



End-of-Life Choice

May 2017 VOLUNTARY EUTHANASIA SOCIETY OF NEW ZEALAND INC Issue 47
Member of the World Federation of Right to Die Societies

OREGON'S 20-YEAR PROOF FOR OUR MPs

Nearly 20 years after the US state of Oregon pioneered far-sighted legislation allowing physician assisted dying for the terminally ill and suffering, we approach our annual general meeting next month still waiting to see if our politicians have seen the light.

After all, it is not as if they are being asked to step boldly into the unknown. Since Canada and California joined the ranks last year, there are now 10 jurisdictions in Europe and the US with a total population of over 110 million where medical assistance to die is legal.

Close to 20% of Americans now live in states where adults can legally get help to end their lives if they are terminally ill and meet eligibility requirements.

A new study shows that the Oregon law is working exactly as was intended (**See Page 7**). The number of assisted deaths over the last 20 years accounts for less than 0.2% of all deaths in the state and no cases of failure to comply with the law's strict safeguards have been referred to the authorities.

About one-third of all sufferers who received a physician-dispensed lethal drug did not use it, happy to have the end-of-life choice it gave them. Four out of every five who did take it had cancer and while most who applied were enrolled in hospice care at the time, almost all who took it died at home in the company of loved ones.

It all goes to prove the saying about a law change: "No more will die, but fewer will suffer."

We were offered a glimmer of hope last month that Parliament's Health Select Committee has been listening to our submissions in its inquiry into the issues surrounding voluntary euthanasia.

Committee chair Simon O'Connor – an avowed Catholic who has made no secret of his personal opposition to a law change – hinted in an interview with Radio NZ's Focus on Politics on 7 April that it would make some recommendations to the House of Representatives when it reports.

"I suspect there will be recommendations," he said. "I think at this stage it probably will go further than simply (ask) the House (to) take note of its report. I think there are some elements coming through - most members, if not all, think there are some things we should be recommending further here."

THE PRESIDENT'S LETTER

Kiaora koutou katoa – greetings to you all.

There has been much activity since our last newsletter in February. The Health Select Committee continued to hear submissions on our petition around the country up until the end of March, giving our cause much exposure in regional and local media. Thanks to all of you who steeled yourself to present your submission in person. It is not an easy task and all our members acquitted themselves extremely well, leaving the MPs present with no doubt as to the urgency and fundamental human rights imperatives for law reform in end-of-life choice.

With the 23 September election looming, members need to identify and approach ALL candidates in their areas, letting them know that we expect them to have thought about end-of-life choices and be able to give us a clear idea of where they stand on the issue. We need to know how they would vote on an End-of-Life Choice Bill if they were elected or remain an MP. All candidates need to know that this issue will not go away and that they WILL be asked about it at public meetings. Resource material for you to use is available on our website and from your branch chairperson.

It also means that it is even more unlikely that David Seymour's End-of-Life Choice Bill will be drawn

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from the Members' ballot between now and when the current Parliament rises for the last time in August. We will be planning our post-election campaign soon, so that we can approach the incoming government with a proposed Bill as soon as possible.

Meanwhile, we have a wonderful opportunity in the forthcoming visit of Professor Jan Bernheim from Belgium. His lifelong and professional involvement in palliative care will help to inform and educate New Zealanders about his country's voluntary euthanasia laws and system. **(See Pages 3 & 4 for details).**

I hope to see many of you at our AGM in Auckland on 17 June. Thank you all for your ongoing support and activism. We could not achieve what we do achieve without you.

With best wishes **Maryan Street**

WE HAVE A GOOD CAUSE - CAN YOU HELP?

You know we are fighting for a good cause – that is why you joined VESNZ.

You also know it costs money to fight for a cause you believe in.

We don't often ask you for more money on top of your annual membership subscription, but afraid this is one of the times we do need a bit more help.

- We have committed to two major items of expenditure this year:**

Firstly legal action against the Police for invasion of privacy and harassment last year as they mounted bogus and illegal breath-testing traffic checkpoints that stopped VESNZ members leaving a private meeting at which end of life choices were discussed;

Secondly the significant forthcoming visit of Professor Jan Bernheim, an expert in palliative care who has for many years been at the forefront of legal and professional changes in Belgium which led to that country's Voluntary Euthanasia system. We are funding his tour of New Zealand this year during which he will be guest speaker at our AGM in Auckland on June 17.

We are appealing for donations to help meet the costs of these activities which are above our usual administrative functions and cannot be sustained by your membership fees.

- Please consider helping.**

Donations by cheque can be posted to:

The Administrator, VESNZ - PO Box 48241 - Silverstream - Upper Hutt 5142.

Or they can be made directly by internet banking to our account:

Name: VESNZ Inc. - **Account No:** 38-9006-0226036-02 -

Reference: Please include your name here - **Code:** Donation

THANK YOU FOR YOUR KIND AND GENEROUS SUPPORT

YOU WOULD DO IT FOR A DOG

While having a pet euthanized could be a harrowing procedure for the owners, it was often one they were most thankful for, a veterinarian told the Parliamentary health select committee's inquiry into euthanasia.

An owner would often comment: "I wish we could have done this to grandma", said Jenny Weston, Dean of Massey University's Veterinary School. "There's certainly a strong view that we are kinder to animals." The committee had asked for specific evidence on the mechanics of the process from veterinarians and an anaesthetist.

The Dominion Post reported on April 6 that Weston told the committee: "Bizarrely, it's one of the most appreciated things by clients - you get more cakes and boxes of chocolates from grateful clients after doing a good job of euthanasing a much loved animal than you do for repairing a terribly fractured leg."

She said the process often triggered emotional responses if owners had also watched a loved family member suffer in their last years.

New Zealand Society of Anaesthetists' President Dr David Kibblewhite said a similar procedure was carried out almost daily as part of open heart surgery. A person is given a sedative and a muscle relaxant followed by a barbiturate that would "arrest" the heart, which cannot be beating or drawing oxygen while a surgeon is operating. It's restarted once the operation is complete and in a euthanasia procedure it wouldn't be restarted. "It's not all that complicated really."

HOW TO PUT THE PRESSURE ON ELECTION CANDIDATES

Political parties and community groups will soon be organising public meetings to introduce the candidates for the general election on September 23.

VESNZ would like members to make Physician Assisted Dying (PAD) an election issue and President Maryan Street has drafted some suggestions on how to go about that.

As a former MP she knows the tricks of the trade, of course, and here are some invaluable tips: Make appointments with ALL candidates in your electorate, including all List candidates. Talk to them about the need for a law change.

Be sure to cover all parties and ask questions of every candidate.

Even if you have visited a sitting MP before, make sure they know that you will be repeating these questions to each candidate at every public meeting they attend.

With VESNZ member friends, draw up a roster when you know dates of meetings in your electorate and ensure that at least one of you attends. Remember – this is the one time when candidates really DO want to hear from you!

Ask them these questions:

- Where do you stand on the issue of physician assisted dying or voluntary euthanasia?
- How would you vote on the 1st, 2nd or 3rd reading of a bill which permitted PAD, seeing it will always be a conscience vote?
- Would you urge a government in which your party was a coalition partner to introduce PAD as a government measure (while still being a conscience vote)?
- Would you vote the way a majority of your electorate wanted you to vote on the issue, even if it was contrary to your own position?

Don't be afraid to make candidates fearful of seeing you approaching over a cup of tea after a public meeting. They need to know that this is an important issue to people in their electorate. Note their answers and send them to office@ves.org.nz for us to collate.

Take a friend who can keep the notes while you are asking the questions.

BELGIAN EXPERT COMING FOR SPEAKING TOUR

Professor Jan Bernheim, a Belgian who is one of the world's leading experts in palliative care and end-of-life issues, is coming to New Zealand this month for a nine-city speaking tour.

He will open his tour in Tauranga on May 27 and speak in five other North Island centres, Christchurch and Nelson and at the VESNZ annual general meeting in Auckland on June 17.

Belgium was the second country to legalise voluntary euthanasia, in 2002, and Professor Bernheim, a retired doctor and oncologist, was co-founder of the first palliative care service on the European continent in 1979.

An internationally-renowned lecturer in medical ethics, he is a senior researcher in the End-of-Life Care Research Group at the Vrije Universiteit Brussel (Brussels) and Ghent University, one of the world's largest organisations specialising in the subject.

He was an expert witness in the legal proceedings on assisted dying in Canada that led to that country passing legislation to allow medically assisted dying for the terminally ill.

VESNZ is sponsoring his visit in order to raise public awareness and provide information on the issue from an international expert in the lead-up to the general election.

With Parliament's Health Select Committee preparing to release a report on its public inquiry into voluntary euthanasia, VESNZ wants to make physician assisted dying an election campaign issue.

Professor Bernheim says the Belgian experience showed that the development of palliative care and the process of legalising voluntary euthanasia could be mutually reinforcing.

He says the provision of adequate palliative care in Belgium made the legalisation of euthanasia ethically and politically acceptable.

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No health professional organisation explicitly opposed the euthanasia law in Belgium, he says, noting that the ethics committee of the national Caritas network of Catholic healthcare institutions (which runs over 70% of Belgian hospitals) had co-operated and drafted a guideline for the application of the euthanasia law.

□ **Jan Bernheim's itinerary**

Saturday 27 May	1.30pm	Tauranga	Public Meeting, Vintage Car Clubrooms, 17 Cliff Road, Tauranga 3110.
Sunday 28 May	2pm	Hamilton	Public meeting, Southwell School Performance Centre.
Monday 29 May	7.30pm	New Plymouth	Public meeting, Community House, 32 Leach Street.
Tuesday 30 May	12.30pm 7pm	Palmerston North "	Private meeting at the Post Graduate Medical Society. Public meeting, St Peter's Anglican Church, Ruahine Street.
Thursday 1 June	10am	Napier	Public meeting, E.I.T. 501 Gloucester St, Taradale.
Saturday 3 June	2pm	Wellington	Public meeting, Wellington Central Public Library.
Sunday 4 June	1:30pm	Nelson	Fairfield House, 48 Van Diemen Street
Monday 5 to Friday 9 June		Wellington	Private meetings with professional bodies in Wellington.
Saturday 10 June	2pm	Christchurch	Public meeting, Burnside Bowling Club, 330 Avonhead Road.
Friday 16 June		Auckland	Private meetings.
Saturday 17 June	2pm	Auckland	VESNZ AGM, Holiday Inn Auckland Airport, 2 Ascot Road, Airport Oaks.

"LAW CHANGE INEVITABLE" SAY NURSES

The New Zealand Nurses Organisation has abandoned its neutral stance on medically assisted dying and has chosen "a principled approach" to advocate for patients having the option, it said in a draft position statement released this year.

The NZNO said recent and highly publicised requests to legalise medically AD in New Zealand indicated a change in public opinion on the right to choose. "Given international trends, it is inevitable that some law will be passed in New Zealand which legalises AD.

"It is extremely important that nurses are involved in the formation of that law to ensure better resourcing and support is available to care for people who are dying. We can also learn from holistic indigenous models of care that openly discuss life and death issues as a way of life rather than way of dying."

The NZNO said its concern was focused on the impact of legislative changes that may affect the day-to-day practice of nurses who work with dying people.

"This approach includes:

- taking a progressive stance in championing individual right to make a fully informed choice.
- ensuring that our members are informed, are safe and competent in their practice and understand their professional and legal obligations.
- lobbying for law changes for those members who wish to object on the grounds of conscience to being involved in AD services; and
- developing clear guidelines to ensure that all nursing and non-nursing staff involved with individuals who are dying across the care continuum have AD training, as death and dying is not restricted to one setting."

OBITUARY



RIP The Very Rev. John Stewart Murray, MA (Otago), MA (Cantab), ONZM
5 November 1929 to 17 February 2017

John Murray was an active member of the VESNZ National Committee who worked tirelessly in crafting the piece of legislation that became the End-of-Life Choice Bill tabled in Parliament by our President, Maryan Street, MP. He was also inaugural chair of the Kapiti-Horowhenua branch.

And he was so much more besides. A scholar and modern theologian, he campaigned vigorously on a range of other social issues including reform of abortion and homosexual laws, human rights, anti-apartheid, and outlawing nuclear weapons at the International Court of Justice. He was an outspoken opponent of New Zealand's involvement in the Vietnam War.

John was founding chairman of the Citizens' Association for Racial Equality (CARE) in 1969 and was active in the Halt All Racist Tours (HART) movement that opposed sporting contacts with apartheid South Africa. He campaigned to save heritage buildings in Wellington and was a member of Amnesty International.

He was ecumenical chaplain at Victoria University of Wellington 1962-67 and Minister of Knox Church, Christchurch, 1967 to 1975 when he moved to St Andrew's on the Terrace in Wellington, turning that church into a centre of social and political debate and action. He was a close friend of the Rev Professor Sir Lloyd Geering, who was tried by the Presbyterian Church for heresy in 1967, and the controversial 99-year-old theologian spoke at John's funeral.

John was Moderator of the Presbyterian Church's General Assembly in 1990-91 and founding chairman of the St Andrew's Music Trust.

His frenetically active life denied his stated recreations in *Who's Who in NZ* of "Swimming, sunbathing and doing nothing."

Maryan Street, EOLC/VESNZ President, recalls:

"John was a presence in my life since I was young person growing up in the Presbyterian Church in New Plymouth. He was the Minister at St Andrew's on the Terrace when I started university at Victoria and I was aware of him being made Moderator of the Presbyterian Church.

"He seemed to me the very epitome of a modern, thinking Christian – wrestling with contemporary issues from a base of profound and informed faith. So it was a great pleasure and privilege to end up working with him on what was to become my Member's bill in the Parliamentary ballot. He was endlessly patient, consultative, intelligent, farsighted and kind.

"He came to support me when I gave my initial submission on the VES petition in August 2015, even though his health was not so good by then. He communicated with me frequently over the bill, the petition and the wider VES purpose. I miss his wisdom and his commitment daily.

Moe mai, moe mai, haere atu ra – rest in peace John. Farewell."



NEWS FROM AROUND THE WORLD

AUSTRALIA Victoria remains poised to be the first state to change the law and allow medically assisted dying (See Newsletter 46, February 2017) with the majority of the Labor government's cabinet reportedly in favour, along with all seven Green MPs and a significant number of opposition Liberals.

Legislation is scheduled to be introduced to the state parliament this year and importantly its passage will be supported by the government for the first time in Australia. All previous attempts to change the law in the states have been made through private members' Bills, therefore lacking government resources and backing.

Significantly, state Health Minister Jill Hennessy appointed Professor Brian Owler, a neurosurgeon and immediate past Federal president of the AMA, to chair an expert committee to advise on technical aspects of the

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new law. The AMA has traditionally opposed a law change, even though an internal survey last year revealed its membership was close to being evenly split on the issue.

The Victorian legislation will be similar to that which has operated successfully in the US, allowing doctors to prescribe lethal medication which is taken by patients themselves. The government believes that all citizens are entitled to end-of-life care, consistent with their preferences and values. This includes access to high quality palliative care, the right to consent and refuse medical treatments through advance care directives and, in limited circumstances, the option of voluntary assisted dying for those with a terminal illness who are dealing with unbearable suffering.

It differs from almost all previous Australian proposals, including that defeated by the Speaker's casting vote in **South Australia** in November, which would have permitted a doctor to administer the lethal dose. The Victorian model has a limited exception allowing voluntary euthanasia for patients physically unable to take the medication themselves.

Labor won a landslide victory in **Western Australia's** state election on March 11, raising hopes of a law change there with new Premier Mark McGowan and Health Minister Roger Cook in favour. Cook said the government would not introduce legislation for a change but would back a private member's Bill and allow a conscience vote. The debate was fired on election day when the former head of Palliative Care WA Clive Deverall, 75, took his life after suffering a rare form of non-Hodgkin's lymphoma for 20 years. His widow told his funeral that he left a note saying "Suicide is legal, euthanasia is not".

"It was a message," she said. "If the legislation [to allow voluntary euthanasia] had been in place, I don't think he would have taken his life on Saturday."

Deverall told the ABC in October that palliative care was not the answer for between 4 and 8 per cent of patients in "a distressed state" who should be offered voluntary euthanasia. "The lack of compassionate law in this state will force some people into taking their own lives in a fairly brutal way."

Dr Rodney Syme was named Humanist of the Year 2017, by the Council of Australian Humanist Societies, for his advocacy and support for physician-assisted dying over more than 25 years. He was president of Dying With Dignity Victoria 1996-2007 and, since then vice-president.

BRITAIN **Noel Conway, 67, who has terminal motor neurone disease and is not expected to live beyond the end of the year, has won the right to challenge the UK's legal ban on assisted dying in the hope that he can end his life at home surrounded by his family.**

The High Court had refused his request for a judicial review of the ban but the Court of Appeal overruled its judgement on April 11.

The two judges noted that as Parliament had decided not to change the law and "the matter is no longer under active consideration" Mr Conway should be "entitled to argue that it is no longer institutionally inappropriate" for the High Court to consider the question of the difference between the existing law and his rights under the European convention on human rights.

They said: "It is arguable that the evidence demonstrates that a mechanism of assisted dying can be devised for those in Mr Conway's narrowly defined group that is practical so as to address one of the unanswered questions" in the case of locked in syndrome sufferer Tony Nicklinson, who failed in a similar court bid in August 2012.

CANADA **The new Canadian Association of Medical Aid in Dying Assessors and Providers (CAMAP), which comprises physicians and nurse practitioners, is inviting other interested parties, including administrators, legislators, lawyers and social workers interested in supporting its work to join.**

It will hold Canada's first national conference on MAiD in Victoria, British Columbia, on June 2-3.

ITALY **A popular Italian DJ, blind and paralysed from the neck down after a car crash in 2014, who campaigned unsuccessfully for a law change to allow him a medically assisted death in his own country, died in a Dignitas clinic in Switzerland on February 27.**

Fabiano Antoniano, known as DJ Fabo, had battled for the right to die at home for three years, appealing to the President to "end my nightmare". But debate on a law change foundered 11 times in the Roman Catholic-dominated Italian Parliament.

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Fabo's death provoked sensational headlines in Italy and prompted calls for a former politician, Marco Cappato, who went to Switzerland with him, to be charged with assisting suicide, and face a possible 12-year prison sentence.

UNITED STATES **A new study published in the *Journal of the American Medical Association* shows that Oregon's pioneering Death with Dignity Act, enacted in October 1997, is working exactly as intended.**

It shows that 1,545 terminally ill patients obtained a lethal prescription from a physician between 1998 and 2015 and on average 64% of them took the drug. The median age was 71, nearly 80% had cancer and most cited decreased quality of life, loss of autonomy or dignity as reasons for using the law. Almost all patients took the drugs at home, surrounded by loved ones, with a physician present in only 16% of cases.

The Oregon Public Health Division's annual report showed that 204 people received a prescription last year, down on 218 in 2015. Of those, 114 (55.9%) ingested the medication and died without regaining consciousness while 36 (17.6%) did not take it and died subsequently of other causes.

A total of 133 people died using a lethal prescription in 2016, including 19 who were prescribed the previous year. This brings the total number of assisted deaths in Oregon over the last 20 years to 1,127, just 0.19% of the total number of deaths in the state over that period.

No cases were referred to the Oregon Medical Board for failure to comply with the law's robust safeguards.

Ninety per cent of people who complete a request for assisted dying in Oregon are enrolled in hospice care, disproving speculation that legalising assisted dying will somehow undermine development of end-of-life care.

Physician-Assisted Dying came into effect in **Washington DC** on February 18 after opponents in Congress failed in bids to overturn the new law. But Death with Dignity's Peg Sandeen warned that opposing Federal legislators were looking at ways to block funding.

The **Hawaii** state House of Representatives effectively killed a proposed Medical Aid in Dying Act on March 17 after the state Senate had passed it with a 22-3 vote. That reversed the fate of a similar Bill in 2002 that had failed in the Senate by only three votes.

The new Act, based on Oregon's physician-assisted dying law, was formally "deferred" for changes and amendments after heated debate in the House Health Committee, but commentators said it was unlikely to be debated again for some time.

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NEWSLETTER EDITOR David Barber

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.

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

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PO Box 48 241, Silverstream, Upper Hutt 5142
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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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