12/2/2018

InterChurch Bioethics Council Submission to the Justice Select Committee:

On the End of Life Choice Bill:

The InterChurch Bioethics Council (ICBC) is an ecumenical, cross-cultural body supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand (www.interchurchbioethics.org.nz). Its role is to increase the knowledge and understanding of church members and the wider community, of the spiritual, ethical and cultural issues connected to biotechnology and related issues, and enable and encourage citizens to take action on their own behalf on these issues. ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education.

In writing this submission against the proposed End of Life Choice Bill introduced to the House by David Seymour, the ICBC recognises that we do not represent all Anglicans, Methodists and Presbyterians, but that as a designated committee, we are providing our “expert” opinion following our own discussions, research and reading over the past 3 years and some limited wider consultation. Our submission will follow 8 areas that we would like to bring to the Justice Select Committee’s attention. We would like to appear before the committee to talk to our submission should the opportunity arise.

We would also like to remind the Justice Select Committee that over the past 2 years the Health Select Committee has undertaken a comprehensive process to determine public attitudes towards legislation permitting medically-assisted dying following the petition of “Maryan Street and 8,974 others” that sought to determine the public opinion on assisted suicide. Their report was presented to Parliament in August 2017, received 21,000 unique submissions and heard from 944 oral submission. The key finding was that “80% of submitters were opposed to a change in legislation that would allow assisted dying or euthanasia”.¹

Before addressing these issues, we believe it is important to clarify terminology in this current debate. The term “assisted dying” we believe is inadequate as this confuses scenarios where the intention of the medical practitioner is actively to cause death with those where the intention is to relieve suffering. Where the intention is to cause death, this may be either through prescription of drugs which the patient takes (assisted suicide) or where the doctor administers a lethal dose of drugs (euthanasia). Where the intention of the medical practitioner is to relieve suffering, this may include withholding or withdrawal of treatment and administration of appropriate treatment through which “nature” is allowed to take its course and death is allowed to occur. This is not defined as euthanasia and is currently legal. For the purposes of our submission the term “euthanasia/assisted suicide, EAS” will be used.

We acknowledge that there is a small but significant population for whom the conditions of their death are horrendous and unacceptable. We would advocate for funding for research and access to resources that helps to alleviate this suffering. We acknowledge also that there will sometimes be family and even medical assistants who will quietly hasten death in these circumstances. However tragic these situations are we do not think the appropriate response is to give everyone the “right to die” or the “right to be assisted in dying”. The cost is too great – for the other vulnerable populations mentioned below, for doctors who have always seen their calling as maintaining life, not taking life, and for all older people who might begin to wonder if they have outstayed their welcome on earth. The enshrining of this right in law would have widespread and deepening repercussions for the way we understand life, and the callings and duties of life.

Indeed, much of the current debate centres on a patient’s right to choose when and how to die in the face of a terminal illness. But the right to self-determination does not take place in a vacuum – no-one is completely free, we are embedded in family and society involving critical relationships, including a debt to future generations. Our personal freedom is always held alongside the rights of others, and from a Christian perspective, our personal rights must be considered alongside our responsibilities to others that reflect our love of God as indicated in the command to love both God and neighbour (Mark 12:28-32). In the face of suffering, the Christian and humane response is to maximise care/compassion for those in most need. Killing, however, is not a part of the arsenal of care/compassion for the dying.

**Reasons for opposing the End of Life Choice Bill.**

In acknowledging that euthanasia and assisted suicide have significant moral and ethical objections, there are also significant discrepancies in this legislation that we suggest make the End of Life Choice Bill untenable.

1. *We believe the scope of the Bill is too large.*
   The purpose of the Bill: “gives people with a terminal illness or a grievous and irremediable medical condition the option of requesting assisted dying” (part 1 clause 4).
   - Provides “assisted dying” for NZ citizens 18+. This criterion is too arbitrary and open to legal challenge. As seen overseas, over time minors (those under 18) have also been granted permission for assisted suicide.\(^2\) If death is a good/right for some it ultimately becomes seen as a good/right for all.
   - *with a terminal illness likely to end his or her life within 6 months* - Medically speaking this is difficult to determine, and overseas evidence shows some people being given permission for assisted suicide living longer than 6 months. In Oregon 2014, the range of days between first request and death was 15-439 days.\(^3\) Even Lecretia Seales was initially given only weeks to live and survived 3½

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Furthermore, significant discrepancies between clinical diagnosis before death and post-mortem findings suggests that misdiagnosis in up to 39% of cases is possible. The problem here is that euthanasia/assisted suicide is a non-reversible ‘solution’, and the 6-month criterion (or any time frame) cannot be provided with absolute certainty.

- **or grievous and irremediable condition.** The Bill is not just about persons with a terminal illness but embraces anyone with a grievous and irremediable condition. This criterion includes those with: depression and mental illness; physical disability; long term illness; or the increasing frailty of old age (as seen in the Netherlands).

- **and in advanced state of irreversible decline and experiences unbearable suffering that cannot be relieved in a manner the person considers tolerable.** In this context, ‘Unbearable suffering’ is self-defined and is effectively euthanasia/assisted suicide on demand. This criterion would allow for euthanasia/assisted suicide even if the patient rejected effective treatment on the basis they deem it intolerable.

- Although this bill is framed to provide an **Option** for euthanasia/assisted suicide, we believe “option” is a loaded term, and one that is not simply a clear rational perspective. Our society projects certain values, including what we value in people - productivity, intelligence, physique – so that people can be made to feel a burden on relatives or society, or feel devalued by not fitting the social stereotype. For example, in the Netherlands there are moves to extend euthanasia/assisted suicide laws with a “completed life” bill. The danger in the suggested law change provided by the End of Life Choice Bill, is that we may be providing a threshold beyond which a person’s life is seen as having little or no value instead of addressing how society hold and value people, especially the vulnerable.

2. **The Bill does not properly characterise the current NZ situation (pg 2-3)**

- **It prioritises the Lecretia Seales case.** Although Justice Collins remarked that “The complex legal, philosophical, moral and clinical issues raised by Ms Seales’ proceedings can only be addressed by Parliament …” all three petitions to the court based on the human right to die/choose death were rejected on legal
grounds. Ms Seales herself stated that she may not have used assisted suicide even if it was legal or the Judge had found in her favour.

- As evidence for a required law change, it is argued in the background to this bill, that the current law has treated with leniency those who have assisted terminally ill family members to end their life (Background pg 2). This however is evidence that the current law works, not that the law needs changing.

- New Zealand First has asked for a binding public referendum on this issue. However, even if a referendum identified a majority position for euthanasia/assisted suicide, this would not mean that the public were suitably informed about the difference in terminology or the significant issues involved.

- As previously mentioned, the claim that there is strong public support for a law change (background pg 2) is incorrect given the Health Select Committee 2017 finding was that “80% of submitters were opposed to a change in legislation that would allow assisted dying or euthanasia”. This figure contradicts previous surveys indicating support for a change (2012, 2969 people 62.9% support; 2015, 2800 people 66% support). These previous survey results reflect the level of public confusion about what the terms euthanasia/assisted dying mean. Significantly, 63.6% of all submissions to the Health Select Committee, equating to 82.5% of all submissions opposed to a law change, used no religious argument in their opposition to change. The Health Select Committee process was an open process, with no leading questions but simply asked for public opinion. The scope of this report, the number of respondents, and the significance of the findings, means that the Health Select Committee report should have significant weight in the Justice Select Committee deliberations.

- Of great significance, the current discussion is largely a rationalist Pakeha conversation. Many cultures in New Zealand other than the majority Pakeha culture have traditional ways of managing death and dying in family/whanau settings. Our conversations and research identify that euthanasia/assisted suicide has no equivalent in language or practice in Māori and Pacific people practices. Therefore, the current debate risks imposing on New Zealand culture a largely individualistic worldview without adequately considering other perspectives. Within Māori and Polynesian communities, euthanasia/assisted suicide is not part of everyday reality or something readily discussed. For many Māori the tribal custom of karanga aituā means that talk about death will ‘call it

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8 https://www.stuff.co.nz/national/69112451/lecretia-seales-did-not-have-right-to-die-high-court-rules
11 ibid, 14-15.
down’, which could further limit discussing the issue of euthanasia/assisted suicide. However, the Bill now brings this issue into the open for us all, and the result of this Bill may affect any one of our whānau. That is why there is a call for Māori and Polynesian families to discuss this Bill, and its impacts on whānau, hapu and iwi. 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”.

3. **Terminology within the Bill.**
   - As defined in the Bill (Part 1:3) “assisted dying” means the administration by a medical practitioner of a lethal dose of medication to a person to relieve his or her suffering by hastening death.
   - The term “assisted dying” as defined above is inadequate as this confuses scenarios where the intention of the medical practitioner is actively to cause death with those where the intention is to relieve suffering. The Bill identifies 4 methods: ingestion or intravenous delivery by the person; or delivery through a tube or injection by a medical practitioner (part 2 clause 15). Where the intention is to cause death as outlined in the Bill this may be either through prescription of drugs which the patient takes and is correctly termed “assisted suicide”, or where the medical practitioner administers a lethal dose of drugs, is correctly termed “euthanasia”.
   - Where the intention of the medical practitioner is to relieve suffering, this may include the withholding or withdrawal of treatment and administration of appropriate treatment through which “nature” is allowed to take its course and death is allowed to occur. This is not defined as euthanasia/assisted suicide and is currently legal.

4. **The Bill claims that relief of suffering and compassion is the motivation for this legislation (Purpose pg 1 and Part 1 clause 3).**
   - We acknowledge there are circumstances where individuals face unbearable suffering, however compassion is a societal value, not only for the individual. There are many arguments against assisted suicide that do not have a religious foundation, and there are some that have their foundation in religious values. One such shared value is our understanding of love and compassion. Care and

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compassion contained within the view of unconditional love is about doing good without doing harm and identifies the intrinsic value and dignity to human life regardless of abilities or situation. Compassion is exercised in relationship with others so the ‘suffering’ of an individual does not happen in isolation. Nor does its treatment, or the choices an individual may wish to make.

- Respect for human dignity applies to everyone throughout life, and to humanity as a whole. In this context, the causing of death is seen as a harm, whereas compassion denotes walking alongside the other so as to not die alone, and where the relief of suffering can include not prolonging the process of dying. 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. For those experiencing suffering, this includes the greater availability of palliative care; research into palliative medicine; and by listening to those who speak for the ‘disabled’ so that there is “nothing about us without us”.16

- This bill identifies the relief of suffering as the major motivator for law change. However, “suffering” is too broad a term and needs further definition. Suffering can be understood as: 1. Pain - physical suffering which can be managed through medication, including terminal sedation near the end of life; 2. Distress – physical/psychological suffering in situations for example when a patient can’t breathe. Again, this can be adequately managed through medication or medical interventions. 3. Suffering – existential, where people feel they have no place, no value, no hope, no autonomy or are a burden. It is this form of suffering that surveys identify as the major reason for people wanting to use euthanasia/assisted suicide.17

- **New Zealand is rightly concerned about the levels of suicide especially** among young people, and men aged between 20 and 65 where the New Zealand rates are high compared with other OECD countries.18 Suicide rates have reached their highest since records have been kept, and have risen three years in a row.19 “From June 2014 to May 2015, 569 people are officially listed as having died by suicide or suspected suicide – the highest number ever recorded in New Zealand.” Furthermore, it is recognised that the rates for suicide are under-

Do we want suicide (whether physician-assisted or not) normalised as an option when a person is in distress? Do we want to be a society that when someone takes their own life, our response is to say, “well that was their choice”? Furthermore, overseas studies show that allowing euthanasia/assisted suicide does increase the rates of unassisted suicide - in the Netherlands unassisted suicide rates have increased 35% over the 6 years up to 2015.

5. **Safeguards for the Bill.**

- Part 2 clause 6 talks about conscientious objection and safeguards. Although a medical practitioner may refuse a request for euthanasia/assisted suicide, the Bill **compels** the medical practitioner to refer the patient to the SCENZ group – an appointed body that does not have an objection to assisted suicide/euthanasia [part 2, clause 7 (2), part 3 clause 19]. This overrides the professional autonomy of the health practitioner and forces him/her into colluding in the process.

- This **undermines the safety processes** in that the SCENZ group will refer the patient to a doctor that has no long-term relationship with the patient and is in no position to assess coercion or other underlying issues. This is of concern in that depression, the commonest factor in requesting assisted suicide or euthanasia, may be difficult to detect even when the doctor knows the patient well.

- In New Zealand the population at risk includes **elderly people and people with disabilities**. There is already concern about the level of elder abuse, and older people have little or no power to resist subtle pressures that they should end their lives, and many worry that they may be a burden to other people. As indicated by the US states of Oregon and Washington, 40-60% of those who used legally prescribed lethal drugs to end their lives cited concerns that they would be a burden on their families as a factor in their decision to end their lives.

- The Two-person safeguard (part 2, clause 10 and 11) has been shown to be inadequate in Oregon over time, with one or both medical practitioners having no long-term relationship with the patient and evidence of “doctor-shopping”. Again, referrals to specialists provided by the SCENZ group does bias the process towards medical practitioners who are in favour of assisted-suicide/euthanasia

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23 http://www.theguardian.com/commentisfree/2015/sep/05/assisted-dying-suicide-bill-justin-welby-archbishop-canterbury

and could constitute “doctor-shopping”. In the Netherlands mobile squads have been established which provide access to such medical practitioners who may never have met the patient before. Furthermore, in Oregon, there was a significant decline in people referred for psychiatric assessment over the first 5 years of legalising euthanasia/assisted suicide. Evidence from Quebec also shows a failure of safeguards after just 2 years of legalised euthanasia/assisted suicide.

- International evidence shows, wherever legislation is introduced to allow assisted-suicide and euthanasia, there is an incremental extension of criteria allowing euthanasia to more groups over time; including lowering the age limit – for example Belgium now allows euthanasia for minors of all ages, the inclusion of other conditions including non-terminal conditions such as depression and other psychiatric conditions. Recent examples are a 20-year-old sexual abuse victim in the Netherlands, and a 17-year-old in Belgium. It has even been argued that euthanasia for prison detainees is permissible under Belgium law based on unbearable psychological suffering. Also there is a gradual shift from voluntary to involuntary euthanasia, for example dementia patients. It is worth noting that in 2007, 32% of euthanasia events in Belgium occurred without request or consent. You might say - surely good legislation can prevent this expansion. The reality is “No”! Legislation cannot stop this. Why – because if death is now seen to be a right and to be a benefit worth having - then it is a right and a benefit for all, not just for some in society. Therefore, as seen overseas, any restriction on assisted suicide is open to legal challenge and over time the numbers increase.

6. Reporting of Assisted Suicide/Euthanasia Practice (Part 2 clause 17).
- The Bill has an inherent contradiction in that it promotes assisted suicide and euthanasia as acceptable practice and a register kept (Part 3 clause 21), yet at the same time proposes an amendment to the Births, Deaths, and Marriages regulations (part 4, clause 28) so that any death through “assisted dying” is recorded as if no assistance has occurred [Part 4 clause 28 (2xiia)]. This clause would prevent an accurate assessment of assisted suicide/euthanasia events and runs the risk of “hiding” this activity.

25 Data retrieved from Annual Death with Dignity Reports, Year 1 – Year 17. [https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx](https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx)
31 The Netherlands saw a 190% increase in euthanasia from 2006-2015. In the 10 years to 2013, the number of euthanasia cases in Belgium has risen from about 1,000 to 8,752, according to official records. [http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-granted-belgium/7855620](http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-granted-belgium/7855620)
• The best legislation in the world cannot restrict this practice. To quote Professor Theo Boer, Professor of Ethics at the University at Groningen, and for nine years a Member of a Regional Euthanasia 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”.  

7. Effects on Medical Professionals carrying out euthanasia/assisted suicide.
• A central aspect of the Bill is to provide immunity from criminal prosecution or disciplinary action for Medical Practitioners (doctors or pharmacists) involved in hastening death (unless provable that they acted in “bad faith”).

• Throughout the Bill there is the assumption that euthanasia/assisted suicide will be administered by a medical professional (doctor). However, euthanasia/assisted suicide is not a medical issue, as seen in the fact that the Justice Select Committee is hearing submissions. Furthermore, it was noted in the Health Select Committee report, that for the NZ Medical Association and the World Medical Association, “assisted dying is incompatible with medical ethics”. The concluding statement of the Gillett report for the New Zealand Medical Association, summarises the caution that is needed in bringing about a legalisation of euthanasia/assisted suicide:

The debate about the legalisation of euthanasia is complex and the medical profession should remain cautious about any change in law that would interfere with principles that have guided medicine and general healthcare to good effect for most people throughout the centuries. The WMA’s resolutions on euthanasia and physician-assisted suicide reflect this tradition; its clear opposition—to what would mark a departure and move towards a different ethos in an area where medical practice needs sound guidance and standards— is worthy of support because of the value it puts on human life. This stance does not prevent a physician from respecting the desire of a patient (or the patient’s guardian) to allow the natural process of death to follow its course in the terminal phase of sickness (where that may involve the withdrawal of life-prolonging treatment or treatment limitation because the treatment is properly deemed futile).

• EAS effects on families and people involved. In countries where euthanasia/assisted suicide is legal, there is a web of people involved in each individual case – doctors, nurses, pharmacists, psychiatrists/psychologists, and often decisions of family members. We note that the proposed bill does not name nurses amongst “medical practitioners” for whom the bill provides legal protection. Also, overseas studies identify that those involved can and do suffer vicarious trauma from being involved in euthanasia/assisted suicide practices, as this quote from a study undertaken in Finland suggests:35

> We can’t go that far and have this or that kind of criteria to let you kill another person. Nobody can cope with it mentally for very long. You have to think about the personnel. Everybody’s talking about the patient but nobody says anything about the one who has to do it and who also has feelings.

• There is an assumption that doctors will be the ones to enact any law change. But doctors see their calling as maintaining life, not taking life. Any law change would have widespread and deepening repercussions for the way we understand life, and the callings and duties of the medical profession. These are fundamental roles within society charged with caring, healing, curing wherever possible. At our most vulnerable times – when we face death - physicians (and others) have a considerable role in the care of people through a relationship in which the real questions are addressed with patient and family, unnecessary treatment is stopped or not started, relief is provided for physical, mental and spiritual distress, and the person who is dying is supported to the end. The intention is a dignified, pain-free, natural death. Euthanasia/assisted suicide and would cut across this trusted relationship. There may also be pressures for doctor to conform to the wishes of families or patients. As Margaret Somerville suggests;36

> We also need to consider how the legalisation of euthanasia could affect the profession of medicine and its practitioners. Euthanasia takes both beyond their fundamental roles of caring, healing and curing whenever possible. It involves them, no matter how compassionate their motives, in the infliction of death on those for whom they provide care and treatment. Euthanasia thus places the soul of medicine itself on trial. We thus need to be concerned about the impact that legalisation would have on the institution of medicine - not only in the


interests of protecting it for its own sake, but also because of the harm to society that damage to the profession would cause.

8. Addressing issues preceding a request for EAS.

Rather than promoting euthanasia or assisted suicide as a ‘compassionate’ solution to unbearable suffering, critical factors that precede the requests could make a great difference to many more people and have a positive effect on society. These include:

- Palliative care services – improve access so all in this situation can receive care, as it has been shown that recipients of these services find hope and relief of suffering;
- Mental health services – improve access to services, provide training for recognition and treatment of depression which is frequently a significant factor in a patient’s suffering and request for EAS;
- Continue/enhance programmes to prevent suicide among all age groups and reduce its normalisation;
- Address social isolation particularly among elderly people – this has been shown to be a cause of depression, and of the sense of being a burden;
- Continue measures to address and prevent elder abuse
- Providing funding and adequate resources so that society can support those in need at their most vulnerable times.