31 July 2015

Ms Lilian Topic
Secretary
Legal & Social Issues Committee
Parliament House
Spring Street
Melbourne VIC 3002

By email to lsic@parliament.vic.gov.au

Parliament of Victoria Inquiry into End of Life Choices

Dear Ms Topic,

The Australian and New Zealand Society of Palliative Medicine Inc. (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.

ANZSPM is grateful for this opportunity to address the Parliament of Victoria Inquiry into End of Life Choices with our submission, which has been endorsed by the elected ANZSPM Council, is attached.

Any inquiries in relation to this submission can be directed to Ms Marita Linkson, [redacted], email [redacted]

I would be happy to provide further evidence at a public hearing.

Yours sincerely

[Signature]

Assoc Prof Mark Boughey
President
Submission to

Parliament of Victoria
Inquiry into End of Life Choices

July 2015

Prepared by Assoc Prof Mark Boughey and Ms Marita Linkson

on behalf of

The Australian and New Zealand Society of Palliative Medicine Incorporated

ABN 54 931 717 498
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.

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 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 part-time Executive Officer.
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)), and believe that much can be done to improve the delivery of quality end of life care. Key to this is enabling a greater breadth of practitioners to effectively provide end of life care, with appropriate specialist palliative care support. This will help to meet the needs arising from increasing public expectation for quality end of life care across the health care system.

Strengthening the capability to provide end of life care and implementing changes to the relevant legal and health funding related frameworks and models of care models within Victoria will improve palliative care provision and engagement, and relieve much of burden and societal angst and suffering anticipated around end of life care, and ameliorate the need to enact regulation to allow physician assist suicide and euthanasia.

Much of the community debate currently fuelling discussions about alternative choices, highlights the inadequacies of the current system. Patients and their carers do not currently have universal access to quality end of life care. Quality end of life care enables timely recognition of a person’s deterioration in the months, weeks and days in the broad conceptualisation of end of life and then provides effective and consistent support for people and their families through to the last days and hours of a person’s dying phase.

This situation highlights the pressing need for legislation to enable proper planning and preparation for dying. This includes Advance Care Plans (ACPs), Advance Care Directives (ACDs), Medical Enduring Power of Attorneys (MEPOAs). Improvements to legislation regarding these issues to strengthen planning will considerably improve the end of life care for the growing population of Victorians who are approaching or at the end of life.

It also highlights the need for significant improvements in palliative care services and interrelated disciplines such as psycho-oncology, to grow and improve the care that is delivered by our society. 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 Victoria, regardless of place of residence.

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Introduction

The Australian and New Zealand Society of Palliative Medicine Incorporated (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 twenty percent of our 450 plus members residing in Victoria, ANZSPM is well placed to comment on end of life practice in Victoria.

Palliative Care is defined by 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 care is defined by ASCQHC\(^3\)

*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.*

*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.*

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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 the Standing Committee 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 to make sure that they can all live as well as possible. Good palliative care supports the patient (along with his carers and health professionals), to recognise that their deterioration is leading to dying and being able to recognise when death is inevitable, so that effective care planning and support can be given to patients and families leading into and including the bereavement period.

Responding to the deteriorating patient and their carers needs in the hours, days, weeks, months (and even years) leading towards death should be a whole-of-health responsibility. The chronicity of appropriately managed medical, surgical and psychiatric care, including cancer and non-malignant diseases means that as people and their carers move towards deterioration, managing to live with increasingly refractory symptoms and a focus on dying that needs become increasingly complex. The perception of burden(s) and fears upon a patient, their carers and family accumulate and often become magnified. 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 standing 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 and burdens presenting. Legislative frameworks, models of care, implementation of standards and clinician education and training need to enable much more meaningful and effective ACP and see adequate end of life care needs met across all setting across Victoria.
Recommendations

Our recommendations fall into three categories around which to focus, to enable better choice and support for Victorians 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).

Ideas for Implementation:

• Systematic health promotion programs
• Build on helpline support services for health professionals and the public for ACP and end of life care advice e.g. Decision Assist Phone Advisory Service.
• Introduce “living with dying” educational programs e.g. programs such as Cancer Council Victoria’s ‘Living with Cancer Education Program’.
• Learning from the lessons of successful online programs such as The Conversation Project.

Recommendation 2. Enable earlier integration of palliative care practices across the health care settings.

Ideas for Implementation:

• Support the adoption of the recommendations for care processes and organisational prerequisites outlined in the ACSQHC National Consensus

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Statement: Essential elements for safe high quality end of life care\(^7\) as standards of care for a deteriorating person’s end of life care.

- Expand the capacity and integrate specialist palliative care into outpatient clinics so that patients can access this care in parallel with care from disease specialists.
  e.g. Victorian Renal Healthcare Network renal pathways and model of care program, supportive care project
  e.g. St Vincent’s Hospital Melbourne outpatient clinics for heart failure, respiratory failure and chronic kidney disease.

**Recommendation 3.** Expand palliative care programs across health care settings, in hospitals and in the community to support patient choice of location for end of life care and dying.

**Ideas for Implementation:**

- Expand hospital-based consultation services for admitted patients to provide 7-day a week servicing. Currently multi-disciplinary care is usually only available five days per week during business hours, with limited weekend medical support for patients.
- Provide funding to support dying at home with hospital-based rapid response specialist palliative care teams that can transfer people with urgent and/or complex care needs, from hospital to the home, and better integrate the transition with community palliative care providers.
  e.g. Victorian Health Independence Program Residential In-Reach\(^8\) (Geriatric In-reach program for tertiary hospital healthcare professionals visiting and supporting community residential aged care facilities).
  e.g. Eastern Palliative Care Priority Assessment Team\(^9\)
- Fund the expansion of integration of specialist palliative care into outpatient clinics (as per Recommendation 2)
- Expand the community based palliative care ‘link nurse’ program. This program builds capacity for healthcare providers to provide

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palliative care in residential aged care facilities and in community housing for the disabled.

Recommendation 4. Mandate basic quality end of life care management and communication skills training for tertiary education and vocational training for all health professionals in Victoria.

Ideas for Implementation:

- Expand Palliative Care Curriculum for Undergraduates (PCC4U)\(^{10}\) or similar programs.

Recommendation 5. Mandate end of life care and communication skills workplace competencies for all clinically based health care professionals in Victoria.

Ideas for Implementation:

- Include end of life care workplace competencies in position descriptions for any health care professional who is likely to manage patients with end of life care needs.

- Health Services adopt palliative care training modules in their orientation program and/or annual competencies for clinical staff e.g. Centre for Palliative Care (Melbourne) Palliative Care Getting Started online learning module\(^ {11}\)

- Include end of life care elements in periodic revalidation for any health care professional who is likely to manage patients with end of life care needs.

2. Advance Care Planning

Recommendation 6. Implement the State Government’s recommendations surrounding its Advance Care Planning strategy to better integrate Advance Care Planning with end of life care frameworks. (Refer to Victorian Department of Health and Human Services “Advance care planning: have the conversation; A strategy for

\(^{10}\) Palliative Care for Undergraduates [http://www.pcc4u.org](http://www.pcc4u.org) (accessed July 31, 2015)

\(^{11}\) Centre for Palliative Care (Melbourne) Palliative Care Getting Started online learning module [http://centreforpallcare.org/palliative-care-getting-started-online-learning/](http://centreforpallcare.org/palliative-care-getting-started-online-learning/) (accessed July 31, 2015)
Recommendation 7. Ensure staff are trained to communicate and facilitate appropriate and effective Advance Care Planning.

**Ideas for Implementation:**
- Include Advance Care Planning in the implementation ideas suggested for Recommendations 4 & 5 above.

Recommendation 8. Adapt a consistent legal framework so that Advance Care Plans and Directives have equivalent legal standing to that of the Medical Treatment Act’s Refusal of Treatment Form.

Recommendation 9. Work towards standardising legislative frameworks for ACPs and ACDs across States and Territories.

### 3. Euthanasia and Physician Assisted Suicide

Recommendation 10. 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.

**Ideas for Implementation:**
- Implement the recommendations in this submission.

Recommendation 11. Ensure “Help line” and responsive health care models are available to support urgent/complex/burdensome care in dying patients.

There is a need to increase the level of public understanding of end of life care, and correct misconceptions about inevitable suffering, fear of opioids, and lack of awareness of the extent of choice and engagement possible in decision making in end of life care.

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12 Victorian Department of Health and Human Services “Advance care planning: have the conversation; A strategy for Victorian health services 2014-2018
References


Palliative Care for Undergraduates http://www.pcc4u.org (accessed July 31, 2015)

Centre for Palliative Care (Melbourne) Palliative Care Getting Started online learning module http://centreforpallcare.org/palliative-care-getting-started-online-learning/ (accessed July 31, 2015)