टेंट लगा दिया। ऑपरेशन के बाद उनके जीपी ने उन्हें एक नर्सिंग होम में रहने की सलाह दी, लेकिन हमें यह विचार पसंद नहीं आया। वह हमसे काफी खुश थे और हम भी खुश थे। इसलिए, हमने ऐसे ही चलने दिया। लेकिन एक दिन, जब मैं काम पर था, वे गिर गए। उन्हें कोई फ्रैक्चर नहीं हुआ लेकिन फिर डॉक्टर ने ज़ोर देकर कहा कि अब समय आ गया है कि उन्हें नर्सिंग होम जाना चाहिए। उस समय तक वे दो बार गिर चुके थे।

तो फिर हमने उनसे बात की। शुरू में वे बहुत खुश नहीं थे - लेकिन अंत में वे मान गए। हमने अपने घर के बहुत करीब उनके लिए एक नर्सिंग होम का प्रबंध किया। तीनों भाई बारी-बारी से प्रतिदिन उनसे मिलने जाते थे। और वहाँ के लोग, नर्सिंग होम में - वे बहुत अच्छे हैं। वे वहाँ खुश थे। वे लोग उनकी अच्छी देखभाल करते थे। हर सप्ताहांत में उन्हें घर ले आता था। शनिवार को उन्हें घर लाने के लिए जाता था और वे पूरी रात हमारे साथ रहते थे और फिर रविवार की शाम को मैं उन्हें वापस छोड़ देता था।

वहाँ एक चिकित्सक आया करता था - वह हर सप्ताह आता था और उनकी मृत्यु से ठीक पहले, शायद कुछ महीने पहले, डॉक्टर ने मुझे फोन किया और कहा, 'तुम्हारे पिता बीमार हो रहे हैं - उनका स्वास्थ्य बिगड़ रहा है। उनकी किडनी खराब हो गई है, इसलिए हमें उम्मीद नहीं है कि वे लंबे समय तक जी पाएँगे।' जैसे, उन्होंने हमें मानसिक रूप से तैयार किया। लेकिन वे अचानक चले गए। बस एक दिन वे ठीक थे और फिर वे गुज़र गए।

ये मेरी बहन उनकी गोद में है - उन्होंने उसे पकड़ रखा है। उस समय उनकी उम्र लगभग 48 वर्ष थी। भारत में, इसे 'शेरवानी' कहते हैं। मुझे लगता है कि यह मूल रूप से ईरान से है, जिसे भारत में अपनाया गया है। यह एक तरह की पोशाक है - आप इसे खुशी के मौकों पर पहनते हैं। तो उन्होंने उस फोटो में यही पहना हुआ है। ये फिलाडेल्फिया में लिबर्टी बेल है। यदि आप देखें कि मेरी माँ कहाँ खड़ी है, वहाँ घंटी में दरार है ... उन्होंने घंटी में दरार को देखा होगा - मुझे लगता है कि यह बिजली गिरने या किसी अन्य कारण की वजह से था। तभी अधिकारियों ने घंटी को जमीन पर उतारा। ये सभी मेरे भाई-बहन हैं। हमारी माँ के गुज़र जाने के ठीक बाद की बात है। लगभग सात साल, मैं कहूँगा। 2009 में उनका निधन हुआ और 2016 में हमारे पिता का निधन हुआ।

यह वाली बहुत, बहुत ही महत्वपूर्ण है। यह हमारा फ़ैमिली ट्री (वंश-वृक्ष) है जिसमें कई पीढ़ियाँ शामिल हैं। उन्होंने इसे बनाया। और मैं उसे पूरी तरह नहीं खोल भी नहीं सका। बड़ा, बहुत ही बड़ा था। उन्हें डर था कि हम अपनी सारी पीढ़ियाँ भूल रहे हैं... इसलिए उन्होंने यह सब संकलित किया। कुछ उर्दू में हैं - लेकिन मैं इसे पढ़ सकता हूँ। मुझे बैठकर इसे फिर से लिखना है - मुझे समय नहीं मिलता है लेकिन मैं इसे एक दिन करूँगा। जब मैं रिटायर (सेवामुक्त) हो जाऊँगा।

यह तस्वीर नर्सिंग होम में ली गई थी। यहाँ उनके द्वारा गुज़ारे गये आखिरी साल। अब मुझे इस बात का अफ़सोस है कि हमें उन्हें नर्सिंग होम नहीं भेजना चाहिए था। उन्हें अभी भी हमारे साथ रहना चाहिए था। मैं खुद को दोष देता हूँ - दोष नहीं, लेकिन मैं काम से एक साल की छुट्टी ले सकता था और फिर उन्हें वहाँ भेजने के बजाय उनकी देखभाल कर सकता था। खासकर उनका आखिरी साल। हालाँकि उन्हें नर्सिंग होम के बारे में कोई शिकायत नहीं थी - वे बहुत अच्छे थे - लेकिन यह सिर्फ एक सांस्कृतिक बात है कि उन्हें अपने बुढ़ापे में हमारे साथ रहना चाहिए था न कि हमसे दूर। भले ही उनका डॉक्टर हमें लंबे समय से उन्हें नर्सिंग होम में रखने के लिए कह रहा था, लेकिन हमने उसमें देरी की, हमने ऐसा नहीं किया - यह एक सांस्कृतिक बात है।

यह बहुत कठिन था। अच्छी बात यह है कि हमने इसे हमेशा पारिवारिक निर्णय के रूप में लिया। सिर्फ एक व्यक्ति नहीं बल्कि सभी चर्चा करते हैं, और हम कुछ तय करते हैं। घर में वे पूजा-पाठ किया करते थे। लेकिन वहाँ - ऐसा नहीं है कि कोई उन्हें प्रार्थना करने से रोकता था, लेकिन वे प्रार्थना करने के लिए एक साफ़ कोना और प्रार्थना की चटाई चाहते थे - उसके पास वहाँ प्रार्थना करने के लिए उचित जगह नहीं थी। इस वजह से वे प्रार्थना नहीं कर पाए। सांस्कृतिक रूप से...वे थोड़ा अलग-थलग महसूस करते थे क्योंकि वहाँ उस सुविधा में उनकी भाषा बोलने वाला कोई नहीं था। हालाँकि वे अंग्रेज़ी बोल सकते थे लेकिन उनके ऐक्सेंट (उच्चारण के लहजे) के कारण, अन्य लोग उन्हें समझ नहीं पाते थे, या वे लोगों के उच्चारण को नहीं समझ पाते थे। वे एक लेखक थे - वे पढ़ते और लिखते थे ... और रात में 8 बजे बतियाँ बंद हो जाती थी इसलिए वे चाहते हुए भी पढ़ नहीं पाते थे, तो यह एक और बात है।

केवल एक चीज़ जो अच्छी हुई वह यह थी कि वह सप्ताहांत के लिए हर सप्ताह हमारे घर आ पाते थे। यह अच्छा था क्योंकि यहाँ वे अपने सभी पोते-पोतियों से मिल सकते थे। यह अच्छा हुआ कि उन्होंने ऐसा किया।



No matter how
old I get, 🙄



I always want my mom
when I don't feel good 😊



Being positive

Urvashi's Story
Cultural identity: Indian
Hindi speaking

So, this is a picture of sunshine – sun rising. That was something that when Mum was in hospital, the hope that every day it is another day. Yes, the bright sun will come out. Every morning I was so positive...I remember saying to her, 'No. You should look at the good side...look how many people, how many nurses there are to help you. How many friends and family are calling you.'

I wanted to see it as positive as well. I was not ready to listen to those words and I always look at this and think, 'OK every day is a new day and hopefully things will get better.' And that positivity did help her...her body was functioning well, but again – I don't know – something happened and then she had a fever and next morning what I heard was that she's gone. And all the strength that I had was gone. So, for two days my body completely – you know the fighting element or the fighting soldiers that you have in your body, in your spirit, in your soul – you can fight – but they were gone completely out of it. Even today – sometimes I have episodes – like you know you feel your Mum is there but sometimes you just miss that phone call. You just want to talk to her. You want her to listen to you.

Dad said that I am the older – I will take the decision, and everyone was happy with my decisions. My siblings never questioned me. I should have given or done more. That's what my regret was – in terms of – just like the decision power was in my hand and just changing a doctor might have helped. I don't know...I just listened that okay everything is working 'cos I'm being positive. Or maybe getting a second opinion might have helped.

I don't know what was going through her head but...she would put it on her phone – those bhajans – and she would listen to it, and she would be calm. Peaceful, I would say. Maybe she might be talking to someone spiritually. Maybe she was trying to connect to some other world...or meditating – I don't know – but it definitely – yeah, she was calm.

This is a photo of two idols. In my culture, which is Indo-Asian, we do worship Lord Ganesha – the one on the right is the Ganesh. This is a god where any first good, auspicious events – you go and bow to this god. Every first ritual should be started with his name, if you start with his name it is believed in Hinduism that it will be always positive and right – it will end right way. Next to him is Saraswathi...goddess of knowledge. First time Mum was admitted to the hospital – when we leave the house, Mum has a picture of Ganesh on the door, and she worshipped that picture. We have to just say, 'Give us your blessing, so she will come back well, home.' When I was having all those negative messages coming that she is not doing well, she might not come back from when she went for the first time – I prayed and yes, she did come back. That's why I believe.

This is Lord Shiva – Shiva is the meditation and Shiva is Om. Lord Ganesha is the son of Shiva. So basically, I am the one who believes in both of them – Shiva and Ganesha. Shiva has a meaning to life. He says everything comes to zero. Everything comes back to me – the cycle of the earth or mankind cycle – it creates, it destroys and then again it creates and again it gets destroyed. So, get away from your sentimentals because everything is definitely coming back and everything is going back – rebirth – the cycle of life.

With us, what my problem was, that to some degree we don't know where to ask for help. So, psychologically that pressure at that moment – if you can ask right question, if you know whom to ask. Because the lack of knowledge is the reason why and believe me with Hindu culture – particularly with Indian culture – I am 100% sure that a lot of families in Sydney, in Western Sydney, are not having access to that information. We all try to – the first thing is – 'Hey, I am your friend. I know your friend, his Father passed away, so can you give me what happened? So, you will access that information, you will pass it to me and I will give it to someone else'. That is the only way. And that also depends on how big your network is and how accessible that information is.

I believe...giving access to those bhajans and the meditation in the ICU section as well...just by mingling or just by giving that laugh therapy in the hospital, in the ICU, people can get well. My observation is that the laughing is the best sometimes. Just like the strength that Lord Shiva and Lord Ganesh – it is photogenic – pictures for them, whether they want to do it. It is important to make your mind calm and it is important to make your mind diverted.

I'm not sure of the proper answer but bringing that positivity.



No matter how
old I get, 🙄



I always want my mom
when I don't feel good 😊



सकारात्मक होना

कहानीकार – उर्वशी
सांस्कृतिक पहचान: भारतीय
हिंदी भाषी

तो, यह सूर्य के उजाले का एक चित्र है - उगता हुआ सूर्य। वह कुछ ऐसा था कि जब माँ अस्पताल में थीं, एक उम्मीद कि हर दिन एक और नया दिन है। हाँ, उज्ज्वल सूर्य जल्द ही निकलेगा। हर सुबह मैं इतना सकारात्मक होती थी ... मुझे याद है मैंने उनसे कहा था, 'नहीं। आपको सकारात्मक पक्ष की ओर देखना चाहिए...देखिए कितने लोग हैं, कितनी नर्स हैं, आपकी मदद के लिए। कितने दोस्त और परिवार वाले आपको फ़ोन कर रहे हैं।'

मैं भी इसे सकारात्मक रूप में देखना चाहती थी। मैं उन शब्दों को सुनने के लिए तैयार नहीं थी और मैं हमेशा इसे देखती हूँ और सोचती हूँ, 'चलो, हर दिन एक नया दिन है और उम्मीद है कि चीज़ें बेहतर होंगी।' और उस सकारात्मकता ने उनकी मदद की... उनका शरीर अच्छी तरह से काम कर रहा था, लेकिन फिर से - मुझे नहीं पता - कुछ हुआ और फिर उन्हें बुखार हो गया और अगली सुबह मैंने जो सुना वह यह था कि वे जा चुकी हैं। और सारी शक्ति जो मुझमें थी, वह चली गई। तो, दो दिनों के लिए मेरा शरीर पूरी तरह से - जैसे आप अपने शरीर के लड़ने वाले तत्व या आपके भीतर जो लड़ने वाले सैनिक हैं, आप उन्हें जानते हैं, जो आपके शरीर में, आपकी आत्मा में हैं - कि आप लड़ सकते हैं - वे पूरी तरह से वहाँ से निकल चुके थे। आज भी - कभी-कभी मेरे साथ एपिसोड होते हैं - जैसे आप जानते हैं कि आपको लगता है कि आपकी माँ यहीं हैं, लेकिन कभी-कभी आप उस फ़ोन कॉल को याद करते हैं। आप बस उनसे बात करना चाहते हैं। आप चाहते हैं कि वे आपकी बात सुनें।

पिताजी ने कहा कि मैं बड़ी हूँ - मैं निर्णय लूँगी, और मेरे निर्णयों से सभी लोग खुश थे। मेरे भाई-बहनों ने मुझसे कभी सवाल नहीं किया। मुझे और देना या करना चाहिए था। यही मेरा अफ़सोस था - कि जैसे निर्णय शक्ति मेरे हाथ में थी और सिर्फ एक डॉक्टर को बदलने से मदद मिल सकती थी। मुझे नहीं पता ... मैंने अभी सुना कि ठीक है सब कुछ ठीक चल रहा है 'क्योंकि मैं सकारात्मक हो रही हूँ। या फिर शायद एक दूसरी राय लेने से मदद मिल पाती।

मुझे नहीं पता कि उनके दिमाग में क्या चल रहा था, लेकिन ... वे इसे अपने फोन पर चला देतीं - वे भजन - और वे उन्हें सुनतीं, और वह शांत हो जातीं। भीतर से शांत, मैं कहूँगी। शायद वे किसी से आध्यात्मिक रूप से बात कर रही थीं। शायद वे किसी दूसरी दुनिया से जुड़ने की कोशिश कर रही थीं...या ध्यान कर रही थीं - मुझे नहीं पता - लेकिन निश्चित रूप से - हाँ, वह शांत थीं।

यह दो मूर्तियों की तस्वीर है। मेरी संस्कृति, जो इंडो-एशियन है, इसमें हम भगवान गणेश की पूजा करते हैं - दाईं ओर गणेश हैं। यह एक ऐसे देवता हैं जहाँ कोई भी पहली, अच्छी या शुभ घटनाएँ होती हैं - आप जाकर इस देवता को झुक कर प्रणाम करते हैं। पहली हर धार्मिक विधि की शुरुआत उनके नाम से करनी चाहिए, अगर आप उनके नाम से शुरू करते हैं तो हिंदू धर्म में यह माना जाता है कि यह हमेशा सकारात्मक और सही होगा - उसका नतीजा सही होगा। उनके साथ मैं सरस्वती हूँ... ज्ञान की देवी। पहली बार माँ को अस्पताल में भर्ती कराया गया था - जब हम घर से निकले, तो माँ के दरवाज़े पर गणेश का चित्र होता है, और उन्होंने उस चित्र की पूजा की। हमें बस इतना कहना होता है, 'हमें अपना आशीर्वाद दो, ताकि वे अच्छी तरह से घर वापस आ जाएँ।' जब मेरे पास वे सभी नकारात्मक संदेश आ रहे थे कि वे ठीक नहीं हैं, वे शायद वापस नहीं आएंगी जब वे पहली बार गई थीं - मैंने प्रार्थना की और हाँ, वे वापस आ गईं। इसलिए मुझे विश्वास है।

ये हैं भगवान शिव- शिव ही ध्यान हैं और शिव ही ओम हैं। भगवान गणेश शिव के पुत्र हैं। तो मूल रूप से, मैं ऐसी हूँ जो उन दोनों में विश्वास रखती हूँ - शिव और गणेश में। शिव का जीवन के लिए एक अर्थ है। उनका कहना है कि सब कुछ शून्य हो जाता है। सब कुछ मेरे पास वापस आ जाता है - पृथ्वी का चक्र या मानव चक्र - यह बनाता है, यह नष्ट करता है और फिर यह बनाता है और फिर से नष्ट हो जाता है। इसलिए, अपनी भावनाओं से दूर हो जाओ क्योंकि सब कुछ निश्चित रूप से वापस आ रहा है और सब कुछ वापस जा रहा है - पुनर्जन्म - जीवन का चक्र।

हमारे साथ, मेरी समस्या क्या थी, कि किसी हद तक हम नहीं जानते कि कहाँ मदद माँगें। तो, मनोवैज्ञानिक रूप से उस समय वह दबाव - यदि आप सही प्रश्न पूछ सकते हैं, यदि आप जानते हैं कि किससे पूछना है। क्योंकि ज्ञान की कमी इस बात का कारण है 'कि क्यों', और मुझ पर विश्वास करें कि हिंदू सभ्यता में - विशेष रूप से भारतीय संस्कृति में - मुझे 100% यकीन है कि सिडनी के, पश्चिमी सिडनी के बहुत सारे परिवारों की उस जानकारी तक पहुँच नहीं है। हम सभी कोशिश करते हैं - पहली बात होती है - 'अरे, मैं तुम्हारा दोस्त हूँ। मैं आपके दोस्त को जानता हूँ, उसके पिता का निधन हो गया है, तो क्या आप मुझे बता सकते हैं कि क्या हुआ था? तो, आपको वह जानकारी प्राप्त होगी, आप इसे मुझे दे देंगे और मैं इसे किसी और को दूँगी।' यही एक मात्र तरीका है। और यह इस बात पर भी निर्भर करता है कि आपका नेटवर्क कितना बड़ा है और वह जानकारी कितनी सुलभ है।

मेरा विश्वास है...उन भजनों तक दी गई पहुँच और आईसीयू सेक्शन में भी ध्यान-साधना... सिर्फ घुलने-मिलने से या अस्पताल में, आईसीयू में उस हास्य-चिकित्सा से ही लोग ठीक हो सकते हैं। मेरा मानना है कि कभी-कभी हँसना सबसे अच्छा होता है। ठीक उसी तरह जैसे भगवान शिव और भगवान गणेश की शक्ति - यह फोटोजेनिक है - उनके लिए ये चित्र हैं, चाहे वे इसे करना चाहें। अपने दिमाग को शांत रखना जरूरी है और अपने दिमाग को दूसरी बातों में लगाना जरूरी है।

इसके सही उत्तर के बारे में तो मैं निश्चित नहीं हूँ लेकिन उस सकारात्मकता को ला रही हूँ।



Dancing out of the depression

Alice's Story
Cultural identity: Chinese
Mandarin speaking

My husband passed away in Australia. Nearly three years now. Thinking about it, it's [gone] so fast. I temporarily lost control, I was suffering depression. He was the rock of the family, he did everything for the family. So after he left, I just completely lost everything. It was very, very sad. Very difficult.

His condition was only discovered one year [before] he passed away. We tried every single medical way. My daughter tried to find all the different doctors. The doctor said he still clear in the mind but if they're going to give him operation, it might make it worse. So, they couldn't operate. Later on, he was sometimes clear, sometimes unclear – like confused. He was not quite conscious all the time.

The palliative care at home was very, very good...I think Australia has done wonderfully in this aspect. I really feel grateful. In China we would never dream to have something like this. The most helpful thing was [the people] coming to help care for him. And also giving us a lot of instruction, teaching us how to care for a patient. The people who carry the services...they've all got a good attitude. I was very touched and moved in all of what they do.

[At times] it was too hard to carry him by myself. [One day] I accidentally dropped him and he fall on the ground just as the nurse came in...I asked, 'Can I have a hand to bring him up' and the nurse refused because she didn't want to hurt her back. So, she couldn't help me. After the nurse left, I tried my very best a little bit by little bit try to bring him up and then we both fell on the ground again. I was disappointed that people are different. Some people just kind enough [to help]. Some will not do it.

Before he went to the palliative care hospital, the palliative care doctor told us, 'You've got to be prepared. He's probably going'. They asked if we wanted to send him to the palliative care hospital or care for him at home. My daughter tried to insist to care for him at home. But my daughter had to go to work. So, I just really think we have to go to the hospital. Even though we made the decision to take him to the palliative care hospital, my daughter after a heavy day of working, she would go to the hospital and stay there the whole night with her Father. I was thankful that I have such a devoted daughter.

One thing that always still bothers me, that in hospital at the very end after he passed, they took clothes off of him and put him into the hospital clothes. In Chinese cultural traditions, we pay great attention to the clothes that the person goes out wearing. When the person passes, when the body's still really warm, we need to put on the formal best clothes for them to go. They didn't give us the opportunity to do all of that. No-one asked, no-one helped to do it, and no-one gave the opportunity to do it.

We cannot ask more, but medical people, you choose your career as medical care for other people. At the end-of-life, that's where people need more care...put your feet into the person's shoes or the family's shoes. Be more respectful for what you do for the people, for the family who are passing.

This photo was taken about half a month after my husband passed away. My daughter tried to divert my attention and bring me out of the sadness, so she took me to the city. It was the celebration for Christmas, Pitt Street mall. That evening the performance was very, very good. I felt that my spirits were lifted up. I was feeling severe depression for the next year, so to get me out of this my daughter took me on a trip to Europe. This was Interlaken, on the highest mountain in Switzerland. Three days in Switzerland but we travelled Europe for more than 20 days. I went back to China...to my hometown, Shandong. A very beautiful city. My daughter and my Granddaughter accompanied me back. It was very, very difficult for me to go back to our house...I felt more depressed. Coming out meeting relatives and friends, especially at night-time to see the beautiful night scenery...it made me feel a little bit better.

This [photo] was about two years later. Because my husband was a professional singer and I love dancing, I had joined this arts group. Before he was diagnosed, I would regularly join the group. But when he got sick, it had been more than two years that I didn't go. I stopped all of this. My daughter suggested I go back to the group for dancing. It helped me emotionally, [I felt] much, much better. This performance [at Darling Harbour], we practiced the rehearsal many times before. We also won the prize! I have to find a way to get myself out of the depression, so participating in this dancing group and the art group has really helped me to get out of it.



跳舞帮我走出了抑郁

爱丽丝的故事
文化背景：中国人
普通话母语人士

我的先生在澳大利亚去世了。那是将近三年前的事了。现在想想，时间过得真快。我有一阵子感觉自己失控了，我得了抑郁症。我先生是全家人的磐石，他为了这个家尽心尽力。他走了以后，我像失去了一切似的。我感到悲痛欲绝，那真是一段艰苦的日子。

我先生是在去世前一年才被诊断出罹患了疾病。我们试尽了各种疗法，我女儿也帮我先生到处求医。医生说先生当时意识清晰，但如果要动手术，可能情况会变得更糟糕，所以医生不能动手术。后来，我先生的意识时好时坏，有时会感到困惑，他不能一直保持清醒。

居家姑息护理服务非常、非常好... 我觉得澳大利亚在这方面做得非常好，我对此非常感激。在中国，我们做梦也想不到能有这种服务。对我们最有帮助的就是能有人上门帮忙照顾他，而且还给了我们很多指导，教我们要怎么照顾病人。提供这方面服务的护理人员态度都非常好，有他们帮忙，真的让我非常感动。

[有的时候]我一个人力气不够，抱不动我先生。[有一天]我手滑，结果他跌到地上了，刚好那个时候护士来了，我说‘可以帮我把他扶起来吗？’护士不愿意，因为她担心会伤了自己的背，所以她无法帮我。护士离开后，我自己努力想慢慢地把他扶起来，结果我们俩后来一起跌坐到地上了。我那时很失望，感到每个人都是不一样的，；有的人心肠很好愿意[帮忙]，而有的人却不愿意帮忙。

我先生进姑息治疗医院之前，姑息治疗医生跟我们说，“你们要有心理准备，他很可能就要离世了。”医生问我们是希望让他进姑息治疗医院理，还是希望在家自己照顾他。我女儿原本坚持要在家照顾我先生，但是我女儿需要工作，所以我觉得还是需要送我先生去医院。后来虽然我们决定送我先生去姑息治疗医院，我女儿工作一整天虽然很累，晚上还是会去医院整晚陪她父亲。女儿这么贴心孝顺，让我感到非常欣慰。

有件事令我到现在都耿耿于怀，就是我先生过世后，医院的工作人员把他的衣服脱下后给他穿上医院的衣服。在中国的文化传统中，我们很重视人走的时候的穿着。在人刚刚去世的时候，趁着身体还有余温的时候，我们需要替死者换上最好的衣服让死者体面地离开，但医院却没有给我们这个机会。没有人问过我们想怎么做，没人帮我们做这件事，医院也没给我们机会这么做。

我们也不能再要求什么了。不过身为医护人员，你们选择了从医，以照顾病人为职业，而人在临终的时候是最需要照顾的时候... 医护人员应该设身处地为病人和家属着想，更加地尊重临终的病人和他们的家属。

这张照片是在我先生走了之后大概半个月拍的。我女儿带我去市中心走走，想帮我散散心不要过度悲伤。当时在 **Pitt Street** 购物商场有圣诞节庆祝活动。当天晚上的表演非常精彩，我的心情确实好了很多。在接下来的一年，我陷入严重的抑郁，所以女儿决定带我去欧洲旅游。这张是在瑞士最高的山因特拉肯上拍的。我们在瑞士呆了三天，这次的欧洲之旅总共去了 20 多天。我后来回中国我在山东的老家。我的老家是个很美的地方。我女儿和孙女跟我一起回中国。其实回家对我来说真的很不容易... 我感觉自己更抑郁了。不过过去拜访亲友，尤其是晚上出门欣赏美丽的夜景，让我感觉好点。

[这张照片]是大概两年后拍的。我先生是职业歌手，我自己很喜欢跳舞，所以后来我就加入了这个康乐小组。在我先生确诊前，我经常参加康乐小组的活动。自从他生病后，我有两年都没有参加康乐小组的任何活动。后来我女儿建议我再次参加康乐小组的跳舞活动。跳舞让我心情好起来，开始参加后[我感觉]好多了。我们为了[在达令港]的舞蹈表演排练了很多次，结果后来我们还得了奖呢！我需要努力走出抑郁，参加舞蹈小组和康乐小组的活动帮助我走了出来。



Community connection, care, and contribution

Anna's Story
Cultural identity: Chinese
Mandarin speaking

In 1996, my Mum had breast cancer and had an operation. It later spread. She got very, very ill. The hospital cannot see any treatable solution, so they suggest to us to take her home. I went back to China April 2004 and Mum passed away in November 2004. We were looking after her under the care and instructions of the doctors. No palliative care, no other support, but most of the relatives came visiting. Especially my brother and my Mother's nephew and nieces – they came from different city of China to come and pay a visit. Only three months before she passed away, we started telling her the truth of her spread of cancer. This is part of the tradition, the cultural thing in China - the people would hide the truth for the person who suffers. If we tell her, she would be more stressed and more worried and that would contribute to the deterioration of her problems. When we told her, she told us that she in fact already knew how seriously ill she was, but she didn't want to worry the family.

My older brothers and all of us at that time were asking my Mum for any last wishes. She told us the only thing she wanted was to go back to her own hometown, Harbin. We lived in my older cousin's house – they hosted the whole family. Had a special room for my Mother allowing us all to take care of her in their place. Nurses came in every day to provide some injections, nutrition stuff and also the pain killer medications they inject for her every day. Everyone was very supportive. Not only my cousin and his wife but also their children. That made me understand why Mum kept asking to go home – go back to her hometown. Because all of the family – the relatives – are the ones that really care about her, and they treated her and all of us really nice.

[In this photo] the two sitting in front are my Father and my Mother and my left hand is my younger sister and the right hand is my older brother. And the two younger ladies at each end are my nieces. Because I came to Australia – my parents were looked after by my younger sister and my older brother. But because my Father was quite strong, he took the main care role for my Mum. When my Mum passed away, I applied for a visiting visa for my Father [aged 81] to come to Australia. My Father really liked Australia, the civilisation, the climate. During the time my Father was in Australia, he was diagnosed with cancer. [After his diagnosis] the family decision was to bring Father home, to get treatment in China because he didn't have Medicare in Australia. I went back to China with my Father straightaway, and he had operation in China. The test says it was already later stage and spread through his system. The doctor said he won't last more than half a year. Because my Father liked Australia so much, I applied another visa for him to visit again in 2006. He came here and spent some really happy time with us. We took him for travelling – to the park, the sceneries, we went to Melbourne and a lot of places. In January 2007, we realised that he's getting worse and in February I sent him back to China. That time the cancer had spread to his kidney, so he started dialysis every week.

Because my Father loves travelling, although we know he's not in very good health, I took him travelling to Shanghai. So, both my Mother and my Father, before they passed away, they were all in a very good happy status. Number one is because the family altogether. Number two is merely that we made sure the painkiller – everything – was adequate. We didn't let them suffer, they both died peacefully. In 2012, me and my husband brought our little Grandson back to China to see my Mother-in-law. She really likes boys – she was very, very happy to see him! I was very pleased that before my Mother-in-law passed away, she has seen her Great-grandsons.

The passing of my parents made me depressed for a number of years until I found and joined The Hills Chinese Association in 2012. Although my little Grandson was only two years old and I was extremely busy at home taking care of the family, joining the association changed my life. The majority of Association members came from China and they're aged between 60 to 80. Now we have members at age of 92. Due to the language barrier and those unable to take transport, I pick them up and drive them home each week after our activities. Since the establishment of our Association, we had about four members die from cancer. We often visit them in the hospital, visit them at home. Having an association like this has given them great mental and spiritual and social support. Our regular activities every week include a choir; Tai-chi; dancing; fashion parade – a lot of different activities. We also have health information or seminars from time to time. This is also the reason for me to continue to lead this Association. It's the best medicine – but it's even better than medicine! Having the social interaction helps people to overcome a lot of difficulties and sadness. It directly helps those who newly arrived to Australia to overcome many challenges and assists them to integrate into Australian Society.



社区联系、护理与贡献

安娜的故事
文化背景：中国人
普通话母语人士

1996，我的母亲罹患了乳腺癌并做了手术。后来癌细胞扩散了，母亲病得很严重。医生认为已经没法治疗了，于是建议我们把母亲带回家。我们在 2004 年 4 月的时候回了中国，母亲在那一年的 11 月去世了。我们当时是在医生的照顾和指导下照顾母亲的。当时没有姑息护理，也没有其他的支持，不过大部分的亲戚都来看望母亲。尤其是我的兄弟和我母亲的侄子和侄女，他们从中国不同的城市来看望母亲。我们在母亲去世前三个月才告诉她癌症已扩散的事实。这是中国人的传统，人们往往会向病人隐瞒真相。如果我们把实情告诉她，她会更忧虑压力更大，这样反倒会加重病情。在我们告诉母亲实情后，她说其实她已经知道自己病得很重了，但是她不希望家人替她担心。

我的哥哥和我们大家都问母亲有什么最后的心愿，她说她唯一的心愿就是想回她的老家哈尔滨。我们当时住在表见的家，他们接待我们全家人，还为母亲准备了一间房间，让我们可以在那里照顾母亲。护士每天都会来给母亲打针，补充营养和为她止痛。大家都互相扶持，这不但包括我的表兄和他的太太，还有他们的孩子。他们让我明白了为什么母亲一直想回家，回老家。这是因为全家人和亲戚们都很关心母亲，大家对我母亲和我们都非常好。

[这张照片里]坐在最前面的是我的父母，在我左边的是我妹妹，在我右边的是我哥哥。站在最外侧的是我的两个侄女。因为我来了澳大利亚，所以父母是由哥哥和妹妹照顾的。我父亲身体挺硬朗，所以母亲主要是由父亲照顾的。母亲去世后，我为我父亲[当时已高龄 81 岁]申请了来澳大利亚的旅游签证。父亲很喜欢澳大利亚的人文和气候。父亲在澳大利亚期间确诊了罹患癌症，之后家人决定把父亲带回国，让他在中国接受治疗，因为他没有澳大利亚的医保卡。我立刻跟父亲回中国，回国后他就接受了手术治疗。检查报告结果显示癌症已经晚期，而且已经全身扩散了，医生估计他大概还有不到半年的时间。因为父亲非常喜欢澳大利亚，我在 2006 年又申请让他来澳大利亚旅游。他来到澳大利亚之后跟我们度过了愉快的时光。我们带他到处走走，去公园，去户外看风景，还去了墨尔本和很多其他地方。2007 年 1 月，我们看出他的健康状况变得更差了，于是在 2 月份的时候我们就送他回中国了。后来癌症扩散到了他的肾脏，于是他每天都需要做透析。

因为父亲很喜欢旅游，虽然知道他的健康状况不好，我还是带他去了趟上海。所以我母亲和父亲在走之前心情都很愉快。主要的原因是家人都在一起，还有就是我们确保止痛药和其他东西都准备妥当。我们没有让他们受苦，他们俩都是很安详地走的。2012 年，我和我先生带小孙子回中国看望我婆婆。她看到孙子的时候真的很高兴！我庆幸婆婆走之前见到了她的曾孙子。

我父母去世后，我有几年的时间心情非常低落，直到我在 2012 年加入了 The Hills Chinese Association 华人社区协会。当时虽然我的小孙子才两岁，我自己也在家忙着照顾家人，但是加入了华人社区协会改变了我的生活。社区协会大部分的会员都来自中国，年龄在 60 到 80 岁之间，现在甚至有高龄 92 岁的会员。因为语言不通，有些人无法搭乘公共交通工具，所以每周活动结束后，我就会送他们回家。自从社区协会成立后，有 4 个会员因癌症去世了，[患病期间]，我们会经常去医院或者去他们家看望他们。成立了这样的华人社区协会后，他们在精神和社交上都得到了很大的支持。我们每周的活动包括合唱团、太极拳、跳舞、时装走秀，还有其他各种各样的活动。我们还经常举办健康方面的讲座。这也是为什么我一直积极投入统筹华人社区协会的活动，因为其实这是最好的良药，甚至比良药更有益处！参与社交活动能帮助人克服许多困难，让人心情好转。华人社区协会协助来到澳大利亚的新移民克服许多困难，并帮助他们更好地融入澳大利亚社会。



Respect and kindness

David's Story
Cultural identity: Chinese
Mandarin speaking

Talking about end-of-life care, I have very strong feelings...no matter whether my parents, or my parents-in-law, and including my Grandparents – they were treated very, very well. The strongest experience and feelings I have, is the tradition of my family.

In 1994, I went to New Zealand and then came to Australia. The biggest regret in my life is that Mum never came to Australia. The reason being Mum was carsick, [when she travelled] she suffered a lot. In 1995, I got a Permanent Residence Visa and I talk to Mum about it, and she started crying. I told Mum not to worry and that I will be back all the time but in fact we didn't permanently go back, but I made sure that I go back to see her every year.

One thing that I was really, really comforted by is that I have a sister and one brother and one younger sister. The four of us. My older sister passed away a bit earlier [than my Mum] and my younger sister and brother respect and treat my [Mother] really, really well. We don't have support from the government. My brother and sisters were a very strong support for Mum. She never lived on her own. She always lived with family members. In Feb 2015, my sister told me Mum might not be able to pass September. So, I went back to China, Mum was okay. Because she was sick, that year, I went back to China three times. She actually passed away in January 2016. Before that there was a family gathering. My Mum was acting normal but said something weird, she said 'You're all coming too early', she felt that she will still live longer. I know that Mum was going, that time...I knew from my heart. Of course, I want her not to be going so soon, but I understood that a human life has an end. You just can't control that. So, I just feel that if she can peacefully go, then that's what it is.

For Chinese people, it's important for someone to die wearing nice clothes, so my wife prepared everything before we left the country. She made all those clothes by her own hands. At the end stage of my Mum, she was asleep all the time...so sometimes I try to feed her a little bit of milk, she would open her mouth, accept a little bit of milk. But my brother and my younger sister, realised that Mum will not get any better, so they kept telling me, 'Don't trouble her anymore because she's a high age and let her peacefully go'. We believe this is the good ending. And also should be celebrated.

The night when she was passing, the whole night, we company Mum. So, everyone was comforting her – reading prayer – Buddhist prayer. Every single person would be shaped around reading those prayers next to her – that whole night until she passed. My sister, my brother and myself. We believe it was ageing, she didn't have a proper diagnosis of medical conditions...she didn't have any medical suffering. She was 92.

This photo was taken in 1987. Mum was living with us. This was my house, located in the campus of the University in Heilongjiang where I was a teacher in Electronic Automotive Control. This other photo was taken 1999, I was 50 years of age and I went to visit Mum and the family. That's the four children of Mum. My brother, my two sisters. My sister passed away 2005, I was there with her as well. I knew that no medical treatment can be provided, so I just thought to be with her is important, so I was there with her. This one is [Mum's 83rd] birthday, 2007, nine years before she passed away.

If I had my Mum here in Australia with me...I would do my very best to do what I can for her. My Mum treated her own Father-in-law so well. My Father left earlier...passed away. And then before my Grandfather was passing away, my Mum bought the coffin and did everything for my Grandfather. Taking care of him. Mum is a person that treated everyone so nicely, including the neighbours, friends, everyone that had been fond of her.

We talk about end-of-life – we should educate our young people. Regardless how many degrees you have got, how much knowledge you have, or the hierarchy you are at, your position...if you can't be a great person then that's all nothing. So, you need to be a kind person. Be a person first. I would suggest to [medical and support teams] that they not just fulfil their job responsibility, but to smile, be friendly and have the right attitude towards others. Smile to the person you care to show your respect in a nice human way...give the person who is passing the feeling: *I love to do what I'm doing for you. Not that I have to do what I do for you.* Very important. Care for end-of-life – the Chinese tradition is respect. Respect to the person who is passing... who is suffering, in pain – give them more understanding and also provide more sympathy rather than be impatient. You need to understand rather than discriminate. Ask them what they want. Everything you do to them, be friendly. Be friendly, be kind. Kindness. Human respect. Very important.



仁慈与尊重

大卫的故事
文化背景：中国人
普通话母语人士

说到对老年人护理，我很有感触…无论是我的父母，还是我的祖父母，包括我的岳父母，他们都对其家人和子女有很好的照料。对于我最有感触的特别是我家人的优秀传统……

1994年我技术移民到了新西兰，99年末全家迁移到悉尼。我这辈子最感到遗憾的是我的母亲没能来到澳大利亚。这是因为母亲她晕车，平时坐车总晕得很厉害。1995年，当我拿到永居签证，告诉我母亲时，我发现母亲立刻就失声痛哭。于是我立即劝说母亲千万别难过，我会经常回来看她的。我虽然并没有回国定居，但是我基本是每年春节都回国看望母亲。

令我感到安慰的是，我有一个姐姐、一个弟弟和一个妹妹，我们兄弟姐妹四人。可我的姐姐却比我母亲早逝。我弟弟和妹妹对我母亲非常孝顺，因此母亲一直都和我弟、妹家人常住一起。2015年2月，妹妹告诉我母亲可能撑不到9月份了，于是我立即回了国。因为回去看到母亲的情况还好，短时间就返回了悉尼。就是因为母亲不是明显病重，那年我回国了三趟。我的母亲是在2016年1月去世。去世之前众多家人亲友曾经团聚一次。当时母亲的状态还算正常，因此她对拜访她的亲友们就说，“你们都要送我，来的太早了，”母亲也觉得自己还能多活久一点。其实当时我心里就意识到，母亲剩下的日子不多了。当然我不希望她那么快就离开我们，但是我也明白人人都会走到人生的尽头路。生死其实并非全由自我掌控。所以我觉得如果母亲能够安详辞世，那就顺其自然吧。

中国人很重视人走的时候要穿得体面，因此我妻子在出国前把东西都准备好了。她亲手做了好多个衣物。母亲在最后那段时间，差不多一直在睡觉，当时我也跟着让她喝点牛奶，她也会张开嘴喝一点。不过我弟弟和妹妹都觉得母亲的情况不会好转，所以他们一直跟我说，“别再叫醒妈妈了，她年纪已经很大，让妈安详地走吧。”我也觉得这样的人生终了还算好，真是希望母亲能如此安详地离去。

母亲去世的那晚，我们整夜陪着她。大家都为母亲能如愿而围绕在她身边为她念经，直到她去世。其实医生也没有给母亲诊断出患了什么病，她也没什么病痛。妹妹、弟弟和我都觉得其实母亲就是因为年龄已大，母亲去世时正是92岁高龄。

这张照片是在1987年拍的。当时我家位于河北省秦皇岛市燕山大学的校园内，母亲一直和我们住在一起。我当时在燕大自动控制系任教。另一张照片拍摄于1999年，我当时50岁。我回去看望母亲和家人。照片是我母亲与我和我弟弟、姐姐及妹妹。我姐姐是在2005年去世。她去世之前我也在身旁陪着她。我知道医生已经无法向她提供治疗了。那个时候我能在姐姐身旁陪着她，就是出于我乐于展示自己对于亲人的由衷爱意，并希望她感受到人间在世的欣慰。这张是母亲83岁大寿时的照片，2007年，母亲去世前9年。

如果当时我母亲跟我在澳大利亚的话，我一定会尽全力好好照顾她。母亲对我的爷爷奶奶都非常好。我父亲走得比较早。我祖父去世前，我母亲就帮他买好了棺材并把一切都打点好了，也一直对我祖父很孝顺。我母亲对每个人都很好，不管是对邻居、朋友都很好，大家都很喜欢她。

说到临终，我们应该在这方面教育年轻人。一个人无论拿了几个学位，学识有多渊博，或者享有多高的社会地位，如果为人不好，那什么都别谈了。做人首先就是要正直善良。我对医疗人员的建议是，不仅要履行身为医疗人员的职责，还要面带微笑，待人和善，以正确的态度对待别人。对你所照顾的人微笑，表示你尊重他，让那个不久之后就要离世的人感觉到你的仁慈、善良与可敬。而不是出于义务不得不做这些事情。我觉得中国人的优秀传统文化，就是临终照顾的核心是尊重。向那些忍受疼痛煎熬，所剩日子不多、即将离世的人表示尊重，对他表现理解、同情，而不是表现出不耐烦的神态。需要理解他而不是看不起他。坚持正常的咨询与安慰。若总是对他们态度仁慈、和善，并能顾及他人的尊严，这些都是非常重要的。这也是我的人生观念。



Love with no ending

Mary's Story
Cultural identity: Chinese
Mandarin speaking

10 years ago, I was running a restaurant. I gave up the restaurant business and just wanted to spend a bit of time to go to China to visit my parents. I went back every year for three months – each time I take care of my parents while I was there. I really treasure the time that I spend with them. I refused to see friends or classmates, I spend every single minute with my parents. I was cooking three meals for them. This is a photo of when I went back to take care of my parents.

Five years ago, both of my parents passed away within months, one by one. Mum had a fall and was unconscious and she had operation, she never recovered, never made it home. She was 90 years old. Dad was very sad, shocked. He followed by one month. He went into hospital and then he passed. I didn't even know Mum had a fall. I had just returned from China. The family decided not to bother me because I only just returned. But after 11 days [in hospital] Mum passed away. I return to China straight away to be with my Dad, but my Father...he just can't come out of it. He was talking about Mum all the time. Everything happened so sudden for him. I knew he was not well...we called the ambulance and after about one week, only just one week, my Father passed. He was 95. Everything happened so suddenly. All of my family were there, I've got five siblings. The family members, two of us at a time, we did shifts at night so we can stay in the hospital every night. Because of my Father's age, we didn't want anyone else. We prefer ourselves to look after him. We were making juice and we purée all the food at home and we bring them into the hospital to feed him. Yes, we were all putting in our hardest, our best, to look after him that time.

Because we saw Mum's operation failed, was unsuccessful, we insist that we wouldn't let Dad suffer. We refused operation or any other treatment, we did not agree to insert the tube but only allow to have him on drips. I left the hospital 10.30 and I was going to go home to cook fish soup for him. My older sister and her husband were there, and Dad was asleep. There was no sign of going to pass. My sister discovered the machine – the heartbeat had stopped. He was asleep so that's how he went. All of us straightaway went back to the hospital. We were all very, very, very sad.

The traditional Chinese way is to put all the clothes for him out. So, there was someone [at the hospital] helped us, instructing us...this is called the Holy Clothes. It's all in silk...including the shoes. Has to be embroidery with flowers. Elderly people when they go, they must have these special clothes. I think in English this word is shroud? We have prepared this for my parent some time ago before they passed away. This is a long tradition. In Australia, there's no way we can decide. It all depends on our children if they still continue do this [tradition] or not. We can't make that decision once the patient is in hospital, the hospital will arrange everything. In this aspect, I think they wouldn't because number one – we couldn't buy those clothes here and the children I don't think they will do it.

Migrating has changed a lot of traditions...a lot of traditions since been given away. Gone. One strong Chinese tradition is that children should always respect their parents, take care of their parents, especially when their parents are getting old. This is not as strong as before...totally different from our generation – we have whole heart full to our parents. These days the young people are a bit different. We talk about this a lot. Chinese people say, 'We're the last generation treat our parents like this'. I really want this kind of moral to be maintained and continued.

I came back from China after my parents passed...I just couldn't come out of the emotional sadness. I was very lucky that I had the Hills Chinese Association...that's helped me a lot to come out of the emotional sadness, bring my life back to normal. I came back and joined the volunteer work. We visit the aged-care facilities, and we prepare many performances so we can concentrate on the rehearsals. So, in that way all my time has been occupied by the busy schedule and it makes me feel better.

This picture was a multicultural event of Celebration on Australia Day. China has 56 nationalities. This is the costume of the Xinjiang Province, you can identify the different nationalities by different dress. This is one of the poses in our performance of the Xinjiang dance. This other one is representing The Chinese Porcelain – these two colours symbolise Chinese tradition. It is called "QING HUA CI" qing is blue; huā is flower...it's this blue and white specifically. We made a dance of that representing the culture of China...the porcelain. I participated in a Family Health Fun Day, The Night of Shanghai – is a very popular piece of music of China. We also held a barbeque during the event. Yes, yes. I feel my life is fulfilled and very full up. Until now, I continue to be a volunteer serving our community in whichever way I can.



无止境的爱

玛丽的故事
文化背景：中国人
普通话母语人士

十年前，我当时是经营餐馆的。我放弃了餐馆生意，只想花一点时间去中国看望我的父母。每年我都会回国三个月，每次回国都会去照顾我的父母。我很珍惜跟父母相处的时光。我回国没去找同学或朋友，我把所有的时间都花在陪伴父母上。我每天为他们准备三餐。这张照片是我回国照顾父母时拍的。

五年前，我的父母在短短的几个月内相继去世了。我母亲因为跌倒昏迷被送进医院接受手术，此后就再也没回家。她去世时享年 90 岁。母亲的去世对我父亲打击很大，他非常伤心，一个月后父亲也走了。他进医院后就去世了。我当时不知道母亲跌倒了，我当时刚刚从中国回到澳大利亚，因此我的家人决定瞒着我，不跟我说母亲跌倒的事。可是母亲住院 11 天后就去世了。我立刻回中国陪我父亲，但是很遗憾，父亲走不出丧偶的哀痛。他一直挂念着我母亲，事情对他来说发生得太突然了。我知道父亲的状况不好，我们叫了救护车，过了大概一个星期之后，我父亲也去世了。他去世时享年 95 岁。当时这一切都发生的太突然了。我的家人都在那里，我一共有五个兄弟姐妹。家人们轮班照顾，每晚都有两个人在医院。由于父亲年纪很大了，所以就没有安排让其他人来照顾他，我们觉得还是我们自己照顾他比较好。我们在家打果汁，把食物打成泥，然后带到医院喂父亲。当时每个家人都竭尽全力照顾父亲。

因为母亲的手术失败了，我们不想让父亲受苦，所以我们拒绝让他接受手术或其他的治疗。我们不同意让父亲插管，只同意让他接受输液。那天晚上 10:30 的时候我离开医院回家给父亲煮鱼汤。我的姐姐和姐夫在医院，父亲睡了。当时没有任何迹象显示父亲要去世了。我的姐姐发现心电图——父亲的心跳停了。父亲在睡梦中安详地去世了。当时我们全都立刻赶回医院。大家都非常、非常地难过。

中国人的传统是为逝者穿寿衣。医院当时有人在这方向我们提供协助，告诉我们要怎么做。寿衣是丝做的，包括穿的鞋子也都是丝做的。寿衣上会绣有花朵。长者去世时都会给他们穿上寿衣。我们在父母去世前就已经帮他们准备好寿衣了，这是历史悠久的传统习俗。在澳大利亚，我们没得选择，这些都要看我们的孩子是否遵从传统习俗。还有，一旦患者入院之后，我们就没法自己做这方面的决定了，因为医院会负责所有的安排。我觉得在这方面，医院是不会决定让给逝者换上寿衣的，因为首先这种特殊的寿衣在澳大利亚买不到，而且年轻人大概也不会遵从这样的传统习俗。

移民到国外后，很多传统都会改变、会流失。中国人一项固有的传统就是孩子要孝敬父母，照顾年迈的父母。如今这项传统观念已经没有以往那么浓厚了，跟我们这一代人比起来已经差很多了；我们都是全心全意孝敬我们的父母。现在的年轻一代比较不一样了。我们经常讨论这个问题。中国人说“我们是会这样孝敬父母的最后一代人了。”我真的希望这种优良传统能继续传承下去。

父母去世后，我回到澳大利亚，但是我感觉自己就是走不出悲伤的情绪。我很幸运能参加 Hills 华人社团，参加社团活动真的帮我走出了阴霾，让我的生活再次上轨道。回到澳大利亚之后，我继续参加志愿服务。我们经常去老人院探望老人，还会练习和排练各种不同的表演活动。这些活动让我的日子过得很忙碌很充实，也帮助我调适了心情。

这张照片是澳大利亚国庆日的时候庆祝多元文化的活动。中国有 56 个民族。这是新疆的传统服饰，各个民族都有自己的传统服饰。这张是我们跳新疆舞蹈的照片。这张是代表中国的瓷器，这两个颜色-青与白-代表中国的传统文化，是“青花瓷”特有的颜色。我们编排的舞蹈 - 青花瓷-象征中国传统文化。我参加了家庭健康日的活动，叫做“夜上海”，这是在中国非常有名的一首曲子。活动期间我们还有烧烤。是的，我觉得我的生活非常丰富充实。直到今天，我仍然经常从事志愿服务，希望尽我所能为社区服务。

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Taking photos and telling your story about caring for someone at the end of their life

Your story is important.

Would you like to share your experience so that it might help other people?

In this storytelling activity, you will be invited to take photos of what was helpful, meaningful or supportive when you were caring for someone at the end of their life, and to tell your story to an English speaking researcher. This conversation will take place either in person or using Zoom video conferencing, at a mutually agreeable time.

Your memories and experience will be treated with respect and sensitivity. You can also choose to have your story and photos published in a community book, using your own name, or you can remain anonymous.

This activity is part of a research project conducted by Western Sydney University and Western Sydney Local Health District. It will help health professionals understand more about the specific traditions, beliefs and needs of your community around caring for someone in the last stages of life.

If you would like some more information about the project, or you would like to participate, please contact the Western Sydney University research assistant Helen Psychogios: **Telephone: 02 4736 0083**

Email: h.psychogios@westernsydney.edu.au



For more information on the project or to help us by participating in a survey, scan this code or type this web address into your browser www.wslhd.health.nsw.gov.au/CALD-end-of-life-needs



Consent Form – Photovoice Participants

Project Title: Understanding the end-of-life needs of CALD and Aboriginal Communities in Western Sydney Local Health District

This study has been approved by the Human Research Ethics Committee at Western Sydney University. The ethics reference number is: H13743

I hereby consent to participate in the above named research project.

I acknowledge that:

- I have read the participant information sheet (or I have had it read to me). I was given the opportunity to discuss the information and my role in the project with the researcher/s.
- I understand what the project is about, what I am expected to do and how long it will take. When I asked questions about the project, I received satisfactory answers.

Please indicate your consent below:

- I agree to be contacted 2-3 times by the Research Assistant, Helen Psychogios, to support me in taking the photos for the project. I would like this to be by telephone/email (cross out whichever you don't want). I understand each call will take about 15 minutes and Helen will take notes for research purposes.
- I agree to participate in a 2-hour conversation to be held over Zoom video conferencing at a mutually convenient time to discuss the photos I have taken and to begin to write my story. I consent to this conversation being video and audio recorded and transcribed. I understand I will see a copy of the transcript and can delete anything I don't want included. I understand a support person can attend the conversation with me if I want them to.
- I understand that the video recording and transcript will be stored for up to 5 years. This will be done in a way that does not reveal my identity.
- I agree to a researcher contacting[insert name/contact number]..... if I become distressed (but please check with me first).

I agree to my story and the photos I've chosen being used in an illustrated book of community stories. This may include them being used in conference presentations, reports about the project and journal articles. I also realise that this may mean that they become visible on the internet.

If applicable:

I agree to photos of me being used in an illustrated book of community stories. This may include them being used in conference presentations, reports about the project and journal articles. I also realise that this may mean that they become visible on the internet.

I am 18 years of age, or more.

I consent for my data and information provided to be used for this project.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity, unless I have agreed otherwise.

I understand that I can withdraw from the study at any time without affecting my relationship with the researcher/s, and any organisations involved, now or in the future.

Signed: **Name:** **Date:**

Return address: Please scan or photograph both sides of this form and email to research assistant, Helen Psychogios at h.psychogios@westernsydney.edu.au

What if I have a complaint? If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Services on Tel 02 4736 0229 or email humanethics@westernsydney.edu.au

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Photovoice Instructions and Tips

Project: Understanding the End of Life Needs of Aboriginal and CALD Communities in Western Sydney Local Health District

In this project, we are interested in learning more about your experiences of care and caring at times of life-limiting illness, death, dying and grief. In particular, what has been helpful or meaningful for you/your community and what services you have found useful or believe could be useful. As a photovoice participant, we ask you to take photos that represent this or are metaphors of this.

Showing us what was helpful – the photos may be of a place, an item/object, or an activity, for example - it is entirely up to you which photos you take and why. There is no right or wrong photo. If an image comes straight to mind, we invite you to pick up the camera and take a photo right now! Sometimes acting on that impulse is important. You don't need to think too hard about this task. We want to see what you want to show us. If you need some prompts these questions might help you:

- What is it that helped? Take a photo of that.
- What image could capture what you did?
- Who else was around and how did they help?
- What things did you use? Take a photo of them.

Whether or not to include people in the pictures – sometimes the photo subject will be people. If you provide images of people, they will not be reproduced/made public without their specific consent.

How many pictures to take – you can take as many photos as you like; and then narrow the selection down to no more than 12 to email to us for looking over during our meeting.

What to do when you've finished taking photos – please email your digital photos to Helen at h.psychogios@westernsydney.edu.au or Joy at joy.paton@westernsydney.edu.au

Once we have received your photos, we will get in touch with you to arrange a time to discuss your photos and write your story. Refer to page 2 of the Participant Information Sheet "What will I be asked to do?" (attached) for further details.

Thank you for choosing to participate in this project, we look forward to your photo stories.

Joy & Helen

