

Committee Secretariat

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Justice Select Committee

Parliament Buildings

Wellington 6160

**Submission on the End of Life Choice Bill**

To the Justice Select Committee

*Personal details:*

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We wish to appear before the committee to speak to our submission.

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We oppose the End of Life Choice Bill and any change to the existing law that might permit euthanasia or assisted suicide (EAS) in New Zealand.

We recognise that this is a very complex issue and we appreciate the time taken by this committee to consider its many aspects.

We wholeheartedly support people's autonomy in withdrawing or not initiating treatments. We would like to see more awareness and resources go into advanced care planning. We support excellent pain relief even if there is an unintended shortening of life. However we maintain there is a crucial difference between letting a disease run its natural course leading to death while addressing their symptoms (palliative care) and intentionally causing the death of a person or assisting them to do so.

The Bill's explanatory note makes many assertions. Among these is that the position with regard to euthanasia has changed materially since earlier bills were considered. It states that *"evidence and developments have established that there are serious problems with the current state of the law in New Zealand that will be ongoing without a legislative solution"*. In support it cites the High Court decision in *Seales v Attorney General* [2015] NZHC 1239. The decision reportedly demonstrated that *"some people in New Zealand are suffering unbearably at the end of their lives and are taking their lives earlier than they would if assisted dying were available to them."* It asserts *"[t]here was a broad consensus that palliative care cannot alleviate all suffering, including suffering that is unbearable for a person."* This is misleading. In *Seales vs Attorney General* (2015) a significant body of evidence was heard including medical experts. The Court acknowledged that witnesses expressed a wide variety of views. At [15]: *"[f]or every proponent of Ms. Seales' case, there is an equally forceful opponent"*. Witnesses were not cross-examined and the decision ultimately focused on the legal, not factual, issues before the Court. While it was accepted that palliative care cannot guarantee relief from suffering, the thrust of the expert evidence before the Court was that palliative care is effective. The Court stated (at [34]) that *"[i]t is accepted that the [recent] development of palliative care medicine as a specialist branch of medicine and the establishment of hospices has greatly improved the clinical care of patients who are terminally ill."* The problem of 'intolerable suffering' has diminished significantly over recent years, not increased.

It is taken as self evident that public opinion is overwhelmingly in favour of a law change. However a significant majority of those who wrote to the Health Select Committee in 2015-2016 were against a change in the current law (Health Select Committee, 2017).

The preamble also states that *"Analysis of overseas jurisdictions where assisted dying is permitted demonstrates that concerns, including concerns about abuse of the vulnerable, have not materialised and that risks can be properly managed through appropriate legislative safeguards."* There is no reference given for this claim. When we scrutinized the data from countries or states where EAS is legal we see significant cause for concern (minimal actual oversight of the doctors involved, EAS requested primarily for reasons of psychological rather than physical suffering, and an increase in EAS in patients with dementia and mental health problems) as we will discuss below.

Therefore our submission will outline why we have concluded that this or any legislation allowing doctors or others to be involved in actively ending people's lives will always be open to abuse, coercion, diagnostic or prognostic errors, and the extension of the law to include groups initially excluded. We are also concerned about the effect on those who are suicidal secondary to mental health issues and finally the undermining of palliative care.

### What leads people to want to end their lives?

Arguments for euthanasia often cite incurable pain and suffering as the main reason for requesting euthanasia. However research has shown that the reasons are much more complex (Stolz, Mayerl, Gasser-Steiner, & Freidl, 2017).

Suffering as termed in the End of Life Choice Bill (ELCB) encompasses not only physical but psychological and social factors. A systematic review across 8 countries found that these included fear of future pain, fear of being unable to express needs or wishes, fear of being a burden, a feeling of being devalued or treated as an object, being forced into a situation that contradicted all they held to be important, and hopelessness or a sense of 'nothing to live for' (Rodríguez-Prat, Balaguer, Booth, & Monforte-Royo, 2017). However, many of these are potentially reversible with good holistic health care. Understanding and addressing these reasons more fully should be prioritised. This is particularly pertinent in our ageing New Zealand population with a growing number of care facilities.

The desire for hastened death in cancer patients admitted to hospital for palliative care has been found in studies to be strongly associated with a clinical diagnosis of depression, severity of depressive symptoms, and hopelessness (Breitbart et al., 2000). The strength of this desire has also been demonstrated to show significant individual fluctuation over time (Chochinov et al., 1995).

The Oregon Death with Dignity Act Data Summary 2017 (Centre for Health Sciences Public Health Division, 2018) listed reasons people requested assisted suicide. Existential reasons are almost always named, while only 21% cite concern about uncontrolled pain (which may be fear of future pain).

### Mental Health and Suicide Prevention

New Zealand society is finally acknowledging the increasing burden of mental health problems. Death from suicide in 2016 and 2017 was the highest recorded since suicide statistics were first collected in 2007. The government has recognised this and proposed strategies to allay this burden (New Zealand Labour Party, 2017). We believe efforts should be focused on reducing this psychological suffering by offering appropriate support rather than affirming an 'acceptable' approach is to end one's life as a result of mental health problems.

As a society New Zealand has taken the view that we have an obligation to protect people from themselves. The personal and societal cost of suicide is enormous. We rightly invest significant energy and resource in preventing suicide and, when it happens, examining the reasons why. Those committing suicide often do so to escape what they perceive to be

unbearable suffering (and irreversible decline), that cannot be relieved in a manner they consider tolerable, and which is caused by a grievous and irremediable illness. It is simply not possible to draw a clear distinction between those eligible for assisted dying under the ELCB criteria and those we, as a community, commit to protecting.

### Broad Criteria

The language used in Section 4 of ELCB is vague and would make it difficult to exclude anyone from accessing help to end their life.

Clause 4. (c)(i) Gives the provision for anyone who is likely to die within the next 6 months the ability to request assisted suicide. While this might seem straightforward, as doctors, we are very aware of how challenging prognosis, “what is likely to happen in the future”, can be particularly when predicting life expectancy. Studies (Forster & Lynn, 1988), (Zibelman, Xiang, Muchka, Nickoloff, & Marks, 2014) show that even experts are poor at accurately predicting prognosis and there will be unexpected long-term survivors. A meta-analysis (considered the highest level of evidence in medicine) published last year showed that doctors are only accurate three-quarters of the time when predicting if someone will die within 6 or 12 months (White, Kupeli, Vickerstaff, & Stone, 2017). The paper’s discussion includes the statement “There was virtually no difference in level of accuracy when considering studies in which the timeframe of the surprise question (SQ, ‘would you be surprised if this patient died?’) had been reduced, which suggests that even when the patient is thought to be imminently dying, there is only moderate accuracy and continued uncertainty.” In addition, the diagnosis is wrong in 10-15% of cases (Graber, 2013) which contributes to inaccurate prognosis. It should also be considered that many conditions such as ischemic heart disease or diabetes could become terminal within 6 months if treatment were to be refused or not adhered to. Therefore, even if clause 4. (c)(ii) was removed, people with treatable conditions could meet the criteria of a terminal condition.

Of even greater concern is the number of people who could be eligible under 4. (c)(ii) “A grievous and irremediable medical condition.” This term could legitimately encompass a range of chronic illnesses from diabetes, to colour-blindness, to bipolar disorder. Any of these conditions could be considered, at certain times in the life of an individual, to 'make life unbearable' or grievous. The following clauses (d, e and f) offer few safeguards to prevent such interpretations.

Regarding section 4.(e), and the term “unbearable suffering”, this is subjective and therefore can only be judged by the person experiencing suffering and not by a doctor or court. Therefore it will prove very difficult to make restrictions on who will be able to access assisted dying.

### Assessing capacity of a person to make decisions and prevent coercion

Assessing the capacity of a person to make a dying versus a living decision is complex and involves more than just ensuring the person understands the procedure (section 4.(f)). Alternative approaches also need to be understood and considered, particularly in the case of treatments which carry a risk of harm. The alternative to assisted dying, living, while

supported by palliative care until a natural death occurs would need to be understood by the person. As euthanasia and assisted suicide constitute irreversible interventions, a robust approach to determining competence is essential given subsequent decisions pose a significant risk of premature death - the ultimate harm.

Determining capacity and competence to make decisions is particularly difficult when a neurological disease is present. It has been found that in those with neurological disease, the largest increase in wish to die, both passively (that is, withdrawing or refusing treatment as is already common and legal in New Zealand) or with an active measure to cause death, has been observed in the stages where decision making capacity is lost (Clarke et al., 2017).

Depression and other psychiatric illness can also affect decision making capacity. This is the foundation of our Mental Health (Compulsory Assessment and Treatment) Act 1992. Even when euthanasia was requested for psychiatric reasons the assessment of capacity by doctors in the Netherlands was found to be far from rigorous (Doernberg, Peteet, & Kim, 2016).

The difficulty in detecting and preventing coercion is also of paramount consideration. Family members, caregivers or associates may have a vested interest in a person undergoing euthanasia or assisted suicide. At the time of considering euthanasia or assisted suicide a person would be in a vulnerable situation and the potential for coercion would be high. Detecting coercion is not part of medical training, and would be difficult to detect in the complex situation of a person expressing their wish to die. Data from Oregon shows that over half of those making a request to end their life were concerned about being a burden to others (Centre for Health Sciences Public Health Division, 2017). A Canadian study (Li et al., 2017) also found the wish to avoid burdening others was a common reason to request euthanasia.

#### Impact on the role of doctor - healer or judge of whose life should be ended?

The basis of the patient-doctor relationship is trust, as the Hippocratic oath highlights. Making doctors the 'gatekeepers' for euthanasia or assisted suicide would strain the integrity of this relationship. In some circumstances doctors would be promoting the life and well-being of their patients. In others, the doctor would be asked to end the life of patients with very similar, perhaps identical conditions. Inevitably doctors would be expected to guide patients as to their suitability for euthanasia or assisted suicide, as well as making that assessment and invoking it. Patients could no longer trust their doctor to always care for them and promote their well-being. Doctors would find themselves forced into the role of judging that some of their patients' lives are no longer worth living, arguably the ultimate act of medical paternalism.

Any involvement of doctors in euthanasia or assisted suicide would change the character of the medical profession in New Zealand forever. It would have wide-reaching effects in the areas of palliative care, internal medicine, general practice, psychiatry and oncology. Patients' expectation of doctors to provide and facilitate death could deeply impact the nature of how medicine is practiced and the psyche of those involved. Further impacts on

workforce recruitment and retention, practitioners' mental health, and the perceived value of a patient's life would be difficult to predict.

### Wider effects on society

Any change in the law to allow euthanasia or assisted suicide would have detrimental effects on vulnerable populations.

For some, chronic physical illness is a part of their daily existence, yet they adjust to and enjoy life, often more than those who are healthy. For others, any change from full physical health is poorly tolerated and greatly affects their enjoyment of life. To try to determine the value of one's life based on current physical health is too simplistic in the complex area of assessing the value of one's life.

We are particularly concerned that those most likely to suffer, should euthanasia or assisted suicide be legalised, are those with long-term health impairments. This includes the elderly, those with mental illness and those with disabilities. All are already vulnerable groups in our society.

There is a readily identifiable bias in New Zealand society towards those who are young, physically fit and economically contributing to society. Over half of older New Zealanders report being lonely and many experience everyday discrimination (Waldegrave, 2012). Those with mental illness can feel alienated and misunderstood, while often struggling with depression and suicidal thoughts. Those with disabilities are impacted by negative societal attitudes and report greater unmet healthcare needs (World Health Organisation, 2018). Should euthanasia or assisted suicide become legalised, societal pressure to consider euthanasia or assisted suicide would be highest on these already vulnerable groups.

### Regulation of euthanasia in jurisdictions where it is legal

The ELCB attempts to put limits on who can access assisted suicide. Therefore it is important to know if similar limits have been effective overseas and if there has been substantial increases in who can access or are eligible for EAS.

Regulation overseas is based primarily on doctors' reports to a review committee or similar. A study in Belgium by Smets et al (Smets et al., 2010) found that only half of all cases were reported and cases not reported were generally dealt with less carefully. A similar survey in the Netherlands showed that only 77% of deaths from euthanasia were reported (Onwuteaka-Philipsen et al., 2012).

Of the cases reported to the Dutch regulatory body, serious breaches have occurred whereby procedure or patient criteria have not been met (for example not consulting an independent doctor or appropriate specialist, issues around how voluntary or well-considered the decision was, if unbearable suffering was present, and no prospect of improvement) (Miller & Kim, 2017). In some cases the doctors involved have been found to have not acted with due care by the review committee but have had past similar behaviour. In others they have refused to disclose details (case 2013-91), knowingly pushed the

boundaries of the law (case 2014-02) or despite an advanced directive stating a patient with Alzheimer's wished for euthanasia "upon my request" the doctor put a sedative into her coffee and the woman was restrained when she tried to resist the lethal injection (case 2016-85). The doctor involved reported that she expected similar situations to become more frequent in the future (Miller & Kim, 2017). Despite this, no doctors in the Netherlands have experienced any legal consequences for reporting cases that have not meet the legal requirements (Miller & Kim, 2017).

The current Bill offers no mechanism for investigating or sanctioning doctors who do not comply with the rules meant to ensure public safety. Instead it offers the excuse that any doctor who has not complied with the Bill (for example only one doctor involved, steps not taken to confirm that request was voluntary or that individual was competent, or request from person themselves) can simply claim that they are acting in good faith (section 26).

Consequently, as a group of doctors, we strongly feel that this is too much trust to place in fallible doctors.

Findings from overseas also demonstrate that cases that would have been considered fringe or controversial initially, even by supporters of euthanasia, become more common and acceptable over time. In Belgium between 2002 and 2007, 0.5% of euthanasia requests were for dementia or psychiatric disorders, but from 2008 onwards this has risen to 3% (Dierickx, Deliens, Cohen, & Chambaere, 2017). In the Netherlands there has been a 10-fold increase in the number of euthanasia cases for psychiatric disorders over a 17 year period (Groenewoud et al., 1997), (Regional Euthanasia Review Committees, 2014). Kim et al (2016) reviewed cases in the Netherlands from 2011-2014 and found that more than a quarter of the patients were assisted in suicide by a doctor they met specifically for the purpose of assisting their suicide. Most of these doctors operated out of a mobile euthanasia clinic. Social isolation was mentioned in more than half of the reports. The majority had made previous suicide attempts. When disagreements arose amongst doctors, most of the time euthanasia was carried out before these disagreements were resolved. The Review Committee generally deferred to the judgement of the doctor who carried out the assisted suicide.

Jurisdictions overseas have shown an increase in assisted suicide over time (Centre for Health Statistics, 2016);(Centre for Health Sciences Public Health Division, 2017). In some places the laws have been expanded to include those initially excluded such as Belgium and the Netherlands where the law now applies to children. There is a push to extend euthanasia in the Netherlands to the elderly who are "tired of living" (Florijn, 2018).

The report from the Health Select Committee (2017) last year states, "A year after introducing the legislation, the Canadian Government is consulting on whether to allow additional categories of people, such as mature minors and those with mental illness, to access assisted dying". There are also increasing problems in Canada with health professionals and organisations who want to conscientiously object to being involved in assisted suicide being pressured to become involved (The College of Physicians and Surgeons of Ontario, 2016) (Dubland Ed, 2016).

## Palliative care

‘Palliative care is care for people of all ages with a life-limiting or life-threatening condition, which aims to:

- optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs
- support the individual’s family, whānau and other caregivers where needed, through the illness and after death’ (Ministry of Health, 2017).

New Zealand already has an effective, world-leading model of palliative care. Doctors are equipped to discuss Not For Resuscitation (NFR) orders, Advance Directives (AD) and Enduring Power Of Attorney (EPOA). Hospice services and palliative care teams are able to provide inpatient care for those with symptoms too difficult to manage with community first line medication. Inpatient wards for these patients are available but in short supply (Client, 2018).

Palliative care aims to empower patients by prioritising their requests and desires for treatment at the end of life. Rights to accept or refuse medical intervention are prioritised and these are targeted to the individual patient. The New Zealand Medical Association ((New Zealand Medical Association, 2005; The New Zealand Medical Association, 2016) confirms that patient autonomy and death with dignity can be maintained without the introduction of euthanasia or assisted suicide. Addressing fear, identifying abuse, neglect, depression, and empowering by educating patients must be our country's focus. This individualised approach is safer and more holistic than an ELCB that attempts to cover all diseases, disease stages and individual situations.

The Asia Pacific Hospice and Palliative Care Network released a statement at their 2017 conference expressing their concern around the move to legalise euthanasia and undervalue the dying and undermine efforts to improve end-of-life-care (Asia Pacific Hospice Palliative Care Network, 2017). In their written submission to the Health Select Committee the Australian and New Zealand Society of Palliative Medicine (2015) stated that “Legalising physician-assisted suicide or euthanasia under any conditions would also compromise the effective delivery of Palliative Care.”

Palliative care is part of the New Zealand Health Strategy and the Healthy Ageing Strategy. A review in 2017 has already identified areas that need to be prioritised, in light of a predicted 50% increase in the total number of deaths in New Zealand, as the population ages (Ministry of Health, 2017). We must prioritise funding towards training and service provision to match the growing need for this invaluable service.

## Conclusion

We have outlined why as a group of doctors and medical students we feel this Bill or any legislation which allows for euthanasia or assisted suicide will lead to considerable harm and unnecessary early deaths in New Zealand. Given the gains palliative care have made in managing end of life symptoms, including pain, the “benefit” to be made by introducing assisted dying is very small. The harm to individuals and society by the undermining of



suicide prevention, further devaluing of those with illness or disabilities, and weakening of palliative care will be great. New Zealand abolished the death penalty in 1961 because the potential risks outweigh the benefits and in doing so Parliament recognised the imperfect nature of the justice system. Our medical system is good but it is not infallible, in terms of diagnosis, prognosis, obtaining informed consent, and particularly in detecting coercion or depression. Allowing any doctor to help end the life of their patient, will lead to a less just New Zealand. We do not want the End of Life Choice Bill to become law as no amendments will ever make it safe enough.

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