

Policy Document

End of Life Care policy

Background

The Australian Medical Students' Association (AMSA) is the peak representative body for medical students in Australia. AMSA believes that all individuals have the right to the highest attainable standard of health, including at the end of life. Accordingly, AMSA recognises the need for high quality palliative care services, as a means to ease the experiences of death and dying.

Palliative care is a means of improving quality of life by relieving suffering when a cure is no longer possible or desired. Palliative care is in contrast to active or curative care, which aims to cure the patient of disease, and often equates death with defeat. The World Health Organization (WHO) defines palliative care as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."
[1]

This comprehensive definition highlights the core features of palliative care [1,2]:

1. Palliative care is patient-centred and the needs and desires of the patient (as well as their families and other caregivers) must be the focus of the care provided.
2. Palliative care is a holistic model of care that goes beyond the biomedical components of death and dying. Psychosocial and spiritual well-being at the end of life is a core component of palliative care.
3. Palliative care can be started at any time during the course of a life-limiting illness, and can be utilised alongside curative treatment. It emphasises improving the quality of life of the patient, regardless of their prognosis. Early involvement with palliative care ensures that the patient's wishes will be respected throughout their illness and that they will feel empowered and prepared for their own experience at the end of life.

Palliative care as it is referred to in this policy is used in the context of end of life care.

Palliative care in the global context

Each year around 20 million people globally need end-of-life care, most commonly due to cancer, progressive illness, and chronic diseases such as HIV and drug-resistant tuberculosis [3]. However, a recent report published by WHO and the Worldwide Palliative Care Alliance (WPCA) [3] estimate that only one in 10 people in this group are receiving palliative care that aligns with the WHO definition [1]. This statistic is largely attributed to significant barriers in access to palliative care, including a lack of clear governmental policies establishing palliative care, education for health professionals surrounding the

principles and practices of palliative care, essential medications needed to deliver palliative care, and organised programmes to deliver palliative care [3,4]. Overall, only 20 countries (including Australia) have integrated palliative care into their healthcare systems [3]. While most palliative care is provided by high income nations, almost 80% of the global need for palliative care is in low- and middle-income countries (LMIC) [3].

Palliative care in the Australian context

The demand for quality palliative care services - which may be provided in-hospital, at home, or in a hospice setting - is increasing in Australia. The growing and ageing population has been accompanied by a rise in the incidence of chronic and incurable diseases. Global projections similarly suggest that chronic disease will increasingly become a leading cause of death [5], and that most people should expect a period of terminal illness to precede death, especially in old age. This is particularly relevant to Australia's population trajectory, which forecasts the proportion of people aged over 65 could grow to 19% (or 5.7 million) by 2031 [6]. In Australia, Medicare expenditure on palliative care services has increased by 80% in the last 5 years alone [5], and such trends seem likely to continue.

Stigma around death, dying and palliative care

Psychological and social factors such as stigma and fear around death is a challenge in ensuring access to quality end of life care services globally [3]. A survey of Australians revealed that while 82% of people thought it was important to discuss how they want to be cared for at the end of life with friends and family, only 28% had done so [7]. This revealed beliefs that discussion around death is uncomfortable, emotional and/or fear-inducing for many people [7]. More specifically, palliative care services can carry negative stigma associated with hopelessness and abandonment amongst patients and families [8]. Stigma is also present in the medical community, with many health professionals still viewing palliative care as a final option or as alternatives to further treatment [9,10].

Investing in palliative care

Health care services must acknowledge impending increases in demand for palliative care services. While cost reduction should not be the primary goal of palliative care, if policy measures can improve patient wellbeing, better align patient desires with outcomes and simultaneously reduce expenditure, this should be pursued.

The end-of-life experience for Australians has become increasingly institutionalised in recent years. At present, only around 20% of Australians die outside of hospital or residential aged care, which is one of the lowest rates in high-income countries. However, half of all people would prefer to receive care and die at home [6]. This clear inconsistency raises concerns regarding unwarranted and excessive (also known as futile) medical treatment at the end of life. A treatment is considered futile when the burdens of treatment outweigh the benefits to the patient [11]. The negative repercussions of unnecessary treatments at the end of life have been recognised for at least two decades [12]. Futile treatments during end of life care are concerning not just because they can betray patient desires, but often they are elaborately expensive [13].

Numerous trials have suggested that engagement with palliative care teams results in lower total healthcare costs [14]. The reduced costs are largely attributed to lower likelihood of ICU use, and reduced length of stay in both hospitals and ICU [13,15]. These improvements in end of life experience and cost reduction are magnified by early

engagement with advanced care planning and the development of advanced care directives [13].

Advanced care planning

Advanced care planning (ACP) is a process that enables people to express preferences for their future care in the event of them losing capacity to make medical decisions [16,17].

One component of advanced care planning is advanced care directives (ACDs), defined as "set[s] of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios" [16]. ACD legislation is governed by state/territory governments in Australia.

ACP embodies the important value of patient-centred healthcare [18,19]. To best reflect the wishes of the patient, ACP should: be undertaken as early as possible in a patient's illness, be regularly reviewed throughout the illness trajectory and reflect the true values of the patient (without any influence of coercion by caregivers, family, health professionals or others). Health professionals must ensure that the patient has reasonable comprehension of the health, legal and other issues discussed during the process of ACP. A patient must display sufficient decision-making capacity to complete a legal document such as an ACD; they must acknowledge their health status and be able to comprehend and exercise their own judgement toward health care information provided to them. These measures and safeguards will also aid in the implementation and interpretation of ACD by health professionals.

ACP leads to a greater respect for patient wishes at the end of life. It has also been shown to reduce stress, anxiety and depression in family members of deceased patients, and to increase patient and family satisfaction [20]. The proportion of Australians adults with an ACD is very low, with estimates ranging from less than 1% to 12.5% [21-23].

There is significant inconsistency in ACD legislation between states of Australia, especially in regards to the level of restriction put on the implementation of ACD [6]. A National Framework for Advanced Care Directives was created in 2011 and provides a set of best practice standards for ACD [24]. Closer alignment to these best practice standards across the states and territories of Australia may promote better consistency in implementation of ACDs.

End of life care in Aboriginal and Torres Strait Islander Australians

Compared to non-Indigenous Australians, Aboriginal and Torres Strait Islander people are at an increased risk of developing life-threatening diseases, including, but not limited to, cardiovascular disease, poor prognosis cancers, mental health issues, diabetes mellitus, renal disease and respiratory diseases [25]. Despite the poorer health outcomes experienced by Aboriginal and Torres Strait Islander communities, studies overwhelmingly indicate that palliative care services are less likely to be used by Aboriginal and Torres Strait Islander people [26-29]. Moreover, a comprehensive study conducted in 2003 indicated that Indigenous clients are often either not referred to palliative care at all, or are referred at a very late stage of their illness [30]. Therefore, Indigenous people, who are more likely to develop complex symptoms, may not be receiving adequate care from healthcare providers at the end of their life [28].

A number of factors have contributed to the reduced use of palliative care services by the Indigenous community. There is a deep mistrust of mainstream healthcare systems among Indigenous Australians, which makes them generally more reluctant to access palliative care services [27-29]. Concurrently, while there is a lack of palliative care trained health professionals in general, Indigenous health workers are further underrepresented in the current healthcare system, which reduces the capacity of end-of-life care services to be culturally safe and relevant [27,31]. There is also a stark lack of palliative care services in rural and remote areas [28,31]. Thus, many Indigenous people from these areas who are in need of end of life care are forced to either rely on the acute care sector or to travel to larger city centres for end of life care [28]. Leaving home to receive palliative care may be particularly distressing for Indigenous individuals and their families, as 'dying in country' is of great importance to many Aboriginal cultures, stemming from the comforting belief that their spirit will return to the homeland [32].

End of life care in ethnic minorities

Statistics indicate that Australia has one of the most culturally and linguistically diverse populations in the world, with more than 75% of Australians identifying with an ancestry other than Australian, and 30% of citizens born in another country [33]. Cultural factors have been shown to strongly influence a patient's preferences around health decision making, receiving bad news and end of life care [34,35]. In fact, choices surrounding end of life care may be more associated with culture and ethnicity than other variables such as age, socioeconomic status and education levels [36]. This means an awareness of cultural differences in dealing with death and a commitment to delivering culturally appropriate palliative care services is of great importance [34]. However, limited attention has been paid to cross-cultural perspectives in the public policy, legislative framework and mainstream health-related research surrounding palliative care and advance care directives [35]. Further, research has shown cultural minorities in Australia suffer reduced access to mainstream health care and palliative care services, let alone culturally appropriate services [35]. In particular, researchers in the area have proposed that the emphasis on patient autonomy and informed consent in contemporary Western biomedical ethics is at odds with the beliefs and values of many cultures who place a greater emphasis on family or community decision making at the end of life [34-36]. There is also some evidence to suggest that uptake of advanced care directives differs significantly across ethnic groups in multicultural countries such as Australia [37,38].

Medical education for end of life care

Deficiencies in end of life education in medical school are well recognised, despite issues around death and dying being pertinent to every medical speciality. Early exposure of medical students to palliative care services provides several important learning opportunities. These include management of pain and other distressing symptoms, and the importance of considering the psychosocial and spiritual aspects of death and dying, among others

Clinical encounters with patients at the end of life are beneficial for medical students, not only in increasing their knowledge of palliative medicine, but also in encouraging broader reflection on patient care [39,41,42]. Many medical students find experiences of death and dying in medical school significantly stressful and emotionally challenging [43]. Therefore, it is important that experiences in palliative care and with patients with terminal illness be provided in a supportive environment with appropriate services available.

Palliative Care Australia supports quality palliative care education for health professionals at all levels: from entry to practice, to continuing professional development and specialist palliative care training programs [42]. Australia has only half the palliative medicine specialists it needs to meet demand under current referral patterns. This shortage is felt much more keenly in rural and remote areas [42]. Efforts to encourage, and build capacity for, palliative care specialisation should be prioritised to meet the increasing demand for palliative care services. This necessarily begins in medical school.

Position Statement

AMSA believes that:

1. Palliative care is an integral part of any healthcare system, and should be accessible by all Australians.
2. Stigma towards death and dying in the medical community and broader community is detrimental to achieving the highest possible quality of life for patients with terminal illness.
3. Skills and knowledge in palliative care and appropriate cultural competence and sensitivity towards death and dying are core proficiencies of all medical professionals.

Policy

AMSA calls upon:

1. The Australian Commonwealth, State and Territory Governments to:
 - a. Promote awareness of health care options at the end of life, including palliative care services and advanced care planning;
 - b. To continue (and, where possible, increase) support and funding for palliative care medical services and non-governmental organisations working in end of life care;
 - c. To prioritise uniformity in advanced care directive legislation between the states and territories of Australia, including alignment with the National Framework for Advanced Care Directives;
 - d. Increase availability of palliative care services in rural and remote areas of Australia;
2. Australian medical schools and Medical Deans Australia & New Zealand (MDANZ) to:
 - a. Provide medical students with academic and clinical exposure to palliative and end of life care. This may include, but is not limited to:
 - i. Clinical palliative care placements including contact with people who have life-limiting illness;
 - ii. Teaching on biomedical aspects of palliative medicine;
 - iii. Teaching and opportunities to practise communication skills with patients and their families at the end of their life;
 - iv. Teaching surrounding holistic care and cultural sensitivity at the end of life;
 - v. Consideration and education on providing end of life services to Indigenous and linguistically & culturally diverse patients;

- vi. Explicit education on advanced care planning and advanced care directives;
 - b. Provide an enabling and supportive environment for medical students to engage with sensitive topics such as death and dying. Examples include:
 - i. Specific time for reflection and debriefing with more senior clinicians;
 - ii. Peer-to-peer learning;
 - iii. Easily available counselling services for students;
3. Australian medical students and health professionals to:
 - a. Make efforts to reduce stigma around death and dying in the clinical environment and wider community. This includes, but is not limited to, encouraging open and sensitive discussion around death and dying and accepting death as a normal human experience;
 - b. Increase awareness about futile, unnecessary and unwanted treatments at the end of life;
 - c. Promote early access to patient-centred and holistic palliative care services for patients with life-limiting illness;
 - d. Support the use of advanced care planning to ensure patient wishes are respected at the end of life;
 - e. Encourage a high standard of cultural competency and sensitivity so that Aboriginal and Torres Strait Islander Australians and Australians from diverse cultures feel respected, safe and empowered at the end of life:
 - i. Respect diverse attitudes towards death and dying;
 - ii. Acknowledge and actively reduce the barriers to accessing palliative care services (including advanced care planning);
 - f. Increase communication about access to end of life care services between specialties;
4. Australian Specialty Colleges, particularly the Royal Australasian College of Physicians and the Royal Australian College of General Practitioners, to:
 - a. Promote and increase palliative care postgraduate training to address the shortage of palliative care physicians in Australia;
 - b. Incorporate high-quality end of life care training within all medical specialties.

References

1. World Health Organisation: WHO Definition of Palliative Care. Geneva: World Health Organisation; 2017 [cited 2017 May 11]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
2. Palliative Care Australia. What is Palliative Care? Australia: Palliative Care Australia; 2017 [cited 2017 May 11]. Available from: <http://palliativecare.org.au/understanding-palliative-care-parent-menu/what-is-palliative-care/>
3. Worldwide Palliative Care Alliance & World Health Organization. (2014). Global atlas of palliative care at the end of life. London: Worldwide Palliative Care Alliance.

4. Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative care: the World Health Organization's global perspective. *Journal of pain and symptom management*, 24(2), 91-96.
5. Palliative Care Services in Australia (AIHW). aihw.gov.au. 2017. Web. 16 May 2017
6. Australian Institute of Health and Welfare 2016. *Australia's health 2016*. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW.
7. Palliative Care Australia. The important conversation we are saving for later [Internet]. Griffith ACT: Palliative Care Australia. 2016 May 25 [cited 2017 June 27]. Available from: <http://palliativecare.org.au/palliative-matters/the-important-conversation-we-are-saving-for-later/#>
8. Dai YX, Chen TJ, Lin MH. Branding Palliative Care Units by Avoiding the Terms "Palliative" and "Hospice" A Nationwide Study in Taiwan. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 2017 Jan 24;54:0046958016686449.
9. Zimmermann C, Swami N, Krzyzanowska M, Leigh N, Rydall A, Rodin G, Tannock I, Hannon B. Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*. 2016 Apr 18;cmaj-151171.
10. Cherny NI. Stigma associated with "palliative care". *Cancer*. 2009 May 1;115(9):1808-12.
11. Australian Medical Association. Position statement on end of life care and advance care planning. Canberra: AMA, 2014. Accessed via: <https://ama.com.au/position-statement/position-statement-end-life-care-and-advance-care-planning-2014> (accessed Sept 2015).
12. Mathers, Colin D, and Dejan Loncar. "Projections of Global Mortality and Burden of Disease from 2002 to 2010". *PLoS Medicine* 2.11 (2006): e442.
13. Khandelwel N, and Curtis JR. "Economic Implications of End-Of-Life Care in the ICU". *Current Opinion in Critical Care* 20.6 (2014): 656-661.
14. Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson RH, Williams MP, Liberson M, Blum M, Penna RD. Impact of an inpatient palliative care team: a randomized controlled trial. *Journal of palliative medicine*. 2008 Mar 1;11(2):180-90.
15. Penrod J et al. "Cost and Utilisation Outcomes of Patients Receiving Hospital-Based Palliative Care Consultation". *Journal of Palliative Medicine* 9.4 (2006): 855-860.
16. Standards for providing quality care of all Australians. Griffith: Palliative Care Australia; 2008. 6p.
17. Australian Government Department of Health. Palliative Care - Advanced Care Planning [Internet]. Canberra; 2017 [updated 15 Feb 2017, cited 13 May 2017]. Available from: <http://www.health.gov.au/internet/main/publishing.nsf/content/acp>
18. Tillyard AR. Ethics review: 'Living wills' and intensive care—an overview of the American experience. *Critical Care*. 2007 Jul 11;11(4):219.
19. Advanced Care Planning. East Melbourne: Royal Australian College of General Practitioners.
20. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj*. 2010 Mar 24;340:c1345.
21. Hawkins H, Cartwright C. Advance health care planning and the GP. Is it time to move forward?. *Australian family physician*. 2000 Jul;29(7):704-7.

22. Seal M. Patient advocacy and advance care planning in the acute hospital setting. *Australian Journal of Advanced Nursing*. 2007 Jun 1;24(4):29.
23. Denniss DL. Legal and ethical issues associated with Advance Care Directives in an Australian context. *Internal Medicine Journal*. 2016 Dec 1;46(12):1375-80.
24. National Advanced Care Directive Working Group. *A National Framework for Advanced Care Directives*. Canberra: Australian Health Ministers' Advisory Council; 2011; 76p
25. Trewin, D., & Madden, R. (2005). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*. Canberra, Australian Bureau of Statistics.
26. Australian Institute of Health and Welfare. *Life expectancy and mortality of Aboriginal and Torres Strait Islander people*. Canberra, ACT: Australian Government, 2011.
27. Palliative Care Australia. *Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians: Position statement*. Canberra, ACT: Palliative Care Australia, 2011. Available: <http://www.palliativecare.org.au/Portals/46/PCA%20-%20Palliative%20care%20and%20Indigenous%20Australian%20-%20position%20statement%20updated%2016-8-11.pdf> (Accessed 9 May 2017).
28. O'Brien, A. P., Bloomer, M. J., McGrath, P., Clark, K., Martin, T., Lock, M., ... & McGrath Margaret, O. C. (2013). Considering Aboriginal palliative care models: the challenges for mainstream services. *Rural Remote Heal*, 13, 2339.
29. Maddocks, I., & Rayner, R. G. (2003). Issues in palliative care for Indigenous communities. *Medical journal of Australia*, 179(6), S17.
30. Mungabareena Aboriginal Corporation Wodonga Institute of TAFE Mercy Health Service Albury. *Providing culturally appropriate palliative care to Indigenous Australians: Practice principles*. Canberra, ACT: Australian Government, Department of Health and Ageing, 2004.
31. McGrath, P., Holewa, H., & Kail-Buckley, S. (2007). "They Should Come Out Here...": Research Findings on Lack of Local Palliative Care Services for Australian Aboriginal People. *American Journal of Hospice and Palliative Medicine*®, 24(2), 105-113.
32. Willis, J. (1999). Dying in country: implications of culture in the delivery of palliative care in Indigenous Australian communities. *Anthropology & Medicine*, 6(3), 423-435.
33. Australian Bureau of Statistics. *2011 Census of Population and Housing*. Canberra (AUST) : ABS; 2012.
34. Clark, K., & Phillips, J. (2010). End of life care: The importance of culture and ethnicity. *Australian family physician*, 39(4), 210.
35. Johnstone, M. J., & Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. *Journal of transcultural nursing*, 20(4), 405-416.
36. Baker, M. E. (2002). Economic, political and ethnic influences on end of life decision-making: A decade in review. *Journal of Health & Social Policy*, 14, 27-39.
37. Giger JN, Davidhizar RE, Fordham P. Multi-cultural and multi-ethnic considerations and advanced directives: developing cultural competency. *Journal of cultural diversity*. 2006 Apr 1;13(1):3.
38. Degenholtz HB, Arnold RA, Meisel A, Lave JR. Persistence of racial disparities in advance care plan documents among nursing home residents. *Journal of the American Geriatrics Society*. 2002 Feb 1;50(2):378-81.
39. Block SD. Medical education in end-of-life care: the status of reform. *Journal of palliative medicine*. 2002 Apr 1;5(2):243-8.
40. Thomas L. Dying as failure. *The ANNALS of the American Academy of Political and Social Science*. 1980 Jan;447(1):1-4.

41. Gawande A. Being Mortal: Medicine and What Matters in the End. First edition. Metropolitan Books/Henry Holt and Company, 2014
42. Workforce for quality care at the end of life. Griffith: Palliative Care Australia. 6p.
43. Pessagno R, Foote CE, Aponte R. Dealing with death: Medical students' experiences with patient loss. OMEGA-Journal of Death and Dying. 2014 May 1;68(3):207-28

Policy Details

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