



End-of-Life Choice

Society of New Zealand Inc

November 2019 END-OF-LIFE CHOICE SOCIETY OF NEW ZEALAND INC Issue 55
Member of the World Federation of Right to Die Societies

WE HAVE DONE IT! WE HAVE DONE IT!! WE HAVE DONE IT!!!

By Dr Mary Panko, EoLC President

YES! But two more years to wait.

Congratulations to every one of us and to all those who struggled so hard and so long for this result, particularly those friends who are no longer with us. If voters agree at a referendum in November next year terminally ill New Zealanders who fulfil stringent criteria will be able to choose a pain-free and dignified death.

It will be a further 12 months before we actually join more than 200 million people around the world with an enlightened law – time needed to set necessary procedures in place - but we have been waiting 24 years already for Parliament to see common sense and the wait will prove worth it.

As we now know – and has been reported around the world – MPs voted by a healthy 69-51 majority on Wednesday 13 November to turn David Seymour's private member's bill into the End of Life Choice Act 2017.

As our Past-President Maryan Street explained, it retains the 2017 date because that was when it was first introduced – a permanent reminder of how long it took to persuade Parliament of the justness of our cause.

Of course, many of us remember that the struggle goes back to 1995 when MPs rejected the first attempt to pass a death with dignity law with an overwhelming 29 to 61 vote.

Yes, there will be more hurdles with die hard, mainly faith-driven, opponents declaring a fight to the end, but we must enjoy this moment and acknowledge the work that has gone into getting us where we are.

We did not believe a referendum was necessary, given strong majority support for a law change from voters over many years, but it will be binding and at least we know that the wording on the voting paper will be simple and straightforward, with no ifs, Buts or Maybes:

"Do you support the End of Life Choice Act 2017 coming into force?"

YES – NO

The additional 12-month delay after what we hope will be a positive outcome will be of no comfort to the terminally ill who desperately want an earlier release from their suffering, but is probably necessary to fine up the details, get the required organisation in place, train medical staff, set up the watchdog Support and Consultation for End-of-Life in New Zealand (SCENZ) and ensure that all goes smoothly on the day medically assisted dying becomes legal.

The EOLC Society, its doctors steered by past-president Dr Jack Havill, its lawyers and all general members will be vital in the set-up stages to make certain that New Zealand enacts successful death with dignity procedures that will withstand all scrutiny.

However, our main struggle in 2020 will be dealing with hysteria from opponents as they predictably roll out their same tired old lies and arguments in attempts to frighten voters away from on-going strong support for the measure.

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We will do everything we can to counteract this stream of misinformation (despite Justice Minister Andrew Little's promise of a misinformation watchdog) by continuing to publicise our case in every avenue available.

You, the members and supporters of the EOLC Society, will be asked to keep writing letters to the press, to keep manning information stalls across the country and to keep up the pressure in any way you can see an opportunity to do so.

Please encourage friends to become "Supporters" (See Page XXXX and the website www.eolc.org.nz) – all you need is their name, email address and postal code. It's free and we promise not to deluge them with information but simply keep them up-to-date with what is happening.

The EOLC Campaign Committee will prepare leaflets, long and short, for you to use and will be there to support your initiatives in every way we can. It is going to be another busy year.

In the meantime: – Thank you, Maryan Street for your long and dedicated service to the cause, – Thank you, David Seymour. And thank you our committed and valued members.



Have a Merry Christmas – you deserve it.

EDITORIAL – TWELVE MONTHS TO FIGHT FOR THE TRUTH

By David Barber, Editor

“For those who use faith as an excuse to keep others in a condition of suffering – I have no polite words for such cruelty.” So said Labour MP Marja Lubeck during Parliament’s last debate on the issue.

It was a comment we will remember over the next 12 months as so-called faith-based opponents wage what Maggie Barry – she of the blindly closed mind – promises “war” to defeat the End of Life Act at the referendum.

For us, it is do-or-die time (excuse the pun). If a majority of voters don't vote Yes, it is unlikely that MPs will revisit the issue for many years. Politicians have historically preferred to ignore those suffering bad deaths and it could be shelved for a generation after what threatens to be a nasty and divisive campaign.

A campaign that is certain to be led by the closed minds of leaders of the Catholic Church who have specialised in lies and misinformation since David Seymour's bill was introduced into Parliament.

Gluten intolerance, asthma and arthritis would qualify for medically assisted dying, six bishops told parishioners of their 300 churches in January 2018 and that sort of mischievous rhetoric is bound to get worse.

Urging the faithful to make submissions to Parliament, they told them to avoid any mention of religion, thereby deviously creating the impression of overwhelming secular opposition. It fooled nobody but their own closed mind supporters and thankfully a majority of MPs saw through the plot.

Will a majority of voters see through it next November? There will be complications, not least in the shape of a concurrent ballot on legalising cannabis for personal use. The conservative Christian Family First organisation has already announced “The Government wants to promote debate on giving your kids legal weed, they now want to promote debate on coming for your grandma.”

The government, of course, is not promoting assisted dying, but it will inevitably and uncomfortably be targeted by an encompassing conservative campaign, if only because 72% of Labour MPs (including Jacinda Ardern) supported the bill against 31% of Nationals, whose leader Simon Bridges opposed it.

Politicians actually have very little reason to take any notice of the Catholics and their satellite Care Alliance. The 2018 census showed that they are of dwindling significance, less than 300,000 out of the 4.7 million people surveyed.

That makes them 6.38% of the population – a drop of nearly half in the five years from the 12.6% in the 2013 census.

Not all religious people oppose assisted dying, of course. Many figure in the average 68% of voters who have supported the cause over the last 20 years. But public opinion is volatile and can be easily manipulated by fear, misinformation and doubts of the kind opponents with unlimited funds for spin doctoring specialise in.

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Parliament voted for end-of-life choice almost exactly 25 years after Oregon became the first American state to legalise assisted dying. Its ground-breaking law has survived multiple legal challenges and worked flawlessly. Most people using it have been white, educated, reasonably well-off cancer patients, giving the lie to claims it would harm the socially disadvantaged and vulnerable.

Recent research in Queensland, which is in the early stages of debate, showed that 168 terminally ill people in the state committed suicide in 2016-17, forced to choose painful, often violent and lonely ends to their suffering.

We can do better than that. "Who else but me should have the authority to decide if and when the disease and its effects are so intolerable that I would prefer to die?" said Lecretia Seales, whose memory will dominate the debate over the next 12 months.

A DOCTOR WRITES ...

By Dr Gary Payinda

Emergency Medicine Specialist, Whangarei Hospital

The topic of death came up yesterday. I'm used to it at work - I am an emergency doctor. But this time was different. This was with a friend and colleague, a vibrant woman who has lived multiple lives' worth of adventure, whose 60's were supposed to be filled with meaningful work, followed by a happy retirement with her husband.

Instead she's dealt like a champion with the side effects of chemo, and the pain and other symptoms of an advancing cancer. Despite modern medicine, great cancer specialists, top surgeons and gastroenterologists, hardworking GPs, many wonderful nurses, and hospice staff that have been a treasure, there is sometimes pain and suffering that doctors just can't fix.

I want her to have everything her doctors can provide her with to ease her suffering, including the ability to end her suffering if she so chooses...when the time is right for her.

I don't want her or anyone else to be forced to suffer needlessly through the last days or weeks of a fatal disease. In this day and age, we would never withhold pain relief from the dying. Nor should we withhold medications that could end the suffering when it can no longer be relieved.

For those who don't want a doctor to give them pain relief when they're suffering, or to end their suffering when they're dying from a terminal disease...by all means, don't ask for it. But don't say no on behalf of someone else. Don't take away their agency, their right to speak for themselves.

As I look at the minority that oppose *end-of-life choice*, I see the expensive mass mailing campaigns that have tried to intimidate every doctor **at their place of work**, their false claims that the End-of-Life-Choice bill targets children or *tangata whenua* or the disabled, their false statements that doctors don't support medical-aid-in-dying (many, many of us do), their arguments about theoretical harms while strenuously ignoring *real* harms happening to *real* people *right now*, every day, despite modern medicine and top-notch care. **They either don't see this, or don't want to see this. But we must move forward.**

I hope the politicians listen to the more than 70% of New Zealanders that want this. But even if they don't, over time either this bill or the next one will pass, as they have in Victoria (Australia), Canada, the Netherlands, Switzerland, and nine US states covering 200 million people around the world. I have no doubt common sense will win out over dogma, as people realise there's nothing sensible about suffering needlessly, or even worse, forcing others to suffer needlessly.

NEW STUDY REFUTES PALLIATIVE CARE "GOOD DEATH" CLAIMS

By Dr Jack Havill

New research published in the *New Zealand Medical Journal absolutely refutes claims by opponents of end-of-life choice that all dying patients receive help from palliative care and can have a good death as a result.**

It reported that growing numbers of terminally ill patients in the last three months of life are being sent to aged residential care (ARC) facilities – aka rest homes – to die because hospitals and hospices cannot cope with the demand from the increasing ageing population.

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The study showed that ARC facilities are not set up, and lack the palliative care expertise, staff numbers, adequate information about the patients transferred, or funding, to handle the complex needs of the dying. It said patients often did not get regular inter-professional care from palliative care physicians, oncologists and other specialists liaising with ARC staff.

“The public hospital environment is considered inappropriate and costly for those dying over weeks to months of incurable illness and hospice capacity is increasingly strained,” the report said. “These facilities are under increasing pressure to free up inpatient beds for acute or urgent care and to manage demand they are discharging patients into ARC facilities who are admitted-to-die.”

The study was headed by Eileen M. McKinlay, associate professor of the Department of Primary Health Care and General Practice at the University of Otago, Wellington, with the Te Hopai Home and Hospital acting as research partners.

The authors said a study this year showed 43% of patients who died in ARC facilities had been admitted inside one year of dying and 24% within the last three months of life. They said patients admitted to die in rest homes had complex palliative care needs “beyond the level of care that ARC facilities are set up or currently funded to provide.

“Given deaths are projected to rise in New Zealand from around 30,000 a year to 55,000 a year by 2068, and the need for palliative care has been estimated to be required for over 80% of deaths by 2038, it is essential to explore and determine how specialist palliative care is to be delivered in ARC if it cannot be provided in public hospitals or hospices.”

Commenting on the report, former EOLC president and intensive care specialist Dr Jack Havill cited the case of a branch chairperson with multiple myeloma who was until near the end receiving good oncological care at home and in a hospice. Finally, she was not stable enough to go home but, her pain stabilised on major drugs, she was sent to a new ARC (with very inexperienced new immigrant staff). “There, she continued to be heavily drugged, fell out of bed several times over a couple of weeks, suffered fractures and ended up in hospital where she later died. A horrible death! All she wanted (repeatedly stated) was a law to allow her to exit this world while able to think properly.”

Jack Havill added: “Palliative care personnel, who can be so opposed to assisted dying, have been pretending that they make sure everybody has a good death. They need to take their blinkers off and recognise that many people die bad deaths in ARC facilities, rather than with the help they receive in hospices.

“It is also clear that government funding should be raised to ensure extended hospice expertise is available to ARC facilities. But there is clearly a place for assisted dying, and it is absolutely untrue to say all the dying can have a good death from palliative care.”

*“What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?” *NZ Medical Journal* 8 November 2019

END OF LIFE CHOICE SUPPORTERS LIST GROWING

The EOLC Society has launched a new scheme to enlist support from members of the public who sympathise with our aims but do not want for whatever reason to become actual members.

It aims to spread our message and keep them informed during the coming campaign with a view to ensuring they vote YES at next year’s referendum.

The scheme came about in acknowledgement that busy people worldwide are increasingly reluctant to commit to the concept of “membership” of clubs, religious and charitable organisations.

Along with many volunteer organisations, our membership numbers have barely increased over the past decade, despite publicity associated with undoubted growing interest in medical assistance in dying. New members have simply replaced the natural attrition rate.

But on the bright side, we know that people who believe in our cause are still willing to become “Supporters” – a category that demands no financial subscription or permanent commitment.

Some active branch members have been manning stalls at street markets and the like and asking sympathetic passers-by to “sign up” with nothing more than an email address in order to receive information via their computers. The Society sees this as the best means to supply our public education messages which will become an essential part of the referendum campaign.

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Inevitably, supporters must have a computer to receive our information, meaning we can reach a slightly younger demographic than in our membership list, which polls indicate is where the majority support for assisted dying lies.

Some use social media to share information received with family and friends, others may be content simply to learn more about the issue or donate.

Kapiti-Horowhenua, Auckland and Tauranga branches signed up more than 120 people by early November and the society will step up efforts over the coming year to enlist more supporters. Check local initiatives with your branch and lend a hand if you are able.

The society is also introducing a small 25mm diameter badge with the EOLC bird logo to promote the campaign. These can be bought from office@eolc.org.nz for \$5, plus p&p.

NEWS FROM AROUND THE WORLD

AUSTRALIA Attempts to extend assisted dying beyond Victoria, where it became legal in June, remained stymied in other states as the year neared an end.

The lower house of Parliament in **Western Australia** passed a bill with a healthy 45-11 majority in September, but it bogged down in the Senate with an opposition MP lodging 357 amendments in a bid to stop an expected vote before Christmas.

The Labour government claimed its bill was “safe and very conservative” – too conservative for veteran campaigner Dr Philip Nitschke, who said the law would be “very difficult to access by people who are in real need”.

Nevertheless, 168 doctors, including oncologists, neurologists, GPs and palliative care specialists, signed a letter of support to state MPs. “We believe that terminally ill patients who are enduring irremediable suffering should have the right to choose a gentle release at the end of life,” they wrote.

In **Queensland**, the deadline for a health committee inquiry to report to Parliament was extended from November to March next year, raising doubts whether a bill could be passed before the state election in October.

Reports said progress on an assisted dying law in **New South Wales** had stymied after a divisive debate on abortion fired up socially conservative opponents.

Lawmakers in **Tasmania**, which rejected a law change by one vote in six years ago, were reported to be deadlocked on the issue.

BRITAIN Eighteen police and crime commissioners wrote to the Secretary of State for Justice calling for an inquiry into the current law on assisted dying, which imposes a maximum 14 year gaol term for helping someone end their life. They said the law “has caused distress, confusion and pain for dying people, their loved ones, and even the investigating police officers themselves.”

The letter followed news that Ron Hogg, the Police, Crime and Victims Commissioner for Durham, has been diagnosed with motor neurone disease and wishes for a law change to allow him to end his life. It said: “We believe it is time for a renewed look at the functioning of the existing law on assisted dying.”

The police chiefs’ call was backed up by a cross-party group of 24 MPs in a letter to *The Guardian* urging the government to review the law.

“While there are clearly differences of opinion as to whether or how the law should change, we contend that the law is not working as well as it could and seek an inquiry to confirm that.” The letter referred to several recent high profile cases, including that of Mavis Eccleston, 80, acquitted of murder and manslaughter by a jury in September after being charged with helping her husband, who was suffering from advanced bowel cancer, end his life. The court in Stafford heard that Mavis and her husband, Dennis, 81, who had been married 60 years, made a pact to end their lives together. They both took an overdose of medicine but she survived. They had written a note to their children explaining their decision.

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Dignity in Dying UK reported research showing that 17 people a day suffered as they died, even if everyone had access to the very best palliative care. Another report of interviews with GPs, palliative care consultants and nurses, patients and bereaved families said 11 terminally-ill people in Scotland died in pain every week.

The High Court rejected in November a bid by motor neurone disease sufferer, Phil Newby, 49, (See Newsletter No.54) to challenge the law that makes assisting a death a criminal offence. Lord Justice Irwin said: "It is impossible not to have very great sympathy for the situation in which Mr Newby finds himself. "His clear and dignified statement compels admiration and respect."

But the judges said the court was "not an appropriate forum for the discussion of the sanctity of life". Newby cannot walk or use his arms and his lawyers said he would appeal to a higher court.

BELGIUM Marieke Vervoort, a gold-medal winning Paralympic athlete who suffered from reflex sympathetic dystrophy and made headlines around the world in 2016 when she revealed that she wanted medical assistance to die when her illness became too much to bear, carried out her end-of-life wish on October 22. She was 40.

Her degenerative spinal condition caused constant pain and made sleeping very difficult. She won gold and silver medals at the 2012 Paralympics, competing in the T52 classification for athletes with limited or no mobility below their waists and impaired motor skills in their arms and hands.

She won two more medals at the 2016 Paralympics in Rio, and retired admitting it had become "too hard on my body". As required by Belgian law, three doctors had approved her application for MAiD. "I no longer have a fear of death," she said. "For me, it's something peaceful. I don't want to suffer when I'm dying. I think there will be fewer suicides when every country has the law of euthanasia. I hope everybody sees that this is not murder, but it makes people live longer."

ITALY Euthanasia is justified in cases where a person is suffering from an irreversible condition and "intolerable" pain, Italy's constitutional court ruled in a landmark decision in September.

Judges said that, in certain circumstances, anyone who "facilitates the suicidal intention... of a patient kept alive by life-support treatments and suffering from an irreversible pathology" should not be punished. They said that assisted dying should be allowed if a patient had an irreversible condition causing severe physical and psychological suffering.

The court decision centred on the case of Marco Cappato, a right-to-die activist who was accused of assisting the suicide of Fabiano Antoniani, 40, left a tetraplegic after a car accident in 2014. The man, better known as DJ Fabo, died at a Swiss euthanasia clinic in 2017.

Cappato, who was charged with "instigating or assisting suicide" welcomed the ruling, saying that "as of today, all of us in Italy are freer."

SWITZERLAND

The Swiss assisted dying organisation Dignitas, which started operations 20 years ago this year, reported in July that its membership had topped 10,000 for the first time.

"It shows that our cause is finding increasing support worldwide," it said. "It also confirms that many people who are by law denied their right to a self-determined end of life where they live do not simply put up with this. They support our international efforts to implement and preserve their freedom of choice in "last matters" and they want to be able to claim this right for themselves should they ever, due to unbearable suffering and without hope of improvement, come to the conclusion that they want to end their lives in a manner they personally consider dignified."

Another Swiss voluntary assisted dying association called Pegasos, based in Basel, announced its formation in August. Pegasos said it had been founded by the same Swiss professionals who helped 104-year old Australian Professor David Goodall to die in May 2018.

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Its staff had worked in other assisted dying Swiss clinics for the past decade.

USA Opponents of Maine's Death with Dignity Act failed to get enough signatures for a state-wide ballot to veto the measure (See Newsletter No. 54) and it came into effect as scheduled on September 19.

Courts in New Jersey, which became the ninth state with an enlightened law in August, also rejected bids to stop its operation.

WHAT THEY SAID

"Pain is a part of life; but it seems cruel and heartless to try and not ameliorate suffering when we can do so." Chris Bishop, National MP.

"Young people are tragically opting out of their lives because they are not receiving support and they don't have faith in a better future. They've had autonomy and choice stolen from them. Don't dare equate that to people on their death bed seeking dignity in their final days." Chloe Swarbrick, Green MP.

"It is not up to the government to decide who may die and who may live, when they shall die or how long they shall live." Janet Mills, Governor of Maine, signing the state's Death with Dignity Act.

"After careful consideration, internal reflection and prayer, I have concluded that, while my faith may lead me to a particular decision for myself, as a public official I cannot deny this alternative to those who may reach a different conclusion. I believe this choice is a personal one and therefore signing this legislation is the decision that best respects the freedom and humanity of all New Jersey residents." Governor Philip Murphy, signing his state's Medical Aid in Dying for the Terminally Ill Act.

BRANCH EVENTS

Bay of Plenty **Friday 13 December 2019** **10am**
Friday 14 February 2020 **10am**
Coffee morning group at Zest Café, 187 Chadwick Road, Greerton, Tauranga

Christchurch **Sunday 1 December** **1.30pm**
Sydenham Room, South Library, 66 Colombo Street, Christchurch
EoLC President, Dr Mary Panko, will speak on the progress of the EoLC Bill.
All South Island members are welcome!

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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*.

The book contains moving accounts of bad deaths of relatives and friends as told in heart-breaking submissions to Parliament's Health select committee. This can be downloaded free on our special campaign website www.eolc.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 321, Gisborne 4040.

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 321, Gisborne 4040**
- 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.

- 1 You can download a FREE copy, which you can print yourself from the website <http://www.eolc.org.nz>
- 2 If you would prefer a printed and bound booklet to be posted to your home address for just \$18, send an email to office@eolc.org.nz or write to **PO Box 321, Gisborne 4040**. You can make payment by cheque or direct debit to our account 38 9006 0226 03602. Include your name and the word "**Guide**" if using Internet banking.

