



End-of-Life Choice

Society of New Zealand Inc

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Member of the World Federation of Right to Die Societies

EDITORIAL - PHONY WAR HEADS INTO LAST BATTLE

We are in what David Seymour calls the “phony war” as Parliament’s Justice Committee ploughs through 37,000 submissions on his End of Life Choice Bill and most MPs focus on other things, knowing they do not have to vote on it for at least six more months.

If you look at the submissions as they are posted on Parliament’s website, it has reluctantly to be said it appears to be a war that at this stage we are not winning.

For as we know, our opponents have divine motivation to fight enlightened legislation that would give the terminally sick the option of relief from their suffering. Encouraged by a barrage of lies and misinformation fed them weekly from the pulpit they are flooding the committee with a litany of ignorant claims about the measure. It does not matter that they are often illiterate – and rarely show any sign that the writers have actually read the bill – they believe the committee can be persuaded that it is a numbers game.

“They will say anything and stop at nothing to create fear, uncertainty and doubt (FUD) over the bill,” Seymour said in a message for this Newsletter. And he warned that the weight of the opposition’s campaign will test the resolve of MPs who may decide it is all just too difficult.

“That’s why it is essential that EoLC members maintain a counterweight to the intense lobbying that is going on from the FUD campaign,” Seymour said.

Noting that every reliable and scientific opinion poll on the issue shows an overwhelming majority of voters want medically-assisted dying to be legalised, he said: “MPs need to be reminded that for every shrill anti, there are five people who think it is time for change and choice.

“They must be reminded that for every speculative (and wrong) theory about what happens when Assisted Dying is legalised, there is a group of real people committing amateur violent suicide, suffering intolerably, or being informally euthanised under the very hypocritical, and not at all Hippocratic, ‘double effect’.”

Although the bill’s first reading won a healthy 76-44 vote in favour, Seymour said retaining a majority in the next two ballots would be tough, He conceded that he may have to compromise on the conditions of the bill to get it passed.

Regrettably, the conduct of the Justice Committee’s inquiry has done little to instil confidence in a better outcome than the last Parliamentary inquiry by the Health Committee. (That, you recall, was chaired by Simon O’Connor, who proudly told a Catholic newspaper that he would not forget the 10 years he trained to be a priest, and the committee’s report proved him true to his word.)

The current Justice committee ousted three members who voted in favour of the bill at its first reading and the National Party drafted two rabid opponents of assisted dying on to the panel, Maggie Barry and Nick Smith.

The performance of Barry, who became the deputy chair, has been so appalling that it provoked our President Maryan Street into making a formal complaint about her to the chairman, Raymond Huo. Past president Dr Jack Havill called for Barry to be removed as deputy chair and another member wrote to Parliament’s Speaker about her. (*See story Page 2*)

The eight-member committee is supposed to be assessing all the evidence put to it in submissions before making its report to the House of Representatives on March 27 next year. Barry has demonstrated the same level of impartiality on the issue as O’Connor did in his time, campaigning vigorously against the bill around the country as well as showing blatant disrespect to our members in committee hearings.

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Overwhelmed by the number of people who wanted to appear personally to make their submissions, the committee not only split up into paired sub-committees but in some places asked local MPs to sit in as substitutes for them,

This provoked an alarming exchange at a Hamilton hearing when a group of EoLC supporters were told by a local member that no one on the “real committee” would take any notice of what he and his fellow MP would report to Wellington after listening to their submissions.

It was equally alarming to see former prime minister Sir Bill English and palliative care doctor Sinead Donnelly using emotive language, untruths and misinformation to decry the bill at one of a number of meetings designed to help the public understand. At no time did they confess their opposition was based on religious dogma, though English did say at one time that he was opposed “on principle”.

But we must not despair. There is encouraging progress over the Tasman, where Western Australia is poised to join Victoria in changing the law, and it is inevitable that New Zealand will follow suit in time.

Keep up the pressure on your MPs to make that time next year.

David Barber, Editor

WRITE LETTERS TO THE PAPERS - A FEW HINTS

It is important to write to the newspapers to refute lies and misinformation in letters from opponents of choice and to respond to articles reflecting opposition to assisted dying.

A few hints on how to improve your chances of getting a letter published:

Almost without exception papers put a limit of 200 words on letters for publication - if you exceed that, your letter will not be printed.

Even then, it is good practice to keep well below that. Do not try to cover everything on the issue if you are replying to another letter or an article - shorter letters confined to one succinct point have a much better chance of being printed.

You must add your name, address and telephone number to demonstrate authenticity, but only your name and town or suburb will actually be printed.

WE COMPLAINED ABOUT MP'S RUDENESS AND DISCOURTESY

The End-of-Life Choice Society lodged a formal complaint about MP Maggie Barry, deputy chair of the Justice Select Committee considering the assisted dying Bill, President Maryan Street accusing her of being rude and aggressive when hearing submissions.

Maryan Street complained about Barry's “trademark rudeness and discourtesy” in a letter to the committee's chairman Raymond Huo. She said many EOLC Society members had registered concern at the MP's treatment of them when they appeared to make submissions on David Seymour's End of Life Choice Bill.

“They have found her to be discourteous, disrespectful, dismissive and aggressive during their hearings,” she said. While Barry's views on the Bill were well known, “it is one thing for an MP to hold a dissenting view from a submitter; it is quite another to be rude and belittling when members of the public are submitting a contrary opinion.”

In a separate complaint, the society's past-president Dr Jack Havill called for the MP to step down as the committee's deputy chair when he made his personal submission in Hamilton. He said her blatant bias and discourtesy was bringing the process into disrepute. He also wrote to the Minister of Justice Andrew Little and the leader of the National Party Simon Bridges.

Another Waikato member of the society Brent Evans wrote to Parliament's Speaker Trevor Mallard saying it appeared that the MP was “undertaking a campaign designed to engender fear, uncertainty and doubt regarding the provisions of the Bill... using the emotive language of murder and killing”. He also said the situation was bringing the Parliamentary process into disrepute and asked if there was a code of conduct for MPs.

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The complaints fell on deaf ears. Raymond Huo told Maryan Street that under Parliament's Standing Orders, select committees could not consider such complaints. "MPs largely have freedom to carry out their parliamentary duties as they see fit, and are politically accountable.

"The conduct of MPs in parliamentary proceedings can be formally examined only on the referral of a question of privilege, No such matter has been raised."

Huo said all members of the select committee recognised that it took courage for submitters "to give voice to their perspectives and, in many cases, convey their deeply emotional experience to MPs in a public forum".

Speaker Mallard told Brent Evans: "Freedom of speech is a cornerstone of our democracy, and members are expected to hold strong views and advocate for particular positions. When a member shares views in a public forum, he or she will be judged on the basis of those words and can be held accountable by electors for them."

He said the Standing Orders Committee had previously considered the issue of a code of conduct for MPs and there had been "a general reluctance to implement any initiative that would fetter the legitimate freedoms of members".

Bets Blake, a retired palliative care nurse with 52 years' experience, told the Stuff news website that making an oral submission to the committee was "traumatic".

She said: "Maggie demonstrated an interest in what submitters opposing the bill were saying, smiling and nodding at them. At the end of their submissions she thanked them. She didn't challenge them at all. If they cited statistics, these weren't challenged."

While Bets was still speaking, Barry got up from her seat to get a refreshment. "I felt she was dismissive of people who held an alternative view. I went back to my seat feeling upset and angry. It was an awful and tortuous experience."

The hearings were broadcast live on Parliament's website which invited comments from viewers. Ironically, the committee said: "Please ensure that you are making thoughtful and constructive comments that are considerate of the opinions and views of others."

Barry told Stuff she was "considerate" to all views. "I respect the process and debating the issue. I've spent many hundreds of hours hearing this. It's tough hearing it and saying it, and I'm aware of this and treat people with absolute respect. It is not up to lobby groups who are campaigning on an issue to try and force MPs whose views they don't agree with to stand down."

WORLD FEDERATION COMMITTEE

The World Federation of Right to Die Societies elected a new committee to serve for the period 2018-2020 at its conference in South Africa.

Sean Davison (South Africa) - **President**

Jean-Jacques Bise (Switzerland) - **Treasurer**

Masahiro Nomoto (Japan)

Jeanne Arthur (Australia) - **Secretary**

Asunción Alvarez (Mexico)

Rob Jonquière (Netherlands) - **Executive Director**

Vice-President Mary Panko represented the End-of-Life Choice Society New Zealand at the World Federation of Right to Die Societies 2018 Conference in Cape Town on September 6 - 10.

She writes: It was what happened a few days later that caught the headlines. Professor Sean Davison, a New Zealander who has lived in South Africa for the last 26 years and is currently President of the WFRtDS, was charged with murdering 43-year-old doctor Anrich Burger in 2013, who was left a quadriplegic after an accident eight years earlier.

Sean has been talking publicly about this event for the last four years, using it to underline the need for a law change in South Africa. He has explained on several occasions that Dr Burger wrote his own prescription and administered it to himself. Sean's "crime" was to sit with him while he died to ensure his friend did not die alone. This is one of the main reasons why EOLC has been campaigning for a law change in New Zealand for several decades.

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At the conference the different approaches to the issue by various member societies were argued fiercely. There were two basic philosophies – the “Medical Model” which has EOLC backing and is promulgated most widely around the world and the “Autonomous Model” where the choice and ultimate decision remains solely with the individual seeking death. EXIT, for instance, argues that choice of death should remain with the person and not require the sanction of a medical professional - an on-going debate.

Staying with the ethics of choice in dying, Professor Willem Landman from South Africa laid bare the moral hypocrisy of some members of the medical profession who, while supporting extensive medical treatments for a variety of illnesses and who may also accept terminal sedation in conjunction with the withdrawal of treatment and life support, refuse to permit Physician Aid in Dying.

Somehow a slow, painful and lingering death is morally acceptable to them, regardless of the wishes of the dying person. It was also frustrating to hear from several other South African speakers that they believed that their government’s view was that it was a “whites” only issue and not therefore of great national significance.

This despite the outright support offered publicly by Archbishop Emeritus Desmond Tutu and emphasised by black South African lawyers who spoke at the conference.

A number of doctors from Canada described their experiences in a session devoted to the current situation there. One of the major difficulties several encountered was finding a suitable venue where MAiD could be undertaken once it had gone through the rigors of approval.

This was mainly due to the large proportion of rest homes and palliative care facilities run by religious organisations that refused to permit the procedure, even though many are funded directly by the government. In spite of these problems two doctors commented on the immense and rewarding gratitude they had received from patients whom they agreed to help.

The debates showed that once the End of Life Choice Bill is eventually enacted in New Zealand, our efforts will still be needed to make certain it operates as intended.

The WFRtDS issued a statement “to express its admiration for Professor Davison’s courage and sincere engagement with those who are suffering at the end of life despite the ongoing persecution he has experienced by governments who maintain outdated, cruel law that forces its citizens to die of disease and to hang, gas or shoot themselves if they do not want that so-called ‘choice’”

NEWS FROM AROUND THE WORLD

AUSTRALIA

West Australia could follow Victoria in legalising voluntary assisted dying next year after a cross-party parliamentary committee recommended a law change, saying it would limit "unnecessary suffering at end of life".

During its year-long inquiry the committee was told by WA Coroner Ros Fogliani that one person suffering terminal or debilitating illness took their own life every nine days in the state. Anaesthetist Dr Peter Beahan said that “about 20% of those who receive terminal sedation may experience some suffering” whereas VAD “is quick, painless and certain”. He said: “Patients do not fear death; they fear the process of dying, and with good reason.”

WA public health physician Dr Richard Lugg told the committee that “In our view, and we are doctors after all, there will be advantages in having the area under the control of a health administration rather than a criminal justice administration.”

The coroner’s figures prompted the head of the WA Police Union, George Tilbury, to call for VAD to be legalised so that “there would be less horrific suicides, and first responders would be spared having to see as many graphic scenes, most of which stay with them forever”.

The committee, chaired by Labor MP Amber-Jade Sanderson, recommended the government to bring a bill to Parliament itself after drafting it with the assistance of a panel of health and legal experts. Just one committee member dissented and MPs are expected to have a conscience vote.

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The report recommended that those eligible for voluntary assisted dying "must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person". Death would need to be a "reasonably foreseeable" outcome of the condition suffered by the patient who must have "decision-making capacity" at the time of making a choice to die.

A doctor could administer a lethal dose if the patient is physically unable to do so, but the committee recommended that health practitioners should not be forced to act if they did not.

Perth Doctor Alida Lancee, a long-time campaigner for euthanasia, challenged police to charge her when she admitted in an ABC 60 Minutes programme hastening the deaths of at least eight people. She was cleared after police investigated the death of one of her patients but has now identified an 80-year-old woman with end stage lung disease who she helped to die. "My problem isn't that I've done the wrong thing," she said. "'My problem is that society hasn't caught up with what people need, that's all."

Fellow doctors Frank Kotai and Rodney Syme also admitted helping patients to die, Syme claiming he had assisted 300 to end their suffering.

Queensland is also to hold an inquiry into the issue. Labor Premier Annastacia Palaszczuk said: "The parliamentary health committee will begin examining all issues to do with what's known as end-of-life care. I have personally listened to those who have watched their loved ones suffer ... and I too have watched my own family suffer."

The opposition is against a law change, a spokesman saying the government should focus on other things like "the cost of living and traffic and congestion issues."

Although the states can pass laws on euthanasia, that right is denied legislators in the **Australian Capital Territory** and the **Northern Territory** and the Senate narrowly confirmed this with a vote of 36-34 on August 15.

The vote defeated a bill to overturn a 1997 law that removed the power of the two territories to legislate on euthanasia. That law was introduced after the Northern Territory became the first legislature in Australia to allow euthanasia in 1995. The bill, sponsored by independent Senator David Leyonhjelm, a prominent campaigner for assisted dying, was widely supported by members of the Australian Labor Party and minor parties, but opposed by most Senators of the coalition government. The narrow loss followed days of debate on the issue, and ACT Chief Minister Andrew Barr, who supports euthanasia, said he would continue to campaign for change.

BRITAIN

The UK Supreme Court confirmed on July 30 that judicial approval is not needed to withdraw life-prolonging treatments from individuals in a minimally-conscious or persistent vegetative state if the family and doctors agree.

Ruling on the case of a patient identified only as Mr Y, who is in a vegetative state following severe brain injury caused by cardiac arrest, the judges upheld an earlier High Court decision that clinically assisted nutrition and hydration (CANH) can be withdrawn from a patient in a prolonged disorder of consciousness without having to seek a court's permission, if the family and medical team agree that would be in the best interests of the person.

Natalie Koussa, Director of Partnerships & Services at Compassion in Dying, welcomed the ruling saying it brought much needed clarity to doctors and relatives of those left in a vegetative or minimally-conscious state following severe illness or injury. "Today's judgment is an important move towards more person-centred care, because it means that what's best for the individual can be decided by their medical team and loved ones, and acted upon more quickly, rather than spending months or even years waiting for a court decision. The court's decision also recognises the fact that sometimes, sadly, it is in someone's best interests to withdraw treatment. It will allow those closest to a person to feel supported and empowered to make the right decision for the person, even when it is a difficult one."

Advocating the use of Advance Directives, she said Mr Y's case was a tragic example of what could happen when people did not record their wishes for future medical treatment and care.

UNITED STATES

Death with Dignity US has submitted an *amicus curiae*, or friend of the court, brief to the California Fourth District Court of Appeal to counter a legal challenge to the state's End of Life Option Act (See Newsletter 51, July 2018, Page 7).

In May, a judge upheld a right wing religious group's claim that the state's legislature violated the constitution by passing the law during a special session limited to healthcare. Opponents argued that assisted dying was not a health issue.

The amicus brief argues that death with dignity and healthcare are inextricably bound. In a nutshell: Healthcare includes end-of-life care. End-of-life care, in turn, includes death with dignity as an end-of-life option, which complements palliative care, hospice care, and other options of last resort.

The California End of Life Option Act relates to healthcare by requiring a medical diagnosis, a patient-physician relationship, a second medical opinion, a patient's informed consent, and health-related regulatory oversight. The Act provides relief, comfort, and control to terminally ill Californians whether they take the prescribed medication or not. While there is still significant opposition to Voluntary Assisted Dying by medical groups in the US, 10 state chapters of the American Medical Association have switched from being "opposed" to "neutral" on the issue, along with some specialist groups.

The American Medical Association Council has spent two years reviewing the group's stance on VAD and recommended continued opposition. However, at the annual conference in June, 56% of delegates voted not to accept the council's report and to send it back for further review.

WHAT THEY SAID

"Regardless of what you might choose for yourself, why should you deny others the right to make this choice?" South African Archbishop Emeritus Desmond Tutu.

"Recent proposals for assisted dying legislation actually contain more safeguards against disabled people being officiously treated as terminally ill against their wishes than exist at the moment. Assisted dying legislation is about giving people choice and control at the end of life. This is what disabled people campaign for in every other aspect of life. Why would they not also wish for it at the end?"

Lord Colin Low, a British MP, who is blind.

"...not to allow people to either terminate their lives or have professional assistance to end their lives constitutes, in the words of the United States constitution, 'cruel and unusual punishment'. The right to die and dying with dignity is a societal issue, not a medical issue, and as a societal issue is a public health issue. Every state, country or similar legal jurisdiction should allow those residing within its borders the right to die and to die with dignity with laws not unduly interfering with these rights."

US Doctor Leonard Bernstein

"Evidence recently given by countless victims of Catholic paedophile priests clearly show the abyss and total lack of understanding by the Catholic Church for the suffering endured by those victims. Many of these victims went on to take their own lives in dreadful circumstances - in a cruel irony compared with the Church position on voluntary assisted dying. I certainly do not write in the hope of changing your mind on this issue. By all means feel free to endure whatever suffering comes your way in your end of life, but I do pray and urge you not to use your position to force me and every other Australian to do the same."

Ian Wood National Co-ordinator, Christians Supporting Choice for Voluntary Euthanasia, Australia, in a letter to Catholic Archbishop Christopher Prowse.

"I think those who have a terminal illness and are in great pain should have the right to choose to end their lives and those who help them should be free from prosecution."

Professor Stephen Hawking (1942-2018).

"The status quo is simply unacceptable; it's barbaric and we should be ashamed of it in 2018 in a country like New Zealand."

Dr Andrew Butler, lawyer who acted for Lecretia Seales.

DYING BADLY - NEW ZEALAND STORIES

If anyone tries to tell you there is no need for a medically-assisted dying law and that palliative care can ensure a peaceful death for everybody, point them in the direction of our book

Dying Badly – New Zealand Stories.

It contains moving accounts of bad deaths of relatives and friends as told in heart-breaking submissions to Parliament's Health select committee.

It can be downloaded free on our special campaign website

<https://yestodignity.org.nz>

where you can also buy the printed paperback for only \$12, including postage, by internet banking or order a copy from our office PO Box 48 241 Silverstream, Upper Hutt 5142.

The website also contains videos, blogs and media stories of interest

BRANCH EVENTS

AUCKLAND Sunday 28 October 9 - 11.30am at Takapuna Market - Celebrate Right to Die Day.

Sunday 2 December 2pm at Fickling Convention Centre, 546 Mount Albert Road, Three Kings.
Speaker: Bets Blake on "How Advanced Care Directives guide you, your family, and health professionals in planning end-of-life care".

BAY OF PLENTY

Friday 2 November 11am - 2pm at Bethlehem Shopping Centre - Celebrate Right to Die day.

Tuesday 6 November and Tuesday 3 December 10m at Zest Cafe, Chadwick Road, Greerton - morning tea.

KAPITI-HOROWHENUA

The branch has developed an innovative, neutral presentation of the End-of-Life Choice Bill in Question and Answer format, which has been well received locally and is prepared to take to other branches. Contact **Linda Kennington 022 017 1256** or **Ann David 04 293 8375**.

WELLINGTON

Saturday 17 November 2pm at Wellington City Library - Branch meeting.

Speaker: Chris Bishop, National MP.

Between 16 February and 17 March 2019 - stalls planed at weekend markets in Lower Hutt, Harbourside and Newtown.

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YOUR FINAL WISH - MAKING A BEQUEST

Bequests are vital to the survival of any non-profit organisation.

Bequests provide ongoing funding streams. And make it possible to create long-term plans. Bequests are the cornerstones of non-profit organisations, like **End-of-Life Choice**, because they provide stability.

If you can hear yourself saying, **"This is what I support, and I want this issue to be important even after I'm gone"** then please consider making **End-of-Life Choice** a beneficiary of your will by creating a bequest.

Ours is a unique issue, one in which our most ardent supporters might not be with us for long. Our fiercest opponents might later turn to us for help.

You could consider asking friends to make a donation, in lieu of flowers, at your funeral.

Please take the step to support End-of-Life rights in your will.

DONATIONS AND CONTRIBUTIONS

You can make a contribution in any amount of your choice - in single, monthly, or yearly donations.

- 1 Cheque payments can be mailed to
PO Box 48 241, Silverstream, Upper Hutt 5142
- 2 Direct payments into our bank account **Kiwibank 38 9006 0226036 02**
(Be sure to include your **NAME** and **"DONATION"** in the bank details).

Your donations help us to continue the expansion of our work and help us continue to work for your right to make decisions for your End-of-Life Choice.

GUIDE TO DYING - YOUR WAY

End-of-Life Choice has teamed with medical and legal experts to assemble a comprehensive **step-by-step guide to help you create an Advance Directive that reflects your wishes.**

It also contains information on choosing an Agent, someone you entrust to ensure your wishes are carried out. This answers important questions you may have about writing an **Advance Directive**, which meets your personal wishes; it offers tips for relief of pain and suffering, the legality of an **Advance Directive** in New Zealand, and keeping your **Advance Directive** up to date.

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