White Paper

Submission to the New Zealand Parliament Health Select Committee Investigation on Euthanasia and Suicide

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Introduction

I have been invited by the office of the Chair of the New Zealand Health Select Committee to make an oral submission to that Committee's investigation of the issue of euthanasia and suicide. This paper is intended as a more detailed rendering of the short presentation I will make to the Committee, and a further exploration for their members of themes and issues that are important when considering suicide and euthanasia. The terms of reference[1] for the investigation outlined the nature of their inquiry as follows:

> *[T]he Committee will undertake an investigation into ending one's life in New Zealand. In order to fully understand public attitudes the committee will consider all the various aspects of the issue, including the social, legal, medical, cultural, financial, ethical, and philosophical implications. The Committee will investigate:*
> *1. The factors that contribute to the desire to end one's life.*
> *2. The effectiveness of services and support available to those who desire to end their own lives.*
> *3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation.*
> *4. International experiences.*

The Committee's investigation has been occasioned by a petition of almost 9,000 people led by former member of the New Zealand Parliament Maryan Street, requesting "[t]hat 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",

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[1] *Petition of Hon Maryan Street and 8,974 others*: http://bit.ly/2gYOVgL

and also requesting a change to existing law[2]. I note that Street proposed her own Bill when she was an MP (the **'End of Life Choice Bill'**; hereon, the **'Street Bill'**)[3], and that this has since been amended and proposed again by the New Zealand (NZ) Voluntary Euthanasia Society (hereon, the **'VES Bill'**)[4].

It also comes concurrently with the proposal of a Private Member's Bill by Louisa Wall MP, called the **'Authorised Dying Bill'** (hereon, the **'Wall Bill'**)[5]. If passed into law, this would introduce euthanasia into New Zealand law and medical practice regulated through an 'Ethics Committee'. Proposed previously but also recently has been another Bill by David Seymour MP, the **'End of Life Choice Bill'** (hereon, the **'Seymour Bill'**)[6], which would introduce both assisted suicide and euthanasia by the regulation of a 'two Doctor' system much as has been proposed in the United Kingdom and more recently in South Australia.

The website section for the Committee's investigation further states that "[i]n order to fully understand public attitudes the committee will consider all the various aspects of the issue, including the social, legal, medical, cultural, financial, ethical, and philosophical implications". With such a wide frame of reference, it seems helpful for contributions to be focused on a few areas of special relevance and interest.

In order to best inform the Committee's investigation then, I will restrict my own comments to the contexts with which we are familiar in UK discussions of these issues:

- The relationship of laws against the medicalised killing of patients to suicide prevention and the right to life;
- The failure of arguments in favour of the introduction of such practices;

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[2] *Ibid.*

[3] End of Life Choice Bill 2012: http://bit.ly/2haQBql

[4] End of Life Options Bill 2015: http://bit.ly/2gILugb

[5] Authorised Dying Bill 2016, recoverable after 13th paragraph: http://bit.ly/2h7mcFc

[6] End of Life Choice Bill 2015: http://bit.ly/2gLu2Yh

- The insufficiency of proposed 'safeguards';
- The experience in particular of euthanasia practice in Belgium and the Netherlands;
- The importance of palliative care and its reform.

In discussing the above, I will also comment on the construction of the Wall and Seymour Bills, as well as their antecedents, comparing them to the proposals rejected by the UK Parliament in 2015 and other international models. I believe this well illustrates that attempts to prevent abuses after the introduction of physician involvement in the death of their patients are grossly insufficient, and cannot but fail to protect against violations of human dignity.

Altogether, I believe these considerations will most effectively contribute to the Committee's considerations, and contextualise both the human experience of dealing with terminal or severe illness and the place of laws against so-called 'assisted dying' as a part of protecting the human right to life, especially for the most vulnerable members of society.

Euthanasia and the Law

Definitions and Legality

Voluntary Euthanasia (a term coined from the Greek εὖ 'good/well' and θάνατος 'death'), is the killing of a patient by a medical professional – usually their doctor – at the patient's behest. This is distinct from **Assisted Suicide**, the provision of life-ending drugs to a patient by a medical professional – usually their doctor – at the patient's behest, for them to use to end their own lives. Confusing matters, both terms are often used interchangeably, or are jointly referred to as '**assisted dying**', a recent euphemism created by the campaigners in favour of either – or both – practices, and which we will critique in the next section.

Still, the distinction is no less important for being subtle, and this is true legally as well as materially: New Zealand (hereon, 'NZ') law, like the law of other Anglophone countries, contains *separate* provisions against euthanasia and assisted suicide. The **Crimes Act 1961**, a partial re-codification of NZ criminal law, criminalises the killing of others in section 179 of that Act, and of involvement in the suicide of another in section 172. This corresponds to the laws in the United Kingdom relating to murder, which find their foundation in Common Law, but also in laws such as the **Offences Against The Person Act 1861**[7], the last consolidation of the criminal law of England, Wales, and Ireland, in the 19th century (which colonial New Zealand at the time adopted). It also corresponds to the law of the UK as a whole relating to assisted suicide, which was the **Suicide Act 1961**[8].

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[7] Offences Against The Person Act 1861: http://bit.ly/OAPA1861

[8] Suicide Act 1961: http://bit.ly/2gYXVm3

Given the analogous nature and (to an extent) shared history of our respective legal frameworks, I would contend that the British experience is instructive for that of New Zealand also, in both its purposes and its operation.

Purpose and Operation of Laws Against Euthanasia

Both practices involve the assistance to actualise the suicidal wishes of another person, and the laws that forbid assisting and encouraging suicide, or even causing the death of another at their behest, serves several functions:

- It serves a **cultural purpose** in indicating the fundamental social principle that society values human life, and that the taking of human life is normally and *prima facie* to be regarded as wrong.
- It possesses an important **public safety role** in providing appropriate special protection to those who are psychologically vulnerable, from pressures to kill themselves both within and without.
- Through both these means, it is an expression of every Government's obligation to **safeguard the human right to life**.

The law reflects and reinforces an important cultural value in society to the effect that, whilst individuals who attempt to take their own lives should not be prosecuted for doing so but given help and compassion, suicide as a rule is nonetheless an objectively negative phenomenon, and not something another person should encourage or assist. This is why developed societies maintain emergency responses to attempted suicides, 'suicide watches' of those who may seek to harm themselves, and Government suicide prevention strategies (such as that, I note, of the New Zealand Government itself[9]). This is a crucial point with regards to the relationship between euthanasia and suicide.

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[9] New Zealand Suicide Prevention Action Plan 2013–2016: http://bit.ly/2gcylez

Moreover, the way that the law can be prosecuted can be both **strong** in the sense of successfully discouraging would-be assisters in suicide who are taking advantage of those in a compromised and vulnerable state (e.g. due to illness, infirmity, or disability), whilst having the **merciful flexibility** for those cases where it is discerned that someone acted for genuinely 'merciful' reasons. In the former case, there is a clear public interest in prosecution, especially for the general purpose of discouraging similar actions. In the latter, prosecutor discretion and mercy, even if later at the judicial level, may be shown.

Take, for example, section 2 of the UK Suicide Act 1961. Two elements may be noted about this law: firstly, it is very widely drawn, and secondly in section 2(4) it requires that no prosecution for an offence of encouraging or assisting suicide be undertaken without the consent of the Director of Public Prosecutions (DPP). Both elements exist for a similar reason: a wide spectrum of circumstances may be involved when individual acts of assisting suicide occur.

The law recognises that some may involve malice on the part of the perpetrator with the assistance of the suicide of another person being designed to secure personal gain. Others may involve a reluctant assistance given after much soul-searching and with genuinely compassionate intent. Prosecutorial discretion is necessary therefore, as with other applications of criminal law, in order to discern what these circumstances are, and whether they constitute 'aggravating' or 'mitigating' factors that affect the decision to prosecute.

A widely drawn offence is therefore desirable in order that the law might properly protect as many people in as many cases as possible. Precisely due to this latitude however, a possibility exists that the law might be abused by prosecutors who are either insensitive or partisan. It is for that reason that the DPP must specifically consent to every prosecution.

Prospective prosecutions must go through a '**Full Code Test**', which involves two stages:

1) The **Evidential Stage**, where it is determined whether or not here is sufficient evidence to justify prosecution.
2) The **Public Interest Stage**, where it is determined whether or not prosecution would be in the public interest. Prosecution does not follow automatically whenever an offence is believed to have been committed. As a convention and rule however, a prosecution will usually take place unless the prosecutor is satisfied that there are public interest factors tending against prosecution which outweigh those tending in favour.

In 2010, the serving DPP Keir Starmer QC released guidelines[10] that clarified what the bases would be for prosecution according to the Code Test, in cases of assisted suicide (having been required to do so by the Law Lords after they ruled[11] that a lack of prosecutory clarity was a violation of the right to a private and family life).

In the UK, our experience is that both the law's purposes can be seen to be fulfilled, and its flexibility demonstrated, by the record of prosecutions for the offence of assisted suicide. In 2014, Lord Faulks reported[12] to the House of Lords that:

> *Records show that from 1 April 2009 to 13 February 2014, 91 cases have been referred to the CPS [Crown Prosecution Service] by the police recorded as assisted suicide or euthanasia. Of those 91 cases, 65 were not*

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[10] *Policy for Prosecutors in respect of cases of encouraging or assisting suicide*, Crown Prosecution Service, February 2010: http://bit.ly/1UcrYVd

[11] *R (Purdy) v DPP* (2009) UKHL 45: http://bit.ly/1HvB0sV

[12] Lord Faulks, Hansard, 5 Mar 2014: Column 1429: http://bit.ly/1HsvHZk

> *proceeded with by the CPS, 13 were withdrawn by the police and there are currently eight ongoing cases. One case of attempted assisted suicide was successfully prosecuted in October 2013. The facts of the matter would not trouble anyone, whichever side of the argument they were on. It involved someone with lower mental capacity. Four cases were referred onwards for prosecution for murder or serious assault.*

What we see then is that no plainly inappropriate prosecutions have been brought. In the light of the DPP's guidelines it is evident that no one will face prosecution who, in the light of genuine compassion, should not face prosecution. The law, meanwhile, continues to make an important declaration about basic principles, and continues to protect the vulnerable, in particular by forcing would-be assisters or encouragers to consider their position very carefully.

The small numbers of such prosecutions are also evidence of the law's efficacy. That so few cases (roughly 15 a year) are presented to the DPP suggests that the law effectively deters assistance in suicide. When prosecutions do occur, they are rare, because the law has both the clarity and 'teeth' to make anyone minded to encourage or assist another person's suicide think very carefully before doing so. As a result the handful of cases that pass the evidential test and reach the DPP's desk tend to be those where the assistance given has been of a minor nature or there is evidence of genuinely compassionate motivation and of serious soul-searching.

Laws against euthanasia and assisted suicide certainly therefore serve an important purpose as part of legal and cultural framework of a society that cares to provide strong protections for the vulnerable, whilst having the capacity to show mercy on those who involve themselves in the deaths of others for genuinely 'merciful' reasons. It is, as has been said, 'a hard law with soft face', and when practised correctly can achieve the right balance. It is in contrast to this, and in light of the purposes and merits of such laws, that we should view the arguments in favour of euthanasia and the legal proposals that have been made for it.

Euthanasia in Theory

Autonomy and the Purported 'Right To Die'

The arguments in favour of introducing the practice of euthanasia, and removing legal obstacles to it, all focus on the concept of **'autonomy'**. The idea being that we have a right to autonomously decide when and how we will die. This is also referred to as a **'right to die'**, a right that mandates that people be provided with physician assistance in the causation of their own death.

This is related to the preferred use of the term **'assisted dying'**, rather than the traditional terms euthanasia or assisted suicide. The argument in favour of this use is that those presenting for (e.g.) a doctor-administered lethal injection are not 'suicidal', in that they do not wish to die. Rather, they simply wish to be able to control the time and manner of their dying.

This is of course casuistical. The adjective 'suicidal' means 'deeply unhappy or depressed and likely to commit suicide'. What other word could one use to describe someone who, motivated by their own unhappiness with a severe or terminal illness, seeks a physician to cause their own death, or assistance in ending their own life? Such a person might not ideally want to die so soon, but they do want to end their own lives, or have their lives ended by another. To oppose this to their evident desire to be able to control the time of their death is to create a false dichotomy.

Regardless, the point of the 'autonomy' argument is that whilst it is employed to sound like the extension of a freedom, it is in fact anything but. After all, the law does not penalise us for attempting to commit suicide. So what is being asked for on the basis of a 'right to die' is not allowing people to do something, but giving them what they want. The argument for assisted suicide is that those people who cannot kill themselves have the right to be enabled to do so. With euthanasia it goes even further – the 'right to die' is the right *to be killed*. These are not 'negative' liberties; they are 'positive' rights: not freedoms, but *entitlements*.

Given this, we can see that the issue is not about 'autonomy' at all. Autonomy is not the state of being enabled to do whatever it is you desire. Rather, it is the right or condition of self-government; the individual ability to freely try to attain what you want by your own lights, free from external restraint. Yet suicide is decriminalised – we are already autonomous when it comes to trying to determine the span of our own lives (though circumstance may frustrate us), and neither euthanasia nor assisted suicide extends that legal reality one whit.

The advocates of assisted suicide, however, argue that the health system should be obligated to provide patients with the physical act that would kill them, or the lethal drugs and physician oversight that would enable them to take their own lives. Whatever arguments there may be for this, they have nothing to do with 'autonomy' properly understood.

The Logical Cliff of the 'Right To Die' Argument

If a proper understanding of autonomy leads us to see its abuse in arguments for the introduction of euthanasia, a realistic appreciation of the autonomy of individuals should lead us to reject the legal enabling of someone to kill themselves, in any form. This is because the people that 'right to die' advocates want to provide with assistance to end their own lives are precisely those with the least personal autonomy – the terminally ill to begin with, and then (as we shall see in countries like Belgium and Holland), the elderly, the disabled, and the depressed. So far from enabling personal autonomy, assisted suicide is readily abused precisely due to a lack of it.

Anyone who has experienced serious illness, whether in themselves or in others, or is even sufficiently well-read on the issue to be basically cognisant of what it involves, knows that those in that situation are most often at their least mentally free and independent. The debilitating effects of being sick or otherwise physically and/or mentally compromised tend to not only cloud the clarity of our desires, but significantly erode the strength of our will. The same is true of the tiredness of many in old age, those who are miserable and dejected, and those who struggle with disability. What assisted suicide does is open up thousands of such people who exist in a personally compromised state to the possibility of being pressured into death.

Of course, it might be argued that proposals for the introduction of euthanasia do not extend to these groups due to the restricted **eligibility criteria** within the Bills proposed to the NZ Parliament. The Wall Bill after all, only allows for the provision of euthanasia to those who are "suffering from a terminal illness"[13] and "is reasonably expected to die within 12 months"[14]. The Seymour Bill extends it to those with "a terminal illness that is likely to end his or her life within 6 months"[15], or those with "a grievous and irremediable medical condition"[16], and who "experiences unbearable suffering that cannot be relieved in a manner that he or she considers tolerable"[17]. This is similar to the provisions within the revised Street Bill proposed by the Voluntary Euthanasia Society (VES), in which "constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable"[18] is a separate condition to that of the terminal illness that is likely to end someone's life

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[13] Authorised Dying Bill 2016, section 6(c).

[14] *Ibid.*, 8(a).

[15] End of Life Choice Bill 2015, section 4(c)(i).

[16] *Ibid.*, 4(c)(ii).

[17] *Ibid.*, 4(e).

[18] End of Life Options Bill 2015, section 6(1)(b)(ii); cf. 11(3(b).

within 6 months[19]. All three Bills require the applicant for euthanasia to be aged 18 years or over[20], and be mentally competent[21]. This is all very well, but the problems with these supposedly limited eligibility criteria are manifold.

The limitation to people who are expected to die of terminal illness within six to twelve months, for example, is not as simple as might first be thought. For one thing, it is notoriously difficult to prognose the death of a patient, and the expectation of death within six months will more often not be a necessary and objectively demonstrable clinical judgement. In fact, it is extremely common for medical prognoses of death within such a period to be mistaken, and many people prognosed with death in a short time frame go on to live much longer and happier lives. Prognoses are based on statistical averages, which are very unreliable in determining what will happen to an individual patient. Research has indicated[22] that only cancer patients show a predictable decline, and even then, it's only in the last few weeks (as opposed to a year or even half a year) of life. With every disease other than cancer, prediction is unreliable.

Consequently, the definitions of terminal illness given in each of the three Bills encompass not only illnesses such as advanced cancers, which might be expected to result in death in the short or medium term, but also fluctuating long-term conditions like, for example, Multiple Sclerosis, Parkinson's and heart disease. People with these and other inevitably progressive conditions can live for many years but, where they are frail or have other medical problems, they could be reasonably expected to die within six months. Bills that limit the applicability of euthanasia to patients who are expected to die within a six-month time frame therefore bring within their eligibility criteria a

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[19] *Ibid.*, 6(1)(b)(i); cf. 11(3)(a).

[20] *Op. cit.*, Authorised Dying Bill 2016, 6(a); End of Life Choice Bill 2015, 4(a); End of Life Options Bill 2015, section 4 definition of 'qualifying person'.

[21] *Op. cit.*, Authorised Dying Bill 2016, 6(d); End of Life Choice Bill 2015, 4(f); End of Life Options Bill 2015, 5(1).

[22] *Terminal Uncertainty*, Nina Shapiro, Seattle Weekly, 13/01/09: http://bit.ly/2g5OVyu

wider range of people than just those with end-stage terminal illness. So, the three Bills before the NZ Parliament have a wider potential remit than their proponents suggest.

So, like the definition of 'terminal illness' within the Bill, the potential reach of assisted suicide on the six month prognosis is broader, than the supposedly narrow group its proponents claim. This could affect many people who may be mistakenly diagnosed as terminal but who have many meaningful years of life ahead of them[23].

Even putting this issue to the side, two other more general problems form with the ostensible limitations within the Bills. For one thing, that "constant and unbearable physical or psychological suffering" is involved in the Seymour and VES Bills sows the seeds of gradual expansion of euthanasia. Since what is 'unbearable' is defined entirely subjectively in the VES Bill, as indeed is 'grievous and irremediable', there is no obvious restriction to terminal illness in either Bill. Indeed, these mirror the on-paper 'safeguards' in the Belgian[24] and Dutch[25] laws that a patient presenting for euthanasia be in a "medically futile condition of constant and unbearable... mental suffering that cannot be alleviated", or be experiencing suffering that is "lasting and unbearable". Just as extensions have occurred in those countries, so there is no reason for thinking that this could not happen here.

For another, even with the omission of subjective criteria that exists in the Wall Bill, the precedent set by granting the premises of the Bill would establish a means by which euthanasia could be extended. One of the purposes of the Wall Bill is "to provide a regulated and compassionate process for individuals suffering from a terminal illness who wish to determine the time and manner in which they will die"[26], and one of the

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[23] As an illustrative example, see: *Assisted suicide prompts some terminally ill patients to give up on life prema*turely, Ravalli Republic, 28/11/12: http://bit.ly/2ggT412

[24] Belgian Euthanasia Act 2002: http://bit.ly/2efDCmj

[25] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002: http://bit.ly/2fwj8TU

[26] *Op. cit.*, Authorised Dying Bill 2016, section 3(a).

principles of the Bill is set as "respecting the right to dignity and personal autonomy"[27]. Given this, the obvious question arises as to why the right to dignity and personal autonomy that purportedly necessitate a regulated and compassionate process for individuals to determine the time and manner in which they will die, should be at all restricted to the terminally ill.

These are problems that have plagued international attempts to introduce euthanasia. In the most recent such battle in the State of South Australia last month, the **'Death with Dignity Bill' 2016** proposed by Duncan McFetridge MP (hereon, the **'McFetridge Bill'**)[28], and the similarly ill-fated **'Voluntary Euthanasia Bill' 2016** of Steph Key MP (hereon, the **'Key Bill'**)[29] both contained versions of these issues.

Like the VES and Seymour Bills and the Dutch and Belgian laws, the Key Bill defined those eligible for euthanasia widely, as those taken to be "subject to unbearable and hopeless suffering"[30]. Again, what is 'unbearable' was defined entirely subjectively[31] and what is 'hopeless' was defined semi-subjectively according to the availability of "medical treatment that would reduce or relieve the suffering to a level bearable to the person"[32] (thus effectively voiding the objective criteria of the nature, availability, and potential effectiveness of medical treatment). This would have opened up abuse in exactly the same way.

The same problem of nakedly insufficient safeguards existed with the McFetridge Bill. The Bill defined those eligible for euthanasia, as those suffering from "a terminal medical condition [that] is causing suffering that is intolerable to the person"[33], and for

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[27] *Ibid.*, 4(b).

[28] Death with Dignity Bill 2016: http://bit.ly/2fWuhjJ

[29] Voluntary Euthanasia Bill 2016: http://bit.ly/2fw34l4

[30] *Ibid.*, section 10(b).

[31] *Ibid.*, Section 4(2).

[32] *Ibid.*, Section 4(4).

[33] *Op. cit.*, Death with Dignity Bill 2016, 9(2)(b)(i).

whom there are no "reasonably available medical treatment or palliative care options that would, having regard to both the treatment and any consequences of the treatment, relieve the person's suffering in a manner that is acceptable to the person"[34]. This may seem an improvement along the lines of the Wall Bill, but within the limitations of these eligibility criteria and the principles of the Bill, lie the means of further expansion. If you grant the premise that "every person has the right to choose how he or she should live their life"[35], then this is precisely the line off of which society falls down the 'logical cliff' I referred to above. If everyone has the 'right to die' (i.e. the 'right to be killed'), then this cannot logically be limited to patients in terminal medical situations.

All of this would easily allow the same kind of incremental extension that (as we shall see) has been allowed in the Benelux countries. Given the potential dissatisfaction and suffering of people who are severely ill but not terminally so, elderly, disabled, depressed, and a host of other conditions, the potential expansion of euthanasia to these groups would be precisely enabled by the passing of legislation rooted in these flawed principles and arguments.

This is especially true when we consider the more extreme cases of paraplegia or long-term mental deterioration, who might not be catered for by the restrictions of the Seymour or Wall Bills. Especially since the 'hardest' of cases are not the terminally ill, but precisely those who are suffering from such extreme non-terminal medical situations (such as high profile people like Tony Nicklinson[36] or Diane Pretty[37]), the limitation to terminal illness could not possibly last. Such a tokenistic gesture is a short-term compromise tactic, and not a line that can keep vulnerable people safe in the

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[34] *Ibid.*, Section Section 9(2)(b)(ii).

[35] *Ibid.*, Section 7(a).

[36] *Tony Nicklinson dies six days after losing 'right to die' case*, Sarah Boseley, The Guardian, 22/07/12: http://bit.ly/2h2KDrm

[37] *Diane Pretty loses right to die case*, The Guardian, 29/04/02: http://bit.ly/2h1ReQp

medium to long term. Even the stipulation that euthanasia would only be open to those for whom palliative medicine is not 'reasonably available' (as was proposed in the South Australian debate) endangers those who do not live near, or have the means to enjoy, the best hospice or specialist hospital care.

This is not a merely 'slippery slope' but a necessary **'logical cliff'** to which there is little if any potential limitation once the fundamental grounds on which euthanasia is introduced have been granted.

The Failure of Other Procedural 'Safeguards'

Equally if not more concerning is the way in which the various Bills proposed to the NZ Parliament have copied previously debated 'safeguards' that other Parliaments have examined and found extremely wanting. When advocates of euthanasia or assisted suicide discuss 'safeguards', they usually refer to procedures through which the abuse of someone who is vulnerable may be detected, and their untimely death averted.

The standard form in which this has occurred has been through a process that was proposed to the UK Parliament in 2015 in the **Assisted Dying (No. 2) Bill** of Rob Marris MP (hereon, the **'Marris Bill'**)[38], itself a copy of an earlier Bill by Lord Falconer of Thoroton, by which two doctors, an 'attending' doctor and an 'independent' doctor, must be satisfied that a patient applying for assisted suicide meets the eligibility criteria in the Bill possesses "a clear and settled intention to end their own life that has been reached voluntarily, on an informed basis and without coercion or duress".

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[38] Assisted Dying (No. 2) Bill 2015: http://bit.ly/2hcR5sf

We see essentially the same system repeated in the VES Bill[39] as it was in the Key Bill[40], and the Seymour Bill[41] as it was in the McFetridge Bill[42] (in both these cases of later Bills, a third safeguard of a psychiatric specialist was added).

The problem with the system as laid out in these Bills is that nowhere do they set out how a doctor might go about evaluating a patient to discern that they are not acting under any form of duress, inducement or undue influence (including that due solely to a perception or mistake on the part of the person) in relation to his or her wish to request voluntary euthanasia, nor is there any requirement that they have psychological training, but even with the stipulation of a qualified psychiatric specialist, such a question of motivation is not a medical one, but a personal, social, and domestic one, outside of the expertise of doctors and even psychologists.

Even if all this were not the case, this also relies on both Doctors knowing the patient well enough, and their families, to be able to evaluate their intentions, mental capacity, and freedom from duress such as subtle pressure from relations. Given the relationship between most patients and even their General Practitioners, which is much less familiar than would be required, this is incredibly unrealistic. Not only would their time with the patient be limited, it would be very unusual for any doctor nowadays to have the kind of deep relationship with their patient that would allow them to detect undue influence, or even feeling a burden and other incentives, all of which undermine the ‘voluntary’ desire to end their own lives.

With the work of the psychiatrist, the amount of time s/he would have to check the patient would also be limited, and given this there is no way they would be able to

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[39] *Op. cit.*, End of Life Options Bill 2015, sections 7-10.

[40] *Op. cit.*, Voluntary Euthanasia Bill 2016, sections 12-14.

[41] *Op. cit.*, End of Life Choice Bill 2015, sections 9-11.

[42] *Op. cit.*, Death with Dignity Bill 2016, sections 11-13.

develop the kind of similarly long term and in-depth rapport with the patient that *might*, and only *potentially*, allow them to detect (for example) the problems mentioned above. Since the process is inherently flawed, the so-called 'safeguards' in the Bill are effectively toothless, and lack the detail and power to protect vulnerable people.

The same problems are relevant to the Wall Bill, which proposes a system operating not on the basis of a two doctor system, but an Ethics Committee on Assisted Dying (ECAD)[43]. How a Committee would have any greater relationship with a patient, or have the requisite expertise, or have any way of detecting undue pressure, is left entirely unclear, but there seems little reason to think that this would function as any greater safeguard than two or three medical professionals, especially as the Committee need not even necessarily meet the applicants for euthanasia in person, but may use a video or skype link[44].

Suffice it to say, the theoretical underpinnings of voluntary euthanasia are greatly lacking, and sadly, the human cost of this ill-thought practice in reality are demonstrable. We see this most especially in the way euthanasia is practised in Belgium and the Netherlands.

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[43] *Op. cit.*, Authorised Dying Bill 2016, Part 3, Ethics Committee.

[44] *Ibid.*, 15(1)(d).

Euthanasia in Practice

Belgium and the Netherlands

As previously mentioned, and similar to the VES and Seymour Bills, both Belgium and Holland have introduced euthanasia not only for people who are terminally ill, but also for those who request it for 'mental suffering'. This has had appalling consequences, as a number of cases have come up in the last few years in which people who in the UK would have been given the help they need to heal the mental health problems from which they suffer, have been euthanised:

- Godelieva De Troyer[45], a 64-year old healthy Belgian woman who was living with depression, was killed by lethal injection at her own request in a Brussels hospital in April 2012, despite at least two of the experts who assessed not agreeing that she was beyond treatment. Her son was not contacted until after his mother had been euthanised, when a hospital rang asking him to retrieve her body from the morgue.
- Marc and Eddy Verbessem[46], 45, a pair of deaf twins, were euthanised due to the fear that with the onset of blindness they would be unable to communicate with each other.
- Ann G[47], a 44-year old Dutch woman who asked for euthanasia for psychological pain after being sexually exploited by her psychiatrist who was treating her for anorexia.

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[45] *Son challenges Belgian law after mother's 'mercy killing',* Bruno Waterfield, Daily Telegraph, 02/02/15 (http://bit.ly/2fvAOkI). See also *The Death Treatment,* Rachel Aviv, The New Yorker, 22/06/15 (http://bit.ly/2fw8n42).

[46] *Marc And Eddy Verbessem, Deaf Belgian Twins, Euthanised After Starting To Turn Blind*, Eline Gordts Huffington Post, 14/01/13 (http://huff.to/2fa4tiG).

[47] *Sex abuse victim in her 20s allowed to choose euthanasia in Holland after doctors decided her post-traumatic stress and other conditions were incurable*, Steve Doughty, Daily Mail, 10/04/16 (http://dailym.ai/2fhjnRU).

- Nathan[48], born Nancy, and also 44-years old, was euthanised in 2013, after a series of failed gender reassignment surgeries.
- Mark Langedijk[49], a 41-year old Dutch alcoholic, ended his life by fatal injection as a means of escaping his condition.
- Tine Nys[50], a 38-year old who had experienced the break-up of a relationship, was euthanised in 2009 on the basis that she had autism. Her family have recently complained about the 'nonchalant' way she was treated[51].
- An unnamed Dutch woman[52] in her 20s, who had suffered sexual abuse from the age of five to 15 and suffered from post-traumatic-stress disorder (PTSD) and chronic depression amongst other mental health problems, was euthanised earlier this year. Doctors judged her to be "totally competent" and that there was "no major depression or other mood disorder which affected her thinking".

More such cases exist, and include people who have been given permission to be euthanised for borderline personality disorder, and chronic-fatigue syndrome[53]. Others have publicly called for access to euthanasia:

- In 2015, the now 52-year old Belgian serial rapist and murderer Frank Van Den Bleeken[54] was meant to be euthanised in prison. Van Den Bleeken claimed that

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[48] *Nathan Verhelst Chooses Euthanasia After Failed Gender Reassignment Surgeries*, Eline Gordst, Huffington Post, 10/05/13 (http://huff.to/2efFbka).

[49] *Dutch euthanasia law is used to kill alcoholic, 41, who decided death was the only way to escape his problems*, Steve Doughty, Daily Mail, 29/11/16 (http://dailym.ai/2grDugV).

[50] *Controversial case re-opens euthanasia debate*, Andy Furniere, Flanders Today, 04/0216 (http://bit.ly/2g2fUpD).

[51] *Terzake*, 02/02/16 (http://bit.ly/2ha0RPH).

[52] *Sex abuse victim in her 20s allowed by doctors to choose euthanasia due to 'incurable' PTSD*, Matt Payton, Independent, 11/05/16 (http://ind.pn/2gDx4L8).

[53] For an excellent account and further information, see the cases discussed in *The Death Treatment*, by Rachel Aviv, The New Yorker, 22/06/15: http://bit.ly/2fw8n42

[54] *Belgian rapist Frank Van Den Bleeken 'to be euthanised' in prison this week*, Roisin O'Connor, Independent, 05/01/15: http://ind.pn/2gzs3Dx

was experiencing “unbearable psychological suffering” in prison, where he had already spent 30 years. His wish was initially granted, but the decision was reversed[55].

- A 39-year old gay man in Belgium pseudonymously called ‘Sébastien’[56], is trying to end his life because he cannot accept his sexuality. He had said of euthanasia, “For me, it's just a kind of anaesthesia”.
- Emily[57] (who went under the pseudonym ’Laura’ when her story was being reported) was approved for lethal injection[58], even though she was physically healthy and only 24-years-old. She said, “Leven, dat is niets voor mij” (“Life, that's not for me”). Thankfully, she changed her mind.

All this has happened despite the on-paper ‘safeguards’ in the Belgian[59] and Dutch[60] laws that a patient presenting for euthanasia be in a “medically futile condition of constant and unbearable... mental suffering that cannot be alleviated”, or be experiencing suffering that is “lasting and unbearable”. It has even got to the point that, whilst voluntary euthanasia is defined as ending life *on request*, in the Netherlands euthanasia has been extended to occurring without request to newborn infants with disabilities[61].

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[55] *Belgian serial rapist will not be euthanised*, Bruno Waterfield and Andrew Marszal, Daily Telegraph, 06/01/15: http://bit.ly/2hebK2Y

[56] *Man seeks euthanasia to end his sexuality struggle,* Jonathan Blake, BBC News, 09/06/16 (http://bbc.in/2efDJ17). An interview with ‘Sébastien’ can be found here: http://bbc.in/2gHnoQp

[57] *24 and Ready to Die*, The Economist (YouTube), 10/11/15: http://bit.ly/2fhmFEM

[58] *Right to die: Belgian doctors rule depressed 24-year-old woman has right to end her life*, Rose Troup Buchanan, The Independent, 02/07/15: http://ind.pn/2ewqrso

[59] Belgian Euthanasia Act 2002: http://bit.ly/2efDCmj

[60] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002: http://bit.ly/2fwj8TU

[61] You can see a description of the ‘Groningen Protocol’, through which this extension took place, given by two authors who helped develop this practice, in *End-of-Life Decisions in Newborns: An Approach From the Netherlands*, A. A. E. Verhagen and P. J. J. Sauer, Pediatrics (September 2005), 116(3):736-739 (http://bit.ly/2ewwFsb).

The incremental extension of such laws away from the situations they were initially conceived to cover illustrates the fundamental problem with laws permitting medicalised killing. If we grant that there exists a 'right to die' such that people have the right to have their doctors not only enable their death, but be agents of that death, then it is logically impossible to limit that right only to one sort of person.

This descent down the logical cliff is affected not just by the reason of the grounds for euthanasia and assisted suicide, but by the cultural effect such legalisation brings about. A study in 2013 that looked at opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands found an increase in support for euthanasia or assisted suicide for non-terminal conditions. Among professionals, a significant number (24%-39%) were found to be in favour of ending the lives of individuals who experience mental suffering due to loss of control, chronic depression or early dementia. Further, a third of doctors and 58% of nurses were in favour of euthanasia in the case of severe dementia, given the presence of an advance directive[62].

Moreover, studies have also shown a further corruption in not only does the 'Groningen Protocol' for disabled infants described above illustrate this point, but the repeated reportage of cases of involuntary euthanasia taking place. In the 1990s, the initial evidence of a number of deaths without explicit patient request (in other words non-voluntary euthanasia). The rates were 0.8% and 0.7% being equivalent to 1,000 and 900 deaths per year[63]. More recently, a 2007 study found that in Holland in 2005,

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[62] *Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach*, Palliative Medicine (March 2013), 27:3:273-280: http://bit.ly/2fwm0Aq

[63] *Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995*, P J Van der Maas *et al*, New England Journal of Medicine 335.22 (1996): 1699-1705 (http://bit.ly/2fUehPf); *Euthanasia in the Netherlands: Sliding down the Slippery Slope*, J Keown, Notre Dame Journal of Ethics & Public Policy 407 (1995) (http://ntrda.me/2fa7j7k); *Reports from the Netherlands. Dances*

500 patients were given a lethal injection without request[64]. For such reasons the law and practice of euthanasia and assisted suicide in the Netherlands has been criticised twice by the United Nations Human Rights Committee, in 2001[65], and in 2009[66].

In Belgium, a June 2010 study of assisted suicide/euthanasia examined 208 euthanasia deaths in the region of Flanders. The study found that 66 (32%) of the euthanasia deaths were done without explicit request or consent, and the life-ending drugs were sometimes administered by nurses (as opposed to physicians) in some of the cases of euthanasia, operating "beyond the legal margins of their profession"[67]. More recent research has even shown that organ donors (including 23.5% of all lung donors) had been euthanised, raising concerns that patients may be given an emotional inducement to be killed, believing that they can be better use being euthanised and harvested[68].

Not only has the wording and intention of the law been effective as a safeguard for such practices, but nor have the procedural elements. A recent study in the British Medical Journal[69] found that only half of euthanasia cases in Flanders had been

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with data, J M van Delden, L Pijnenborg, and P J van der Maas, Bioethics 7 (1993), 4:323-329 (http://bit.ly/2fUfOF4); *Non-voluntary and involuntary euthanasia in The Netherlands: Dutch perspectives*, R Cohen-Almagor, Issues in Law and Medicine 18.3 (2003) (http://bit.ly/2efFzza).

[64] *End-of-Life Practices in the Netherlands under the Euthanasia Act*, Van der Heide *et al*, New England Journal of Medicine, 10/05/07: http://bit.ly/2eOK9Ri

[65] UN Human Rights Committee (HRC), UN Human Rights Committee: Concluding Observations: Netherlands, 27 August 2001, CCPR/CO/72/NET: http://bit.ly/2fsvSuy

[66] UN Human Rights Committee (HRC), Concluding observations of the Human Rights Committee: Netherlands, 25 August 2009, CCPR/C/NLD/CO/4: http://bit.ly/2fvDA9y

[67] *Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey*, Chambere *et al*, Canadian Medical Association Journal 182(9):895-901 (2010): http://bit.ly/2fvJNSZ

[68] *Initial experience with transplantation of lungs recovered from donors after euthanasia*, Van Raemdonck *et al*, Applied Cardiopulmonary Pathophysiology 15:38-48 (2011): http://bit.ly/2fwhX7h

[69] Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases, Smets *et al*, BMJ 341:5174 (2010): http://bit.ly/2ewv3Pe

reported to the Federal Control and Evaluation Commission. There were no repercussions for failing to report euthanasia deaths to the commission, a situation likely aided by the fact that nearly half of the sixteen members on the commission are affiliated with 'right-to-die' associations.

It should be little wonder then, that the idea of euthanasia and proposals for assisted suicide have met with the opposition of British and international medical institutions, and the groups that represent the rights and welfare of the elderly and persons with disabilities. It has even met with renewed criticism and opposition from past supporters. Professor Theo Boer, who for nine years was a member of one of the five Regional Review Committees that assess the compliance of euthanasia cases with Dutch law, has written about how the Committees have been insufficient to stop a series of developing abuses, such as subtle pressure being put on people who present for euthanasia by relatives[70].

More prominently, the late Dr. Els Borst, who was formerly the Health Minister and Deputy Prime Minister who guided legalisation of legalised euthanasia through the Dutch parliament, stated that legalised euthanasia has led to a severe decline in the quality of care for terminally-ill patients in Holland, and that 'safeguards' haven't been sufficient, in an interview with anthropologist Dr Anne-Marie The for a book on the history of euthanasia[71].

Another important element of the practice in countries where assisted death/euthanasia are allowed, such as Holland and Belgium is also brought out by Dr. The's research: the absence of sufficient palliative care. Dr The, who studied

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[70] *Dutch Ethicist – "Assisted Suicide: Don't Go There"*, Professor Theo Boer, Euthanasia Prevention Coalition Blog, 16/07/14 (http://bit.ly/2fwkheb).

[71] *Now the Dutch turn against legalised mercy killing*, Simon Caldwell, Daily Mail, 09/12/09 (http://dailym.ai/2fy7Xse).

euthanasia for over a decade, points out that palliative care is so inadequate in Holland that patients "often ask for euthanasia out of fear" of dying in agony because care and pain relief is so poor. She adds that a crisis has developed and that "to think that we have neatly arranged everything by adopting the euthanasia law is an illusion"[72].

Although euthanasia in the Netherlands is meant to be a strictly voluntary activity, the 2005 report found that there were about 1,000 deaths a year (0.7% of all deaths) where physicians end a patient's life without an explicit request[73]. In Holland in 2005, 500 patients were given a lethal injection without request[74]. The nature of regulation for what constitutes a truly 'voluntary' euthanasia is also concerning: This year, a case was reported of a Dutch doctor who was amazingly cleared of any wrongdoing after asking the family of a woman due to be euthanised who was resisting her to hold her down whilst the lethal injection was administered[75].

Further evidence only compounded concerns about involuntary euthanasia[76]. More recently, the latest (2012) report of the Dutch Central Bureau for Statistics has said that of the almost 4,000 euthanasias and assisted suicides it recorded, 310 were

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[72] *Euthanasia law is no cure-all for Dutch doctors*, Wubby Luyendijk, NRC, 30/11/09 (http://bit.ly/2ewwkWq).

[73] *Ibid.*, section 171. See also *Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995*, P J Van der Maas *et al*, New England Journal of Medicine 335.22 (1996): 1699-1705.

[74] *End-of-Life Practices in the Netherlands under the Euthanasia Act*, Van der Heide *et al*, New England Journal of Medicine, 356 (2007):1957-1965.

[75] *Panel clears Dutch doctor who asked family to hold patient down as she carried out euthanasia procedure*, Daily Telegraph, 28/01/17 (http://bit.ly/2ku6Gol).

[76] *Euthanasia in the Netherlands: Sliding down the Slippery Slope*, J Keown, 9 Notre Dame J.L. Ethics & Public Policy 407 (1995); *Reports from the Netherlands. Dances with data*, J M van Delden, L Pijnenborg, and P J van der Maas, Bioethics 7, no. 4 (1993): 323-329; *Non-voluntary and involuntary euthanasia in The Netherlands: Dutch perspectives*, R Cohen-Almagor, Issues in Law and Medicine 18.3 (2003).

ended without the patient's explicit request[77]. This is little surprise, given the ill-regulated nature of the Dutch system.

As the Mackay Report found, involuntary euthanasia deaths often involved comatose patients and severely disabled newborn babies[78]. The latter is due to an extension of the law to include infants[79], an example of how initially voluntary euthanasia laws can slip into the gradual allowing of horrifying involuntary forms due to the steady corruption of medical culture.

This incremental extension was illustrated further in March 2012, when the Dutch introduced mobile units to deal with what they call the 80% of people with dementia or mental illness currently being "missed" – their words – by the country's euthanasia laws[80]. Similarly, the 2011 annual report of the five Dutch Regional Euthanasia Review Committees[81] found that 13 psychiatric patients were killed by euthanasia in 2011, up from 2 in 2012. This, despite a notional legal requirement that the patient should be mentally competent.

In 2005, a UK House of Lords Select Committee Report on the 'assisted dying' Bill of Lord Joffe. predicted that a Dutch-style law in Britain would lead to 13,000 euthanasia deaths annually[82] (that would be roughly 800-850 deaths if implemented in New Zealand). That number needs to be revised upwards in the light of more recent

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[77] CBS Statistics Netherlands, *Deaths by medical end-of-life decision; age, cause of death* (2012): http://bit.ly/1nwHdMC

[78] *Ibid.*, section 178.

[79] A description of this protocol (known as the 'Groningen Protocol') is given by two authors who helped develop this practice: *End-of-life decisions in newborns: an approach from the Netherlands*, A.A.E Verhagen and P.J.J Sauer, Pediatrics 116.3 (2005): 736-739.

[80] *Go-ahead for world's first mobile euthanasia unit that will allow patients to die at home*, by Simon Caldwell, Daily Mail, 10th February 2012. Retrievable at http://dailym.ai/1nW9ZGU

[81] Regional Euthanasia Review Committees Report (2011): http://bit.ly/23BHRJF

[82] Select Committee on Assisted Dying for the Terminally Ill Bill, Report 1 (2005): http://bit.ly/2hek6HK

figures, such as a five-yearly study from the Lancet[83] (published in 2012 and relating to 2010) which found that overall numbers of deaths by euthanasia had risen by more than 60% in five years. This was not due to an increase in reporting – this has actually declined slightly from the 2005 rate of 80% – but due to increased numbers of requests, and an increased percentage of requests accepted.

Another matter of concern from the same report is the steep rise in cases of continuous deep sedation (12.3% of deaths in 2010). This may account for the rise in deaths by an 'intensified alleviation of symptoms' (from 18.8% of deaths in 1990, to 36.4% of deaths in 2010). This may cover more deaths ending without request.

The state of euthanasia in the Netherlands, and Belgium, despite attempted 'safeguards' into the law, shows how the human reality can follow the law of unintended consequences and be very different from the good intentions of the framers of laws to 'assist dying'. When medical professionals get used to the idea that they can kill their patients at their request, it is not too difficult to see medical culture corrupted into accepting euthanasia according to the doctor's own judgement, or the extension of the principle to other less 'autonomous' groups of people.

Oregon

The Oregonian system is one of assisted suicide, rather than euthanasia, but it is nonetheless a popular model for many advocates for the introduction of medicalised killing, regardless of the method. This popularity may have something to do with the fact that little can be said about it, due to the sheer paucity of data available.

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[83] *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*, B D Onwuteaka-Philipsen, A Brinkman-Stoppelenburg, C Penning, G J de Jong-Krul, J J van Delden, & A van der Heide, The Lancet, 380(9845), 908-915 (2012).

The Oregon State Public Health Division publishes a 'Death With Dignity' Act Report every year, purporting to provide informed oversight of the implementation of the system of assisted suicide allowed by the act. This functions however, as minimal data collection. The law requires doctors to report any prescription they make of lethal drugs, but there are no penalties for those who fail to report, and so no enforcement of this requirement. Nor is noncompliance, underreporting, or any violation monitored by the State Health Division, which admitted in its first year that "*[W]e cannot detect or collect data on issues of noncompliance with any accuracy*", with other reports admitting that "*[O]ur numbers are based on a reporting system for terminally-ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the law*".

Since the information is voluntarily reported by doctors, no information is collected from patients, or their relatives, and there is no official means by which the public can complain about abuses of assisted suicide. There is thus no strong oversight of assisted suicide exercised by the State Government.

In fact, an Oregon State official, Dr. Katrina Hedberg. when questioned by the UK House of Lords Select Committee on Lord Joffe's 'Assisted Dying for the Terminally Ill' Bill in 2004[84], acknowledged that even what data they do collect is ultimately lost, as the State Health Division destroys each year's underlying data records after it issues each annual report. Little wonder then, that an editorial in *The Oregonian* pointed out over ten years ago that the law established "a system that seems rigged to avoid finding" abuses[85]. There may be many other abuses in Oregon, but the data the State Government releases is so limited, and so temporary, that is essentially hidden.

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[84] *House of Lords Select Committee Report on the Assisted Dying for the Terminally Ill Bill*, Volume II: Evidence, pg. 262, Question 592 (http://bit.ly/2kQ8NGj).

[85] *Living With the Dying Experiment*, The Oregonian, 08/03/05.

Nonetheless, from what data is available, we can learn some very telling lessons from the Oregonian experience. In Oregon, between 1999 (two years after assisted suicide was introduced) and 2010 the suicide rate among those aged 35-64 increased by almost 50% (compared to 28% nationally)[86]. Oregon's largest city, Portland also sees high levels of suicides[87]. What this has suggested is that assisted suicide exacerbates the number of suicides, as the idea of ending one's own life becomes normalised.

The latest Oregon figures[88] show that the numbers of assisted suicides have risen from 16 in 1998, to 132 in 2015. That is an increase of over 900%. In 2013 alone, the numbers of assisted suicides rose by 44%.

Moreover, as in Belgium and Holland, reports of individual assisted suicide cases show that patients are receiving assisted suicide in Oregon who suffer from depression and dementia, and 2008 study published in the British Medical Journal examined 58 Oregonians who sought information on assisted suicide. Of them, 26% met the criteria for depressive disorder, and 22% for anxiety disorder. Three of the depressed individuals received and ingested the lethal drugs, dying within two months of being interviewed. The study's authors concluded that Oregon's law "may not adequately protect all mentally ill patients"[89].

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[86] *Suicide Among Adults Aged 35–64 Years — United States, 1999–2010*, Mortality and Morbidity Weekly Report Centres for Disease Control and Prevention, 03/05/13 (http://bit.ly/2knlv0M).

[87] *An Analysis of Completed Suicides: April 2011-June 2013*, Frank Silva, Portland Police Bureau Behavioural Health Unit, 30/09/13 (http://bit.ly/2lgpZWa).

[88] Oregon Public Health Division Death with Dignity Act Report (2015): http://bit.ly/2h3md0I

[89] *Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey*, Ganzini, Goy, and Dobscha, BMJ 2008;337:a1682.

There are signs that the provision of assisted suicide has also effected the extent of healthcare provision. In 2008, ABC News reported that a 64-year-old Oregon woman, Barbara Wagner, whose lung cancer had been in remission, learned the disease had returned and would likely kill her. Her last hope was a $4,000-a-month drug that her doctor prescribed for her, but the insurance company refused to pay. It might be a temptation to blame that on a system of predominating private health insurance governed by the profit motive, which is operative in the United States. Yet the cost-cutting and cost-saving motive in public health insurance programmes can also lead to inhumane consequences, as Oregon itself demonstrates. In Barbara Wagner's case, what the Oregon Health Plan – the state's 'Medicaid' (state-provided healthcare) programme – agreed to cover, were drugs for a physician-assisted death. Drugs which then costed about $50[90].

Indeed, under the Oregon Health Plan, some necessary services and medicines – including some analgesic drugs to relieve pain – are not covered, but assisted suicide (which is cheap to provide) is covered. According to Oregon's 'Prioritised List of Health Services 2015', cancer treatment was limited according to relative life expectancy: 'treatment with intent to prolong survival is not a covered service for patients who have progressive metastatic cancer…'. By contrast, 'It is the intent of the Commission that services under ORS 127.800-127.897 (Oregon Death with Dignity Act) be covered for those that wish to avail themselves to those services'[91].

Finally, the Oregon State Public Health Division brings out an Annual Report each year, and in 1998, the year in which the 'Death with Dignity' act, legalising assisted suicide in Oregon took effect, it reported that 13% of patients applying for medication to commit suicide did so because they were frightened of being a burden on their

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[90] *Death Drugs Cause Uproar In Oregon*, ABC News, August 6th, 2008: http://abcn.ws/2ghc7bc

[91] Health Evidence Review Commission, Prioritized List of Health Services (1 January 2015), Guidance Note 12 and Statements of Intent, pg. 1.

families[92]. This percentage has substantially increased since, even whilst fluctuating, to the extent that in 2014 almost four times more patients (40%) were opting for assisted suicide for this reason[93]. Last year, it was 48.1%[94]. In 2012, only four years ago, this figure had exceeded it, at 57.1%[95]. Meanwhile, in Washington State, which also uses a similar system, the most recent figure for this reason cited by those opting for assisted suicide is 61%[96].

All of this illustrates the degree to which a so-called ‘right to die’ (more accurately a right to be killed) can in fact become a *duty to die*. Those of us in other jurisdictions must ask ourselves whether we really want to live in a society where this is the attitude engendered in the elderly and the terminally ill. Surely instead, we would rather want a compassionate society in which people are valued for who and what they are – human beings with inherent dignity, who are always valued – and which consequently invests in good quality palliative care? It is on this point that we should consider the final element to this debate, one that is critical in finding the real answers to terminal illness and patient suffering.

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[92] Oregon Public Health Division Death with Dignity Act Report (1998), Table 3: ‘Characteristics of case patients and matched controls’, sub-heading ‘End of Life Concerns’, page 16: http://1.usa.gov/1IJI6XT

[93] Oregon Public Health Division Death with Dignity Act Report (2014), Table 1: ‘ Characteristics and end□of□life care of 857 DWDA patients who have died from ingesting a lethal dose of medication as of February 2, 2015, by year, Oregon, 1998□2014’, sub-heading ‘End of Life Concerns’, page 5: http://1.usa.gov/1G0jDub

[94] *Op. cit.*, Oregon Public Health Division Death with Dignity Act Report (2015), Table 1: ‘ Characteristics and end□of□life care of 857 DWDA patients who have died from ingesting a lethal dose of medication as of February 2, 2016, by year, Oregon, 1998□2015’, sub-heading ‘End of Life Concerns’, page 5: http://bit.ly/2h3md0I

[95] Oregon Public Health Division Death with Dignity Act Report (2012), Table 1: ‘Characteristics and end-of-life care of 673 DWDA patients who have died from ingesting a lethal dose of medication as of January 14, 2013, by year, Oregon, 1998-2012’, sub-heading ‘End of Life Concerns’, page 5: http://1.usa.gov/1LdpEum

[96] Washington State Department of Health 2013 Death with Dignity Act Report, Table 2: ‘End of life concerns of participants of the Death with Dignity Act who have died’, page 7: http://1.usa.gov/1Tqy18k

Palliative Care: Lessons from the UK

Putting the rhetoric about ‘autonomy’ and a ‘right to die’ aside, it is obvious that what most basically and viscerally drives the desire for some for the introduction of euthanasia is the suffering of patients.

Not all pain of course is physical. The existential suffering of those who are paraplegic, or suffering mental breakdown, are those frequently pointed to as the ‘hardest cases’ justifying euthanasia, though it is very much notable that such conditions need not mean a life of hopeless and hellish experience.

In 2012, the BBC interviewed a man with ‘locked-in syndrome’ called Michael Cupiss, who, despite his paralysis and inability to talk, is “amazingly happy”[97]. Similarly, very recently, scientists who were able through new technology to communicate with four people whose illness was so debilitating that they could not even move their eyes, found that in 7 out of 10 occasions the patients reported being ‘happy’[98].

This is supported by the evidence supplied by a study reported in 2011[99], in which many people with ‘locked-in syndrome’ communicated that they experienced happiness. Researchers questioned 168 members of the French Association for Locked-in Syndrome, and of the 65 people who responded, 47 patients professed happiness, while 18 said they were unhappy. Only 7% (4 people) said they wanted euthanasia, whilst 68% reported never having had suicidal thoughts.

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[97] *Man with locked-in syndrome ‘amazingly happy’, says wife*, BBC News, 22/08/12 (http://bbc.in/2kPzfQm).

[98] *Locked-in patients tell doctors they are ‘happy’ after computer reads thoughts*, Sarah Knapton, Daily Telegraph, 31/01/17 (http://bit.ly/2ko9qah).

[99] *People with locked-in syndrome are happy, study says*, Daily Telegraph, 24/02/11 (http://bit.ly/2ktBupk).

Regardless, in the popular imagination, it seems that the immediate and extreme suffering of physical pain is what is most immediately concerning. The answer to this for the vast majority of people however, and therefore arguably the main obviation of euthanasia and assisted suicide, is the developed specialism of palliative care. This means not merely analgesia (pain relief), but a comprehensive approach to treating serious illness that focuses on the physical, psychological and spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and symptoms.

The development of palliative care originally in the UK is primarily due to Dame Cicely Saunders (1918-2005), who started the started the Hospice Movement. Before her efforts, Hospices were run by religious organisations for the dying poor, and she helped develop them into places of palliative medicine.

The ethic and development that Saunders introduced into British medicine has meant that the UK has the best system of end of life care system in the world, a fact that was most recently affirmed by the most recent 'Quality of Death Index', a comparative study of 80 nations undertaken by the Economist Intelligence Unit[100]. This is due to "comprehensive national policies, the extensive integration of palliative care into its National Health Service, and a strong hospice movement", with quality of care also being ranked as the world's best. Despite this, the UK health system is still not perfect in its provision of palliation to patients. The structure and organisation of health services can mean that some people who need expert palliative care are not always able to access it. I bring this up because it seems to me that if New Zealand were to emulate the best of what the UK does, and avoids its current issues, it could resolve much of the demand for the practice of euthanasia by satisfying the concerns that drive the lobby for it.

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[100] *The 2015 Quality of Death Index: Ranking palliative care across the world*, Economist Intelligence Unit (October 2015): http://bit.ly/1Q6gvl0

Whilst being consistently qualitative overall, the UK struggles with under-supply, limited application outside of a hospice setting, and sometimes poor organisation. An independent review[101] commissioned by the Government reported in 2011 that of just over 470,000 people who die in England each year, some 355,000 require palliative care, yet only 171,000 receive specialist palliative care. It also found a postcode lottery of palliative care that led to gross inequities, with only 56% of Primary Care Trusts providing 24-hour community nursing.

This "unacceptable variation" and other similar problems were confirmed earlier this year both by a Commons Health Committee report[102], and by researchers at the London School of Economics, in a report[103] commissioned by the cancer charity Marie Curie, which found that more than 100,000 people a year who would benefit from palliative care are not getting it, leaving them without the sufficient pain relief they need. Groups most likely to be so affected were the "oldest old" (aged 85 and over), people living alone, people living in deprived areas, and black, Asian and ethnic minority groups.

In May, a report[104] by the Parliamentary and Health Service Ombudsman into complaints about end of life care found serious issues with the provision of that service. This included poor communication with families – tragically, meaning that some reported losing a chance to say goodbye to a dying loved one – and poor pain

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[101] Palliative Care Funding Review, *Funding The Right Care and Support for Everyone*, Hughes-Halllett *et al* (July 2011): http://bit.ly/1MqeFNi

[102] *End of Life Care: Fifth Report of Session 2014–15*, House of Commons Health Committee (March 2015): http://bit.ly/1J7yXWv

[103] *Equity in the Provision of Palliative Care in the UK: Review of Evidence*, Dixon *et al* (April 2015): http://bit.ly/1LdUlQN

[104] *Dying Without Dignity: Investigations of the Parliamentary and Health Service Ombudsman into complaints about end of life care* (May 2015): http://bit.ly/1J7zZBU

management resulting in unnecessary suffering of patients. The report also reported what the independent review, Health Committee, and LSE identified: poor planning and fragmented, uncoordinated care, often compounded by inadequate out of hours services.

In response to these structural problems, the pathway to proper reform is known, has been made clear, and could save money rather than lead to a greater strain on the public purse. The Commons report recommended access to palliative care in community settings and hospitals, as well as hospices. The 2011 review estimated that provision of more community-based services could reduce the number of hospital deaths by 60,000 a year, calculating that the annual saving to hospitals would be £180 million. The LSE report came to similar conclusions, finding that providing palliative community care to those that need it could improve the quality of life for thousands of patients and save millions in NHS money by preventing unwanted and distressing hospital treatment.

To address this, Lady Finlay of Llandaff, a cross-bench peer, immediate former President of the British Medical association, co-chair of end-of-life think tank Living and Dying Well, and one of Britain's leading experts in palliative care medicine, has tabled an Access to Palliative Care Bill[105] in the House of Lords that would ensure that all health and social care providers receive the necessary education and training in palliative care and are thereby enabled to provide a quality service for patients who need it. This would mean that the individual analgesic requirements of patients would become a priority and a duty for all medical professionals. It would also involve training all staff in how to handle the sensitive communications between themselves, dying patients, and their loved ones, so that needed psychological and emotional support is provided at all times. This would give the comforting sense of control back to people at one of the most uncertain times of their lives. In addition to this, Lady Finlay's Bill aims

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[105] *Access To Palliative Care Bill* 2016-2017: http://bit.ly/2hdp8UX

to resolve problems such the access needed by healthcare workers to the essential palliative medication for patients at all times, and to the specialist advice needed to properly care for those with complex conditions.

I point all this out to illustrate the challenges that even the world's best palliative care system can experience, and how the debate on provision of palliative care may lead to answers relevant to NZ. The 'Quality of Death Index' ranks your country as having the third best palliative care system on the planet, behind only the UK and Australia. The Country Profile for NZ[106] describes the adoption of a "comprehensive national strategy" in 2001, and "a generous welfare insurance system that covers all palliative care costs", with the national Government pledging over NZ$50m in funding to expand care for the terminally ill at hospices and in their homes. Whilst it is reported that all doctors have undergone a basic level of palliative training, the profile describes "a lack of academic specialists in palliative medicine", and the possibility of under-servicing of remote areas.

If there were an expansion of the number of palliative specialists in NZ, the humane care that is perceivably lacking to many of those sympathetic to euthanasia due to their own experience, or those of loved ones, might be provided. Other elements of palliative provision lacking in NZ as in the UK might be solved by the same prescribed remedies put forward by Lady Finlay and other similar experts in these fields.

These are not perfect answers; palliative care may not satisfy every person. Regardless, the best means of ensuring that those in pain and terminal illness are given the compassionate care that they need, is to guarantee that no-one suffers due to a

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[106] *The 2015 Quality of Death Index: Country Profiles*, Economist Intelligence Unit (October 2015), pg. 50: http://bit.ly/2ktz3D2

deficiency of such provision in the health services of your country. As this is a challenge that must be met in the UK, so it is one that must be met in New Zealand.

Conclusion

In addressing the twin problems of suffering and suicide, laws against euthanasia and assisted suicide are a vital part of the social framework that protects vulnerable people from harm. They operate with the strength that can protect, and yet also the flexibility that can show compassion. If there is a deficiency in either of those areas, it can be addressed by better prosecutorial guidelines, but when these protections are abandoned, the evidence from foreign jurisdictions shows the abuse that can occur.

What the evidence shows from European countries that are, like New Zealand, modern developed liberal democracies, is that the introduction of voluntary euthanasia – like (but even more so than) assisted suicide – enables the violation of the right to life of some of the most vulnerable human beings. It corrupts medical culture, worsens society's view of dying and illness as well as those who are dying and ill, retards and undermines the development of palliative care, and leads society off of an easily foreseeable 'logical cliff', in which those particularly who suffer mental illness become the victims of a coarsened culture.

When the Marris Bill was debated in the UK in 2015, MPs were faced with the opposing voices to the Bill of leading voices in the disability rights community, such as the late Kevin Fitzpatrick, Baroness Campbell of Surbiton, and the actress and activist Liz Carr. These were joined by medical bodies such as the Royal Colleges of Physicians[107], Surgeons[108], and General Practitioners[109], the Association of Palliative Medicine, the British Medical Association[110] (which in June voted to maintain its

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[107] *RCP Briefing: Assisted Dying Bill 2015-16* (http://bit.ly/2ewhCPe).

[108] *Royal College of Surgeons, House of Lords Briefing: Assisted Dying Bill* (http://bit.ly/2eFJOTc).

[109] *RCGP announces continued opposition to change in law on assisted dying*, 21/02/14 (http://bit.ly/2fxWsBq).

[110] *BMA Policy: Assisted Dying*, 06/09/12 (http://bit.ly/2fxVjth).

opposition to assisted suicide), and the World Medical Association[111], as well as by organisations that represent and campaign for the welfare of the disabled and elderly, such as the British Geriatric Society[112], Scope[113], the UK Disabled People's Council[114], Not Dead Yet UK[115]. Similarly, I noted in watching the South Australian debate that the Australian Medical Association actively opposes euthanasia[116], as do leading disability rights activists there such as Craig Wallace, the President of People with Disabilities Australia[117], as well as groups such as Lives Worth Living[118].

As you know, the situation is similar in New Zealand. New Zealand Medical Association[119], the Australian & New Zealand Society of Palliative Medicine (ANZSPM), Hospice New Zealand, New Zealand Health Professionals Alliance, Palliative Care Nurses New Zealand, and Not Dead Yet Aotearoa, are all examples of organisations that oppose euthanasia, and no doubt they have all contributed to the Health Select Committee's considerations.

This alliance of those who care about the welfare of the most vulnerable members of the human family is surely in itself instructive. They have all listened to the same stories and looked at the same evidence. They know on objective medical and humanitarian grounds that euthanasia does not promote or extend patient choice; it

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[111] *WMA Statement on Physician-Assisted Suicide*, adopted September 1992; and reaffirmed 2015 (http://bit.ly/2efFrzw).

[112] *Physician-Assisted Suicide – BGS Position Statement*, 19/04/11 (http://bit.ly/2fLGTe2).

[113] *Why Scope is against legalising assisted suicide* (http://bit.ly/2fy0ARR).

[114] *UKDPC Position Statement: Assisted Suicide* (http://bit.ly/2fxXRYL).

[115] *About Not Dead Yet UK* (http://notdeadyetuk.org/about/).

[116] "The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life", *Position Statement on the Role of the Medical Practitioner in End of Life Care 2007 (amended 2014)*, section 10.5 (http://bit.ly/2fa6fAy).

[117] *Euthanasia: let's look at the bigger picture*, Craig Wallace, ABC, 21/01/13 (http://ab.co/2fa0tid).

[118] Lives Worth Living: http://livesworthliving.com.au/

[119] *NZ Medical Association warns against euthanasia*, Radio New Zealand: http://bit.ly/2h2jGBB

invites and enables coercion. This is not speculative hypothesis; it is evidenced reality. This risk of even subtle coercion of vulnerable people is precisely why NZ law, as UK law, exists as it does. As Baroness Butler-Schloss, the former President of the High Court Family Division, once put it, “Laws, like nation states, are more secure when their boundaries rest on natural frontiers”. This is about asserting a fundamental principle of law that serves to protect vulnerable people from lethal coercion.

There is no such thing as a perfect world. Neither the current laws, nor the introduction of euthanasia would serve everyone. What we can know, however, is that euthanasia can and does compromise the right to life and welfare of those who most need the safeguarding of the law. Instead of aiming for a false utopia, it is important for Government to try to deal with the reality as it is of legal and medical necessity. The current legal situation in NZ, like that in the UK, when practiced properly, allows for the best balancing of justice and mercy, protection and compassion; introducing euthanasia would destroy this balance and endanger those whom the law has a duty to soundly protect.

Finally, there are better answers to the problems of terminal illness and patient pain, and they lie in serious-minded and comprehensive palliative care reform, not in the introduction of a practice that will abuse the elderly, the disabled, the terminally and severely ill, and many others whom the law owes protection. I urge the Health Select Committee of the New Zealand Parliament to stress the importance of the current laws, to think imaginatively about how current issues can be resolved without removing vital protections, and to stand for a legal and medical framework that best serves true social justice and the common good.