

# SUBMISSION TO THE JUSTICE SELECT COMMITTEE: THE END OF LIFE CHOICE BILL

WE WISH TO APPEAR BEFORE THE COMMITTEE TO SPEAK TO OUR SUBMISSION

## EXECUTIVE SUMMARY

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**We are opposed to the End of Life Choice Bill.** The dangers of this Bill lie at its very core and cannot be fixed. In fact, any legalisation of euthanasia and assisted suicide creates a distinction in law that places the value of some lives above others.

**The eligibility criteria outlined in the End of Life Choice Bill are vague and broad and do not offer effective protection for vulnerable people.**

- *Terminal illness likely to end his or her life within 6 months:* When a person is “six or eight months away from [death], [the prognosis] is pretty desperately hopeless as an accurate factor.”<sup>1</sup>
- *Grievous and irremediable medical condition:* Canada’s experience with this terminology has included someone struggling with severe arthritis, while similar legislation in Belgium allowed euthanasia for deaf twins who discovered they were going blind.<sup>2</sup>
- *An advanced state of irreversible decline:* While this might seem like an additional safeguard, in practice it merely restates the previous criteria.
- *Unbearable suffering that cannot be relieved in a manner he or she considers tolerable:* This criteria is leading to an increasing number of people in The Netherlands seeking euthanasia “due to mental health problems and trauma caused by sexual abuse.”<sup>3</sup>

**Despite public promises that the End of Life Choice Bill includes many rigorous safeguards to ensure vulnerable people are protected from abuse, closer analysis shows they are not effective or rigorous.**

- *An independent, second medical practitioner’s opinion:* In Oregon and Washington this has led to a selection bias, with a small number of medical practitioners providing euthanasia and assisted suicide for a disproportionately larger number of patients.
- *Conscientious objection and the SCENZ Group:* The SCENZ list of medical practitioners have volunteered to practice euthanasia or assisted suicide and as a result are less likely to be objective in providing an opinion on the patient’s eligibility.
- *Competence Measures:* Determining a person’s competence is incredibly complex. Research has found that in Oregon “some potentially ineligible patients [may] receive a prescription for a lethal drug.”<sup>4</sup>
- *Freedom from pressure:* Detecting pressure requires a long-term relationship with the patient. In both Washington and Oregon, however, some patients only knew their doctor for one week, and in Washington, 52 percent of people cited being a burden on family, friends, and caregivers as a reason for accessing assisted suicide in 2015.<sup>5</sup>
- *Review Committees:* Despite the presence of review committees in the Netherlands, “surveys have shown that, ... not only have doctors in thousands of cases breached the requirement to report, but they have also ended the lives of thousands of patients without the required request.”<sup>6</sup>

**After euthanasia and/or assisted suicide has become law, the number of people who choose to die in this way each year will inevitably grow.** In Oregon for example, 24 people received prescriptions for lethal drugs in 1998, of which 16 died, but in 2017, 218 people received prescriptions for lethal drugs, of which 143 died.<sup>7</sup>

**Around the world, bills that propose to legalise euthanasia and assisted suicide are rejected much more often than they are passed.** In the last year alone, four jurisdictions have rejected euthanasia and assisted suicide legislation, compared to just one jurisdiction where legislation has passed.<sup>8</sup>

**New Zealand should reject the End of Life Choice Bill.** Our ability to choose how and when we die must be limited to protect those people in our society most susceptible to wrongful death. We need to stand in solidarity with the vulnerable in our society with laws that will do their best to protect them. We can only achieve this protection if the law continues to prohibit euthanasia and assisted suicide.

## 1. INTRODUCTION

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We are opposed to the End of Life Choice Bill. This bill is fundamentally unsafe. Its dangers lie at its very core and cannot be fixed.

We recognise that everyone comes to this conversation with a desire for a compassionate response to suffering and uncertainty at the end of life. However, after three years of in-depth research and analysis, considering the international experience of jurisdictions who have enacted similar legislation, it is clear to us that this bill does not present a safe way to respond with compassion. Evidence shows that the criteria and safeguards proposed in the Bill are unsafe and the Bill creates a fundamental distinction in law that provides less protection for the lives of some people than for others. This sends a broader cultural message that some lives are not as valuable as others.

This submission will outline why the End of Life Choice bill is unsafe, particularly through its vague eligibility criteria and inclusion of vulnerable populations. We will then discuss why the proposed safeguards are unable to protect people who are vulnerable to abuse by the law, and examine the international experience—showing how these safeguards and criteria are expanding to include more vulnerable people over time. We will then note that more often than not the legalisation of euthanasia and physician assisted suicide is rejected by parliamentarians who, after careful consideration,

recognise it is unsafe, before concluding with what we can and should do to provide a compassionate response to suffering and uncertainty at the end of life.

We recognise that there are additional reasons for opposing the End of Life Choice Bill, and trust that these will be addressed by experts in the relevant fields of the practice of medicine, the treatment of suicide, and especially the perception of people with disabilities.

*We would like to appear before the Select Committee and make an oral submission.*

## 2. THE BILL ISN'T SAFE: IT CREATES BROAD COVERAGE AND PUTS VULNERABLE PEOPLE AT RISK

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Even advocates and drafters of euthanasia legislation recognise that the practice of assisted dying legislation must be limited. Eligibility criteria plays a key role in this and defines who should, and who should not, have access to the provisions of a specific law. The eligibility criteria outlined in the End of Life Choice Bill, however, are vague and broad and do not offer effective protection for vulnerable people.

### 2.1 Broad eligibility criteria

#### 2.1.1 *The End of Life Choice Bill says:*

4. *Meaning of person who is eligible for assisted dying*  
*In this Act, person who is eligible for assisted dying means a person who—*
  - (c) *suffers from—*
    - i. *a terminal illness that is likely to end his or her life within 6 months; or*
    - ii. *a grievous and irremediable medical condition; and*
  - (d) *is in an advanced state of irreversible decline in capability; and*
  - (e) *experiences unbearable suffering that cannot be relieved in a manner that he or she considers tolerable;*

#### 2.1.2 *Terminal illness likely to end his or her life within 6 months*

Clause 4(c)(i) of the End of Life Choice Bill follows the examples of Oregon and Washington, where assisted suicide is available for terminally ill patients who have a prognosis of 6 months or less to live. While this may sound like a clear distinction between those who are nearing death and those who are not, the reality is not so black and white. Medical professionals will often refer to prognosis as more of an art than a science, which gets more accurate in the final weeks and days of someone's life, but when a person is "six or eight months away from [death], [the prognosis] is pretty desperately hopeless as an accurate factor."<sup>9</sup>

Palliative care expert and professor Baroness Ilorra Finlay and Lord Alex Carlile, barrister, and former Member of Parliament in the United Kingdom, were both members of the House of Lords Select Committee which examined Lord Joffe's Assisted Dying for the Terminally Ill Bill in 2004-2005. They heard that "statements such as 'six months to live' may sound authoritative to the layman, but doctors themselves know that prognosis is an inexact science. As one physician put it to the select committee, 'the reality in clinical practice is that we can be wrong.'"<sup>10</sup> Or as Sandy MacLeod, Adjunct Associate Professor, Palliative Medicine Specialist and Psychiatrist, states, "estimating prognosis in the severely ill remains an imprecise impression. It does become more accurate as death approaches but even in the last days of life, let alone the remaining weeks, some still defy the sincere prognostications of health professions."<sup>11</sup>

This difficulty and inaccuracy of prognoses are also seen in the annual Oregon Death with Dignity data summary where "some individuals with an incurable and irreversible disease may be issued a prescription for lethal medication, opt

not to use it, and live longer than six months.”<sup>12</sup> In fact, in 2017 somewhere between 1 and 14 people who qualified for assisted suicide and were prescribed lethal drugs in Oregon lived beyond their prognosis of six months left to live.<sup>13</sup> A prognosis of “six months to live” is not as clear as it sounds, and this terminology in the Bill would functionally allow access to euthanasia and assisted suicide to people who could otherwise live for months or even years longer than expected.

### *2.1.3 Grievous and irremediable medical condition*

As in clause 4(c)(ii) of the End of Life Choice Bill, Canada allows euthanasia and assisted suicide for a person with “a grievous and irremediable medical condition.”<sup>14</sup> Their experience with this terminology has included everything from cancer patients, to someone struggling with severe arthritis.<sup>16</sup> Practical medical and legal interpretation of this broad terminology could also mean that this includes someone with almost any permanent disability. Under similar legislation in Belgium, media reported deaf twins were deemed eligible for euthanasia after discovering that they were also going blind.<sup>16</sup> When Montana considered the legalisation of physician assisted suicide, a “terminally ill adult patient,” was described as someone “who has an incurable or irreversible condition that, without the administration of life-sustaining treatment, will in the opinion of his or her attending physician, result in death within a relatively short time.”<sup>17</sup> It was found that such a definition was “broad enough to include an 18 year old who is insulin dependent or dependent on kidney dialysis, or a young adult with HIV/AIDS.”<sup>18</sup> Grievous and irremediable medical conditions can clearly include a very wide range of people.

### *2.1.4 An advanced state of irreversible decline in capability*

While at first glance clause 4(d) of the End of Life Choice Bill might seem like an additional safeguard, in reality, the clause restates elements of clauses 4(c)(i) and 4(c)(ii). It is therefore redundant and only creates an illusion of safety.

### *2.1.5 Unbearable suffering that cannot be relieved in a manner he or she considers tolerable*

While we often think of suffering as associated with pain and physical suffering, the term could include mental and emotional suffering. Research from The Netherlands found “patients put more emphasis on psychosocial suffering, such as dependence and deterioration.”<sup>19</sup> In fact, during the United Kingdom’s House of Lords investigation into Assisted Dying for the Terminally Ill, the Royal College of Physicians believed “that it would be necessary to establish also that an expression by a patient of unbearable suffering did not derive from ‘unresolved psychosocial issues,’ which should be identified and treated.”<sup>20</sup> Examples of psychosocial suffering qualifying for euthanasia are found in The Netherlands. In fact, media have reported an increasing number of people there are seeking euthanasia “due to mental health problems and trauma caused by sexual abuse.”<sup>21</sup>

Even if suffering was limited to physical pain, the concept is always subjective and what is “unbearable” for one person will be completely acceptable for another. Rather than society attempting to help in finding solutions to manage that suffering, this will tell these people that the best solution is to give up.

## *2.2 Many eligible people are vulnerable and face heightened risk*

### *2.2.1 People vulnerable to abuse by legal euthanasia and assisted suicide*

Traditionally, socioeconomic categories, culture, and sex are key determining characteristics of vulnerable groups. For euthanasia and assisted suicide, however, this is not the case. Instead, studies have found key vulnerable groups to include the elderly (people aged 65 and above), people with disabilities, people struggling with depression, and people with chronic illnesses.<sup>22</sup> For these groups the legalisation of euthanasia and assisted suicide encourages a significant change in perception of the value of their lives. That is, legalisation encourages people to think that suicide is a legitimate pathway for these people, suggesting that their lives are less valuable, or not worth living.

Other groups that are particularly vulnerable to abuse in a society with legal euthanasia and assisted suicide include those with specific characteristics relevant to the operation and criteria of the law, such as difficulties in communicating, unrelieved symptoms and distressing medical conditions, situation in life (particularly financial situation), and those who feel socially undervalued.<sup>23</sup> For example, the vulnerability of people with a less stable financial situation has become apparent over the past year as numerous stories have emerged from the United States where patients with terminal illnesses were denied expensive, lifesaving treatment by their insurance companies and offered lethal drugs instead.<sup>24</sup>

### *2.2.2 Legalised euthanasia and assisted suicide creates a category of people whose lives are marked as less worthy of living*

This bill divides society into two groups. First, those whose lives hold enough perceived value to be worthy of protection under the law, and second, those whose lives have characteristics that mark them as eligible for euthanasia and assisted suicide and therefore not worthy of the same protection under the law.<sup>25</sup> These people are particularly likely to be vulnerable to the implicit societal message of the law that their life is worth less than others. Amongst these groups there is an increased likelihood of choosing euthanasia or assisted suicide because they feel they are a burden, because they believe their life is less valuable than someone else's, or because they feel a societal obligation to do so. Furthermore, in Oregon eight people named the "financial implications of treatment" as a reason for being assisted to die in 2017.<sup>26</sup>

## **3. THE BILL HAS FEW SAFEGUARDS AND THEY WON'T WORK**

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Despite public promises that the End of Life Choice Bill includes many rigorous safeguards to ensure vulnerable people are protected from abuse, closer analysis clearly shows that this is not the case.<sup>27</sup> In fact, there are very few safeguards included in this Bill, none of which could be classified as "rigorous."

### **3.1 Second, independent opinion**

#### *3.1.1 The End of Life Choice Bill says:*

11. *Second opinion reached*
  - (1) *This section applies if the attending medical practitioner reaches the opinion described in section 10(2) (a) or (c).*
  - (2) *The attending medical practitioner must—*
    - (a) *ask the SCENZ Group for the name and contact details of an independent medical practitioner;*  
*and*
    - (b) *ask the independent medical practitioner for his or her opinion on whether the person is a person who is eligible for assisted dying.*
  
19. *SCENZ Group*
  - (2) *The functions of the SCENZ Group are—*
    - (a) *to make and maintain a list of medical practitioners who are willing to act for the purposes of this Act as—*
      - i. *replacement medical practitioners*
      - ii. *independent medical practitioners*

#### *3.1.2 Selection bias minimises the ability of medical practitioners to be independent*

An independent, second medical practitioner's opinion on the eligibility of a person seeking euthanasia or assisted suicide is not a unique safeguard. We have seen similar examples practiced in Canada, Oregon, The Netherlands, and Belgium.<sup>28</sup> None has proven a truly effective safeguard and have instead resulted in a selection bias with a small

number of medical practitioners providing euthanasia and assisted suicide for a disproportionately larger number of patients. For example, in Oregon, at least one medical practitioner wrote up to 25 prescriptions out of the total 204 written in 2016, and up to 29 of the 218 given to patients in 2017.<sup>29</sup> Medical practitioners who have a conscientious objection or who are not supportive of euthanasia and assisted suicide are less likely to participate in this process. As a result, a small number of medical practitioners who are in favour of assisted dying, and perhaps more likely to consider that eligibility criteria have been met, are writing a large number of assisted suicide prescriptions.

## 3.2 Conscientious Objection and the SCENZ Group

### 3.2.1 *The End of Life Choice Bill* says:

7. *Effect of conscientious objection*
  - (1) *This section applies when—*
    - (a) *a person tells the attending practitioner under section 8(1) that the person wishes to have the option of receiving assisted dying; and*
    - (b) *the attending medical practitioner has a conscientious objection*
  - (2) *The attending medical practitioner tells the person that—*
    - (a) *the medical practitioner has a conscientious objection; and*
    - (b) *the person may ask the SCENZ Group for the name and contact details of a replacement medical practitioner.*

### 3.2.2 *Conscientious objection and the SCENZ Group heighten the danger of selection bias*

The danger of selection bias is heightened under the End of Life Choice Bill as patients can be referred to the SCENZ list of medical practitioners who are willing to practice euthanasia and assisted suicide when their medical practitioner has a conscientious objection.<sup>30</sup> Those medical practitioners included in the SCENZ list are more likely to be in favour of the practice of euthanasia and assisted suicide and as a result less likely to be independent in providing an opinion on the patient's eligibility. This will increase the likelihood of their approving euthanasia and assisted suicide requests.

## 3.3 Competence measures

### 3.3.1 *The End of Life Choice Bill* says:

4. *Meaning of person who is eligible for assisted dying*

*In this Act, person who is eligible for assisted dying means a person who—*

  - (c) *has the ability to understand—*
    - i. *the nature of assisted dying; and*
    - ii. *the consequences for him or her of assisted dying.*

### 3.3.2 *Competence measures are minimal at best*

The competence measures used in the End of Life Choice Bill are minimal. They ask the person to understand the “nature of assisted dying,” and its consequences for that person.<sup>31</sup> When compared to competence measures for other laws this is severely lacking.

For example, the 2005 Mental Capacity Act in the United Kingdom states that “a person is unable to make a decision for himself if he is unable [...] to understand the information relevant to the decision, to retain that information, to use or weigh that information as part of the process of making the decision, or to communicate his decision.”<sup>32</sup>

Likewise, Richard Sainsbury's comments on assessing competence in end of life issues in *Cole's Medical Practice in New Zealand* state that a person must be able to “understand the consequences of choices open to them,” “retain

the necessary information and maintain attention enough to form a judgement based on all the data,” and “outline a process of reasoning for their decision which takes into account the likely outcomes.”<sup>33</sup>

These examples require a person to be able to reason and to use judgements to weigh the pros and cons before making a decision. A person might be able to take in information, but competence also requires the ability to use it to reason to a decision. The End of Life Choice Bill does not require this standard level of competence.

### 3.3.3 *Measuring competence is extremely difficult*

Whether legislation has strict criteria around measuring competence or not, determining a person’s competence is incredibly complex. As MacLeod notes, “depression, dementia, fatigue, and delirium all may adversely impact upon decision-making. The cognitive abilities reasonably required to make a rational decision about suicide have never been established.”<sup>34</sup>

Professor Baroness Finlay and Lord Carlile support this:<sup>35</sup>

*The judgement of mental capacity must be decision-specific: a person may be judged to have sufficient capacity to make some decisions but not others – for example, those with serious risks or consequences. A decision to seek “assisted dying,” if the practice were ever to be made lawful, would be at the high end of the spectrum of risk. This is not to say it would be impossible to be sure that one person seeking “assisted dying” had and another had not the required mental capacity for such a life-or-death decision but rather that there is a large grey area covering persons who lie between these extremes and that, given the nature of the decision, a very high level of assurance of mental capacity would be required.*

Measuring competence is not just asking the right set of questions and filling out a form. This kind of qualitative assessment requires knowledge of a patient’s history, context, and emotional state in order to detect the range of vulnerability factors which can affect competence. These include “communicative difficulties, having unrelieved symptoms or a distressing medical condition, or being socially undervalued,” the presence of which increases in likelihood for those people with terminal illnesses.<sup>36</sup>

### 3.3.4 *Diagnosing depression in terminal patients is complex*

Not only is mental competence difficult to measure, one of the key vulnerability factors—depression—is also particularly challenging to detect in terminal patients and in the “medically frail.”<sup>37</sup>

A study by the New York State Task Force on Life and the Law found that “cancer patients face approximately twice the risk of suicide than the general population does, although few commit suicide.”<sup>38</sup> They go on to state that “treating cancer patients for depression and pain reduces levels of suicidal ideation.”<sup>39</sup> It is concerning then, that “many doctors do not recognise depression or know how to assess for its presence in the terminally ill and that, even when they do recognise it, often think that ‘understandable depression’ is not real depression or cannot be treated.”<sup>40</sup> This is not the reality. MacLeod notes that “depression encourages ‘desire for hastened death’ thoughts, but effective treatment of this disorder may abolish such ideations.”<sup>41</sup>

The difficulty of diagnosing depression in terminally ill patients is highlighted in a study by Professor of Psychiatry and Medicine Linda Ganzini, with colleagues Elizabeth Goy, and Steven Dobscha. The assisted suicide law in Oregon attempted to safeguard against the difficulty of diagnosing depression by requiring a patient to be referred to counselling “if in the opinion of the attending physician or the consulting physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment.”<sup>42</sup> Ganzini and colleagues, however, found that in “some cases [of physician’s aid in dying] depression is missed or overlooked,” and “the current practice of legalised aid in dying may allow some potentially ineligible patients to receive a prescription for a lethal drug.”<sup>43</sup>

## 3.4 Freedom from pressure

### 3.4.1 *The End of Life Choice Bill says:*

8. *Request made*
  - (1) *A person who wishes to have the option of receiving assisted dying must tell the attending medical practitioner of his or her wish.*
  - (2) *The attending medical practitioner must—*
    - (a) *give the person the following information:*
      - i. *the prognosis for the terminal illness or grievous and irremediable medical condition; and*
      - ii. *the irreversible nature of assisted dying; and*
      - iii. *the anticipated impacts of assisted dying; and*
    - (b) *talk with the person about his or her wish at intervals determined by the progress of his or her terminal illness or medical condition; and*
    - (c) *ensure that the person understands his or her other options for end of life care; and*
    - (d) *ensure that the person knows that he or she can change his or her mind at any time; and*
    - (e) *encourage the person to talk about his or her wish with others such as family, friends, and counsellors; and*
    - (f) *ensure that the person knows that he or she is not obliged to talk to anyone; and*
    - (g) *ensure that the person has had the opportunity to talk about his or her wish with those whom he or she chooses; and*
    - (h) *do his or her best to ensure that the person expresses his or her wish free from pressure from any other person by—*
      - i. *talking with the other health practitioners who are in regular contact with the person; and*
      - ii. *talking with members of the person’s family approved by the person*

### 3.4.2 *Detecting pressure and influence is incredibly difficult*

Clause 8 of the End of Life Choice Bill requires the medical practitioner to talk through the procedure, consequences, and alternative options with the patient to detect competence and pressure. As in measuring competence, however, detecting pressure on a patient to seek euthanasia or assisted suicide can be incredibly difficult. Pressure placed on individuals can be subtle or indirect. At the very least, detecting pressure requires physicians to have a long-term and strong relationship with the patient, and an understanding of their family, cultural, financial, and social context. A long-term doctor-patient relationship and “an investigative process, with careful interviewing of the applicant and others known to him or her” is necessary.<sup>44</sup> This is often lacking.

Similar to the End of Life Choice Bill, Oregon and Washington require any person seeking assisted suicide to voluntarily express this wish.<sup>45</sup> In 2015 in Washington, however, 51 percent of people who received assisted suicide knew their doctor for less than 25 weeks, and since the law was enacted in Oregon in 1997 the median number of weeks for a doctor-patient relationship prior to an assisted death is just 13 weeks.<sup>46</sup> In fact, in both Washington and Oregon some patients only knew their doctor for one week.<sup>47</sup> Such short-term relationships, which this Bill does nothing to prevent, cannot allow physicians to form a relationship strong enough to detect pressure from family members or others to take up euthanasia or assisted suicide.

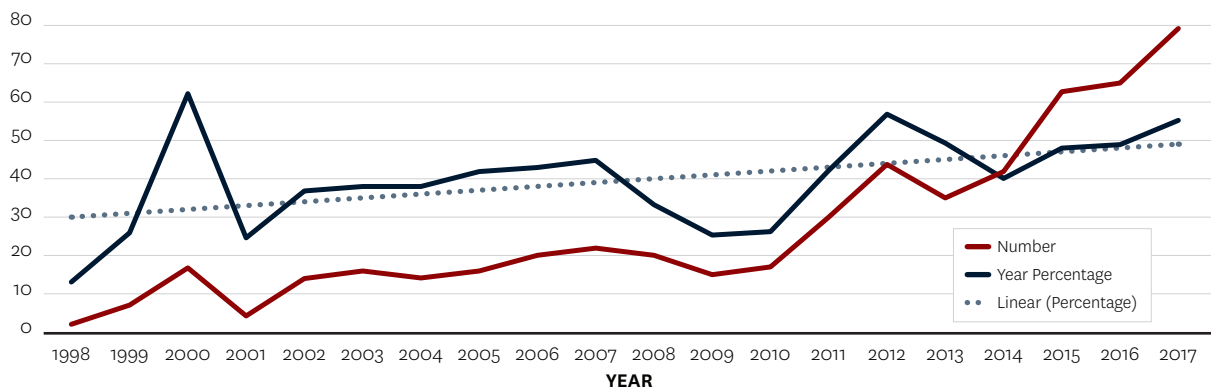
### 3.4.3 *Hidden pressures accentuate this difficulty*

Pressure can come in a multitude of forms, some more obvious than others. As outlined in the 2005 United Kingdom House of Lords report on Assisted Dying for the Terminally Ill, “some terminally ill people might feel under pressure, if the option of assisted suicide or voluntary euthanasia were available in law, to avail themselves in the interests of others (in particular, family members) rather than because they themselves positively wished to die this way.”<sup>48</sup>



International example has shown that these fears are a reality. In Washington in 2015, 52 percent of people cited being a burden on family, friends, and caregivers as a reason for accessing physician assisted suicide.<sup>49</sup> This is not a one-off result. In Oregon in 2017, 55.2 percent of people who accessed physician assisted suicide cited being a burden on family, friends, and caregivers as a reason for accessing the law.<sup>50</sup> In fact, Figure 1 below shows that increasing numbers of people seeking assisted dying are naming “becoming a burden on family, friends, and caregivers” as a concern.<sup>51</sup>

**Figure 1: Identifications of being a burden on family, friends and caregivers as one reason for requests of assisted suicide in Oregon 1998-2016\***



\*as at January 19 2018

Source: Adapted from Oregon Health Authority, Death with Dignity Act Annual Reports, available at: [www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx](http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx) (February 9, 2018), accessed February 5, 2018

Whether family members are intentionally putting pressure on the person to access euthanasia or assisted suicide or not, for people who are considered eligible under the law its very existence could create increased pressure to end their lives.

## 3.5 Review committees

### 3.5.1 The End of Life Choice Bill says:

#### 20. Review committee

- (1) The minister must appoint an end of life review committee
- (2) The review committee has the following functions:
  - (a) to consider reports sent to it under section 17(3); and
  - (b) to report to the registrar about its satisfaction or otherwise with the cases reported; and
  - (c) to recommend actions that the registrar may take to follow up cases with which the review committee was not satisfied.

### 3.5.2 Review committees are unable to stop abuse

The review and reporting process in The Netherlands and Belgium bear a strong resemblance to what we find in the End of Life Choice Bill. As in the proposed Bill, these committees were set up with the goal of oversight, providing checks on the application of the law, with the intention of limiting the possibility of abuse of vulnerable people.<sup>52</sup> The experience of The Netherlands, however, has shown their ineffectiveness and inability to achieve this. Despite the presence of review committees, “surveys have shown that, since legalisation in 1984, not only have doctors in thousands of cases breached the requirement to report, but they have also ended the lives of thousands of patients without the required request.”<sup>53</sup> That is, in The Netherlands doctors are not reporting, or facing prosecution for, non-voluntary euthanasia, and yet evidence shows that non-voluntary euthanasia is occurring in large numbers. We will consider each of these two issues in turn.

Surveys from The Netherlands “have consistently found that a significant proportion of assisted suicides and acts of euthanasia go unreported, even though Dutch professional and legal guidelines allow the practices and expressly require them to be reported to public authorities.”<sup>54</sup> In fact, a study from Tinne Smets of the End of Life Care Research Group and colleagues found the reporting rate of euthanasia practices to be 80.2 percent, which means almost 20 percent of euthanasia deaths go unreported.<sup>55</sup> The Belgian experience has been similar, and even heightened in the Flanders region where the reporting rate for 2007 was only 52.7 percent, leaving almost half of all euthanasia deaths unreported.<sup>56</sup> A comment by Professor Linda Ganzini and colleagues of the Columbia Center for the Study of Chronic, Comorbid Mental and Physical Disorders, Health Service Research and Development highlights the danger of unreported cases of euthanasia and assisted suicide. They note:<sup>57</sup>

*Physicians have also admitted that they are far less likely to consult with colleagues or family members, or ensure an explicit patient request, in the cases of assisted suicide and euthanasia they choose not to report to state authorities.*

Despite these high levels of unreported euthanasia and assisted suicide deaths, and the increased likelihood of abuse these suggest, only one doctor has been formally reprimanded for “overstepping the line.”<sup>58</sup> Moreover, there is yet to be a prosecution of any Dutch doctors for abusing the law.<sup>59</sup> If review committees were effective, there would have been many prosecutions of doctors for flouting the requirements of the law over the 15 years since euthanasia and assisted suicide was first introduced into The Netherlands.

It’s also important to note that review committees can only act as an ambulance at the bottom of the cliff. By their very nature, they are unable to prevent abuse before it occurs, too late for the patient who suffered the abuse.

### 3.6 There will be wrongful deaths

The End of Life Choice Bill will result in wrongful deaths. International example shows that the safeguards outlined in the End of Life Choice Bill are unable to prevent abuse of vulnerable people. The existence of criteria and safeguards demonstrate that even proponents of this law would differentiate between people who should be eligible for euthanasia and assisted suicide and people who should not. These eligibility criteria then, require us to negotiate an acceptable boundary of those who are and those who are not eligible. Yet experience shows that wherever we place this line, it will be overstepped and there will be wrongful euthanasia and assisted suicide deaths that were not intended by either the people who drafted the legislation or those who voted it into law.

## 4. THE PRACTICE WILL EXPAND OVER TIME: INTERNATIONAL EXPERIENCE

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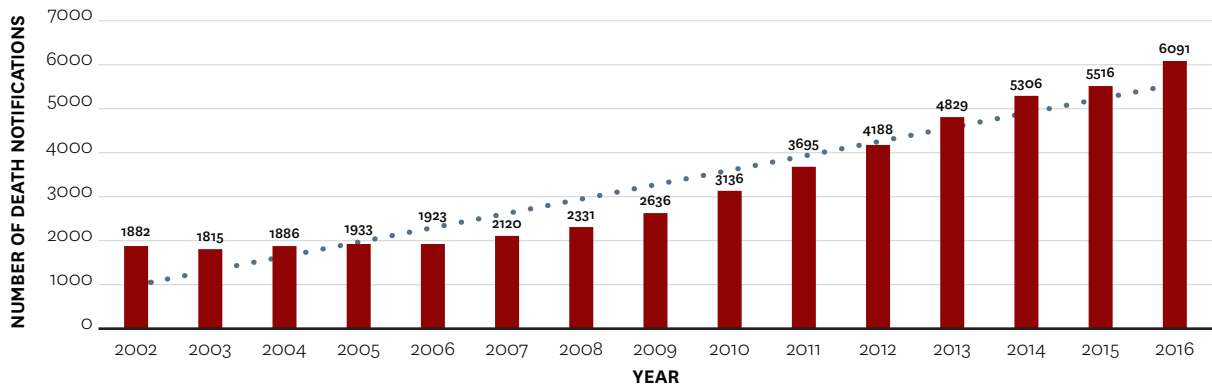
Not only does legalising euthanasia and assisted suicide put vulnerable people at risk, international experience shows that the number of vulnerable people open to abuse by the law expands over time. This is due to changes in practice, as well as changes to the law.

### 4.1 The practice expands

After euthanasia and/or assisted suicide has become law, international experience shows us that the number of people who choose to die in this way each year will inevitably grow.

Euthanasia and assisted suicide were first legislated in The Netherlands in 2002. In that first year the Regional Review Committees were notified that 1,882 people were assisted to die. Since then, this number has more than tripled, with committees notified of 6,091 assisted deaths in 2016.<sup>60</sup> We see this in Figure 2 below.

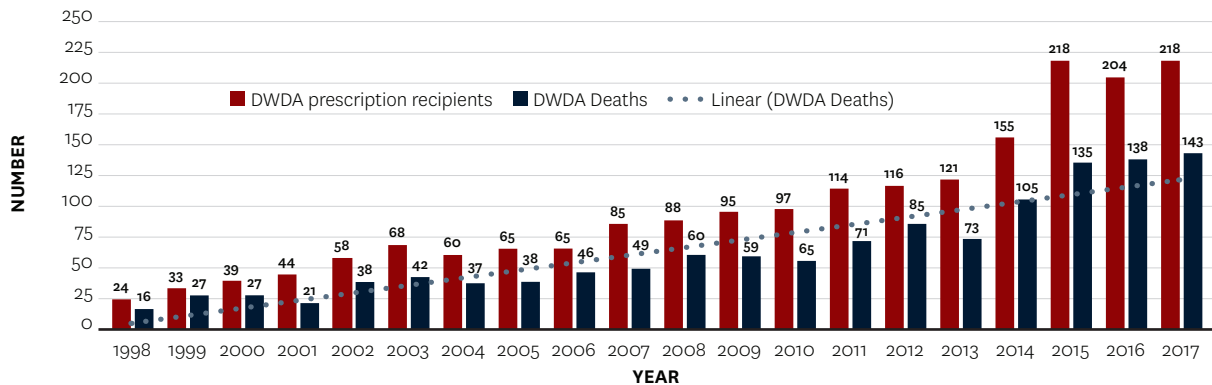
**Figure 2: The Number of Euthanasia and Assisted Suicide Deaths Reported by the Regional Review Committees in The Netherlands from 2002 – 2016**



Source: Adapted from data found in Regional Euthanasia Review Committees, "Annual Reports," available at [english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports](http://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports) (accessed 2 February 2018)

This growth is not isolated to The Netherlands. Oregon, where assisted suicide came into effect in late 1997, has seen a very similar trend line. In 1998, 24 people received prescriptions for lethal drugs, of which 16 died. In 2017, 218 people received prescriptions for lethal drugs, of which 143 died.<sup>61</sup> This is seen in Figure 3 below.

**Figure 3: DWDA prescription recipients and deaths\*, in Oregon from 1998 - 2016**

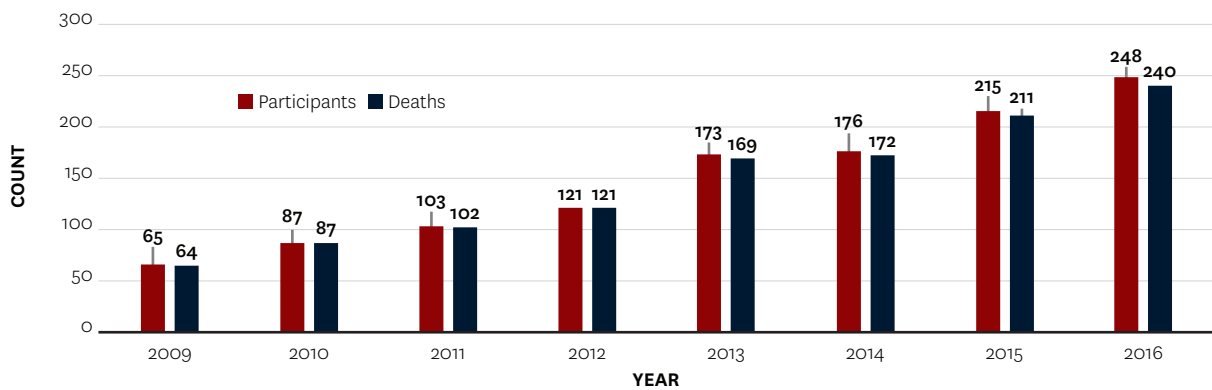


\*As of January 19, 2018

Source: Adapted from Oregon Public Health Division, Center for Health Statistics, Oregon Death with Dignity Act, Data Summary 2017, (February 9, 2018), 12.

Figure 4 shows a similar, upward trend line in the eight years since assisted suicide was legislated in Washington, with 240 assisted suicide deaths in 2016 compared to 64 in 2009.<sup>62</sup>

**Figure 4: Number of Death with Dignity Participants and Known Deaths, in Washington from 2009 - 2016**



Source: Washington State Department of Health, "2016 Death with Dignity Act Report," (September 2017), 5.

## 4.2 The law expands

As well as the practice and interpretation of the law expanding over time, international example shows us that the law itself can also change over time, and in doing so, increases the risk to vulnerable people. This is clear in numerous international examples, but perhaps shown most clearly in the example of age restrictions in Belgium. In 2014 Belgium removed the requirement for an individual seeking euthanasia to have reached an “age of majority.”<sup>63</sup> Now, despite strong opposition from paediatricians, children of any age are eligible for euthanasia (albeit with tighter restrictions on the practice).

In The Netherlands, the government is currently considering opening up euthanasia and assisted suicide to those people who have “completed life.”<sup>64</sup> This will mean people who do not necessarily have a terminal illness or health issue, but “who are generally of an advanced age, who in their own opinion no longer have any life prospects and have as a result developed a persistent, active desire to die.”<sup>65</sup> These changes to the law will certainly increase the number of vulnerable groups open to abuse, particularly the elderly and those people struggling with depression or other mental health issues.

Even Canada, where euthanasia and assisted suicide was brought into law as recently as 2016, is already seeing requests to extend the law to include children and people with mental health problems. In fact, media have reported that reviews are currently underway to explore expanding the law to “mature minors, those whose sole medical condition is mental illness and those who have provided advanced consent.”<sup>66</sup>

## 4.3 Boundaries are fluid

As international experience has shown, it is not possible to draw a clear and sturdy line between people who are eligible for euthanasia and assisted suicide and those who are not. There will always be someone who does not quite fit the criteria but feels that they are deserving of inclusion, and there will always be people who turn out to be eligible that others believe should not be. For example, while the Bill’s criteria could include a young person who is tetraplegic, someone with Alzheimer’s disease would not qualify.<sup>67</sup> This will inevitably lead to pressure to expand the laws coverage, and boundaries that are essentially arbitrary, like six month prognosis and subjective suffering, will not be able to contain this growth. To quote retired eminent English judge Elizabeth Butler-Sloss:<sup>68</sup>

*Laws, like nation states, are more secure when their boundaries rest on natural frontiers. The law that we have rests on just such a frontier – it rests on the principle that involving ourselves in deliberately bringing about the death of others, for whatever reason, is unacceptable behaviour. To create exceptions, based on arbitrary criteria such as terminal illness or mental capacity, is to create lines in the sand, easily crossed and hard to defend. The law is there to protect us. We tinker with it at our peril.*

Once euthanasia and assisted suicide has been legislated, the ability to maintain clear boundaries is impossible. The number of people being assisted to die will expand, and the eligibility criteria of the law will expand.

## 4.4 We can expect the same in New Zealand

When looking at the experience, and especially failures, of other jurisdictions some may argue that we will do it better. The reality, however, is that we must learn from the experience of jurisdictions where euthanasia and/or assisted suicide has been legislated and acknowledge there is no reason to think the same trends will not happen here. Examples like the continually expanding law in The Netherlands and Belgium, as well as the increasing numbers of people in Washington and Oregon admitting the fear of being a burden on family and friends as a reason for pursuing assisted suicide, should give us reason to pause.<sup>69</sup>

# 5. BILLS LIKE THIS USUALLY FAIL BECAUSE LAWMAKERS RECOGNISE THEY ARE UNSAFE

Around the world, bills that propose to legalise euthanasia and assisted suicide are rejected much more often than they are passed.

## 5.1 This is legal in only 5 percent of jurisdictions worldwide

Of a total 252 jurisdictions considered (195 countries, 50 US states, the District of Columbia, and six Australian states) only 12 allow some combination of euthanasia and assisted suicide with two additional jurisdictions where the practices are somewhat allowed.<sup>70</sup> That means euthanasia or assisted suicide are legal in only about five percent of jurisdictions worldwide.<sup>71</sup>

## 5.2 Euthanasia and assisted suicide legislation is rejected more often than it is passed

In the last year alone, four jurisdictions have rejected euthanasia and assisted suicide legislation, compared to just one jurisdiction where legislation has passed.<sup>72</sup> In fact, over the past three years, eight jurisdictions have considered legalisation of euthanasia and assisted suicide and have decided that the dangers were too great to bring it into law, compared to four jurisdictions that have passed euthanasia and/or assisted suicide legislation. These jurisdictions are outlined in Table 1 below.

**Table 1: Jurisdictions where euthanasia and/or assisted suicide legislation has passed or been defeated since 2015**

Jurisdiction	Year(s)	
Victoria	2017	Voluntary Assisted Dying Bill ratified by the Lower House <sup>73</sup>
New South Wales	2017	Voluntary Assisted Dying Bill rejected 20 to 19 <sup>74</sup>
Maine	2017	LD 347 voted down in House 85 to 61 <sup>75</sup>
Tasmania	2017	Voluntary Assisted Dying Bill rejected 16 to 8 <sup>76</sup>
New Mexico	2017	SB 252 voted down in Senate Judiciary Committee and in the full Senate 22 to 20 <sup>77</sup>
District of Columbia	2016	D.C. Death with Dignity Act passed final reading 11 to 2 <sup>78</sup>
Colorado	2016	Colorado voters passed Proposition 106, the End of Life Option Act by 65 to 35 percent <sup>79</sup>
South Australia	2016	Death with Dignity Bill rejected 24 to 23 <sup>80</sup>
New Hampshire	2016	SB 426 voted down in House 174 to 123 <sup>81</sup>
California	2015	End of Life Option Act passed the Senate 23 votes to 14 <sup>82</sup>
United Kingdom	2015	Rob Marris’ Private Member’s Bill rejected 330 to 118 <sup>83</sup>
Scotland	2015	Patrick Harvie’s Assisted Suicide Scotland Bill rejected 82 to 36 <sup>84</sup>

Key: ■ Jurisdictions that rejected euthanasia and/or assisted dying legislation  
■ Jurisdictions that passed euthanasia and/or assisted dying legislation

This trend of rejecting euthanasia and assisted suicide legislation is not new. Since the 1990s, hundreds of bills have been considered, and have either been rejected, stalled or withdrawn due to lack of support, or passed on for further study and debate.<sup>85</sup> This is an overwhelming record when compared to the just 12 jurisdictions where such legislation has passed.<sup>86</sup> We should take note of the considered judgement of so many lawmakers, the vast majority of whom considered such measures, and were not prepared to write euthanasia or assisted suicide into law.

## 6. WHAT WE CAN AND SHOULD DO

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Euthanasia and assisted suicide legislation fails to sufficiently protect vulnerable people from abuse, and cannot provide a compassionate response to suffering and uncertainty at the end of life. Standing in solidarity with the vulnerable people in our population, as well as strengthening the current strategy to end of life care, will provide a response that is compassionate while still protecting vulnerable people.

### 6.1 Show solidarity with the vulnerable and those facing the end of life

The ability to make personal decisions about how we live is important. A well-functioning society that stands in solidarity with its most vulnerable, however, is also important and this requires our autonomy to be reasonably limited. A key role of government is to defend society's most vulnerable groups from harm and abuse. For example, we might want to drive down the motorway as fast as we'd like, but we recognise that this could harm both ourselves and others, and so we have speed limits. Our ability to choose how fast we can drive down the road is limited to protect us and the other users of that road. In the same way, our ability to choose how and when we die must be limited to protect those people in our society most vulnerable and susceptible to wrongful death under such a law.

This need for a limitation to protect the vulnerable is clearly recognised by proponents of the law. Their answer is to include safeguards that they hope will provide the necessary protections.<sup>87</sup> What we have seen in other jurisdictions, however, is that these safeguards are insufficient and will fail to protect the vulnerable from abuse, resulting in wrongful deaths. As Professor Onora O'Neil of UK think tank Living and Dying Well points out:<sup>88</sup>

*How are we to tell which requests for help to commit suicide express robust individual autonomy and which do not? How can we tell which choices express compliance with the (spoken or unspoken) desires of burdened carers and relatives, or of expectant heirs, whose compassion may be limited? How are we to tell which families and professionals are "wholly compassionate?"*

She goes on to say:<sup>89</sup>

*In a world of idealised wholly autonomous patients, and of wholly selfless and compassionate families and professionals, legislation providing for assisted dying might, if ethically acceptable, not be risky. But we do not live in that world, and I doubt whether we can draft legislation that is safe for human beings with their full variety of situations and dependence on one another.*

We need to stand in solidarity with the vulnerable in our society with laws that will do their best to protect them. We can only achieve this protection if the law continues to prohibit euthanasia and assisted suicide.

### 6.2 Support and extend currently available responses

The legalisation of euthanasia and assisted suicide is often framed as the only compassionate response to people with terminal illnesses or degenerative diseases. However, this is not the reality. New Zealand has been recognised as providing the third best palliative care services in the world.<sup>90</sup> These services aim to "optimise an individual's quality of life until death by addressing the person's physical, psychological, spiritual and cultural needs and supporting the individual's family, whanau and other carers where needed through the illness and after the death."<sup>91</sup>

Alongside this, Refusal of Treatment and Do Not Resuscitate orders allow patients and their families to "let go" of life when the time is right, allowing nature to take its course rather than intervening with further medical treatment.<sup>92</sup>

Each of these treatments provide a compassionate response to people at the end of life and with terminal illnesses or degenerative illnesses. Moreover, unlike legalisation of euthanasia and assisted suicide, these options are better able to

protect vulnerable people from abuse by providing care that finds value in every person and every day of life, as well as recognising that medical intervention is not always the answer.

In 2015 Scotland investigated a bill on assisted suicide. In their report, the Health and Sport Committee recommended the Scottish Parliament not pass a bill to legalise euthanasia and assisted suicide. They found that “there are ways of responding to suffering (such as increased focus on palliative care and on supporting those with disabilities), which do not raise the kinds of concerns about crossing a legal and ethical ‘Rubicon’ that are raised by assisted suicide.”<sup>93</sup> Rather than passing assisted suicide legislation then, the Committee proceeded to complete an investigation into palliative care services. They believed that improving palliative care services was the best and most compassionate response to people suffering in the final stages of their lives.<sup>94</sup>

In 1994 a New York State Task Force on Life and the Law investigated assisted suicide and euthanasia in a medical context. They considered the role of the medical practitioner in treating and caring for terminally and severely ill patients. They found that practices in providing pain relief for these patients needed improvement, and that most medical practitioners were underprepared to talk with patients about their diagnoses, illness, and the dying process.<sup>95</sup> In improving the current practice of medicine in these areas the Task Force believed the suffering euthanasia and assisted suicide hoped to address would be significantly relieved.

### 6.3 Reject the Bill: it is inherently unsafe and therefore can never be fixed

New Zealand should reject the End of Life Choice Bill. The flaws in the Bill are fundamental to its make-up and cannot be fixed. It not only fails to provide a compassionate response to people at the end of their life, and with severe illnesses, it also places vulnerable people in our society at a significantly increased risk of abuse. In fact, any euthanasia and assisted suicide legislation creates a much deeper change in the very makeup of our society, sending the dangerous message that some lives are worthier of protection than others.

Regardless of intention, this law will communicate an implicit suggestion to people in the second group that society agrees that their life is less worthy of living. We need to remember that the law is for everyone, both those people we deem healthy, and those people who live with disability, severe or terminal illness, the elderly, or those people who struggle with mental health. It is the role of government and the law to protect the vulnerable people in society. Passing the End of Life Choice Bill will ensure the government fails to fulfil this role and instead open vulnerable people up to further abuse.

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