



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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Secretary
Select Committee on End of Life Choices in the ACT
Legislative Assembly for the ACT
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22 March 2018

Dear Secretary,

**Select Committee on End of Life Choices in the ACT:
Inquiry into End of Life Choices in the ACT**

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) appreciates the opportunity to provide the attached submission to the Select Committee on End of Life Choices in the ACT in regard to its *Inquiry into End of Life Choices in the ACT*.

ANZSPM is the specialty medical society that represents medical practitioners who provide care for people with a life limiting illness. It facilitates professional development, support and advocacy for its members across Australia and New Zealand to promote best practice in palliative medicine.

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We would be happy to meet with members of the Committee to provide further information in support of this Inquiry.

Yours sincerely,

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Prof Meera Agar
President

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Simone Carton
Chief Executive Officer

ANZSPM Submission:

INQUIRY INTO END OF LIFE CHOICES IN THE ACT

MARCH 2018

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1. Introduction

- 1.1 This submission is made by the Australian and New Zealand Society of Palliative Medicine (ANZSPM), a not-for-profit specialty medical society for medical practitioners who provide care for people with a life-limiting illness in Australia and New Zealand.
- 1.2 ANZSPM appreciates the opportunity to make this submission to the Select Committee for End of Life Choices in the ACT (the Committee) with respect to its *Inquiry into End of Life Choices in the ACT* (the Inquiry). As the representative body for practitioners of palliative care in Australia and New Zealand, including in the ACT, ANZSPM is well placed to comment on the practices being utilised in the medical community at the end of life in the ACT.
- 1.3 In this submission, we firstly provide our comments on the Inquiry terms of reference. We then provide background information on ANZSPM, the role of palliative medicine in the context of end of life care and ANZSPM's published position on euthanasia and physician-assisted suicide in order to provide the Committee with context of ANZSPM's activities with respect to end of life choices.
- 1.4 We welcome the opportunity to meet with the Committee to provide additional information that may be of assistance with the Inquiry.

2. Executive Summary

- 3.1 Palliative Medicine exists to improve the quality of care 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. Palliative medical practitioners recognise that care is not just focused on the last stage of life, i.e. dying. The focus is broader; involving the last days, weeks and months of life and focuses on supporting people to live as well as possible.
- 2.1 As a specialist society of medical practitioners working in palliative care, we recognise the increasingly complex nature of end of life care (as defined by the Australian Commission on Safety and Quality in Health Care (ACSQHC)¹) and believe that much can be done to improve the delivery of and equity of access to high quality end of life care.
- 2.2 Critical factors to enable this are to ensure that all health care practitioners can effectively provide end of life care, with appropriate specialist palliative care support; and specialist palliative care services are available for people with more complex needs.
- 2.3 Much of the community debate currently fuelling discussion about alternative choices highlights inadequacies in the current systems across Australia and New Zealand. People with life limiting illness and their carers do not currently have universal access to quality end of life care, which may extend over the last days to years of the person's life dependent on need. Legislating for assisted dying in this context presents a risk that decisions will be made by persons who have not been given optimum choices for their end of life care.

¹ 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 20 March 2018).

- 2.4 ANZSPM's published position on euthanasia and physician assisted dying makes clear that palliative medicine does not include those practices and that ANZSPM does not support the legalisation of euthanasia and/or physician assisted suicide (refer Part 4 C of this submission). This is consistent with the positions of the Australian Medical Association and the World Medical Association.
- 2.5 ANZSPM believes the solution to suffering and loss of dignity as one approaches the dying phase lies in improving care.
- 2.6 The delivery of quality end of life care requires a health workforce equipped at recognising progressive life limiting illness, assessing need and tailoring effective and consistent clinical care and support for people and their families through to the last days and hours of a person's dying phase, and for families into bereavement. This care needs to be integrated, nimble and responsive to changing needs, and to be provided in the location of the person's choosing. Clinical care needs to be integrated with other critical social and community services.

3. ANZSPM comments on the Terms of Reference

- 3.1 We address in this part each of the terms of reference, insofar as it is relevant to ANZSPM's role as the peak body representing practitioners of palliative medicine in Australia and New Zealand.
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 ANZSPM's members include practitioners of palliative medicine, and other medical practitioners with an interest in palliative care, across Australia and New Zealand, including those working in the ACT. As such, ANZSPM is well placed to comment on the current practices utilised in the medical community to assist a person in the ACT to exercise their preference in managing the end of their life, in particular with respect to the provision of palliative care.
- 3.3 Palliative medical practitioners recognise that care is not just focused on the last stage of life, i.e. dying. The focus is broader; involving the last days, weeks and months of life and focuses on supporting people to live as well as possible.
- 3.4 Good palliative care supports the person (along with his/her carers and health professionals) 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.
- 3.5 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.

- 3.6 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.
- 3.7 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

- 3.8 As stated in our Position Statement on *The Practice of Euthanasia and Physician Assisted Suicide*², ANZSPM recognises that ultimately decisions to legislate for euthanasia and/or physician assisted suicide are matters for government, having regard to the will of the community. At the same time, we highlight the importance that such decisions are informed by appropriate research and consultation with the medical community, including palliative medicine practitioners.
- 3.9 We also acknowledge that, as with the diversity of opinion in the general and medical communities across Australia and New Zealand, there are divergent views on euthanasia and physician assisted suicide within our membership.
- 3.10 We encourage the ACT government to support the ACT community in its understanding of the role of palliative care in end of life care and to ensure that the ACT community is well supported by a palliative care workforce that delivers genuine choice in end of life care. This is of critical importance prior to any assessment on community sentiment on voluntary assisted dying.

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.
- 3.12 As noted above (at paragraph 3.6), the complexity of a life limiting illness and changing needs of a person with such illness may be associated with a perception of burden and fear for ongoing care upon a person, their carers and family, especially where the required support is not forthcoming. This may result in a person seeking to end their life.

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)

- 3.13 We consider that much of the community debate that is currently fuelling discussion about alternative end of life choices, including assisted dying, points to inadequacies in the current systems for end of life care across Australia and New Zealand, including in the ACT. Legislating for assisted dying in this context presents a risk that decisions will be made by persons who have not been given optimum choices for their end of life care.
- 3.14 Legislative processes for assisted dying cannot guarantee protection for persons who may change their minds with the right support and treatment, recognising that such wishes often wax and wane through the course of one's illness. Persons with life limiting illness may make these decisions with irreversible consequence at their most vulnerable time.
- 3.15 Legislative processes also cannot ensure that no wrongful death has taken place because of misdiagnosis, uncertainties around prognostications or determination of mental capacity, or guarantee that the request for assisted dying was free from coercion (direct or indirect).
- 3.16 Introducing legislation to facilitate assisted dying without first ensuring that people can receive end of life care in any clinical setting or location, and ensuring adequate and appropriate care including palliative care, does not provide genuine choice for end of life care.

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

- 3.17 ANZSPM has made submissions on legislation proposing to introduce assisted dying in NSW and Victoria, as well as in New Zealand, outlining its position on euthanasia and physician assisted suicide and the important distinction between palliative medicine and assisted dying (refer Part 4 of this Submission). In other jurisdictions, we express concerns that many other strong recommendations have been made concurrently to improve the equity of access to palliative care and quality of care at the end of life which have not had urgent and proactive action.
- 3.18 We consider that legislating for assisted dying (as in Victoria's case) fails to deal with the pressing need to address current deficits in palliative care, that have far reaching and serious negative impacts on the quality of life and decision-making for people at the end-of-life and their carers.
- 3.19 We are concerned that the legislative proposals being considered or implemented in other jurisdictions diverts attention away from the larger problem of service gaps for the broader population of people currently receiving end-of-life care in Australia, for whom the priority is access to high quality palliative care and support.

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

- 3.20 ANZSPM does not have any comment on this Term of Reference.

6. Any other relevant matter

- 3.21 The Committee's work reflects the increasing concerns of the public, health care and specialist palliative care professionals, including ANZSPM members, 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.
- 3.22 This Inquiry presents an opportunity to facilitate greater consistency in the delivery of palliative care services across Australia having regard to the broader National Palliative Care Strategy.
- 3.23 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.
- 3.24 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), Enduring Powers of Attorney and Enduring Powers of Guardianship. Ensuring legislation and systems provide that people are communicated to and respected by health professionals delivering care regarding these issues would strengthen planning and considerably improve the end of life care for the growing population in the ACT who are approaching or at the end of life. Health care professionals also need ongoing training to be equipped to engage and support conversations about planning for future care, and to respectfully discuss care preferences.
 - Significant growth in palliative care services and workforce, and other support services are required to meet the gap in current needs, improve integration and responsiveness; but also address future population needs as those who will need end of life care is expanding 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.
 - 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.

4. Context of ANZSPM activities with respect to end of life choice

A. About ANZSPM

- 4.1 ANZSPM is a not-for-profit specialist medical society for medical practitioners who provide care for people with a life limiting illness.
- 4.2 ANZSPM facilitates professional development, support and advocacy for its members across Australia and New Zealand to promote best practice in palliative medicine.

4.3 ANZSPM promotes the discipline and practice of Palliative Medicine in order to improve the quality of care of patients with palliative diagnoses and support their families.

4.4 Our members include palliative medicine specialists, doctors training in the Palliative Medicine discipline, General Practitioners and doctors who are specialists in other disciplines such as oncologists, haematologists, intensivists, psychiatrists and geriatricians. ANZSPM currently has more than 480 members, including 7 members based in the ACT.

4.5 ANZSPM's objects are to:

- a. Provide a forum for Registered Medical Practitioners engaged in the practice of Palliative Medicine or related disciplines to facilitate their professional development and to provide mutual support.
- b. Advance the discipline of Palliative Medicine.
- c. Provide a voice on policies relating to Palliative Medicine.
- d. Promote undergraduate and postgraduate education and training in Palliative Medicine and to support Palliative Medicine Trainees.
- e. Promote research in and evaluation of medical and related issues in Palliative Medicine.
- f. Liaise with other relevant bodies.

4.6 ANZSPM is overseen by a Council of members, which includes representation from Australia and New Zealand and also from the Royal Australasian College of Physicians' Australasian Chapter of Palliative Medicine. ANZSPM's day-to-day operations are managed by a small team of staff based in Canberra ACT.

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

4.7 End of life is defined by ASCQHC³ 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.

4.8 End of life care is defined by ASCQHC⁴ 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

³ 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).

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).

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

4.9 Palliative Care is defined by the World Health Organisation (2013)⁵ 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.”

4.10 ANZSPM embraces the definition of Palliative Medicine adopted in Great Britain in 1987:

“Palliative Medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.”

4.11 It is a fundamental tenet of Palliative Medicine that it neither hastens death nor prolongs life.

4.12 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 about life, not death.

C. ANZSPM Position on Euthanasia and Physician Assisted Suicide

4.13 ANZSPM has published a *Position Statement on Euthanasia and Physician Assisted Suicide*⁶, produced following a survey of our members to ensure that the statement is reflective of member views, with the most recent review in late 2016.

4.14 Key points from the Position Statement that we draw to the Committee’s attention to are:

- a. There remain significant inequities in provision of palliative care services, particularly in rural areas where the shortages of Palliative Care Specialists are most evident.

⁵ “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)

⁶ 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)

- 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.
 - 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.
- 4.15 ANZSPM's position is consistent with 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.
- 4.16 The WMA's Declaration on Euthanasia⁷ 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."*
- 4.17 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."⁸*
- 4.18 These Position Statements strongly urge physicians to refrain from participating in euthanasia even if national law allows it or decriminalises it under certain conditions.
- 4.19 For completeness, we note that the debate around euthanasia and physician assisted dying sometimes makes reference to withdrawal of treatment by a medical practitioner. The basic ethical principles that govern medicine include patient autonomy, beneficence or simply do good, non-maleficence (do no harm), justice and futility. A competent patient is able to decide

⁷ 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)

⁸ 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)

to stop treatment of any form. Equally, a medical practitioner is able to withdraw a treatment that is deemed to be futile. This results in the disease progressing on its natural course.

- 4.20 It is helpful to remember that for many conditions, patients would not ever have survived without modern medicine ‘artificially’ keeping them alive. Therefore stopping a treatment is not a decision to actively cause death. Rather, it is a decision to allow a natural death. In contrast, euthanasia and assisted suicide involve actively seeking death and are irreversible decisions. While some members of the public and some advocates for euthanasia may not understand the distinction, as highlighted by the WMA Position Statements above, medical professionals and ethicists are clear that the distinction is absolute.

5. Recommendations

- 5.1 Our recommendations fall into three categories around which to focus, to enable better choice and support for ACT residents at the end of life:

- A. End of life care
- B. Advance Care Planning
- C. Euthanasia and Physician Assisted Suicide

A. End of Life Care

- Recommendation 1.** Systematically and consistently promote community awareness, to improve health literacy and understanding, and enculturate dying as a normal part of living.
- (This will hopefully reduce misconceptions and fears around dying and suffering at the end of life as well as fear of opioids, and lack of awareness of the extent of choice and engagement possible in decision making in end of life care).
- Recommendation 2.** Remedy shortages in the specialist palliative care workforce (including in the specialist medical, nursing and allied health fields).
- Recommendation 3.** Enable earlier integration of palliative care specialist clinical services across health care settings.
- Recommendation 4.** Expand palliative care programs across health care settings to ensure equitable, integrated and responsive access to care (including geographically - regional, rural and remote areas; and setting - hospitals, residential aged care and in the community) supporting people’s choice of location for end of life care and dying, and ability to receive timely high quality care regardless of diagnosis.
- Recommendation 5.** Mandate training in minimum competencies in end of life care management and communication skills for tertiary education and vocational training for all health professionals in the ACT.

- Recommendation 6.** Mandate end of life care and communication skills workplace competencies and continued professional development to ensure currency of skills for all clinically based health care professionals in the ACT.
- Recommendation 7.** Invest in increased carer support including opportunity for quality respite care to address the important issue of the sense of being a burden which is a concern held by many people at the end of life.

B. Advance Care Planning

- Recommendation 8.** Implement policy directions which support and value advance care planning and patient preference.
- Recommendation 9.** Ensure staff are trained to communicate and facilitate appropriate and effective Advance Care Planning.
- Recommendation 10.** Adapt a consistent legal framework so that Advance Care Plans and Directives have appropriate legal standing.
- Recommendation 11.** Work towards standardising legislative frameworks for ACPs and ACDs across States and Territories.

C. Euthanasia and Physician Assisted Suicide

- Recommendation 12.** Refrain from legislative change to enact Physician Assisted Suicide or Euthanasia and instead, support a more responsive approach to the complex care needs in End of Life care and dying, for patients and their carers (having regard to the recommendations outlined above).
- Recommendation 13.** Ensure rapid response specialist palliative care models are available to directly support urgent or complex issues, and other care needs in the location of the person's preference, in particular when a person is imminently dying.

6. Conclusion

- 6.1 Palliative Care Specialists have the privileged position of spending our working life listening to, supporting and advising families and patients at the most vulnerable time of their lives.
- 6.2 We commend the ACT Legislative Assembly for convening this Committee and the Committee for considering the important issues around provision of end of life care and ensuring that citizens of the ACT are supported to make informed decisions about their end of life care.
- 6.3 ANZSPM calls on the ACT Government to refrain from legislating for assisted suicide and instead, support a more responsive approach to the complex care needs in end of life care and dying, for patients and their carers. In particular, ANZSPM calls on the Committee to make recommendations for the ACT Government to focus its attention on health reform and investment which will immediately strengthen palliative and end of life care.