deeble institute issues brief

**Summary: Paper 19**

**14/12/2016**

title

# Improving end-of-life care in Australia

author

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This issues brief was developed following workshops held by the Deeble Institute for Health Policy Research on end-of-life (EOL) care. The intention of this brief is firstly to raise awareness of the issues surrounding EOL care and to provide recommendations on what can be done to facilitate discussions on these issues among consumers and all sectors of the health system. It also provides recommendations on improving EOL care and care services.

## Context

A key issue facing health consumers, policy-makers and health care providers, both internationally and in Australia, is how to improve EOL care.

Australia faces an increasing demand for EOL care due to an ageing population and increasing rates of chronic disease. Two-thirds of Australians die between the ages of 75 and 95, and while most of these deaths are expected, recent reports indicate that the care most Australians receive at EOL often does not reflect their values, goals or informed choices. Evidence also shows that Australians are paying a high price for EOL care they do not want in a place they would not choose. Death has become institutionalised, and while most Australians would prefer to die at home, only 14% achieve this. Preference for dying at home does not align with current practice, emphasising the ethical and economic implications for ensuring suitable EOL care.

## What we know

Australians are living longer with a greater burden of chronic disease. Overall, deaths are occurring later but within a narrower 'window' of time, and people are more commonly dying with multiple chronic diseases. Over the next 25 years the annual number of deaths in Australia will double, and people will more frequently die with multiple chronic medical conditions. This will make the EOL period more prolonged but also more predictable, highlighting the need to adequately prepare people and medical professionals for the challenges of dying.

The health care costs of people who are dying are high, particularly in the last year of life. While there is international evidence that home-based palliative care increases the chance of dying at home and reduces the burden of symptoms, there is a lack of strong evidence around the cost-effectiveness of home-based palliative care services in Australia—although it is predicted that high quality EOL care may lower health costs by reducing hospitalisations.

When death is near and quality of life is low, it is difficult for medical professionals to know how far to pursue treatment, and understand at what point that treatment may become futile. Societal expectations and medical and technological advances have resulted in an environment where pressure to prolong life at all costs is widespread, often even in futile situations. Currently the health system is unable to adequately support people to effectively communicate their goals, values and preferences regarding care delivery in the later stages of life. There is broad Australian and international evidence demonstrating that medical professionals frequently continue to provide futile healthcare at EOL and it is often counterintuitive for doctors not to do so.

## Where we are today

EOL care has a low profile in Australia, and is not widely recognised as a public health concern, despite knowledge that EOL conversations and planning improve care. Individuals and medical professionals often feel uncomfortable discussing preferences for EOL care, resulting in low Advance Care Planning completion rates and poor implementation. At present, too many Australians experience uncertainty, pain and suffering in the final months and days of their lives, and die in a way that does not conform with their preferences or expectations.

## What clinicians and policy-makers can do

### *Recognising and defining futile care*

Futile healthcare can cause or prolong patient suffering, cause moral distress to healthcare workers and draws upon scarce resources. Identifying that a person may be dying is an important step in recognising when restorative treatment aims are appropriate and, equally, it allows time to plan and deliver effective EOL care. Recognition systems should aim to identify people at two critical points:

- When a person is likely to die in the medium term (within the next 12 months), where episodes of acute clinical deterioration may be reversible; and
- When a person is likely to die in the short term (within days to weeks), and clinical deterioration is likely to be irreversible.

This complex clinical decision commonly relies on the skill and experience of the clinician, which can be complemented by clinical tools developed to assist in recognising the dying patient and avoiding potentially harmful and futile treatments. Raising clinician awareness and access to screening tools may help to minimise prognostic uncertainty and futile care, promoting transparent conversations about treatment choice and care limitations.

*Legislative framework for clinicians*

The decision to withdraw care is challenging, with medical practitioners reporting that in some circumstances they provided futile treatment because of concerns about legal consequences. Currently legislation supporting ACP varies across jurisdictions. There are two kinds of directives: statutory directives that require documentation that meets specific government requirements; and, in some jurisdictions, common law directives that require a person's wishes, however they are documented, to be legally respected.

Concerns among medical practitioners have been identified around substitute decision-making, powers of attorney, the role of guardianship tribunals, and the legal consequences of making the wrong decision for care withdrawal. Harmonisation of laws about advance care planning documents and substitute decision-makers, across all jurisdictions, will support a nationally consistent approach that will protect clinicians from medico-legal risk and improve outcomes for medical professionals and people.

*Information technology*

My Health Record accepts uploads of advance care planning documents; however, access to these documents should be enhanced, with greater linkage and alerts to the existence of these documents in primary health, hospital and community IT systems. This will facilitate continuity and coordination of care, improve clinician awareness, and assist in providing care that aligns with advance care planning decisions. Additionally, such systems could potentially prompt discussion and documentation of advance care planning at key times in the patient journey.

*Improved end-of-life care services*

Estimates from Australian research suggest that as many as 50–90 per cent of all people who die could benefit from access to palliative care services. Evidence also indicates that reducing or delaying institutional care through home-based palliative care reduces healthcare costs incurred at EOL and increases the likelihood of dying at home.

Despite recognition of the importance of high-quality palliative care by the Australian Government through support of education, research, promotion and initiatives to support specific communities, there remains significant disparity in access across communities and these services have not been broadly embedded into the health system. Palliative care services are fragmented, with varying access and capacity across the country.

Services will require transformational change to meet demand and create a new model of integrated EOL care, including reallocation of funding in the community or through home based care and away from specialised services such as ICU.

## Supporting health professionals in end-of-life discussions

Medical practitioners are trained to treat, and patients and families do not like being told care is futile, resulting in clinicians avoiding these conversations. A number of factors contribute to clinicians avoiding these conversations. These include systemic factors such as shortage of time or a lack of appropriately private space; educational factors such as inadequate training and mentoring in necessary communication skills; and personal factors such as discomfort with talking about dying.

For ACP to be effective, planning and discussion around people's health care preferences need to become an ongoing part of routine clinical practice. To achieve this, clinician training must include caring for people at EOL, and should include medical practitioner responsibility for recognising dying and supporting EOL, in addition to curative care. Including EOL care in continuous professional development, through providing access to peer support mentoring and clinical supervision of all health care providers, will support medical practitioners and clinicians in managing the emotional and ethical challenges of these discussions.

## Supporting the community in end-of-life discussions

Failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying. While most people understand death and mortality, individuals and their families often struggle to come to terms with a terminal diagnosis.

Population health awareness campaigns covering dying, death and EOL care will assist in lessening misconceptions and improving understanding of the limitations of healthcare, and the potential adverse consequences of futile health care, especially at EOL. Such campaigns could also support people in making their choices known, and engaging in ACP. These simple, widely available tools that uphold autonomy and allow people, in consultation with family members and medical professionals, to make plans and document in a tangible way their preferences for medical and EOL care.

## Conclusions and recommendations

Balancing health care expectations with the resource-constrained health system to provide satisfactory EOL care remains challenging; however much can be done to improve the quality of EOL care:

- Conversations around preferences when nearing EOL, and understanding when care becomes futile
- Improved capacity to identify people who will die in the short to medium term
- A nationally consistent legislative framework to support EOL decision making
- Enhanced integration of advance care planning documents in My Health Record with primary, hospital and community health IT systems
- Improved access to EOL care in multiple care settings
- Promotion and engagement in public awareness programs that support EOL conversations.