



6.18 End-of-life care

The inevitable human experience of dying has changed substantially in Australia over the last century. In the early 1900s, dying at home was common. While advances in medical interventions throughout the 20th century have substantially contributed to increased life expectancy for all Australians, these interventions have also had an impact on the dying experience, shifting a large proportion of end-of-life care into institutions such as hospitals and residential aged care facilities. Whether this institutional approach to dying can deliver what people want at the end of their life is a conversation gaining importance in Australia.

Emeritus Professor Ian Maddocks, Senior Australian of the Year 2013 and eminent palliative care specialist, has observed that 'Sometimes I think it's better to step back and say you don't need all that procedural stuff, what you need is good care now. You are going to die. Let's do it well.' This concept of 'dying well' (Jones et al. 2013)—that is, that the end-of-life care experience is positive and meets the needs and expectations of the person dying and of their loved ones—is the focus of this feature article.

The terms 'end-of-life care' and 'palliative care' tend to be used interchangeably. However, they are different concepts. The Australian Commission on Safety and Quality in Health Care (the ACSQHC) recently released a national consensus statement titled *Essential elements for safe and high-quality end-of-life care* (ACSQHC 2015), which defines the broader end-of-life care and palliative care concepts (Box 6.18.1). Importantly, 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. The ACSQHC makes note of two different components of the end-of-life definition: 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. In contrast, palliative care may not be limited to the last 12 months of life—the need for palliative care may be episodic over an extended period, depending on the illness.

Both end-of-life care and palliative care have been the subject of a number of state and territory and Australian government consultations and inquiries in recent years. The most recent of these consultations occurred in 2015, when the Victorian Parliament's Legal and Social Issues Committee invited Victorians to have their say on end-of-life care and the services that they want to support them at their end of life (Parliament of Victoria 2015).



Box 6.18.1: Definitions of end-of-life care and palliative care

End-of-life care: includes physical, spiritual and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff. It also includes the support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Palliative care: an approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

Source: ACSQHC 2015.

The need for appropriate end-of-life care and palliative care is important given that Australia's population is both growing and ageing. The proportion of the population aged 65 and over is forecast to increase from 12% (2.1 million people) in 1996 (ABS 1998) to around 15% (or 3.7 million people) in 2016 (ABS 2015a). By 2031, the proportion of people aged over 65 is forecast to be around 19% (or 5.7 million), and could be as high as 25% (between 9 and 12 million) by 2066 (ABS 2013). The vast majority of Australians who died in 2013 were people aged 65 and older (81%, or 119,000 people), with a further 8.9% and 4.6% aged 55–64 and 45–54 respectively (ABS 2014). Therefore, the number of people who will die each year will rise substantially over the next 50 years, and more people will die due to chronic progressive diseases, increasing the need for an end-of-life care system that meets the needs and expectations of individuals and their families.

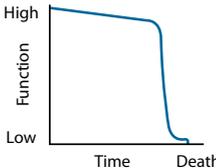
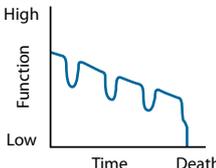
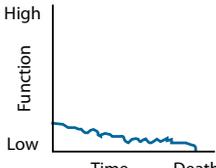
Pathways to death

Death can either be caused by sudden, unexpected events or be the result of longer term chronic health conditions. Sudden death events include accidents, infections, assault, anaphylactic shock, poisoning, suicide and unintended adverse consequences or mishaps from medical interventions. *Ischaemic heart disease* was the leading underlying cause of death in Australia in 2013, followed by *Dementia and Alzheimer disease*, and *Cerebrovascular diseases* (which includes stroke) (ABS 2015b). *Trachea, bronchus and lung cancer* and *Chronic lower respiratory diseases* made up the other top five leading underlying causes of death in Australia in 2013. While it is important to recognise that these sudden, unexpected circumstances are a type of pathway to death, end-of-life discussions are commonly associated with Australians experiencing a chronic and progressive decline in health and function associated with older age.



End-of-life experiences that involve chronic conditions and deterioration of body and/or cognitive function are unique to each individual, but typically follow three broad patterns, often characterised by the type of illness or condition encountered at the end of life (Table 6.18.1).

Table 6.18.1: Types of chronic disease trajectories

Pattern of illness leading to death	Functional capacity	Time period	
Short period of evident decline (e.g. Cancer).	 <p>High Function</p> <p>Low Function</p> <p>Time</p> <p>Death</p>	Body function declines rapidly and shows no sign of recovery.	Relatively short time period between onset of functional decline and death.
Long-term limitations with intermittent serious episodes (e.g. heart and lung failure).	 <p>High Function</p> <p>Low Function</p> <p>Time</p> <p>Death</p>	Body function slowly declines with intermittent sudden decline but some recovery after each episode.	Longer time period between onset of condition and death.
Prolonged decline (e.g. frailty and dementia).	 <p>High Function</p> <p>Low Function</p> <p>Time</p> <p>Death</p>	Body function low with further decline progressing slowly over time.	Longest time period of all chronic conditions.

Source: Adapted from Lynne et al. 2003.

The pathway or trajectory that defines a person's end of life is integral to understanding the concept of 'dying well'. For example, those experiencing a sudden death will have a vastly different end-of-life care experience to a person who gradually approaches old age and eventually dies from a chronic illness. The resultant diversity in individual needs and expectations poses challenges for the design of efficient and effective health and welfare services that deliver quality end-of-life care.

End-of-life care services in Australia

Australia's health system is well regarded internationally, ranking fourth overall behind the United Kingdom, Switzerland and Sweden in a recent Commonwealth Fund comparison (Davis et al. 2014). A recent international study ranked quality of death for Australians second out of 80 comparison countries, judged across a range of palliative care measures, including palliative care and health care environment; human resources; affordability; quality of care; and community engagement (The Economist 2015). However, there is also a perception that Australian end-of-life care services are fragmented and difficult to navigate for patients, their carers and families during an end-of-life journey that can be emotionally confronting and stressful (ACSQHC 2015).

Australian end-of-life care services are delivered across various government portfolios at both the federal and state and territory levels, with a range of government-subsidised and regulated services provided to people as they near their end of life. While many services are directly funded by the Australian Government, such as aged-care and Medicare-subsidised



services, states and territories all have different approaches to planning, investment and delivery of their publicly funded services, employ different local service delivery practices, and therefore have differently structured health care systems. The private and not-for-profit sectors are engaged differently in each state and territory to provide a range of health-related services. States and territories also have varying demographic and geographical remoteness profiles and, consequently, varying demands for particular types of services.

End-of-life care is provided in many health care settings in Australia, including neonatal units, paediatric services, public and private acute hospitals, general practices, and residential and community aged care services. Support services are also delivered to people in their own homes. Services targeted towards older Australians provide the majority of end-of-life care, and tend to be the focus of discussion about system-wide improvements; however, around 20% of deaths each year are for people aged under 65. Depending on the illness trajectory, this 20% may require acute medical care (for example, admitted patient care in hospital care, which adds the full spectrum of health services to the end-of-life care discussion). Specialist palliative care services, a component of end-of-life care services, also operate from a variety of settings, including specialist admitted patient consulting services; specialist admitted patient settings; hospices; and community-based specialist services.

A range of health professionals, other workers, carers and volunteers provide end-of-life and palliative care services. These include:

- nurses, both registered and non-registered, with and without specialised palliative care qualifications
- medical practitioners, including specialist palliative care physicians, hospital-based specialist palliative care trainees, other medical specialists, hospital-based non-specialists and general practitioners
- other health professionals, including psychologists, physiotherapists, occupational therapists, pharmacists
- social workers, spiritual and pastoral carers
- other occupations, including personal care assistants, chaplains, massage therapists and music therapists
- informal carers (such as relatives, friends and neighbours who provide care on an unpaid basis)
- volunteers.

End-of-life care service activity in Australia

The end-of-life experience for Australians has become increasingly institutionalised over the last century, with only around 20% of Australians dying outside of hospital or residential aged care in the first decade of the 21st century (Broad et al. 2013)—one of the lowest rates in the developed world. While the majority of Australians report that they want to die at home if faced with a terminal illness (Foreman et al. 2006), the reality when the time comes can be vastly different. As Australians approach the end of their lives, they often confirm where they want to die, or sometimes make a change to their preferred place of death. However, even when a person has made their preferred place to die known to others, only around half of people have their preferences met. Similar results have been found across the developed world (Aoun et al. 2013; Burge et al. 2015; Hunt et al. 2014).



Information about where Australians die, their preferred place of death and the end-of-life support they received is fragmented, because data are not standardised or collated into a single source. Rather, information is typically collected and published according to the service individuals were receiving at their time of death, with variation among the way service types record this information. While an overall picture of the type, amount, and quality of end-of-life care Australians receive is not currently possible, nonetheless, data are available to describe the broad characteristics of end-of-life care at the time of death across Australia.

Aged care services

For permanent residents of aged care facilities, the most common reason for separation from the facility for their last care episode was due to death, accounting for around 95%, or 54,000 people, in 2013–14 (AIHW 2015c). Less than half of these people had stayed for less than 12 months in the residential care facility. Around 15% of deaths in residential aged care facilities involved patients who were accessing palliative care services in 2013–14 (AIHW 2015b). While data are available on the proportion of services meeting national standards, there are no national level data on the quality of patient-assessed end-of-life care across the aged care service sector.

Admitted patient care

There were over 60,000 public hospital separations that ended in the death of the patient and an additional 13,000 in private hospitals in 2013–14 (AIHW 2015a). This equates to around half of all deaths in Australia occurring in hospitals, with rates relatively unchanged over the last decade (AIHW 2014). While there are detailed data regarding hospital stays in the last year of life (for example, O'Connell et al. 2014), little is known about the patient's perspective of their end-of-life care experience.

Palliative care services

Hospital separations with a palliative care component (about 57,000 separations) account for less than 0.6% of all hospital separations. However, they make up nearly one-third (32%) of all deaths in hospitals (AIHW 2015a). General practitioners provided an estimated 140,000 palliative care-related services in 2012–13, with an additional 63,000 MBS-subsidised services provided by palliative medicine specialists (AIHW 2014).

Cost of end-of-life care

As previously noted, end-of-life care services are provided by all levels of government and cross a number of government portfolios. The national costs of hospital and residential aged care services in the last year of life have been estimated to be in the order of \$2.4 billion and \$2.3 billion respectively, substantially higher than the estimated \$77 million spent on community-based care (Swerissen et al. 2014). Observations about the cost of palliative care services have a similar theme, with estimates of around \$7,700 per episode of subacute hospital care compared with \$2,500 for community-based care (SCARC 2012).



As with other aspects of the end-of-life care discussion, data on the cost-benefit of providing home- or community-based care are mixed and difficult to interpret. It is known that hospital admissions increase in the last year of life, with an average of nearly eight admissions per person, for an average total of 44 care days, in the final year of life (Rosenwax et al. 2011). Silver Chain, a large Western Australian-based not-for-profit organisation operating in four states, provides some evidence that a well-coordinated community-based palliative care program has the potential to reduce emergency department presentations and hospital use in the last year of life, and increase the rate of dying out of hospital, thereby reducing the cost of hospital-based care and therefore overall palliative care costs (Silver Chain 2015) (see Box 6.18.2).

Unless the observed pattern of primarily dying in hospitals and residential aged-care facilities changes, there will be a substantial rise in the cost of providing end-of-life care to Australians over the next 25 years, simply due to the increasing number of people dying.

Box 6.18.2: Silver Chain—Hospice Care Services

Silver Chain provides community-based Hospice Care Services (HCS), supporting people and families with complex needs to remain at home. As a part of the broader palliative care network of services, Silver Chain works closely with hospital palliative care teams and in-patient palliative care units to meet the unique individual needs and preferences of people with terminal illnesses. Care addresses physical symptoms, psychosocial and spiritual concerns through mixed palliative care teams consisting of nurses, doctors, care aides, social workers, counsellors and chaplains. The care provided is adaptable to the changing needs of the individual and their families/carers and is available 24 hours a day, seven days a week.

Silver Chain has evaluated the impact of their HCS in a 'whole of population' study using person-level linked data comprising those dying of cancer between 2001 and 2011 in Perth, Western Australia. More than half of all cancer patients who died (58%) had used HCS at some stage. The main outcomes of this work to date include:

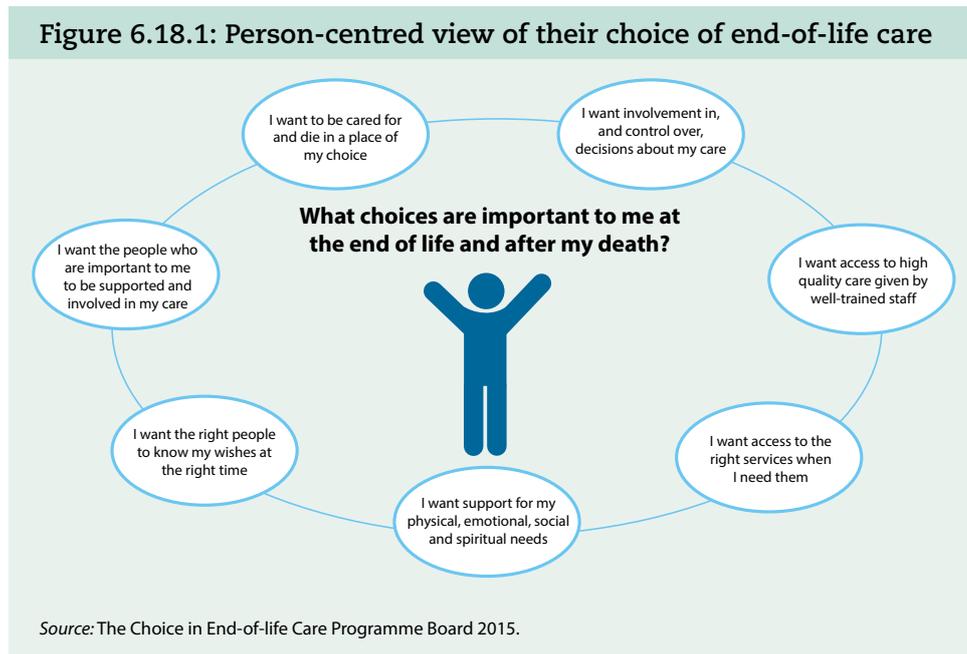
1. Reduced hospital-based care. HCS recipients had, on average, 8.0% fewer emergency department presentations and spent 5 days less in hospital over the last year of life, compared with those who did not access the service. The total effect of the service was a reduction of approximately 90,900 bed days over the 10-year period.
2. Increased likelihood of a person dying out of hospital. HCS recipients were three times more likely to die out of hospital, compared with those who did not access the service. Cancer patients aged under 50 years are eight times more likely to die out of hospital. Having a partner also increased the likelihood of death out of hospital by around four times.
3. Factors associated with increased likelihood of accessing the service were lower socioeconomic status, being born outside of Australia/New Zealand, being female, younger age, having a partner, and increasing time living with cancer.

Source: Silver Chain unpublished.

Improving end-of-life care—'dying well'

Gregory and Armstrong (2013) observe that, despite medical advances, mortality is 100%, and argue that a 'good death' is an important health outcome. However, exactly what constitutes a 'good death' or 'dying well' is open to conjecture. A 2015 Victorian Government consultation 'Greater say for Victorians: improving end-of-life care' generated a diverse range of views. A recent United Kingdom end-of-life care consultation generated a similar diversity of views which were distilled into seven main themes that mirrored the recent Victorian experience—see Figure 6.18.1.

Figure 6.18.1: Person-centred view of their choice of end-of-life care



Swerissen and Duckett (2014) suggest that four changes to the Australian end-of-life care setting would facilitate a 'good death' for more Australians:

- More public discussion about the limits of health care as death approaches, and what Australians want for the end of life.
- Increased planning of individual end-of-life choices to support improved compliance with choices.
- Increased compliance with an individual's expressed choices.
- Reorientation of services providing end-of-life care so that they focus more on people's wishes to die at home and in homelike settings, rather than in institutions.

Notwithstanding the diversity of opinion about what constitutes a 'good death', it is apparent that Australians expect that end-of-life care services should be high quality and meet the needs of the individual and their carers, as advocated by the ACSQHC's national consensus statement (ACSQHC 2015). However, the term 'quality' can be subjective, and can mean different things depending on a person's individual circumstances. For example, 'quality' for a person nearing the end of their life may mean comfort and wellbeing, which may be in contrast to 'quality' of a service which might include aspects such as safety and preventing harm.



Planning for death: Advanced Care Plans

A lack of planning for, and talking about, death is considered to be a substantial barrier to quality end-of-life experiences. Trankle (2014:3) quotes an Australian intensive care specialist as saying:

...a good death...it shouldn't come as a surprise to everyone, that there's actually been some time...just to recognise that, the patient's life is ending, and so there's a plan in place; people know what they're doing and what they're treating.

Faced with illness and possible death, patients, clinicians and loved ones are forced to make decisions under adverse conditions—for example, making choices about medical interventions under stress due to the progression of a long-term illness along an unexpected path. Making choices under such circumstances can impact on the quality of the end-of-life experience.

There are circumstances where individuals and family members may not consider medical interventions aimed at prolonging life to be appropriate for the needs and wishes of the individual. An Advanced Care Plan (ACP) or Advanced Care Directive (ACD) provides a way to document personal expectations about medical intervention well in advance of any critical medical incident.

ACPs or ACDs need not only be made when illnesses begin to impact on a person's life. All Australians are able to develop plans that guide decisions about their care should the need arise. While ACPs/ACDs provide the basis for an individual's wishes to be met, there is evidence that sometimes plans are not followed (Rhee et al. 2012). This can occur for a number of reasons: for example, the presence of an ACP/ACD may not be known to medical staff, or the plan may provide insufficient detail to guide clinical decision making. Evidence on the reasons plans are not followed in Australia is very limited.

While all states and territories in Australia have regulatory and legislative frameworks to support the use of ACDs/ACPs, their use remains relatively low, with an estimated 14% of Australians having an ACP (White et al. 2014). Improvement in the use of ACPs/ACDs would imply that Australians are planning and talking about their individual needs and wishes prior to when the time arises, which may improve the end-of-life journey.

Patient outcome measures—asking patients and their carers about services

Measures of patient experience of care, based on asking patients about their views on their level of care, are difficult to implement and administer, especially when the care provided can span a broad range of health and welfare service providers. Evidence regarding cancer patients suggests that data from patient-centred outcome measures (PCOMs) provide information on unmet need and may improve service providers understanding of patients' needs (Etkind et al. 2015).

Work is ongoing to develop outcome measures specific to end-of-life issues, for example, the End-of-life Patient-reported Outcome Measure, which assesses whether a patient has finalised their affairs at the end of life (McCaffrey et al. 2014). However, at present, standardised PCOMs tend to be highly specialised (for example, the recent publication of an international standardised measure for advanced prostate cancer) (Morgans et al. 2015).



Patient outcome measures are used by some Australian end-of-life care services, primarily palliative care services. At the national level, the Palliative Care Outcomes Collaboration (PCOC), established in 2005, uses a range of measures, collected from 106 Australian specialist palliative care service providers, to assess patient outcomes, including how long it takes for people to access palliative care, the amount of time a patient is in an unstable phase, and changes in pain experienced by patients. The most recent data (AIHW 2014) indicate that:

- The majority of patients (94%) requiring palliative care services started their episode of palliative care on the day of, or the day following, the day that they were ready for care.
- One-fifth (20%) of palliative care patient episodes involved an unstable phase of more than 3 days—that is, when a change in the plan of care or emergency treatment was required due to a new problem; there was a sudden deterioration of an existing condition; or a sudden change in family/carer circumstances had an impact on care.
- Pain management is meeting most benchmarks for the majority of patient episodes.

It is also important to understand the end-of-life journey from the perspective of carers of people who are dying. Research indicates that around half of caregivers report an experience of caregiving that was worse, or much worse, than expected (Burns et al. 2015). The reasons for this are unclear—however, there is evidence suggesting that the realities of caring 24 hours a day for a loved one who is dying can be vastly different to the imagined scenario (SCARC 2012).

Service integration

Given the wide range of services providing end-of-life care, service fragmentation has been acknowledged as a major barrier to achieving quality outcomes for those at their end of life (SCARC 2012). Trankle 2014 comments that the 'intensive care unit can be an inappropriate place to die and education and planning to allow death to occur elsewhere is crucial'. Person-centred, integrated services that enable effective communication between the services about a person's changing needs are paramount to ensuring overall effectiveness of end-of-life care (ACSQHC 2015). The service integration challenge is not unique to end-of-life care, but there are examples of successfully integrated models of care which could guide reform.

Palliative care service integration has made inroads into integration of care. The Victorian Palliative Care Resource Allocation Model acknowledges the importance of integrated care to ensure people at the end of their life receive integrated care that responds in a timely manner to an individual's changing needs (Department of Health 2011). Medicare-subsidised palliative medicine specialist services for case conferencing activities made up 7.9% of all services in 2012–13 (AIHW 2014), an increase from 6.1% in 2010–11 (AIHW 2012). However, there is no additional qualitative information about the utility or effectiveness of case conferencing. Also, system-wide approaches to care coordination must be based on strong evidence that the investment in coordination is of clear benefit to the patient (Yates 2015).



What is the AIHW doing?

The AIHW will continue its discussions with Australian, state and territory governments and other state and territory stakeholders to expand the range of available national end-of-life and palliative care information, including filling data gaps in relation to the end-of-life care experience as a whole.

What is missing from the picture?

Current data sources do not allow for reporting on a range of aspects of end-of-life and palliative care. For example, we do not have access to data to allow reporting on topics including palliative care-related expenditure; community-based palliative care services; MBS-subsidised services provided by general practitioners and non-palliative care medical specialists; and the number of palliative care beds in hospitals, both acute and subacute. This makes it difficult to provide a comprehensive overview of end-of-life and palliative care service provision in Australia.

It is apparent, from recent consultation activities, that end-of-life care remains a community concern. A number of themes about how the end of life could be improved for all Australians and better meet contemporary community expectations, are evident:

- Encouraging all Australians to have conversations about and plan for death.
- Providing timely advice about availability of end-of-life and palliative care services and carer respite.
- Facilitating Australian's ability to 'die in place' rather than in hospital.
- Better integration of end-of-life services between various components of the health sector, including potentially enhancing the role of primary care services in managing end-of-life care.
- Providing appropriate training and support for the end-of-life and palliative care workforce.
- Greater utilisation of ACP/ACD.
- Greater understanding of access to end-of-life care provision, including understanding barriers to accessing end-of-life care (Parliament of Victoria 2015).

A clear message from this is the need for 'consistent' data collection to better inform the community and enable decision-makers at all levels to monitor whether end-of-life care being provided to Australians is high quality and meeting their needs. The PCOC data illustrate that measurement of patient experiences can be achieved and can provide a valuable feedback mechanism to drive service level improvement (Currow et al. 2015). The publication and implementation of version 2 of the National Safety and Quality Health Service Standards is imminent, and includes standards for patients regardless of where they receive care—that is, whether they receive institution-based or home-based care.

A wide-ranging, standardised experience of end-of-life care measure for patients and carers, applicable to all death trajectories would also provide insight into whether services are supporting an experience of 'dying well', and how Australians feel about their end-of-life care.



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