



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,  
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

## Submission Cover Sheet

### End of Life Choices in the ACT

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# Inquiry into End of Life Choices in the ACT

Submission

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HammondCare

An independent Christian charity

## About HammondCare

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HammondCare is an independent Christian charity specialising in dementia care and palliative care. Regarded nationally and internationally as one of Australia's most innovative health and aged care providers, HammondCare offers hospital care, residential care and community care. Throughout 2016-17, HammondCare supported close to 3,000 people through its specialist palliative care services. In the ACT, HammondCare provides home care services to older people, including those living with dementia, through the Home Care Packages program and the Commonwealth Home Support Program.

HammondCare is passionate about improving quality of life for people in need and has a particular commitment to research as well as to people who are financially disadvantaged. HammondCare does not support physician-assisted suicide or euthanasia.

## Contacts

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### **Mr David Martin**

General Manager, HammondCare At Home  
HammondCare

E: [REDACTED]

### **Prof Rod MacLeod**

Senior Staff Specialist and Consultant in Palliative Care

E: [REDACTED]

## Palliative care

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According to the World Health Organization (WHO), palliative care is: “an approach that improves the quality of life of patients and their families facing the problem 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”.

Importantly this definition recognises the various aspects of palliative care, including the physical, emotional and spiritual. Palliative care is not only for the weeks preceding death, but for any person and family who has received a terminal diagnosis. It can extend for months and even years. Palliative care supports patients to live as actively as possible until death and may positively influence the course of illness. At the same time, it neither acts to hasten nor postpone death.

Palliative care employs a team approach, involving a number of different medical and health professionals at different times. Specialist palliative care teams can be made up of doctors, nurses, physiotherapists, occupational therapists, chaplains, pastoral care workers and very often volunteers undertaking a wide range of jobs for the patient and their family. Most teams will also be able to offer bereavement counselling where it is needed or wanted. Other health and medical professionals, such as general practitioners and aged care workers, are involved in providing palliative and supportive care to people at the end of life.

## Why people ask for assistance to end their life

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There are significant misunderstandings in Australian society about the nature, role and efficacy of care at the end of life. HammondCare believes that, along with inequitable access to palliative care services, these widespread misunderstandings often contribute to support for medical assistance in dying.

There are many reasons that people give when requesting assistance to end their life. A systematic review aimed at understanding the ‘wish to hasten death’ from the perspective of patients highlighted six major themes. They included: the response to physical/psychological/spiritual suffering; loss of self; fear; a desire to live but ‘not in this way’; a way of ending suffering; and seeking to have a kind of control over life (or death), “to have an ace up one’s sleeve just in case” (2012 Monforte-Royo; 5). Significantly, many of the reasons given related to emotional feelings and existential needs and were not responding primarily to physical symptoms such as unremitting pain.

Unbearable pain is often advanced as an argument for the legalisation of physician-assisted suicide but various studies have highlighted that the wish to hasten death is often based on “anticipated suffering rather than suffering right now”. Patients who request physician-assisted suicide are often seeking to avoid deterioration related to their illness in the future (Radbruch et al 2015, 7; Pestinger et al 2015). Pain management remains an important aspect of palliative care, and is one symptom that can be managed successfully in almost all cases with appropriate medical and psychological support.

Another significant reason given for seeking euthanasia or physician-assisted suicide is the desire to not be a burden to family, friends or care-givers. In 2014, 59 per cent of people choosing

physician-assisted suicide in Washington cited being a burden to family and caregivers as a key reason, and a further 8 per cent cited 'financial implications of treatment' (Washington State Department of Health, 7). This raises concerns about peoples' self-valuation and whether, under stressful financial or familial circumstances, some may feel they would be 'helping' those around them by ending their life.

It is also important to recognise that people's personal preferences for euthanasia vary significantly over time. Seeing changes in patients' attitudes toward euthanasia and palliative care is a common experience for palliative care clinicians working in HammondCare's services. These clinicians have noted that palliative care patients almost never persist with requests for euthanasia once they are receiving palliative care and have had time to adjust to their new situation.

## Community views on legalising assisted dying

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HammondCare is not aware of any published information on community attitudes towards physician-assisted suicide or euthanasia that are specific to the ACT. Polls conducted throughout Australia suggest broad support for physician-assisted suicide. For example, surveys conducted in 2017 and 2012 (Davey 2017) have found that more than 70 per cent of Australians were in favour of assisted dying.

However, studies have demonstrated that the choice and order of words used in survey questions on physician-assisted suicide and euthanasia has a statistically significant impact on the results (Magelssen et al 2016). For example, an analysis conducted by Gallup in the US found that attitudes towards assisted dying were much less favourable when the term "suicide" was used (Saad 2013). An Australian study found that surveys of attitudes to assisted dying must be treated with caution unless the terms used are "carefully defined" (Parkinson et al 2005, 88). This is often not the case. At the same time, based on an experimental changes in question wording, researchers have found that most surveys and polls on this subject are "naïve and simplistic" (Magelssen et al 2016).

Given the findings of this research, caution should be used in interpreting the findings of surveys or polls on physician-assisted suicide and euthanasia. With clearer definitions and more explanation of what is involved in proposed assisted dying frameworks, public sentiments may be subject to change.

## Risks associated with assisted dying

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There are a number of significant risks, both to individuals and the broader community, that arise from assisted dying. Based on evidence from other jurisdictions, HammondCare remains unconvinced that these risks can be managed effectively.

While a number of legislated safeguards in other jurisdictions have been designed to protect vulnerable individuals, these safeguards cannot detect coercion behind closed doors. It is all but impossible to identify subtle or hidden psychological pressure from family members or others set to gain from the death of a person with a life-limiting illness. This is particularly concerning for potentially vulnerable groups such as older people, given that more than one in 10 older people experience psychological abuse in any given year (Yon et al 2017).

Provisions for protecting people with mental health disorders and limited decision making capacity are commonly included in frameworks underpinning legalised physician-assisted suicide and

euthanasia. In many jurisdictions where assisted dying is permitted, people with mental disorders and impaired decision making capacity may be encouraged or required to seek assessment from a psychiatrist or other specialist. These provisions, however, have significant limitations. Where these specialist referrals are optional, they are rarely used; where they are mandatory, significant concerns remain about the assessment of capacity and the presence of mental illness in people with a terminal illness (MacLeod 2012).

Other provisions aimed at protecting potentially vulnerable individuals have been eroded over time in overseas jurisdictions. Laws allowing physician-assisted suicide and euthanasia in the Netherlands and Belgium were initially intended only for people with terminal illnesses but have now been extended to include people with psychiatric conditions, dementia, depression and old age. In Belgium, physician-assisted suicide and euthanasia were originally restricted to people aged 18 and over but they can now be accessed by people under the age of 18 (Radbruch et al 2015).

As a result, people from vulnerable population groups are increasingly receiving assistance to end their lives where these safeguards have been removed. In the Netherlands, for example, 141 people living with dementia were euthanased in 2016 (compared with just 41 in 2012), including some people with advanced dementia. A further 244 people were euthanased due to a range of “ailments associated with old age” and 60 people were euthanased as a result of psychiatric disorders (European Institute of Bioethics 2017).

HammondCare is also concerned that the introduction of state sanctioned assisted dying will undermine the value that we as a community place on human life. By assisting people to end their life, our society would be sending the message that some lives are not worth living. Such a change in attitude could place pressure on vulnerable people including those living with disability and dementia.

Laws that allow medical professionals to assist patients to die could impact negatively on the relationship between doctors and patients more generally. If, as well as promoting quality of life, medical practitioners also began to assist with suicide and euthanasia, there is a valid and widely held concern that this would undermine the relationship of trust between other patients and their doctors (McLachlan 2010, 307). The Australian Medical Association (AMA 2016, 2) and the Australian and New Zealand Society of Palliative Medicine (ANZPSM 2017, 2) do not actively support medical involvement in assisted dying.

Furthermore, there is widespread evidence of a negative impact on doctors who take part in supporting patients to end their life. In the Netherlands, many physicians have found that their involvement in performing euthanasia has been a “drastic and sometimes even traumatic event” (Van Marwijk 2007, 612). In other jurisdictions doctors who have participated in physician-assisted suicide have reported that this subsequently affected their ability to practice medicine (MacLeod 2012, 90).

Finally, the introduction of legal physician assisted suicide has been linked to reductions in the use of palliative care in other jurisdictions. The utilisation rates of hospice and palliative care services in US states where physician-assisted suicide was legalised have reduced compared to other states where the practice remains illegal (Ballentine et al 2016; Wang et al 2015). This is a particularly concerning given the inequitable access to palliative care services in Australia.

## The applicability of the Victorian scheme

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It is important to recognise and acknowledge that Victoria's voluntary assisted dying scheme is not yet in operation and many of the details are yet to be determined. The Victorian Government is still in the process of preparing regulations for the new scheme that will not come into effect until the middle of 2019.

These details include, for example, such basic things as the types of controlled substances that will be prescribed to patients seeking assistance to end their life. More work is also needed to develop the education that will be provided to the medical professionals who will take part in the scheme. With no data and no evidence about the effectiveness of the scheme's safeguards, there is very little that Victoria has to offer other jurisdictions when it comes to physician-assisted suicide and euthanasia at this stage.

## Improving palliative care

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Rather than introducing an assisted dying scheme in the ACT, HammondCare urges the parliament to do all it can to improve palliative care provision. This can be done by improving education for health and medical professionals, encouraging the uptake of advance care planning and increasing funding for palliative care initiatives and programs.

There is a need for more and better education in palliative care for all health professionals. People involved in health care, and particularly those involved in care for older people, will inevitably face issues around death and dying. Many doctors and healthcare workers find conversations around death and dying difficult and do not feel equipped to assist in palliative care (Detering et al 2014, 1).

HammondCare supports the integration of palliative care education within all health undergraduate and relevant post-graduate curricula. The foundation for this has already been laid with the development of a core curriculum by the Australian and New Zealand Society of Palliative Medicine in 1995. While this curriculum is available, palliative care education currently remains optional and self-directed.

For non-university trained health professionals, including care staff in residential care homes, HammondCare recommends that palliative care training courses be promoted to increase uptake. The Program of Experience in the Palliative Approach (PEPA), funded by the Australian Government Department of Health, provides free palliative care workshops and placements in palliative care services. This program operates in each state and territory but uptake, particularly among residential aged care staff, remains low.

Teaching styles that encourage students to draw on their own experiences and skills have been most effective in palliative care training (MacLeod et al 2007, 63). Palliative care education in Australia has often been diverse and imaginative (MacLeod et al 2007, 67) drawing upon multimodal approaches. These ways of teaching have been helpful in assisting students to understand that palliative care is best delivered in a person-centred approach and not according to imposed formulae (MacLeod et al 2007).

HammondCare believes that Australian governments should promote advance care planning in order to increase its uptake. For advance care planning to become normalised it needs to be promoted across all sectors (primary, acute and aged care) and barriers to uptake need to be addressed. Currently there are legislative differences in how advance care directives are recognised between different states and territories. HammondCare recommends that different jurisdictions work together to achieve consistency in advance care planning arrangements.

Finally, more must be done in all jurisdictions of Australia to increase the reach and impact of palliative care services.

## Conclusion

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HammondCare does not support physician-assisted suicide or euthanasia. The risks these practices pose are significant and legislated safeguards designed to protect vulnerable citizens are subject to abuse and erosion over time. Rather than introducing such a framework, we urge the ACT parliament to continue to invest in high quality palliative care services and to identify opportunities for increasing equitable access to these services for all citizens.

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