Public Health Association
AUSTRALIA

Palliative Care and End of Life Choices

Policy Position Statement

Key messages:	From a public health perspective, palliative care and end of life choices means ensuring equitable access to appropriate and timely care, and the prevention of suffering and futile treatment. All people in Australia should be able to access appropriate end of life care when needed, and to be involved in their care plans in advance of death or cognitive decline. Respecting the choices of individuals improves the quality of life for the individual, and their support network.

Key policy positions:

1. Increased Commonwealth and State/Territory funding to support palliative care and of end of life services, including research, workforce development and access to services, particularly for in-home and rural and remote services, and First Nations and culturally and linguistically diverse communities.
2. All persons diagnosed with a life limiting illness or entering aged care should have the opportunity to participate in end of life discussions that include advance care planning and directives, palliative care and voluntary assisted dying (when eligible). These discussions must be conducted with a qualified practitioner, must be culturally appropriate for the patient, and all discussions must be patient-centred to respect the patient's choices, beliefs, and autonomy. The choice of one option should not be made on the basis of a lack of access to other services.
3. Jurisdictions with voluntary assisted dying laws should participate in consistent review and evaluation to align with new evidence and community sentiment as well as improve safeguards and remove barriers, such as amending the Criminal Code Act 1995 (Cth) to enable access to voluntary assisted dying health care via telehealth. National consistency is also important to minimise disparities and ensure equitable access across Australia.

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Palliative Care and End of Life Choices

Policy position statement

PHAA affirms the following principles:

1. Health is not merely the absence or presence of disease.(1) Health is influenced by mental, social, physical, and spiritual wellbeing.(1) Those living with life-limiting illness (a disease from which they are likely to die from, such as cancer) deserve to live the remainder of their life with the best health and wellbeing possible. From a public health lens, this means ensuring equitable access to appropriate and timely care, and prevention of suffering and futile treatment.

2. PHAA recognises that issues around end of life and palliative care choices are complex and, given the role of beliefs and values, difficult to resolve in a purely objective manner. In framing legislation and policy for end of life and palliative care, the beliefs of the person who is dying should have primacy. For important definitions, please see the appendix.

3. Advance care planning is important to support the care and treatment preferences, and cultural and religious requests, as well as identify a trusted chosen person to make decisions on another's behalf should they later lose capacity.(2)

4. Palliative care is recognised under the human right to health.(3) High-quality, person-centred care that optimises quality of life must be available and accessible to all people with a life-limiting illness, at all points of disease progression.(4)

5. Voluntary assisted dying (VAD) legislation should balance safety and accessibility. Laws should contain strict safeguards, but the safeguards should not be unnecessarily onerous so that otherwise eligible people are unable to access VAD. The choice to pursue VAD should not be made on the basis of a lack of access to palliative care.(4)

6. Withdrawing or refusing life sustaining treatment or providing strong medication(s) to relieve suffering, as per the individual's informed request, does not constitute VAD.(4)

7. VAD Legislation must accommodate the diversity of ethical stances in Australian society as well as ensuring that people wanting to access VAD do not face undue delays. Therefore, all health providers/professionals/services that conscientiously object to VAD (in jurisdictions where VAD is legal) should facilitate timely access to information about VAD and VAD services when requested by patients/people with a life-limiting condition. National consistency and alignment is important to minimise disparities between jurisdictions and health providers to increase equitable access

PHAA notes the following evidence:

Palliative Care

8. Palliative care can be required at any age and at any stage of illness; people do not have to be at the end of life and can receive palliative care for extended periods of time and alongside curative treatment.(5)

9. Continuing futile treatment can cause unnecessary suffering, repeated hospitalisation and removal from places or people that provide individuals with social support.(6)

10. Patients who receive palliative care are less likely to die in intensive care units, or while receiving cardiopulmonary resuscitation at time of death.(7) Ultimately, palliative care patients are less likely to die during or after a traumatic medical intervention.

11. A study examining emergency department admissions in the final months of life for those who accessed palliative care identified that the use of emergency care services was reduced by 30%, and the use of inpatient care was 60% less among palliative care patients in the last 90 days of life, than those who did not access palliative care.(8)

12. Integrated, multidisciplinary palliative care can decrease health system and other economic costs.(9) Decreased futile inpatient stays, emergency unit visits, intensive care admissions, and medication use are co-beneficial for the patient (avoids unnecessary suffering) and provides some cost relief to the health system.(9) Also, palliative care that includes family/carers can provide better coping mechanisms during their bereavement, as grief itself can cause health issues that may require treatment.(9)

13. Structural or systemic barriers to accessing palliative care exist,(5) such as the limited number of specialist palliative care services (particularly in rural and remote communities), and insufficient culturally appropriate options for culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander communities.(10)

14. As Australians live longer, more people will live with life-limiting conditions, thus the need for palliative care will increase.(5,10)

15. The Royal Commission into Aged Care Quality and Safety indicates palliative care as one of the four priority areas requiring immediate action. Recommendations include:
    - The right to receive fair, equitable and non-discriminatory access to palliative… care
    - Amendment of the Aged Care Quality Standards to assure high quality palliative care in residential aged care, including staff capacity (underway)
    - Palliative care training for all medical, nursing and allied health workers.(11)

Voluntary Assisted Dying

16. Although laws differ slightly between jurisdictions, the broadly emerging "Australian Model" of VAD legislation is as follows:(12)
    - Be diagnosed with a disease, illness, or medical condition that is advanced, progressive, and will lead to death within 6-12 months and is causing suffering that the person considers intolerable.
    - Be capable of making decisions about their medical treatment, able to communicate those decisions throughout the assessment process, and be acting voluntarily and without coercion.
    - Be aged 18 years old and over and meet residency requirements.
    - Make at least three separate requests for VAD, be assessed as eligible by two independent doctors and be referred to a psychiatrist or other qualified specialist if any doubt exists as their decision-making capacity in relation to VAD.

17. Currently, VAD is legislated in all six states of Australia: Victoria Voluntary Assisted Dying Act 2017, Western Australia Voluntary Assisted Dying Act 2019, Queensland Voluntary Assisted Dying Act 2021, South Australia Voluntary Assisted Dying Act 2021, Tasmania End-of-Life Choices (Voluntary Assisted Dying) Act 2021, New South Wales Voluntary Assisted Dying Act 2022. The VAD system has been reported to be operating safely and as intended.(13)

18. Since the passing of the 2022 Restoring Territory Rights Bill, the Australian Capital Territory has now passed their own VAD legislation, intending to commence late 2025.(14) The Northern Territory is expected to pass their own VAD laws in the coming years.(15)

Access Barriers to VAD

19. Legislation in Victoria and South Australia prohibits registered health practitioners from initiating discussions about VAD with patients.(16) Although intended to prevent undue influence by health professionals, this often limits the scope of the discussion that practitioners can have with patients about their end of life choices,(16) and presents a barrier of access.(17) Some eligible patients face difficulties initiating and articulating their interest in VAD clearly enough, preventing practitioners from concluding that VAD has been raised, thus delaying access.(17)

20. Many caregivers and their family members do not know VAD is an option, especially for older people, those from CALD backgrounds, or for those with little or poor health literacy.(18) If people don't know about VAD, then they cannot access this choice.

21. Procedural delays occur frequently, especially for those living in rural and regional areas. Participants in one study found the process to be complicated and drawn-out, especially when considering the physical condition of VAD applicants.(19) For patients with clinical expectation of death within six months, they often become too unwell to navigate the VAD system and lose decision-making and communication capacity before they can access VAD.(19)

22. Doctors have reported problems with the lack of institutional support and peer networks that are available to those that participate in VAD.(20) In addition to the rigorous time commitment required, this creates burdens on the already small pool of participating practitioners, negatively affecting the sustainability of the medical workforce, and in turn adversely affect patient's VAD access and care.(21)

23. Institutional objection is another barrier to access. While some States require health providers/services that conscientiously object to VAD to facilitate timely access to information about VAD and VAD services when requested by patients/people with a life-limiting condition, some State laws are silent on the issue.(16) This silence can lead to undue delays for people who want to access VAD services

Telehealth and VAD

24. The Australian Criminal Code Act 1995 prohibits the discussion of 'suicide' via a 'carriage service' (electronic means of communication including telephone and internet).(22) In 2023 the Federal Court ruled that VAD does fall within the definition of suicide. This has led many, including the Australian Medical Association, to call for the law to be clarified so that electronic communications can be used in the delivery of VAD care.(23)

25. The prohibition of VAD via telehealth creates burdens on patients to travel, which may not be possible depending on their conditions, or for doctors to travel large distances to see patients.(24) This particularly disadvantages patients living in rural and remote areas. Also, requiring the patients and healthcare practitioners to meet face-to-face can lead to delays in the process.(18)

Advance Care Planning/Care Directives

26. Advance care plans (ACP) promote individual autonomy and respect for a person's values and beliefs.(25) ACP is associated with benefits including reduced hospitalisation and futile treatment, increased likelihood of dying at a preferred place,(26) and less risk of stress and depression in family members during bereavement.(25,27)

27. Key to ACPs is autonomy and capacity, both are particularly critical to consider when an individual has a neurodegenerative disease, such as dementia.(28) For such cases, advance care planning discussions must be initiated by trained professionals at time of diagnosis to ensure capacity and autonomy are secured and respected.(28)

28. During ACP, individuals may choose to make an advance care directive (ACD). ACDs are recognised by specific legislation or under common law and come into effect when an individual loses decision-making capacity.(29,30) ACDs outline a patient's care goals and wishes and can appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf.(29,30) The law about creating and enforcing ACDs differs in each jurisdiction in Australia.

29. Barriers to participating in ACP include lack of knowledge about the process, limited time with health providers, the emotional difficulty of the subject and the health providers skills to have these discussions.(31)

PHAA seeks the following actions:

30. Increased Commonwealth and State/Territory funding to support palliative and end of life care. This includes research funding for ways to improve access to palliative care and VAD for those who are eligible, workforce development and service delivery, particularly for in-home services, rural and remote, First Nations, and CALD communities to ensure end of life choices are accessible for everyone, and ensuring the sustainability of the workforce and practice.

31. Palliative care should be a core function of aged care. States and Territories should continue to match funding palliative care in aged care and ensure that aged care residents (and their families if necessary) are educated on ACPs as an option upon entry to the facility.(32)

32. Healthcare practitioners should be appropriately trained on how and when to conduct end of life discussions that include ACP and palliative care. Practitioners should also be able to initiate VAD with eligible individuals in jurisdictions where VAD is legal.

33. Advocate for greater legislative consistency for supporting ACDs across all jurisdictions to appropriately safeguard both individuals and health professionals.

34. Encourage jurisdictions with VAD laws to participate in consistent review and evaluation to align with new evidence and community sentiment. Legislation for VAD must include safeguards to protect both patients and health professionals, as well as include a commitment to improve death literacy, access to palliative care and structured end of life communication such as ACDs.

35. Greater national legislative consistency across jurisdiction regarding VAD is important to minimise inequity and streamline processes.

36. VAD should be accessible for eligible Australians as a matter of equity. This includes reform of the Criminal Code Act 1995 (Cth) so that people in rural, regional and remote areas - and those too unwell to travel - can access VAD health care via telehealth where it is deemed clinically appropriate.(33)

PHAA resolves to:

37. Advocate for the above steps to be taken, based on the principles in this position statement across all of Australia.

(Adopted 2018 and revised 2021 & 2024)

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Appendix

Definitions:

End-of-Life: People are 'approaching the end of life' when they are likely to die within the next 12 months.(34)

Palliative care: An approach that improves the quality of life of patients and their families who are experiencing a life-limiting illness, through the prevention and relief of suffering through early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. An eligible individual can pursue voluntary assisted dying while receiving palliative care, however, voluntary assisted dying must not be conflated with palliative care, they are two separate care pathways.(34)

Voluntary Assisted Dying: This term is now commonly used in Australia, rather than euthanasia or physician-assisted suicide/dying. It includes: 'self-administration', where the person takes the VAD medication themselves, and 'practitioner administration', where the person is given the medication by a registered practitioner.(4)

Futile Treatment: Also known as medical futility or non-beneficial treatment. This term is not defined in law. It can be used to describe treatment that has a very low, to no chance of providing meaningful benefit to the patient, such as improving quality of life or sufficiently, sufficiently prolonging life of acceptable quality; or bringing benefits that outweigh the burdens of treatment.(35)