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living and dying well
Clear thinking on the end-of-life debate

THE END OF LIFE CHOICE BILL - An Analysis

Introduction

1. Mr Seymour's Bill was given its First Reading in the New Zealand Parliament on 13 December 2017 and has been referred for detailed examination to the Justice Committee. In this document we analyse the Bill and draw attention a number of important features which, we would suggest, require careful consideration.

2. The Bill seeks to change the law to legalise what it calls 'assisted dying' - which is defined[1] as "*the administration by a medical practitioner of a lethal dose of medication to a person to relieve his or her suffering by hastening death"*. As is made clear in Section 15 of the Bill, this provides for **both** physician-assisted suicide (PAS), involving the supply of lethal drugs for self-administration by a patient; **and** physician-administered euthanasia (PAE), meaning the administration of lethal drugs directly to a patient - for example, via an intravenous injection.

3. The Explanatory Note to the Bill states that "*the motivation for this Bill is compassion"*. Undoubtedly the Bill is well-intended. However, it needs to be recognised that what is being proposed is a major change to the criminal law which, if enacted, would permit actions to be taken with the deliberate intent of ending human life. Whether such a change can be justified depends, we would suggest, on the answers to two questions:

(a) Is the existing law in need of change? and, if so,

(b) Could the law be changed without putting vulnerable people at risk of harm?

4. The Committee's examination of the Bill will, presumably, focus largely on the second of these two questions and consider whether the Bill, as presented, is fit for purpose or needs amendment. However, it is our understanding that the Committee's remit does not exclude the first question. While we recognise that some Members may be of the view that the law should be changed and that the focus should be on how rather than whether to change it, we would respectfully suggest that the two questions are not mutually exclusive and that an understanding of what the existing law says, why it says it and how it is applied provides a proper context for consideration of the Bill as it stands.

5. This memorandum is therefore in three parts. Part One considers the existing law and its purpose and application; Part Two focuses on Mr Seymour's Bill and its provisions; and Part Three raises some major issues of substance.

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[1] Section 3 of the Bill

Part One - The Existing Law

6. The Explanatory Note to Mr Seymour's Bill states that "*there are serious problems with the current state of the law in New Zealand that will be ongoing without a legislative solution*". Is this the case? To answer that question it is necessary to understand what the existing law is and how it is applied.

7. Aiding and abetting suicide is a criminal offence in New Zealand under Section 179 of the 1961 Crimes Act. PAS is therefore unlawful. There is no specific offence of euthanasia under New Zealand law. Acts of euthanasia are regarded as culpable homicide under Section 160 of the 1961 Crimes Act and may result in a charge of either murder or manslaughter.

NEW ZEALAND CRIMES ACT 1961

160 Culpable homicide

(1) Homicide may be either culpable or not culpable.

(2) Homicide is culpable when it consists in the killing of any person—

(a) by an unlawful act; or
(b) by an omission without lawful excuse to perform or observe any legal duty; or
(c) by both combined; or
(d) by causing that person by threats or fear of violence, or by deception, to do an act which causes his or her death; or
(e)by wilfully frightening a child under the age of 16 years or a sick person.

(3) Except as provided in section 178, culpable homicide is either murder or manslaughter.

(4) Homicide that is not culpable is not an offence.

179 Aiding and abetting suicide

(1) Every one is liable to imprisonment for a term not exceeding 14 years who—

(a) incites, counsels, or procures any person to commit suicide, if that person commits or attempts to commit suicide in consequence thereof; or
(b) aids or abets any person in the commission of suicide.

(2) A person commits an offence who incites, counsels, or procures another person to commit suicide, even if that other person does not commit or attempt to commit suicide in consequence of that conduct.

(3) A person who commits an offence against subsection (2) is liable on conviction to imprisonment for a term not exceeding 3 years.

8. Breaches of the law do not inevitably result in prosecution. The Solicitor-General's Prosecuting Guidelines make clear that "*it is not the rule that all offences for which there is sufficient evidence must be prosecuted. Prosecutors must exercise their discretion as to whether a prosecution is required in the public interest*" (Paragraph 5.5) and that "*there will be circumstances in which, although the evidence is sufficient to provide a reasonable prospect of conviction, the offence is not serious and prosecution is not required in the public interest*" (Paragraph 5.7)

9. A prosecution requires evidence not only that the law has been broken but that a breach of the law has involved criminality. As with all criminal offences, the prosecuting authorities have discretion over whether to prosecute and, where a prosecution takes place and there is a conviction, the courts have discretion to tailor sentencing to the circumstances of the offence.

10. The Explanatory Note to the Bill states that "*the courts are treating the family members who have assisted their loved ones to die at their request with increasing leniency and compassion".* This is a simplistic view which ignores the link between deterrence and behaviour. The penalties which the existing law holds in reserve make anyone minded to engage in assisting a suicide think very carefully before proceeding. As a result the incidence of the offence is small and the cases that do occur are likely to be those where assistance has been given reluctantly and after much soul-searching. The law recognises that there could be exceptional circumstances where ending or helping to end another person's life at his or her request need not prosecuted or, if prosecuted, punished with the maximum penalty.

11. However, changing the law to license such acts in advance and in prescribed circumstances changes the dynamic. Laws are more than just regulatory instruments: they send social messages. An 'assisted dying' law sends the message, however unintended, that ending or helping to end the lives of seriously-ill people is seen as acceptable behaviour. While such a subliminal message may make little difference to a small number of strong-minded individuals who are in control of their lives and circumstances, many - if not most - seriously ill people are not in that position. They may be struggling to come to terms with their mortality or worried about how their illness will develop or anxious about the strains it is placing on those around them or under pressure, however subtly expressed, to remove themselves as a burden. To people in this position an 'assisted dying' law, however well-intentioned, can all too easily convey the message that, where terminal or otherwise serious illness or disability is concerned, taking one's own life is seen as an appropriate course of action to be considered.

12. Creating a licensing system for assisted suicide or euthanasia also weakens the existing law's deterrent against abuse. Under the present law a malicious assister with suicide has to reckon with a spotlight being shone on his or her actions and motivations and on any criminal behaviour coming to light as a result. Under an 'assisted dying' a law, on the other hand, all that a malicious or manipulative relative has to fear is that the request will be rejected. The existing law has the teeth to deter criminal behaviour while also having the discretion to deal appropriately with

genuinely compassionate situations. It may not suit everyone - no law does that. But the purpose of the law is not to offer options and choices to some but to protect society as a whole, and especially its most vulnerable members, from harm - including self-harm.

13. There is also widespread misunderstanding or misrepresentation of the law relating to end-of-life decisions. For example, in the record of the First Reading debate on 13 December 2017 one of the Bill's supporters quoted the New Zealand High Court as having stated, in connection with an appeal by the late Lecretia Seales, that that "*it was unlawful for Lecretia to be allowed a doctor's help to die at a time of her choosing".* This is a misrepresentation of the real position. It is open to any terminally- or otherwise seriously-ill person to die at a moment of his or her choosing. A person in this position needs only to request that the treatment which is prolonging his or her life be discontinued. There is no law against cessation of treatment: all medical treatment requires the consent of the patient. There already exists, therefore, what is sometimes called a 'right to die'. What does not exist is a right to involve other people in deliberately bringing about our deaths. When a doctor withdraws life-sustaining treatment, he or she does not do so in order to end the patient's life but because the treatment has proved futile or the patient no longer wishes to have it.

14. Moreover, removal of life-sustaining treatment does not mean that the patient is abandoned to his or her illness. When treatment is removed, a doctor has a duty of care to ensure that the symptoms of the illness are managed effectively. There are protocols for managing a range of conditions in such circumstances and it is usually possible to ensure that the ensuing death is pain-free and peaceful. The argument that serious illness involves a bipolar choice between suffering and taking one's one own life is without foundation.

15. In a responsible society acts are not licensed by law simply because it is possible to empathise with them in exceptional circumstances. No one would want to see a mother prosecuted who stole in desperation because her family was starving. No one would want to see a father prosecuted for assault if he injured a nocturnal intruder while protecting his family. Yet few people would seriously advocate changing the law to legalise theft or assault in advance and in prescribed circumstances. We expect these laws to be maintained to protect everyone and for exceptional situations to be dealt with exceptionally. That is what happens now in the case of what is being called 'assisted dying'. The existing law has a stern face and an understanding heart. But that is a completely different matter from creating a licensing system for acts of assisted suicide and administered euthanasia. It is this change in the dynamic that is almost certainly a major factor of the rising numbers of such acts in those jurisdictions where legalisation has taken place.

16. For these reasons, and having regard to the arguments put forward in the First Reading debate, we would respectfully suggest that the case for legalisation has not been made. However, for readers who may not share this conclusion, we move now

to consider the second of the two questions: does the Bill provide safeguards which could be expected to protect vulnerable people from harm?

Part Two - Protecting Vulnerable People from Harm

17. The proposed safeguards in the Bill may be said to fall into two main groups:

- the definition of the categories of people to be eligible for PAS or PAE;

- the processes for deciding whether those who apply fulfil the eligibility criteria.

We consider these two issues below and then focus (in Part Three) on what, we believe, are some other important matters of substance.

Eligibility

18. Those who would qualify under the Bill for PAS or PAE are:

- people who have been diagnosed as terminally ill and are thought likely to die within six months;

or

- people with "*a grievous and irremediable medical condition*" who are "*in an advanced state of irreversible decline in capability*" and are experiencing "*unbearable suffering that cannot be relieved in a manner that he or she considers tolerable*" and be able to understand "*the nature of assisted dying; and the consequences for him or her of assisted dying*".

19. These are widely-drawn parameters. They include people with serious and long-term chronic illnesses, such as MS, Parkinsons, diabetes and heart disease, as well as people with conditions such as cancer with relatively short trajectories to death. There can scarcely be a street in New Zealand where there is not someone who might qualify in one way or another.

20. The condition that an applicant must be "*in an advanced state of irreversible decline in capability*" may possibly narrow the field, though it is vaguely-worded and open to wide interpretation. Some chronic illnesses follow a pattern of successive decline and recovery. A doctor could well say, at one of the low points, that an irreversible decline had begun, yet the patient may recover.

21. Even in cases of confirmed terminal illness accurate prognosis is often little more than a best guess. In 2004 the UK Royal College of General Practitioners told the Mackay Committee's investigation into 'assisted dying' that "*it is possible to make reasonably accurate prognoses of death within minutes, hours or a few days*" but that "*when this stretches to months, then the scope for error can extend into years*"[2]. Oregon's experience of legalised PAS supports this view. The official annual reports from the Oregon Health Authority show that many of those who receive prescriptions for lethal drugs under the terms of that State's PAS law and on the

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[2] House of Lords Report 86-I (Session 2004-05), Paragraph 118

strength of a six-months-or-less prognosis live for months, in some cases years, before using them to end their lives. How long they might have lived if they had not been supplied with lethal drugs is anyone's guess.

22. There is another question which Oregon's PAS law has brought to light. Many people have medical conditions - for example, diabetes or heart disease - which are incurable but successfully managed through medication and/or treatment. Without such management what is a chronic but managed illness can become a terminal illness. The question therefore arises: what is to happen in a situation where a person with a chronic but managed medical condition discontinues or threatens to discontinue prescribed medication, such as insulin for diabetes? In such a situation the patient would become terminally or critically ill as a result of stopping the maintenance therapy. Is he or she to be considered eligible for PAS or PAE as a result of that action? A paper[3] published recently in Sweden records an admission by the Oregon Health Authority that that would be the case, yet that was clearly not the intent of Oregon's PAS law when it was passed and, presumably, it is not the intent of Mr Seymour's Bill.

23. This is particularly relevant as the Bill defines 'unbearable suffering' as suffering that "*cannot be relieved in a manner that he or she considers tolerable*". In other words, under the terms of the Bill an applicant may access PAS or PAE simply because he or she rejects the relief of suffering that is offered. That aside, 'unbearable suffering' is itself an entirely subjective criterion. Under the terms of the Bill it means whatever an applicant for 'assisted dying' decides it should mean. As such, it cannot be considered as a safeguard: to be effective a safeguard must be objectively verifiable.

Process

24. Sections 8 to 14 of the Bill set out the process to be followed where a person seeks 'assisted dying'. They prescribe various steps which the two doctors considering a request must take before agreeing (or not agreeing) to proceed. This is, however, little more than a checklist. It treats the process of assessment as a series of Yes-or-No answers to what are in many cases complex questions.

25. Section 8(b) of the Bill requires a doctor assessing a request for 'assisted dying' to "*talk with the person about his or her wish at intervals determined by the progress of his or her terminal illness or medical condition*". These words give the impression of a lengthy process of consultation in which a request for PAS or PAE has been discussed by doctor and patient over several weeks or months. Yet there is nothing in the Bill to prevent a decision being taken by an assessing doctor on the basis of a single consultation. The settled nature of a wish for 'assisted dying' is an important ingredient of any decision-making process.

26. One way of dealing with this issue would be to require that applicants for legalised PAS or PAE should have made an advance declaration some time (say, six

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[3] Stahle, F, Oregon Health Authority Reveals Hidden Problems with the Oregon Assisted Suicide Model, https://drive.google.com/file/d/1xOZfLFrvuQcazZfFudEncpzp2b18NrUo/view

months) before making a request to the effect that they would wish to consider requesting 'assisted dying' if they should at a future date find themselves to have a qualifying medical condition. Such a declaration would carry no obligation to proceed to making a request, but it would provide some evidence of a settled wish and would enable those who feel strongly to register their view ahead of time. Under the Bill as it stands, however, there is nothing to prevent requests by people who may find themselves seriously ill and make requests for PAS or PAE out of transient depression or despair.

27. Section 8(c) requires an assessing doctor to "*ensure that the person understands his or her other options for end of life care".* However, simply informing an applicant for PAS or PAE that there are other courses of action is insufficient to enable him or her to make a properly-informed decision. In 2004 Hospice UK told the Mackay Committee that "*experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed"*[4]*.* Specialists in palliative care regularly come across seriously ill patients who have heard of the existence of this form of treatment but, until they have experienced it at first hand, have little idea of how it could transform their lives. Yet, with palliative medicine physicians being near-unanimous in their opposition to 'assisted dying', these are very unlikely to be the doctors assessing requests under the Bill. There should, at the least, be a mandatory referral to a palliative care specialist as part of any assessment process.

28. Nowhere is it stated in the Bill that to qualify for 'assisted dying' an applicant must be acting voluntarily and without pressure. Section 8(h) requires an assessing doctor to "*do his or her best to ensure that the person expresses his or her wish free from pressure from any other person"* but the Bill does not require, as a condition of 'assisted dying', that the applicant is acting voluntarily and without duress. This is a surprising and critical omission. Even if a doctor assessing a request is able to establish that the person making it "*expresses his or her wish free from pressure from any other person",* that does not mean that no prior pressure has been applied or that the person is not suffering from internalised pressure - for example, feeling an obligation to hasten his or her death in order to remove a care or a financial burden from the rest of the family. Such feelings are common in people with serious illness.

29. No one would question that an applicant for 'assisted dying' must have decisional competence. Yet the Bill is vague as to how this is to be established. It states a requirement that an applicant must understand "*the nature of assisted dying; and the consequences for him or her of assisted dying*". However, it is one thing for a person to understand what 'assisted dying' is and that, if he or she proceeds, it will result in death. But establishing a person's decision-making competence, especially for a decision as grave as this, is a very different matter. It involves, among other things, verifying that the person's mental processes are functioning properly, that he

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[4] House of Lords Report 86-I (Session 2004-05), Paragraph 258

or she is able to weigh the decision fully and consider the implications and that his or her judgement is not being impaired by, for example, depression or circumstances.

30. Section 10 of the Bill states that the two doctors must establish that an applicant has competence, but it mandates no minimum steps in order to establish whether such competence exists. There is a requirement for referral to a 'specialist' (what kind of specialist is not stated) in the event that either of the assessing doctors should have doubts about an applicant's competence, but such a referral is presented as an optional supplement to, rather than as an integral part of, the assessment process. Research[5] in Oregon has revealed that this 'if in doubt' approach to referrals results in missed cases of clinical depression.

31. Section 14(2)(c) and (d) requires an assessing doctor, where an application for 'assisted dying' has been approved, to "*discuss with the person the likely timing of the assisted dying*" and "*make provisional arrangements to be available to administer the medication at the time indicated".* There seems to be an assumption that, once a request has been approved, assisted suicide or administered euthanasia will follow, if not immediately, then fairly quickly. This is not, and should not be, the case. In Oregon around one in three approved requests for PAS does not result in assisted suicide and some people postpone taking lethal drugs supplied to them. It is one of the claims of the Oregon system that it provides seriously ill people, not necessarily with hastened death, but with an 'insurance policy'. By contrast, these sections of Mr Seymour's Bill have the potential to accelerate the process towards PAS or PAE and could risk being misperceived by applicants as implying that, having put others to the trouble of assessing their requests, they should get on with it and give effect to them. These two sub-sections should be deleted from the Bill.

Part Three - Major Issues of Substance

PAS or PAE?

32. Any examination of proposals for legalised 'assisted dying' has to consider how, if such a law were to be enacted, it would turn out in practice. An important element of this is the predictable uptake of any such law. Legalisation is often presented as an escape hatch for a tiny number of people rather than just another choice at the end of life for larger numbers. It is necessary therefore to ask: if a law along the lines of Mr Seymour's Bill were to be enacted, how many people could be expected to take their own lives in New Zealand under its provisions?

33. Similar laws have been passed in a handful of other jurisdictions and it is possible to draw on their experience to arrive at reasonably accurate predictions of what would happen in New Zealand. However, it is necessary to recognise two things at the outset: first, that there is a considerable difference of outturn between those jurisdictions which have legalised PAE (physician-administered euthanasia) alongside PAS (physician-assisted suicide) and those which have legalised PAS alone; and,

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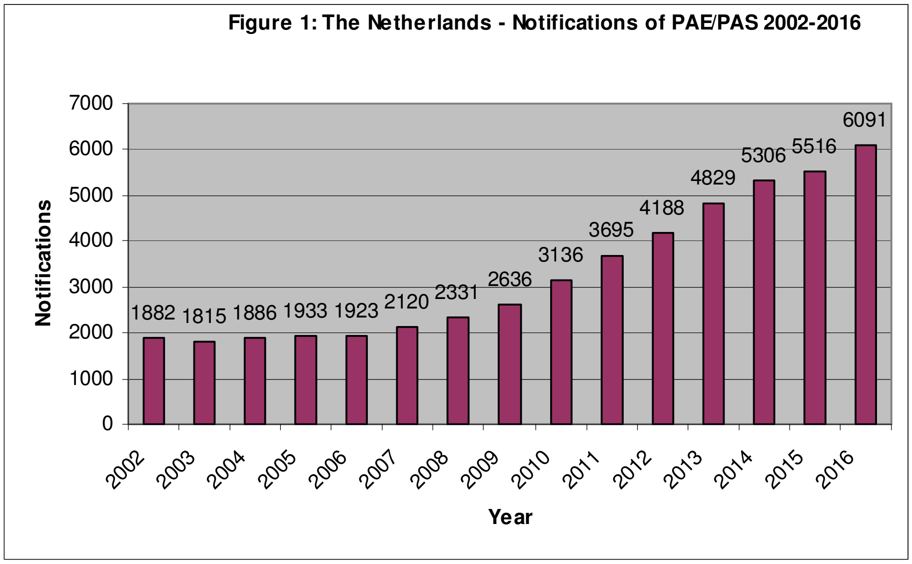
[5] Prevalence of depression and anxiety in terminally ill patients pursuing aid in dying from physicians, Ganzini et al, BMJ 2008; 337:al682

second, that we are dealing with a moving target, as the numbers of deaths in 'permissive' jurisdictions are rising year on year.

34. The ten[6] jurisdictions which have legalised 'assisted dying' may be divided into three groups. Group 1 comprises the six US jurisdictions of Oregon, Washington, Vermont, California, Colorado and Washington DC, which have legalised PAS only. Group 2 comprises Canada and The Netherlands, which have legalised both PAS and PAE; and Group three consists of Belgium and Luxembourg, which have legalised PAE only.

35. Mr Seymour's Bill, with its provision for both PAS and PAE, falls into Group 2, and the jurisdictions which offer the nearest parallels are therefore The Netherlands and Canada. The latter enacted its 'Medical Aid in Dying' (MAID) law only recently (2016), so evidence of outturn is at this stage fairly scanty. However, in the first year following enactment there were 1,982 deaths under MAID: all but five of them were the result of PAE[7].

36. The MAID law accounted for 0.9 per cent of deaths in Canada in its first year. However, the first year of such a law does not provide an accurate guide as to its longer-term outturn. A more reliable picture can be obtained from The Netherlands, which enacted its transparently-titled 'Termination of Life on Request and Assisted Suicide' law in 2001 and on which there have been 15 official annual reports over the period 2002-2016. Figure 1, which is derived from the data provided in these reports, shows the numbers of Dutch deaths from PAS and PAE over that period:



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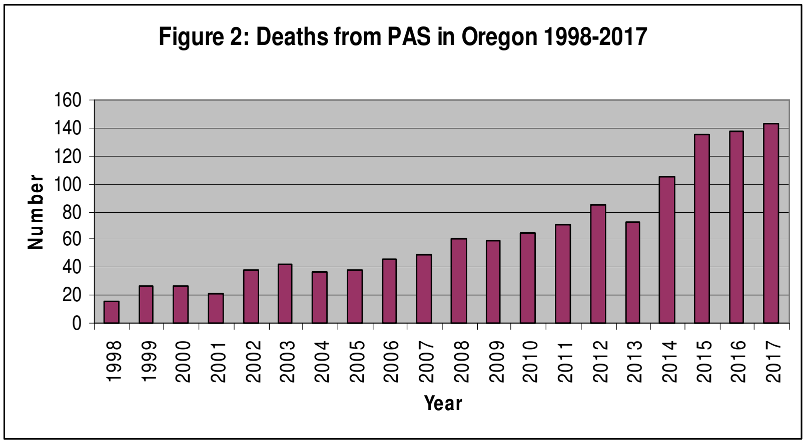
[6] Omitted from the list is Switzerland, which has not enacted an 'assisted dying' law but which has an exception to its criminal code permitting assistance with suicide (not specifically medical assistance) provided that such assistance can be shown to have been given for non-self-serving reasons. This exception from the Swiss criminal code dates from 1942 and was not enacted in the context of assistance with suicide as a response to serious illness.

[7] https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-sep-2017.html

37. In 2016 1 in 25 of all deaths in The Netherlands was the result of PAS or PAE. Moreover, of the 6,091 deaths in 2016, 96 per cent were the result of PAE: only 3.5 per cent were the result of PAS[8]. Why is there this difference between the two procedures? One explanation is that PAS, which requires an applicant for 'assisted dying' to self-administer lethal drugs, requires more determination on the part of the individual than does PAE, where the doctor is the active participant and the patient occupies the role of passive recipient. Another is that the direct involvement of a doctor in the act of bringing about death via administration of intravenous injections presents the process as a clinical and best-interests procedure and PAE as being analogous to a general - though in this case permanent - anaesthetic. The reality is different: PAE consists of two injections - a deep sedative to put the patient into a coma, followed by a muscle-relaxant, such as curare, to bring about death from asphyxia. Whatever the reasons, there can be no doubt that legalisation of PAE alongside PAS has the effect of driving out the latter and of resulting in much higher death rates.

38. By contrast, Oregon's PAS-only law reveals a rather different picture. Figure 2, which is based on data provided in the official annual reports published by the Oregon Health Authority, shows the numbers of recorded deaths from PAS in the State of Oregon since 1998:



39. What would all this mean for New Zealand? Oregon's death rate from PAS in 2017 was officially estimated as 39.9 per 10,000 deaths. Oregon's population is similar to that of New Zealand - 4.14 million as against 4.73 million. Its current death rate from PAS, therefore, provides a fair indication of what could be expected in the longer term if PAS - and PAS only - were to be legalised in New Zealand. There were 31,179 deaths in New Zealand in 2016. If Oregon's most recent death rate from legalised PAS is applied to that figure, that would point to some 124 PAS deaths occurring annually in New Zealand. By contrast, if the death rate in The Netherlands in 2016 from PAS **and** PAE is applied, the result would be 1,247 deaths.

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[8] Another 3.5 per cent resulted from a combination of both PAS and PAE

40. However, another important factor of outturn is the ambit of any 'assisted dying' law. The boundaries of Mr Seymour's Bill are set considerably wider than those of Oregon's law. The latter is restricted to persons with a diagnosed terminal illness and a prognosis of six months or less. The figure of 124 deaths is, therefore, likely to be an under-estimate. It is difficult to make an accurate comparison between Mr Seymour's Bill and Dutch law as the two are expressed in different terms, but overall there would seem to be little difference in ambit between the two, and the experience of The Netherlands probably provides a better guide of longer-term outturn than does that of Oregon.

41. As we have observed above, deaths from both PAS and PAE are a moving target. Occasionally the numbers fall slightly between individual years, but the overall trend, wherever these practices have been legalised, is upwards and there is no sign of any levelling-off. Moreover, though the rise in deaths in Oregon recorded between 2016 and 2017 appears at first sight to be small, the 2017 figure includes only PAS deaths which had been reported to the Oregon Health Authority by the cut-off date of 19 January 2018: it takes no account of 44 persons who received lethal drugs in 2017 but who are categorised by the OHA as 'ingestion status unknown' - ie the Authority had no information at the time of going to press as to whether they had died by ingesting those drugs. The 2017 figure is therefore likely to prove an under-statement.

Doctors

42. The Bill claims to be seeking legalisation of 'assisted dying'. In reality, it is seeking *physician*-assisted dying. It is placing the assessment and decision-making process, as well as its implementation, on the shoulders of doctors. This immediately brings the Bill up against a major problem. In Oregon, after 20 years of legalised PAS, only one in three doctors is willing to consider a request[9]. In the UK, a 2015 survey[10] of 1,000 GPs found that only one in seven would be prepared to consider a request for 'assisted dying' if it were to be legalised. It would be surprising if the situation in New Zealand were significantly different. Even some doctors who say they favour legalisation are not willing personally to provide the service.

43. A result of this medical reluctance is that requests for 'assisted dying' often end up being considered by referral doctors who have not met the applicants before and who have no first-hand knowledge of them as patients. The Bill requires two doctors to assess a request (an *'attending medical practitioner*' and an "*independent medical practitioner*") and it creates a SCENZ (Support and Consultation for End of Life in New Zealand) Group, consisting of doctors who are willing to consider requests. Where a patient's regular doctor refuses to consider a request, he or she may approach the SCENZ Group for the contact details of a willing doctor, who then becomes 'the attending medical practitioner'. Given majority medical reluctance to participate in PAS or PAE, it is likely that both the assessing doctors will in many - if

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[9] Ganzini L, Lessons from Legalized Physician-Assisted Death in Oregon and Washington, in Palliative Care and Ethics, Ed. Quill TE and Miller FG, Oxford University Press, 2014, Page 270

[10] Medeconnect, published May 2015

not most - cases be drawn from the SCENZ Group and that they will have no first-hand knowledge of an applicant as a patient.

44. This raises two issues. Even our regular doctors often know little of us beyond our medical history and what they may pick up in the course of consultations. As medicine become more specialised, the days of the 'family doctor' who knows his or her patients and their families well are in many countries becoming a thing of the past. A referral doctor knows nothing beyond an applicant's case notes. For normal clinical purposes of diagnosis and treatment this is not a problem. But in the case of 'assisted dying' it is of major importance, as the criteria go beyond the medical and into the social sphere. It is important that at least one of the two doctors should have first-hand knowledge of an applicant for 'assisted dying' as a patient over a period of time. Yet in many cases, as the experience of Oregon has shown, this is unlikely to be the case.

45. A doctor who is willing to consider a request for 'assisted dying' is likely to be one of a minority who are supportive of the concept and who may well see PAS or PAE as a rational response to serious illness. To say this is not to impugn the integrity of the individuals concerned. It is to recognise the reality that doctors, like other people, are human beings who have their own perceptions, prejudices and values. This raises the question: could a referral doctor - a doctor chosen for his or her willingness to consider a request for 'assisted dying' - be relied on to bring a sufficient level of challenge to considering an application?

46. The reluctance of most doctors to participate in 'assisted dying' and a reliance on referral doctors leads inevitably to multiple-prescribing. In Oregon in 2017 one doctor wrote no fewer than 29 prescriptions for lethal drugs. The question has to be asked: is the growth if such 'euthanasia practices' in New Zealand acceptable?

47. The SCENZ proposal is an adopted version of Holland's SCEN (Support and Consultation for Euthanasia Netherlands) system. It has one potential advantage - the building up of a core of expertise in the consideration of 'assisted dying' requests. It has the disadvantage, however, of placing persons seeking 'assisted dying' in the hands of doctors who know little or nothing about them as patients.

48. It needs to be recognised that a request for PAS or PAE is essentially a personal or social rather than a medical issue. To the extent that an applicant has a serious medical condition there is an obvious medical dimension. Consideration of such a request needs to be informed by expert advice as to an applicant's diagnosis, prognosis and options for treatment. These are relatively straightforward questions to answer - though, it should be noted, diagnosis and especially prognosis of serious illness are not exact sciences and are subject to error. However, the crucial questions - does the request reflect a settled wish? is depression or are personal circumstances affecting the person's judgement? are there any external or internal pressures affecting the request? - are much harder to judge, and they are personal or social rather than medical in nature.

49. The proper place for such decision-making is the courts rather than the consulting room or hospital ward. The role of doctors in such decision-making is to provide expert advice in regard to the strictly-clinical aspects of a request. Exploring the personal or social dimensions and reaching decisions which balance the rights of individuals against those of society as a whole is the role of the courts - and, given the serious nature of what is proposed, a senior court. A court-based rather than medicine-based assessment and decision-making system not only recognises the true nature of requests for 'assisted dying' and places responsibility where it belongs: it also allows doctors to fulfil their proper role of expert witnesses - a role which they already perform in regard to other cases which come before the courts - rather than judges. In the UK survey referred to above[11], while only one in seven GPs said they would be willing to consider a request for 'assisted dying', nearly two out of five said they would be prepared to supply expert advice on strictly-medical aspects to decision-making by the High Court.

50. The Committee may wish to consider therefore whether, in the event that 'assisted dying' were to be legalised in New Zealand, the responsibility for decision-making should be placed with the courts rather than with doctors and that the role of the latter should be to provide expert advice on one aspect (a patient's clinical state) of an application.

Accountability

51. Section 20 of the Bill proposes the creation of a Review Committee to consider reports of acts of PAS or PAE submitted by doctors via the proposed 'Registrar (Assisted Dying)'. The Review Committee is to "*report to the registrar about its satisfaction or otherwise with the cases reported*" and to "*recommend actions that the registrar may take to follow up cases with which the review committee was not satisfied*".

52. The concept of a review body is a fair one. It is necessary that someone should oversee how doctors are behaving under an 'assisted dying' law. Oregon has no such post-event audit machinery - only forms to be filled in by doctors and sent to the Oregon Health Authority. Mr Seymour's Bill is modelled on The Netherlands, which has five Regional Euthanasia Review Committees (RERCs) charged with reviewing how each reported case of PAS or PAE has been handled and establishing whether it has been within the law. The Dutch RERCs are, however, very light-touch in their approach. In the 15 years of their existence they have passed over 99.5 per cent of cases as being within the law, though many of these are such as to raise eyebrows.

53. Though the concept of a review committee is a fair one, a practical problem arises when it comes to finding suitable individuals to serve on such a body. A review committee is essentially an auditing body. To be effective, audit calls for a sceptical mind-set. For most everyday audit activities this does not present a major problem. Here, however, we are dealing with an issue which is highly divisive and on which there are strongly held views on both sides as to its acceptability. The

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[11] See Paragraph 42

question therefore arises: how are individuals to be found who are sufficiently unencumbered by 'baggage' (on both sides of the debate) to apply objective and searching scrutiny to reported cases of PAS or PAE? It is hard to believe that anyone who has reservations about 'assisted dying' would be willing to serve. It would seem inevitable that a review committee will attract persons who are sympathetic to the concept of 'assisted dying' and who, albeit with the best will in the world, may not bring to the task of auditing the level of rigorous challenge that scrutiny of such life-or-death decision-making requires. The Bill ignores this practical problem: it seems to assume that there is a group of impartially-minded people out there who can be drawn on to review reports of 'assisted dying' objectively and without prejudice. This is not the case.

Penalties

54. The Bill also prescribes what seem to be very lenient penalties for breaches of its terms. Section 27 states that a person who has failed to comply with its provisions is liable to "*a term of imprisonment not exceeding 3 months*" and/or "*a fine not exceeding $10,000*". Given the life-or-death consequences of such a breach of the law, the proposed penalties are little more than a rap across the knuckles.

Conclusion

55. We conclude where we began - that any law to legalise 'assisted dying' must pass two tests. It must demonstrate that the existing law is defective; and, if (and only if) that is so, it must be constructed in such a way as to ensure that it does not put vulnerable people at risk of harm, including self-harm. In our view the Bill does not pass either of these tests. The Committee will wish to reach its own conclusions and this memorandum is submitted in support of that process.

56. We would be willing to provide oral evidence to the Committee if that should be required.

Robert Preston
Director
Living and Dying Well
11 February 2018