



palliAGED Aged Care Standards Insight

May 2020 Addressing end-of-life needs

Professor Jennifer Tieman

The Australian Institute for Health and Welfare (AIHW) analyses of the nearly 250,000 older people who died in Australia in the 2 years to 30 June 2014 showed that most people (80%) had used an aged care program before their death¹. We need to recognise that palliative care, endof-life care, and dying are core business for aged care and that this has implications for the aged care workforce who deliver care. Even if palliative care services are involved with a resident or client, much of the care will be delivered by the aged care workforce within residential aged care or alongside the family for those on homecare packages.

The AIHW data also showed that coronary heart disease (14%) was the leading underlying cause of death for people who had used aged care, followed by dementia (11%). For people who had not used aged care, coronary heart disease was also the leading underlying cause of death (16%), but this was followed by Lung cancer (9%)¹. Cancer-related causes were more common among those who had not used any aged care. For many older people in receipt of aged care, end of life may be less acute terminal illnesses and more related to chronic progressive disease, multimorbidity, and dementia².

Australian palliative care data shows that people with dementia have earlier functional decline, and higher and prolonged rates of functional impairment which will require substantial care support³. The challenge is how to recognise and respond to the changing needs, experience, and expectations of frail older patients who are ageing and dying within a context of complex multiple morbidity.

The National Palliative Care Strategy acknowledges that our population is ageing and that as a result

of an increasing proportion of the population being over 65 years, an increasing number of deaths should be anticipated. The strategy acknowledges that as a result, service providers in all settings need to be able to recognise clinical deterioration and dying⁴.

More generally the World Health Organization in the World Report on Ageing and Health underline the complexity of concepts around ageing in terms of expectation, perception and diversity⁵. This highlighted the need for a population health approach and public health frameworks for care as well as clinical care interventions.

What care is needed in the last year of life?

Patients who have been asked about what would be a good death or what do they want at the end of life report that the core elements of a "good death" are being in control of pain and symptoms, being able to make plans and decisions, a feeling of closure, being seen and perceived as a person, and being prepared for death. Other factors such as culture, financial issues, religion, disease, age, and life circumstances also shape the concept of a "good death" across groups. So, a "good death" is both individual and personal with common concerns and issues⁶.

Similar needs have been identified by family carers in their description of good end-of-life care in nursing homes. Providing basic care and spiritual support; recognising and treating symptoms; assuring continuity in care; respecting the resident's end-of-life wishes; offering environmental, emotional and psychosocial support; keeping the family informed and helping them understand what is happening; and establishing a partnership with family carers shared decision-making were all seen as important⁷. This highlights the importance of being able to respond to the specifics of care issues around symptoms and diagnoses as well as being able to ensure meaningful communication and engagement with the person who is at the end of life.

What skills are needed in the workforce?

Providing care at the end of life for an increasingly large population of people over 65 years will require a whole of system approach to ensure that care needs regardless of setting can be addressed. Both the health and aged care workforces will need to be able to recognise and respond to palliative care needs within their scope of practice. Aged care service provision relies on a range of different groups such as GPs, community pharmacists and allied health to support their core workforce which consists primarily of nurses, careworkers and support services staff. Each of these groups will have different roles and responsibilities and require different knowledge and capabilities. Services need to ensure that they have an appropriate mix of staff and that staff are skilled and trained to deliver care that meets the end of life needs of the older person.

Many elements of palliative care capabilities have been articulated in the National Palliative Care Workforce Development Framework produced by QUT. This provides guidance for individual health care providers, education providers, health service managers, and policy makers to ensure all health care providers are equipped with capabilities relevant to their context to provide care for people who are dying.

Person-centred care is fundamental to care at the end of life and requires organisations and their staff to understand the people they are providing care for and their individual and personal views, fears and hopes. It also means that staff must be supported in addressing these needs and in managing their own well-being.

What resources are available to support workforce?

Aged care services can access a range of high quality and specific palliative care resources that have been funded through the National Palliative Care Program that are relevant to aged care. They include a range of information resources and learning activities.

- Advance Care Planning Australia
- <u>CareSearch: Palliative Care Knowledge Network</u>
- <u>caring@home:</u> Symptom Management for Palliative Patients
- ELDAC: End of Life Directions for Aged Care
- EELC: End of Life Law for Clinicians
- End-of-Life Essentials: Education for Acute Hospitals
- Palliative Care Online Training
- palliAGED: Palliative Care Aged Care Evidence
- PCOC: Palliative Care Outcomes Collaboration
- <u>PCC4U: Palliative Care Curriculum for</u> <u>Undergraduates</u>
- <u>PEPA: Program of Experience in the</u> <u>Palliative Approach</u>
- The Advance Project

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