



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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SUBMISSION TO THE INQUIRY INTO END OF LIFE
CHOICES IN THE ACT

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1. Introduction

- 1.1 My name is Dr Michael Chapman, a palliative medicine specialist and geriatrician working in the ACT, and I am the author of this submission.
- 1.2 I am the director of Palliative Care at Canberra Hospital, and the chair of the ACT Palliative Care Clinical Network. I also have academic roles at ANU medical school and the University of Technology Sydney. However, this submission represents my opinion, and does not necessarily represent the views of these organisations.
- 1.3 As a specialist in palliative medicine working within the ACT I feel that I am well placed to contribute to the discussion on end of life choices within our territory.
- 1.4 In this submission, I will comment on the Inquiry terms of reference. I will then provide additional supportive information including reference to notable peak-body position statements relevant to end of life choices and voluntary assisted dying.
- 1.5 I would welcome the opportunity to meet with the Committee to provide additional information that may be of assistance with the Inquiry.

2. Background and summary

- 2.1 Palliative care's aim is to improve the experience of patients with life-limiting illnesses and their families. It encompasses not just the physical but emotional, social, spiritual, and cultural needs of the individual and family unit. Due to this palliative care is more than just care at the end of life. Palliative care is about living well with advanced illness.
- 2.2 Providing for people's palliative needs and for their end of life care is complicated. Existing structures cannot always meet the needs that are present. Providing for these needs requires further development of palliative care resources. Specialist services need to be proactive, integrated, flexible and available at the point and location that they are needed. Quality palliative care provision also needs all healthcare clinicians to be able to provide care, and access support to meet the needs of patients and their families. Meeting these needs will require ongoing adequately resourced specialist palliative services available where they are needed including within acute care settings, adoption of flexible and responsive models of care provision, and a focus on palliative care capacity building within ACT healthcare services.
- 2.3 While an area of debate, current Australian peak-body consensus is that the practice of palliative care does not include euthanasia or voluntary assisted dying. This is reflected within the Palliative Care Australia position statement on *Euthanasia and Physician Assisted Suicide*¹.
- 2.4 Access to voluntary assisted dying is a clear concern for many Australians. Many who desire community access to voluntary assisted dying cite the laudable wish to empower individuals to have more choice about the manner and timing of their dying. However, access to voluntary assisted dying, as a single change, will not have the capacity to relieve the unmet palliative needs of those with advanced illness, and those approaching end of life in the ACT.

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- 2.5 The debate around voluntary assisted has potentially contributed to communities' fears about dying. Supporting communities to understand the options available to support them, and to understand dying as a natural part of living is an important response to these concerns, regardless of decisions about access to voluntary assisted dying.
- 2.6 If voluntary assisted dying becomes available within the ACT multiple additional elements should be considered. Determining what changes will need to be put in place to limit the number of people who feel that voluntary assisted dying is their only choice, providing support to those who are bereaved through these choices, and supporting clinicians who are involved in providing access to voluntary assisted dying should be considered within any approach to allow access to voluntary assisted dying within the ACT. In addition, a lack of clarity on key issues such as within the process of clinician assessment for suitability for voluntary assisted dying, and the mediation of differences of opinion or clinicians' willingness to be involved in voluntary assisted dying processes would need consideration.

3. Comments on the Terms of Reference

- 3.1 I have addressed each of the terms of reference in this section. I am aware that ACT Health has submitted a response to the select committee which includes a detailed description of current models of palliative care provision within the ACT. The following then will highlight key points and elaborate on my own opinions rather than repeat an exhaustive description of current practice within the ACT.
1. [Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care](#)
- 3.2 Palliative care practitioners recognise that care is not just focused on the last stage of life, i.e. dying. The focus is broader; potentially involving the time from the point of diagnosis with a life-limiting illness, or when palliative needs arise. This care focuses on supporting people to live as well as possible until they die.
- 3.3 Good palliative care supports the person (along with his/her carers and the health professionals involved in care) to be informed about their condition; supports their involvement in shared decision-making and communication of preferences for care; and provides proactive clinical care to address physical, psychological, and emotional needs. Support and empowerment for informal caregivers is also critical, which includes the bereavement period.
- 3.4 Responding to the changing needs for a person with a life limiting illness and their carers' needs in the hours, days, weeks, months (and even years) leading towards death should be a whole-of-health responsibility. In both cancer and non-malignant disease there is increasing complexity of illness, and many people live with multiple comorbidities all impacting on care and clinical needs.
- 3.5 Significantly, this is often associated with a perception of burden(s) and fears for ongoing care upon a person, their carers and family. This perception can accumulate and often become magnified over time especially if the required support is not forthcoming. It can present as

significant psychiatric, psychological, psychosocial, and/or existential concerns which can be so overwhelming that the accumulated suffering may cause a person to seek to end their life to potentially re-establish a sense of control.

- 3.6 Palliative care medical practitioners, and the many health care professionals who provide the necessary interdisciplinary care, play a key leading role in facilitating end of life choice for patients and their carers. It is important for people with advanced disease to make management and treatment choices to reflect their values and changing needs. A system that promotes and embeds standards of care to give this capacity for people and their carers will enhance their quality of life.

2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT

- 3.7 I am not able to speak for the ACT community regarding their views on voluntary assisted dying, although I hope that this inquiry will shed some light into what these might be.

- 3.8 As a palliative medicine specialist, I can anecdotally say that I feel that I am increasingly being asked about voluntary assisted dying by patients and families. Likewise, I feel that those under my care increasingly express a sense of terror about the dying process. My personal view is that this represents both an increasing public interest in access to voluntary assisted dying as a norm, but additionally a heightened concern about the “horror” of death and dying. While much attention is appropriately placed on the first of these issues, I also believe that we should attend to the second. While the ACT may have access to voluntary assisted dying in the future it is unlikely that this will be utilised by a large number of people. While the number of people utilising voluntary assisted dying is growing in other jurisdictions where it is available, it remains a proportionally rare event compared with natural dying. Given these concerns it will remain important for ACT residents to have confidence in the support that will be provided to them when they approach dying. A notable additional point is that improving the “death literacy” of Australians may aid in their understanding of natural dying, enabling a sense of empowerment and support. The compassionate cities movement, and its suggestion of “health promoting palliative care” and other grass-roots movements such as Groundswell, death over dinner, and death cafes, are all important potential steps towards these outcomes. Simply making voluntary assisted dying legal may not be able to diminish our community’s fears without a focus on other interventions such as these.

- 3.9 There are diverse opinions within the healthcare community regarding voluntary assisted dying. Similarly, there are significant concerns about the practical issues with its legalisation within the ACT including in the processes that may be used, and the implications for healthcare services. I am frequently conscious that community members and clinicians assume that specialist palliative care clinicians are both supportive of voluntary assisted dying and will be involved in providing it if it becomes legal. In reality, evidence would suggest that specialist palliative care clinicians are less likely to support voluntary assisted dying². Relatedly, many have concerns about palliative care’s involvement in assisted dying practices and believe that palliative care is

² ANZSPM Position Statement on Euthanasia and Physician Assisted Suicide (updated 31 March 2017) <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1491523669&sid=> (accessed 1 February 2018)

and should be different from voluntary assisted dying³. I also feel that there is considerable risk in associating palliative care with voluntary assisted dying. Palliative care remains misunderstood and feared by many within our communities. Palliative care's close involvement in the provision of assisted dying would likely constitute a further reason to avoid accessing palliative care for some community members when they may benefit from it. Despite this it is very likely that ACT residents who may wish to legally access voluntary assisted dying, may also benefit from specialist palliative care. If voluntary assisted dying is legalised in the ACT those who wish to explore this option should have access to all available and appropriate care supports including specialist palliative care.

3.10 I am aware that many clinicians, some who support the idea of voluntary assisted dying, are also concerned about the impact that their involvement in these practices may have on them. Self-care is a needed focus for clinicians, particularly those involved in practicing palliative care, and attention to the potential additional supports needed for clinicians involved in voluntary assisted dying is highly relevant.

3. Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed

3.11 Persons making end of life decisions are some of the frailest and most vulnerable patients the medical profession has the privilege to care for. Similarly, persons who are already vulnerable due to social or economic disadvantage, extremes of age, LBTQI status, cognitive impairment, or disability, being imprisoned, being a cultural minority or migrant, or those with stigmatising illness also face end of life choices, and their vulnerability may be compounded.

3.12 Requests for voluntary assisted dying are often closely tied to concepts of empowerment and dignity, and we still have much to understand about these issues for vulnerable people facing end of life choices. Interventions other than access to assisted dying may have an impact on these concerns, and yet be unavailable. The complexity of a life limiting illness and the changing needs of a person with such illness may be associated with concerns about being a burden on others, particularly when there are fears that the required support is not available. Such concerns may contribute to a person seeking to end their life.

3.13 In this way, much of the community debate fuelling discussion about alternative end of life choices including assisted dying may be indicating our awareness that current systems and supports are inadequate, or not addressing needs. In this context there is a risk that we assume that legalising voluntary assisted dying will meet all our current needs. Unfortunately, legalisation of voluntary assisted dying may provide an additional choice for ACT residents, but may not actually provide optimum choices for their end of life care.

3.14 There are clear tensions in legislating for assisted dying and protecting persons who may be influenced by a variety of factors and or change their minds with the right support and treatment. Wishes around end of life choices often change during one's illness. Persons with life limiting illness may make these decisions with irreversible consequence at their most vulnerable time.

³ ANZSPM Position Statement on Euthanasia and Physician Assisted Suicide (updated 31 March 2017) <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1491523669&sid=> (accessed 1 February 2018)

3.15 Likewise, there are tensions between legislating for voluntary assisted dying and risks of misdiagnosis, uncertainties around prognostication. A specific concern here is risks related to determination of decision making capacity. Decision making capacity is a key protective assumption within frameworks for assisted dying, and yet many highly-skilled clinicians do not adequately understand the assessment required to determine this in practice.

3.16 Clearly, balancing the risks introducing legislation to facilitate assisted dying with its presumed benefits is complicated. A key step will be to ensure that people receiving end of life care in any clinical setting or location have access to adequate and appropriate care, including palliative care.

4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme

3.17 While there is much to commend within the rigour and thoughtfulness of the Victorian scheme to address these issues there are notable ongoing concerns.

3.18 The Victorian scheme does not clearly provide for how currently unmet palliative care needs will be provided for, and therefore how people will be able to choose assisted dying having access to all other options. Similarly, it does not clearly articulate the support that will be offered to clinicians to develop the skills necessary to be able to be involved in providing assisted dying (such as awareness of alternative options, or assessing capacity), or how the self-care of such clinicians will be supported given their involvement.

3.19 The Victorian scheme does not clearly articulate how disagreements in clinical opinion will be considered and managed. For instance, if one clinician agrees that voluntary assisted dying is appropriate, and another does not, it is unclear what the response to this is. Likewise, it is unclear what is to stop the patient seeking a third or fourth opinion in search of the perspective that they wish. It is unclear how the scheme would manage these dissenting views if they were captured.

3.20 The Victorian scheme does not clearly articulate how to manage differences in perspective within teams. There is a clear and appropriate protection for clinicians to not be involved in providing access to assisted dying if they have a conscientious objection to doing so. However, it is less clear about the rights of other clinicians who are involved in care but are not making this decision. For instance, what are the protections for members of nursing staff who may object to voluntary assisted dying, but be rostered to care for an inpatient who will be receiving this intervention?

3.21 The Victorian scheme does not clearly articulate what support will be offered to family members and loved ones whose bereavement is complicated by these interventions. While some have suggested that access to voluntary assisted dying is supportive for the bereavement of families and carers this is not always the case, particularly if decisions are conflicted.

5. The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change

3.22 I am not qualified to comment on this term of reference.

6. Any other relevant matter

3.23 As has been discussed this work being undertaken by the committee reflects the increasing concerns of the public, health care and specialist palliative care professionals, that our health care system is failing to adequately manage the complexity of needs and burdens presenting for people at the end of life; in terms of access to services, quality of care, health professional competencies and responsiveness to preferences and choices.

3.24 The dialogue around end of life choices within this inquiry presents an opportunity to facilitate greater consistency in the delivery of palliative care services across Australia in concert with the broader National Palliative Care Strategy.

3.25 To meet increasing public expectations for quality end of life care across the health care system focus needs to be on legislative, funding and service model frameworks within the ACT which directly target improved palliative care provision and engagement, provide choice in the location of care, and tangibly support informal caregivers.

3.26 There are several areas of action needed to improve end of life choices:

- The capacity for people to articulate choice and have this respected requires legislation that facilitates proper planning and preparation for dying. This includes Advance Care Plans (ACPs), Advance Care Directives (ACDs), and Enduring Powers of Attorney. In the ACT further work is required to support appropriate use of ACDs and ACP processes, and to make sure these are communicated to, understood, and followed by others. Continuing to strengthen planning will considerably improve the end of life care for the growing population in the ACT who are approaching or at the end of life. Healthcare professionals in the ACT need ongoing training to engage in conversations about planning for future care, and to respectfully discuss care preferences.
- Significant growth in the palliative care workforce, the education and training provided to clinicians around palliative care provision, and the resources for other support services are required to meet the gap in current needs, improve integration and responsiveness; and also address future population needs as an increasing number of people will need end of life care and their clinical and demographic characteristics are changing.
- Improvements should support the growing need for expert end of life care in all settings of care, especially aged care, and equality of access across the ACT, regardless of place of residence or diagnosis. Creative quality solutions to problems need to be embraced. As an example, a new approach to specialist Palliative Care access for aged care residents within the ACT is being explored through the ACT government funded, and award-winning INSPIRED trial. Novel approaches to improving quality care need to be supported into the future. A further concern in the ACT is providing for palliative care needs within acute care hospitals. A recent Health Care Consumers report suggested that access to palliative care services within Canberra Hospital was among the most urgent priorities. In response to this the report recommended resourcing inpatient palliative care beds at Canberra Hospital. Meeting such needs would be a requirement in

ensuring that ACT residents have access to genuine choices at the end of life. In making these observations it is important to acknowledge that further work to understand the palliative needs of Act residents would be beneficial as existing studies have been small and limited in scope.

- Informal caregivers play a significant role in the support and delivery of care for people with life limiting illness, and there are significant gaps in the practical, financial, and emotional support available. Publicly funded bereavement support is available to a small minority of ACT residents. Further attention to the support available to families and carers of those with advanced illness in the ACT including bereavement support is required.

4. Additional relevant information

A. The Role of Palliative Medicine in end of life care

4.1 End of life is defined by ASCQHC⁴ as:

The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.

This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.

4.2 End of life care is defined by ASCQHC⁵ as:

Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months.

This includes people whose death is imminent (expected within a few hours or days) and those with:

- *advanced, progressive, incurable conditions*
- *general frailty and co-existing conditions that mean that they are expected to die within 12 months*
- *existing conditions, if they are at risk of dying from a sudden acute crisis in their condition*

⁴ Australian Commission on Safety and Quality in Health Care, National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2015), <http://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf> (accessed 30 October 2017).

⁵ Australian Commission on Safety and Quality in Health Care, National Consensus Statement: Essential elements for safe and high-quality end-of-life care (2015), <http://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf> (accessed 30 October 2017).

- *life-threatening acute conditions caused by sudden catastrophic events.*

4.3 Palliative Care is defined by the World Health Organisation (2013)⁶ as:

“...an approach to care that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care also respects the choice of patients and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement.”

4.4 Palliative Care affirms life and regards dying as a normal process. It improves the quality of life of patients and their families facing the problems associated with life-limiting illness. It aims to prevent and relieve suffering by means of early identification, and assessment and treatment of pain and other problems – physical, psychosocial, and spiritual. It is primarily about living, not dying.

B. Relevant additional position statements on Euthanasia and Physician Assisted Suicide

4.5 As the peak medical society in palliative medicine ANZSPM’s position statement on voluntary assisted dying is of particular relevance to this discussion. ANZSPM published a *Position Statement on Euthanasia and Physician Assisted Suicide*⁷, produced following a survey of its members, with the most recent review in late 2016.

4.6 Key points from the Position Statement worth attention the Committee’s attention are:

- a. There remain significant inequities in provision of palliative care services, particularly in rural areas where the shortages of Palliative Care Specialists is most evident.
- b. ANZSPM advocates, and its members deliver, excellent quality care for people living with life threatening illness by proactive assessment, treatment, and prevention of physical, psychological, social, and spiritual concerns; and support for caregivers.
- c. For people who are requesting assisted dying, particular care is needed to ensure that access to high quality care that addresses symptom control and other issues, including specialist palliative medicine referral is available
- d. According to international best practice, the discipline of Palliative Medicine does not include the practices of euthanasia or physician assisted suicide.

⁶ “The Australian and New Zealand Society of Palliative Medicine Position Statement (2014) on Quality End-of-Life Care – Part 1: *Essential Elements for quality, safety and appropriate clinical care at the end of life*”, <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1393375205&sid=> (accessed 1 February 2018)

⁷ ANZSPM Position Statement on Euthanasia and Physician Assisted Suicide (updated 31 March 2017) <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1491523669&sid=> (accessed 1 February 2018)

- e. ANZSPM does not support the legalisation of euthanasia or physician assisted suicide, but recognises that ultimately these are matters for government to decide having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners.

4.7 An additional relevant position statement that is consistent with ANZSPM's position is that of the World Medical Association (WMA), an international organisation representing physicians which provides ethical guidance to physicians through its Declarations, Resolutions and Statements. These also help to guide National Medical Associations, governments, and international organisations throughout the world.

4.8 The WMA's Declaration on Euthanasia⁸ states:

"Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness."

4.9 The WMA Position Statement on Physician-Assisted Suicide likewise states:

"Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession. Where the assistance of the physician is intentionally and deliberately directed at enabling an individual to end his or her own life, the physician acts unethically. However, the right to decline medical treatment is a basic right of the patient and the physician does not act unethically, even if respecting such a wish results in the death of the patient."⁹

4.10 While the Committee is unlikely to require these clarifications, it is relevant to note the distinctions between consideration of voluntary assisted dying and withdrawal of treatment by a medical practitioner. Commonly accepted principlist bioethics suggest the importance of respect for autonomy, beneficence, non-maleficence, and justice. A competent patient is able to decide to stop treatment of any form. Equally, a medical practitioner is able to withdraw a treatment that is deemed to no longer be clinically appropriate nor able to meet its intended goal. Such decisions results in the disease progressing on its natural course rather than causing death.

C. Michael Chapman brief biography

Michael Chapman is a specialist geriatrician and palliative medicine specialist who works as the director of palliative care at Canberra Hospital. He is the chair of the ACT Palliative Care Clinical Network, and has had representative roles in peak-bodies in palliative care including sitting on the National Policy Advisory Committee for Palliative care Australia, and serving as Secretary for the Australian and New Zealand Society of Palliative Medicine. Michael is an academic with ANU medical school where he is involved in research work, student support and education and has a particular focus on teaching communication skills, ethics, palliative medicine and professionalism. Michael also

⁸ WMA Declaration on Euthanasia (adopted by the 53rd WMA General Assembly and reaffirmed with minor revision by the 194th WMA Council Session, Bali, Indonesia, April 2013) <https://www.wma.net/policies-post/wma-resolution-on-euthanasia/> (accessed 1 February 2018)

⁹ WMA Position Statement on Physician-Assisted Suicide (adopted by the 44th World Medical Assembly in Marbella, Spain, in September 1992 and editorially revised by the 170th WMA Council Session in Divonne-les-Bains, France, in May 2005 and reaffirmed by the 200th WMA Council Session, Oslo, Norway, April 2015) <https://www.wma.net/policies-post/wma-statement-on-physician-assisted-suicide/> (accessed 1 February 2018)

has an honorary role at UTS. Michael has recently submitted his PhD entitled “The ethics of decision-making in dementia: making sense of senselessness”. Michael has authored over 15 peer-reviewed publications on topics related to palliative care and geriatric medicine. He is frequently invited to speak at local and national events, and sits on several steering committees for national palliative care projects. Michael is a co-founder and editor of [Palliverse](#) an online community seeking to expand discussions about palliative care.