

Petition 2014/18 of Hon Maryan Street and 8,974 others

Report of the Health Committee

Fifty-first Parliament Simon O'Connor, Chairperson August 2017

Presented to the House of Representatives

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1 Introduction

Recommendation

The Health Committee has considered Petition 2014/18 of Hon Maryan Street and 8,974 others and recommends that the House take note of its report.

This report gives us the opportunity to summarise, for the benefit of the House and the public, what we heard and considered during our review of more than 21,000 submissions from the petitioner and others. This issue is clearly very complicated, very divisive, and extremely contentious. We therefore encourage everyone with an interest in the subject to read the report in full, and to draw their own conclusions based on the evidence presented in it.

Background

On 23 June 2015, we received Petition 2014/18 of Hon Maryan Street and 8,974 others requesting:

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

The petitioner, Hon Maryan Street, was a member of Parliament between 2005 and 2014. While a member, she sought to introduce the End of Life Options Bill as a member's bill. The purpose of this bill was to provide individuals with a choice about how they end their life and allow them to receive assistance from a medical practitioner to die under certain circumstances. The petition originated with the Voluntary Euthanasia Society of New Zealand (VES) before being adopted formally by Hon Maryan Street. Since leaving Parliament, Ms Street has become the President of VES.

There have been two first reading debates in Parliament on similar bills. Both were unsuccessful. In 1995, members voted 61 to 29 against Michael Laws' Death with Dignity Bill. In 2003, members voted 60 to 58 against Peter Brown's Death with Dignity Bill.

The petitioner's bill was formally removed from the members' bill ballot in December 2014.

Submission process and terms of reference

To fully investigate public attitudes, we agreed to seek submissions from the public. Submissions were open between 27 August 2015 and 1 February 2016. The long submission period allowed time for anyone with an interest in the subject, in New Zealand or overseas, to make a submission.

Members' bills are introduced by members who are not Ministers. There must be at least eight members' bills awaiting first reading on the Order Paper each Members' Day (every second Wednesday). Members' bills are drawn by ballot. Members enter bills in the ballot by lodging notices of proposal with the Table Office and providing a copy of the proposed bill. Further information is available at https://www.parliament.nz/en/pb/bills-and-laws/proposed-members-bills/

To help our consideration of the petition, we formulated our own terms of reference. The terms of reference for considering the petition were:

The petition asks for a change to existing law. Therefore the committee will undertake an investigation into ending one's life in New Zealand. In order to fully understand public attitudes the committee will consider all the various aspects of the issue, including the social, legal, medical, cultural, financial, ethical, and philosophical implications. The committee will investigate:

- 1. The factors that contribute to the desire to end one's life.
- 2. The effectiveness of services and support available to those who desire to end their own lives.
- 3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation.
- 4. International experiences.

The committee will seek to hear from all interested groups and individuals.

We received more than 21,000 unique written submissions from individuals and organisations. Copies of these submissions can be found on the Parliament website www.parliament.nz.

We heard from the petitioner on 14 October 2015.

We agreed to hear from the more than 1,800 submitters who had initially indicated that they wished to appear before the committee. These submitters were invited to meetings in Wellington, Christchurch, and Auckland. Submitters who were unable to make it to these locations were heard by teleconference. A number of submitters were not available for a variety of reasons, often due to scheduling conflicts, and some submitters declined to appear once invited. We eventually heard from 944 submitters over 108 hours of hearings. We began hearing from submitters on 24 August 2016 and concluded our oral hearings on 5 April 2017.

Structure of this report

We have structured the chapters of our report in the following way:

- An overview of what New Zealand's legislation does and does not allow in relation to assisted dying.
- The petitioner's submission.
- Attitudes to assisted dying raised by submitters during the submission process.
- An overview of legislation in international jurisdictions that allow assisted dying and/or euthanasia.
- Information about jurisdictions that have voted against euthanasia in recent years.
- Individual chapters about health professionals and assisted dying, proposed safeguards, palliative care, and suicide. These matters were raised by submitters throughout the submission process. We have given them separate chapters because these topics covered several issues.
- Our concluding remarks.

Petition vs legislation

Because of the amount of public attention around the issue, there was a need to differentiate this process from a separate process which was David Seymour of the ACT Party's End of Life Choice Bill. This bill was entered into the ballot in October 2015 and was drawn from the ballot on 8 June 2017. At the time of this report, the bill had not had its first reading. We were therefore not considering any legislation throughout this process.

Terms used in this report

Submitters held different views on the language used for the subject of assisted dying. Throughout this report, we have used the terms that the petitioner used in her submission.

Assisted dying refers to a patient receiving lethal drugs at their request, which they take by themselves.

Euthanasia refers to a patient being administered a lethal drug. This can be voluntary or involuntary.

Submitters used a variety of terms. They included suicide; assisted suicide; euthanasia; voluntary euthanasia; physician-assisted suicide; medically assisted dying; and medical aid in dying.

As can be seen, there was a wide range of terms used within this debate—from the technical to the colloquial. Medical professionals, lawyers, and ethicists preferred the technical terms such as physician-assisted suicide and euthanasia.

The public's terminology was much more varied. This frequently depended on the submitter's position. Submitters wanting a law change used terms such as medically assisted dying. Those opposed tended to use the technical terms including suicide, assisted suicide, and euthanasia.

We noted that palliative care professionals were very reluctant to use terms such as "assisted dying" because they view their current work as already assisting people to die without it being euthanasia or physician-assisted suicide. For those arguing for euthanasia, there was concern around the use of the technical terms of suicide and assisted suicide because they did not consider the actions equivalent.

2 What does New Zealand legislation allow?

What is not considered euthanasia or assisted dying?

There is general consensus that it is ethically and legally permissible to withdraw treatment at a patient's request or because treatment is not working. This is not euthanasia and section 11 of the New Zealand Bill of Rights Act 1990 provides that everyone has the right to refuse to undergo any medical treatment.

Some submitters believe that euthanasia is commonly practised in New Zealand. This stems from the idea that dying patients are given increased amounts of morphine, which results in their deaths. However, we heard from palliative care physicians and the New Zealand Medical Association (NZMA) that this view is inaccurate. They said that opioids delivered in the appropriate concentration are unlikely to hasten a patient's death. Doses of opioids may increase over time as needed by the patient to manage pain.

It was acknowledged that opioids could have the side effect of hastening death. This is because opioids are powerful drugs, which have risks like any other medicine. However, there is an important distinction between giving pain relief that may shorten a person's life and deliberately causing death.

Advance directives

An advance directive is a written or oral directive by which a person makes choices about future health care procedures. The Code of Health and Disability Services Consumers' Rights allows health consumers to use an advance directive.

Advance directives give individuals the chance to state what they would like to happen if their mental capacity becomes impaired. They are used when a person is no longer mentally competent, is unconscious, or is no longer able to communicate.

Individuals cannot ask for anything in an advance directive that they cannot ask for while conscious or mentally competent. This means that patients cannot request euthanasia or assisted dying in an advance directive.

Crimes Act 1961

It is an offence under section 179 of the Crimes Act (Aiding or abetting suicide) for a person to incite, counsel, or procure any person to commit suicide, if that person commits or attempts to commit suicide as a result, or to aid or abet any person in the commission of suicide. Any person convicted of this offence is liable to a prison term not exceeding 14 years.

Section 63 of the Crimes Act (Consent to death) provides that a person cannot consent to have death inflicted upon themselves. If a person is killed, their consent shall not affect the criminal responsibility of any person who was party to the killing.

Section 160(2)(a) of the Crimes Act (Culpable homicide) states that homicide is culpable when it consists in the killing of any person by an unlawful act. Section 160(3) states that culpable homicide is either murder or manslaughter.

Section 164 (Acceleration of death) provides

that everyone who by an act of omission causes the death of another person kills that person, although the effect of the bodily injury caused to that person was merely to hasten his death while labouring under some disorder or disease arising from some other cause.

The Crimes Act 1961 repealed the previous offence of attempting suicide. However, the offence had been largely superseded by changes in practice formalised by the Health Amendment Act 1960. This Act provided for courts to refer attempted suicides to treatment services.

Prosecutions for assisted dying under the Crimes Act

There have been several high profile cases in New Zealand involving prosecutions for assisted dying and euthanasia. The current law provides for the investigation of these incidents and permits discretion in sentencing. In 2004, Lesley Martin, a former intensive care nurse, was convicted of attempting to murder her mother, Joy Martin. This was done by administering a 60 milligram dose of morphine in 1999. She was released from prison in December 2004 after serving half her 15 month term.

In 2011 Sean Davison was convicted for assisting his 85 year old mother, Pat Davison, to end her life. His mother, who was terminally ill with cancer, was on her 33rd day of a hunger strike. Mr Davison was sentenced to five months' home detention.

In 2012, Evan James Mott was discharged without conviction. He had pleaded guilty to assisting his wife, Rosemary Mott, to commit suicide. Ms Mott was in pain, losing the ability to walk and take care of herself, hated the perceived indignity of her condition, and made the decision to end her life.

Seales v Attorney-General [2015] NZHC 1239

In 2015, a 42 year old Wellington woman, Lecretia Seales, sought declarations that sections 179 and 160 of the Crimes Act (the offence provisions) were inconsistent with sections 8 and 9 of the Bill of Rights Act.

Section 8 (Right not to be deprived of life) states that no one shall be deprived of life, except on such grounds as are established by law and are consistent with the principles of fundamental justice. Section 9 (Right not to be subjected to torture or cruel treatment) states that everyone has the right not to be subjected to torture or to cruel, degrading, or disproportionately severe treatment, or punishment.

Ms Seales was dying from a brain tumour and wanted the legal ability to end her life. Her doctor was willing to administer or provide a lethal drug to Ms Seales to enable her to end her life by herself. However, her doctor was unwilling to do so unless she could be assured that she was not breaching either:

- section 160(2)(a) and (3) (Culpable homicide) of the Crimes Act, if she administered medication to Ms Seales that caused her death, or
- section 179(b) (Aiding and abetting suicide) of the Crimes Act, by giving Ms Seales medication that Ms Seales could take to cause her own death.

Justice Collins did not issue the requested declarations. This was because the changes to the law sought by Ms Seales could only be made by Parliament. Justice Collins stated, "I would be trespassing on the role of Parliament and departing from the constitutional role of

Judges in New Zealand if I were to issue the criminal law declarations sought by Ms Seales".

In his judgment, Justice Collins analysed the offence provisions of the Crimes Act. These were:

- section 160(2)(a) (Culpable homicide)
- section 179(b) (Aiding and abetting suicide)
- section 63 (Consent to death)
- section 164 (Acceleration of death).

Justice Collins concluded that:

- Ms Seales' consent would not provide a lawful excuse to Ms Seales' doctor if she administered aid in dying to Ms Seales (Section 63 of the Crimes Act).
- If Ms Seales' doctor were to administer a lethal dose of pain relief to Ms Seales, this may not be an unlawful act within the meaning of Section 160(2)(a) of the Crimes Act if the doctor intended to provide Ms Seales with palliative relief. This would be on the condition that what was done was reasonable and proper for that purpose even though Ms Seales' life would be shortened as an indirect but foreseeable consequence (Section 164 of the Crimes Act).
- If Ms Seales' doctor were to administer a fatal drug to Ms Seales with the intention of terminating her life, two offences may be committed. By administering a lethal drug, Ms Seales' doctor would intentionally apply force to Ms Seales by the lethal drug being inserted into Ms Seales or through the pharmacological effects of the lethal drug on Ms Seales' body. This could be considered committing an assault, which is an offence under Section 196 of the Crimes Act. In this circumstance, Ms Seales' doctor would also likely have breached Section 200 of the Crimes Act. This makes it an offence to administer a poison or other noxious substance to another person intending to cause him or her grievous bodily harm (Section 160(2)(a) and (3) of the Crimes Act).
- Ms Seales would die by suicide if she took a fatal drug supplied to her by her doctor and died from that drug. This was because Ms Seales would intend to bring about her own death, would be acting voluntarily, not altruistically or subject to coercion, and the immediate cause of her death would be the fatal drug, not natural causes. Therefore Ms Seales' doctor would be exposed to prosecution under Section 179 of the Crimes Act if she supplied Ms Seales with a fatal drug knowing that Ms Seales would use that drug to take her own life, and Ms Seales did so.

Ms Seales then asked for a declaration that sections 160 and 179 of the Crimes Act interfered with section 8 of the Bill of Rights Act. Ms Seales believed that the offence provisions in the Crimes Act, under which her doctor could be charged, meant that she would be forced to take her own life prematurely before her condition deteriorated to the extent that she was no longer able to do so.

Justice Collins' starting point was that section 8 of the Bill of Rights Act does not guarantee that a State will never deprive a person of life. A State will do so only on grounds established by law and where it is consistent with principles of fundamental justice.

Justice Collins found that the offence provisions in the Crimes Act constituted grounds established by law because they were enacted by Parliament.

Justice Collins found that the phrase "consistent with the principles of fundamental justice" had not been determined in New Zealand. Therefore, he relied on Canadian case law, which identified the following three tests in considering whether the principles of fundamental justice were breached:

- The law must not be arbitrary (there must be a rational connection between the objective and the law).
- The law must not be overly broad (it must not go further than necessary to achieve the objective).
- The impact of the law on an individual's life must not be grossly disproportionate to the relevant objective (protection of human life).

Justice Collins ruled that the offence provisions were not arbitrary, overly broad, or grossly disproportionate to the relevant objective.

Ms Seales also argued that her right under section 9 of the Bill of Rights Act was engaged—not subjecting her to torture or cruel treatment—because:

- Her suffering was preventable.
- The State (through the offence provisions) was depriving her of an opportunity to end her suffering.

To reach his decision, Justice Collins reviewed Canadian and United Kingdom case law which dealt with similar arguments. He concluded that Ms Seales' right under section 9 of the Bill of Rights Act was not engaged because:

- Ms Seales' distressing circumstances were a direct consequence of her tumour, not her treatment.
- Ms Seales' treatment was designed to alleviate, to the extent that it was possible, the worst effects of her tumour.
- The State's obligation under section 9 of the Bill of Rights Act was a positive obligation. That positive obligation was not engaged when the criminal law prevents culpable homicide.

3 Submission from the petitioner

The petition originated from the Voluntary Euthanasia Society of New Zealand but was subsequently adopted in the name of Hon Maryan Street and supported by the Voluntary Euthanasia Society of New Zealand. The petitioner told us that the petition was worded to encourage us to consider more than our own views about the subject and to investigate how New Zealanders, regardless of their background, feel about the right to determine their own end-of-life choices.

Factors contributing to a desire to end one's life

In her work as an MP the petitioner stated that she regularly spoke about physician-assisted dying to audiences of 300 to 400 in urban settings and between 50 and 150 in provincial and rural settings. These audiences often consisted of older people.

The petitioner told us that the primary reason people she spoke to gave for supporting assisted dying is a desire for autonomy. Having considered themselves autonomous, self-determining adults throughout their life, supporters believe that they should continue to be autonomous, self-determining adults at the end. The petitioner supports physician-assisted dying when a mentally competent person has one, or both, of the following:

- a terminal illness which is likely to end their life within the next six months
- constant and unbearable physical or psychological suffering which cannot be relieved in a manner that the patient deems tolerable.

The petitioner believes that a mentally competent person should be allowed to make an end of life directive to carry out their wishes should they subsequently become mentally incompetent. End of life directives would be refreshed every five years and could be cancelled or changed at any time. A person registering an end of life directive could appoint one or more persons to advocate for them, should they become mentally incompetent.

The petitioner stated that supporters of assisted dying also cite the fear of dementia and attempting to take their own life unsuccessfully as reasons for their views. The petitioner does not believe that these people are suicidal in the clinically understood use of the word, or suffering from depression that can be treated.

The petitioner told us that these people have decided that they wish to die before they become a different person in the eyes of themselves or their loved ones, or become violent, unpredictable, or a danger to themselves because of dementia. These people wish to die free from pain, surrounded by their loved ones, and without their loved ones breaking any law by assisting them in their death.

Safeguards

The petitioner stressed that safeguards are essential in any assisted-dying legislation. Suggested safeguards include that an individual:

- is a New Zealand resident or citizen
- is aged 18 years or over

- has had two medical practitioners assess that they are mentally competent to decide to end their life and that they fully understand the implications of the decision
- has not been coerced
- has been given 7 days to reflect before taking any drug that will end their life
- has been offered, but not compelled, to have counselling
- has been encouraged, but not compelled, to talk with their family and loved ones
- has not had another person prevent their explicit end-of-life wishes.

Effect of assisted dying on suicide rates

The petitioner told us that people are often concerned that assisted-dying legislation will encourage suicide by others who do not meet the criteria for assisted dying. She noted that people claim that rates of youth suicide in Oregon, where physician-assisted dying is legal, have increased. The petitioner encouraged us to scrutinise these assertions in our consideration of this petition.

Living wills

The petitioner stated that the idea of a living will is a good one and an important part of her draft bill. The petitioner's contention is that a living will should be allowed to incorporate an end of life directive; that is, that the person should have an assisted death given certain pre-agreed conditions, triggered by a nominated person. An end of life directive should not be stopped by someone else at a person's death bed.

Definition of suffering

One of the criteria the petitioner suggests for assisted dying is constant and unbearable physical or psychological suffering which cannot be relieved in a manner that the patient deems tolerable. We asked the petitioner how suffering and tolerability should be defined. The petitioner told us that legislators need to introduce safeguards that provide assurance that people are making their own choices and that choices are not being made for them by other people. The petitioner believes that people need to establish their own threshold of what suffering and dignity are when establishing end of life directives. She said that there should be a protected provision for the person's own definition in any legislation.

We were interested in the situation of people with life-limiting or life-threatening diseases, where death may be more than six months away. We asked about people choosing assisted dying because their quality of life had diminished. The petitioner agreed that, in her proposal, an individual could choose assisted dying if they considered their quality of life had slipped below the level that they could tolerate with dignity or without pain.

New Zealand Bill of Rights Act 1990

The petitioner is concerned that New Zealand's legislative framework does not criminalise suicide but does prohibit assisted suicide. The Bill of Rights Act explicitly allows people to refuse medical intervention. The petitioner told us that she believes people with unbearable suffering often opt to refuse food and water. This can be distressing for the individual and their loved ones. The petitioner believes that it usually takes between 17 and 19 days for an unwell person to die of malnutrition and dehydration.

The petitioner asserted that there are no safeguards when a person exercises their right to refuse medical intervention, food, or water. A person does not have to be assessed by two physicians for mental competence, have any period of reflection, talk to family or loved ones, or seek counselling.

The petitioner emphasised that legislation to allow assisted dying would not directly compel anyone who disagrees with it to choose assisted dying. However, it would make assisted dying available, in certain circumstances and under certain conditions, to those who wish to lawfully choose to end their life.

Effect on palliative care of allowing assisted dying

The petitioner said that opponents of assisted dying have expressed concern that any legislation would compromise and undermine palliative care in New Zealand. She does not view assisted dying as a replacement for palliative care. However, she told us that palliative care is not universally accessible across New Zealand and is not consistent in quality. The petitioner supports additional funding for palliative care and hospices.

Public views

In 2012, when developing her original bill in consultation with the Voluntary Euthanasia Society, the petitioner was contacted by Horizon Research Ltd. It asked for a copy of the bill to conduct a detailed survey on its contents. Horizon sampled 2,969 people online, weighted by age, gender, income, ethnicity, and region to reflect the population. It also weighted by party vote at the 2011 General Election.

The survey found that:

- 62.9 percent of people supported or strongly supported the availability of medical assistance to end one's life in specific medical circumstances
- 12.3 percent of people were opposed or strongly opposed
- 15.8 percent of people were neutral
- 9 percent of people were unsure
- men and women were equally likely to support it (62.6 percent of men and 63.1 percent of women)
- 65 percent of Europeans and Māori, 61.5 percent of Pasifika peoples, 55.3 percent of Asians, and 65 percent of Indians supported it
- slightly fewer Māori (10.2 percent) opposed it
- slightly more Pasifika peoples than average (13.9 percent) opposed it
- support was high amongst the 45 to 54 age group, at 71.6 percent.

We asked about those who are worried about the "slippery slope" argument. Those arguing a "slippery slope" are concerned that any initial restrictions around assisted dying will gradually be removed or abused and an ever-increasing number of people will seek to end their life. The petitioner told us that those who are concerned about widening the scope of assisted dying tend to be more in the middle (that is, not strongly committed to one side of the debate or the other) and need some reassurance about the safeguards.

4 Public attitudes towards assisted dying

Public attitudes towards assisted dying

There are many ways of measuring public attitudes towards assisted dying. One of these is by surveying randomly selected samples of the population (polls). Several recent polls of New Zealanders have shown high levels of support for euthanasia.

Curia Market Research poll

A Curia Market Research poll conducted during the period 14 to 30 June and 7 September to 6 October 2015 stated that "some people believe that the law should be changed to allow doctors to assist in ending the life of a person with an incurable illness, if the patient requests it" and asked, "what is your view on whether voluntary euthanasia should be legal – strongly oppose, somewhat oppose, somewhat favour, strongly favour?"

There were 2,800 responses. The poll found that:

- 66 percent of respondents supported a law change to allow euthanasia
- 20 percent were opposed
- 10 percent were neutral
- 2 percent were unsure.

TV3 news/Reid Research poll

A July 2015 Reid Research poll conducted for TV3 news asked "should law be changed to allow 'assisted dying' or euthanasia?" A total of 71 percent of respondents said yes, 24 percent said no, and 5 percent were undecided.

One News/Colmar Brunton poll

A July 2015 Colmar Brunton poll conducted for TVNZ's One News asked 1,000 people "should a patient be able to request a doctor's assistance to end their life?" A total of 75 percent of respondents said yes, 21 percent said no, and 5 percent were unsure.

These polls were taken around the time of Lecretia Seales' case.²

Submitters' attitudes towards assisted dying

Another way to measure public opinion on assisted dying and euthanasia is to analyse the submissions made to this committee in response to this petition. These submissions provided not only a numerical indication of submitters' sentiments, but also allowed them to explain their position in more detail than could be provided in response to a simple question in a poll.

The majority of submitters were opposed to legislation that would allow assisted dying in New Zealand. Advisers reported that 80 percent of submitters opposed any change to assisted dying legislation, while 20 percent favoured a law change to permit assisted dying.

Seales v Attorney-General [2015] NZHC 1239

We heard from a wide variety of submitters. They included many individuals speaking from personal experience. In some instances it was their own pain or experience of health issues, but more often they recounted the experience of a family member, friend, or loved one. We heard from a range of academics, including lawyers, ethicists, and bioethicists. We also heard from a significant number of medical and health professionals—doctors, nurses, palliative care experts, psychologists and psychiatrists, hospice workers, carers, youth workers, grief counsellors, and social workers. Submitters included representatives from various organisations, including cultural, religious, and professional bodies, as well as advocacy groups from both sides, disability groups, and suicide prevention organisations.

We also took the opportunity to speak with numerous people overseas, often those leading calls for, or opposition to, change in their respective jurisdictions. In respecting the petitioner's request to "investigate fully public attitudes", we were pleased to hear from such a wide cross section of New Zealand society.

A statistical analysis of all submissions was undertaken by one submitter. According to that report, the majority of those writing in support of a law change did so for reasons of choice—both individual freedom and that the law should enable such choices to be made (74 percent of those in favour). The majority of those writing to oppose a law change did so on the basis that human life has an innate value that should be upheld in law (40 percent of those opposed).

Other arguments that predominated among those supporting a law change included the desire to not lose their abilities or a sense of self (41 percent of those in favour), and the desire to not suffer (41 percent of those in favour). Key arguments from those against included the dangers to vulnerable people (38 percent of those opposed) and that modern palliative care is sufficient to treat suffering (31 percent of those opposed).

Another common message in support of a law change was the desire to save families from watching a family member suffer. For those against a law change, a further common issue was concern about sending mixed messages about suicide.

Dignity and independence

Both supporters and opponents of assisted dying raised the idea of dignity. Proponents often defined dignity on the basis of maintaining independence, and physical and mental capacity. There was a clear desire to maintain bodily functions and not become reliant on others. Submitters often spoke of not wishing to be a burden, either to family or society, and commented that to be a burden would lessen their own self-worth. Submitters would often refer to specific circumstances that, for them, would be undignified and unbearable. They described such limitations as making their life not worth living. Some limitations that were frequently mentioned included requiring a wheelchair, needing assistance with toileting, being unable to fully communicate, and developing dementia. Many often spoke of not wishing to spend their last weeks on large doses of painkillers. While not wishing to experience pain, the concern was that drugs might impair their mental faculties and therefore their dignity. Dignity was acknowledged as being specific to each person, so it was up to each individual to define what dignity meant for them.

Opponents argued that this perspective undermines the idea of human dignity by equating an individual's worth with their ability to contribute to society. Several submitters said that this was a very utilitarian perspective and was a threat to the elderly, disabled, and minorities. Dangers could arise if some lives are considered by others to be not worth

living. We heard that assisted-dying legislation would be particularly concerning for disabled people because people could see their lives as being of less value. The view of some supporters of assisted-dying legislation—that needing support to carry out everyday tasks results in a lack of dignity—was seen as inaccurate and demeaning for disabled people. They maintain that, although advocates argue that they are concerned only with perceptions of their own dignity, it would be impossible for their actions not to make an implicit statement about the value of others in similar circumstances.

Some submitters were concerned that disabled people would be pressured to choose assisted dying. However, several submitters who identified as disabled rejected this view, and argued that they should have the right to make end-of-life choices.

Submitters were particularly concerned about dementia, or the loss of independence through another age-related degenerative condition. Several advocates of assisted dying and euthanasia felt that these options should be available to dementia patients, while other advocates felt that such processes should be reserved for those of sound mind. Both groups expressed the belief that the onset of dementia would impinge on their perceptions of dignity. We also heard from many submitters who had cared for parents with dementia and felt that such challenges had enriched their lives. They were concerned that advocating the ending of someone's life is not an appropriate response to serious mental health issues.

The fear of becoming a burden on friends and families—losing one's independence—was also cited as a reason for wanting the option of assisted dying.

Opponents were concerned that the mere perception of being a burden, however that might be defined by individuals, could induce people to end their life. We noted that some submitters spoke of the burden that an ill relative was placing on them and their family. These burdens included physical, mental, and emotional exhaustion, and they commented that they felt relief once that relative had passed.

We also heard from numerous submitters who were concerned that their health issues would place an undue burden on the health system. They often spoke of ending their life so as to free resources for those more in need or younger. An organisation of health professionals spoke in support of euthanasia as an alternative to an increase in funding. It argued that, in the absence of increased funding, assisted dying and euthanasia could play a role in sustaining the health system.

Pain and suffering

Pain and suffering were common reasons for submitters wanting assisted-dying legislation.

Many submitters recounted stories of family and friends who had died in pain over extended periods of time in hospital. They expressed regret about the suffering and felt that this should not have happened and could have been avoided through assisted-dying laws. Many submitters questioned why anyone would let a loved one suffer a prolonged and undignified death when they would not allow the same for a family pet.

Many others feared that they might experience pain and suffering in the future. To avoid this, they would like to have the option of assisted dying. They viewed pain and suffering as "worse than death" and something to be avoided. Submitters were clear that pain and suffering are subjective, noting that what might be unbearable for one person may not be for another. Some submitters thought that pain and suffering should not be confined to physical pain but also include mental and emotional suffering. Submitters noted that in

some jurisdictions, such as Belgium, the suffering necessary to warrant assisted dying was determined by the sufferer alone. There were also submitters who felt that assisted dying and euthanasia should not be limited to those suffering in any particular way but should be available to anyone for any reason. Reasons given included old age and the general "burden of living".

Medical and health practitioners stated that no one should be dying in pain in New Zealand in the 21st century. Instances of this indicated a failure in care and a deviation from the norm. It was also stated that many people misunderstand serious health issues and frequently misinterpret symptoms as indications of pain.

We heard that there have been great advances in pain management, and most pain can be effectively managed. However, some palliative-care clinicians acknowledged that there are some, rare, instances where pain cannot be alleviated. Submitters demonstrated that the public is not clear on whether pain can always be effectively relieved. Members of the public spoke of relatives dying in extreme pain because the pain relief was not working, while many medical professionals stated that such tragedies almost never occur. We found it difficult to reconcile these perspectives and suspect that greater communication between health professionals and the general public is required to explain the dying process and alleviate fear. For example, we heard from several submitters whose dying relatives had stopped eating and drinking in what they perceived to be an attempt to hasten death. We heard from doctors and nurses that this is actually a normal symptom of the dying process rather than a cause. They say that it is not uncommon for people who are extremely ill to lose their appetite and reduce fluid intake.

Several hospices made submissions on the nature of pain and suffering. They pointed out that not all pain is physical, and that in addition to treating physical discomfort, they also pursue the treatment of emotional, social, and spiritual suffering. They argued that the very nature of hospice care and the underlying philosophy of neither hastening death nor prolonging life, precludes the use of assisted dying or euthanasia. While some submitters felt that these options were a perfectly acceptable extension to palliative care, the hospice submitters were unambiguous in their assertions that palliative care and assisted dying are incompatible.

There was some discussion around palliative sedation, the process of inducing varying degrees of unconsciousness in extreme cases in which patients' pain cannot be managed. Some submitters found this practice a perfectly reasonable solution in such cases. Others, however, found it to be an unacceptable treatment, undignified, and one which merely prolonged suffering.

Autonomy

Supporters of assisted dying seek autonomy to make decisions about their end-of-life choices. They said that an essential part of life in a liberal democracy and of medical ethics is individual autonomy: the right to make decisions about the course of one's life. Many submitters felt that current laws circumscribe their right to make decisions about how and when to end their life. They placed a high value on their own autonomy and desired the right to end their life at the time of their choosing.

Other submitters argued that in a society, individual autonomy is frequently limited for the good of other members of that society. They illustrated their point by highlighting the need for traffic speed limits, and controls on guns and tobacco. Public safety was frequently

cited by submitters as a reason why assisted dying could not be legalised. They believed that the individual's right to autonomy must be balanced against the effect that assisted dying could have on others, such as patients' families and vulnerable members of society.

Many submitters felt it was inappropriate to completely remove an individual's right to choose because of the potential risks others may face. The principle of individual freedom is applied widely throughout New Zealand and should not be abridged on this important issue. Many supporters argued that the ability to choose the manner of one's death is a fundamental human right. Supporters expressed certainty that legislators could devise a system which permitted individual autonomy while preserving general public safety, because safeguards would be an essential part of any legislation on this matter. A variety of safeguards were proposed, including age limitations, medical certification, and review panels.

Whether the right to die is a human right was a source of much discussion and debate. Some submitters argued that if there is a right to life there must be a concomitant right to death. Others queried how such a human right could be limited to only certain groups, such as those who are terminally ill or have an intolerable condition. Any human right would have to be applicable to all humans, and to deny it to any group would be discriminatory.

Submitters also raised concerns about an individual's ability to make a truly autonomous decision. Many factors were raised which may influence someone's decision-making process, such as family pressures, financial considerations, social expectations, and frame of mind at a given time. Submissions from several psychiatrists and psychologists, as well as doctors and counsellors, noted that depression and feelings of hopelessness are common responses to terminal diagnoses or chronic pain and suffering. Health professionals expressed concern that an individual's decision-making abilities could be compromised under such circumstances. The belief that one could make a decision to end one's life without being affected by many surrounding factors was highly contentious.

Advocates of assisted dying and euthanasia suggested that any concerns around an individual's ability to make an autonomous decision could be mitigated in various ways. Proposals included assessment by counsellors, a close relationship with a medical practitioner, and the use of advance directives. Others stated that these requirements actually limited or removed personal autonomy. They noted that any requirement to seek the permission of others, such as a counsellor or medical practitioner, was inherently an infringement on their autonomy. This would also apply in the case of advance directives in which someone other than the patient is required to make the decision on their behalf.

Advance directives in particular were seen as a concern by some palliative care specialists because they are written by individuals for circumstances they are not currently experiencing. Health practitioners frequently stated that terminal illnesses and disability are often feared more by those anticipating them than those living with them.

Supporters of assisted dying wished for autonomy to make decisions about their end-of-life choices. Others believed that the right to autonomy needs to be balanced against the effect that assisted dying could have on others, such as patients' families and vulnerable members of society. Several submitters asked why legislation could allow autonomy for one group—those who are terminally ill or have an intolerable condition—but not allow another person the right to autonomy; for example, somebody with depression.

Effect on families

Some submitters were concerned that if there were a change of legislation, some people might request assisted dying and euthanasia only because it was convenient for the remaining family members. They would not want to see people choosing to end their own life because they felt that they were a burden. There is also a risk that some families may pressure a relative to end his or her own life.

Submitters told us about the effect that illness can have on the family members of the dying person. We heard personal stories from many submitters about the trauma of watching family members suffer through what they considered to be a bad death. Palliative care clinicians acknowledged that the dying process can be more traumatic for families to witness than it is for the individual who is dying.

On the other hand, we heard that the end of life can be a chance for families to spend time together and reconcile any past grievances. Submitters were concerned that this special time at the end of life would be lost if assisted dying was legalised.

We heard from some submitters that the current legislation can actually result in less time with loved ones. This is because family members might choose to suicide while they are still able to do so. These submitters pointed to evidence from proceedings in the Seales v Attorney-General case³ that, were assisted dying legal, their loved ones would not have to choose to end their life at that time and on their own. Many submitters advocated assisted dying and euthanasia as a way to prevent people suiciding on their own using unreliable methods.

Numerous submitters conveyed to us tremendous feelings of guilt from being unable to mitigate the suffering of a dying family member. On the other hand, some submitters expressed sadness at the premature deaths of their family members due to suicide. Others were concerned that if, in the future, they were asked to help a family member to die, they might be happy to do so at the time but could later feel guilty.

Grief counsellors and some medical professionals explained the effects of a suicide in the family and expressed concerns about the intergenerational impact. It was stated that families that experience a suicide are at greater risk of further suicides. It was suggested that this could also apply to assisted dying and euthanasia.

Effect on vulnerable populations

Opponents of a law change argued that vulnerable populations, such as the elderly and the disabled, would be adversely affected by assisted-dying legislation. The Ministry of Health could find no evidence of adverse effects on ethnic minorities or the economically disadvantaged in jurisdictions where assisted dying is permitted. In Oregon, for example, 95 percent of individuals accessing assisted dying are white, and more than half have at least a bachelor's degree.

Some submitters pointed out that those groups traditionally considered disadvantaged are not necessarily those most vulnerable on this issue. When it comes to making end of life decisions, these submitters contend that more appropriate markers of vulnerability include difficulties communicating, having a distressing medical condition or unrelieved symptoms, or being socially marginalised.

³ Seales v Attorney-General [2015] NZHC 1239

We heard many different cultural, ethnic, and gender perspectives from groups and individuals. Some raised concerns that women are over-represented in cases of assisted dying around the world. Others expressed concern about the further marginalisation of members of communities that already suffer disproportionately high suicide rates, such as the LGBTIQ* community, where legally assisted dying might be seen as incongruous with anti-suicide campaigns. Cultural reservations were raised as to how assisted dying could be incorporated into cultures that have high regard for the elderly, or traditions that include multi-generational care. Others questioned how legalising assisted dying would affect the already high levels of elder abuse in New Zealand.

While some acknowledged the concerns of these groups, many submitters felt that it was unnecessary to limit the individual choices of some in deference to these groups. They also stressed that they were advocating a voluntary approach to euthanasia and assisted dying, which no individual or group would be compelled to endorse. They further expressed certainty that safeguards could be developed to mitigate any concerns that vulnerable groups may have.

Risk of coercion

Submitters were concerned that individuals could be coerced into assisted dying. Submitters also argued that people with life-limiting illnesses are vulnerable, even if they are well educated and have family support.

Several submitters spoke about the fear that family members would put subtle pressure on individuals because they wanted to inherit, or to avoid spending money on care. Many submitters expressed fear that if assisted dying or euthanasia were institutionalised, the disabled, the elderly, and the ill could experience greater social prejudice. We heard various stories from overseas in which members of these groups felt societal pressure to end their life. Submitters were also concerned that the option could evolve into an expectation, and that the right to die would soon be seen as a duty to die.

Other submitters rejected this view, believing that adequate safeguards would prevent coercion. Some submitters suggested that overseas stories had been exaggerated.

Discretion within sentencing

While many submitters considered it inappropriate for anyone to assist in ending someone's life, some submitters believed that in some cases people could be considered to have acted reasonably in assisting a death, so punishment would be inappropriate. These submitters said people should not fear being punished for helping their loved ones. Others argued in response that the current law adequately addresses the few hard cases in which assisted dying might be appropriate, because the courts have discretion in sentencing.

Widening of scope: the slippery slope

Submitters, regardless of their views, were concerned about the "slippery slope" effect—a tendency for assisted-dying laws to widen beyond the initial intentions. Submitters cited the Netherlands and Belgium as examples of jurisdictions where the scope of legislation to assist dying has widened since it was introduced. Their laws were initially intended only for the terminally ill, but some submitters now point to evidence of assisted dying or euthanasia being used in cases of psychiatric conditions, dementia, depression, and old age.

In Belgium the initial law, passed in 2002, restricted euthanasia to those over the age of 18. However, in 2014 the scope was extended to people under the age of 18 in highly specific

circumstances, including having a terminal condition and where a psychiatrist has deemed them competent.

Some submitters expressed concern that the expansion of scope for assisted dying has seen the number of people ending their life increase. One of the more extreme examples offered by submitters was the increase that occurred in Belgium between 2002 and 2015. The number of people euthanised annually rose from 24 to 2,021. Other submitters argued that changes in scope are part of the democratic process, and that an increase in such deaths only demonstrates public awareness and acceptance over time.

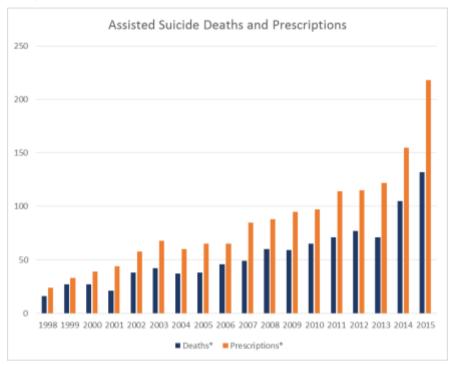
Submitters also expressed concern about the increasing number of people ending their life in jurisdictions where the scope of assisted dying has not changed over time. For example, submitters cited Oregon where the number of people accessing assisted dying had expanded over time. In 1998, when assisted dying was legalised, 16 people took lethal drugs. In 2016, 133 people did so, representing 37.2 per 10,000 total deaths.⁴

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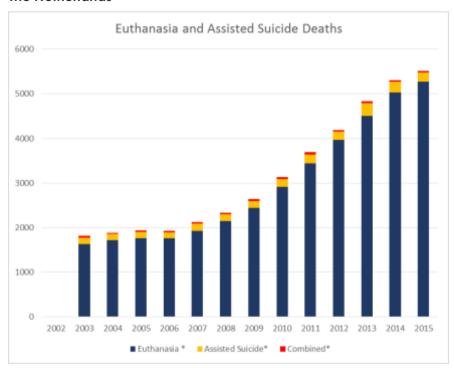
Oregon Public Health Authority (2017). Oregon Death with Dignity Act: Data Summary 2016.

The following graphs show the long term trends in Oregon, the Netherlands, and Belgium.

Oregon⁵



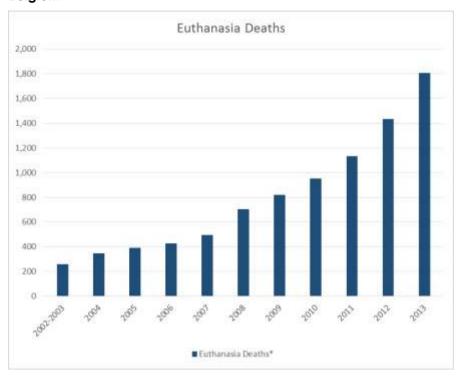
The Netherlands⁶



Murphy S. (2016). Assisted suicide reported in Oregon, U.S.A.: statistics compiled from the Oregon Public Health Division annual Death with Dignity Act reports. Protection of Conscience Project, September, 2016.

Murphy S. (2016). Euthanasia reported in Netherlands: statistics compiled from the Regional Euthanasia Review Committees' Annual Reports. Protection of Conscience Project, September, 2016.

Belgium⁷



Adverse events

There is an assumption among some supporters of assisted dying that a lethal injection is painless and uncomplicated. We asked for statistics about adverse events associated with assisted dying. The Ministry of Health told us that a study in the Netherlands in the 1990s found that technical problems occurred in 35 cases (5 percent), complications in 24 cases (4 percent), and problems with completion in 44 cases (7 percent). Complications were less frequent when the drug was delivered by specialists (only 2 percent of cases).⁸

Data from the Oregon Health Authority is incomplete because it does not require a doctor or other official to be present at ingestion. It shows complications in 3 percent of cases, which are almost always vomiting because the drug can only take by oral ingestion. There was also a highly publicised case in 2005 involving an individual who regained consciousness 65 hours after ingesting lethal drugs.

Other matters

Cultural, religious, and ethnic community views

We heard submitters from a wide range of cultural communities and ethnic groups, and with various religious beliefs, who spoke on behalf of their groups in opposition to a legislative change. For example, many submitters said that their culture's beliefs about death mean that hastening it would be unacceptable to members of that culture. Similarly, people of faith told us that assisted dying was incompatible with their beliefs. Cultural and

Murphy S. (2016). Euthanasia reported in Belgium: statistics compiled from the Commission Fédérale de Contrôle et d'Évaluation de l'Euthanasie Bi-annual Reports. Protection of Conscience Project, September, 2016.

⁸ Groenewoud, J. H., van der Heide, A., Onwuteaka-Philipsen, B.D., Willems, D. L., van der Maas, P. J., & van der Wal, G. (2000). <u>Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands</u>. New England Journal of Medicine, 342, 551-556

Oregon Public Health Authority (2016). Oregon Death with Dignity Act: Data Summary 2015.

religious groups are not homogenous, however we also heard from some members who were in favour of a law change.

Insurance implications

We heard that assisted dying legislation could have insurance implications relating to how a death is reported, the validity of insurance policies, and inheritances. Specifically, that a deliberate action to cause death would invalidate the policy.

Proponents suggested explicit exceptions be made in cases of assisted dying and euthanasia to allow insurance claims to be made. Others suggested that death certificates should make no reference to assisted dying but instead state the underlying condition believed to be likely to cause death. Others believed that this would be falsifying records.

5 Jurisdictions that have voted for assisted dying and euthanasia

Switzerland

Article 115 of the Swiss Federal Criminal Code provides that it is not a crime to assist another person to commit suicide, as long as there are no selfish motives. Euthanasia is not permitted under Article 114 of the Code.

Competent adults can request assistance to commit suicide. There are no medical criteria and doctors do not have to be involved. Swiss law does not require that a person be terminally ill but only that the motive of the assistant is not selfish.

Since the 1990s, Switzerland has had four private right-to-die organisations assisting people to die. These organisations provide patients with counselling and lethal drugs. Swiss citizens and foreigners can seek assistance from these organisations, although not all accept non-residents.

The organisations notify the police and coroner when they assist a person to die. The police and coroner determine whether any crime has taken place. This includes whether there are any selfish motives, the competence of the deceased, and the autonomy of their choice. If they find no evidence of wrongdoing, the death is reported as a suicide. If the suicide does not comply with the law, the case is referred to the public prosecutor.

There are no regulations or official statistics about the number of such deaths in Switzerland because assisted suicides are not recorded centrally by a national body. The lack of regulations appears to stem from the belief that the right to make an end-of-life decision is personal and individual, and the State should not interfere.

Oregon

Oregon's Death with Dignity Act was passed in 1997. Competent adults with a terminal diagnosis can legally be prescribed and self-administer drugs from a doctor if they are a resident of the state. They must have a terminal diagnosis, with a life expectancy of less than six months. A person must make three separate requests (two oral and one written) to access medication. Each request must be separated by a minimum of 15 days. An individual's suffering does not have to be intolerable. Euthanasia is not permitted.

Patients who are approved for assisted dying most commonly ingest a lethal drug, without the presence of their healthcare provider. We heard that those accessing the drugs were meant to have six months to live, but some took them years later. This appears to be supported by an Oregon Government report which notes that in 2007 up to 698 days passed between the prescribing and taking of the lethal drug.¹⁰

Several procedural requirements must be satisfied. Deaths must be reported to the state health department which monitors compliance and issues statistical reports.

Oregon's Death with Dignity Act. (2007).

Netherlands

In 2002, the Netherlands passed the Termination of Life on Request and Assisted Suicide Act. It specifies criteria that give doctors an exception to Article 293–294 of the Penal Code, which makes euthanasia a form of murder.

In Dutch law and society, there is generally considered no distinction between euthanasia and assisted dying. The Act applies to both under the term "euthanasia". The Act codified the practice of euthanasia that had developed through judicial decisions and professional guidelines over the previous several decades. From 1973 onwards, Dutch courts recognised the defence of necessity. This involved a physician assisting an individual to die as the only way to end that individual's unbearable and irremediable suffering.

Patients must be suffering unbearably and have no prospect of improvement to request euthanasia. The law does not require the patient to have a terminal condition but at the time of adoption it was assumed that most patients' unbearable suffering would be due to a terminal condition. This law has not changed, but the interpretation of what constitutes sufficient suffering has broadened. Individuals can now make a request on the grounds of mental suffering.

There must be a close physician–patient relationship for assisted dying. This means that non-residents cannot seek assisted dying in the Netherlands.¹¹

Several procedural requirements must be satisfied. Deaths must be reported to a Regional Review Committee which evaluates all cases to ensure that the requirements are met. The committee assesses whether the physician acted in accordance with the criteria set out in the Act. The committees contain, at a minimum, a medical doctor, an ethicist, and a legal expert. Publicly available statistics are collated by the regional review committees in an annual report.

Minors can request euthanasia from the age of 12. Sick children require parental consent if they are aged between 12 and 16. Youths aged 16 or 17 do not require parental consent but their parents should be involved in the decision-making process. Parental involvement is not required from the age of 18 onwards.

We heard from a submitter about elderly people in the Netherlands wearing "do not euthanize me" bracelets. This is in case they are unexpectedly admitted to hospital or if they are unable to speak for themselves. The Ministry of Health found no evidence of these bracelets. However, a disability rights organisation, the Dutch Patients' Association, has developed wallet-size cards which state that if the signer is admitted to hospital "no treatment be administered with the intention to terminate life". These cards are not commonly used because individuals in the Netherlands generally use living wills to state their choices about euthanasia.

Groningen Protocol

The Groningen Protocol was developed by a team at Groningen University Hospital in 2005. It outlines the conditions under which the Government of the Netherlands considers it permissible for doctors to euthanise infants. The protocol requires that:

• the child's suffering must be unbearable, with no chance of improvement

Netherlands Ministry of Foreign Affairs. <u>Euthanasia: A guide to the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures Act).</u>

- there must be no doubt about the child's diagnosis and prognosis
- the physician and the child's parents must be convinced that there is no reasonable alternative given the child's condition
- the parents must consent to the termination of the child's life
- the parents must be fully informed about the child's diagnosis and prognosis
- an independent physician must have examined the child and agreed in writing that the criteria of the protocol have been met
- the termination must be performed with due care.

Belgium

In May 2002, Belgium passed the Belgian Act on Euthanasia. It was designed to stop the practice of physicians administering life-ending drugs without an explicit request from a patient. This practice was known as LAWER and had been happening in some regions of Belgium.

The Act states that competent patients can request euthanasia from doctors if they have continuous and unbearable physical and mental suffering that cannot be alleviated. The suffering does not have to be physical, but it should result from a medical condition.

The law was expanded in 2014 to include children. However, there are narrower criteria and stricter safeguards. These include being in constant and unbearable physical pain, being likely to die in the short term, and having parental permission. Psychological pain is not considered a criterion for children.

Several procedural requirements must be satisfied for euthanasia deaths. They are more rigorous if a patient is not terminally ill. Deaths must be reported to the Federal Control and Evaluation Commission (FCEC) following the death of an individual. It verifies that the correct procedures were followed and provides statistical reports to the legislature every two years. If two-thirds of the commissioners or more believe that the statutory conditions have not been met, the individual's file is sent to the local state prosecutor. A 2010 study found that in the Flanders region, just under half of all cases were not reported as legally required. However, the study found that the main cause of the under-reporting was that physicians did not perceive the act to be euthanasia.¹²

The Belgian Euthanasia Review Committee collates yearly reports. The Euthanasia Control and Evaluation Commission, which consists of 16 lawyers and doctors, meets monthly in Brussels to review physicians' reports.

The Belgian Act does not mention assisted dying. However, the FCEC has since clarified that the Act includes cases of suicide where a physician has assisted by prescribing or supplying the drugs.

Luxembourg

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In 2009, Luxembourg passed the Law on Euthanasia and Assisted Suicide. Competent adult patients suffering from constant and unbearable physical or mental suffering, without any hope of recovery, can ask for euthanasia or assisted dying from a doctor.

Smets, T., Bilsen, J., Cohen, J., Rurup, M. L., Mortier, F. & Deliens, L. (2010). <u>Reporting of euthanasia in medical practice in Flanders</u>, Belgium: cross sectional analysis of reported and unreported cases. BMJ. 2010;341:c5174.

The patient must make a written request to a doctor. The doctor must then inform the patient about his or her health condition, life expectancy, and about the possible therapeutic and palliative options and their consequences. The doctor must then consult a second physician about the serious and incurable nature of the disorder. The second physician must be independent of the patient and the attending doctor, be competent to give an opinion about the patient's disorder, and examine the patient and report on the findings.

Doctors who perform an act of euthanasia must submit a declaration document within four days to the National Commission for Control and Assessment. The commission consists of nine members and monitors compliance. The doctors must also submit documentation which is reviewed for compliance. A 2015 report found that all cases had been carried out within the legal framework.¹³

United States of America other than Oregon

The following states also allow assisted dying. Their Acts are all modelled on Oregon's:

- Washington: the Death with Dignity Act came into effect in 2009.
- Vermont: the Patient Choice and Control at End of Life Act was passed in 2013.
- California: the End of Life Option Act was passed in 2015.
- Colorado: the Colorado End-of-Life Options Act was passed in 2016.
- District of Columbia: the Death with Dignity Act was passed in 2016.

In 2009, a Montana Supreme Court ruling removed legal obstacles to assisted dying. There is no legislative or regulatory framework, and there are no limits or restrictions on the use of assisted dying. There is no reporting mechanism and no statistics are collected or published.

Colombia

In 2014, a Constitutional Court ruling in Colombia reaffirmed that ending a life was not a crime when it was requested by a terminally ill patient. This followed an initial ruling in 1997. In 2015 the Government published Resolution 2016, which provided a detailed federal policy. This allows adults who are expected to die soon because of a progressive and irreversible serious condition to request euthanasia from a doctor.

Canada

In 2015, the Supreme Court found that the prohibition on euthanasia and assisted dying violated section 7 of the Canadian Charter of Rights and Freedoms. The Court's declaration was suspended to allow the Government to amend legislation.

In June 2016, the Medical Assistance in Dying Act (Bill C-14) received Royal assent. It allows competent adults to request medical assistance in dying if they have a grievous and irremediable medical condition. This covers both assisted dying and voluntary euthanasia. An individual must meet the following criteria:

• They have a serious and incurable illness, disease, or disability.

¹³ Luxemburger Wort (2015). <u>Luxembourg euthanasia report finds no abuses of the law.</u>

- They are in an advanced state of irreversible decline in capability.
- The illness, disease, or disability or the state of decline causes them enduring physical
 or psychological suffering that is intolerable to them and that cannot be relieved
 under conditions that they consider acceptable.
- Their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Individuals who are ineligible for government-funded healthcare and foreign visitors to Canada cannot currently access medically-assisted dying.

The Act provides the following safeguards which must be ensured by the practitioner administering the assisted death:

- The patient must meet all of the eligibility criteria.
- The patient must submit a written request stating that they want to have a medically-assisted death.
- The written request must be signed and dated before two independent witnesses who
 must also sign and date the request.
- The patient's physician or nurse practitioner must ensure that the patient is eligible for medical assistance in dying according to all of the listed criteria.
- A second independent practitioner must confirm the patient's eligibility.
- The patient must be informed that they have the right to withdraw the request at any time.
- Ten days must elapse between the time the patient signs the written request and assisted dying is administered.

The legislation requires that the Minister of Health make regulations to collect information and publicly report on medical assistance in dying in Canada. Consultation with stakeholders and the public is taking place in 2017 to ensure that the regulations are appropriate. The monitoring system, including data collection and reporting activities, will begin in 2018. A year after introducing the legislation, the Canadian Government is consulting on whether to allow additional categories of people, such as mature minors and those with mental illness, to access assisted dying.

6 Jurisdictions that have voted against assisted dying and euthanasia in recent years

United Kingdom

In England and Wales, section 2(1) of the Suicide Act 1961 states that a "person who aids, abets, counsels, or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years."

The Act was primarily designed to decriminalise suicide. In doing so, the crime of assisting suicide was created. The Act indicates that no prosecution should take place without the agreement of the Director of Public Prosecutions.

In Scotland, suicide has never been a crime and no specific crime of assisting suicide exists. However, assisting a suicide is likely to fall under the law of murder or culpable homicide, which is the Scottish equivalent of manslaughter.

Euthanasia is prohibited in the United Kingdom by common law, rather than statute. The common law makes it clear that, except in cases of rape where consent is central to the offence, consent is no defence against criminal charges. Therefore in Scotland, where there is no crime of assisting suicide, a person who kills another can be prosecuted for the crime of murder. Despite the lack of Scottish cases, it can be concluded that although a murder charge is possible, it would be unlikely when the individual was motivated by compassion. The most likely charge would be culpable homicide.

Assisted Dying Bill [HL] 2014-15

The Assisted Dying Bill [HL] 2014-15 was a private member's bill. It started in the House of Lords and was sponsored by Lord Falconer of Thoroton. The bill aimed to "enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes".

The bill reached the second day of committee stage on 16 January 2015. ¹⁴ Line by line examination of the bill took place during this stage.

The 2014/15 session of Parliament was prorogued¹⁵ and the bill made no further progress. It was reported that Lord Falconer considered that such a bill would be best placed in the House of Commons.

Assisted Dying (No 2) Bill 2015

The Assisted Dying (No 2) Bill 2015, a private member's bill, was tabled by Rob Marris MP after he was drawn first in the ballot in the 2015/16 Parliament. It aimed to "enable competent adults who are terminally ill to choose to be provided with medically supervised assistance to end their own life; and for connected purposes".

In the House of Commons and the House of Lords, bills are not referred to a select committee. The committee stage involves line-by-line examination of the separate parts of a bill. Any member of the House of Lords can take part. It usually starts about two weeks after the second reading debate.

¹⁵ This is when a session of a Parliament or legislative assembly is discontinued without dissolving it.

The bill was presented to Parliament through the ballot procedure on 24 June 2015. In the United Kingdom, this is known as the first reading. No debate takes place at this stage. The bill did not pass its second reading debate on 11 September 2015 and made no further progress. It was defeated by 330 votes to 118.

Assisted Suicide (Scotland) Bill

In the Scottish Parliament in 2013, Margo MacDonald MSP introduced a member's bill. It was sponsored by Patrick Harvie MSP following Ms MacDonald's death in 2014. The bill aimed to legalise assisted suicide for individuals who met all of the following conditions:

- had been diagnosed with a terminal or life-shortening illness or progressive condition
- had concluded that their quality of life was unacceptable and that there was no prospect of improvement
- were aged 16 or over
- were registered with a Scottish medical practice
- had the legal capacity to make the decision.

The Health and Sport Committee was designated the lead committee to look at the bill. The Justice Committee was designated the secondary committee.

In its report published in April 2015, the Health and Sport Committee concluded that the bill contained significant flaws, which presented major challenges to the bill being progressed. The majority of the committee did not support the general principles of the bill but made no formal recommendation to Parliament on the bill. This was because the issue of assisted suicide is a matter of conscience.

At the Stage 1 debate in May 2015, which asked whether the general principles of the Assisted Suicide (Scotland) Bill were agreed to, the bill was defeated by 82 votes to 36.

Australia

South Australia

In November 2016 the South Australian Parliament rejected the Death with Dignity Bill proposed by Liberal MP Duncan McFetridge. The bill passed the second reading stage with a vote of 27 to 19. However, when it was examined clause by clause, the conscience vote was tied at 23. The Speaker Michael Atkinson used his casting vote against the bill. The bill would have legalised voluntary euthanasia.

Tasmania

In May 2017 the Voluntary Assisted Dying Bill, co-sponsored by Labor MP Lara Giddings and Greens leader Cassy O'Connor, was defeated in the Tasmanian Parliament by 16 votes to 8 at the first reading stage. This followed unsuccessful votes at the second reading stage in 2009 for the Dying with Dignity Bill (15 against and 7 in favour) and 2013 for the Voluntary Assisted Dying Bill (13 against and 11 in favour).

United States of America

In the last 10 years, multiple pieces of assisted dying legislation have been introduced in 34 states. The majority have been defeated, withdrawn, or discontinued in committee. It is common in the United States for unsupported bills to not be referred back from

committees, rather than for there to be a vote. States which have voted against assisted dying legislation in the recent years are:

- Massachusetts: the Death with Dignity Initiative was defeated in 2012 with 51 percent against and 49 percent in favour.
- New Mexico: In 2017 Senate Bill 252, which would have legalised assisted dying for terminally ill patients, was defeated by 22 votes to 20.
- Maine: In 2017 Bill LD 347, which would allow doctors to prescribe life-ending drugs to those with less than six months to live, was defeated in the Maine House of Representatives by 85 votes to 61.

7 Health professionals and assisted dying

Any discussion about assisted dying or euthanasia almost always involves the role of medical practitioners. Many submitters queried whether assisted dying is compatible with medical ethics and whether it would conflict with the very nature of medicine and other health professions.

Medical ethics

There are four generally accepted principles of medical ethics:

- respect for patient autonomy
- beneficence (doing the best for the patient)
- non-maleficence (doing no harm)
- distributive justice (fairly allocating scarce medical resources).

It is possible to construct ethical arguments both for and against assisted dying, depending on the understanding of and weighting given to each principle.

We heard from the New Zealand Medical Association that, although patients have a right to autonomy in their health care choices, ethical and societal considerations inherently limit personal autonomy. It also pointed out that assisted dying or euthanasia does not only involve a patient's own personal autonomy, it also necessarily requires the involvement of a health practitioner. The New Zealand Medical Association believes that assisting dying is incompatible with medical ethics. The World Medical Association holds the same view. However, we note there are other jurisdictions, such as Belgium, where medical associations support or are neutral towards assisted dying or euthanasia.

We heard from some individual doctors who support assisted dying in specific circumstances. Some submitters noted that Lecretia Seales' doctor was willing to assist her to die. This was only on the condition that the law would allow it and her doctor would not be charged under the Crimes Act.

Other health professionals

Whether doctors would have to be involved in assisted dying was not an area widely covered by submitters. However, if the involvement of health practitioners is required, this does not necessarily need to be restricted to doctors. In New Zealand, an increasing number of other practitioners are able to prescribe medication.

When the New Zealand Nurses Organisation (NZNO) appeared before the committee, it told us that most of the 145 nurse practitioners in New Zealand could prescribe medication. The NZNO told us that nurses have mixed views. However, in the event of assisted dying legislation being passed, it supports individual nurses being able to choose whether to take part in the practice or not.

Would assisted dying affect the public's confidence in doctors?

We were interested in whether assisted dying would adversely affect public confidence in doctors.

Medical practitioners who addressed the committee, as well as other submitters, noted several concerns about doctors' involvement in assisted dying and euthanasia. These included the effect it may have on doctor–patient relations, the effect on the public's confidence in doctors, and the effect on doctors themselves.

Several doctors described the special relationship doctors have with their patients, especially when those patients are seriously or terminally ill. Due to the complicated nature of many treatments and conditions, doctors tend to have considerable power, responsibility, and trust placed with them. Many doctors were worried that their patients' trust in them might be eroded if assisted dying or euthanasia became a legal option.

On a societal level, several doctors were concerned that the legalisation of assisted dying and euthanasia could have an adverse effect on public confidence in doctors. We sought advice from the Ministry of Health about jurisdictions where assisted dying or euthanasia is legal.

The International Social Survey Programme collected data between 2011 and 2013. It found that public trust in doctors was the highest in Switzerland. A total of 83 percent of respondents agreed or strongly agreed with the statement "All things considered, doctors in [our country] can be trusted". In the Netherlands, the figure was 78 percent, while in Belgium it was 74 percent. In the United Kingdom and France, where assisted dying is not permitted, the figures were 76 percent and 75 percent respectively.¹⁶

A 2005 US survey of a random sample of 1,117 adults found that, for the majority of respondents, trust in doctors would not reduce if euthanasia were legal. Respondents were asked about the level of agreement with the statement "that they would trust their doctors less if euthanasia were legal and doctors were allowed to help patients die". Only 20 percent of participants agreed with this statement, while 58 percent of participants disagreed, and the remainder were neutral.¹⁷

Many health professionals talked to the committee about the effect that legalising assisted dying and euthanasia may have on their own conscience, mental health, and their understanding of their profession. Several doctors said that they entered medicine to heal people, not to kill them. They cited studies from jurisdictions where assisted dying is legal demonstrating the negative impact the procedure had on the health professionals involved. They also worried that the right to refuse to participate in such a procedure might not be permanently protected and that an expectation might develop that doctors unwilling to participate would be obligated to refer their patients to someone who would. Some stated that they would not be able to remain in the field of medicine if such concerns eventuated.

Euthanasia and veterinarians

Several submitters suggested that research shows veterinarians to be under worse stress than other professions. The Ministry of Health told us they could not find any research

Blendon, R.J., Benson, J. M. & Hero, J. O. (2014). <u>Public Trust in Physicians - U.S. Medicine in International Perspective</u>. New England Journal of Medicine 371, 1570-1572.

Hall, M., Trachtengerg, F. & Dugan, E. (2005). <u>The impact of patient trust of legalising physician aid in dying.</u> Journal of Medical Ethics. 31(12), 693-697.

that directly compared veterinarians' stress levels with other professions. It told us that some research suggests that veterinarians may have higher levels of stress than the general public.¹⁸ The major causes appeared to be client grief and financial stresses. Euthanasia was considered a further contributing factor.¹⁹

A systematic review of 36 studies found that veterinarians are highly satisfied with their work.²⁰ There appears to be little evidence to suggest that they have poor levels of mental health. However, suicide rates among veterinarians are much higher than for other professionals and the general public.²¹

In 2013, researchers investigated why the rates of suicide were high when veterinarians do not have high levels of stress or mental illness. They concluded that although veterinarians had similar levels of stress and mental illness to the public, individuals with repeated experience of euthanasia were less fearful about their own death.²²

We invited veterinarians from the Massey Veterinary School, the New Zealand Veterinary Association, and the Veterinary Council to appear before us to discuss their experiences of euthanasia. They told us that their primary focus is on animal welfare and they consider euthanasia absolutely justified to ease animal suffering. The veterinarians said it was common when euthanising pets for an owner to comment that they wished that they had been able to do this for a relative.

Veterinarians also euthanise dangerous dogs and animals for which they are unable to find a home. They said that some veterinarians refuse to euthanise healthy animals. However, they noted that this was not a comparable situation for humans, because it is unlikely that healthy humans would be euthanised.

We asked whether animals ever experience any adverse reactions to the lethal drugs. We heard that, provided the drug is injected correctly into the vein, it is usually very peaceful. However, people are often unaware that death entails several normal physiological responses, such as releasing the bladder and gasping for breath in older animals.

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Platt, B., Hawton, K., Simkin, S., & Mellanby, R. J. (2010). Systematic review of the prevalence of suicide in veterinary surgeons. Occupational medicine, 60(6), 436-446.

Wallace, J. E. (2015). The Downs: What Stresses Veterinarians and Technicians Out.

Platt, B., Hawton, K., Simkin, S., & Mellanby, R. J. (2012). Suicidal behaviour and psychosocial problems in veterinary surgeons: a systematic review. Social psychiatry and psychiatric epidemiology, 47(2), 223-240.

²¹ Witte, T. K., Correia, C. J., & Angarano, D. (2013). Experience with euthanasia is associated with fearlessness about death in veterinary students. Suicide and Life-Threatening Behavior, 43(2), 125-138.

²² Ibid

8 Criteria and safeguards

Opponents and supporters of a law change both identified effective safeguards as an important part of any assisted dying legislation. Many of the safeguards proposed were actually eligibility criteria. These criteria and safeguards were discussed by various submitters, though many frequently disagreed on the specifics.

Criteria that may be considered for assisted dying and euthanasia:

- age
- the nature and particulars of a person's condition(s)
- mental competency
- residency status.

Considerations that may regulate assisted dying and euthanasia:

- how many medical practitioners' assessments are required, if any
- the nature of the medical practitioner–patient relationship
- conscience rights of medical practitioners
- availability of appropriate lethal drugs and ancillary equipment
- the need for counselling
- a stand-down period
- family involvement.

Who should be responsible for approving an application for assisted dying and euthanasia:

- the patient alone
- health or medical practitioner(s)
- lawyers
- a committee that might include health practitioners, lawyers, ethicists, cultural advisors, lay people, and others
- a Family Court judge
- a Registrar, assigned by the Director-General of Health, to co-sign for lethal drugs.

9 Palliative care

What is palliative care?

The World Health Organization (WHO) describes palliative care in the following way:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help the family cope during the patients' illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.²³

Palliative care in New Zealand

Palliative care is provided to people of all ages with a life-limiting or life-threatening condition. It aims to enhance a person's quality of life until death by addressing their physical, psychosocial, spiritual, and cultural needs. It also provides bereavement support to a person's family, whānau, or caregiver.

In New Zealand, palliative care services are delivered in the community, including in private homes and residential aged care facilities, hospitals, and hospices.

Primary palliative care is provided by health care professionals as part of standard clinical practice. Individuals are assessed by providers and referred to specialist palliative care services when their needs extend beyond the scope of primary palliative care services.

Palliative care was introduced as a medical speciality in New Zealand in 2001. Specialist palliative care is provided by people who have had specific training or are accredited in palliative care or palliative care medicine. The training includes both an understanding of pharmacology (particularly in relation to pain management) and an appreciation of a

²³ World Health Organization (2017). "WHO Definition of Palliative Care"

person's emotional and psychological needs. This also includes working with families and their needs as they support a dying loved one.

Funding for palliative care

District health boards (DHBs) fund some palliative care services. These include assessment, care coordination, clinical care, and some support services, including grief and loss support services to family and whānau of people receiving specialist palliative care.

Most DHBs do not fund hospital specialist palliative care as a separate service. This is because many elements of palliative care are similar to non-palliative care. Therefore, the services are often integrated with other parts of service delivery and coding, such as long-term conditions.

Additional services to non-clinical patients and family support services are also provided. These are usually provided by volunteers and are funded through community fundraising.

Budget 2015 delivered an additional \$76.1 million of funding for hospice services. This included \$24.1 million over four years to support new palliative care services and innovation in aged residential care, primary care, and community settings. Forty new palliative care positions have been established across 15 DHBs.

Review of adult palliative care services

Between October 2015 and September 2016, the Ministry of Health reviewed adult palliative care services in New Zealand. The purpose of the review was to identify priorities to ensure that New Zealand adults continue to receive high-quality palliative care services when needed.

Increased demand for palliative care services

Demand for palliative care services is expected to increase by 51 percent between 2016 and 2038. This equates to an increase from 24,680 individuals in 2016 to 37,286 in 2038. Based on historic patterns of places of death, by 2038 the need for palliative care is expected to increase:

- by 37.5 percent in public hospitals
- by 84.2 percent in aged residential care
- by 51.8 percent under hospice care. This includes those in hospice services in aged residential care facilities and in the community.

Shortage of palliative care specialists

Some parts of New Zealand are experiencing shortages in palliative medicine specialists. DHBs are also having difficulties recruiting and retaining palliative medicine specialists in some places, particularly rural areas. This creates inequities in access to palliative care.

The sustainability of the palliative medicine specialist and nursing workforce is also a concern. This is because the workforce is ageing. Although this trend affects the whole health workforce, it is particularly relevant to palliative medicine specialists. By 2020, 56 percent of the palliative medicine workforce will be over the age of 65.

An ageing population means that demand for palliative care services will increase. This, combined with the ageing palliative care workforce, means a declining ratio of palliative medicine specialists to people aged 60 years and over.

Palliative care action plan

On 30 March 2017, the Minister of Health launched the Adult Palliative Care Services in New Zealand – Review and Action Plan. The review identified five priority areas to improve services over the next three to five years, while addressing the increased demand for palliative care services over the next 10 to 20 years. The priorities are to:

- improve the emphasis on primary palliative care
- improve the quality of palliative care in all settings
- grow the capability of informal carers in communities
- respond to the voices of people with palliative care needs and their families and whānau
- ensure strong strategic connections.

The action plan supports the review and provides a roadmap to address the five priority areas.

Submitters' views on palliative care

Palliative care services were a common focus in the submissions process. Submitters noted that New Zealand has a high-quality palliative care system, and generally agreed that palliative care is a valuable aid at the end of life. Submitters had different views on whether palliative care was sufficient in New Zealand. Regardless of whether they thought palliative care services are adequate, submitters agreed that palliative care in New Zealand needs more resources. Submitters generally agreed that, in most cases, good palliative care services are available and adequately relieve pain at the end of life. A few submitters suggested that assisted dying and euthanasia could be a further option within the palliative care space. We heard from a significant number of palliative care specialists, doctors, nurses, and support workers. Almost all stated that assisted dying or euthanasia was incompatible with the principles of palliative care.

Some submitters believed that palliative care does not always relieve pain and suffering. Specialists acknowledged that such rare cases do exist, but said they are always due to issues of access, delivery, and misperceptions. We heard that access to palliative care services is not uniform throughout New Zealand, particularly in rural and provincial areas. Late referral to palliative care services and other delays could also potentially diminish the efficacy of the care. Some medical practitioners noted that access to palliative drugs was also restricted by regulations. In these cases, an attending doctor would require the approval of a separate authority. This sometimes leads to the drugs not being used, or a delay in their use.

Some submitters noted that as palliative care has become a very specialised service, more training is needed for doctors and nurses who are not palliative care specialists to better understand what palliative medicine consists of. Further, more needs to be done to encourage new practitioners to enter the field to meet the increasing demand for these services.

These matters may affect the quality of palliative care, but are not a reflection of the efficacy of the service so much as a need to ensure better access to, and application of, the existing services.

Some submitters argued that even if access was uniformly available, there are examples in which palliative care has failed to relieve loved ones' pain and suffering.

When we put these examples to palliative care specialists, nurses, and others working in the field, they stressed that such instances were anomalies. Such cases indicated errors in the delivery of palliative care services, not in the nature of the services themselves. They also noted in these cases that family members frequently misunderstand what is happening to their loved one and this creates a perception that palliative care was ineffective. It is clear that better communication is needed by some palliative care workers to ensure that not only the patients, but family and friends, fully appreciate what is happening.

Specialists stressed that pain is always manageable within palliative care. However, they noted that it is important to acknowledge that life-limiting conditions frequently involve more than just physical pain. In addition to physical discomfort, such conditions often include elements of psychological and emotional pain. These can include anxiety, depression, and feelings of hopelessness. Some medical specialists, including psychologists and psychiatrists, reported that terminal diagnoses were often accompanied, initially, by severe depression, though this often abates with time. Treatment for such pain is an important part of palliative care. People suffering from depression and suicidal thoughts are treated in the same way regardless of whether their underlying condition is terminal or not. A few specialists, and several disabilities advocates, expressed serious concern that terminal patients might seek assisted dying and euthanasia while suffering from the depression related to their diagnosis. Such depression almost always passes if given time and treatment. Concerns about making it easier to end one's life during such episodes were also echoed by suicide prevention groups.

In contrast, some submitters referred to the Oregon model. About a third of individuals in Oregon who have a prescription for lethal medicine filled do not take it. Submitters argued that having options can have a palliative effect. Others expressed serious concern that this phenomenon indicates that a large quantity of lethal prescription drugs is circulating unsupervised throughout the state.

Some submitters were concerned that any change to legislation would lead to reduced support for palliative care services. However, the only study on this issue, conducted in 2015, did not support this assertion. (It compared the development of palliative care services in three countries where assisted dying is allowed with four countries where it is not.) In fact, the legislation may have promoted the expansion of palliative care in Belgium.²⁴

We were concerned to hear that Pasifika peoples and members of other ethnic communities are less likely to access palliative care. We heard that this maybe because the individuals are cared for by families in their own homes. One submitter suggested Pasifika people were not accessing palliative care because they were unaware of its benefits, rather than because they did not want it.

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²⁴ Chambaere, K. and J. L. Bernheim (2015). "Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience." Journal of Medical Ethics 41(8): 657-660.

Our response

We note that there appears to be a lack of understanding from the general public and some submitters about what palliative services can do. We urge the Government to invest in a campaign to better communicate the role of palliative care services in New Zealand, with particular emphasis given to communities that do not generally access the services.

We considered whether hospices should be funded as a core health service, rather than as a service that relies on some community fundraising. However, we note that hospices appreciate the way fundraising allows engagement with the community. Smaller hospices in particular value the contributions that families and the wider community make, and families that have used hospice services appreciate being able to give back.

We recognise that a fully funded model could undermine community engagement. We believe that the Government should investigate palliative care funding and consider whether palliative care should be funded and coded as a separate service. This would ensure that hospices receive a consistent and certain amount of funding each year.

We were concerned to hear that access to palliative care may be uneven around New Zealand, particularly in rural communities and some ethnic communities. We suggest that the Government investigate how it can promptly reduce the inequities in palliative care across the country.

We were concerned to hear that some areas have difficulties in recruiting palliative care specialists and that the sustainability of the workforce is uncertain. We are interested in how the Government plans to address the shortages in the palliative care workforce.

Some doctors expressed concern that it is difficult for primary care doctors to prescribe palliative care drugs, such as dexamethasone. This can create unnecessary delays for patients requiring these drugs. We encourage the Government to improve primary care access to palliative care pharmaceuticals.

10 Suicide

Assisted dying, euthanasia, and ending one's life

New Zealand has a high suicide rate. About 500 people die each year by suicide. Almost three-quarters of those are male. A further 20,000 people attempt suicide. ²⁵ Suicide disproportionately affects Māori, Pasifika peoples, and youth.

The relationship between assisted dying and suicide was a common theme for submitters. Many referred to the definition of suicide and highlighted the parallels to the definition of assisted dying. The World Health Organization acknowledges significant definitional difficulties in its most recent publication on the issue. In its 2014 report, "Preventing Suicide: A global imperative", it defines suicide as the act of deliberately killing oneself.²⁶

Some submitters were concerned that changing the law would be seen as normalising suicide. They felt that it was not possible to make a distinction between a suicide undertaken by someone with a terminal condition and one undertaken by someone without such a condition. Most advocates of assisted dying argued that suicide and assisted dying should not be conflated. They often made a distinction between some forms of suicide and others, suggesting that they can be categorised as either "rational" or "irrational". This distinction was not supported by any submitters working in the field of suicide prevention or grief counselling. On the contrary, we heard from youth counsellors and suicide prevention organisations that suicide is always undertaken in response to some form of suffering, whether that is physical, emotional, or mental. All forms are deliberate and intentional. It was pointed out by a few submitters that when the media cover assisted dying stories, they always accompany the story with suicide prevention contact details.

Many submitters were concerned that if assisted dying was legalised, people would see death as an acceptable response to suffering. It would be difficult to say that some situations warranted ending one's life while others do not. These submitters were concerned that while terminal illnesses would initially be the only scenario in which ending one's life would be considered acceptable, this would quickly widen to include any degree of physical pain, then to include mental pain, and then in response to many other situations that arise throughout life. They pointed to several overseas jurisdictions where they believe this happened, such as Belgium and the Netherlands.

Submitters told us about their experiences of depression and suicidal thoughts. Several submitters suggested that, during their worst periods of depression, they would have opted for euthanasia had it been available in New Zealand.

A submitter suggested that about 5 to 8 percent of suicides are undertaken by sick people. Submitters therefore argued that assisted dying would make suicide less likely. There was some debate as to whether in these cases, "assisted dying" was merely reclassifying those suicides. We heard it argued that when assisted dying is not available, some people intent on ending their lives will do so while they are still physically capable, in a method that they

²⁵ Ministry of Health (2017). A Strategy to Prevent Suicide in New Zealand: Draft for public consultation

²⁶ World Health Organization (2014). Preventing suicide: A global imperative

considered less dignified than assisted dying. These individuals might choose to do this earlier than they might have otherwise done, if assisted dying was available.

Rates of suicide where assisted dying is legal

Some submitters suggested that suicide rates are higher in jurisdictions where assisted dying is legal. We sought advice about this claim. The Ministry of Health told us that there does not appear be any connection between assisted dying or euthanasia and rates of suicide. We heard that because causes of suicide are complex, increases in suicide rates are unlikely to be caused by one single factor, so certainty in this area is very difficult.

Oregon was often cited as an example of a jurisdiction that saw suicide rates increase when assisted dying was made available. While suicide rates in Oregon are significantly higher than the national average, they have been high for the last 30 years. Assisted dying was legalised in Oregon in 1998. Although the rate of suicide declined in 1999, it has grown since then. This follows the United States national trend.

In 2002, the law change in the Netherlands codified accepted practice of doctors not being prosecuted for assisting a patient to die. Suicide rates in the Netherlands had declined between 1987 and 2007. However, they have increased since 2007.

Suicide prevention support services

Submitters highlighted the lack of support services and counselling for families bereaved by suicide. A submitter also suggested that suicide prevention is underfunded.

We asked the Ministry of Health about suicide prevention support services and funding for counselling services. The Ministry of Health told us that the Government is committed to investing in suicide prevention and postvention.²⁷ It defines suicide as "a death where evidence shows that the person deliberately brought about their own death".²⁸ In New Zealand a coronial ruling decides whether a death is classified as suicide.

The New Zealand Suicide Prevention Strategy 2006–2016 provided a framework for suicide prevention efforts. The New Zealand Suicide Prevention Action Plan 2013–16 was a cross-government plan to reduce the risk of suicide, involving eight government agencies. A draft revision of the strategy, "A Strategy to Prevent Suicide in New Zealand", was released for consultation in April 2017, led by the Ministry of Health. It includes new research and evidence about changes in society. The draft strategy does not deal with assisted dying or euthanasia because the Ministry of Health considers that there are separate legal, ethical, and practical issues to consider.

Other initiatives include "Rising to the Challenge", which is a five-year service development plan for mental health and addiction services, the rural mental health initiative in partnership with the Ministry for Primary Industries, and the Prime Minister's Youth Mental Health Project, which takes a cross-agency approach.

All DHBs have suicide prevention action plans for their areas. They include providing suicide awareness and prevention training for influential people in the community, such as teachers and ministers. DHBs also target support to local priority areas, including rural communities, schools, and workplaces.

²⁷ Postvention is an intervention conducted after a suicide. It primarily involves providing support for the bereaved, who may themselves be at increased risk of suicide.

²⁸ Ministry of Health (2017). A Strategy to Prevent Suicide in New Zealand: Draft for public consultation.

The Ministry of Health also funds the following:

- Waka Houra, a national programme which supports Māori whānau, hapū, iwi, and Pasifika families and communities. Annual funding is \$2 million.
- The Kia Piki te Ora Māori suicide prevention service, which operates in eight DHBs, with a long term goal of reducing suicides and harm associated with suicidal behaviour in Māori communities. Current funding is \$1.5 million a year, excluding GST.
- The national suicide prevention training programme. The aim of the training programme is to create a supportive environment or safety net for those at risk of suicide by increasing the number of people aged 18 years and over who are able to identify individuals at risk of suicide in their communities and refer them to agencies and services that can help. The training will increase participants' understanding of suicide risk factors in New Zealand, help them identify signs that an individual may be at risk of suicide, and teach them the skills to intervene safely and constructively. The annual cost is \$530,775.
- The Family/Whānau Suicide Prevention Information Service, which develops and provides resources and information for those bereaved by suicide. Total funding for the current financial year is \$404,000.
- A support service for peer support groups for those bereaved by suicide. Funding for the current financial year is \$120,000.
- A service that works with media to promote safe reporting on suicide, suicide recovery stories, and information on suicide prevention. Funding for the current financial year is \$125,000.
- Training for the facilitators of the WAVES suicide bereavement programme. Funding for the current financial year is \$50,000.
- The Initial Response Service, which supports family, whānau, and friends in the aftermath of a suicide. This is provided by volunteers managed by Victim Support. Funding for the current financial year is \$785,000.
- Expert advice and support for communities experiencing "suicide clusters or contagion", to help them develop an appropriate response. Current funding for this is \$443,000.
- A coronial data-sharing service that promptly exchanges information about suspected suicides with DHBs. This allows them to deliver better postvention responses in the community. Funding for the current financial year is \$84,455.
- MH101 mental health and addictions literacy training, which provides training for "those in front-line positions who in their day to day work or life come into contact with people experiencing mental distress, so that they can recognise, relate to, and respond appropriately to that distress". Funding for the current financial year is \$394,506.

Our response

We acknowledge that the Government, through the Ministry of Health and other government agencies, has done significant work on suicide prevention programmes and providing support services for families bereaved by suicide. However, we were concerned to hear that some people affected by suicide do not feel that they are getting adequate support services and counselling. We encourage the Government to continue to improve access to, and funding for, suicide prevention services and wellbeing education, particularly for young people. We also urge the Government to consider the effectiveness of its bereavement programmes for families, friends, and communities affected by suicide, and consider changes to these programmes to ensure that those affected are able to access grief counselling.

11 Conclusion

We thank the petitioner for bringing this petition before the committee and encouraging us to ascertain the views of New Zealanders on ending one's life in this country. We appreciate that people come from a range of backgrounds and that this is a subject on which people hold strong views. We believe that the written submission and oral hearing process has provided a platform for people to share these views and discuss the issues with us. This report gives us an opportunity to summarise what we heard for the benefit of the House and the public.

Eighty percent of submitters were opposed to a change in legislation that would allow assisted dying and euthanasia. Submitters primarily argued that the public would be endangered. They cited concern for vulnerable people, such as the elderly and the disabled, those with mental illnesses, and those susceptible to coercion. Others argued that life has an innate value and that introducing assisted dying and euthanasia would explicitly undermine that idea. To do so would suggest that some lives are worth more than others. There were also concerns that, once introduced, eligibility for assisted dying would rapidly expand well beyond what was first intended.

Supporters of assisted dying feared their loss of dignity, independence, and physical and mental capacity. Submitters also spoke about the fear of pain and of having to watch loved ones suffer from a painful death. Supporters stressed their personal autonomy and that they should have the choice as to when to end their life.

Many submitters discussed their experiences of palliative care. We commend the service given by palliative care providers and hospices. However, we were concerned to hear that there is a lack of awareness about the role of palliative care, that access to it is unequal, and that there are concerns about the sustainability of the workforce. We urge the Government to consider ways in which it can better communicate the excellent services that palliative carers provide, address the unequal access, consider how palliative care is funded, and address the workforce shortages.

The relationship between assisted dying and suicide was a common concern for submitters. Some believe that assisted dying should not be considered until New Zealand's high suicide rate is reduced. Others believe that the lack of assisted dying legislation means that people are more likely to suicide.

We recognise that a lot of work and investment has gone into suicide prevention programmes and support services. However, we were concerned to hear that people feel that there is a lack of grief counselling. We therefore encourage the Government to investigate improving access to these services.

We have not made any recommendations about introducing assisted dying legislation. We understand that decisions on issues like this are generally a conscience vote.

The petitioner asked us to investigate attitudes towards the introduction of legislation that would permit assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable. However, some submitters thought that the criteria would or should be broader than terminal illness or an irreversible condition. This has made it

difficult for us to consider what the safeguards should be. We were particularly concerned about protecting vulnerable people, such as individuals with dementia or reduced capacity. Some of us remain unconvinced that the models seen overseas provide adequate protection for vulnerable people.

We would like to thank all of the submitters for sharing their stories with us and for the respect submitters showed for opposing views when they appeared before the committee.

This issue is clearly very complicated, very divisive, and extremely contentious. We therefore encourage everyone with an interest in the subject to read the report in full and to draw their own conclusions based on the evidence we have presented.

New Zealand First minority view

New Zealand First congratulates the petitioner for bringing this issue before the Select Committee. Medically-assisted dying is a serious matter and is so serious that it is not one that should be taken by temporarily empowered politicians. New Zealand First cannot support such a fundamental change without a clear sign that this is the will of most New Zealanders. That would be achieved by either a binding Citizens' Initiated Referendum, or a Government Initiated Referendum held with a future General Election thus allowing for a period of informed debate.

Appendix

Committee procedure

Petition 2014/18 of Hon Maryan Street and 8,974 others was referred to the committee on 23 June 2015. We received written submissions from 21,891 individuals and organisations. This total includes supplementary submissions from some submitters. We heard oral evidence from the petitioner and the 944 individuals who wished to appear before us. We received advice from the Ministry of Health.

Committee members

Simon O'Connor (Chairperson) Dr David Clark Sarah Dowie Julie Anne Genter Barbara Kuriger Melissa Lee Dr Shane Reti Barbara Stewart Poto Williams

Ria Bond replaced Barbara Stewart for some of the consideration for this item of business.

David Seymour was a non-voting member for this item of business.

We would also like to acknowledge Hon Jacqui Dean, Kevin Hague, Hon Annette King, and Hon Scott Simpson who were committee members during our consideration and hearings of evidence for this petition.