18/1/2016

InterChurch Bioethics Council (ICBC) Submission to the Health Select Committee:

On the petition of Maryan Street and 8,974 others requesting that:

> "The House of Representatives investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable".

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** introducing legislation to allow "physician-assisted dying", 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. We also note that the Health Select Committee is considering the social, legal, medical, cultural, financial, ethical, and philosophical implications, but have negated to include spiritual considerations which are also part of current legislation guidelines (The HSNO Act, section 68 amended to include cultural, ethical and spiritual criteria). Our submission will follow the 4 areas that the Committee is investigating, and **we would like to appear** before the committee to talk to our submission should the opportunity arise.

Before addressing these issues, we believe it is important to clarify terminology in this current debate. The term "physician-assisted dying" we believe is inadequate as this confuses scenarios where the intention of the physician 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 (physician-assisted suicide) or where the doctor administers a lethal dose of drugs ("active euthanasia"). Where the intention of the physician 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 "physician-assisted suicide" will be used.

1. *Factors that contribute to the desire to end one's life.*

Whatever your outlook on life, most people would agree that two scenarios we greatly fear are those of suffering a painful drawn-out death, including suffering debilitating loss of function or dignity, or watching someone we love suffering such a death. This is, in part, what drives the current debate on euthanasia and the growing moves to decriminalise/legalise physician-assisted suicide.

And 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 that helps to alleviate this suffering. We acknowledge also that there will always 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" to order. 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 have to 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. However killing is not a part of the arsenal of care/compassion for the dying.

Alongside the physical suffering there is also psychological suffering, including depression, which needs to be adequately addressed before allowing any move towards physician-assisted suicide.

2. *The effectiveness of services and support available to those who desire to end their own lives.*

For those with terminal illness effective care is now possible through palliative care which includes modern methods for the management of pain and distress through people trained to help the terminally ill die well and with dignity. Currently palliative care services are significantly underfunded, with most hospices engaging in public fundraising to offer this service, rather than being fully publically funded as part of state provided medical care.

A change in the law to permit physician-assisted suicide would cross a fundamental legal and ethical boundary, since the respect for the lives of others goes to the heart of both our criminal and human rights laws and ought not to be abandoned. While it is not a crime for someone to take his or her own life, as a society we recognise that it is a tragedy and we, rightly, do all that we can to prevent suicide. Any move towards physician-assisted suicide requires us to turn this stance on its head, not merely legitimising suicide, but actively supporting it and sanctioning doctors to participate with individuals taking active steps to end their lives.

Any change to our current laws would also place those who are vulnerable in our society at increasing risk. 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.[1] Once physician-assisted suicide is allowed, there can be no protection against such perceived pressures. Slippery slope arguments are not always valid, but one has only to note the increase in Caesarean births in most Western countries to realize that what was once done in emergencies is now often arranged for convenience. In New Zealand the population at risk includes the elderly people and people with disabilities. There is already concern about the level of elder abuse,[2] 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. Furthermore, those with a variety of disabling conditions experience assumptions about the 'worth' of their lives.

Proponents of law change are confident that subtle pressures and bullying can be detected. Schools, however, have found it notoriously difficult to stamp out bullying. Why would it be a less difficult task at the end of life? If such a law change was to be approved, there would be a need for trained specialists outside of health professionals to assist with any case assessment in order to determine if perceived pressure was a component is a person's decision to opt for physician-assisted suicide.

3. *The attitudes of New Zealanders towards the ending of one's life and the current legal situation.*

Suggested public opinion is playing a significant role in the current debate, however we risk poor legislation if such a decision was left up to public opinion alone, so that the determinant of public policy becomes the lowest common denominator capable of securing public consensus. We need to remember that ultimately euthanasia is a medical issue and as the Palliative Care Council of NZ note, "both euthanasia and assisted suicide are against the current ethical positions of the medical and nursing professions in New Zealand".

Intent is a very important ethical/legal criteria in the current debate on "physician-assisted suicide". There is a significant difference between actively/assisting in killing another person and withdrawing (or with-holding) treatment so that the person dies as a result of their illness. In both situations the intent of the action is critical. In forms of euthanasia, the intent is to relieve suffering by ending life. By contrast, when treatment is futile and is stopped or withheld, palliative care given by skilled professionals who

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

[2] Ministry of Health Guidelines, *Elder Abuse and Neglect*. See www.health.govt.nz.

address the pain and suffering caused by terminal illness provides the best means to respond compassionately to terminal illness and suffering. The intention here is to address the many needs of the suffering person and their family, and to enable a dignified pain-free death.

Furthermore, the importance of intent along with our responsibility to others also resonates with traditional Maori customary practices where physician-assisted suicide or euthanasia have no equivalent in language or practice. Therefore the current debate risks imposing on other cultures a largely "secular western worldview" without adequately considering other cultural viewpoints. For many Māori the tribal custom of karanga aituā means that talk about death will call it down,[3] which could limit engagement with the issue of euthanasia. Maori also are a vulnerable group when it comes to end-of-life care, as there is a strong emphasis on the whānau to provide care with the resulting financial costs, and a low level of palliative care health literacy.[4] As Tess Moeke-Maxwell *et al* 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".[5]

Another ethical consideration is that health care professionals are trained and trusted to promote health and wellbeing and provide appropriate treatment for the living and dying - they are trusted *not* to cause death. There may also be pressures for doctor to conform to the wishes of families or patients. As Margaret Somerville suggests,

> 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. [6]

4. *International experiences.*

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[3] 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.

[4] Tess Moeke-Maxwell, Linda Waimarie Nikora, Ngahuia Te Awekotuku, "End-of –Life Care and Māori Whānau Resilience". *Mai Journal*, Vol. 3, Issue 2 2014, pp. 140-152. Merryn Gott, Ruth Allen, Tess Moeke-Maxwell, Calre Gardiner and Jackie Robinson, "'No matter what the cost': A qualitative study of the financial costs faced by family and whanau caregivers within a palliative care context". *Palliative Medicine* 2015, pp 1-11. DOI 10.1177/0269216315569337.

[5] 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.

[6] Margaret Somerville, "What would we lose by legalising euthanasia?" ABC Religion and Ethics, May 2013. http://www.abc.net.au/religion/articles/2013/05/24/3766685.htm.

Beyond the desire to relieve individual suffering there are societal pressures which lead us to reflect on the reasons for this debate at this time. We recognise the escalating costs of health care (particularly in the last year of life). This then raises the issue of justice where the Christian response is to ensure that people who are weak and vulnerable receive compassionate care. As international experience has shown, incremental extension of euthanasia laws to new categories is inevitable, and voluntary euthanasia quickly becomes non-voluntary (as in the Netherlands).[7] The rights of vulnerable individuals are ignored when decisions are made without their input or consent, based on their perceived lack of value to, or burden on, society.

A recent Daily Mail article provides figures to support how the extension of euthanasia is being used in the Netherlands:[8]

- In 2013, a total of 42 people with ‘severe psychiatric problems’ were killed by lethal injection compared to 14 in 2012 and 13 in 2011.
- The latest official figures also revealed a 15 per cent surge in the number of euthanasia deaths from 4,188 cases in 2012 to 4,829 cases last year.
- The incremental rise is consistent with a 13 per cent increase in 2012, an 18 per cent rise in 2011, 19 per cent in 2010 and 13 per cent in 2009.
- Overall, deaths by euthanasia, which officially account for three per cent of all deaths in the Netherlands, have increased by 151 per cent in just seven years.
- Most cases - some 3,600 people – involved cancer sufferers but there were also 97 people who died at the hands of their doctors because they were suffering from dementia, the figures show.

Furthermore, the report by the Netherlands Regional Euthanasia Review Committees shows a 10% increase in euthanasia in 2014 (5306 cases) compared with 2013.[9]

A 2012 article in *Lancet*, also shows increased usage of euthanasian the Netherlands 2.8% of all deaths in 2010 compared with 1.7% of all deaths in 2005 (but comparable with 1995 and 2001). Significantly, in 2010 77% of all cases of euthanasia or physician-assisted suicide were reported to a review committee (down from 80% in 2005). Ending of life without explicit patient request occurred less in 2010 (0.2%) compared with 2005 (0.4%) and 2001 (0.7%).[10]

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[7] The Netherlands is the classic example. See Scott B Rae and Paul M Cox, *Bioethics: A Christian approach in a pluralistic age* (Grand Rapids: William B Eerdmans Publishing Company, 1999), pp. 248-52 (a summary of research into euthansia in the Netherlands). M Whipp, *Euthanasia - a Good Death?* , vol. 117, Grove Ethics Series (Cambridge: Grove Books Limited, 2000), pp 17-18. Professor Margaret Somerville as outlined in Helen Bichan, "The Euthanasia Debate: Why now? ,"(2010), http://www.interchurchbioethics.org.nz/publications/.

[8] Simon Caldwell, “Number of mentally ill patients killed by euthanasia in Holland trebles in a year as doctors warn assisted suicide is ‘out of control’. Mail Online, 2016 (First Published October 2014). http://www.dailymail.co.uk/news/article-2779624/Number-mentally-ill-patients-killed-euthanasia-Holland-trebles-year-doctors-warn-assisted-suicide-control.html.

[9] Regional Euthanasia Review Committee, 2014. https://www.euthanasiecommissie.nl/overdetoetsingscommissies/jaarverslag/

[10] Bregje D Onwuteaka-Philipsen, *et al* (2012). “Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* vol. 380: 908-915.

> Philosophically, it is understandable how incremental extension of physician-assisted suicide laws occurs, since by allowing this practice death is now viewed as a “benefit” for the relief of suffering. As a “benefit” it would then be unreasonable to withhold such a practice from others who ask for it and potentially those who cannot.
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> It is also worth noting that in the UK, proposed law changes to allow physician-assisted suicide have been opposed by the British Medical Association, the Royal College of General Practitioners, the Royal College of Physicians, the Association of Palliative Care Physicians, and the British Geriatrics Society.

Conclusion

The ICBC would not support legislation for decriminalising or legalising physician-assisted suicide, especially since current law and palliative care already protects the rights of the vulnerable and allow death with dignity.

Instead, we advocate recognising that death is a natural part of life, and that many cultures have traditions for managing the process of dying which should be respected and from which we can learn.

We recommend that skilled palliative care is made freely available (and publicly funded) to all of those who suffer to enable them to die “well”.

In addition, we commend current efforts to address the needs of vulnerable groups, to prevent elder abuse, and to include people with disabling conditions in making decisions about their own treatment and care. We note that support for carers, including adequate remuneration, needs to be strengthened

However, should there be a change in legislation, we recommend the following requirements be included:

1. Compulsory Doctor-Family/Whanau conferences
2. Appointment of a patient advocate who is not a health professional but trained to identify if coercion is occurring.
3. Appointment of 2 independent physicians (not affiliated to pro-euthanasia groups) to consider each case before physician-assisted suicide is approved.
4. Maintenance of robust statistical records (including ethnic information) to accurately monitor practice.