ANZSPM

The Australian & New Zealand Society of Palliative Medicine Inc. ABN 54 931 717 498

ANZSPM Submission:

JUSTICE COMMITTEE – END OF LIFE CHOICE BILL

FEBRUARY 2018

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The driving force in palliative medicine in New Zealand and Australia

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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 both New Zealand and Australia.

1.2 ANZSPM has a dedicated New Zealand branch, ANZSPM Aotearoa, which delivers professional development and membership services and undertakes advocacy to promote the important role of Palliative Medicine in New Zealand.

1.3 ANZSPM appreciates the opportunity to make this submission to the Committee with respect to the proposed *End of Life Choice Bill* (the Bill). As the representative body for practitioners of palliative care in Australia and New Zealand, ANZSPM is well placed to comment on the practices being utilised in the medical community at the end of life and on the intent of the Bill to legislate for assisted dying in New Zealand.

1.4 In this submission, we firstly provide our comments on the Bill itself. We then provide background information on ANZSPM, the role of palliative medicine 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, being the subject of the Bill.

1.5 We wish to appear before the Committee to speak to our Submission.

2. Executive Summary

2.1 ANZSPM opposes the intent of the Bill to legalise assisted suicide and/or euthanasia in New Zealand.

2.2 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.

2.3 ANZSPM has published a Position Statement opposing Euthanasia and Physician Assisted Suicide (refer Part 4 C of this submission) in line with the New Zealand Medical Association and the World Medical Association.

2.4 As a specialist society of medical practitioners working in palliative care, we recognise the increasingly complex nature of end of life care 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.

2.5 We consider that much of the community debate currently fuelling discussion about alternative choices, including assisted dying, highlight inadequacies in the current system. 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.

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.

2.7 ANZSPM believes the solution to suffering and loss of dignity as one approaches the dying phase lies in improving care. Assisted dying legislation poses risk of wrongful deaths as the result of inherent uncertainties of medical diagnosis, prognostication, and determination of mental capacity.

3. ANZSPM comments on the Bill

3.1 ANZSPM opposes the intent of the End of Life Choice Bill to legalise assisted suicide and/or euthanasia in New Zealand. This view is consistent with ANZSPM's published *Position Statement on Euthanasia and Physician Assisted Suicide* (refer Part 4 C of this submission).

3.2 ANZPM considers there are a number of specific problems with the Bill itself, which represent an unacceptable risk to the New Zealand community as well as medical practitioners in New Zealand. We have addressed specific sections of the Bill below.

3.3 The very definition of "assisted dying" at **Section 3** of the Bill requiring a medical practitioner to administer a lethal dose of medication to relieve suffering by "hastening death" is inconsistent with the commitment of Palliative Medicine Specialists to deliver palliative care, as it is understood internationally. The World Health Organisation definition of Palliative Care makes clear that "Palliative care …intends neither to hasten or postpone death".[1]

3.4 The Bill emphasises the role of the "attending medical practitioner" in delivering assisted dying where requested. This assumes that assisted dying fits within the boundaries of medical practice. As discussed at Part 4 C of this submission, ANZSPM affirms the internationally accepted position that palliative medicine does not include euthanasia and physician assisted suicide. Further, there is a strong view in the medical community that physician assisted suicide and euthanasia are unethical and contrary to the fundamental tenets of medical practice.[2]

3.5 **Section 4(c)(ii)** introduces the concept that a person may be eligible for assisted dying if they have a "grievous and irremediable medical condition". This means that assisted dying would be available not only to patients with a terminal illness, but also to someone with a chronic condition.

3.6 Under this Bill a patient could potentially bypass palliative care or psychiatric care for a treatable condition to alleviate their symptoms. As a result, "assisted dying" is an alternative option to available and appropriate treatments.

3.7 **Subsection 8(b)** suggests that the attending medical practitioner must talk with the person about his/her wish to receive assisted dying "at intervals". It is unclear what this means,

[1] WHO (2002) http://www.who.int/cancer/palliative/definition/en/. Accessed on 1 February 2018.
[2] New Zealand Medical Association Position Statement on Euthanasia (Approved 2005) http://www.nzma.org.nz/__data/assets/pdf_file/0004/16996/Euthanasia-2005.pdf. Accessed on 1 February 2018.

although it suggests that physicians are required to continually discuss "assisted dying" with the person once the request has been made, which is an onerous responsibility on physicians (including from the perspective of physician mental health).

3.8 **Subsection 8 (h)** attempts to address the potential risk that a person may be coerced into making a request for assisted dying. The language used in the Bill, that the attending medical practitioner should "**do his or her best to ensure** that the person expresses his or her wish free from pressure from any other person" suggests an acceptance by the drafters of the legislation that it is impossible to exclude coercion as a factor in all circumstances. It is also an uncertain measure which presents risk to the attending medical practitioner. For example, in the case of a complaint or legal dispute, how is an attending medical practitioner to demonstrate that he or she did "his or her best" in this area?

3.9 **Section 28** with respect to recording the "causes of death" is concerning, as it suggests that physicians are being asked to be dishonest when completing a death certificate by not allowing the physician to reference "assisted dying".

3.10 The review processes provided in the Bill (**Sections 21 and 22**) are limited to ensuring that the correct procedures have been followed, in accordance with the Act. That is, they focus on matters of legal administration only. They do not and cannot ensure that no "wrongful death" has taken place because of misdiagnosis, uncertainties around prognostications and determination of mental capacity or that the request for assisted dying was guaranteed to be free from coercion.

3.11 The law does not protect patients who may change their minds with the right support and treatment and such wishes often wax and wane through one's illness. Patients in fact make these decisions with irreversible consequence at their most vulnerable time.

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 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.

4.3 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 approximately 480 members, 127 of which are in New Zealand.

4.4 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.

B. The Role of Palliative Medicine

4.5 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."

4.6 Palliative Care is defined by the World Health Organisation (2013)[3] 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."

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

4.8 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.

4.9 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.

4.10 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. 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] "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)

4.11 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.

4.12 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 re-establish a sense of control.

C. ANZSPM Position on Euthanasia and Physician Assisted Suicide

4.13 ANZSPM has published a *Position Statement on Euthanasia and Physician Assisted Suicide*[4], 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 ANZSPM's Position Statement confirms the strong belief that euthanasia and assisted suicide is in conflict with the basic ethical principles of medical practice. Key points that we draw to the Committee's attention to are:

a. There remain significant inequities in provision of palliative care services, particularly in the rural areas where the shortages of Palliative Care Specialists is most evident. *{Review of Adult Palliative Care Services in New Zealand, Ministry of Health March 2017}*

b. There appears to be a deficit in understanding of the general public about what palliative care services can do. *{Health Select Committee Report on Petition 2014/18 of Hon Maryan Street and 8974 others, August 2017}*

c. 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.

d. For people who are requesting assisted dying, particular care is needed to ensure that access to high quality care that address symptom control and other issues, including specialist palliative medicine referral is available

e. According to international best practice, the discipline of Palliative Medicine does not include the practices of euthanasia or physician assisted suicide.

f. 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] 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)

4.15 Legalising physician-assisted suicide or euthanasia under any conditions may compromise the effective delivery of Palliative Care and places at risk the frailest and most vulnerable patients the medical profession has the privilege to care for.

4.16 Those advocating for law change to legalise euthanasia state that it will not affect medical ethics because doctors will not be forced to engage in physician-assisted suicide if they choose not to participate (a "conscientious objection" as provided for in the Bill). This misses the point. Our opposition to physician-assisted suicide and euthanasia is not based on personal values. Our Position Statement reflects the strong belief that physician-assisted suicide and euthanasia are contrary to the fundamental tenets of medical practice.

4.17 ANZSPM's position is also consistent with the New Zealand Medical Association's opposition to euthanasia and doctor-assisted suicide.[5] The New Zealand Medical Association Position Statement approved in 2005 states:

a. The NZMA is opposed to both the concept and practice of euthanasia and doctor-assisted suicide.
b. Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's request or at the request of close relatives, is unethical.
c. Doctor-assisted suicide, like euthanasia, is unethical.
d. The NZMA however encourages the concept of death with dignity and comfort, and strongly supports the right of patients to decline treatment, or to request pain relief, and supports the right of access to appropriate palliative care.
e. In supporting patients' right to request pain relief, the NZMA accepts that the proper provision of such relief, even when it may hasten the death of the patient, is not unethical.
f. This NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical.

4.18 ANZSPM's position is also 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.

4.19 The WMA's Declaration on Euthanasia[6] 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."

4.20 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

[5] https://www.nzma.org.nz/__data/assets/pdf_file/0004/16996/Euthanasia-2005.pdf (accessed 1 February 2018)

[6] 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)

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."[7]

4.21 These Position Statements strongly urge physicians to refrain from participating in euthanasia even if national law allows it or decriminalises it under certain condition.

4.22 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 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.

4.23 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.

4.24 In stark contrast, euthanasia and assisted suicide always and actively seeks death and is an irreversible decision. 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

Recommendation 1. 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.

Recommendation 2. 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 ANZSPM does not support any changes to the current law. Existing legislation safeguards these vulnerable members of our society and the medical professionals who are trained to provide medically ethical care.

6.3 ANZSPM calls on the New Zealand Government to 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.

[7] 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)