

End-of-Life Care

Dying is a normal and inevitable part of life. Australians are living longer, with the number of deaths in Australia set to double over the next 25 years. More frequently people live with multiple chronic medical conditions, making death more prolonged, but also more predictable, allowing for a planned approach (Swerissen & Duckett, 2014). Palliative care services have inadequate capacity to provide consistent and coordinated care for current or future needs for end-of-life care.

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 end-of-life often does not reflect their values, goals or informed choices (Bartel 2016). Patient preferences for dying at home do not align with current practice (Bekelman et al. 2016) emphasising the ethical and economic implications for ensuring suitable end-of-life care.

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 healthcare in the later stages of their life.

There is broad Australian and international evidence demonstrating that medical professionals continue to provide futile healthcare at the end-of-life (Downer et al. 2015; Jox et al. 2012; Oerlemans et al. 2015; Willmott et al. 2016). Futile care is a concern as it uses scarce health resources and can cause added distress for patients, families and clinicians (White et al. 2016). The decision to withhold or provide life extending or death delaying therapies affects patients, their families, clinicians, the health system and the broader community.

The healthcare costs associated with dying are high, particularly in the last year of life (Tanuseputro et al. 2015). Compared with home based care, Palliative Care Australia estimates the cost of caring for a chronically or terminally ill person in hospital is significantly higher (PCA, 2015). The evidence suggests that the provision of high quality end-of-life care may in fact lower health costs by reducing hospitalisation at the end-of-life (Smith et al. 2014).

AHHA POSITION:

- ✧ End-of-life care should:
 - Relieve suffering and preserve dignity
 - Be accessible and enable individuals to die in a place of their choice
 - Provide care in a culturally and spiritually appropriate manner that is person-centered
 - Provide individuals and families with ongoing information to allow informed choice about healthcare preferences and end-of-life care options
 - Be supported by organisational governance systems that monitor safety and quality of end-of-life care
 - Be provided by healthcare professionals trained to provide appropriate, high quality end-of-life care to individuals and their families

- ✧ Advance care planning should be:
 - Supported through nationally standardised legislative frameworks
 - Supported through improved My Health Record integration and connectivity to hospitals, primary care, community and aged care. This will alert care givers to the presence of advance care planning documents to ensure patient preferences are respected and to improve coordination of care.
 - Prompted by healthcare providers at agreed milestones

- ✧ Additional research to reliably predict people approaching the end-of-life is necessary to enable advance care planning and provision of care that aligns with these preferences.

- ✧ Education/public information campaigns are necessary to foster public awareness and engagement on death and dying, advance care planning and end-of-life care.

- ✧ System-wide transformation of palliative care services and models of care are necessary to better respond to end-of-life needs and to meet increasing demand. These changes will require a coordinated and integrated approach across primary, community, specialist and hospital care.

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Released December 2016

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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.

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.

Jox RJ, Schaider 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.

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*, Submission, Palliative Care Australia, Canberra.

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.

Swerissen H and Duckett S 2014, *Dying well*, Grattan Institute, Melbourne.

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.

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.

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Released December 2016