

no: 19

date: 14/12/2016

Title Improving end-of-life care in Australia

Authors Amanda Jones

Manager, Deeble Institute for Health Policy Research
Australian Healthcare and Hospitals Association
Email: ajones@ahha.asn.au

Katharine Silk

Policy Analyst
Australian Healthcare and Hospitals Association
Email: ksilk@ahha.asn.au

Contents

Acknowledgements.....	1
Introduction	2
What we know	2
Where we are today	3
What clinicians and policy-makers can do	4
i. Recognising and defining futile care.....	4
ii. Legislative framework for clinicians.....	5
iii. Information technology	5
iv. Improved end-of-life care services	6
Supporting health professionals in end-of-life discussions	7
i. Primary care	7
ii. Acute care	7
Supporting the community in end-of-life discussions	8
Conclusions and recommendations.....	8
References	9
Contact.....	13

Executive summary

A key issue facing health consumers, policy-makers and health care providers, both internationally and in Australia, is how to improve end-of-life (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, the Australian Centre for Health and Research (ACHR) has recently reported 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 (Bartel 2016).

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.

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. We also provide recommendations on improving EOL care and care services. In the meantime other research aimed at providing deeper insights and more sophisticated evidence continues. This will be important in building new models of care for the future.

Acknowledgements

This brief was developed following workshops held by the Deeble Institute for Health Policy Research on end-of-life care. We would like to thank speakers and participants who contributed to those workshops and those who provided valuable feedback on this brief.

Introduction

Dying is a normal and inevitable part of life. In recent times much has been written in Australia and internationally about the challenges facing people to make informed decisions about end-of-life (EOL) care. 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. The combined effect is that death should be more predictable.

Within Australia there is increasing recognition of the importance of EOL care. The Deeble Institute for Health Policy Research has brought together researchers, health professionals, policy-makers and the public for discussions centred on improvements to EOL care practices in the Australian health care system.

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. We also provide recommendations on improving EOL care and care services. In the meantime other research aimed at providing deeper insights and more sophisticated evidence continues. This will be important in building new models of care for the future.

What we know

In 2014 there were 153,580 deaths in Australia, which represents an annual increase of 1.6% for females and 1.4% for males since 2004 (ABS 2015). Due to the ageing Australian population, 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 (Swerrissen and Duckett 2014). Elderly people approaching EOL can be broadly classified into three trajectories, each requiring different EOL care priorities:

- Cancer trajectory—most people with malignancies maintain comfort and function for some time, with rapid decline in the final weeks and days preceding death.
- Organ failure trajectory—people in this category often deteriorate over a longer time, maintaining moderate function. Periodically they experience acute deterioration followed by partial recovery, with death occurring quickly from exacerbation or complication.
- Dementia and frailty trajectory—function deteriorates over time, and these people generally die at an advanced age of either neurological failure (such as Alzheimer's or other dementia) or generalised frailty of multiple body systems (Lynn and Adamson 2003).

Two-thirds of Australians die between the ages of 75 and 95, and while most of these deaths are expected, the Australian Centre for Health and Research has recently reported that the care most Australians receive at the EOL often does not reflect their values, goals or informed choices (Bartel 2016). Death has become institutionalised, and while most Australians would prefer to die at home, only 14% achieve this (Swerrissen and Duckett 2014). Preference for dying at home does not align

with current practice (Bekelman et al. 2016), emphasising the ethical and economic implications for ensuring suitable EOL care.

The health care costs of people who are dying are high, particularly in the last year of life (Tanuseputro et al. 2015). While there is international evidence that home-based palliative care increases the chance of dying at home and reduces the burden of symptoms (Gomes et al. 2013), there is a lack of strong evidence around the cost-effectiveness of home-based palliative care services in Australia—although Smith et al. (2014) and McCaffrey et al. (2013) suggest 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 (Downer et al. 2015; Jox et al. 2012; Oerlemans et al. 2015; Willmott et al. 2016) and it is often counterintuitive for doctors not to do so. This is concerning, as futile care may prolong suffering and use scarce health resources (White et al. 2016). The decision to withhold or provide life-extending or death-delaying therapies affects people, their families, health professionals, the health system and the broader community.

Where we are today

The Grattan Institute identifies in its 2014 report 'Dying Well' that, when asked, most people have clear preferences for the care they want at the end-of-life, but rarely do they have open conversations that lead to effective EOL care plans.

EOL planning may become more relevant months or years before death, depending on the individual's underlying condition. Advance care planning (ACP) documents are 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 (Jones et al. 2015). These plans aim to take a holistic approach to an individual's care that is outcome-based, rather than listing medical interventions that a patient consents to or refuses in advance (AMA 2014).

While hospitalisation at EOL is common, with a planned approach it is possible to improve care and reduce healthcare costs by providing access to inpatient palliative or hospice care (McCarthy et al. 2015). This can involve redirecting people from high intervention curative treatment pathways (such as Intensive Care Units) to supportive care approaches or by providing palliative care (PCA 2014). Recent research has indicated that ACP in nursing home residents has demonstrated benefits including reduced numbers of hospitalisations, reduced numbers of residents dying in hospitals, and

improved compliance with providing medical treatments consistent with people's preferences (Martin et al. 2016).

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. A Newcastle hospital study was unable to identify any intensive care patients who had been involved in ACP (Zib and Saul 2007), while a Melbourne study of elderly emergency department attendees found that although 20% had discussions about ACP, only 8% had ACP documents in place (Taylor et al. 2003). Rhee et al. (2012) explain that individuals and medical professionals often feel uncomfortable discussing preferences for EOL care, resulting in low ACP 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 (Bartel 2016).

Australian conversations around EOL care are, however, gaining momentum. Innovative population awareness programs such as Dying to Talk (dyingtotalk.org.au), and Death over Dinner (deathoverdinner.org.au), offer strategies and toolkits to encourage conversations about EOL care at the kitchen table rather than in the acute care setting, to normalise these discussions and to help Australians determine what is right for them at the end of their lives. Other initiatives such as the Australian Government's End of Life Essentials Project provide e-learning opportunities and resources for medical professionals to improve the quality and safety of EOL in hospitals. The advocacy work of clinicians such as Dr Charlie Corke at University Hospital, Geelong, and Professor Ken Hillman at Liverpool Hospital, are increasingly creating awareness of end-of-life care in the acute care setting.

What clinicians and policy-makers can do

i. Recognising and defining futile care

While broad consensus on the definition of futile healthcare has not been reached, it is recognised as clinical care that offers no reasonable hope of a cure or benefit. Futile healthcare can cause or prolong patient suffering (Cruz, Camaliente and Caruso 2015), cause moral distress to healthcare workers (Borhani, Mohammadi and Roshanzadeh 2015; Mobley et al. 2007) and draws upon scarce resources (Huynh et al. 2013).

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 (Kennedy et al. 2014). 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 (ACSQHC 2015).

Research has shown that despite some optimism bias, medical professionals are reasonably good at estimating when people will die in the next year of life (Wolf and Wolf 2013). However, recognising

and diagnosing dying is marred by prognostic uncertainty. 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 (Cardona-Morrell and Hillman 2015; Kennedy et al. 2014; Richardson et al. 2014). 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.

ii. Legislative framework for clinicians

Recent Australian research has demonstrated that there are significant gaps in doctors' knowledge of the laws relevant to EOL decision-making (Willmont et al. 2016). Currently legislation supporting ACP varies across jurisdictions (Carter et al. 2016). 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 (Ries 2016).

The decision to withdraw care is complex, with medical practitioners reporting that in some circumstances they provided futile treatment because of concerns about legal consequences (Willmont et al. 2016). This is particularly relevant when pressure from people to continue curative treatment is high or there is family conflict. The Avant Mutual Group, an Australian medical defence organisation, has identified concerns among its members around substitute decision-making, powers of attorney, and the role of guardianship tribunals, and found that medical practitioners also report concerns about the legal consequences of making the wrong decision for care withdrawal (White et al. 2010). While medical practitioners perform critical legal functions during EOL decision-making, they are not obliged to provide treatments they believe are ineffective or harmful (Kasman 2004).

To this end, as recommended by the Senate Community Affairs Reference Committee (2012), 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. This should include agreed and consistent terminology, and the use of national guidelines and standardised documentation. The Victorian Government has recently taken significant steps to improving EOL care through the introduction of the *Medical Treatment Planning and Decisions Bill* (2016) to recognise advance care planning documents in legislation to ensure that they are authoritative and enforceable.

iii. 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:

- at agreed milestones (such as 75+ health assessments)
- during chronic disease planning, and with the development of multiple comorbidities
- at onset of dementia.

Alerts could also be in place for residents of aged care facilities and recipients of high-needs home care packages that guide clinicians to complete an ACP as part of continued management and care planning.

In the acute setting, My Health Record triggers could also be established:

- following multiple MET calls
- following multiple recent admissions to hospital for exacerbation of a chronic condition
- for unplanned or unexpected prolonged stays in hospital.

iv. 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 (Rosenwax et al. 2005). Evidence also indicates that reducing or delaying institutional care through home-based palliative care reduces healthcare costs incurred at EOL (Georghiou and Bardsley 2014; Hongoro and Finat 2011; Langton et al. 2014; McCaffrey et al. 2013; Tanuseputro et al. 2015) and increases the likelihood of dying at home (Gage et al. 2015; Shepperd et al. 2016).

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 (Mitchell 2011) 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, depending on diagnosis, age, cultural background, geographical location, available resources and clinician knowledge (PCA 2014). Primary Health Networks could play a key role managing funding and take responsibility for improved coordination and implementation of palliative care services.

A broadening of the definition of palliative care services beyond its current application mostly to terminal cancer diagnosis will refocus services to people experiencing terminal illness for all causes. 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. Costs for such structural reform would be likely be offset by a reduction in acute care costs in hospitals, including from unnecessary and unwanted hospital admissions (PCA 2014).

Supporting health professionals in end-of-life discussions

Srivastava (2012) describes a deep reluctance among medical practitioners to imagine and discuss mortality and communication around EOL care, highlighting deficiencies in current medical training programs and continuing professional development. 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 (ACSQHC 2013).

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 (Willmont et al. 2016). 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.

i. Primary care

Future inclusion of EOL care discussions as an item on the Medical Benefits Schedule, or as a priority supported by Practice Incentive Payments, recognises the value and importance of these conversations occurring in the primary care setting, rather than after an acute event in hospital. For planning to be effective, ACP needs to be a component of everyday care. Multiple long consultations may be required, including meeting with the person concerned and family members, holding case conferences with the person's care team, and in coordinating the necessary care. There is also an opportunity to fund nurse practitioners through MBS or other means to perform or support EOL care discussions and advance care planning (Rhee 2012).

ii. Acute care

In the acute setting, medical practitioners report difficulties in stopping or de-escalating active treatment. Admission to hospital is likened to being on a treadmill—once a treatment trajectory has been set, a cascade of interventions follows, with considerable effort and time being required when redirecting patients to a palliative approach (Willmont et al. 2016). Existing hospital systems constrain EOL planning as they focus on the delivery of care through distinct specialties, rather than making a holistic assessment of the patient.

At the national level the Australian Commission on Safety and Quality in Health Care (2013) has identified safe high quality EOL care as a priority. The Commission's National End-of-Life Consensus Statement (2015), and e-learning tools such as the End-of-Life Essentials Project, provide opportunities to improve the provision of EOL care through online education modules tailored to acute care clinicians. Similarly, the Australian Government Department of Health, supported by the Australian Healthcare and Hospitals Association (AHHA), has developed online training for health

workers and carers who provide palliative care to aged people in the community (<http://ahha.asn.au/pallcareonline>).

Bringing a systematic approach to EOL care serves to link EOL discussions with existing policies and procedures such as: the REACH (Patient and Family Activated Escalation) program in NSW; safety huddles; and METs (Medical Emergency Teams). It will also allow medical professionals, people and family members to communicate concerns about the care being provided. To enable this, EOL care must be supported by organisational governance systems that monitor safety and quality of EOL care (ACSQHC 2015).

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 (Bartel 2016). While most people understand death and mortality, individuals and their families often struggle to come to terms with a terminal diagnosis. While family and carers play an important role in supporting decision-making, there is an imperative to keep the person who is dying at the centre of the conversation. Families should also be aware that ACP is an ongoing means of communication that should be reviewed over time and as a person's condition changes.

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 (Bartel 2016).

Conclusions and recommendations

End-of-life care should relieve suffering, preserve dignity, be accessible and enable people to die in a place of their choice. The health system in Australia today provides increasingly aggressive therapies for the frail elderly that often extend life but also have the potential to cause harm. As a nation we have been slow to adapt to the care requirements of the advent of chronic diseases and an aging population. Medicine and healthcare have traditionally been designed around diagnosis and interventions, not normal ageing and the inevitability of death. Based on the workshop findings and evidence reviewed, the following actions are recommended:

- Education about EOL care options for medical professionals
- 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
- Public awareness programs that promote and support EOL conversations.

References

- Australian Bureau of Statistics (ABS) 2015, *3302.0 – Deaths, Australia, 2014*, ABS, Canberra.
- ACSQHC 2013, *Safety and quality of end-of-life care in acute hospitals: A background paper*. Australian Commission on Safety and Quality in Health Care, Sydney.
- ACSQHC 2015, *National consensus statements: Essential elements for safe and high-quality end of life care*, Australian Commission on Safety and Quality in Health Care, Sydney.
- Australian Medical Association (AMA) 2014, *Position statement on end of life care and advance care planning 2014*, AMA position statement, Australian Medical Association, pp. 1–10.
- Bartel R 2016, *Conversations: Creating choice in end of life care*, Australian Centre for Health Research (ACHR), Melbourne.
- Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, Kaasa S, Kwietniewski L, Melberg HO, Onwuteaka-Philipsen B and Oosterveld-Vlug M 2016, 'Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries', *JAMA*, vol. 315, no. 3, pp. 272–283.
- Bohani F, Mohammadi S and Roshanzadeh M 2015, 'Moral distress and perception of futile care in intensive care nurses', *Journal of Medical Ethics and History of Medicine*, vol. 8, no. 2, pp. 1–7.
- Cardona-Morrell M and Hillman K 2015, 'Development of a tool for defining and identifying the dying patient in hospital: Criteria for Screening and Triaging to Appropriate Alternative care (CriSTAL)', *BMJ Supportive & Palliative Care*, vol. 5, no. 1, pp. 78–90.
- Carter RZ, Detering KM, Silvester W and Sutton E 2016, Advance care planning in Australia: what does the law say? *Australian Health Review*, vol. 40, no. 4, pp. 405–414.
- Community Affairs Reference Committee (CARC) 2012, *Palliative care in Australia*, Community Affairs References Committee, The Senate, Commonwealth of Australia, Canberra.
- Cruz VM, Camaliente L and Caruso P 2015, 'Factors associated with futile end-of-life intensive care in a cancer hospital', *American Journal of Hospital Palliative Medicine*, vol. 32, no. 3, pp. 329–334.
- Downer J, You JJ, Bagshaw SM, Golan E, Lamontagne F, Burns K, Sridhar SK, Seely A, Meade MO, Fox-Robichaud A, Cook D, Turgeon AF, Dodek P, Xiong W and Fowler R 2015, 'Nonbeneficial treatment Canada: definitions, causes, and potential solutions from the perspective of healthcare practitioners', *Critical Care Medicine*, vol. 43, no. 2, pp. 270–281.
- Gage H, Holdsworth LM, Flannery C, Williams P and Butler C 2015 'Impact of a hospice rapid response service on preferred place of death, and costs', *BMC Palliative Care*, vol. 14, no. 75, pp. 1–11.

- Georghiou T and Bardsley M 2014, *Exploring the cost of care at the end of life, Report*, Nuffield Trust, London.
- Gomes B, Calanzani N, Curiale V, McCrone P and Higginson IJ 2013, 'Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers', *Cochrane Database of Systematic Reviews*, June 6, no. 6, article no. CD007760.
- Hongoro C and Finat N 2011, 'A cost analysis of a hospital-based palliative care outreach program: Implications for expanding public sector palliative care in South Africa', *Journal of Pain and Symptom Management*, vol. 41, no. 6, pp. 1015–1024.
- Huynh TN, Kleerup EC, Wiley JF, Savitsky TD, Guse D, Garer BJ and Wenger NS 2013, 'The frequency and cost of treatment perceived to be futile in critical care', *JAMA Internal Medicine*, vol. 173, no. 20, pp. 1887–1894.
- Jones B, Appleton W, Heazlewood T, Ironside J, and Dugdale P 2015, 'Introduction of an advance care planning clinic in a regional care coordination service', *World Hospitals and Health Services*, vol. 51, no. 4, pp. 12–16.
- Jox RJ, Schaidt A, Marckmann G and Borasio GD 2012, 'Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians', *Journal of Medical Ethics*, vol. 38, no. 9, pp. 540–545.
- Kasman DL 2004, 'When is medical treatment futile', *Journal of General Internal Medicine*, vol. 19, no. 10, pp. 1053–1056.
- Kennedy C, Brooks-Young P, Gray CB, Larkin P, Connolly M, Wilde-Larsson B, Larsson M, Smith T and Chater S 2014, 'Diagnosing dying: An integrative literature review', *BMJ Supportive and Palliative Care*, vol. 4, no. 3, pp. 236–270.
- Langton JM, Srasubkul P, Reeve R, Parkinson B, Gu Y, Buckley NA, Haas M, Viney R and Pearson SA 2015, 'Resource use, costs and quality of end-of-life care: observations in a cohort of elderly Australian cancer decedents', *Implementation Science*, vol. 10, no. 1, pp 1–14.
- Lynn J and Adamson DM 2003, *Living well at the end of life: Adapting health care to serious chronic illness in old age*, Rand Health White Paper, California, USA.
- Martin RS, Hayes B, Gregorevic K and Lim WK 2016, 'The Effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review', *Journal of the American Medical Directors Association*, vol. 17, no. 4, pp. 284–293.
- McCaffrey N, Agar M, Harlum J, Karnon J, Currow D and Eckermann S 2013, 'Is home-based palliative care cost-effective? An economic evaluation of the Palliative Care Extended Packages at Home (PEACH) pilot', *BMJ Supportive & Palliative Care*, vol. 3, no. 4, pp. 431–435.
- Mitchell GK 2011, 'Palliative care in Australia', *The Oschner Journal*, vol. 11, pp. 334–337.

- Mobley MJ, Rady MY, Verheijde JL, Patel B and Larson JS 2007, 'The relationship between moral distress and perception of futile care in the critical care unit', *Intensive & Critical Care Nursing*, vol. 23, no. 5, pp. 256–263.
- McCarthy IM, Robinson C, Huq S, Philastre M and Fine RL 2015, 'Cost savings from palliative care teams and guidance for a financially viable palliative care program', *Health Services Research*, vol. 50, no. 1, pp. 217–236.
- Oerlemans AJ, van Slusveld N, van Leeuwen ES, Wollersheim H, Dekkers WJ and Zegers M 2015, 'Ethical problems in intensive care unit admission and discharge decisions: a qualitative study among physicians and nurses in the Netherlands', *BMC Medical Ethics*, vol. 16, no. 9, pp. 1–10.
- PCA 2014, *Palliative Care Australia: submission to the National Commission of Audit*, Palliative Care Australia, Canberra.
- Rhee JJ, Zwar NA and Kemp LA 2012, 'Uptake and implementation of advance care planning in Australia: findings of key informant interviews', *Australian Health Review*, vol. 36, no. 1, pp. 98–104.
- Richardson P, Greenslade J, Shanmugathasan S, Doucet K, Widdicombe N, Chu K and Brown A 2014, 'PREDICT: a diagnostic accuracy study of a tool for predicting mortality within one year: who should have an advance healthcare directive?', *Palliative Medicine*, vol. 29, no. 1, pp. 31–37.
- Ries N 2016, 'Take control over the end of your life: what you need to know about advance care directives', *The Conversation*, published 15/09/2016, <http://theconversation.com/take-control-over-the-end-of-your-life-what-you-need-to-know-about-advance-care-directives-62905>.
- Rosenwax LK, McNamara BA, Murray K, McCabe RJ, Aoun SM and Currow DC, 2011, 'Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care', *The Medical Journal of Australia*, vol. 194, no. 11, pp. 570–573.
- Shepperd S, Gonçalves-Bradley DC, Straus SE and Wee B 2016, 'Hospital at home: home-based end-of-life care', *Cochrane Database of Systematic Reviews*, Feb 18, issue 2, article no. CD009231.
- Smith S, Brick A, O'Hara S and Normand C 2014, 'Evidence on the cost and cost-effectiveness of palliative care: a literature review', *Palliative Medicine*, vol. 28, no. 2, pp. 130–150.
- Srivastava R 2012, *Dying for a chat: the communication breakdown between doctors and patients*, Penguin Books, Melbourne.
- State of Victoria Department of Health (VIC DOH) 2014, *Advanced care planning: a strategy for Victorian health services 2014-2018*, Victorian Government, Melbourne.
- Swerissen H and Duckett S 2014, *Dying well*, Grattan Institute, Melbourne.

- Taylor, DM, Ugoni, AM, Cameron PA and McNeil JJ 2003, 'Advance directives and emergency department patients: ownership rates and perceptions of use', *Internal Medicine Journal*, vol. 33, no. 12, pp. 586–592.
- Tanuseputro P, Wodchis WP, Fowler R, Walker P, Bai YQ, Bronskill SE and Manuel D 2015, 'The health care cost of dying: a population-based retrospective cohort study of the last year of life in Ontario, Canada', *PloS one*, vol. 10, no. 3, e0121759.
- White B, Willmott L, Close E, Shepherd N, Gallois C, Parker MH, Winch S, Graves N and Callaway LK 2016, 'What does "futility" mean? An empirical study of doctors' perceptions', *The Medical Journal of Australia*, vol. 204, no. 8, pp. 318.e1-318.e5.
- White B, Willmott L and Allen J 2010, 'Withholding and withdrawing life-sustaining treatment: criminal responsibility for established medical practice?', *Journal of Law Medicine*, vol. 17, pp. 849–865.
- Willmott L, White B, Gallois C, Parker M, Graves N, Winch S, Callaway LK, Shepherd N and Close E 2016, 'Reasons doctors provide futile treatment at the end of life: a qualitative study', *Journal of Medical Ethics*, vol. 42, pp. 496–503.
- Wolf JH and Wolf KS 2013, 'The Lake Wobegon effect: are all cancer patients above average', *The Milbank Quarterly: A Multidisciplinary Journal of Population Health and Health Policy*, vol. 91, no. 4, pp. 690–728.
- Zib M and Saul P 2007, 'A pilot audit of the process of end-of-life decision-making in the intensive care unit', *Critical Care Resuscitation*, vol 9, pp. 213–218.

Contact

Susan Killion

Director, Deeble Institute for Health Policy Research

Australian Healthcare and Hospitals Association

T: 02 6162 0780

E: deeble@ahha.asn.au