Patrick Shea
[redacted]
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July 30, 2015

Lillian Topic
Secretary, Legal and Social Issues Committee
Parliament House
Spring Street
Melbourne Victoria 3002

Dear Lillian Topic:

RE: Inquiry into End of Life Choices – Legal and Social Issues Committee

I offer the following submission to the inquiry and request that you take account of the following eight key points when reporting back to the Parliament.

1. Improvements in effectiveness, availability of and access to palliative care are needed to give any credence to end of life "choices." Improved care, not killing, should be offered to us when facing the end of our lives.

2. Legalizing euthanasia or assisted suicide would undermine palliative care. It would affect the amount of investment of resources in improvements to palliative care if the seemingly easier and cheaper option of euthanasia or assisted suicide were legally available.

3. Euthanasia and assisted suicide are not palliative care.

4. Euthanasia and assisted suicide are against the codes of ethics of peak medical bodies.

5. Experience in countries where euthanasia and assisted suicide is legalised is that it opens the way to expand the categories of persons who can request it.

6. Safe guards can never be adequate to protect the vulnerable.

7. Australian parliaments have rejected 16 euthanasia and assisted suicide bills moved since 2002.

8. Advanced Care Directives should be descriptive, rather than prescriptive. They would be better called Advance Care *Plans*, which focuses on what is *planned* rather than setting in writing a legally enforceable directive that a person does not want specified medical care/treatment if a specified health issue arises. As an illness or as age advances a person's experience of reduced mobility and reduced ability to engage or to deal with the illness or frailness may very well change and they may not make the same decision about refusing medical care/treatment they did when making the ACD.

The following more detailed data if offered in support of the above opinion:

1. Palliative Care

In reality not every Australian has reasonable access to palliative care. The Australian and New Zealand Society of Palliative Medicine says that 1.0 full time equivalent (FTE) palliative medicine specialist per 100,000 people is the minimum ratio for a reasonable provision of service. Palliative Care Australia recommends palliative care specialists should be provided to the level of 1.5 FTEs per 100,000 people. Yet the Australian Institute of Public Welfare 2013 report on palliative care services in Australia (see http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545131 Table 7.3) found that nationally, in 2011, the average ratio of FTE palliative care specialists per 100,000 people was only 0.4. And it varied from state to state and between the city and regional areas. In major cities access was at 0.5 while in outer regional areas it was 0.3 and an even lower 0.2 in inner regional areas (see Table 7.4).

- At present in Australia what palliative care services are reasonably available to a patient varies according to where they live and is in any case availability is below that recommended by peak Australian palliative care bodies.
- Adequate palliative care and equity of access regardless of where the patient lives is a serious social justice issue and should not be ignored.

Palliative care should not include euthanasia or assisted suicide. **Palliative Care Australia** believes:

- "Euthanasia and physician assisted suicide are not part of palliative care practice." (see http://www.palliativecare.org.au/Portals/46/PCA%20Voluntary%20Euthanasia%20and%20Physician%20Assisted%20Suicide%20Position%20Statement.pdf)
- If euthanasia/assisted suicide was legalized that would undermine the ethic of palliative care and caring for the vulnerable, and there is a danger that there would be reduced investment in improving palliative care by research and clinical trial, nor in increasing the availability and access to palliative care. Availability and accessibility of palliative care is an essential component of care for those facing death. In Australia the number of full time palliative care specialists is not at the level needed for reasonable provision of service as recommended by the ANZ Society of Palliative Medicine or by Palliative Care Australia. This is a serious issue that needs to be addressed.

- Claims that palliative care in the Netherlands and Belgium since legalization of euthanasia has not lagged behind countries that have not legalized euthanasia state on the face of the record that euthanasia is part of palliative care. A 2013 report in the European Journal of Palliative Care on palliative care in the Flanders region of Belgium openly reports on " …the growing involvement of palliative care professionals and teams in the accompaniment of euthanasia." The report also states that: "Today, one in two non-sudden deaths in Flanders occurs with the support of specialist palliative care professionals, whether within mobile home care teams, hospital support teams (which are available in every hospital), hospital palliative care units (there are 29 in the region totaling 209 beds) or through 'reference persons for palliative care' in homes for the elderly." (see http://www.palliatief.be/accounts/143/attachments/Publicaties/ejpc_20_6_vdb_am_md_gh.pdf) Euthanasia is becoming or is already embedded in palliative care. The report states that one in two, that is half, 50%, of euthanasia or assisted deaths ("non-sudden deaths" i.e. planned) in Flanders are facilitated by or carried out by specialist palliative care specialists.

2. Euthanasia Bills rejected by Australian parliaments since 2002:

- **New South Wales**

  Voluntary Euthanasia Trial (Referendum) Bill 2002

  Voluntary Euthanasia Trial (Referendum) Bill 2003

  Rights of the Terminally Ill Bill 2013 (defeated in May 2013 in the Legislative Council, 23 votes to 13).

- **Western Australia**

  Voluntary Euthanasia Bill 2002

  Voluntary Euthanasia Bill 2010 (defeated September, 2010, 24 vote to 11)

- **Victoria**

  Medical Treatment (Physician Assisted Dying) Bill 2008 (defeated September, 2008, 25 votes to 1)

- **Tasmania**

  Dying with Dignity Bill 2009

  Voluntary Assisted Dying Bill 2013 (defeated in the Legislative Assembly in September, 2013, 13 votes to 11)

- **South Australia**

  Dignity in Dying Bill 2002

The Voluntary Euthanasia Bill 2006

Voluntary Euthanasia Bill 2007

Voluntary Euthanasia Bill 2008

Voluntary Euthanasia Bill 2010

Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010

Voluntary Euthanasia Bill 2012 (defeated on the 14th of June 2012 by the margin of 22 to 20 votes in the Legislative Assembly).

Medical Defenses Bill 2012

3. Peak Medical Professional Bodies

Peak Medical Professional bodies oppose euthanasia and assisted suicide – euthanasia and assisted suicide are against the codes of ethics of peak medical bodies:

- **World Medical Association:**

  "Adopted by the 53rd WMA General Assembly, Washington, DC, USA, October 2002
  and reaffirmed with minor revision by the 194th WMA Council Session, Bali, Indonesia, April 2013

  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.

  The WMA similarly opposes assisted suicide:

  Physicians-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.

  BE IT RESOLVED that:

  The World Medical Association reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice, and

The World Medical Association strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions."

From - http://www.wma.net/en/30publications/10policies/e13b/. .

After the Second World War, and primarily because of human rights abuses by doctors in Nazi Germany, the World Medical Association adopted two modernized forms of the Oath - the Declaration of Geneva in 1948 and the International Code of Medical Ethics in 1949.

The Declaration of Geneva states, 'I will maintain the utmost respect for human life from the time of conception' and the International Code of Medical Ethics says that 'a doctor must always bear in mind the obligation of preserving human life from the time of conception until death'.

- **The Australian Medical Association:**

Although no longer has a position statement specifically on euthanasia still makes reference to the WMA position statement. Seehttps://ama.com.au/codeofethics (reference 2)

© The Australian and New Zealand Society of Palliative Medicine position statement of 31 October, 2013:

"The purpose of this position statement is to state that:

(a) The discipline of Palliative Medicine does not include the practice of euthanasia or assisted suicide;

(b) ANZSPM endorses the World Medical Association Resolution on Euthanasia, adopted by the 53rd WMA General Assembly, Washington, DC, USA, and October 2002, which states:

"The World Medical Association reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice, and The World Medical Association strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions."

- **ANZSPM opposes the legalization of both euthanasia and assisted suicide."**

- **British professional medical bodies:**

"The opposition to euthanasia is strongest amongst doctors who work most closely with dying patients and are most familiar with treatments available. One of our members is the Association for

Palliative Medicine of Great Britain & Ireland, which represents over 800 UK specialists in palliative care. Well over 90% of its members are strongly opposed to euthanasia. The British Medical Association (BMA), the Royal College of Physicians (RCP), the Royal College of General Practitioners (RCGP), the Royal College of Anaesthetists, the Royal College of Surgeons of Edinburgh, The Royal College of Nursing and the British Geriatric Society also remain strongly opposed to euthanasia." (http://www.carenotkilling.org.uk/about/faqs/)

4. Voluntary euthanasia becomes involuntary euthanasia:

The experience where euthanasia and assisted suicide have been legalized is that the categories of those who can ask for euthanasia or assistance to suicide has been extended. In the Netherlands euthanasia has been extended by practice beyond the provisions of the law to children and in Belgium the original voluntary euthanasia law has been extended to those suffering from dementia and to children (see http://noeuthanasia.org.au/blog/1683-belgium-and-the-netherlands-escalate-their-children-s-euthanasia-programmes.html).

To quote Paul Russell, Director of the organization HOPE, Preventing Euthanasia and Suicide: "This all points to another reality: that the existence of euthanasia laws creates deep and almost indelible changes to any society where it is legally practiced. What is legal is moral. The law provides boundaries that human nature pushes against almost constantly. Move those boundaries to accommodate the push and, inevitably over time, the push will come against the newly defined boundary. This is the human experience and why, until relatively recently, all societies resisted such changes."

(http://noeuthanasia.org.au/blog/1856-the-arbitrary-nature-of-euthanasia-safeguards.html)

5. Safe guards – can they ever be adequate?

- Wherever euthanasia has been legalized experience has shown the "safe guards" do not work and vulnerable people are therefore at risk. In the Netherlands, Belgium, Luxembourg, Oregon, the record shows that the "safe guards" are often ignored and there is no investigation or any consequences.
- The main 'safe guards' usually proposed in euthanasia bills are:

  Voluntary, written request which indicates informed consent – This is proposed in the Bill in Clause12. In the Netherlands despite this "safe guard" more than 500 people are involuntarily euthanized each year (see "End-of-life practices in the Netherlands under the Euthanasia Act." van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ, Hanssen-de Wolf JE, Janssen AG, Pasman HR, Rietjens JA, Prins CJ, Deerenberg IM, Gevers JK, van der Maas PJ, van der Wal G N Engl J Med. 2007 May 10; 356(19):1957-65.)

Attempts at bringing those cases to trial have failed (see "The medical practice of euthanasia in Belgium and The Netherlands: legal notification, control and evaluation procedures." Smets T, Bilsen J, Cohen J, Rurup ML, De Keyser E, Deliens LHealth Policy. 2009 May; 90(2-3):181-7.)

Mandatory reporting of assisted suicide/euthanasia cases –Where reporting is required that requirement is often ignored. In Belgium, nearly half of all cases of euthanasia are not reported to the Federal Control and Evaluation Committee (see "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases." Smets T, Bilsen J, Cohen J, Rurup ML, Mortier F, Deliens L BMJ. 2010 Oct 5; 341():c5174.) In the Netherlands, at least 20% of cases of euthanasia go unreported (see "End-of-life practices in the Netherlands under the Euthanasia Act." van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ, Hanssen-de Wolf JE, Janssen AG, Pasman HR, Rietjens JA, Prins CJ, Deerenberg IM, Gevers JK, van der Maas PJ, van der Wal G N Engl J Med. 2007 May 10; 356(19):1957-65.)

Second opinion and consultation - This "safe guard" is meant to ensure that all criteria have been met before proceeding with assisted suicide or euthanasia. However, there is evidence from Belgium, the Netherlands, and Oregon that this process is not universally applied (see "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey" Chambaere K, Bilsen J, Cohen J, Onwuteaka-Philipsen BD, Mortier F, Deliens L CMAJ. 2010 Jun 15; 182(9):895-901 and "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases", Smets T, Bilsen J, Cohen J, Rurup ML, Mortier F, Deliens L BMJ. 2010 Oct 5; 341():c5174.) In the Netherlands there is evidence of consultation not being sought in 35% of cases of involuntary euthanasia (see "End-of-life practices in the Netherlands under the Euthanasia Act", op cit). In Oregon a patient must be referred to a psychiatrist or psychologist for treatment if the prescribing or consulting physician is concerned that the patient's judgment is impaired by a mental disorder such as depression. In 2007, none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist (Oregon Department of Human Services (dhs) Death with Dignity Act. Portland, OR: dhs; 2007. Available online at: www.oregon.gov/DHS/ph/pas/ors.shtml). Further a 2010 study revealed that among terminally ill patients who received a prescription for a lethal drug under the Oregon assisted suicide/euthanasia law, 1 in 6 had clinical depression and that, of the 18 patients in the study who received a prescription for the lethal drug, 3 had major depression, and all of them went on to die by lethal ingestion, despite having been assessed by a mental health specialist (see "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey." Ganzini L, Goy ER, Dobscha SK BMJ. 2008 Oct 7; 337():a1682).

For a detailed examination of whether "safe guards" are effective or adequate see http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3070710/ .

6. Other reasons for not legalizing assisted suicide or euthanasia:

For 9 years Theo Boer was a member of a regional euthanasia review committee in the Netherlands set up to oversee the operation of the euthanasia law in that country. At first he was in favour of the legislation but now says that, from his experience, legalizing assisted suicide is a slippery slope toward widespread killing of the sick. In six years the numbers of deaths doubled. He said: "I used to be a supporter of legislation. But now, with 12 years of experience, I take a different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort?"
(http://www.calgaryherald.com/news/Boer+wrong+euthanasia+slippery+slope/10039178/story.html
)

In the UK House of Lords 62 Peers spoke against the current UK assisted suicide/euthanasia bill - http://www.theguardian.com/society/2014/jul/18/assisted-dying-legalisation-debate-house-lords. We in Australia should also think very carefully before we legalize assisted suicide/euthanasia.

7. Advanced Care Directives:

If Advanced Care Directives were made legally binding and person has not updated or changed his/her expressed wishes then the original directive stands and the person may find that his/her doctor is bound to carry out a directive he/she no longer wishes. Like Birth Plans, Advance Care Plans (ACP) should be flexible as things may not turn out as one thought they would. An ACP should be a narrative describing what the person's most important wishes are in dying and not just a list of medical care/treatment/interventions the person doesn't want. It should include the things most important for that person such as spiritual, emotional and relational issues e.g. opportunity to say goodbye to family, a priest or pastor visiting, prayer, opportunity to express real fears of the dying process or what lies ahead. ACDs should be renamed ACPs to focus on flexibility and allow for the unexpected and be a wish list that cover more than mere refusal of medical treatment.

For an example of an ACP form
see http://www.cha.org.au/images/resources/Future%20Health%20Document.pdf . Catholic Health Australia sums it up very well: "No one, however, should be compelled to issue instructions about future care, nor should any guidance we leave be too prescriptive." - A description of wishes rather than prescriptive, legally -enforceable directions.

In summary I implore you to advise the Parliament to reject attempts by some parties to legalize euthanasia and physician assisted killing. Victoria will be a better place, and a better society if we show a fundamental

respect for life, and care for the dying, the suffering, the depressed and the imperfect. Advanced Care Directives are nothing more than watered down language for physician assisted killing and should be avoided. I believe strongly in Palliative Care and Advanced Care Plans, and I hope and pray you will emphasize these options to the Parliament.

Sincerely,

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Patrick Shea