

A submission to the Justice Select Committee, New Zealand parliament regarding its inquiry into the End Of Life Choice Bill

January 2018

Dr John Geddes

36 Worsleys Road

Cracroft

Christchurch 8025

I write this submission regarding the proposed 'End of Life Choice' bill from my perspective as a practising Geriatrician within New Zealand. My scope of practice includes the assessment of patient capacity, and my clinical practice ranges across a wide range of patients, including frail older people with multimorbidity, those with neurodegenerative disease, involvement with older spinal trauma patients, management of amputees, those patients with terminal illness, consulting on preoperative decisions for patients undergoing cancer treatment, and care for those suffering from elder abuse and coercion.

I wish to state my opposition to the bill, and request the Select Committee and the government reject this bill in its entirety.

I wish to state my support for the formal position statement of my professional society, The Australian and New Zealand Society for Geriatric Medicine (ANZSGM). I also wish to affirm the position statement of the Australian and New Zealand Society of Palliative Medicine (ANZSPM), which also opposes this legislation.

Furthermore this opposition is consistent with the following national and international organisations

- The ethical standpoints of the World Medical Association, and the independent ethical review of the New Zealand Medical Association. These ethical standpoints also reflect the ethical viewpoints of the vast majority of international medical organisations.
- Hospice New Zealand
- The Palliative Care Nurses New Zealand Society (PCNNZ).
- The Worldwide Hospice Palliative Care Alliance
- The overall themes of the New Zealand Committee of the Royal Australasian College of Physicians (RACP) submission to the 2015 Health Select Committee enquiry into end of life care.

I wish the select committee to be aware of the excellent work in seeking to provide quality end-of-life care being carried out in the United Kingdom by the government of the United Kingdom and by the British Medical Association (who also oppose assisted dying legislation in that country) and urge the committee to investigate these evidence based approaches. The example of the United Kingdom is extremely relevant given that nation's top ranking in the 2015 'Quality of Death' Index produced by the Economist Intelligence Unit. This high quality is a likely contributing factor to why both

England and Scotland voted in recent years to keep the practice of euthanasia illegal in their jurisdictions.

I wish to state the following concerns which I believe have direct relevance to the bill before the New Zealand Parliament.

1) Difficulty with diagnostic accuracy and prognostication

- Misdiagnosis is a common occurrence in medicine, and evidence suggests high rates of misdiagnosis in many diseases, particularly early in disease processes. There continue to be reports of people who have been misdiagnosed across a wide range of conditions. This has significant implications for patients with decision making capacity thought to be suffering from early dementia, who proponents of this bill clearly see as candidates for euthanasia. I have personally experienced cases of patients who have been misdiagnosed by successive doctors, and can also acknowledge instances of misdiagnosis made by myself and other doctors, despite being specialists in our field.
- Prognostication of a 6 month mortality risk is extremely difficult, and will likely to be either made based on *literature* based median survival times (hence meaning half of the patient population would NOT have a 6 month mortality), or based on *subjective* judgement, which is acknowledged to be variable, and can differ widely between clinicians
- Locally based evidence in the Canterbury region regarding those approved for 'end-of-life' funding for residential care suggests a 10% survival beyond the required clinician predicted mortality of less than 3 months. It would therefore hold that using the 6 month timeframe proposed by this bill, the amount of poorly judged survival times is likely to be significantly higher, which is line with my above concerns.
- The vaguely termed 'grievous and irremediable medical condition' and 'advanced state of irreversible decline in capability' as set out in the proposed bill essentially appear to negate the 6 month mortality requirement, as almost any patient at any stage of a chronic or terminal illness would qualify under those criteria. This could include spinal injury, inborn and acquired disability, and a large number of neurological illness for which the prognosis and treatment response is unclear. This element of the criteria for euthanasia is especially concerning and wide ranging in its intent. I note that for many of these longer term illnesses and disabilities there are emerging new therapies, which offer great hope for both improvement of quality of life, and disease modification.

2) Assessment of Capacity

- This bill fails to recognise the complexity of decision making capacity. Capacity for a decision of this magnitude should be at the 'testamentary capacity' level. It is acknowledged that up to 1/3 of New Zealand General practitioners do not feel comfortable making decisions regarding patient capacity. The judgement of testamentary capacity is even more difficult to assess.
- I have coordinated the teaching programme for trainees in Geriatric Medicine for several years, and have regularly put capacity training on this programme due to requests from trainees recognising its complexity. It is *standard* practice that

capacity cannot be assessed by an individual doctor in a single setting (such as is suggested by the framework described in the proposed bill), and requires at least 2 interviews to adequately assess. Therefore the capacity requirements outlined in this bill do not meet current best practice in this area of medicine. Given the impact of medications on capacity, and the often subtle effects of many conditions upon cognition the inadequate capacity assessment structure outlined in the proposed bill is unacceptable. .

- Capacity is best judged by either the doctor most familiar with the patient, or at the end of life by specialists in this spectrum of medicine, these being geriatricians, palliative care physicians, and psychogeriatricians. The proposed capacity checks in the bill therefore specifically *exclude* many clinicians who are both a) highly experienced in this process and b) familiar with the patient over a long period of time (as overseas evidence suggests the doctors performing these acts are a very small proportion of the overall medical profession).
- Given the inherent bias *towards* euthanasia that both 'replacement' and independent' doctors will have, this makes the validity of their capacity checks highly suspect in light of my above points.

3) Risk for Coercion

The introduction to this bill claims that concerns regarding abuse of the vulnerable have not eventuated overseas. This claim again denies many aspects of the available literature. . The low number of investigations into risk of abuse appear to reflect a lack of rigorous research in this area, and is likely to reflect the inherent bias of supervising bodies such as the proposed SCENZ group, particularly I these groups do not have external monitoring or independent scrutiny. The lack of evidence of coercion and abuse therefore rests on a likely lack of recognition of this phenomenon, and minimal desire to truly investigate these instances.

- In overseas situations a strong indicator of desire for hastened death is that of being a 'burden to family'. In my practice as a geriatrician I frequently see cases of people entering residential care, or making health decisions, not because this is their preferred decision, but because is it '*best for the family*'. It is important for the committee to note that elder abuse is a) common in society b) frequently unreported and c) most often perpetrated by those closest to the individual. As such these familial reasons quoted for desire of hastened death are highly open to pressure and coercion, which is unlikely to be documented, as those performing euthanasia either do not recognise this, or choose to downplay its importance.
- Social isolation is a well-recognised risk factor for elder abuse, as well as being a predictor of low mood in older people, and again is a factor felt to be part of the existential reasons underlying requests for hastened death.
- Overseas evidence suggests high rates of 'non-consenting' or 'involuntary' euthanasia. For these cases to occur within frameworks which claim to be highly regulated demonstrates how easily emotional coercion, financial pressure, and frank elder abuse can occur.

- An independent bioethics based review of the euthanasia system in Belgium performed in 2014 noted the broad scope of that country's law offers potential for abuse, and further notes that controversial cases that are widening indications for euthanasia in Belgium are also increasing the risk of abuse.

4) The role of Psychiatric Illness

- A desire for hastened death amongst sufferers of terminal illness is highly associated with both atypical presentation of depression and hopelessness. Given the opposition in the Royal Australian and New Zealand College of Psychiatrists (RANZCP) position statement 67 (Physician Assisted Suicide) to those with psychiatric illness being considered candidates for euthanasia, it also stands to reason that those with coexisting depression, even when it is not the primary diagnosis, should receive assessment and treatment for this rather than euthanasia.
- Depression in terminal illness, cancer, or in later life, can present atypically, and is often associated with tiredness, decreased energy, and decreased appetites, rather than the popular impression of depression as 'sadness' per se. This atypical presentation makes diagnosis difficult, particularly if assessed by doctors who either do not know a patient, do not have appropriate training, or who have a bias towards an outcome (in this case euthanasia).
- Hopelessness, and depression are part of the 'existential suffering' complex that those who request euthanasia appear to suffer from. These are symptoms for which viable intervention strategies exist. *As such they are open to treatment and not appropriate for euthanasia.*
- The concept of 'unbearable suffering' is shown in the medical literature to be a) difficult to define b) variable in nature, as shown by studies looking both at people approved for euthanasia who then decided against this pathway, and through research into such suffering in those whose requests for euthanasia were declined. It is of particular interest that 'unbearable suffering' in this latter group was only found consistently in those with psychiatric illness. As such treatment of psychiatric illness, and appropriate recognition of depression in end-of-life situations, appears to be paramount, and would be a more appropriate system level response than euthanasia would be in these circumstances.

5) Similarity to suicide

- Many of the acknowledged risk factors for suicidality are also strong predictors of the existential reasons literature suggest underlie requests for euthanasia. These risk factors include depression, hopelessness, loneliness and isolation, loss of control or meaning, and disconnectedness from family. I am concerned regarding reports of increased suicidality in several districts and regions which have legalised forms of assisted dying and euthanasia, particularly with regard to increase in suicidality in older people. I also wish the committee to be again be aware aware of the position statement 67 of the RANZCP, which notes that common misconceptions exist regarding the role of chronic, debilitating or terminal illness in the suicide of older people, and notes the reasons for suicide in older people are in actual fact far more

complex than this. It goes on to state concern regarding the impact of the euthanasia debate on older people. Whilst associations with suicide and euthanasia are controversial, there appears to be little literature clearly showing a decrease in suicidality relating to legalisation of euthanasia. It is inconsistent for a government to state that unbearable existential suffering is a valid option for some people but not others. It should be noted that the final judgement of the *Seales* case considered the request before the court at that time to be a request for suicide, thereby offering a legal opinion linking euthanasia and suicide.

- 6) Role of 'Conscientious objection', SCENZ, the 'independent' list and 'specialist' list
- I hold grave concerns about all aspects the bill with regard to the rights of conscientious objectors, of the bias inherent towards the practice of euthanasia that members of a group labelled 'independent' would have, and the role that the proposed SCENZ group would have.
 - A conscientiously objecting doctor is still required to give a patient, who the law assumes is competent, information regarding access to euthanasia. As such there is no true 'opt-out' even for conscientious objectors. Surely a competent patient can access information themselves, or can instruct an appointed representative to source such information. However even this situation opens the bill up to potential coercive and abusive practice, as described above.
 - Conscientious objectors face significant fines, or even imprisonment, despite adhering to ethical frameworks, whilst practitioners who participate in euthanasia are protected in this bill through the principle of 'good faith', which would be able to be invoked in almost all circumstances, even should those doctors be manipulating the already vague definitions. Overseas situations hold many examples of such manipulation going unchecked by doctors practising euthanasia.
 - Both the SCENZ list, and the 'independent' list are likely to be biased towards euthanasia. Any ethicist involved would likely hold a minority viewpoint within the New Zealand bioethics community. The creation of the 'independent list' would likely require vetting by the SCENZ group to ensure those individuals are happy to participate in the entire process described in the bill. The 'replacement' practitioner would also be an individual prepared to participate in this process, and approved by the inherently biased SCENZ group. It should be recognised by the committee that this is likely to be a small number of individuals whose views are likely to be more extreme towards euthanasia, than many other doctors, who may be ambivalent towards euthanasia but who would not wish to personally participate in the actual life-ending process. I also wish the committee to note the difficulty there has been in maintaining these lists in Ontario following the alteration of Canadian end-of-life law. The demand for increased financial remuneration to be part of this process is a significant concern, as this suggests a commercialisation of death, and *a potential pecuniary interest towards the practice of euthanasia* by a sub-group of doctors.
 - For conscientious objectors (who would be all those doctors unprepared to actually end a life, regardless of their overall views on euthanasia) it appears both opinions required for patient assessment will come from SCENZ approved lists, creating an

even more biased situation, which dissociates lead clinicians from the end-of-life care of their patients.

- Regarding the ‘specialists’ in the bill, it should be noted these are not viewed as arbitrators of prognosis, or diagnosis, but are only to be legislated as assessors of capacity. These individuals are not specialists trained in the management of the conditions presenting for euthanasia, and so have an extremely limited scope. The bill makes no provision for specialists within the scope of practice for the relevant diseases, and it is of particular concern that psychiatry is only involved in this aspect of the entire process, despite the clear and heavy burden of psychiatric disease that may be present in these patients. Again the specialists are likely to have a high level of bias, and I refer to the points above regarding the complexity of capacity assessment.
- It is unclear in the proposed bill what position *institutions* can hold with regard to conscientious objection. This is particularly relevant to hospice given their opposition to euthanasia, and also to elements of the residential care sector. It is critical that the right of institutions and to oppose euthanasia at an organisational level is recognised. In this context the committee should be aware of, and investigate, attempts overseas to challenge the independent rights of both hospices, objecting hospitals, and care facilities.

7) A perspective regarding human rights, international obligations, and legal considerations

- This bill proposes to adjust the Crimes Act in a way that differentiates New Zealanders. It is not consistent to have a bill that outlaws actions by some members of society, but which condones those actions by other members of society.
- Doctors, and other health practitioners, are bound to act within the auspices of the Health and Disability Commission ‘Code of Rights’ (henceforth referred to as ‘The Code’). This affirms a patient’s right to decline treatment, and also validates advance care plans that limit care. Doctors are required to inform patients of treatment options, but the prime expression of patient autonomy is in the right to refuse treatment. This is consistent with right 11 of the New Zealand Bill of Rights. The proposed bill, when considered under The Code, may require doctors to introduce the option of euthanasia, where it would be otherwise unstated. This has implications for *all doctors*, as this would then be required to be part of treatment conversations, and these discussions could be performed by any clinician a patient comes in contact with. *This has significant implications for doctors with conscientious objections, as they would still be required to introduce this possibility, whilst for those with strong pro-euthanasia views this would be considered a method to introduce the concept, where it might otherwise not exist.*
- This is particularly relevant when considering those aged over 80 years, who literature shows are more likely to be influenced by doctors, and by family, and who in the literature have been shown to be less likely to be properly consented in overseas cases of euthanasia. This inherently causes a situation of possible coercion and abuse of power and relationship.

- Article 3 of the the United Nations Universal Declaration of Human Rights, and Right 8 the New Zealand Bill of Rights (NZBOR) include the declaration of the right to life. *The committee should note that this right was not breached in the recent Seales case.* This right is at risk for many people should they have misdiagnosis or inaccurate prognostication as discussed above. The bill also appears to inherently place a differential value on this right, both for those near the end of life.
- I note that right 9 of the NZBOR, the right not to be subjected to cruel treatment, *was not breached in the Seales case.*
- As referred to above, Right 11 of the NZBOR is the right to refuse medical treatment. This is consistent with current medical practice, the Code of Rights, and the predominant ethical viewpoints.
- Right 19 of the NZBOR: The right to be free from discrimination is at risk due to the provisions of this bill. There is a large group of New Zealanders potentially viewed as suffering from a ‘grievous and irremediable condition’. This group includes those with acquired or inborn disability across a vast scope of presentations, and conditions. The proposed bill appears to actively encourage both individual, and societal attitudes in breach of this right. The bill also appears at risk of breaching article 1 of the United nations declaration,
- Article 27 (i) of the Universal Declaration of Human Rights gives individuals the *right to share in scientific advancement.* Within the end-of-life setting this right is best promoted through access to the evidenced base practice of palliative care, and is also relevant in the context of emerging treatments and practices, both in palliative care, analgesic practice, and developing fields of oncology and genomic medicine. I believe this right to be compromised for a large proportion of our society, should the proposed bill be enacted.
- The committee should note New Zealand’s obligation as a member nation of the World Health Organisation (WHO), under the World Health Assembly resolution WHA67.19, to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care. It should be further noted that the WHO definition of palliative care is states that Palliative Care ‘intends neither to hasten nor to postpone death’. It is also recognised in the New Zealand palliative care strategy that palliative care covers a broad range of medicine (and is not restricted to palliative specialists per se, despite that specialty being the paramount experts and practitioners in the field). The introduction to this bill makes the claim that palliative care will be strengthened due to the introduction of euthanasia. An alternative view of this statement would be that clinicians have *demande*d improvements in palliative care following the introduction of euthanasia, rather than euthanasia being the cause of these improvements.
- I encourage the committee to review the findings of the 2017 judgement ‘Farn v Loosley [2017] NZHC 317’. This judgement is particularly relevant as it pertains to the validity of ‘deathbed wills’ and the validity of testamentary capacity towards the end of life. As per my above points on capacity it appears capacity to end one’s life should be at the testamentary level, is difficult to assess in complex settings near the end of life, and so legal precedent regarding this capacity in the context of a ‘deathbed will’ should be considered.

- I note that the proposed bill appears to be in conflict with aspects of New Zealand's Palliative Care Strategy (which has relationships to the Ageing Strategy), and needs to be considered in the context of New Zealand's mental health and suicide prevention strategies, particularly pertaining to older people. The committee should acknowledge the recent announcements to aim strategies towards loneliness, particularly in older people. This strategy appears to be more consistent than euthanasia, with regard to treating the underlying existential aspects of desire for hastened death.
- Current palliative practices such as correctly titrated opiate pumps, withdrawal of active care, and moving patients to palliative pathways, are often considered by proponents of the proposed bill to be forms of euthanasia. *The committee should note that the final judgement in the Seales case considered these forms of treatment, differentiated them from the act of assisted dying, and did not find them to be illegal.*
- This proposed law change needs to be consistent with principles of the Treaty of Waitangi, and needs to consider established Maori frameworks towards end of life care, and the 4 pillars of Hauora Maori. Furthermore in this context the committee should recognise that poor health literacy in Maori and minority groups, and poor access to culturally appropriate services, at both urban and rural levels, are barriers to provision of palliative care, and in which the practice of euthanasia may further confuse people regarding the benefits of palliative care. The introduction to this bill seeks to exclude some cultural attitudes, and in doing so implicitly affirms the suggestion that desire for euthanasia is most prominent in pakeha. It would be inconsistent for New Zealand to affirm a law based on a pakeha world-view, that seeks to minimise or disregard the cultural views of other, growing, aspects of our society.

Final statement

Finally, I wish to affirm that compassion and maintenance of dignity are core parts of current medical practice. For those of us who are professionals involved in advocacy for those who are older, or who are close to death, we desire to travel with our patients on their journeys, we desire to maintain or improve quality wherever possible, and to advocate for appropriate access to ethical and beneficial treatment pathways for our patients. Management of symptoms in the final phase of life is a core treatment in the clinical practice for geriatricians and palliative care specialists. We seek to *first do no harm*, to heal where possible, and to care always.

We currently have a government claiming to be a government of hope, which is concerned about a mental health crisis in our society, and which wishes to promote improved societal attitudes. Euthanasia appears to affirm the existential symptoms of hopelessness, depression, isolation and disconnectedness. I implore our government to reject the nihilism of euthanasia, and to answer hopelessness with hope, depression with better psychiatric care for those who are dying or chronically unwell, and disconnectedness with strategies to combat isolation and loneliness, and with affirmation of the principles of palliative care within a compassionate society.