



Submission to the Health Select Committee (NZ) on the
Petition of Hon Maryan Street and 8,974 others regarding euthanasia
from the Care Not Killing Alliance (UK)

Care Not Killing (CNK) is an alliance of some forty organisations (spanning healthcare, law, disability rights, education and religion), backed by thousands of individual supporters. Formally established in 2006, CNK operates throughout the UK, seeking to (1) promote more and better palliative care, (2) ensure that existing laws against euthanasia and assisted suicide are not weakened or repealed and (3) influence the balance of public opinion against any further weakening of the law. In our first ten years, we have successfully made the case against bills in the House of Lords (2006, 2009), House of Commons (2015) and Scottish Parliament (2010, 2015); intervened in key court cases up to the level of the Supreme Court; and we continue to highlight unequal or inadequate access to good care and support for those with terminal or incurable illnesses and disabilities. We oppose proposals such as these because they are invariably uncontrollable, unethical and unnecessary, and we support friends and partners opposing this petition in New Zealand. To that end, we offer our perspective, four months on from a major debate in the elected house of the UK Parliament culminating in MPs' rejecting assisted suicide by a massive 3-1 margin.

Concerning the content of the petition

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

While recognising that many people have differing views on this subject, we feel no reasonable debate on this subject can be founded on euphemisms. While Ms Street favours 'medically-assisted death', proponents in the UK prefer 'assisted dying' (cf the Assisted Dying Bill and Assisted Dying (No. 2) Bill). For a doctor to provide care and support for those who are dying is right and good, but to accept such terms as these in place of assisted suicide or euthanasia is to knowingly conflate good medical care with deliberately ending life. Regardless of what illness a patient might die from days, weeks, months or years from now, and regardless of whether a doctor prescribes or administers the means of death, it remains the fact that so-called 'medically-assisted death' involves a doctor intentionally causing a patient's death. This consultation should thus give particular weight to the submissions of healthcare professionals and their representative bodies – which continue in the UK to reject assisted suicide – but the Committee should also refuse to base their deliberations on euphemisms.

The petition also refers to the context of '*a terminal illness or an irreversible condition*'. The petition is of course by nature a brief treatment of the topic, but these phrases form another hotly disputed area of this debate. This is, first, because there is enormous debate within the movement for legal change as to where the line should be drawn: British bills have been based on the Oregon model (6-month prognosis, assisted suicide), but many have argued that this does not go far enough, including many at the forefront of the associated campaign who see the proposed legislation as a first step. Assurances from campaigners and Parliamentarians who say that 'the law

would only go thus far' may in many cases be well-meaning, but they lack any evidence base in jurisdictions which have changed the law. The pattern is rather one of incremental extension. Ms Street's petition, of course, goes beyond terminal diagnoses. Perhaps the New Zealand Parliament will be asked to follow the lead of the Netherlands, where professional guidance supporting the euthanasia law requires that 'the patient's suffering must always be rooted in medically classifiable somatic or psychological illness; and that providing euthanasia or assisted suicide when there is no "unbearable suffering" with a medical basis falls outside the scope of the legislation.'¹ Under what sound like firmly defined parameters, the Dutch euthanise increasing numbers of patients with dementia and mental disorders, and research published last year found that more than a quarter of Dutch doctors would consider euthanasia applications based on being 'tired of life'.² Proponents can never agree how far they want to go and the compromises they reach hang on definitions which swell, sag and lose objective meaning as society considers which suicides should be discouraged and which should be facilitated by the health service. Why is it so hard? Because every limit considered is arbitrary, fatally undermining the most basic principles of suicide prevention. If we were to be glib, we might adapt Orwell: all lives are equal, but some lives are more equal than others. Noted disability campaigner and member of the House of Lords Jane Campbell has it better, however:

The existing law on assisted suicide rests on a natural frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about the deaths of other people. What the proponents of 'assisted dying' want is to replace that clear and bright line with an arbitrary and permeable one. At the moment they say they want assisted suicide for people who are terminally ill, but for how long will that last, and who decides what is terminal? If terminal illness, why not chronic and progressive conditions? And, if chronic and progressive conditions, why not seriously disabled people? I am already on the list.³

The term 'unbearable' is an example of a word which is not only entirely subjective, but which oversimplifies and obscures the complex visage of dying. For example, there are many examples of healthcare professionals freely admitting that patients have sought euthanasia, with all or almost all subsequently finding that when they properly understood their illness, the treatment and the care and support available, and when the symptoms which first drove such a desire were attended to, they no longer wanted to end their lives prematurely.⁴ Such doctors include the eminent palliative medicine physician Prof Rob George, who has additionally observed that often, the suffering so often talked about in this debate is in fact that of families who struggle with loved ones' illnesses rather than the patients themselves, and this side of things should be borne in mind when considering wider public sentiment:

For example, a gentleman I saw today, severely disabled with a neuro disability, nervous system disability – most people observing him would say he had unbearable suffering. If you actually ask him, that's not the case at all. So through my eyes, were I not to be informed, then I would be inclined to think that; and I think that for many of us in society, to observe these situations is exceptionally difficult. It's what we call the burden of witness. An example from my personal life was when my father was dying from dementia and my mother said, 'I can't bear all of this suffering'. I said 'mother, why don't we just ask him?' So I asked him, and he said 'don't be ridiculous, I'm not suffering at all.' So I said 'mum, he's just said he's not suffering'; she said 'yes but I can't bear seeing all this suffering'. She was speaking about herself.⁵

One of the greatest dangers associated with legalising assisted suicide or euthanasia is that we undermine the place in society of those with serious conditions. A 2014 poll commissioned by disability charity Scope found that

¹ British Medical Association, *End-of-life care and physician-assisted dying: Vol 1 Setting the Scene* (2015) p104

² Bolt EE, Snijdwind MC, Willems DL et al. Can physicians conceive of performing euthanasia in cases of psychiatric disease, dementia or being tired of living? *J Med Ethics* 2015; 0: 1-7. (<http://bit.ly/23AQ2FX>)

³ Campbell, J, 'It sends a shiver down my spine', Daily Telegraph (24 March 2014) <http://bit.ly/1Dy7mwa>

⁴ For example: 'Westminster Rally, July 2014: Dr Trevor Stammers' https://youtu.be/oG72jiv_QbM

⁵ Westminster Faith Debates – Should we legislate to permit assisted dying? – Intro by Rob George (2 May 2013) <http://bit.ly/1VA93V5>

a majority of disabled people ‘believe that disabled people are often seen by the public as a burden to society’, ‘believe that the current ban on assisted suicide protects vulnerable people from pressure to end their lives’ and were ‘concerned about a change in the law worry that pressure would be put on disabled people to end their lives prematurely’.⁶

Concerning the Committee’s first point of interest

1. The factors that contribute to the desire to end one’s life.

The issues raised by Prof George and the Scope poll tie in closely with probably the most saddening of the factors reported by those undergoing assisted suicide in Oregon and Washington. In 2014, 40% and 59% of assisted suicides cases on Oregon and Washington respectively were based wholly or partly on not wishing to be a burden on family, friends or care-givers. We say this is the most saddening because we must ask: to what extent are we as a society knowingly (as suggested in the Scope survey) or unknowingly (as could easily have been the case in examples like Prof George’s) prompting the concept of ill and disabled people being a burden?

The main argument advanced for assisted suicide is unremitting pain. But the Oregon data⁷ show that those people citing ‘inadequate pain control or (even) concern about it’ constitute just 31.4% of cases overall. So what are the main reasons given for taking one’s life? In 2014, 91.4% cited ‘loss of autonomy’, 86.7% said they were ‘less able to engage in activities making life enjoyable’ and 71.4% listed ‘loss of dignity’. These are not physical but existential symptoms. But should lethal drugs be prescribed to people who feel their lives no longer have meaning and purpose? The fact that almost a third of patients dying under the Act report inadequate pain control or concerns about pain also shows that palliative care provision in Oregon is unsatisfactory. But surely this is an argument for better care rather than assisted suicide.

Concerning the Committee’s second point of interest

2. The effectiveness of services and support available to those who desire to end their own lives.

The UK remains the world leader in the development of palliative care, yet it is a little-known and much misunderstood area of healthcare, and the tenor of the debate on assisted suicide could easily leave the impression that a dignified death must be impossible unless it is at one’s own hands – but we know better.

In its 2015 report on end of life care around the world, the Economist Intelligence Unit said: ‘a pioneer in palliative care, the United Kingdom maintains cutting-edge services and is the world’s best location to receive terminal care and pain-alleviating treatment.’⁸ The modern hospice movement began here, and we at CNK are privileged to work with extraordinary doctors and nurses providing this care.

There are problems. Palliative and hospice care can help people with a vast range of conditions, including incurable conditions which are life-limiting but not yet terminal, yet cancer is vastly overrepresented in terms of accessed palliative care.

There are many barriers to extending palliative care to people with non-cancer diagnoses. They include less predictable disease trajectories, greater difficulty in identifying a terminal stage, potential lack of clarity about appropriate palliative care goals, greater likelihood of comorbid conditions, insufficient

⁶ Scope, ‘New research: Majority of disabled people fear change to assisted suicide law’ (17 July 2014) <http://bit.ly/103pOA0>

⁷ Oregon Public Health Division, ‘Oregon’s Death with Dignity Act—2014’ <http://1.usa.gov/1zIFyBI>

⁸ Economist Intelligence Unit, *The 2015 Quality of Death Index, Country profiles* (2015) p75

*resources, lack of condition-specific expertise, poor coordination between healthcare professionals and, in dementia, communication challenges and potential ethical and legal considerations.*⁹

Yet the potential is there, and new approaches to all areas of end of life care are constantly being developed. If properly nurtured these will help answer the big question: 'what is there at the end of life for people like me?'. We have already noted that many requests for assisted suicide come from patients as yet unaware of what care and support is available to them, who relent when receiving the care they need. Improving this care and support need not even weigh heavily on the public purse, according to an LSE/Marie Curie Cancer Care report last year:

*Palliative care aims to improve quality of life and reduce distress. It is also commonly considered to have the potential to reduce acute care costs near end of life, by reducing unnecessary hospital admissions and acute interventions. Such savings may help to offset the costs of further investment in palliative care services.*¹⁰

With regular media reports of restrictions on particular cancer drugs¹¹ and lazy stereotyping of 'grotty hospices'¹², it is easy to understand people's fears, but we have every reason to shout out about what we can and do already achieve in support dying people, and we have no excuse not to continue improving services.

Concerning the Committee's third point of interest

3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation.

It is always presented as a clear picture: 70-80% of the general population support a limited change in the law to allow physician-assisted dying. Set aside for a moment the references to 'unbearable suffering' which are aimed at drawing an emotional response. Set aside the steady flow of 'hard cases' – campaigners with much-publicised personal stories, for many of whom the proposed legislation would not apply and who are too readily accepted as being representative of all sufferers of the disease. Set aside the lack of understanding among the general public about palliative care's potential. Even after many setting-asides, we are able to look at polling and dig deep. Ahead of a 2014 debate in the House of Lords, one of our member organisations commissioned a poll¹³ which suggested 73% support for the bill before the House, and 12% opposition. The pollsters then put five of the arguments against such legislation to respondents. Overall 42% of those who originally supported the bill changed their minds on the basis of at least one of the arguments. When these were added back into the original sample, aggregating all who opposed as a result of the arguments put to them, and incorporating all who still supported AS having heard each argument, they found the following: 43% supported the Bill, 43% opposed it and 14% didn't know. The issue is clearly far more complex than a simple 'support'/'oppose' question can do justice to. This polling strongly suggests that when offered evidence about the nature or source of opposition to assisted suicide, and some of the key arguments against it, the supposedly high level of support dwindles rapidly.

We will make no comment on the current legal situation in New Zealand, but we will note that even before the Director of Public Prosecutions for England and Wales was required to publish the criteria upon which he (now she) decides whether to prosecute in cases of assisting suicide, the DPP had that discretion, and we consider that to be right. Our legal settlement (that in Scotland works on a similar principle) is based on a strong law tempered by mercy. We do not bay for prosecutions, but to seek to put such a principle in a legislative framework would remove disincentives to the deliberate ending of human life and collaboration therein.

⁹ Care Not Killing, 'Palliative care reality floodlit' (16 April 2015) <http://bit.ly/1QzUU7i>

¹⁰ *Ibid*

¹¹ Care Not Killing, 'Medication cuts could feed PAS' (7 September 2015) <http://bit.ly/1QzUU7i>

¹² J Ellis, 'The BBC Drama Department Is A Terrible Place To Die', *Huffington Post* (10 June 2015) <http://huff.to/1MLn50z>

¹³ Care Not Killing, 'Assisted dying' & public opinion' (18 July 2014) <http://bit.ly/1TuqKVK>

Concerning the Committee's fourth point of interest

4. *International experiences. The committee will seek to hear from all interested groups and individuals.*

As we have noted, the most recent Westminster bills have been based on the Oregon 'Death with Dignity Act', and as we have also noted, Oregon is considered the best model to present when seeking change. It is not the model advocates would wish it to be. In a briefing¹⁴ produced ahead of last September's Commons debate, we advised MPs of just ten of Oregon's troubles – here are the headlines, with selected excerpts:

- **1 There has been a steady increase in annual numbers of people undergoing assisted suicide in Oregon** *In 1998 there were 24 prescriptions written and 16 assisted suicide deaths. By 2014 these numbers had risen to 155 and 105 respectively. This is a 546% increase in prescriptions and a 556% increase in assisted suicide (AS) deaths in 17 years.*
- **2 The Oregon health department is funding assisted suicide but not treatment for some cancer patients** *Barbara Wagner... had recurrent lung cancer and Randy Stroup had prostate cancer. Both were on Medicaid, the state's health insurance plan for the poor that, like some NHS services, is rationed. The state denied both treatment, but told them it would pay for their assisted suicide.*
- **3 Patients are living for many years after having been prescribed lethal drugs for 'terminal illness' showing that the eligibility criteria are being stretched**
- **4 The vast majority of those choosing to kill themselves are doing so for existential reasons rather than on the basis of real medical symptoms**
- **5 Many people in Washington and Oregon give 'fear of being a burden on others' as a reason for ending their lives**
- **6 Fewer than one in twenty patients are being referred for formal psychiatric or psychological evaluation**
- **7 A substantial number of patients dying under the Oregon act do not have terminal illnesses** *In Oregon in 2014, 8.6% of those killing themselves under the Act did not have cancer, heart disease, chronic lung disease or motor neurone disease but were classified as having 'other illnesses'. What were these? A footnote in the annual report 5 tells us that this 'includes deaths due to benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson's disease and Huntington's disease), musculoskeletal and connective tissue diseases, cerebrovascular disease, other vascular diseases, diabetes mellitus, gastrointestinal diseases, and liver disease.'* *Many of these conditions might be considered life-shortening but it beggars belief that all these cases were terminal (with less than six months to live).*
- **8 It is virtually certain that there is underreporting of assisted suicide cases in Oregon** *The Lancet recently published a long awaited meta-analysis study¹⁵ which indicated that in 2010 in the Netherlands, 23% of all euthanasia deaths were not reported. Could similar under-reporting be happening in Oregon? It is a virtual certainty. Oregon officials in charge of formulating annual reports have conceded¹⁶ 'there's no*

¹⁴ Care Not Killing, 'Don't Make Oregon's Mistake' (4 September 2015) <http://bit.ly/1Oi5pKp>; also submitted as an appendix to this submission

¹⁵ Alex Schadenberg, 'Lancet Study proves significant growth in euthanasia deaths in the Netherlands', *Care Not Killing* (18 July 2012) <http://bit.ly/1rRTGWC>

¹⁶ Patients Rights Council, 'Ten Years of Assisted Suicide in Oregon' <http://bit.ly/200wshQ>

way to know if additional deaths went unreported' because Oregon DHS 'has no regulatory authority or resources to ensure compliance with the law'. The DHS has to rely on the word of doctors who prescribe the lethal drugs. Referring to physicians' reports, the reporting division admitted: 'For that matter the entire account [received from a prescribing doctor] could have been a cock-and bull story. We assume, however, that physicians were their usual careful and accurate selves.'

- **9 Some doctors know the patient for less than a week before prescribing the lethal drugs**
- **10 The confirmed presence of independent witnesses in fewer than 20% of cases is a recipe for elder abuse**

In the UK, proponents of a change in the law all but refuse to discuss the experiences of jurisdictions other than Oregon, as it presents the most controlled foreign example, but to understand how fast the logic flows once a country says that it is acceptable and even right to cause citizens' deaths, it is necessary to consider our near neighbours Belgium and the Netherlands. We have already noted euthanasia deaths based on dementia, mental illness and tiredness of life in the Netherlands. In Belgium, which legalised euthanasia in 2002 there has been a 669% increase in euthanasia deaths between 2003 and 2013, and assisted suicide and euthanasia now account for 6.3% of all deaths.¹⁷ High profile cases include Mark and Eddy Verbessem (deaf and blind twins),¹⁸ Nathan/Nancy Verhelst (depressed following gender reassignment)¹⁹ and Ann G (anorexia).²⁰ Belgium and the Netherlands both now allow euthanasia of children (on different models). Baroness Campbell sketched well the natural progression as additional forms of suffering and adversity are considered answerable by barbiturates or lethal injection.

Conclusion

We are often told that if we don't want to undergo assisted suicide (or whatever it is being called on that particular day), we simply need not apply. Such a mindset is at best short-sighted, and at worst wilfully ignorant.

British law was changed in 1961, decriminalising suicide. This was not done because it was decided that suicide was in fact all right. It was done because those who attempt suicide and fail, and those who mourn the premature loss of loved ones, should be given proper help and support – the hallmark of a caring society. We retain as a criminal act assistance of suicide – indeed, we strengthened this provision in 2009 – and much time and energy has been invested in suicide prevention. A society which marks out certain people as not warranting help to live but rather help to end living chooses to neglect its duty of care to neighbour, and a patient given a relevant diagnosis, and who previously would have known unrelenting love and support in their gravest hours now must face such times knowing that suicide is not just possible, but acceptable. Reasonable. And, come to that, quick and cheap. And when 'equality' is sought for those whose conditions park them just beyond the reach of such laws, more who would have fought now find themselves with that same message ringing in their ears.

Laws are for everyone, and euthanasia laws are never just for the few determined advocates of early days. They are for the lonely, for the scared and for those who in always too great numbers slip through the nets of palliative and social care. We implore the Health Committee to recognise that such proposals are uncontrollable, unethical and unnecessary, and should be rejected.

London, 31 January 2016

¹⁷ Care Not Killing, '6.3% of Belgian deaths now E&AS' (24 March 2015) <http://bit.ly/1WF6mCg>

¹⁸ Care Not Killing, 'Belgian twins' euthanasia, and what it represents' (30 January 2013) <http://bit.ly/1wanbIK>

¹⁹ BBC News, 'Belgian helped to die after three sex change operations' (2 October 2013) <http://bbc.in/1v9nXkT>

²⁰ M Cook, 'Another speed bump for Belgian euthanasia', *BioEdge* (8 February 2013) <http://bit.ly/1tBtmV2>