

**InterChurch Bioethics Council Oral Presentation to the
Justice Select Committee.
June 11, 2018.**

Introduction

- The InterChurch Bioethics Council (ICBC) has existed since 2002, as an ecumenical, cross-cultural body supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand (www.interchurchbioethics.org.nz). ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education. Today we are represented by
- **Rev Dr Graham O'Brien:** Anglican representative and Co-Chair InterChurch Bioethics Council. Also, Ministry Education Coordinator Nelson Anglican Diocese/Bishopdale Theological College (PhD Molecular Biology, Masters in Theology and Ethics).
- **Dr Helen Bichan ONZM:** Presbyterian representative. Fellow in Colleges of both psychiatry and public health medicine, experience in public health medicine (including international) and health administration. Foundation member of the NZ Bioethics Council.
- **Mr Filo Tu:** Director of Missions for the Samoan Synod of the Methodist Church. Administrator for the InterChurch Bioethics Council:
- We appreciate the opportunity to present to the Justice Select Committee our oral submission against the “End of Life Choice” Bill.

Key points from our submission

Graham

- **As in our submission** we believe it is important to clarify terminology. The term “**Assisted Dying**” confuses scenarios where the intention is to relieve suffering through means such as palliative medicine, the withdrawal of life supporting treatments, patient choice of any treatments or withdrawals; with scenarios where the intention is to cause death. The End of Life Choice Bill identifies 4 methods of providing a lethal dose of medication correctly termed “assisted suicide” and “euthanasia” (AS/E). [part 2 clause 15, ingestion or intravenous delivery by the person; or delivery through a tube or injection by a medical practitioner] [As seen in these definitions, the notion of intent is critical in both law and ethics: law distinguishes between murder and manslaughter based on intent of action; In ethics intention defines the rightness of an action. Currently the intentional taking of a life is both illegal and against medical ethics]
- **We propose that the legal changes of this Bill are of a different nature to other pieces of legislation.** The law is there to protect us as a society and provide recourse if our rights are broken, however in this instance there is no recourse once you are dead if the system has failed you. Laws are fallible in preventing bullying, elder abuse or coercion, and we believe there is no aspect of AS/E legislation that can fully protect the patients’ rights. [In the 2017 Health Select Committee process 80% of submitters chose not to change the law on AS/E.]
- **The End of Life Choice Bill is premised on providing people with individual choice at the end of their life,** however choice for a few has to be balanced with responsibility towards the many, especially when the freedom of choice for some impacts on the rights and choices of others – especially the vulnerable such as children, people with disabling or mental health conditions, older people who might question their value, as well as doctors who have always seen their calling as maintaining life.
- If passed, **this Bill will restrict choice by limiting the available options for people.** By requiring referral to the SCENZ group – medical professionals

who approve of AS/E - vulnerable people will not hear about the other options that might satisfy their concerns when faced with terminal illness or chronic health issues. Overseas evidence shows that when terminal patients are presented with palliative options, the majority reject AS/E.

- **Health funding constraints and increasing numbers of elderly, there is a risk that AS/E becomes part of normal medical treatments.** A recent case in Canada illustrates this point, where 42-year-old Roger Foley who has an incurable neurological disease, is now suing Ontario health services, because they will not provide him with the assisted home care team of his choosing to assist life, instead offering among other things, medically assisted dying as part of his care options.¹
- **NZ is rightly concerned about the levels of suicide** where our rates are high compared with other OECD countries and are increasing.²³ However, the point we want to make is that the “precautionary principle” would suggest that extreme caution should be taken if there is any possibility that suicide could be normalised. With this legislation there is no turning back the clock – death is final.
- **Overseas experience shows that “Choice” and “Option”, can become “expectation” over time.** For example:
 - AS/E is becoming the normal means of dying for cancer patients in the Netherlands.⁴
 - The extension of criteria to include; those under 18 years, non-terminal conditions including depression, even a “completed life”.⁵⁶⁷

¹ <https://www.ctvnews.ca/health/the-solution-is-assisted-life-offered-death-terminally-ill-ont-man-files-lawsuit-1.3845190>

² JESS MCALLEN. Suicide toll reaches highest rate since records kept. Last updated 07:28, July 3 2015.

<http://www.stuff.co.nz/national/health/69920289/Suicide-toll-reaches-highest-rate-since-records-kept>

³ AMY MAAS. The story of one woman, a suicide note, and blind justice. Last updated 10:17, May 29 2016.

<http://www.stuff.co.nz/national/health/80450197/the-story-of-one-woman-a-suicide-note-and-blind-justice>

⁴ Boer, T. Rushing toward death? Assisted dying in the Netherlands, March 28 (2016) at

<http://www.christiancentury.org/article/2016-03/rushing-toward-death>

⁵ Simone Mitchell Euthanasia debate reignited by 20yo sexual abuse victim. Monday May 16, 2016.

http://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11639637

⁶ <http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-granted-belgium/7855620>

⁷ <https://www.theguardian.com/world/2016/oct/13/netherlands-may-allow-assisted-dying-for-those-who-feel-life-is-complete>.

- The gradual shift from voluntary to involuntary euthanasia for example in dementia patients. [It is worth noting that in 2007, 32% of euthanasia events in Belgium occurred without request or consent.⁸]
- The increasing number of legal challenges to “restrictive” AS/E laws in Canada to allow people with a wider range of conditions to access AS/E.
- The call in NZ for binding Advanced Care Directives enabling people to nominate AS/E as part of their long term medical treatment.
- To quote Professor Theo Boer, *professor of ethics at the University at Groningen, and for nine years a Member of a Regional Review Committee* in the Netherlands, “the very existence of a euthanasia law turns assisted suicide from a last resort into a normal procedure – don’t make our mistake”.⁹

⁸ <http://www.alexschadenberg.blogspot.ca/2013/09/euthanasia-is-out-of-control-in-belgium.html>

⁹ <http://www.dailymail.co.uk/news/article-2686711/Dont-make-mistake-As-assisted-suicide-bill-goes-Lords-Dutch-regulator-backed-euthanasia-warns-Britain-leads-mass-killing.html#ixzz475CQjW5M>. See: Boer, T. Rushing toward death? Assisted dying in the Netherlands, March 28 (2016) at <http://www.christiancentury.org/article/2016-03/rushing-toward-death>. Also see Theo Boer, I supported our euthanasia law, but I was terribly wrong: Dutch ethicist. <https://www.lifesitenews.com/opinion/i-supported-our-euthanasia-law-but-i-was-terribly-wrong-dutch-ethicist>

Filo:

NZ cultural inclusion:

- In a society that has become more individualistic and less tolerant of those who are less fortunate or vulnerable, **the current discussion is largely a rationalist pakeha conversation** focusing on a “life” or “not life” options that does not consider Maori Tikanga or Pacifica views. As Tess Moeke-Maxwell and colleagues state, “the dying and their whānau are proactive in doing whatever they can to ensure a high quality of life is achieved to enable the individual to live for as long as possible and as comfortably as possible” – “They do not give in easily to death”.¹⁰
- **Many cultures in New Zealand have traditional ways of managing death and dying in family/whanau settings** and see this as sacred time that has a lasting impact on all those who are assisting in the care of a loved one. Euthanasia robs whanau of this sacred time. Our conversations identify that assisted suicide or euthanasia has no equivalent in language or practice in Māori and Pacific people practices and is not something readily discussed. For many Māori the tribal custom of karanga aituā means that talk about death will ‘call it down’,¹¹ limiting discussion on the issue of euthanasia. For Māori and other Pacific people, talk of assisted suicide is as an unnatural conversation to discuss or contemplate.
- **We need to acknowledge that this Bill affects not only the individual but also the whānau, hapu and iwi.** We are answerable to our mokopuna and future generations, so what we decide now impacts on the present, but also the past and the future.

¹⁰ Tess Moeke-Maxwell, *et al.*, “Māori End-Of-Life Journeys”, pp. 382-383. Tess Moeke-Maxwell *et al.*, “End-of-Life Care and Māori Whānau Resilience”. p. 145.

¹¹ Tess Moeke-Maxwell, Linda Waimarie Nikora and Ngahuia Te Awekotuku. “Māori End-Of-Life Journeys”. In *Human Development: family, place, culture* 2nd ed, W Drewery and L Bird Claiborne eds.. North Ryde: McGraw-Hill Education, 2014.pp. 382-383.

Helen:

- **This bill identifies the relief of suffering** as perceived by the person, as the major motivator for law change. However, “suffering” needs further definition since overseas studies have shown there are a variety of reasons why people request AS/E,¹² the majority of which are psychological or social concerns rather than pain related. Subjective suffering can be understood as:
 1. Physical pain which can be managed through medication
 2. Physical/psychological distress –for example when a patient can't breathe, which is also medically treatable.
 3. Existential suffering, where people feel they have no place, no value, no hope, no autonomy, no dignity or are a burden. It is this form of suffering that surveys identify as the major reason for people wanting to use assisted suicide/euthanasia.
- **Depression is a central** issue in all these situations and in my experience, it is not easy to assess the degree to which depression is distorting their view on life. What people have appreciated is having others support them through the period of depression, and they are glad that they have not ended their lives through suicide.
- **The Trojan Horse of “Terminal” and “Irremediable”**. In using the terms “Terminal” and “Irremediable” together, this Bill is some of the most liberal AS/E legislation in the world based on the Oregon model. There is a “trojan horse” in this legislation – where “terminal” is defined as: *should the disease be allowed to take its course, absent of further treatments, is the patient is likely to die within six months.*¹³

¹²<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> (2014). Also <http://www.theguardian.com/commentisfree/2015/sep/05/assisted-dying-suicide-bill-justin-welby-archbishop-canterbury>

¹³ Fabian Stahle., **Oregon Health Authority Reveals Hidden Problems with the Oregon Assisted Suicide Model**, January, 2018. <https://www.masscitizensforlife.org/oregon-health-authority-reveals-hidden-problems-with-the-oregon-assisted-suicide-model>

- As a result, by stopping medication a range of conditions that can be treated move a patient from chronic to terminal and thus eligible for AS/E.
 - Risks interpretive creep as to what incurable means
 - Makes legislation vulnerable to financial pressure – for example if an insurance company or Pharmac will not cover expensive but beneficial treatment (such as Herceptin) a person can move from being chronic to terminal and hence eligible for AS/E.
 - Fails to acknowledge that any time frame cannot be provided with medical certainty. [As seen in Oregon and other places there are people who have been given permission for PAS/E based on being terminal who live longer than 6 months.^{14]}
- **The End of Life Choice Bill tries to identify safeguards** to reduce fears about AS/E and provide safe practice. However, we note that none of the SCENZ group of doctors will have had a long-term relationship with the patient seeking AS/E necessary to inform assessment of coercion or depression, nor do they need to be specialists in the medical area for which the patient is deemed terminal or irremediable. Proper ‘safeguards’ would require a level of relationship with the patient that can assess the degree to which each of these elements of subjective suffering is operating, and is able to prescribe/provide/offer the appropriate remedies/responses to alleviate that suffering. None of the legislation (from elsewhere) or in this bill adequately addresses the provision of that degree of assessment or capacity to provide alternative ways to address suffering.
[Oregon: the two-person safeguard is inadequate to prevent under reporting; significant decline in people referred for psychiatric assessment over the first 5 years.¹⁵ Quebec: a failure of safeguards after just 2 years of legalised euthanasia/assisted suicide.^{16]}

¹⁴ www.vaeh.org/doctors-often-misdiagnose-the-terminally-ill/
(case studies <https://www.theguardian.com/lifeandstyle/2015/jun/02/doctors-predict-patient-die-prognosis-wrong>)

¹⁵ Data retrieved from Annual Death with Dignity Reports, Year 1 – Year 17.
<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>

¹⁶ Aubert Martin, *Two years of euthanasia in Quebec: the facts*, 2017.
<https://www.mercatornet.com/careful/view/two-years-of-euthanasia-in-quebec-the-facts/20831>

Graham: Summing up

- In summing up, as a society we have a shared multicultural value where care and compassion is about doing good without doing harm, and identifies the intrinsic value and dignity of human life regardless of abilities or situation. In this context the intentional causing of death is a harm, whereas compassion denotes walking alongside the other so the other does not die alone, and where the relief of suffering can include not prolonging death. Furthermore, there is also the preferential care for the vulnerable within society, so that our compassion and care extends to create conditions where all can flourish.
- There already exists the means to provide hope and support for those who face terminal and chronic illness through palliative care and the hospice movement, so that people can “live and die well”, but there needs to be increased public funding to ensure access to palliative care and mental health services is available equally to all New Zealanders.
- Upholding the choice of a few will effectively take away the choice for many. This will change New Zealand society now and for future generations, by sending a “better off dead” message at a time of increasing health costs and a growing elderly population. Overseas evidence shows that narrow criteria for assisted suicide/euthanasia cannot be contained by laws.

Invite questions for clarification?

Other issues:

- A referendum will only secure the lowest common denominator leading to public consensus as there is no guarantee that the public will be fully informed of all the issues surrounding AS/E.
- We would also like to remind this committee that in the recent Health Select Committee process completed in 2017, 80% of submitters were against a law change, and it will be interesting to see how this compares with the 34,000 submissions you have received.