

Submission to

Joint Select Committee on End of Life Choices

***Inquiry into the need for laws in Western Australia
to allow citizens to make informed decisions
regarding their own end of life choices***

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The Australian and New Zealand Society of Palliative Medicine Incorporated

ABN 54 931 717 498

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About ANZSPM

The Australian & New Zealand Society of Palliative Medicine (ANZSPM) is a not-for-profit specialty medical society for medical practitioners who provide care for people with a life limiting illness.

Our members include palliative medicine specialists, palliative medicine training registrars and other doctors such as, but not limited to, general practitioners, oncologists, haematologists, intensivists, psychiatrists and geriatricians. Forty-two (42) of our members are currently based in Western Australia, out of nearly 500 members across Australia and New Zealand.

ANZSPM facilitates professional development and support for its members, promotes the practice of Palliative Medicine and advocates for those who work in the field of palliative medicine. ANZSPM's activities aim to improve the quality of care for people with a life limiting illness.

ANZSPM is managed by a Council of members, which includes representation from 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 part-time team of staff based in Canberra ACT.

CONTACT

The Australian & New Zealand Society of Palliative Medicine Inc.
PO Box 7001 WATSON ACT 2602 Australia
Ph: +61 458 203 229
email: info@anzspm.org.au
www.anzspm.org.au

ABN 54 931 717 498

Executive Summary

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. 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.

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

Much of the community debate currently fuelling discussions about alternative choices, highlights the inadequacies of the current system. 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. 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.

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

1. The capacity for people to articulate choice and have this respected requires urgent attention to legislation to enable 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. Improvements to legislation and systems to ensure they are communicated to and respected by health professionals delivering care regarding these issues to strengthen planning will considerably improve the end of life care for the growing population of Western Australians 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.
2. 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

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 30 October 2017).

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 Western Australia, regardless of place of residence or diagnosis. In Western Australia particular focus is needed on meeting the needs of those living in regional, rural and remote settings.

3. 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.

Introduction

The Australian and New Zealand Society of Palliative Medicine Incorporated (ANZSPM) welcomes the opportunity to present this submission to the Joint Select Committee on End of Life Choices (the Committee) in regard to its *Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices* (the Inquiry).

ANZSPM represents doctors working in Palliative Medicine in Australia and New Zealand. As practitioners of palliative care, we are well placed to comment on practices being utilised in the medical community at the end of life. With close to ten percent of our nearly 500 members residing in Western Australia, ANZSPM is also well placed to comment on end of life practice in Western Australia.

Palliative Care is defined by the World Health Organisation (2013)² 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.”

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.

² “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> (accessed 30 October 2017)

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).

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.

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 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.*

Context of ANZSPM activities and Inquiry terms of reference

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.

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 focusses on supporting people to live as well as possible. 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.

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

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).

a whole-of-health responsibility. In both cancer and non-malignant disease there is increasing complexity of illness, and many people live with multiple comorbidity all impacting on care and clinical needs. Significantly, this is often associated with a perception of burden(s) and fears for ongoing care upon a person, their carers and family, which can accumulate and often become magnified over time especially if the required support is not forthcoming. They 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 reestablish a sense of control.

The Committee's work reflects the increasing public, health care and specialist palliative care professionals' concerns, 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. Legislative frameworks, models of care, implementation of standards and clinician education and training need to enable much more meaningful and effective Advance Care Planning (ACP) and see adequate end of life care needs met across all settings throughout Western Australia.

This Inquiry presents an opportunity to build on the work already invested in development of the Western Australian Department of Health's *End of Life Framework* and to facilitate greater consistency in the delivery of palliative care services across Australia having regard to the broader National Palliative Care Strategy, currently under review.

The Committee will also be aware of the current debate in other Australian jurisdictions about euthanasia and physician assisted suicide.

ANZSPM has published a *Position Statement on Euthanasia and Physician Assisted Suicide*, 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. The Position Statement is available on the ANZSPM website (www.anzspm.org.au) and is also **attached** for reference.

Key points in the ANZSPM Position Statement that we draw the Committee's attention to are:

- There remain significant deficits in the provision of palliative care throughout Australia, including in Western Australia.
- 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.
- 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.
- According to international best practice, the discipline of Palliative Medicine does not include the practices of euthanasia or physician assisted suicide.

- 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.

ANZSPM considers that the proposed legislation in Victoria and NSW fails to address that the pressing need is to address those 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.

We are concerned that legislative proposals in other jurisdictions will divert 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.

We commend the Western Australian Parliament for convening this Committee and the Committee for considering the important issues around provision of end of life care and ensuring that citizens of Western Australia are supported to make informed decisions about their end of life care.

ANZSPM calls on the Committee to make recommendations for the Western Australian Government to continue to urgently focus its attention on health reform and investment which will immediately strengthen palliative and end of life care.

Recommendations

Our recommendations fall into three categories around which to focus, to enable better choice and support for Western Australians at the end of life:

1. End of life care
2. Advance Care Planning
3. Euthanasia and Physician Assisted Suicide

1. 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 Western Australia.
- 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 Western Australia.
- 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.

2. 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.

3. 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.