The End in Mind: A holistic approach to Palliative Care in the Residential Aged Care Setting | Adj Professor Bridget Laging, 2023

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1. Acknowledgments

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The overarching aim of the ISS Institute is to support the development of a 'Better Skilled Australia'. The Institute does this via the provision of Fellowships that allow Australians to undertake international skills development and applied research that will positively impact Australian industry and the broader community.

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The purpose of the foundation is to support and strengthen communities in Melbourne and rural Victoria, establish educational opportunities, build leadership skills in young people, help the elderly and the economically and intellectually disadvantaged, and promote the enhancement of cultural life of Victoria.

2. Executive Summary

Residential aged care provides accommodation and personal care for older people who can no longer live independently at home. As more older Australians are supported to remain in their homes for as long as possible, the acuity and complexity of older people living in residential aged care is increasing and the average length in residential aged care is reducing. The importance of high-quality palliative care provision that extends beyond medical care to embody a fully personalised experience is core business for all residential aged care providers.

In a little town in eastern Canada with a population of no more than 70,000 some extraordinary things are happening in a residential aged care facility catering to the needs of 100 older people. Loch Lomond Villa provides a place of comfort embedded in a philosophy of person-centred palliative care. Ultimately, this report highlights the importance of residential aged care providers supporting older people to maximise the time they have left to its highest potential. There is great potential to improve the delivery of palliative care in the residential aged care setting and the findings from this fellowship bring this to life!

Fellowship Aim

The aim of this fellowship was to explore innovative or novel ideas that Australia could adopt from the Canadian system to enhance the delivery of person-centred palliative care in residential aged care facilities.

Fellowship Question

What innovative strategies support person-centred palliative care in the residential aged care setting?

Methodology

A qualitative descriptive design was used for this explorative study. Unstructured observation and semi-structured interviews were undertaken with residential aged care providers, nursing and care staff, residential aged care executive teams, older people living in residential aged care and university researchers engaged in innovative palliative care programs across Eastern Canada.

Findings

The Fellowship enabled me to gain a wealth of knowledge and a deeper understanding of innovative strategies to enhance the delivery of spiritual aspects of palliative care in the residential aged care setting. It also provided an opportunity to develop a network of local and international contacts in the field of gerontology and palliative care. Fellowship learnings were developed into

five themes: 1) Embedding research onsite; 2) Creating the physical environment 3) Mobile-x-ray; 4) The Dream Team: Granting final wishes; 5) “It takes a village”: No One Dies Alone.

Outcomes and recommendations

The Fellowship investigation provides detailed insights into the delivery of spiritual aspects of palliative care in the Canadian residential aged care context. There is opportunity to pioneer a modern movement of patient-centred care so that all older people living in residential aged care can access holistic person-centred palliative care, not just in islands of excellence, such as Loch Lomond Villa, but across the whole scale of health care delivery. The learnings from this Fellowship paves the way for broader inquiry into how personalised palliative care can be incorporated into the broader healthcare context in Australia.

Government

It must be acknowledged that the Australian government has taken steps to improve palliative care implementation across the health sector. However, there are opportunities for innovative changes to enhance this further, particularly in the realm of the personalised spiritual experiences of older people at the end-of-life. To support enhancing spiritual care into palliative care for older people living in residential aged care it is recommended that:

1. Changes are made to the application of the Aged Care Funding Instrument (ACFI) which currently specifies that palliative care should be recommended in the ‘last weeks or days’ of a resident’s life. To more accurately capture older people living in residential aged care with palliative care needs it is recommended that this is adjusted to incorporate those in the ‘last months, weeks or days’.
2. Palliative Care and End-of-Life Care Key Performance Indicators for national reporting of quality palliative care include spiritual care components.
3. Aged care funding models include specialised spiritual care support.
4. Australian aged care standards embed a new standard focused on end-of-life care delivery.

Healthcare Service Providers

Healthcare services providers need to be supported to further embed personalised palliative care into their day-to-day delivery as follows:

1. Aged care facility building infrastructure is designed to accommodate family and/or friends, including private spaces for gatherings for special occasions such as birthdays, and facilities to accommodate close family-members/friends when a resident is dying.
2. Spiritual screening tools are incorporated into end-of-life care planning to identify holistic end-of-life care and personalised preferences (texts to be read, people present, music, aromatherapy etc).
3. Older people living in residential aged care are supported to identify outstanding experiences that they may wish to engage in, and where possible, resources are allocated to support these wishes to be realised.
4. All older people living in residential aged care receive the offer of a support person to be present with them when they are dying.

Community Engagement

1. engAGE Care is establishing a not-for-profit or charity organisation, akin to the Make-A-Wish Foundation, to support older people living in residential aged care to engage in a personalised meaningful experience towards the end-of-life. This organisation would engage in fundraising efforts and the establishment of community connections to support the end-of-life wishes for older people.
2. engAGE Care is also establishing a not-for-profit or charity organisation to provide volunteers for residents who have requested to have someone present with them when they are dying. This organisation will engage in the recruitment, screening, training, rostering and debriefing of volunteers and the establishment of collaborative relationships with aged care providers across Victoria.

3. Fellowship Background

3.1 Introduction

Death is something that we will all experience one day. The circumstances around how and where we die may be beyond our control, however for many, there is time to consider what we want to do with our remaining time and what a 'good death' might be. Older people living in residential aged care (also referred to as long-term care or nursing homes) are in the last years of their lives. The median length of stay is 22 months however 39% will die within one year of admission and 23% die within three months of admission. At this time there are missed opportunities to support personalised palliative care provision and there is a need for international collaborations to support innovative changes.

My connection with Canada started when I was writing my PhD. On the other side of the world, in a small town in Canada, Professor Rose McCloskey in a small town in Canada had published the findings from her PhD and there was a kindred connection in the way that she was approaching her research and the innovative strategies that she was trialling to improve aged care both within individual organisations and across health system processes. We collaborated on some projects, and I was invited to be an Adjunct Professor at the University of New Brunswick. This ISS fellowship supported me to visit Saint John, a little town in Eastern Canada with a population of no more than 70,000. In this town, some extraordinary things are happening in a residential aged care facility catering to the needs of 100 older people. Within the town of Saint John, Loch Lomond Villa has enhanced spiritual aspects of palliative care in the residential aged care setting. The findings from this report shed light on opportunities to expand the provision of personalised end-of-life experiences for older people living in residential aged care.

Figure 1. Myself with Prof. Rose McCloskey

3.2 Background

3.2.1 Older people living in residential aged care in Australia

Residential aged care provides accommodation and personal care for older people who can no longer live independently at home. It includes accommodation and personal care 24 hours a day, as well as access to nursing and general health care services. In Australia, around 188,000 older people are using permanent or respite residential aged care, including 48,501 in Victoria(2). As

more older Australians are supported to remain in their homes for as long as possible, the acuity and complexity of older people living in residential aged care is increasing and the average length in residential aged care is reducing. The importance of high-quality palliative care provision that extends beyond medical care to embody a fully personalised experience is core business for all residential aged care providers.

3.2.2 Definitions of palliative care and end-of-life care:

The terms ‘end-of-life care’ and ‘palliative care’ tend to be used interchangeably. However, they are different concepts. Palliative care is defined by the World Health Organisation (WHO) as an approach that: improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial and spiritual (3). In their national consensus statement, the Australian Commission on Safety and Quality in Health Care identified that end-of-life care typically refers to the 12 months prior to death, in contrast to palliative care which is typically care specifically tailored to assist with the effects of life-limiting illnesses (4). End-of-life care is often described as a component of palliative care and there are two different stages within end-of-life care: likely to die in the next 12 months (involving periods of exacerbated illness that may be reversible); and likely to die in the short term (within days to weeks), where clinical deterioration is likely to be irreversible.

Provision of palliative care in residential aged care in Australia

The palliative care needs of older people living in residential aged care are under-recognised. Only 2.0% of permanent residents in residential aged care had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for palliative care. Those with an indication for palliative care increased with age, with 10% for those aged under 70 to just over half of people aged 85 years and over (5). Similar proportions were male (51.1% or 1,625) and female (48.9% or 1,553), however, as a proportion of all people living in residential aged care, males were almost twice as likely to be appraised as requiring palliative care than females (1.9% and 1.0%, respectively) (5). Such findings highlight subgroups within residential aged care who are less likely to have their palliative care needs recognised, specifically, older people who have an increased length of stay, are female and have a non-cancer diagnosis.

Quality of end-of-life care in Australia

Quality palliative care in residential aged care is characterised by a respectful, person-centred and integrated approach. The Australian Institute of Health and Welfare has established the Palliative Care and End-of-Life Care Key Performance Indicators for national reporting of quality palliative care. A Comprehensive Palliative Care in Aged Care Measure – Baseline report and Progress

Report 2, updated in June 2023 identified that “The quality of palliative care in RACFs is variable with some residents having low quality care that does not meet their physical, psychosocial, cultural and spiritual needs.” (6) It was reported that residential aged care staff may not have the skills and confidence to recognise and respond to the holistic palliative care needs of residents, in a culturally safe way. It was also identified that access to quality palliative care in residential aged care facilities is variable, with many residents not accessing effective palliative care.

Defining a ‘good death’.

A systematic review identified key elements on the conditions of a “good death” including: dying at the preferred place; relief from pain and psychological distress; emotional support from loved ones; autonomous treatment decision making; avoidance of futile life-prolonging interventions and of being a burden to others; effective communication with professionals; and performance of rituals (7). However, it has been reported that “the medicalisation of life under the influence of health-care systems, focused on curing diseases, has made dying well challenging” (7). Creative strategies are urgently needed to broaden the focus of end-of-life care provision beyond the medical lens and to embed the prioritisation of personalised care into every older persons’ experience at the end-of-life.

Person-centred palliative care.

Holistic person-centred care encompasses the biological, psychological, social, and spiritual aspects of a person’s well-being (8). Person-centred care is a systemized approach to delivering healthcare in a way that centres on the perspective of the whole patient and their loved ones, while promoting a healthy, encouraging environment for caregivers and addressing the health needs of the organization’s surrounding community. Within this model, staff partner with residents and families to prioritise comfort, dignity, empowerment and well-being as key elements of providing top quality clinical care. A person-centred, approach embodies dignity based palliative care, which is essential in assisting older people living in residential aged care to navigate their end-of-life journey with integrity, supporting them to connect with their own wholeness. It is every human’s intrinsic need to achieve happiness, self -awareness and fulfilment (9). Palliative care provision that is consistent with the persons core values supports an improved sense of meaningfulness and supports the likelihood of reaching self-actualisation and affirms resident’s quality of worth (10).

In 2019, Loch Lomond Villa was awarded Gold Certification for Excellence in Person-Centred Care by Planetree International. The Planetree Initiative is a passionate not-for-profit healthcare leader setting the global standard for person-centred excellence across the continuum of care. Planetree delivers the leading evidence-based framework for co-designing a roadmap to improve patient and family engagement, better clinical outcomes, increase staff retention and recruitment, and high value care. Originating in San Francisco in 1978, Planetree now has more than 800 partner

organisations across 35 countries. The findings in this report demonstrate why Loch Lomond Villa has achieved this status and the unique innovations that they have implemented to support person-centred palliative care.

Fellowship Aim

The aim of this fellowship was to explore opportunities to integrate holistic, person-centred palliative care in the residential aged care setting.

Fellowship Question

What factors influence the provision of person-centred palliative care in the residential aged care setting?

Setting

Loch Lomond Village is a 100-bed nursing home consisting of four resident houses. Each is home to 25 residents. The amenities within the Village include: glass-covered atriums, an open-air courtyard, a theatre, a resident run café, celebration rooms for activities, the library, a walking path and a labyrinth.

Methodology

A qualitative descriptive design was used for this explorative study. Unstructured observation and semi-structured interviews were undertaken with residential aged care providers, nursing and care staff, residential aged care executive teams, older people living in residential aged care and university researchers engaged in innovative palliative care programs across Eastern Canada.

3.3 Biography

I was first introduced to aged care when I was about four years old. My Great Aunt Bunny, a nursing sister in a small town in New Zealand, would take me across to visit the older people living in a nursing home nestled within a large botanical garden. These early experiences had a profound effect on me and after completing high school, I worked as a personal care worker at a residential aged care facility and hospice in Christchurch, New Zealand. I became a registered nurse and enjoyed many years traveling and working in emergency departments throughout remote, rural and metropolitan Australia. I loved the fast-paced ‘stand clear, charge’ environment and the feeling of being part of a team of incredible people. However, like many of my colleagues, I felt concerned about how emergency departments were set up to meet the needs of older people, particularly those with confusion or dementia and at the end-of-life. The hard trolleys, bright lights and noisy environment made the emergency department an unfriendly space and the rates of older people coming through the door on ambulance trolleys was increasing. I presented my concerns

to the Department of Health and Human Services, Victoria and they provided me with funding to undertake a PhD exploring the factors influencing decisions to transfer to hospital. The findings were shared extensively at conferences and via journal articles and the media and highlighted the importance of a carefully engineered and well-supported aged care workforce and a systemic shift across the healthcare system to recognise the specialist gerontological needs of older people.

10 In 2020, the aged care industry experienced unprecedented media and political focus with the Royal Commission into Quality and Safety in Residential Aged Care and the onset of Covid-19. Over this time, I advocated for significant change to the aged care workforce structures, including enhanced financial and professional recognition for personal care workers and improved educational oversight to support their vital role in care delivery. I was appointed Deputy Chair of the Healthy Ageing and Co-Chair (workforce) for the Australian College of Nurses. At this time, I was also appointed as a Senior Research Fellow at ACU and Mercy Health to co-design and evaluate an intergenerational program engaging adolescents and older people living in residential aged care in regional Victoria. I collaborated with Griffith University and we were awarded a Perpetual Impact grant, which supported us to successfully continue this program virtually during the Covid-19 lockdowns. The findings from our research highlighted the benefits of intergenerational engagement for both older people and adolescents and the importance of reducing societal siloing on the basis of age.

Most recently, I co-founded engAGE Care Consultancy. In collaboration with Monash University and Alfred Health, we have been awarded an Aged Care Research & Industry Innovation Australia (ARIIA) grant to trial an innovative palliative care referral service in response to unmet palliative care needs in older people living in residential aged care who are transferred to hospital at the end-of-life.

4. Fellowship Learnings

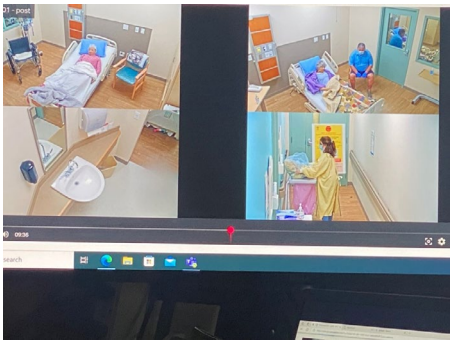
The Fellowship enabled me to gain a wealth of knowledge and a deeper understanding of innovative strategies to support holistic, person-centred end-of-life care in the residential aged care setting. It also provided an opportunity to develop a network of local and international contacts in the field of gerontology and palliative care. In this section, I will describe the key learnings that have emerged from this Fellowship experience. Five themes were identified that influenced the capacity to provide personalised end-of-life care in residential aged care: 1) Embedding research onsite; 2) Creating the physical environment 3) Mobile-xray; 4) The Dream Team: Granting final wishes; 5) "It takes a village": No One Dies Alone.

Embedding Research onsite

Prof Rose McCloskey scans us through the door, "they've given me keys". Rose McCloskey is a Professor of Nursing at the University of New Brunswick and she has been embedded at Loch Lomond Villa for several years. She knows the residents and the staff and she is currently working on nine projects at the site. The simulation centre was built in 2020. The simulated design space is seamlessly set up in a residential aged care arrangement with two resident rooms, a bathroom and hallway. Three researchers sit behind one-way mirrored glass observing the scenario playing out. On this occasion, a resident's relative enters the simulation space and dons personal protective equipment (PPE) prior to visiting their wife, a resident in the aged care facility with influenza. Prior to entering the simulation, he has watched a pre-education video on how to don and doff the PPE (consisting of a gown, gloves and mask) to reduce the spread of infection. A brief pre-interview reveals that in theory he knows what is required, however, the practical application proves challenging when he engages in a simulation. As we observe from behind the one-way glass, it becomes immediately apparent that the PPE is not friendly for people with limited range of movement, with the older relative struggling to get his hands around to his back to tie the gown closed. His arthritic hands also struggle with putting on the gloves. The need for a change in the types of gowns and gloves for people with reduced range of movement, including gowns that velcro at the front and loose-fit gloves is an important finding.

I am working on a number of projects in collaboration with researchers at UNB including a novel simulation centre that is based onsite at a residential aged care facility. One of the most important aspects of an onsite simulation laboratory is that it supports opportunities for residential aged care staff to collaborate closely with researchers to co-design solutions that are grounded in the context where the care is being delivered. The ability for researchers and residential aged care staff to review clinical scenarios enables insight into the stressors that lead to decision-making overload and the identification of factors that lead to exceeding the capacity of what can be delivered in the residential aged care facility. It also enables us to trial innovations to see how they may impact on the delivery of care and to reflect with staff on the barriers and enablers to embedding

new innovations into practice. We will be collecting data via observation and EEG monitoring, enabling deeper insight into the level of stress experienced by residential aged are staff and pinpointing particular aspects that contribute to workload overload to support the development of tailored processes and resources. In the simulation lab, a set of glasses are sitting on the bench in preparation for the next simulation project. The glasses have inbuilt technology to identify pupil dilation, a sign of increasing distress. These will be complemented with a headband that measures brain wave patterns and a fitbit wrist band to measure vital signs. It is well known that the aged care workforce experience heavy workloads and the work has been described as ‘stressful, underpaid and undervalued. Further understanding of the workplace stressors will support opportunities to bolster the capacity for staff to meet the personalised needs of individual residents. This project is under review with the university ethics committee and due to commence later this year.



The physical environment: Welcoming Family and Friends

The transition to residential aged care has been reported as one of the most stressful life events for older adults (11) as it involves leaving the psychological and social support system of friends, relatives, and society. Physical spaces that reduce siloing of older people into 'institutional walls' and support ongoing engagement with family friends are vital to the wellbeing of older people. Loch Lomond Villa had innovative spaces to support older people and their family and friends to maintain connections.

Within the aged care facility, there is a private space that can be 'hired out' for family events, such as birthdays or special celebrations. It is set up as a lounge with a dining room, kitchenette and lounge chairs. In this 'lounge' families and friends can prepare their own food on the bench spaces, heat their food in the oven, cool their drinks in the fridge and spend an afternoon or evening together. It is a supportive space, enabling older people who would prefer to remain in a location where they can still access support to go to the bathroom, or assistance with medications can still have a gathering and host a party!

The resident run café is abuzz with visitors, staff and residents alike. Two residents are operating the café on the morning that I visit and it is open to anyone who would like to visit, including the community.

At the end-of-life, the doors of Loch Lomond are open for family to stay at the home when a resident is dying. A small sunny room with two chairs that fold out into single beds is situated near the residents rooms. It has a kitchenette a phone, a bathroom and shower and family members can order food from the kitchen if they would prefer to have prepared meals. A registered nurse explains: "Many residents have family who are not living in the same town, or they simply don't want to leave when their loved one is dying and they need a space that they can go to".

In the memory support unit, computerised wall sets were located at various locations. Personalised videos of familiar places where residents routinely drove to and from their home were recorded and uploaded. A resident could sit at the steering wheel and drive down familiar lanes and locations. There was also a phone where residents could sit and listen to messages from family and friends and view photographs that were sent through from family or friends. This dynamic engagement was enjoyed by residents and supported opportunities for residents to engage with the things that were familiar, comforting and personal to them.

Mobile x-ray

Hospital transfer increases in the last year of life. Transferring older people living in residential aged care to the hospital for x-rays is common and often requires an ambulance for transport(12). It is important that when older people experience a change in their health that they have timely access to healthcare to support comfort and quality of life. Loch Lomond has recently trialled a mobile x-ray service that allows residents to stay in onsite. A compact and transferrable x-ray machine can be wheeled into the aged care facility, directly into the resident's room, or a living room. The majority of x-rays are chest xrays, and lower limb and hip xrays post falls. Professsor McCloskey explains that "the majority identify the absence of a fracture, so we have saved them a trip to hospital and we can provide pain relief and care on-site. If a fracture is identified, the resident can attend an outpatient clinic for a cast. If they require surgical repair, we have established a streamlined access to surgery whereby, the older person can go directly to the operating room bypassing the ED. Prof McCloskey explains "It's about comfort and limiting the distress associated with waiting in hospital". A qualitative study of residents' experiences for mobile x-ray services, identified positive perceptions, particularly as they were able to receive healthcare-in-place, with familiar people and surroundings(13). McCloskey concurs "If we can keep older people comfortable and provide high quality care interventions on-site then that is a good thing". Our next mission is to train the radiologists to also provide casts on-site". The success of this project has resulted in the state government funding a further five cars to cover the state of New Brunswick.

The Dream Team: Granting final wishes

A systematic review of patient's preferences in palliative care identified that seriously ill and dying people want to be supported to feel that they have maximised "living a meaningful life" (14) and this includes the desire to discuss and to accomplish personal last wishes(15). The provision of individualized care that support patients' notion of a meaningful life is also valued by healthcare workers (16). Over the past decade, there has been a large focus on advance care planning. Advanced care planning has arguably contributed to a reductionist approach to end-of-life care planning and the over-medicalisation of a profound and significant event. The research is replete with masses of data reporting the impact of advance care planning on hospital use at the end-of-life, rates of cardiopulmonary resuscitation, however, there is limited understanding of how older people are supported to maximise the 'meaningfulness' of their end-of-life experience to support self-realisation. It is imperative that healthcare workers knowledge of residents wishes need to extend beyond the medical domain, which focuses on harmonising a person's treatment choices with their values and medical conditions (11).

Interventions to support an older person's spirituality may be associated with a range of positive health outcomes including coping, quality of life, life satisfaction and lower levels of psychological distress (17). A recent systematic review and Delphi study concluded that spiritual care should be routinely incorporated into the medical care of patients with serious illness and spiritual care education should be included in the training of members of the interdisciplinary medical team (18). Whilst spirituality is a core component of palliative care, an integrative review of spiritual practices in residential aged care identified limited understanding of how older adults maintain their spirituality (19).

The Dream Team at Loch Lomond Villa engages with residents, identifies their wishes and collaborates with community organisations to make them a reality. Once a wish had been identified the 'Dream Team' consisting of the facility manager, lifestyle workers, nurses and carers get to work. A wall of photographs lines the hallway. These photos are of beaming faces in restaurants, outside the Anne of Green Gables house, in front yards, at football matches, down at the beach. One of the leisure activity workers explains: "Some people want to do big things, some people just want something small. We do our best to make it happen". There are so many beautiful stories behind each photo. "We sat down with them and we said, okay if you had one thing that you wish you could do, what would it be? They said, well we never got to have a honeymoon. We would love to do that before one of us goes". So, we found a hotel in town with a lovely restaurant downstairs. We found a table and arranged for a bunch of roses. They had a candlelit dinner and then stayed in the hotel room upstairs. One of the staff accompanied them and stayed in a room next-door". Some community members, such as restaurant owners, hotel owners provide discounted or free

of charge services and some residents are self-funded. Staff at the aged care facility may be paid and some volunteer their time.

"It takes a village": No One Dies Alone

Isolation in the community is a strong predictor of admission to residential aged care. Findings from a recent systematic review identified that many older people experience loneliness even once they have entered residential aged care and that while aged care facilities are well placed to meet these physical and safety needs of older people, however, they are less equipped to meet the social needs of residents (20). In Australia, many older people living in residential aged care do not receive visitors, and many residents receive very few. However, at this time, visitation rates in residential aged care have not been reported and it is unknown how many people die alone, without the presence of someone to support them at the end.

Loch Lomond has embedded the No One Dies Alone (NODA) program into their aged care facility, offering companionship and support to residents who have no family or close friends to sit with them at the end-of-life (21). "Bling" a small private Facebook group of about 50 volunteers receive a message in their inbox. A resident who does not have family or friends to be present with them is dying. In the months before this time, a nurse has discussed whether they would like to have someone with them when they die. "We ask them, would you like to have someone with you? Would you like them to hold your hand? Is there any particular music that you would like to have playing? Any text that you would like to have read to you?".

The volunteer program is designed to enable a compassionate and caring presence for residents who are dying alone. All volunteers have a criminal record check and participate in preparation training. Volunteers undergo training relating to what happens when we die, including physical, emotional, social and spiritual aspects of dying. They learn about being compassionately present, supporting cultural and religious diversity, and what they can say and do to support a patient and/

or family. “We have a rotating roster, people can put their name down for the time or times that suit them and then they come in a sit with the resident. It is not uncommon for volunteers to be retired healthcare workers and at Loch Lomond, several aged care workers were also volunteers in the program. “We actually have about 15 staff who also volunteer and sometimes staff will say “I’ll just stay with them for a couple of hours after work”. They are volunteers, not health care workers, so they do not engage in any direct care, such as mouthcare or repositioning the resident. The volunteers just use the call bell and a nurse will come and attend to the resident. Their role is to be present, to brush the resident’s hair, hold their hand, read to them, listen to their stories”.

5. Personal, professional and sectoral impact

This fellowship supported me to explore innovations to inform positive changes to support personalised palliative care delivery in residential aged care within Australia. Reflecting on the integrated approach to palliative care to support onsite end-of-life care delivery at Loch Lomond in Canada has personal and professional impact and brings with it opportunities to explore sectorial change.

5.1 Personal Impact

At a personal level the fellowship has given me the confidence to pursue the practical application of good ideas. I love to read the newspaper and to hear about stories where healthcare workers have supported personalised end-of-life experiences - an ambulance officer has taken someone to the beach, or driven by the old family home on a terminal trip to hospital – a last glimpse at the ocean, a trip down memory lane, before an inevitable end. I have a vivid memory of a newspaper article and the accompanying picture of an old man sitting on a balcony, cigarette, and a glass of red wine in hand, with the sun setting in the distance. The nurses in a Danish Hospital broke the ‘rules’ opening sealed balcony doors, abandoning the no smoking regulations and heading to the liquor store in an extended tea break to fetch a fine wine. I also smile fondly when I recall my husband returning home from a shift at the hospital as he had managed to locate a shrimp cocktail for a terminal patient who had jokingly made the request when he had asked ‘Is there anything else that we can do for you?’. To this day, it is still one of the fondest memories in his career. In my earlier years, I remember chasing a hearse down a street in Christchurch with a resident’s false teeth, as we had removed them in her final hours due to discomfort. We only realised after she had left that they were sitting on the counter. All healthcare workers will have their own stories, which highlight the joy and honour they have experienced when supporting a person’s dignity and access to self-realisation at the end-of-life. However, in reality the system is stretched, the resources are tight and the personalisation of end-of-life wishes relies heavily on individual acts, rather than an integrated health system design. These stories make the news because they are the exception, someone stepping outside of the status quo, going the extra mile, not just operating within the ‘system’ and it fills our hearts. The practical application of these ‘exceptional’ stories requires deviation from standardised care. It is the standardisation of care delivery that serves as a barrier to the personalisation of the end-of-life care. What I gained from my time in Canada, is the hope that we can build a system that goes beyond marvelling at the exceptions and instead, encourages, supports and enables organisations to prioritise the personalisation of end-of-life care and embeds the application of each person’s final journey into the core of their day-to-day business.

5.2 Professional Impact

This Fellowship provided me with the opportunity to step into an aged care facility where person-centred care has been embedded and operationalised beyond a 'philosophy of care' to a reality of palliative care delivery. My time at Loch Lomond Villa revealed unexpected ways to support older people's spiritual needs in the residential aged care setting.

This Fellowship has provided me with opportunities to advocate for innovative environmental changes that can be integrated into residential aged care facilities to support the spiritual needs of older people, including private social spaces where older people can host their guests and private spaces to support families and/or friends to be present with their loved ones at the end-of-life. Environmental changes including the simulation centres onsite in the residential aged care setting also enable contextually grounded research that provides much greater opportunity to explore challenges that are unique to this setting.

I have also returned with the building blocks to develop, implement, and evaluate a No-One Dies Alone program and the establishment of Dream Teams in collaboration with health service providers. Establishing programs such as No-One Dies Alone and Dream Teams and embedding them into the core business of health service delivery will take considerable time and effort, with changes required across all levels. I returned to Australia to the news that I had been awarded an Aged Care Research & Industry Innovation Australia (ARIIA) grant with Alfred Health and Monash University. As part of this grant, I am working with clinicians to evaluate the quality of end-of-life care for older people who die in hospital following transfer from residential aged care. In Australia, one in five older people living in residential aged care die in hospital (22). Hospital transfer is a distressing and further isolating experience as older people are removed from a familiar environment with staff and other residents. Most recently, I have engaged with the Patient Experience & Consumer Engagement team who oversee the volunteer program across Alfred Health and commenced the first steps towards developing a NODA initiative at Alfred Health. I am also working to develop connections with residential aged care providers to support the integration of this program into their service delivery options.

To support the development of No-One Dies Alone in Victoria, I have established connections with global initiatives surrounding NODA, including the medical school participation programs in Texas where medical students become volunteers, and the NODA education program at John Hopkins Foundation. Closer to home, there are NODA programs running in Perth and in New Zealand. I will be seeking additional funding to support me to visit these sites to foster collaboration with established NODA services. This will support our efforts in program design, to understand the barriers and facilitators to embedding such a unique program into a health service and opportunities for collaborative research to evaluate the impact of these programs.

5.3 Sectorial Impact

Viewing the possibilities for supporting personalised experiences at the end-of-life is something that can be developed across the health sector to meet the palliative care needs of older people living in Victoria, Australia.

Innovative building design

The residential aged care sector could benefit by Incorporating spaces where simulated research can take place on-site to supports an integrated approach to research that is contextually grounded in the culture of residential aged care practice. Additionally, advocating for innovative building design – older people enter residential aged care not as an individual, but a part of a social unit. The provision of private social spaces where older people can continue to 'host' their family and friends is important, including at the end-of-life. To do so, there are opportunities within the sector to create private group spaces that accommodate ongoing connections with community, family and friends, such as a private lounge room and kitchen space for birthdays and other celebrations. This includes the provision of accommodation for family members when an older person is dying. This accommodation includes a separate shower, bathroom, kitchenette, phone and small lounge room where family members are able to stay if they want to maintain presence with their loved one at the end-of-life.

Expanding the scope of mobile x-ray services.

Mobile Assessment and Treatment Services are well established throughout Victoria to support older people to receive medical treatment onsite at the residential aged care facility and avoid hospital transfer. Mobile x-ray services exist in Melbourne, Victoria, however there is opportunity to expand these services including onsite cast application for some fractures and establishing hospital connections to support streamlined access to surgery whereby, the older person can go direclty from the residential aged care facility to the operating room bypassing the emergency department.

Granting Final Wishes Program

Lifestyle teams already exist within the residential aged care sector and the findings from this fellowship identify opportunities to support the role of lifestyle workers to establish 'Dream Teams' and where needed, collaborate with an established charity, akin to the Make-A-Wish Foundation, to support older people to engage in their end-of-life wishes.

No One Dies Alone (NODA)

Most health service providers have a volunteer program. engAGE Care Consultancy has collaborated with international organisations and palliative care clinicians to create volunteer screening processes, scope of practice parameters and an education program and debriefing support that can be accessed by providers who demonstrate an interest in integrating NODA in their service.

6. Outcomes and recommendations

The Fellowship investigation provides detailed insights into the delivery of person-centred palliative care innovations in the Canadian context. Embedding person-centred palliative care into the Australian context relies on a much greater focus on the spiritual needs of older people living in residential aged care across all levels of health service delivery. The following recommendations provide the foundational changes that need to occur to enable person-centred palliative care to be embedded and operationalised beyond a 'philosophy of care' to a reality of care delivery.

Government

It must be acknowledged that the Australian government has taken steps to improve palliative care implementation across the health sector. However, there are opportunities for innovative changes to enhance this further, particularly in the realm of the personalised spiritual experiences of older people at the end-of-life. To support enhancing spiritual care into palliative care for older people living in residential aged care it is recommended that:

1. Changes are made to the application of the Aged Care Funding Instrument (ACFI) which currently specifies that palliative care should be recommended in the 'last weeks or days' of a resident's life. To more accurately capture older people living in residential aged care with palliative care needs it is recommended that this is adjusted to incorporate those in the 'last months, weeks or days'.
2. Palliative Care and End-of-Life Care Key Performance Indicators for national reporting of quality palliative care include spiritual care components.
3. Aged care funding models include specialised spiritual care support.
4. Australian aged care standards embed a new standard focused on end-of-life care delivery.

Healthcare Service Providers

Healthcare services providers need to be supported to further embed personalised palliative care into their day-to-day delivery as follows:

1. Aged care facility building infrastructure is designed to accommodate family and/or friends, including private spaces for gatherings for special occasions such as birthdays, and facilities to accommodate close family-members/friends when a resident is dying.
2. Spiritual screening tools are incorporated into end-of-life care planning to identify holistic end-of-life care and personalised preferences (texts to be read, people present, music, aromatherapy etc).

3. Older people living in residential aged care are supported to identify outstanding experiences that they may wish to engage in, and where possible, resources are allocated to support these wishes to be realised.
4. All older people living in residential aged care receive the offer of a support person to be present with them when they are dying.

Community Engagement

1. A not-for-profit or charity organisation, akin to the Make-A-Wish Foundation, is established to support older people living in residential aged care to engage in a personalised meaningful experience towards the end-of-life. This organisation would engage in fundraising efforts and the establishment of community connections to support the end-of-life wishes for older people.
2. A not-for-profit or charity organisation is established to provide volunteers to engage with residents who have requested to have someone present with them when they are dying. This organisation would engage in the recruitment, screening, training, rostering and debriefing of volunteers and the establishment of collaborative relationships with aged care providers across Victoria.

7. Conclusion

The Fellowship investigation provides detailed insights into innovative person-centred approaches to palliative care in the Canadian residential aged care context. There is opportunity to pioneer a modern movement of patient-centred care so that all older people living in residential aged care can access holistic person-centred palliative care, not just in islands of excellence, such as Loch Lomond Villa, but across the whole scale of health care delivery. The learnings from this Fellowship paves the way for broader inquiry into how personalised palliative care can be incorporated into the healthcare context in Australia.

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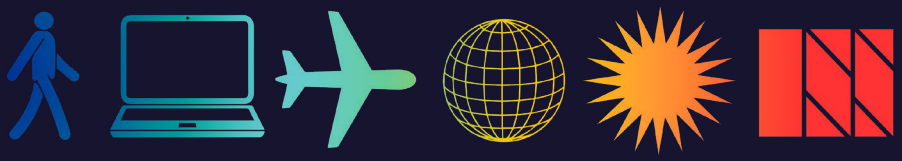

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