



**Submission of the Care Alliance Charitable Trust
to the Justice Select Committee consideration of
the End of Life Choice Bill**

6 March 2018

Introduction

1. This submission is made on behalf of the Care Alliance Charitable Trust (Care Alliance).
2. The trustees of Care Alliance are John Kleinsman, PhD (Chair), Sinead Donnelly, MD, FRCPI, FRACP, FACHPM (Deputy Chair) and Michael Hallagan (Treasurer). The Secretary is Professor Emeritus Peter Thirkell, PhD, Honorary Fellow ANZMAC.
3. The Care Alliance is a coalition of groups and individuals that has been working together since 2012 to nurture better conversations about dying in Aotearoa New Zealand. All members share an understanding that a compassionate and ethical response to suffering does not include euthanasia and assisted suicide.
4. Organisations that are members include:
 - ANZSPM Aotearoa (the New Zealand chapter of the Australian & New Zealand Society of Palliative Medicine)
 - Christian Medical Fellowship
 - Euthanasia-Free New Zealand
 - Family First New Zealand
 - Hospice New Zealand
 - Lutherans for Life
 - New Zealand Health Professionals Alliance
 - Not Dead Yet Aotearoa
 - Pacific Leaders Forum
 - Palliative Care Nurses New Zealand
 - The Nathaniel Centre
 - The Salvation Army in New Zealand
5. Individuals in the Care Alliance are Quakers, Catholics, Protestants, Buddhists, agnostics and atheists. We never argue the question of intentionally ending the lives of patients from a faith perspective because we simply wouldn't be able to agree what it was.
6. Our focus is on the practical effects of the Bill presently before this Committee, and particularly its impact on the most vulnerable members of our society should it become law. In short, we argue that the provisions of this Bill are unable to achieve their stated purpose without placing other people within the community at significant risk, including the risk of wrongful death. Even if the eligibility criteria set down in Part 1 Clause 4 were to be restricted to persons with a terminal illness, we would still argue that unacceptable risks to public safety remain.

7. We acknowledge that there is a problem – that there are people in New Zealand who continue to experience a ‘bad’ death, by which we mean a death involving needless suffering. The reasons for this are complex and, in the considerable experience of our members, relate to issues of accessibility to palliative care and the competence of health practitioners who attend to patients at the end of life. A particular challenge identified by our member groups is the need to upskill and to support health professionals who have not received sufficient training in end-of-life palliative care. *There are other and better means by which the intention of this Bill – namely the prevention of needless suffering – can be realised without resorting to the administration of lethal medications to deliberately and immediately end the life of any patient.*
8. Our palliative care members, in particular, work tirelessly to reduce the very real physical, psychological, social and spiritual suffering that often attends terminal and non-terminal illnesses and conditions. It is their raison d’être. That is to say, this Submission draws on the vast experience of skilled practitioners who have a deep knowledge of the needs of those who are dying.
9. In the Explanatory Note of the End of Life Choice (EOLC) Bill the assertion is made that “Extensive evidence and analysis considered in the case of *Seales v Attorney-General* [2015] NZHC 1239 demonstrated ... [t]here was broad consensus that palliative care cannot alleviate all suffering, including suffering that is unbearable for a person.” Our members disagree with this statement based on their experience. That misgiving aside however, it is a matter of legal fact that “the Court in *Seales* did not, and could not, reach any such conclusions. *Seales* was argued and decided on points of statutory interpretation: the evidence before the court was strictly limited, and none of it was subjected to cross-examination. The case was heard urgently and Ms Seales’ counsel strongly opposed any external intervention, resulting in further limitations to the evidence available to the Court. More importantly, however, the expert evidence from both sides was clear that in the worst-case scenario, palliative sedation (which is temporary and fully reversible) was available to address intractable physical pain.”¹
10. We note that, of the more than 31,000 people who die in New Zealand annually, more than half of them (who have some form of life limiting condition) will receive support from the 35 hospice services throughout the country.² Support is also typically provided to the families and friends of each person both before and after their death. Palliative and hospice care is not a niche service for the lucky few. It already operates effectively at scale, and our single-minded focus should be upon expanding and improving the scope, quality and consistency of services provided.

¹ Victoria Casey, Legal Counsel for the Care Alliance in *Seales v Attorney-General* (2015) in ‘The Right to Die’ and ‘Rational suicide’: Respecting human rights for All or a Claim for Privilege by the Strong? The Case for the Status Quo available at: <https://www.victoria.ac.nz/law/centres/nzcpl/publications/human-rights-research-journal/previous-issues/volume-ten,-2015/Victoria-Casey-HRR-2015.pdf>

² Hospice New Zealand submission to Health Select Committee, Feb 2016, https://www.parliament.nz/resource/en-NZ/51SCHE_EVI_51DBHOH_PET63268_1_A472592/72304e1b263bca0be0693e85ea264b2cd3935fcc

11. While hospice care is not yet uniformly available across all regions, we nonetheless see this as the more compassionate and equitable goal to pursue rather than resorting to the termination of a patient's life merely because of inadequate resourcing. We argue that the relief of suffering should be, and can be, addressed directly by striving to improve the health and social services available to *all* New Zealanders. Properly resourced palliative care can alleviate suffering effectively in a way that retains respect for the person and without necessitating the termination of the life of the person who is suffering.
12. Our members consistently report that proponents of a law change are already creating heightened levels of anxiety in people with life-limiting illnesses and in their families through their use of stories of bad deaths. As well as improving equity of access to high quality end-of-life care, there is an urgent need to educate all New Zealanders about the efficacy of palliative care so as to allay people's fears. As ANZSPM have noted in their submission to the Justice Select Committee on the *End of Life Choice Bill*: "There appears to be a deficit in understanding of the general public about what palliative care services can do" (4.14(b)). Indeed, the *Report of the Health Committee on Petition 2014/18 of Hon Maryan Street and 8,974 others* came to the same conclusion: "We note that there appears to be a lack of understanding from the general public and some submitters about what palliative services can do."³
13. We argue that removing the bright line of prohibition against euthanasia and assisted suicide and replacing it with another line, as proposed in the EOLC Bill, will introduce an era of arbitrary law which will bring a new set of intractable problems. There will always be another 'hard case' on the 'wrong side' of the boundaries of eligibility. Overseas experience from countries which have legalised euthanasia (or euthanasia and assisted suicide) shows that, once an arbitrary boundary for state sanctioned termination of life is set down in law, rights-based arguments are inevitably introduced to shift that arbitrary boundary and broaden the criteria for eligibility.
14. Our current laws which provide essential protection for all citizens and residents of New Zealand are not broken. We reject the assertion in the preamble to this Bill that there are serious problems with the current state of the law in New Zealand. No specific evidence is provided to support this assertion. As already noted above, in our opinion the preamble misinterprets the evidence that was provided in *Seales v Attorney-General* [2015] NZHC 1239 in several important respects.
15. It is an essential underpinning of any euthanasia/assisted suicide regime that it creates different classes of citizens – those whose lives are worthy of living and those whose lives don't warrant the same protections offered by the State in favour of life that to date all citizens enjoy. The fundamental danger of legalising euthanasia and assisted suicide, which is the essential purpose of this Bill, is that

³ See https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24, p. 42.

we would have crossed a ‘Rubicon’ – a line of no-return – by allowing the State to determine, in certain circumstances, that a particular life is not worth living and should therefore be terminated.

16. In addition, the Bill imposes on health professionals the onerous duty of deciding whose lives should and should not be ended via the administration of lethal medications. It does so using ambiguous and highly subjective eligibility criteria which remain undefined in the interpretation section of the Bill (Part 1 Clause 3).
17. In effect, while the patient may trigger the process, it is the doctors who have the ultimate power to decide if a person lives or dies. We note with concern that, by virtue of the process laid down in this Bill, the two doctors involved are also likely to be predisposed to support euthanasia and assisted suicide. This Bill delegates to doctors the overwhelming burden of deciding who is eligible for being put to death and who is not eligible.
18. Prudent legislators must consider the future environment in which such a law as proposed in this Bill would be enacted if it was passed. In particular, they should consider whether a future Government faced with constrained finances might reduce therapeutic or palliative care because, after all, there is a ‘choice’ available. Can the advocates of euthanasia and assisted suicide as proposed in this Bill guarantee that their ‘choice’ will not become, for future generations of New Zealanders, the *only* available choice in constrained circumstances?

About this submission

19. Our submission, informed by the expertise of our palliative care members (see especially section 3), focuses on the intention of the EOLC Bill to legalise euthanasia and assisted suicide (EAS) for people with a terminal illness or irremediable conditions. We see insurmountable difficulties in being able to practically implement any regime based on the subjective and broad eligibility criteria of “grievous and irremediable medical conditions” set down in Part 1 Clause 4 Sub-section (c) of this Bill. The advice of medical experts with whom we have spoken is that the situations covered would in practice include a wide range of common conditions such as rheumatoid arthritis and insulin dependent diabetes. It is impossible to legalise such criteria in a consistent and just manner to avoid wrongful deaths, as many groups have pointed out in their submissions.
20. In the event that the Justice Select Committee elected to reduce the eligibility criteria to ‘terminal illness’ only, we will continue to argue that the Bill remains intrinsically unsafe and that there are no safeguards able to adequately protect the public from wrongful deaths. We reiterate our informed view that the far safer and more effective course of action for the Committee to address the concerns expressed in the preamble to this Bill would be for it to recognise the other options that already exist to mitigate suffering. Thus, we urge the House to make a single-minded commitment to the provision of high quality and consistently delivered palliative care for all New Zealanders, thereby removing the pressure to sanction the use of lethal medications as advocated in this Bill.

1. The Purpose of the EOLC Bill

Language and Terminology

21. The case for the State to make assisted suicide and/or euthanasia legally available often focuses on particular individuals and their tragic circumstances. Such ‘hard cases’ have been presented regularly in the New Zealand media over many years, and they are alluded to in the preamble to this Bill. They are also the subject of a recent social media campaign by the sponsor of the EOLC Bill, MP David Seymour.
22. These cases engage us emotionally, raising important questions. Above all, they highlight the fact that the provision of end-of-life care in New Zealand needs to improve, a point we have already noted above. However, robust ethical debate and deliberation about changing the current law must move beyond individual cases to ask questions about the consequences for our society as a whole.
23. The repeated appeal to ‘hard cases’ fosters an impression that the EOLC Bill is primarily about people who are imminently dying and in extreme pain. Many people have yet to appreciate that the changes being sought in this Bill are much broader because they will embrace and affect significant numbers of New Zealanders who are not dying – that is, those with a “grievous and irremediable medical condition” who are “in an advanced state of irreversible decline in capability.”
24. The use of such phrases provides the most compelling reason to avoid the term “assisted dying” as used in the wording of this Bill. The term is highly misleading because provisions in the Bill clearly apply to people with non-terminal conditions – that is, to those who are not imminently dying.
25. A recent Curia Market Research poll demonstrated that New Zealanders are confused about what “assisted dying” means, with 85% of respondents who strongly support ‘assisted dying’ thinking that it includes turning off life support, an action which is already lawful and ethical. On the other hand, about a third of all respondents did not realise that assisted dying means receiving a deadly dose of drugs.⁴
26. The confusion and ambiguity surrounding the terms and definitions used by proponents of this Bill mask what is being proposed and for whom, and bring into question the true level of public support for a law change, something which is consistently claimed by proponents. We use the terms “euthanasia” and “assisted suicide” rather than “assisted dying” because they are accurate descriptions which avoid euphemistic language.
27. Whatever terminology is preferred, the primary question is whether or not “the administration of a lethal dose of medication to a person” (intentional premature death) should be deemed a societally acceptable response to suffering. The

⁴ Euthanasia Free NZ, <http://www.scoop.co.nz/stories/PO1712/S00123/widespread-confusion-about-assisted-dying.htm>

question about the acceptability/desirability of EAS needs to be considered first, and separately, from the question about who the agents of this process might be. It is a major, and to our mind a 'fatal', flaw of the proposed EOLC Bill that it does not separate these two very different questions and that it assumes, uncritically, that an EAS regime should be situated within the practice of healthcare.

Distinguishing euthanasia from palliative pain management

28. Palliative care services in New Zealand are excellent in relieving and ameliorating pain, and intractable pain is extremely rare. As Clark et al (2016) state in the Journal of Palliative Medicine:

One of the major concerns expressed by patients and families facing the end of life is that the dying process will be complicated by distressing, intractable symptoms especially pain and breathlessness. Although it is impossible to understand from this work whether or not people were already medicated, it is possible to conclude that the majority were either not highly symptomatic at the time that they were assessed as dying or were well palliated or both. Only 4.2% were documented as experiencing severe pain that urgently required attention. This is not suggesting that this low figure is acceptable. However, these data do provide clinicians with sufficient confidence to honestly reassure people that for the majority, the final stages of life are not likely to be complicated by unbearable or unmanageable pain.⁵

29. People's perception of pain will be impacted by emotional, social, physical and existential features. How to help a patient in pain can be quite complex. Patients may be referred to specialist pain clinics for advice on how to manage their particular pain.
30. Great strides have been made in the past 30 years as palliative medicine has become recognised as a medical specialty in its own right. This has allowed research and training to integrate the tools and techniques of the rest of medicine to the unique requirements of end of life care. Palliative medicine specialists learn how to apply this knowledge to individual patients and their particular needs.
31. Pain can have non-physical aspects. For example, a person may have unresolved issues in their lives. Emotions that relate to a fear of dying, regret, hurt, harm or lack of forgiveness can all affect how pain is felt. Even though physical pain might be alleviated quite easily in one person, for another person with high levels of anxiety, pain may be magnified. The physical pain might be just the 'tip of the iceberg', and the ethical palliative care response will be to address the complexity of that particular pain through a multi-disciplinary team approach.
32. In the rare cases of intractable pain or distress, symptom control can be achieved using palliative sedation. As with all pain relief, the dose is titrated, starting at the

⁵ Clark, K., Connolly, A., Clapham, S., Quinsey, K., Eagar, K., & Currow, D. C. (2016). Physical symptoms at the time of dying was diagnosed: A consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care. *Journal of palliative medicine*, 19(12), 1288-1295.

lowest dose, and evaluating its effectiveness in settling the person's pain and distress over the next few hours. The dose is reviewed frequently in order to achieve the optimum treatment for the person.

33. This is not 'deep sedation' and nor is it accurately described as 'terminal sedation'. It is carefully monitored and the focus is symptom relief. It is extremely rare for this to be used for any length of time.
34. This is not the same as euthanasia or assisted suicide.

The option of requesting assisted dying

35. The purpose, as set down in the explanatory note, begins with a claim (sentence one) that "This Bill gives people with a terminal illness or a grievous and irremediable medical condition the option of requesting assisted dying."
36. The barely hidden rationale behind this claim is that New Zealanders with terminal or serious medical conditions do not already have reasonable and sufficient options at the end of their lives to experience a natural death. It also implies that dying people in New Zealand have insufficient choices when, in fact, they have a number of options and choices that are legally available to them:
 - a. The Code of Health and Disability Services Consumers' Rights passed into law in New Zealand in 1996 grants all patients ten rights, including:
 - Right 4: the right to services of an appropriate standard
 - Right 7: the right to make an informed choice and give informed consent (which includes refusing any service and making an advance directive in accordance with common law)
 - a. The 1990 Bill of Rights Act gives everyone the option to refuse medical treatment. Discontinuing treatment at a patient's request is lawful and ethical. Medical practitioners are also permitted to discontinue medical treatment that is deemed futile.
 - b. The use of pain relief at levels intended to ameliorate that pain constitutes good medical care, even if, in exercising the option, there is a foreseeable risk of hastening death.
 - c. As noted, palliative sedation is in extreme cases an option available to medical staff to relieve pain, and this intervention can be, and sometimes is, reversed to good effect in assisting a patient to die well.
 - d. More than 16,000 people with some form of life limiting condition receive support each year from the 35 hospice services throughout the country. It is an insult to the dedicated physicians, nurses, volunteers and others to suggest that they are not already assisting and supporting people to have a natural death with as many choices as possible.
 - e. The simple act of holding the hand of a loved one who is near the end of his or her life is helping them in the process of a natural death, and it does a disservice to the many families and friends who bring love, support, caring and hope to those who are dying to imply otherwise.

37. People's choices about end-of-life care can be recorded in an Advance Care Plan.
38. In summary, the opening purpose set down in support of this Bill misleads the public into thinking that people with a life-threatening or life-limiting illness or medical condition don't already have effective options to deal with suffering (both physical and psychological) and to support them in dying a natural death. This is dishonest and untrue.

Choosing to end one's life in peace and dignity

39. The purpose, as set down in the explanatory note, continues with the claim (sentence two) that "The motivation for this Bill is compassion. It allows people who so choose, and are eligible under this Bill, to end their lives in peace and dignity, surrounded by loved ones."
40. Again, the reader might reasonably conclude that the options currently facing New Zealanders at the end of life are not motivated by compassion, and that there is presently no choice to end one's life in peace and dignity, surrounded by loved ones. This inference is untrue. The origin of present day approaches to the provision of compassionate care for the dying goes back more than a century. The relatively modern practice of palliative care evolved because of people with a deep desire to show love and compassion to others at the end of their lives while helping them to manage an intractable condition. For example, Calvary Hospital, established in Wellington in the 1930's, grew out of a nursing order set up by Mary Potter in the late nineteenth century, with a "special mission of care for the dying." In the 1970's five beds at Calvary hospital were set aside to care for the terminally ill, expanding in June 1979 to a whole ward called Mary Potter Hospice – recognised as New Zealand's first hospice. Te Omanga Hospice has also provided free, high quality palliative care services to the Hutt Valley community since 1979.
41. While a claim for improved ways to show compassion might have been reasonable in the past, such a claim now ignores the significant advances that have been made by the hospice and palliative care sector over the last three decades in particular. This sector exists specifically to deal with human pain and suffering in a holistic manner: physical, emotional, social and spiritual. Hospice staff make more than 142,000 annually to people in the community, and more than 11,000 volunteers from the community are involved.
 - a. In 2001 the New Zealand Palliative Care Strategy was put in place by then Health Minister Annette King to provide a systematic approach to the provision and funding of palliative care services.⁶ To quote the Minister: "This Government is concerned to ensure that all people who are dying and their family/whānau have access to palliative care services, provided in a co-ordinated and culturally appropriate way."
 - b. In May 2015 then Finance Minister Bill English announced a significant boost in palliative care funding, with \$76.1 million to be spent on

⁶ See <https://www.health.govt.nz/publication/new-zealand-palliative-care-strategy> (accessed 26 February, 2018).

hospices and community care services over the following four years. Commenting on the increase Health Minister Jonathan Coleman later remarked: “Palliative care is a priority for the Government and we are keen to ensure high quality and well-coordinated care is available to all who need it.”

- c. In March 2017 the Ministry of Health published its review of Adult Palliative Care Services in New Zealand, a “refreshed strategic direction for adult palliative care [which] proposes a suite of initiatives to help manage future increases in demand for palliative care.” The Review identifies five broad areas which are addressed in a separate Palliative Care Action Plan which sets out 19 actions to address each of the five focus areas.⁷
 - d. In December 2017 Prime Minister Jacinda Ardern, at a community fundraising event for Mary Potter Hospice, pledged to find a sustainable funding model for the palliative care sector. We applaud this renewed commitment and argue that, if carried out with single-minded determination, it could result in New Zealand becoming the best provider of palliative care in the World.
 - e. In the more than sixteen thousand submissions to the Health Select Committee in 2016 opposed to legalising euthanasia and assisted suicide, many speak of the care and compassion effectively shown to patients, family members and friends by hospice staff and palliative care physicians across 35 hospice services around New Zealand.
42. In summary, *the second stated purpose of the EOLC Bill misleads people into thinking that end of life care is not presently motivated by compassion, and that there are insufficient choices already available for people to end their lives in peace and dignity.* This is also demonstrably untrue and an affront to the thousands of health professionals and volunteers who work tirelessly and effectively in showing compassion, love and care to people who are dying or who are facing difficult medical circumstances.

Other concerns about the Bill

43. The background to the EOLC Bill (Explanatory Note page 1) states “evidence and developments have established that there are serious problems with the state of the law.” However, no evidence is provided to support this assertion. We are not aware of any concerns expressed by any court about the state of the law in New Zealand during at least the last twenty years.
44. The background to the Bill further claims that “under [the current state of our law] it is becoming permissible in effect for family members to assist loved ones to take their own lives.” Legal advice that we have reviewed⁸ suggests that the courts in New Zealand have consistently rejected any suggestion that “mercy

⁷ See <https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand>, (accessed 26 February, 2018).

⁸ See legal opinion Supplement 1 (Clause 69.1) to NZHPA (New Zealand Health Professionals Alliance) submission on this Bill.

killings” are to be treated as a separate category of offences. Our understanding is that such offences are prosecuted and judged in the same way as any other offence.⁹

Conclusion

45. The stated purpose of the *End of Life Choice Bill* is to allow people in certain circumstances the choice to end their lives by way of assisted suicide or euthanasia. Equity of access issues aside, we argue that palliative care already provides patients with sufficient and effective options to support them in dying a natural death. It is therefore unnecessary to introduce a euthanasia and/or assisted suicide regime that sanctions the intentional administering of lethal medications.

2. What would be the unjust consequences of this Bill?

Risk of miscarriage of justice – i.e. a wrongful death

46. As noted above, the current legal options for end-of-life care in New Zealand are capable of meeting people’s physical and existential needs at the end of life. There is, then, practically speaking, no compassionate ‘need’ for euthanasia and assisted suicide as advocated in the *End of Life Choice Bill*. However, since choices are not always tied to ‘need’, the question arises as to why we would not allow persons to access assisted suicide or euthanasia simply on the basis of choice.
47. We recognise that in an open society such as New Zealand, individual choice is seen as an important value and there must be good reasons to limit the freedom of choice of citizens. Disagreements about the place of choice in euthanasia debates encapsulate the tension inherent in a democracy – balancing individual rights and freedoms with broader considerations relating to society at large.¹⁰
48. Firstly, and most strikingly, euthanasia and assisted suicide are not the autonomous actions of an individual. The processes require other individuals to produce, supply and administer lethal prescription drugs. They involve the State (and by extension the whole of society) to approve, fund and oversee a regulatory regime such as the one proposed in this Bill.
49. Secondly, the approval of each request requires an explicit approval by others that the individual is right to be afraid of dying naturally or of living with a “grievous and irremediable condition”; that they are right to fear that society will not provide them with the support and services they need. To affirm such fears,

⁹ See for example *R v Ruscoe* (1992) 8 CRNZ 68 (CA); *R v Meikle* HC Nelson S11/96, 7 October 1996; *R v KJK* HC Christchurch CRI-2009-009-14397, 18 February 2010; *R v Davison* HC Dunedin CRI-2010-012-4876, 24 November 2011; *R v Mott* [2012] NZHC 2366. On s 160 of the Crimes Act 1961: *R v Novis* HC Hamilton T42/87, 5 February 1988; *R v Stead* (1991) 7 CRNZ 291 (CA); *R v Simpson* HC Auckland T010609, 12 October 2001; *R v Law* (2002) 19 CRNZ 500 (HC); *R v Bell* HC Wanganui S011886, 8 March 2002; *R v Martin* HC Wanganui CRI-2003-083-432, 30 April 2004 (and CA199/04, 14 February 2005); *R v Faithfull* HC Auckland CRI-2007-044-7451, 14 March 2008; *R v Crutchley* HC Hamilton CRI-2007-069-83, 9 July 2008.

¹⁰ See, for example, Paragraph 5 of the British Geriatric’s Society Position Statement on Physician Assisted Suicide: <http://www.bgs.org.uk/ethicslaw/subjectreference/ethicslawcapacity/position-assisted-suicide>

rather than do something practical to alleviate them, is dishonest and unethical, and therefore an intrinsically unjust consequence of the EOLC Bill.

50. Thirdly, there is the serious issue of coercion in suicide. In 2015, Parliament saw fit to extend the protections afforded to people who are emotionally and psychologically vulnerable to pressure to commit suicide through the Harmful Digital Communications Act. The HDCA recognised the terrible reality of how acutely sensitive people can be to their social environment. This highlights the logical absurdity of trying to define some suicides as ‘unacceptable’ while providing legal assistance to others to commit suicide.
51. Such coercion, whether direct or indirect, overt or covert, extends to requests to die by the terminally and chronically ill. The British Geriatrics Society is blunt in assessing the coercion and influence that families put on older people: “... the vast majority, but not all, will have their well-being at heart. Even so, many requests to end life – made either directly or indirectly to us as geriatricians – come from the patients’ families and not the older person themselves.”¹¹
52. Those of our members who are palliative care specialists, along with many other doctors, are adamant that there is no basis upon which they could reliably assess whether a person who says they want to die is entirely free of any pressures – whether societally generated, personally generated or the result of covert pressure from family members or carers. Clause 30 of the NZMA submission to this Committee underscores this concern. Indeed, the wording of the EOLC Bill – that the “attending medical practitioner must ... do his or her best to ensure that the person expresses his or her wish free from pressure from any other person” is a tacit admission by the Bill’s sponsor that it will in practice be impossible to detect and exclude coercion as a factor in people’s choices. We concur.
53. We believe the first responsibility of the State is to protect its citizens’ right to life, to the very best of its ability. To the contrary, the explicit aim of the End of Life Choice Bill is to cause an individual to die: that is not a side-effect or accident or unintended consequence, it is the specific intention. To legalise euthanasia and assisted suicide, while knowing that no safeguards have ever been fully effective in any field of human activity, would be to accept that at some point the State will cause the wrongful death of some of its citizens.
54. The starting assumption that some citizens will die wrongly is consistent with the fact that there is (i) an extremely low level of investigation of abuses in jurisdictions with euthanasia and assisted suicide accompanied by (ii) a high level of assertion that everything is going well. Knowing that this occurs in overseas jurisdictions will make New Zealand politicians accomplices to the wrongful deaths that will inevitably occur in New Zealand if this Bill were ever to become law.

Changing New Zealand’s Narrative of Care

¹¹ Physician Assisted Suicide: The British Geriatric’s Society’s position. 10 July 2015. Available at: <http://www.bgs.org.uk/index.php/specialinterest-main/ethicslaw-2/4067-position-assisted-suicide>

55. As explained above, a critical danger of passing this Bill into law is the impact it would have on our perceptions of others and the way it will subtly but surely (i) impact on our relationships with those who are most vulnerable and (ii) reshape our understanding of what represents good care.
56. While the following words of Matthew Parris (British journalist and former politician) may seem extreme, they are the truest expression of the paradigm highlighted above.

‘Some day soon we’ll all accept that useless lives should be ended’
And just as we feel ourselves looking more sympathetically at those who wish to end it all, so we shall be (unconsciously) looking at ourselves in the same way. The stigma will fade, and in its place will come a new description of selfishness, according to which it may be thought selfish of some individuals (including potentially ourselves) to want to carry on.¹²

57. The impact of legalising assisted suicide and euthanasia will inevitably reshape the way we look at all people who are not productive, fully functional, independent and healthy. It will reinforce a depleted notion of the concept of ‘care’, that will impact negatively on those whose care needs are costly – whether at the emotional, social or financial level or a combination of all three – and change our societal narrative of what ‘good’ care looks like into one that reflects the ‘ableist’ prejudice that has increasingly come to define our society.
58. The ‘narrative of care’ underlying euthanasia and assisted suicide regimes in overseas jurisdictions is culturally and economically narrow: a striking fact of the Oregon experience is that people who receive a lethal prescription are disproportionately white, well-educated and wealthy. That is, the idea of ‘end-of-life choice’ resonates most strongly with those who are highly educated, who have led relatively privileged lives and are fearful of the so-called ‘indignities’ associated with needing the personal care that many other people accept and live with daily.
59. Such a narrow narrative of care runs counter to New Zealand’s bicultural, multicultural and egalitarian aspirations, and cannot be corrected simply by changing the eligibility and scope requirements of the Bill. A changed narrative of care becomes intrinsic to the very process of legalising euthanasia and assisted suicide.

Placing people at risk of a premature death through coercion

60. The number of older persons requiring support is rising as the ‘baby boomers’ generation reach retirement age. In a context in which there are growing pressures on our health system, growing pressures on providing sufficient places and carers for our elders, and growing economic pressures on families, families

¹² M. Parris, “Some day soon we’ll all accept that useless lives should be ended,” (2015), <http://www.spectator.co.uk/2015/09/some-day-soon-well-all-accept-that-useless-lives-should-be-ended>

and the State both find themselves less able to provide care at the very time the needs are greatest. *This context puts our elders at risk of EAS as a result of both implicit and explicit coercion from families and caregivers.*

61. In a society that emphasises individuality, independence and productivity, 'dignity' becomes largely identified with being strong, self-reliant, fit, healthy and useful. The flip-side to this is that people increasingly perceive that it is a weakness to become a 'burden' to others. *This context puts our elders at risk of "assisted dying" coercion as a result of systemic social prejudices.*
62. Those of our elders who are subject to a loss of physical and mental function, and consequently a loss of autonomy, become exceptionally vulnerable to internalising the negative messages from a functionalist societal narrative that advantages and promotes the strong and independent. *This context puts our elders and others struggling with disabilities at risk of "assisted dying" coercion as a result of their own internalised feelings of loss of worth.*
63. While proponents of a law change consistently maintain that the EOLC Bill does not include disabled people in its scope, Not Dead Yet Aotearoa NZ, a member organisation of the Care Alliance, argue from experience and research that there are no hard and fast lines that can be drawn between disabled people and the disabilities that accompany life-limiting illness such as cancer. This point was well-illustrated recently by MP Louisa Wall who, in a speech to Parliament supporting the first reading of the EOLC Bill, stated that Lecretia Seales wanted to choose a point at which her life would end because of the indignity of the disabilities associated with her illness:

*[Lecretia] argued that her definition of dignity, which was her human rights argument, was actually about the respect that she was starting to lose for herself. She couldn't care for herself. She couldn't go to the toilet. People had to look after her. It was degrading for her ...*¹³

64. As one of our member organisations, *The Nathaniel Centre*, has noted:

The need for help with bathing and toileting on a daily basis is an integral part of life for many disabled people. If, as Louisa Wall suggested, this is seen as 'degrading', and if such 'loss of dignity' is worse than death then, in many if not most people's minds, the introduction of an EAS regime will send a message to all disabled people, including people whose disabilities are primarily a function of age, that they would be 'better off dead'.

Legalising EAS for the reason that the end stages of a terminal illness might be 'undignified' underscores the belief that a life with a severe disability is not worth living. It will thus put disabled people at risk of being pressured to choose suicide over living life with disability. Above all, Louisa Wall's comments serve to highlight the fact that there can be no bright line drawn

¹³ Louisa Wall, Hansard Reports, Wednesday, 13 December 2017 - Volume 726.

between euthanasia and assisted suicide for persons with a terminal illness and disabled people. The difference can only exist as a construct in people's minds.

65. As Diane Coleman (Not Dead Yet New York) argues:

The primary underlying practical basis for the physician's determination that the individual [with a terminal illness] is eligible for assisted suicide is the individual's disabilities and physical dependence on others for everyday needs, which is viewed as depriving them of what nondisabled people often associate with "autonomy" and "dignity," and may also lead them to feel like a "burden." This establishes grounds for physicians to treat these individuals completely differently than they would treat a physically able-bodied suicidal person.

66. Baroness Campbell of Surbiton, former Commissioner of the *Equality and Human Rights Commission* and of the *Disability Rights Commission*, who has spinal muscular dystrophy has likewise argued in the UK House of Lords:

"... imagine that it is already law and that I ask for assistance to die. Do your Lordships think that I would be refused? No; you can be sure that there would be doctors and lawyers willing to support my right to die. Sadly, many would put their energies into that rather than improving my situation or helping me to change my mind. The Bill offers no comfort to me. It frightens me because, in periods of greatest difficulty, I know that I might be tempted to use it. It only adds to the burdens and challenges which life holds for me".¹⁴

67. Closer to home, New Zealand disability activist John Fox puts it like this:

We already know as disabled people that we have to fight to have a job, fight to be born, fight structural prejudice, patronising assumptions, and cultural realities which call us less than, and worth less. Those challenges are likely not equal for you and me, and the impact of David Seymour's bill would not be equal either.¹⁵

68. In conclusion, if the EOLC Bill passes into law, the risk of premature death would significantly increase for disabled people in a society such as ours – one which is already negatively pre-disposed towards disabled people who are either pitied and/or perceived as having little or nothing to contribute while consuming large amounts of health care resources.

Confused signals about suicide and its prevention

69. We acknowledge that the debate about euthanasia and assisted suicide and its connection to suicides in the general population is a contentious one. However, our firm and considered view is that providing suicide assistance for some

¹⁴ See [https://hansard.parliament.uk/Lords/2014-07-18/debates/14071854000545/AssistedDyingBill\(HL\)#contribution-14071854000185](https://hansard.parliament.uk/Lords/2014-07-18/debates/14071854000545/AssistedDyingBill(HL)#contribution-14071854000185)

¹⁵ See <https://thespinoff.co.nz/society/18-07-2017/assisted-dying-devalues-the-disabled/>, (accessed 26 February, 2018).

people undermines suicide prevention for *everyone*. There is no bright line between so-called 'rational' and 'irrational' suicide because the same social, economic and health factors are involved.

70. In the first instance it is worth noting that people with physical disabilities are significantly more likely to seriously contemplate committing suicide, and the risk is even greater among younger people.¹⁶ These findings highlight the risks of euthanasia and assisted suicide for young disabled people in particular in a society which is strongly ableist in its attitudes and actions if not policies. Once again, this shows that the hard line that many people draw between EAS and disability will not hold up in real life.
71. Secondly, while an argument is made by some that a law change is required to reduce the rates of suicide in the general population (persons with life-limiting illness who, it is argued, have no other options), there is no evidence of this. Indeed, conversely, since euthanasia was legalised in the Netherlands in 2002, the rate of completed suicides (*excluding* premature death by euthanasia) has risen [from 9.6 to 11.1 per 100,000 population](#) (1,500 people in 2003 to 1,871 people in 2015).¹⁷ At the same time, the Netherlands has seen exponentially increasing numbers of persons ending their lives prematurely by way of euthanasia. Similarly, legalising assisted suicide in Oregon and Washington states "has been associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides." (Jones and Paton, 2015).
72. Most importantly, the recent *Health Select Committee Investigation into Ending One's Life in New Zealand* noted:

*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.*¹⁸

¹⁶ See Russell, D et al. (2009). Physical disability and suicidal ideation: a community-based study of risk/protective factors for suicidal thoughts, available at: <https://www.ncbi.nlm.nih.gov/pubmed/19792985>

¹⁷ See <https://www.cbs.nl/en-gb/news/2016/26/more-suicides>

¹⁸ See https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24, p. 43.

Dangers and risks with ambiguous and wide-ranging eligibility criteria (Part 1 Section 4)

Section 4(a) Age of eligibility

73. In 2017, then Attorney General, Hon Chris Finlayson, found the EOLC Bill to be inconsistent with the Bill of Rights' section pertaining to age. In a legal sense, the age restriction of 18 on Seymour's bill is discriminatory under the Act.
74. Before Canada had amended the Criminal Code in June 2016 to allow for medical assistance in dying (MAID), UNICEF Canada challenged the age limit of 18 years on 'child's rights' grounds.
75. In New Zealand, the Code of Health and Disability Services Consumers' Rights does not fix a particular age for consent to or refusal of treatment; children, like other, are presumed 'competent', unless it is otherwise established.
76. Belgium, which introduced euthanasia for those at least 18 years of age in 2002, voted to extend the practice to children in 2014.
77. Euthanasia became legal in the Netherlands in 2002. It allows euthanasia for those aged at least 12 years of age. Children aged from 12 – 15 years require parental consent. Since that time some Dutch doctors are urging lawmakers to extend the euthanasia law to include children aged 1 to 12.¹⁹
78. It is inevitable that the arbitrary age limit of 18 years will be challenged. This has already happened in Canada, where the age limit defined in its present law is challenged on child rights grounds. Paediatricians in Canada also report discussions with parents of never-competent patients about assistance in dying. The Canadian Paediatric Society's position statement notes: "In the foreseeable future, parents may challenge health care decisions in court on the grounds that continued life, as experienced by their dying or profoundly disabled child, is not in that child's best interests."²⁰

Section 4b) terminal illness

79. The EOLC Bill proposes that a person who is eligible for assisted dying needs to suffer 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.
80. In fact, the first criterion for eligibility, 'terminal illness', is redundant, since any terminal illness is covered by the second criterion: 'a grievous and irremediable medical condition'.
81. The qualifier for a terminal illness, 'likely to end his or her life within 6 months', is problematic since diagnosis is not exact and it is simply not possible to make an accurate prognosis of the limit of a patient's life. Autopsy studies identify major

¹⁹ See, for example: "Give children under 12 the right to die, say Dutch paediatricians" available at <https://www.telegraph.co.uk/news/worldnews/europe/netherlands/11686716/Give-children-under-12-the-right-to-die-say-Dutch-paediatricians.html> (accessed 26 February, 2018).

²⁰ Medical Assistance in Dying: A Paediatric Perspective. Position Statement of the Canadian Paediatric Society. Oct 26 2017. <https://www.cps.ca/en/documents/position/medical-assistance-in-dying>

diagnostic discrepancies in 10-20% of cases²¹. A review of studies that investigated potentially lethal diagnostic errors in Intensive Care Units, found that 28% of autopsied ICU patients had at least one misdiagnosis²².

82. In Oregon, which also requires 'reasonable medical judgment' of death within 6 months, the duration between first request and death in 2017 ranged from 15 to 603 days; that is, at least one person lived for almost a year and eight months after requesting assisted suicide. Over the period from 1998-2016, the duration between first request and death ranged from 14 to 1009 days, so at least one person survived for 2 years and 9 months after requesting assisted suicide²³. An accurate prognosis of length of life is clearly problematic.

Section 4c) grievous and irremediable medical condition

83. The criterion 'grievous and irremediable medical condition' requires doctors to make a judgement about a patient's condition when, as noted above, even with the best of intentions and the availability of diagnostic technology, diagnosis is often inaccurate.
84. Moreover, the term 'grievous and irremediable medical condition' is vague and subjective. It can include psychiatric disorders, such as depression. In the Netherlands, the requirement for euthanasia that the physician must 'be satisfied that the patient's suffering is unbearable, with no prospect of improvement' has, in practice, allowed for the euthanasia of patients with psychiatric disorders, dementia, and 'multiple geriatric syndromes'.²⁴
85. The EOLC bill specifies that 'unbearable suffering' 'cannot be relieved in a manner that he or she [the person who requests assisted dying] considers tolerable'. Even if it is the doctor's clinical assessment that a therapy is appropriate and effective, this is insufficient to allow the doctor to reject a request for assistance to die.

Conclusion

86. If introduced into law in New Zealand, the *End of Life Choice Bill* would lead to a number of unavoidable and unjust consequences. These include wrongful deaths, a changed narrative of care by which the state affirms that some lives are no longer worth living, people being placed at unavoidable risk of subtle coercion and undue influence by unscrupulous others, confused signals about suicide and its prevention, likely litigation regarding the eligibility criteria and inexorable pressure to permit euthanasia and assisted suicide on demand.

²¹ Graber, M. L. (2013). The incidence of diagnostic error in medicine. *BMJ Qual Saf*, bmjqs-2012. P.ii21.

²² Winters, B., Custer, J., Galvagno, S. M., Colantuoni, E., Kapoor, S. G., Lee, H., ... & Newman-Toker, D. (2012). Diagnostic errors in the intensive care unit: a systematic review of autopsy studies. *BMJ Qual Saf*, 21(11), 894-902.

²³ Oregon Death With Dignity Act 2017 Data Summary. Oregon Health Authority, Public Health Division. <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>

²⁴ "Regional Euthanasia Review Committees RTE. Annual Report 2016". <https://english.euthanasiacommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports>

3. The Bill and the medical profession

This Bill undermines the core ethical stance of the medical profession

87. The New Zealand Medical Association Position Statement on Euthanasia states: “Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient’s request or at the request of close relatives, is unethical. Doctor-assisted suicide, like euthanasia, is unethical. The NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical.” The World Medical Association Resolution on Euthanasia “strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions”.²⁵
88. The New Zealand Medical Association Position Statement on Euthanasia states: “Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient’s request or at the request of close relatives, is unethical. Doctor-assisted suicide, like euthanasia, is unethical. The NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical.” The World Medical Association Resolution on Euthanasia “strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions”.²⁶
89. The Australia and New Zealand Society of Palliative Medicine (ANZSPM) Position Statement on Euthanasia (2017) states: “In accordance with best practice guidelines internationally, the discipline of Palliative Medicine does not include the practices of euthanasia or physician assisted suicide.”
90. The Scotland Report on Assisted Suicide records that supporters and opponents alike of the Assisted Suicide Bill acknowledge that “the involvement of healthcare professionals in assisted suicide, even if it were legal, would *not* amount to ‘medical treatment’” (n. 207). Similarly, Boudreau and Somerville note “... healing and euthanizing are simply not miscible [able to be combined] and euthanasia can never be considered ‘medical treatment’” (p. 63).
91. We note that the most common recent argument for euthanasia and assisted suicide is “that patients have a right to control when and how they die – [this argument] in fact points to the involvement not of doctors but of legal agencies as decision makers, plus technicians as agents.”²⁷

²⁵ See <https://www.wma.net/policies-post/wma-resolution-on-euthanasia/> (accessed 26 February, 2018).

²⁶ See <https://www.wma.net/policies-post/wma-resolution-on-euthanasia/> (accessed 26 February, 2018).

²⁷ See Assisted suicide and voluntary euthanasia: role contradictions for physicians. [Randall F¹](#), [Downie R](#), p. 323.

92. In Oregon, the most common reasons for requesting assisted suicide are social/existential rather than medical; aggregated figures from 1998 to 2017 show 91% are concerned about losing autonomy; 90% are concerned about being unable to engage in enjoyable activities; 76% are concerned about loss of dignity; and 44% fear being a burden on family and/or friends/caregivers. Only 26% cite inadequate pain control or *concerns* about inadequate pain control as one of their reasons.²⁸
93. This leads to one conclusion: Euthanasia and assisted suicide are not medical treatment. “Doctors are not necessary in the regulation or practice of assisted suicide. They are included only to provide a cloak of medical legitimacy”.²⁹

It compromises the palliative care approach

94. The background to this Bill (Explanatory Note page 2) claims that “the evidence considered in Seales and overseas studies show that, when assisted dying is permitted, the quality and uptake of palliative care increases and the doctor – patient relationship is positively enhanced.” *Expert evidence from leading palliative care experts in New Zealand and internationally did not support this view.* Rather, in many instances it showed that assisted suicide would damage irrevocably the doctor-patient relationship and significantly compromise palliative care. The expert evidence of Professor Montero, for example, described the integration of euthanasia into end of life care in Belgium as “disastrous”.³⁰
95. It is claimed by some that euthanasia and/or assisted suicide, rather than being opposed to palliative care, have a place alongside it. These protagonists claim that physicians can cooperate with a patient’s request for euthanasia as part of their role of caring for their patient right to the end and that it is possible to provide euthanasia integrated with palliative care. The problem, however, is that euthanasia and palliative care represent, philosophically, two distinct, incompatible approaches to end of life care.
96. Palliative Care affirms life and regards dying as a normal process. It improves the quality of life of patients and their families by the early identification, assessment and treatment of pain and other sources of suffering – physical, psychosocial and spiritual. The overarching concept is to provide a cloak or a shield (pallium) that, cloaks the person and their whānau in unconditional care while acknowledging that their illness cannot be taken away.
97. The intensive care which palliative specialists give to a person is not easy to provide. It is demanding and challenging. It is also very effective.

²⁸ See:

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>

²⁹ See “Doctors want no part in assisted suicide”, available at <http://doctorssayno.nz/>

³⁰ See also the affidavits of Dr Donnelly, Baroness Finlay, Dr George, Dr Landers, Dr MacLeod, Tony O’Brien, Judith Pickthorne and Mary Schumacher (for Hospice New Zealand), available at <http://carealliance.org.nz/issues/seales-v-attorney-general/>

98. Palliative care takes a multi-disciplinary approach involving not just doctors and nurses, but physiotherapists, occupational therapists, dieticians, pharmacists, volunteer visitors, art and music therapists, social workers, and chaplains. The focus is on living fully in the moment while preparing for the person's inevitable death. Palliative care workers use all their resources to maximise independence and to achieve the patient's goals for living. They explore carefully with the person who is facing death how much the patient wishes to discuss, and they move at the patient's own pace. A patient may choose to explore their deepest personal issues with anyone on the multidisciplinary team or with their family or their General Practitioner.
99. In caring to the best of our ability for someone who is dying, we ease the grief and reduce the burden of bereavement for both the person with the illness and those left behind. It is true that many people suffer physically, emotionally, and psychologically with advanced illnesses, facing existential uncertainty, anxiety, and a fear of dying and death. *It is also true that the intervention of palliative care can transform such suffering by easing physical symptoms, by resolving social worries, and by attending to existential and spiritual issues.*
100. Doctors take into account the risk-benefit balance, the reversibility of an intervention, the progress of the underlying illness, and the patient's comfort. For example, if a person is dying imminently, surgery or a stent might be considered if it would improve the quality of that person's life. If the obstruction cannot be overcome, discussions with the patient and her or his family would continue to decide how best to keep the person comfortable. The benefits and risks of each intervention are discussed, as well as how long a person is likely to live, the preferred for that care as well as the preferred carers.
101. The distinction between the two approaches is clear: palliative care is 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness'³¹ while euthanasia occurs through "the administration by a medical practitioner of a lethal dose of medication" (Section 3 EOLC Bill).
102. The incompatibility of the two approaches reveals itself³² in the different ways of responding to the question of autonomy: 'Proponents of the legalization of euthanasia take the request of the patient as the point of reference of the patient's autonomy and try to comply with this personal preference. Palliative care experts while acknowledging requests for euthanasia from those patients who express them, make this the starting point of holistic care, beginning with comprehensive assessment and communication and trying to understand the motivation and attitude behind the patient's wish.'

³¹ Radbruch, Lukas, et al. "Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care." *Palliative medicine*(2015): p.5

³² *Ibid.*, p. 11.

103. The *European Association for Palliative Care* position paper concludes that 'euthanasia is not a part of palliative care,'³³ and that the normative frameworks of palliative care and euthanasia/physician-assisted suicide are incompatible. Furthermore, all professional bodies involved in palliative care in New Zealand are opposed to the legalisation of euthanasia and assisted suicide. As one of our experienced palliative care physicians observes:

We believe that allowing a person to go through the process of a natural death is better for the patient and their family. In the process of dying there is much living to be done, and we have witnessed time and time again how much people grow through this process. This is what holds those of us who work in palliative care: we witness this growth and hope and transformation so often, and we have the privilege of helping it, and walking along side those who make this journey. We work hard and work to increase our skills and develop the knowledge in this area because we see what huge benefits it delivers to people, in this most vulnerable period of their lives.

Conclusion

104. If the EOLC Bill passes into law and assisted dying becomes available and accepted as an appropriate response to a terminal diagnosis, there is a real risk that people will simply not engage with palliative care. People who would otherwise move through the early stages of grief at their diagnosis and come again to find hope and meaning in their lives would opt instead for an early death. This Bill could quite literally deprive people of months or even years of their natural lives.

105. Even if patients do engage in palliative care, the mind-set will be fundamentally changed and irreparably harmed by this Bill. Instead of working through their journey to a natural death, people would always have before them the prospect that it might be a better option for them to commit suicide or to be euthanised. Engagement in palliative care would be conditional. It is possible that such contact would not be supported by their families, or that families would be divided on the issue, or that the decision would be argued and revisited over and over again.

106. All of this confusion around which path of care to follow would be very stressful and would place an enormous additional burden on the person who is dying. *Prematurely ending the life of a patient is simply unnecessary to achieve relief from suffering.* A person with an advanced progressive illness might say that the struggle is hard, that they wished it was over, that they have thought about the option of euthanasia. *It is the experience of our member organisations that when each person is listened to carefully, attended to, respected and provided with dignified care, such cries for help dissipate.* It is also the experience of our members that persistent requests for a premature death are extremely rare.

107. People who work with the dying every day are not romanticising this process: *"This is what we see. Palliative care is effective. It is the appropriate and compassionate response to the needs of this group who are among the most vulnerable people in society."*

³³ Ibid., p. 11.

4. What does overseas experience tell us about where the Bill would take us as a society?

108. The Explanatory Note of this Bill claims “analysis from overseas jurisdictions where assisted dying is permitted demonstrates that concerns, including concerns about the abuse of the vulnerable, have not materialised and that risks can be properly managed through appropriate legislative safeguards.” *We strongly refute this claim and argue that peer-reviewed research on overseas jurisdictions reveal numerous and growing areas of concern and risk.*

109. The overwhelming evidence provided by international experts and reports from these jurisdictions in *Seales* demonstrated significant concerns with the operation of the overseas regimes.³⁴ Reviews by independent tribunals (including the courts in the UK, Ireland and the US, and the Scottish and UK Parliaments) expressed similar conclusions. The United Nations Human Rights Committee and the UN Committee on the Rights of Persons with Disabilities also expressed strong concerns.

110. The Belgian Federal Commission for Euthanasia Control and Evaluation reports “it is not possible for [the Commission] to assess the proportion of the number of euthanasia acts reported in relation to the number of euthanasia acts actually performed.”³⁵ The President of the Control Board, Professor Wim Distelmans, confirmed in an interview that the actual numbers of unreported euthanasia cases in Belgium remain unknown, “which prevents us from having a real view of the magnitude of the issue.”³⁶

111. Other concerns have emerged in overseas jurisdictions to do with consent, competency to consent, the widening scope of eligibility criteria, inadequacies of reporting, and the normalisation of euthanasia and assisted suicide as increasingly “go-to” solutions to relieve suffering.

Consent

112. Doctors in Belgium are intentionally shortening the lives of patients without an explicit request to die. Ostensibly this is motivated by compassion on the part of the physicians, but the doctors did not know the wishes of the patients.^{37 38}

113. In the Netherlands, there is clear evidence³⁹ that euthanasia in these countries is regularly carried out without an explicit patient request. Such events are

³⁴ See legal opinion Supplement 1 (Clause 69.3) to NZHPA submission on this Bill.

³⁵ <https://www.ieb-eib.org/en/document/7th-report-of-the-federal-commission-for-euthanasia-control-and-evaluation-468.html>

³⁶ <http://www.ieb-eib.org/en/bulletins/belgique-plus-de-2000-euthanasies-declarees-en-2015-361.html>

³⁷ Cohen-Almagor, Raphael. “First do no harm: intentionally shortening lives of patients without their explicit request in Belgium.” *Journal of medical ethics* (2015) Aug, 41(8), 625-9.

³⁸ <https://www.bioedge.org/bioethics/belgiums-euthanasia-commission-is-under-fire/12604>

³⁹ Onwuteaka-Philipsen, B.D. et al. “Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey.” *The Lancet*, 2012; 380: 908-15. In 2010, of 475 deaths as a result of euthanasia, 13 (2.7%) were without an explicit patient request.

technically known as “termination of life without explicit request” and are not included in the officially recorded number of euthanasia cases.

114. The reasons for not discussing euthanasia or not obtaining consent include deliberate decisions made by doctors who believed that euthanasia was 'clearly in the patient's best interest' (17%) or because the discussion 'would have been harmful' (8.2%).⁴⁰ This unlawful behaviour by health professionals highlights the fact that the introduction of so-called ‘voluntary euthanasia’ leads inevitably to a growth in the exercise of medical paternalism.
115. There is evidence that in other situations where there was not an explicit request from a patient, the reasons for terminating a patient’s life reflected “the wish of the family” 50% of the time.⁴¹
116. While these decisions could be called ‘compassionate responses’ to what might have been futile medical situations, it remains the case that physicians were deciding ‘in the patients’ best interests’, often under pressure from families, without knowing with certainty what the patients wanted.
117. It is not surprising that physicians, having accepted the desirability of euthanasia for patients who makes a voluntary request, do not want to deny such a ‘benefit’ to other patients simply because they are unable to make the request. Ironically, whatever one’s attitude towards such a ‘paternalistic’ response, it constitutes a denial of patient autonomy, the central argument used by most advocates of the End of Life Choice Bill.
118. All of the above concerns around consent have arisen over periods of time since the introduction of assisted dying regimes not dissimilar to the EOLC Bill.

Competence to consent

119. There is evidence that in the Benelux countries, many patients’ competence to consent is in doubt. Numerous studies have found that a desire to die is linked with depressive symptoms,^{42,43} and research shows the prevalence of depression in terminally ill patients ranges from 3.7-58%, depending on the study, the type and stage of disease, setting and population characteristics.
120. In addition, it has been found that a total of 5-15% of people with cancer meet the criteria for major depression, and another 10-15% present with symptoms

⁴⁰ Chambaere, Kenneth, et al. "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey." *Canadian Medical Association Journal* 182.9 (2010): p.896.

⁴¹ *ibid.*, p 896.

⁴² McCormack, Ruaidhrí, and Rémy Fléchais. "The role of psychiatrists and mental disorder in assisted dying practices around the world: a review of the legislation and official reports." *Psychosomatics* 53.4 (2012): 319-326." ...depression is more influential on the desire to hasten death than physical pain...A recent cross-sectional survey of 300 palliative patients estimated that major depressive disorder was present in 19% of cases. The true prevalence may be even higher." P.324.

⁴³ Macleod, S. (2012). Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician’s view. *Australian & New Zealand Journal of Psychiatry*, 46(10), p. 940: “At least 15% of terminally ill cancer patients are experiencing major depression.”

that are somewhat less severe. In people with significant levels of physical impairment, at least one-quarter of those with advanced disease experience a clinically relevant and treatable depression.⁴⁴

121. In the Netherlands and Belgium, the number of patients referred for psychiatric assessment is much lower than would be expected given the prevalence of depression and other mental illnesses in patients with a terminal illness.
122. In Washington State, only 4% of participants in 2015 and 5% in 2016, were referred for psychiatric/psychological evaluation.⁴⁵

Widening of Scope

123. A particular phenomenon in countries which have legalised regimes similar in scope to that proposed in the EOLC Bill is the steady widening of scope – both in the eligibility criteria themselves, and how they are interpreted in practice. In the Netherlands it is now no longer necessary that a patient's condition is 'terminal'⁴⁶, and patients with mental illness including depression are eligible for euthanasia.⁴⁷ Likewise, in Belgium, a 'terminal' condition is unnecessary and patients with psychiatric conditions can request euthanasia.⁴⁸
124. 'Exit', a Swiss organisation that provides assisted suicide, has extended its services to elderly people who are not terminally ill.⁴⁹ Exit now defines assisted suicide as "the right to the freely responsible death of a very old person wishing to die". Those at an older age have a lower threshold of eligibility than younger people.
125. In Belgium, the primary reason for seeking euthanasia in 2002 was cancer, but this has now reduced to about two thirds of all cases. There were 124 deaths in 2014-2015 for mental and behavioural disorders. A patient in that country is entitled to refuse palliative care and then to make an application for euthanasia on the grounds of unbearable suffering as determined by the patient.⁵⁰
126. Physical suffering is mentioned in a majority of cases to justify euthanasia, and psychological suffering is mentioned in 5% of cases.⁵¹ The types of reported

⁴⁴ Vachon, M. L. S. "In the terminally ill, a wish to die is a manifestation of depression and should be treated accordingly." *Clinical Oncology* 16.5 (2004): 319-320. P.319.

⁴⁵ Washington State Department of Health 2016 Death with Dignity Act Report. DOH 422-109 2016. <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2016.PDF>

⁴⁶ See: <https://www.government.nl/topics/euthanasia/contents/euthanasia-assisted-suicide-and-non-resuscitation-on-request>

⁴⁷ <https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2016/april/12/jaarverslag-2016> The committees have since 2013 noted an increase in willingness among physicians to carry out euthanasia and assisted suicide in cases involving a mental disorder.

⁴⁸ Thienpont, Lieve, et al. "Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study." *BMJ open* 5.7 (2015): e007454.

⁴⁹ Maddy French, The Guardian, Monday 26 May 2014. Available at: <http://www.theguardian.com/society/2014/may/26/swiss-exit-assisted-suicide-elderly-not-terminally-ill>

⁵⁰ See Analysis of The Seventh Report of the Federal Commission for Euthanasia Control and Evaluation to the Legislative Chambers (for the Years 2014 and 2015), <https://www.ieb-eib.org/en/pdf/20161008-en-synthese-rapport-euthanasie.pdf> (accessed 26 February, 2018).

⁵¹ <https://www.ieb-eib.org/en/pdf/20161008-en-synthese-rapport-euthanasie.pdf>

psychological suffering include dependence, loss of autonomy, loneliness, despair, loss of dignity, and the fear of losing one's ability to maintain social contacts.

127. In the Netherlands (2016), the suffering caused by dementia was judged as warranting euthanasia in 141 cases notified to regional euthanasia committees (compared with 109 in 2015) and the suffering caused by a psychiatric disorder in 60 cases (compared with 56 in 2015).⁵²
128. In the Netherlands, a law change in 2001 allowed for children aged 12-16 years to be euthanised with parental consent, and in Belgium, in 2014, children of any age became eligible for euthanasia. If the End of Life Choice Bill was passed in New Zealand, there would inevitably be pressure to include children; Maryan Street has indicated her openness to including children by refusing to rule it out: "Application for children with a terminal illness was a bridge too far in my view at this time. That might be something that may happen in the future, but not now."⁵³
129. In Canada, lawsuits have already begun to expand eligibility for euthanasia to those who are not terminally ill and to those unable to give informed consent – for example a Quebec case which is seeking permission to terminate the life of a patient with dementia.⁵⁴
130. The facts from Belgium and the Netherlands, and most recently Canada, all point to a significant widening of the scope of the laws, and it appears that this widening in scope is inevitable following any legalisation. Once the state accepts the principle of terminating some lives as being an appropriate response to suffering, then rights-based arguments to extend eligibility criteria become irresistible.
131. Oregon is often held up as an example of a jurisdiction where the eligibility criteria have not expanded. While on one level this is true, many Oregonians remain dissatisfied with the narrow scope of their law and continue to advocate for broader eligibility criteria than 'terminal illness'. Paradoxically, some the strongest advocates against broadening the law in Oregon are those most in favour of a broader regime. Their case is unashamedly made on political grounds. For example, responding to a move to give patients more time to access the law, Steve Telfer, president of the board of the Portland-based Death with Dignity National Center stated that

... it was unnecessary and would hurt efforts to pass similar laws in other states. 'We think it's a very bad idea,' ... extending it to a year would send the wrong message to lawmakers considering similar laws in other states. 'You just run the risk of the slippery-slope argument big time'".⁵⁵

⁵² "Regional euthanasia review committees Annual Report 2016", p. 13. <https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports>

⁵³ <http://www.stuff.co.nz/taranaki-daily-news/news/9029192/Euthanasia-bill-close-to-MPs-heart>

⁵⁴ <https://www.bioedge.org/bioethics/a-quebec-mercy-killing-prompts-a-rethink-on-euthanasia-law/12387>

⁵⁵ See "Bill to expand Oregon's Death with Dignity Act runs into a buzz saw of opposition" (accessed 26 Feb 2018) http://www.oregonlive.com/mapes/index.ssf/2015/03/bill_to_expand_oregons_death_w.html.

Reporting

132. Various studies have established that large numbers of cases of euthanasia in Belgium and the Netherlands are not reported, despite being required by law in both countries. One study in Belgium found that only half of all estimated cases of euthanasia were reported to the Federal Control and Evaluation Committee.⁵⁶ In the Netherlands it was found that about 20% of cases of euthanasia were not reported, as is required under the Euthanasia Act.⁵⁷
133. In addition, unreported cases were usually dealt with less carefully than reported cases. In particular, a written request for euthanasia was more often absent; other physicians and palliative care specialists were consulted less often; opioids and sedatives were used more often than barbiturates and neuromuscular relaxants; and the drugs were administered more often by a nurse alone.⁵⁸
134. The Control Commission (Belgium) has stated that it 'does not have the possibility of assessing the number of reported euthanasia cases versus the number of euthanasia cases actually performed', which casts serious doubt on the ability of authorities to exercise an effective level of control.⁵⁹

Normalisation

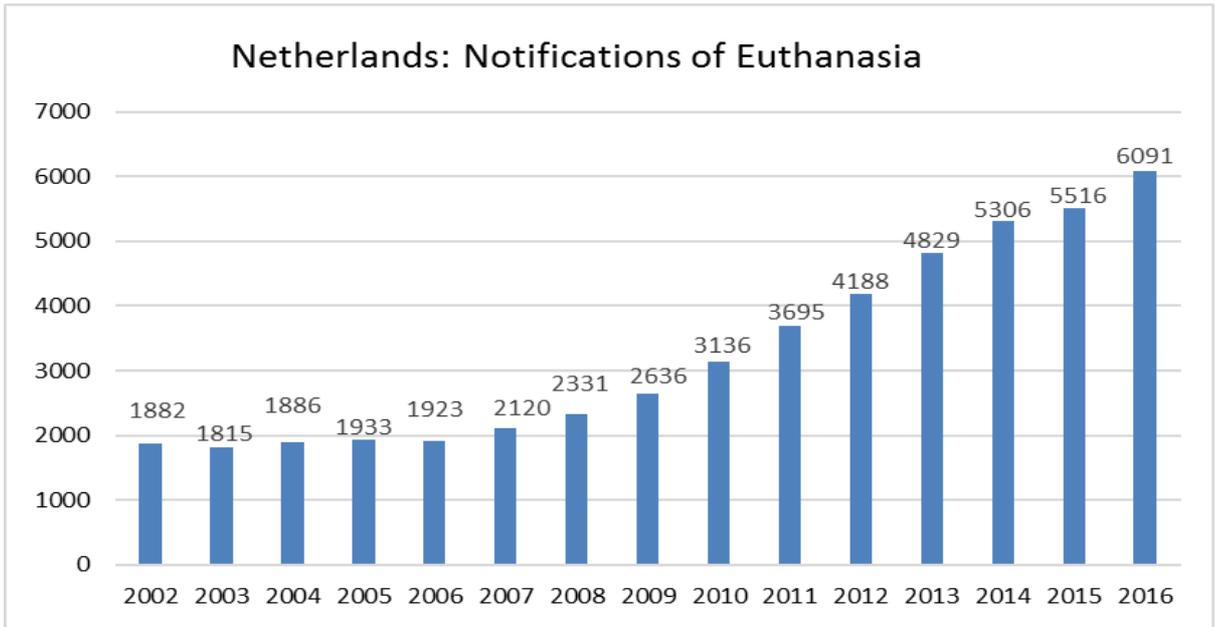
135. It can be inferred that the changes in practice over time described above have occurred in part because euthanasia and assisted suicide have become 'normalised' in these societies. Patients, families and physicians have increasingly come to view euthanasia/assisted suicide as a highly desirable response to difficult medical or psychological problems. This is a significant shift from the position that these practices were to be a rare consideration in only the most dire of circumstances in line with the original intention of the legislators. The shift in approach is evidenced by the inexorable increase in the number of those who seek assistance to end their lives prematurely.
136. The graphs below illustrate this trend.

⁵⁶ Smets, Tinne, et al. "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases." *BMJ* 341 (2010): c5174.

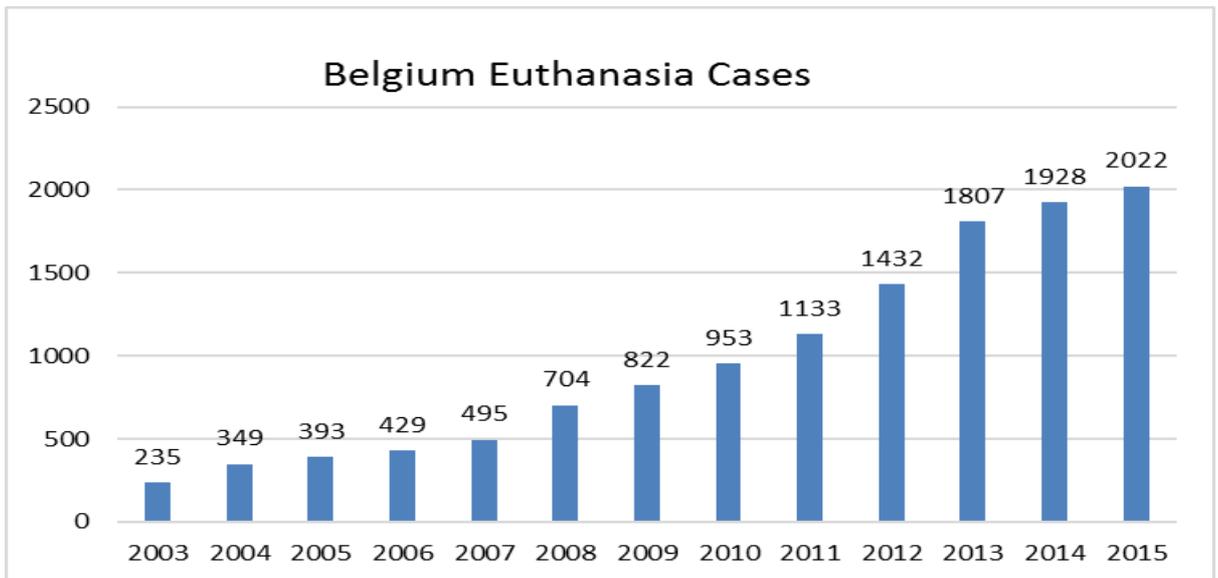
⁵⁷ Van der Heide, Agnes, et al. "End-of-life practices in the Netherlands under the Euthanasia Act." *New England Journal of Medicine* 356.19 (2007): 1957-1965.

⁵⁸ Smets, T., Bilsen, J., Cohen, J., Rurup, M. L., Mortier, F., & Deliens, L. (2010). Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ*, 341, p.4.

⁵⁹ European Institute of Bioethics. Does the Belgian Model of Integrated Palliative Care Distort Palliative Care Practice? P. 3. Available at: <http://www.ieb-eib.org/en/pdf/20151126-euthanasie-et-soins-palliatifs-english.pdf>



Data from Dutch Regional Euthanasia Review Committees: Annual Reports 2002-2016.



Data from Brussels: European Institute of Bioethics <https://www.ieb-eib.org/en/pdf/20161008-en-synthese-rapport-euthanasie.pdf>

5. Conclusion

137. The *End of Life Choice Bill* proposes a regime for New Zealand whereby people in certain circumstances would, with the approval and sanction of the State, be able to have their lives terminated through the administration of lethal drugs.
138. The *Care Alliance* recognises that the issues which sit behind the introduction of such a Bill are complex and challenging. The right of patients to exercise personal autonomy at the end of their lives is acknowledged and, in our view, is enabled to a good degree already in the choices and options that exist under present law. Autonomy is not unbounded. There are some matters where ethics and other societal considerations must place limitations on absolute autonomy so as to avoid harm to some and the likelihood of a wrongful death.
139. Any change in the law as proposed in this Bill, regardless of the eligibility criteria finally determined, would violate the ethics of the medical profession, placing health professionals in an untenable position.
140. The *End of Life Choice Bill* has a number of serious flaws, many of which are inherent in any attempt to legalise euthanasia or assisted suicide. We do not believe that the proposed Bill can be amended sufficiently to address these flaws.
141. Agreeing to assist people to kill themselves is not a compassionate response to those who fear being a burden, or who fear getting old or ill. Instead, it sends a clear message that they are correct to fear that society does not want them and that their lives have less value and little meaning once they become frail. It sends the message that they do not deserve our care and love. It sends them a message that society agrees that it would be better for everyone if they were indeed dead.
142. There is a real risk that some people who would have lived longer if they had felt supported and cared for would instead opt for assisted dying. Others would feel coerced by family or societal expectations to take this option. Instead of protecting these people, society would become complicit in their deaths.
143. There is a real risk also that assisted suicide or euthanasia would become a default position: people would shift to the mind-set that they have to justify to themselves (and others) why they should stay alive. This is not a compassionate response to someone with a life-limiting illness or other serious condition.
144. We firmly believe that providing additional resources to the palliative care sector, thereby improving the quality, consistency, and coverage of services provided, would address the reasons which underlie the introduction of the EOLC Bill. As highlighted in the Report of the Health Select Committee, we also want to see additional measures aimed at increasing the public's understanding of efficacy of high quality palliative care.

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