

## End of Life Choices

### Policy Position Statement

- Key messages:** PHAA recognises the diverse and strongly-held views in Australia on the subject of end of life choices. The issues are contentious and difficult to resolve in a purely objective manner. Many people have personal experiences and cultural frameworks and beliefs that inform their opinions. Legislative backing is important in supporting end of life choices, and the beliefs of the individual who is dying should have primacy in order to respect their autonomy.
- Key policy positions:**
1. Further research and consideration of end of life choices should be encouraged.
  2. Any legislation to legalise euthanasia or assisted dying should include safeguards to protect both patients and health professionals,
  3. Any legislation to legalise euthanasia or assisted dying should include a commitment to improve access to palliative care and structured end of life communication such as advance care directives.
- Audience:** Federal, State and Territory Governments, policy makers and the general public.
- Responsibility:** PHAA Board
- Date adopted:** 26 September 2018
- Contacts:** Ingrid Johnston, Senior Policy Officer, PHAA National Office

# End of Life Choices

## Policy position statement

PHAA affirms the following principles:

### *Beliefs about the sanctity of life*

1. PHAA recognises that issues around end-of-life choices are contentious and difficult to resolve in a purely objective manner. Many people have personal experiences and cultural frameworks and beliefs which inform their opinions.
2. In framing legislation for end of life management, the beliefs of the individual who is dying should have primacy in order to respect their autonomy.
3. Legislation can accommodate the diversity of ethical stances in Australian society. For instance, many jurisdictions with legislation allowing euthanasia or assisted suicide allow health professionals to not participate if they conscientiously object.

### *Practices and issues*

4. Advance Care Planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so that they can guide decision making at a future time when that person cannot make or communicate his or her decisions or wishes.<sup>1</sup>
5. End of life communication, such as Advance Care Planning and Directives, helps patients to overcome communication barriers and provides a structure for ensuring their wishes are clearly outlined and respected. Multifocal interventions which may include lists of questions to be discussed, informal and more formal facilitated discussions and feedback, and group-based education as well as advance care planning may be the most successful in promoting end of life communication and death literacy.<sup>2</sup>
6. Legislative backing is important in supporting end of life choices such as who will make decisions on one's behalf if they are unable to communicate or lack capacity, choices about what treatment is provided or withheld, choices about the location of dying, who might be present and any cultural or religious requests the person might have.
7. Advance care planning and documentation may be either Common Law (NSW & Tasmania) or Statutory (all other jurisdictions) in Australia, and needs to be supported by legislation, such as is the case in all States and Territories in Australia except New South Wales and Tasmania.<sup>3</sup>
8. Legal validity is dependent on a number of variables and if the documentation does not meet legal requirements, a person's end of life wishes may not be carried out.
9. Health care practitioners should have a role in discussing end of life care with patients.<sup>4</sup>
10. PHAA opposes discrimination between Australia's state and territorial jurisdictions, such as is currently imposed through the Commonwealth *Euthanasia Laws Act 1997*.

## PHAA notes the following evidence:

### *Medical possibilities*

11. Social change, public health and medical advances in the last century have increased longevity and changed end of life processes, while simultaneously there has been a move within medical ethics towards person centered care.<sup>5</sup>
12. While euthanasia and assisted suicide have, until recently, been unlawful throughout Australia, a roundtable of doctors, lawyers, former politicians, and ethicists, both in favour and against legalisation, agreed that the practices still occur.
13. Heavy sedation or pain relief may be prescribed even in the knowledge that a side effect of this treatment could be the shortening of the patient's life.<sup>6</sup>
14. Withdrawing life-sustaining treatment is also conducted currently in Australia with patients who lack capacity for decision making, for example in an irreversible coma, with the consent of their next of kin, enduring guardian or substitute decision maker, emphasising the need for broader use of advance care plans.
15. In jurisdictions where euthanasia or assisted suicide are legal, the technical mechanism for dying should be chosen to minimise the likelihood of accidental death. Mechanisms vary in ease of use for the dying. For instance, swallowing 100 pills may be physically difficult or impossible for someone in ill health, particularly if their appetite has been reduced by cancer treatment or a chronic illness such as COPD.

### *Pain and suffering*

16. Palliative care aims to help people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social, and is based on individual needs. The model is person-centred so that family, loved ones and carers can receive practical and emotional support.<sup>7</sup>
17. Euthanasia and assisted dying legislation usually have criteria requiring the patient to be suffering unbearable and enduring pain. However:
  - This option is not available to those not suffering such pain. This is in contradiction with current practices of, for example, withdrawing life support from someone in an irreversible coma, who may not be suffering pain or experiencing severe distress.
  - Further, this option may not be available to those who are suffering such pain but are unable to clearly and repeatedly communicate that. Written requests especially, assume a certain level of ability and may exclude some patients who would otherwise meet the criteria.
  - Also, pain and suffering is usually focused on physical health rather than mental health. This may unfairly exclude people whose experiences of suffering from mental anguish are equivalent to but no less severe than others afflicted by physical pain and illness.
  - Finally, there are large individual differences in the ability to cope with, or desire for, suffering. The subjective nature of this makes it difficult for fair and consistent decisions on who meets the criteria. The AMA position statement notes that there are some instances where it is difficult to achieve satisfactory relief from suffering, and that all patients have a right to receive such relief even where this may shorten their life.<sup>8</sup>

*Competency*

18. Another common feature of euthanasia and voluntary assisted dying schemes, is the requirement for the patient to actively request to die, and be competent to make that decision. When strict timeframes are imposed as well, patients whose competency declines as they near death, for example because of dementia, are unable to meet the criteria. This may have the effect of not respecting decisions made while competent, and also is in contradiction with the decisions currently made for patients who are not competent, for example withdrawing life-support from someone in an irreversible coma.

*End of life care*

19. Inequity exists in Australia in relation to people's access to appropriate palliative treatment and care. This is particularly true of access to high quality end of life care which may be affected by location (there is reduced or lack of access in regional and remote areas), education and knowledge of health professionals, and funding mechanisms which do not support holistic care. All possible action should be taken to ensure that a decision to participate in euthanasia or assisted dying is not driven by a lack of access to appropriate care.

*Legality*

20. Currently health professionals, patients and their loved ones lack the important protection of consistency of legislation regarding advance care planning across the states and territories.
21. In most Australian jurisdictions, current legislation allows doctors to withhold or withdraw life-sustaining treatment, thus allowing the underlying illness to take its course.
22. Euthanasia or assisted dying schemes have been legislated in several places internationally including in the Netherlands in 2001, Belgium in 2002, Luxembourg in 2009,<sup>9</sup> and multiple states in the United States of America.<sup>5</sup>
23. Victoria is currently the only jurisdiction in Australia with legalised assisted dying, legislated in 2017.

*Equity*

24. The absence of legislation on end-of-life choices does not mean that some people do not make these choices.<sup>10</sup> This has been recognised by medical practitioners and experts in Australia<sup>6</sup> and internationally.<sup>11, 12</sup>
25. A lack of legislation does mean that there is inequity, with some people having the knowledge, power and opportunity to make and enact these choices, while others do not. Reasons such as disability or competence results in some people being in a position to end their life whilst others are not.
26. In addition, whether or not the illness results in life being sustained by withdrawable treatment results in some people having the option to stop such treatment and expect the underlying disease to rapidly lead to death.

**PHAA seeks the following actions:**

1. Further research and consideration of end of life choices should be encouraged.
2. Any legislation to legalise euthanasia or assisted dying should include safeguards to protect both patients and health professionals.

3. Any legislation to legalise euthanasia or assisted dying should also include a commitment to improve death literacy, access to palliative care and structured end of life communication such as advance care directives.
4. Consistency of legislation across all States and Territories to support advance care directives is required to appropriately safeguard both individuals and health professionals.

### PHAA resolves to:

5. Advocate for the above steps to be taken based on the principles in this position statement.

### **ADOPTED 2018**

### References

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12. Feigin S, Owens RG, Goodyear-Smith F. Helping a loved one die: the act of assisted dying in New Zealand. *Mortality.* 2017:1-16.