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Dying Well: Why quality palliative and end-of-life care are essential in aged care

White Paper



Dr Margaret O'Connor AM is Emeritus Professor of Nursing at Monash University and a Board Director at Catholic Healthcare. She has extensive healthcare experience as a nurse and researcher specialising in end-of-life care. During her career, Margaret has led the development of several home-based palliative care services in Melbourne. She has held academic roles at La Trobe University, Monash University and Swinburne University of Technology. She has contributed to more than 160 peer-reviewed journal articles and is a regular keynote speaker on palliative care, ageing and dying.

As the final home for many people, residential aged care homes are well positioned to help people finish their life in the place where they've been living, without being transferred to an unfamiliar acute care setting. It's telling, however, that only six in every 100 people who exit residential aged care settings have an Aged Care Funding Instrument (ACFI) appraisal that entitles them to government-funded palliative care.¹ That's too low. It shows the aged care industry has work to do to deliver best-practice palliative care, and that government has work to do to provide access to palliative care.

Not everyone who dies needs palliative care. But everyone in aged care deserves excellent assessment to identify those who do. And everyone is entitled to be heard in understanding what quality of life means as they approach the end of their life.

It is in this context that the Royal Commission into Aged Care Quality and Safety declares: *"Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers."*

WHAT IS PALLIATIVE CARE?

What do we mean by palliative care? The World Health Organisation (WHO) definition first published in 2003 has stood the test of time. It states: *"Palliative care is an approach that improves the quality of life of patients and their families facing the 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, physical, psychosocial & spiritual."*

To summarise this statement:

- Palliative care is for people facing life-threatening illness
- It improves the quality of life of patients and their families
- It prevents and relieves pain and suffering
- Clinicians should strive for impeccable assessment and identify patients early

The term 'life-threatening' is carefully chosen. Palliative care can start at any time there is a need for such care, which may be when death is months away, not necessarily imminent. The goal of palliative care is to support the person and their family and help them achieve their goals in the time that remains for them.

It's about identifying early what's happening for the person. It's important to place an emphasis on impeccable assessment, rather than 'very good' or 'good enough'. There's only one chance to help someone in their dying process, so we need a holistic understanding of their needs and to ensure that their pain and other aspects of care are well-managed and that their dignity and quality of life is maintained.

WHO NEEDS PALLIATIVE CARE?

Many deaths are uneventful, with no need for medical or palliative care. But timely and impeccable assessment is just as essential for those who don't need palliative care as it is for those who would benefit from it. It's people with complex issues like physical pain, psychological, spiritual, or social issues who may benefit from palliative care expertise.

A GOOD DEATH OR DYING WELL?

Death is both a biological and a spiritual phenomenon, and everyone's death is unique. Something that has fascinated me for a long time is the difficulty that contemporary societies have in discussing death and dying. In Irving Yalom's insightful book *Staring at The Sun*, he suggests that just as it is impossible to stare at the sun, so it is difficult to stare at death. We need to find ways to balance our understanding of death and our reluctance to engage with it until it's right in front of us. There's a contemporary, yet false, sense for many people that any disease can be cured.

People talk about a good death, but what does it actually mean? The media creates

“**Palliative care is a moral imperative of health systems and should be integrated into all levels of health care.**”

unrealistic expectations in this regard, with trite reports of people dying peacefully at home surrounded by family and friends. In truth, there's always mess around dying, because it is a human event. Death is not a singular event and as such, there may be difficulties and struggles along the way.

We need to recognise that a 'good death' is not something that happens serendipitously. It needs planning, an understanding of what it is that the person themselves wants, and the involvement of the family and other relevant people.

Perhaps 'dying well' is a better phrase because it acknowledges a personal journey. There may be suffering. Physical suffering, as in pain, is relatively easy to manage. More challenging for health professionals and families supporting the individual, are dealing with emotional, psychological and spiritual pain.

The experience of dying well is shaped by all aspects of a person's life - how society regards death, how it is viewed in their cultural context, and how individual families manage dying. There is more benefit in engaging with what dying well means to an individual, rather than creating an aspiration for everyone to have a good death.

ROYAL COMMISSION RECOMMENDATION

- Residential aged care is often a person's final place of residence before they die. Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers.
- People at the end of their lives should be treated with care and respect.
- Their pain must be minimised, their dignity maintained, and their wishes respected.
- Their families should be supported and informed.

Source: RC Final Report, 2020, p.69

WHAT DOES 'CORE BUSINESS' MEAN FOR RESIDENTIAL AGED CARE?

Death and dying happens in many settings. For residential aged care, it means acknowledging that death is a common occurrence and is no less important than other aspects of care. Many residents may benefit from receiving palliative care support as they approach the end of their life.

While many aged care facilities and many dedicated individuals provide care for a resident at the end of their life, it's not universal. Without an appropriate ACFI funding model, care will continue to be piecemeal and inconsistent without equity of access.

You couldn't imagine a residential aged care home that lacks in-house competence in caring for people with dementia, mobility issues or incontinence.

If dying is common in aged care settings, it seems perplexing to bring in palliative care services from outside. Of more concern is the high number of people in aged care who are transferred to an acute care setting in their last weeks of life.

A new funding model needs to consider everything from training and equipment to the provision of clinical care, non-clinical care and support for families. We also need comprehensive data to give us a clear view of what's going on.

At present, we are limited because acute care, home care and residential aged care report data separately. Currently this data isn't consolidated to create a holistic picture of dying in Australia. This is something Palliative Care Australia wants rectified.

My experience of the communication that happens when a person enters residential aged care is that many aspects of care are discussed, but often there's a reticence to talk about what care people want at the end of their life.

We need to normalise the idea that death is part of life and not try to hide behind euphemisms or vague statements. We can make sure that everybody who enters residential aged care has an advance care plan or is helped to complete one. We must understand what the person values and what they would and wouldn't want for the final stage of their life.

Part of the solution is to improve the public perception of palliative care. Many people think a referral to palliative care means it is the end for them. The fact is that palliative care may be a very supportive service for someone who is indeed facing the end of their life, but their death may be many months away.



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8-POINT PLAN FOR AGED CARE

Palli-8, Palliative Care Australia's eight-point plan (see resources) to make palliative care core business for aged care calls for the following:

1. Person-centred approach
2. Aged Care Quality Standards must include palliative care
3. Training for every health and aged care worker
4. Mind the data gap: We can't improve what we don't measure
5. Fund in full: we can't implement if we don't invest
6. Ensure Equitable Access: palliative care is a universal human right
7. Support Australians who are dying to talk
8. Palliative care must be a priority for all governments

THE ROLE OF FAMILIES

In residential aged care settings, if a person's family is involved, it's important to keep encouraging them to stay involved. You can coach them about recognising that it's difficult to accompany a person in the final stage of their life. I often describe it as keeping vigil, particularly in the last days when a person is approaching their death and many families feel very impatient with a death that to them appears to be occurring slowly.

It makes a difference to stand alongside that person and their family members. To encourage them to hang in there, undertake very small comforting measures like holding their hand, talking to them and just being there. It is important to encourage them to ask health professionals questions about what they're witnessing that they might not understand.

QUALITY OF LIFE AT THE END OF LIFE²

There are tangible things we can do to help improve people's quality of life towards the end of life. For example, in a study of 396 advanced cancer patients and their informal caregivers, Baohui Zhang and colleagues found people have the highest quality of life if they stay out of hospital, have a strong therapeutic alliance with their doctor, are relatively free from worry and pray or meditate. Below is a simple checklist of the determinants of quality of life at the end of life, based on Zhang's findings.

Negative determinants include:

- Dying in a hospital
- ICU in the last week of life
- Emotionally distressed patient
- Feeding tube

Positive predictors for a good end-of-life experience include:

- Receiving pastoral care services
- Good therapeutic relationships
- Spending time in private religious activities
- Attempt to avoid hospital admissions

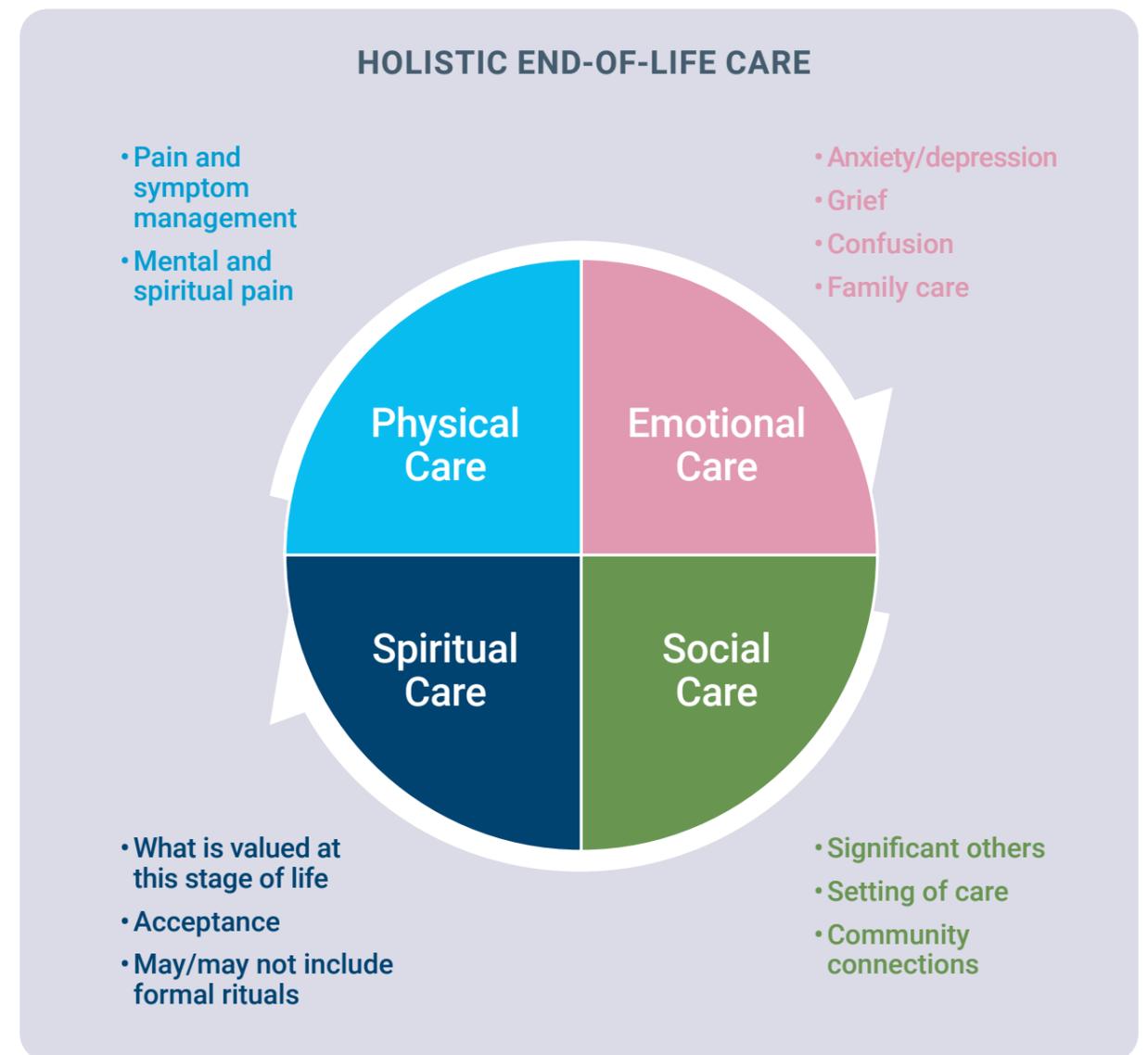
CONCLUSION

The fact is that palliative care and end-of-life care are already core business in residential aged care settings. The problem is that not everyone in these settings has equal access to high-quality, holistic care that takes their wishes and needs seriously.

It is incumbent on the government to implement appropriate ACFI funding mechanisms. However, we don't need to wait. There are many ways that aged care organisations, individual homes and the people who work in them can make a positive difference.

It starts with acknowledging that death is common in aged care settings. We need to talk openly about what care people want at the end of their life. We need excellent early assessment to identify people in need of palliative care.

Finally, we need systems, policies and education to ensure people get the physical, spiritual, social and emotional care they need. The table illustrated is a helpful checklist to ensure all aged care residents have access to person-centred palliative and end-of-life care they deserve.



Resources:

- palliaged.com.au
- The Palli8 plan at palliativecare.org.au
- advancecareplanning.org.au
- Diploma of Ageing Studies and Services, utas.edu.au
- End of Life Directions for Aged Care (ELDAC), eldac.com.au

References:

1. AIHW, *Palliative care services in Australia*; May 2022, aihw.gov.au
2. Zhang B et al., 'Factors important to patients' quality of life at the end of life.' *Archives of Internal Medicine* August 2012, archinternmed.2012.2364



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