

Justice Committee Secretariat  
Committee Secretariat  
Justice Committee  
Parliament Buildings  
Wellington

Re: End of Life Choice Bill

Dear Sir/ Madam,

Thank you for the opportunity to write my views on the “End of Life Choice Bill”. I am grateful for the care and consideration being given to this Bill and the concern by the government to take into account the views of the people of our nation.

I am a radiation oncologist. I have been involved in the treatment of cancer patients since 1995 and have as one of my specialty areas, the treatment of patients with high grade, terminal brain cancer. This background has given me the enormous privilege of walking alongside patients and their families at a stressful, harrowing time in the lives and subsequently for many, being alongside them as they die.

It is this background which I feel has fashioned my views such that I stand in opposition to “active euthanasia/ physician assisted suicide (PAS)” and wish to submit against Mr Seymour’s bill.

At this point I need to stress that to relieve suffering, including the cessation of life saving treatment or terminal sedation is part of established medicine and palliative care and hence it is specifically “active euthanasia” which I oppose.

My submission is in 2 parts. The first describing my reasons I oppose active euthanasia and the second relating my concerns with the bill as it stands.

1. Concerns with “active euthanasia”

The concerns I have as a practitioner are

1. To start, I believe that to allow a doctor the opportunity to end a patient’s life, be that with full consent and with the careful considerations, is to fundamentally erode the doctor patient relationship. At the present time my patients know that I will do all within my power whatever their station in life, age, gender etc to preserve life and to ease suffering. They do not have to fear the fact that I also hold the power to legally end their life. This power breaks trust in the therapeutic relationship, which is so important in the care of patients with oncological illness.
2. As doctors we are trained to support life, promote life and enhance life and when life is ebbing away, relieve symptoms and provide support. We are not trained to take life. To knowingly and intentionally take away life has throughout history been illegal and that law has protected our society. To legalize killing, albeit with the careful constraints proposed, places enormous power into the hands of a profession

who throughout history has always been completely oriented in the opposite direction. It redefines and reinvents our profession: a very significant change. This is seen in statements by the New Zealand Medical association and the World Medical Association who consider euthanasia to be “unethical”.

3. One of the great privileges of my job is that I can care for those who, in societies eyes, may be considered “weaker”, or perhaps “less valuable” in some way. In my practice I care for a patient with brain damage, elderly folk aged 94 and 96, a prisoner, a young patient with extreme learning difficulties, and a number of patients with hearing or visual impairment. Each of these patients is receiving care for incurable conditions. Each of these patients is at present protected by a law which prevents them being open to subtle coercion which results in them feeling that euthanasia would be ‘the right thing to do’, to avoid them being a financial or physical burden to those who care for them or a drain on health resources. A study from Oregon reports that forty percent of patients who requested assisted suicide in 2014 did so out of concern for being a burden on their family. It is in a sense not the intelligent, well informed patient who understand and can clearly express their opinions that I fear for but rather those more vulnerable members of our community for whom the current law provides strong protection against exploitation and poor medical care:

<http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>

4. Another concern I have is the risk that allowing voluntary euthanasia normalises suicide and this is of concern within NZ where youth and other suicide rates are rising. The Southern medical journal compared states in the USA with PAS/euthanasia laws and compared suicide rates in these states prior to and after the passing of the law and then made comparisons with other states where PAS was not legal. The study found an increase of 6,4% compared with pre PAS law rates and also on comparison with other states. The report concluded with concerns that perhaps PAS was “normalising the idea that suicide is a reasonable option in difficult circumstances.

How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?

David Albert Jones, DPhil, David Paton, PhD. Southern medical Journal Volume: 108 Issue: 10 October, 2015: 599-604

DOI: 10.14423/SMJ.0000000000000349

5. I am also not convinced there is a problem to be solved. The Economic Intelligence Unit in both 2010 and 2015 place NZ 3<sup>rd</sup> in the world in terms of a quality of death index and a systematic review of 18,975 terminally ill patients in Australia (with a similar health care and illness profile to ours) found that severe pain was experienced by only 4.4%, indicating that for the vast majority of patients in their final days, symptoms are well controlled.

<https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>

Clark Katherine, Connolly Alanna, Clapham Sabina, Quinsey Karen, Eagar Kathy, and Currow David C.. Journal of Palliative Medicine. December 2016, 19(12): 1288-1295. <https://doi.org/10.1089/jpm.2016.0219>

6. I also see a number of potential dangers

- a. The “creep” which many see as scaremongering, does occur. The Netherlands reported their 25-year experience of euthanasia. In 2015, the percentage of patients who were older than 80 years of age had risen from 22% in 2005 to 35% in 2015 and there was also a rise in the percentage of patients who had an estimated life expectancy of more than a month (27% vs. 16%). In 2015, 92% of the patients who received physician assistance in dying had a serious somatic disease; 14% had an accumulation of health problems related to old age, and a small minority had early-stage dementia (3%) or psychiatric problems (3%)

*N Engl J Med 2017; 377:492-494*

*DOI: 10.1056/NEJMc1705630*

- b. Laws enabling euthanasia, however carefully constructed, are difficult to ensure compliance to and to “police”. A report on the Belgium experience states that “approximately half (549/1040 (52.8%, 95% CI 43.9% to 60.5%)) of all estimated cases of euthanasia were reported to the Federal Control and Evaluation Committee. Cases of euthanasia were reported less often when the time by which life was shortened was less than one week compared with when the perceived life shortening was greater (37.3% v 74.1%;  $P < 0.001$ ). Unreported cases were generally dealt with less carefully than reported cases: a written request for euthanasia was more often absent (87.7% v 17.6% verbal request only;  $P < 0.001$ ), other physicians and caregivers specialised in palliative care were consulted less often (54.6% v 97.5%; 33.0% v 63.9%;  $P < 0.001$  for both), the life ending act was more often performed with opioids or sedatives (92.1% v 4.4%;  $P < 0.001$ ), and the drugs were more often administered by a nurse (41.3% v 0.0%;  $P < 0.001$ )”.

*BMJ 2010;341:c5174 doi:10.1136/bmj.c5174*

- c. The Canadian medical association reports that the cost savings of the introduction of their MAID (medical assistance in dying) bill is between \$35-138 million. In the setting of a tight health budget, the option for the less expensive care may result in less expenditure in palliative care practice and less provision for research and development in the palliative care space.

*Aaron J. Trachtenberg MD DPhil, Braden Manns MD MSc. Cost analysis of medical assistance in dying in Canada. CMAJ, January 2017 DOI: 10.1503/cmaj.161316*

Secondly my concerns with the proposed bill.

Once again, I note the care with which this Bill has been constructed and the considerations made. I am particularly grateful that this Bill does allow for consideration of the conscience of the medical practitioner and I implore the parliament to ensure that this clause is **always** maintained if the end of life choice Bill or something similar is adopted. I also applaud the move to include only NZ residents by this Bill to avoid “euthanasia tourism”.

I do however have some concerns

1. The Bill states that the person is over 18 years of age. Although I applaud this inclusion, my understanding is that it is difficult to support exclusion based on age if challenged on the basis of Human Rights law. It appears in those countries where an initial age limit is set, there are consistently moves to lower this age to include children. For eg in 2002 Belgium legalised euthanasia and in 2014 Belgium legalized euthanasia by lethal injection for children. The situation in Canada appears to be following suit.
2. suffers from—
  - (i) a terminal illness that is likely to end his or her life within 6 months; or
  - (ii) a grievous and irremediable medical condition; and
  - (d) is in an advanced state of irreversible decline in capability; and
  - (e) experiences unbearable suffering that cannot be relieved in a manner that he or she considers tolerable;

I see a number of difficulties with this part of the Bill.

The prognosis of 6 months is difficult to predict as a doctor. From my personal experience it is almost impossible to estimate someone's prognosis as far out as 6 months. I am often questioned by insurance companies, patients, families etc. with "How long have I got doc?" It is a question I often answer with "How long is a piece of string?" I can quote studies, for example the gold standard of treatment for high grade brain tumours gives an average survival of 12-14 months. This means if we have 100 people, number 50 may live between 12-14 months, but number 1 may die within a week and number 100 in 6 years! An article in the British medical journal makes interesting reading. (BMJ 2000;320:469). This study found that for 468 terminally ill patients, the doctor's estimate of survival was accurate in only 20% of cases. Concerning figures for the basis of decision making for assisted suicide.

A further eligibility criterion is "a grievous and irremediable medical condition". Once more this is a vague term and very open to varying interpretation and leaves a door ajar for the creep that concerns so many medical practitioners about a change in the law regarding euthanasia. This term potentially could include the mentally unwell, disabled, those with learning disorders and benign conditions, such as heart disease. It is so difficult to foretell what future life may look like for those with "irremediable medical conditions". One very publicized example reported was the case of Erin Berg who underwent euthanasia with Dr Nietske - for post natal depression. There are perhaps many who in the darkness of post natal depression feel that their suffering is irreversible, however months or years later ending their life could not be further from their thoughts.

Experiences "unbearable suffering" that cannot be relieved in a manner that he or she considers tolerable. My concern here is the fact that suffering "cannot" be relieved may be as a result suboptimal symptom relief and perhaps inadequate access to good psychiatric or palliative care. Should the patient receive this level of

care, then perhaps they would be able to enjoy what remains of their time with family and friends. It also concerns me deeply that this Bill lays the decision regarding the “intolerable suffering” with the patient. I can see the autonomy this gives the patient in giving them the ultimate “choice” in deciding whether to end their life according to the Bill however, I can see real difficulties here as in a sense once part (e) is satisfied, it renders the other criteria of terminal illness, irremediable medical condition etc obsolete. If the patient feels their suffering is intolerable, then this becomes irrefutable. As a doctor, I may know there are many options available to relieve suffering, many of which may be part of standard care. However, if the patient considers suffering to be intolerable and “unable to be relieved” then the condition of the Bill is met despite valid options remaining and the patient by their very own decision making is denied these treatments.

3. (4) At least 48 hours before the chosen time of administration, the attending medical practitioner must—
- (a) write the appropriate prescription for the person; and
  - (b) advise the registrar of the method and time chosen; and
  - (c) provide the registrar with the prescription.

My reading of this part of the Bill is that if a patient’s request is upheld by the national committee the prescription is written and the drug can be delivered in 48 hours. My concern here is there is no “cooling off period” and that a dark couple of days may result in a death, which if some more time had been granted, the clouds may have lifted to give a completely different outlook.

4. There are also a number of practical concerns I have with the Bill. The options for death include

- (i) ingestion, triggered by the person:
- (ii) intravenous delivery, triggered by the person:
- (iii) ingestion through a tube:
- (iv) injection; and

To my knowledge, we do not have the capabilities for IV delivery triggered for the patient and nor do we have readily available drugs used internationally in this setting.

The attending medical practitioner must—

- (a) be available to the person until the person dies; or
- (b) arrange for another medical practitioner to be available to the person until the person dies

For the purposes of subsection (5), the medical practitioner is available to the person if the medical practitioner—

- (a) is in the same room as the person; or
- (b) is not in same room as the person but is in close proximity to the person

This will have significant resource implications if a doctor is to remain with the patient until they die and especially in the public hospital setting there is a real

likelihood that this will fall to junior staff who although present on the ward, may not be the most appropriate person in skill level or experience to manage in the “usual euthanasia setting”, but even more so in the small percentages which do not go according to plan. This would require very careful guidelines around it and my advice here should it be adopted that national guidelines be constructed to allow for uniformity of care.

4. (xiiia) in respect of a person who died as a result of the provision of assisted dying under the End of Life Choice Act 2017, the cause or causes of death as if assisted dying had not been provided: My concern here is that cause of death data for determining response to treatment will be skewed as death in the setting of euthanasia death may occur prematurely, making it difficult to truly assess effectiveness of treatments, life expectancy etc.

Thank you once again for the opportunity to present my views on this very important issue.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Melissa James', written in a cursive style.

Dr Melissa James

MBBS Bsc (hons) FRANZCR