



End-of-Life Choice

Society of New Zealand Inc

May 2018 END-OF-LIFE CHOICE SOCIETY OF NEW ZEALAND INC Issue 50
Member of the World Federation of Right to Die Societies

“We want to die as we want to live: free from pain, connected to people we love, with agency and dignity.”

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"NOW IS THE TIME" SAYS PRESIDENT

This is the year we can realise our ambitions for a humane and compassionate law change. David Seymour's End of Life Choice Bill, now before a select committee, is due to be reported back to Parliament for a second reading by September 27. We have never got this far before.

On previous occasions (1995 and 2003) a similar bill was defeated at its first reading. History was made for our cause when it passed the first reading stage (76-44 votes in favour) in December and since then a record number of submissions on the bill have been sent to the Justice select committee. At March 23, 30,411 submissions had been processed – more than any previous committee of the New Zealand Parliament has ever received on any subject – and there were thousands more waiting to be scanned.

But we know from our petition requesting a Parliamentary inquiry into the issue, which also logged a record number of signatures, that it is the quality, not the quantity, of the submissions that the committee will be critically weighing up.

The most conservative part of the Catholic Church provided pre-printed forms for their congregations to fill out as they left church on a Sunday, fuelled by ignorant claims and deliberate misinformation about the Bill (such as it provides assisted dying for people with gluten intolerance!). But the quality and thoughtfulness of submissions will be the persuasive factor for thinking Members of Parliament – and most of the MPs on the Justice select committee are thinking MPs, who will not be working off ancient prejudices which have never been updated by recent personal experiences of loved ones.

It is to be hoped that both the weight of public opinion, randomly and reputedly gathered by professional pollsters, and the quality of heartfelt and first-hand scientific submissions might overcome the rote-learned and regurgitated responses of those who have left their ability to think for themselves at the altar.

We are taking professional advice as we apply every resource we can muster in our efforts to persuade enough MPs to support the bill through its second reading and then vote it into law before the end of the year, the outcome we have worked for over nearly 40 years.

But that costs money and I appeal for your help in this work. We do not have pockets as deep as our opponents, Any amount you can donate will be gratefully received and applied to this campaign.

You can see what we are doing on <https://yestodignity.org.nz> . We are releasing videos which highlight our reasons for saying what we say and doing what we do weekly on this website and through social media. These show real people sharing their real experiences of loved ones dying badly.

Please support us and spread the word to friends and family who think similarly. You can donate on the special campaign website above, on our usual website at www.eolc.org.nz or by cheque mailed to EOLC headquarters at PO Box 48 241, Silverstream, Upper Hutt 5142.

This is the year. Now is the time.

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Thank you for everything you have done so far. Now we need to make a big push to get this bill passed and have in law the right to choose, under tightly regulated conditions, the moment and method of our dying. Please help us get this over the line.

Kind regards

Maryan Street (President)

"No" VOTERS JOIN SELECT COMMITTEE

The opposition National Party has drafted two opponents of assisted dying onto the Justice Select Committee considering the End-of-Life Choice Bill, in a move that ousted three members who voted in favour of it at the first reading in December.

They include Maggie Barry, who has strongly attacked the Bill inside and out of Parliament and has been named the committee's deputy chairperson, replacing Amy Adams, who lost a bid for the party's leadership to another vocal opponent, Simon Bridges, in February. Adams told the *New Zealand Herald* at that time: "This is a deeply personal issue for me...Four years ago I sat by mother's bedside and watched her die a gruesome and undignified death. While she had access to all the medication and nursing care you could ever want, she wanted the right to choose her own time."

Barry is joined on the committee by National veteran Nick Smith, who also voted No at the first reading. Mark Mitchell, who voted Yes then, is the third newcomer. They replace Andrew Falloon and Matt King.

All eight of the original Justice Committee, which is chaired by Labour's Raymond Huo, voted for David Seymour's Bill at the first reading. Huo said in March that the committee had already processed 30,411 submissions - the highest number any select committee had received in recent parliamentary history - with several thousand more to go. "I am determined to present the committee as balanced, even-handed and open-minded as we prepare to hear from the many thousands of New Zealanders who have taken the time to share their views on this complicated and contentious bill," he said.

There is little doubt that Catholics will have again swamped the committee with rote submissions of opposition as directed by their six bishops. The church has sunk to a new low this time with misinformation to scare parishioners claiming that "irremediable medical conditions" in the Bill could include arthritis, asthma and gluten intolerance.

In early April the committee had still to announce a schedule for public hearings of oral submissions. We understand it failed in a bid for funds to allow its members to travel to overseas jurisdictions with assisted dying laws to see how they work.

The last Parliament's Health committee, which held an inquiry into the issue and produced an anodyne report reflecting the bias of its chairman who had spent nearly 10 years training to be a Catholic priest, did not go overseas.

EOLC was keen for the committee to travel and see enlightened legislation working at first hand, as members undertaking a similar inquiry in the state Parliament of Victoria, Australia, did. That inquiry reported "absolutely no evidence" of the so-called "slippery slope" and resulted in a law scheduled to come into effect next year that is claimed to be the safest and most conservative of its kind anywhere in the world.

The committee will consider whether to add a clause to the Bill allowing for a national referendum on the issue, as the New Zealand First party's nine MPs made a condition of voting Yes at the first reading.

CHECKPOINT BROKE THE LAW

The lengths police went to in hounding voluntary euthanasia supporters were revealed in detail during the trial of former Wellington branch chair Suzy Austen and in the Independent Police Conduct Authority's report on the illegal checkpoint set up to identify people who went to a meeting at her home.

They included:

- Breaking into the empty house to plant a surveillance device,
- Bugging her phone calls and monitoring her emails,
- Secretly taking photos of the people who attended the meeting and recording their car registration numbers,

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- Stopping cars at the checkpoint to identify attendees and get their addresses, an act deemed unlawful by the IPCA and the Privacy Commissioner, who said subsequent “welfare visits” to their homes asking if they were suicidal “caused them harm”.

The 1 hour 50 minute meeting, attended by 22 people on October 2 2016, was under the auspices of Exit International and although the EOLC Society is not associated with that organisation some of our members belong to both and were among those affected.

President Maryan Street said the IPCA’s findings confirmed that those stopped at the bogus checkpoint were targeted for their beliefs and lawful activism, not because of any threat to law and order.

“None of the people visited were at imminent risk of suicide,” she said. “The police frightened and intimidated adults who were not committing any crime in the misguided belief that they were looking after their welfare.”

IPCA chair Judge Colin Doherty told the *New Zealand Herald*: “It was an illegitimate use of police power that unlawfully restricted the right of citizens to freedom of movement.”

He found that police were not justified in establishing the unlawful checkpoint, which stopped 50 cars, only seven of them carrying nine people who attended the meeting. But, in an apparently contradictory corollary, the judge said that even though no immediate risk to the attendees was identified, “the Police decision to complete welfare visits was appropriate and consistent with their duty to protect life.”

This begged the question of how action carried out as a consequence of an unlawful act could be appropriate.

Privacy Commissioner John Edwards said: “Police used an unlawful checkpoint to take advantage of the public’s trust in them and collect information from people who were not legally required to provide it.”

Of the so-called “welfare visits” to 15 attendees, he said police questioned them “about a socially and politically sensitive subject” after unlawfully collecting their information. “It is fair to say that the actions by the police officers caused those complainants harm.”

Otago University law professor Andrew Geddis said complainants had a case for a class action to seek compensation from the police for breaching their rights under the Bill of Rights Act.

The IPCA report said a common sentiment among people who received the welfare visits was that the police misjudged them. “They said that they were not depressed or immediately suicidal. They were well-educated people who wanted to educate themselves on what options would be available to them should their health take a turn for the worse.”

It quoted one woman as saying the police seemed patronising to elderly people. “I mean, why should, just because one’s 85, one be assumed to be kind of helpless and weak and pathetic and needing comforting police to come and pat you on the back.”

Maryan Street said EOLC wanted an apology from the police and assurances that its continuing campaign for a law change would not be targeted with unwarranted surveillance and intervention.

WHAT THE PRIVACY COMMISSIONER SAID

Privacy Commissioner John Edwards says a Police checkpoint in 2016 unlawfully and unfairly collected personal information, harming some of the people affected.

The breath testing checkpoint was set up near an Exit International meeting in Lower Hutt. Police at the checkpoint collected the names and addresses of people who had attended the meeting. Police later visited some of the meeting attendees.

The Commissioner initiated an investigation after the media reported on the incident in October 2016. The Office of the Privacy Commissioner (OPC) later received complaints from individuals affected by the incident. The Independent Police Conduct Authority (IPCA) investigated after complaints from the public and a self-referral by Police.

OPC investigated the collection of personal information at the checkpoint, while IPCA investigated Police actions and the subsequent use of the information. Each organisation investigated under its own Act.

In June 2017, OPC completed their investigation and advised the parties of its final view. It found the collection of personal information at the checkpoint to be both unlawful and unfair. The way information was collected breached principle 4 of the Privacy Act 1993.

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“Police used an unlawful checkpoint to take advantage of the public’s trust in them and collect information from people who were not legally required to provide it,” Mr Edwards said.

“The primary function of Police is to maintain the law and there is an expectation that they will follow the law and their own policies at all times. This is especially the case when they engage with members of the public or use their powers to investigate offences.”

Some complainants said the visits from Police made them feel uncertain about their ability to speak freely and anxious that more visits would follow.

“Police approached them after unlawfully collecting their information, and questioned them about a socially and politically sensitive subject. It is fair to say that the actions by the Police officers caused those complainants harm,” Mr Edwards said.

Mr Edwards acknowledged that Police believed the meeting attendees were at risk, and said that apologies from Police and an undertaking to delete the information collected at the checkpoint were appropriate resolutions to the complaints.

(Full text of the Privacy Commissioner’s report, 15/3/18)

SUZY AUSTEN CLEARED OF ASSISTED SUICIDE CHARGE

Long-time Wellington activist Suzy Austen was acquitted of an assisted suicide charge carrying a potential 14-year prison sentence on February 24 after a two-week trial in the High Court.

She awaits sentence on May 11 on two counts of importing a Class A drug, Nembutal, a charge of minor importance, according to evidence presented during her trial. A Customs investigator said nobody was prosecuted after 54 importations of the drug were intercepted in the 10 years to September 2016 and only one case was referred to the police although several people received warning letters.

Suzy was alleged to have helped Annemarie Treadwell, 77, who suffered clinical depression and crippling arthritis, to obtain Nembutal before she killed herself in her retirement home unit in June 2016.

The jury apparently accepted the defence’s contention that simply possessing a lethal drug, whether it is intended to be used or not, could have a “profound palliative effect to reduce suffering” that may even extend life by reducing anxiety of dying badly.

Treadwell died a few months after she had made an impassioned plea for a law change in a submission to Parliament’s Health select committee’s inquiry into assisted dying. She also had written a note found after her death in which she said that nobody had coerced her or influenced her in any way to take her own life. She wrote in her diary that she suffered seasonal affective disorder (SAD) and had told her daughter that she was determined not to spend another winter alive. She noted the need not to implicate anyone in Exit International.

Treadwell had been university-educated and lived in a number of countries and her diary movingly recorded her despair about her condition and loneliness as she aged. “My world is shrinking and I feel myself becoming boring and pitiful...and – once again I feel foolish in company whereas before people would be keen to hear my input,” she wrote.

Suzy was supported every day in court by a band of friends and EOLC members.

WHAT THEY ARE SAYING

“I have been assured by doctors that there is no reason for people to die in pain, but in my experience of visiting deathbeds, terrible distress often appears to be present. If I were the one suffering at death’s door, I would want to hastily summon the nurse for a drug that would speed my exit from God’s waiting room. I want the “speedy exit” clause established in law.” Writer/commentator **Bill Ralston** in *The Listener*, 14 March 2018

“People who have a terminal illness and we can’t help any more and who want to choose how, when and where to die should be supported to end their lives in dignity and self respect. To decide is human. To provide the ability to choose legally is Parliament’s responsibility in a free society.” **Louisa Wall, MP for Manurewa**, in the *New Zealand Herald*, 13 March 2018.

“Similar systems now operate in a number of states or countries, and claims that they are heading down a slippery slope to state-sanctioned killing are not based on good evidence. Rather, they are a civilised response to a crying need.” *The Dominion Post*, 16 December 2017.

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"Many people with disabilities support assisted dying legislation. Also, the Bill has nothing to do with disability but everything to do with irreversible, escalating, extreme suffering that cannot be palliated by any means." **Philip Patston, Managing Director, Diversity NZ Ltd, and EOLC social media adviser**, 9 March 2018.

"It is cruel to allow anyone to die in a vegetative state." **Bobbie Carroll, 64, Auckland blood cancer victim**.

"My feeling is that an old person like myself should have full citizenship rights including the right of assisted suicide," Australian **Professor David Goodall**, speaking to the ABC on his 104th birthday. Asked if he'd had a happy birthday, he said: "No. I'm not happy. I want to die." He plans to spend the rest of his days campaigning for voluntary euthanasia to be legalised in Western Australia.

"I had a patient a few years ago who died a horrible death, and her lovely husband just couldn't cope so he hung himself. He was healthy but he wanted out. This is how elderly people are killing themselves." Former Wanganui Hospice community nurse **Sue Walkinton**, in the *Wanganui Chronicle*.

NEWS FROM AROUND THE WORLD

AUSTRALIA The assisted dying law passed by the state parliament in Victoria last November is not guaranteed to come into force next year as scheduled.

Matthew Guy, leader of the opposition Liberal/National coalition, has refused to rule out repealing the law sponsored by the Labor Party government if it wins the election on November 24. Labor is seeking a second term in office.

The Go Gentle organisation led by former journalist Andrew Denton has vowed to fight to retain the law, due to take effect from June 2019, when Victoria would become the first Australian state with end-of-life choice. Denton, who came to New Zealand to support our cause in 2016, has announced he is returning to TV work after leading Go Gentle for three years, but will remain involved with fundraising and advocacy. "Just try and shut me up," he says. His assistant Kiki Paul takes over as the campaign moves on to back efforts to introduce assisted dying legislation in Western Australia, Queensland, New South Wales and the Australian Capital Territory.

Victorians have, however, acquired greater powers to set legally-binding plans about future medical treatment preferences and end-of-life care with the *Medical Treatment Planning and Decisions Act 2016* enshrining advance care directives in law for the first time coming into effect in March. Directives can include instructions about treatment and personal values that can guide the type of treatment they would prefer if they lose competency. The Act also allows a person to appoint a medical treatment decision maker and a support person to communicate on their behalf. People of all ages with decision-making capacity can now make a legally binding advance care directive, to be witnessed by two people, including a medical practitioner. Those of under-18s must be witnessed by a medical practitioner or psychologist with expertise in child development.

Anybody coercing someone into an advance care directive can be jailed for five years and health practitioners failing to respect directives will face disciplinary procedures.

BRITAIN The British Medical Journal (BMJ) came out in favour of voluntary assisted dying on February 12 and Editor-in-chief Dr Fiona Godlee called on the British Medical Association (BMA), which is officially opposed, to poll its members on the issue.

The BMJ pointed out that a recent survey of doctors found 55% were in favour and Dr Godlee wrote: "Some royal colleges have polled their members, but social and medical attitudes are changing, so they would do well to repeat this. "Better still, we need a large national and independent opinion poll, perhaps commissioned jointly by the BMA, the royal colleges, and the General Medical Council. In the meantime, a neutral position from medical organisations would do most to promote an open and informed public debate."

The Court of Appeal will start hearing motor neurone sufferer Noel Conway's appeal against a High Court ruling denying him a "peaceful and dignified death" helped by doctors on May 1. Conway, 67, claimed that the Suicide Act 1961 was incompatible with the European Convention on Human Rights which accords respect for private and family life.

Politicians (Deputies) in the Channel Islands state of Guernsey (population about 63,000) will debate a proposal to introduce medically assisted dying laws in May.

Gavin St Pier, who has initiated the proposal with six others of the 38 Peoples' Deputies, has denied media claims that they favoured a Dignitas-style "suicide" clinic for the island, open to non-residents, saying: "It's about wanting to improve the options available for people at the end of their lives." He said the proposal began because of his own experiences with his father's death nine years ago. The local branch of the British Medical Association opposes the move.

INDIA In a landmark ruling, the Supreme Court of India said on March 9 that the terminally ill had a right to die with dignity. It approved for the first time advance directives in which people can authorise the withdrawal of life support if they develop an irreversible or terminal stage of illness.

A five-judge constitution bench headed by Chief Justice Dipak Kumar Misra issued guidelines for passive euthanasia if family members agree and a team of doctors conclude that the patient cannot be revived. The guidelines will remain until the federal government enacts a law allowing passive euthanasia.

Common Cause, a non-profit organisation, asked the court to recognise advance directives - or "living wills" after the government refused to include them in draft laws for passive euthanasia.

Active euthanasia, or death by lethal injection or drug, remains illegal.

UNITED STATES Hawaii became the seventh American legislature to adopt an enlightened death with dignity law on April 5 when State governor David Ige signed the Our Care Our Choice Act.

It had been 16 years since the Hawaii legislature went close to passing an end-of-life choice measure and US Death with Dignity executive director Peg Sandeen said opponents had fought it with wild myths and falsehoods at every corner.

On January 1 next year, Hawaii will join the states of Oregon, Washington, Vermont, Colorado, California and Washington DC in having end-of-life choice if residents are terminally ill with less than six months to live,

In Washington DC, supporters in Congress blocked opponents' efforts to stop the District of Columbia spending local funds to implement its new Death with Dignity Act, ensuring it will remain in place this year. However, Death with Dignity US expects the opposition to try again to block it in 2019.

EOLC LIBRARY - A VALUABLE RESOURCE

Many members may not know that the EOLC maintains a library which has been built up over the 40 years of its existence and contains about 200 publications, six DVDs and some video and audio cassettes for those with older equipment.

The Lending Library page on the website, which members must log in to view, is a work in progress and will eventually list everything we hold. Meanwhile, a printed list can be obtained from the librarian, Frank Dungey, and the collection may be viewed at his Wellington home by appointment. He also regularly takes a selection to Wellington Branch meetings.

The library is divided into sections and includes Advance Directives, Case Histories, Death, Ethics, Euthanasia - for and against, Fiction, the Hospice Movement, Legislation, Medical attitudes, Miscellaneous, Patients' rights, Plays, Poems, Public Opinion, Religion, Right to Die Societies, Self-deliverance, Suicide, and World Federation etc conferences.

The self-deliverance section is popular, and to protect the Society from possible legal action the National Committee ruled that such material may only be borrowed after an application in writing.

The application form, obtainable from the librarian, certifies that the applicant is not contemplating suicide or receiving treatment for mental illness.

This category includes one DVD - Final Exit by Derek Humphry (Demonstrations of Self-deliverance) as well as a number of books. The book lists show the date published and the number of pages so members can judge their topicality and length. Although some books were published many years ago they are classics of their kind and still worth reading,

There is no charge to borrow an item, but members are responsible for sending the material back ASAP and certainly within one month. Borrowers will be held responsible for loss or damage and should reimburse the Society if requested. Borrowed items may not be lent to others, whether members or not.

Donations of books and other material will be gratefully accepted.

Frank Dungey, Librarian.

frankdungey@xtra.co.nz Tel: 04-383-7752

THE "DYING BADLY" BOOK (NZ STORIES)

Our book *Dying Badly – New Zealand Stories*, which comprises moving accounts of bad deaths of relatives and friends as told in submissions to Parliament's Health select committee, is proving very popular.

By mid-April, the free e-book had been downloaded nearly 400 times and the printed paperback available for \$12 inc postage from office@eolc.org.nz is selling well.

If you do not have a copy yet you can order it on our special campaign website

<https://yestodignity.org.nz>

which is also full of videos, blogs and media stories of interest.

As we went to press we heard that Wheeler's, the biggest distributor of books to libraries and schools in New Zealand and Australia, had ordered 15 copies. That means potentially huge exposure for the book we regard as a major weapon in our campaign to get MPs to see the light and adopt an enlightened end-of-life choice law by the end of the year.

ANNUAL GENERAL MEETING - A DATE FOR YOUR DIARY

The End-of-Life Choice Society's national annual general meeting.

Saturday, 16 June 2018 10.30am. Holiday Inn, Auckland Airport.

The AGM's general business will conclude before lunch and be followed as usual by a guest speaker, who is yet to be confirmed, in the afternoon public session.

More information and registration forms will be sent to members in May.

BRANCH EVENTS

- AUCKLAND** **Branch AGM. Past President Dr Jack Havill to speak.**
Sunday 17 June 2pm. Fickling Convention Centre, 546 Mt Albert Road, Three Kings.
- BAY OF PLENTY** **Branch Discussion Group**
Monday 30 April 10am. Zest Cafe, Greerton Village.
- KAPITI-HOROWHENUA** **Ann David to speak on the End of Life Bill before Parliament.**
Saturday 28 April 2pm. Senior Citizens Hall, Ocean Road, Paraparaumu Beach.
- WAIKATO** **President Maryan Street to speak.**
Sunday 27 May 2pm. 17 Claude Street, Hamilton.

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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.

Order your **Guide** and **Advance Directive** today

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- 3 Payment by personal cheque or direct debit of **\$27.00**
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