IN THE HIGH COURT OF NEW ZEALAND WELLINGTON REGISTRY

CIV-2015-485-235

UNDER

The Declaratory Judgments Act 1908 and

the New Zealand Bill of Rights Act 1990

BETWEEN

LECRETIA SEALES

Plaintiff

AND

ATTORNEY-GENERAL

Defendant

AFFIDAVIT OF DR JOHN KLEINSMAN ON BEHALF OF THE DEFENDANT

May 2015

Judicial Officer: Justice Collins Next Event Date: Hearing commencing 25 May 2015

CROWN LAW
TE TARI TURE O TE KARAUNA

PO Box 2858 WELLINGTON 6140 Tel: 04 472 1719 Fax: 04 473 3482

Contact Person:
Paul Rishworth QC
Email: paul.rishworth@crownlaw.govt.nz

I, John Henry Marinus Kleinsman, PhD, Director of the Nathaniel Bioethics Centre, of Wellington, swear:

- 1. I am the Director of The Nathaniel Bioethics Centre.
- 2. The Nathaniel Centre the New Zealand Catholic Bioethics Centre was established for the purpose of promoting the study and practical resolution of ethical, social and legal issues arising out of medical and scientific research and practice. The Centre is routinely called on to act as an advisory and resource centre in bioethics for individuals and for educational and other community groups.
- 3. I was appointed to the position of Director in May 2010. I have worked as a researcher in bioethics at The Nathaniel Centre since 2001.
- 4. I have a PhD in Bioethics and Moral Theology conferred by the Sydney College of Divinity in May 2013. My Research thesis, titled "The Gift of Life in an Age of Assisted Reproductive Technology" looks at the impact of technology on the societal understanding of procreative responsibility. The various philosophical underpinnings of decision making is an integral part of my doctoral thesis as are the notions of dignity, value of life, freedom, solidarity and moral causality.
- 5. I completed both my Bachelor's Degree and Master's Degree (awarded with distinction) through the University of Otago.
- 6. I am a tutor in CLNR 402: "Ethics and Research in Special Populations as applied to Clinical Research" a paper offered by Victoria University of Wellington. I have designed and lectured in a number of courses on bioethics, moral theology, ethics and leadership since 2000. I was a regular contributor to seminars on bioethics for 5th year medical students at the Otago School of Medicine (Wellington) from 2003 to 2009.
- 7. I have been involved in various ethical review committees since 2001. I am a current member of the ACC Ethics Committee (appointed May 2014). I am a current member of the Families Commission Ethics Committee (appointed October 2007).



- 8. I was a Government appointed member (ethics representative) on the Central Region Ethics Committee from 2004 to 2009. Prior to that I was a member of the Central Region Health and Disability Research Ethics Committee from 2001 to 2004.
- 9. I serve as a member of the Clinical Advisory Committee for the Laura Fergusson Trust an organisation providing specialised rehabilitation services, both residential and community based (appointed March 2013).
- 10. I am a member of the Advanced Care Planning Roundtable, a committee of persons that seeks to promote the concept and practice of advance care planning within New Zealand.
- 11. From 1988 until 1996 I was employed by IHC New Zealand in a variety of roles: Child and Family Support Advocate (IHC Kapiti Branch 1988 to 1991); Community Services Manager, vocational and residential services (IHC Taranaki Branch 1991to 1994); Branch Manager (IHC Southland Branch 1994 to 1996). During the time with IHC I was involved in various national working parties developing policies and good practice. The different roles I had with IHC required that I collaborate closely with other organisations involved in the disability sector, including health services (physical and mental) and psychological services. I have a broad and in-depth understanding of disability issues and the disability sector.
- 12. From 1986 to 1988 I was employed by the National Society of Alcohol and Drug Dependency (NSAD) as a counsellor in their residential therapeutic communities (Featherston, Wairarapa and Plimmerton, Porirua).
- 13. I am a member of the International Association of Catholic Bioethicists as well as the Catholic Moral Theologians Association of Australasia.
- 14. I have had an active research interest in the issue of assisted suicide and euthanasia since 2003. I have written extensively on the topic for New Zealand audiences and presented at numerous public meetings over the years.
- 15. I confirm I have read and understood the Code of Conduct for Expert Witnesses and I agree to comply with it. Further, I confirm any opinions I express in this affidavit are within my areas of expertise and experience.

A A

I have prepared this affidavit to assist the Court in its consideration of the issues raised by physician assisted suicide and euthanasia in the particular context of New Zealand society. My evidence has been prepared under urgency. While I am confident of the correctness of views expressed in this affidavit, I am conscious that had further time been available more resources and informed commentary could have been put before the Court. I am also aware that the urgency meant lack of time to edit and polish: to adopt an old apology, I regret the length of this work, but there was not the time to make it shorter.

17. In this affidavit I address the following:

- 17.1 The framework for considering the proposal to legalise assisted suicide and euthanasia in New Zealand, including the role of bioethics, how to frame the debate and the importance of language.
- 17.2 The concept of autonomy.
- 17.3 New Zealand's narratives of care, including the importance of the Treaty of Waitangi.
- 17.4 The harms to New Zealand that would flow from legalising euthanasia and assisted suicide, and in particular the harm to:
 - 17.4.1 New Zealand narrative of care and to society as a whole;
 - 17.4.2 The relationship of law and ethics;
 - 17.4.3 Vulnerable members of society, with particular focus on the elderly and the terminally ill, and the impact on suicide prevention.
- 17.5 Whether jurisdictions that allow euthanasia or assisted suicide are able to demonstrate that they operate safely without risk to the vulnerable.
- 17.6 Whether there is a consensus for change in New Zealand.
- 17.7 The consistency of the current approach in New Zealand with the majority of other jurisdictions.

A note on the references and exhibits

18. For convenience, copies of the material referenced in this affidavit are collated in a separate bundle, in alphabetical order by author (except for legislative and regulatory reports, which have their own section). I have not included all the material referred to here in the bundle: I have excluded the more peripheral documents and/ or those that can be readily accessed on the internet (urls are provided for these). References that are not in the bundle are noted in the footnotes with the term NE (not exhibited). The bundle of materials (volumes 1, 2 and 3) is exhibit JHMK-1.

The framework

Bioethics

- Bioethics is not the same as medical ethics. Bioethics originates in and encompasses medical ethics and this provides a useful way of understanding its function. The two sides of the doctor/patient relationship are not always equally balanced, and this imbalance can lead naturally to a sense of inferiority on the part of the patient. Looked at like this, the function of medical ethics is usefully described in terms of patient well-being ensuring that the potential superiority of the doctor is not abused. At the same time, the function of medical ethics is to provide "a solid philosophical foundation to which appeals can be made when making moral evaluations". Understood like this, "medical morals dictate the particular actions and beliefs which regulate the day to day judgements of doctors while medical ethics analyse the universal principles on which the decisions are made." Both of these aspects are salient for the case at hand.
- 20. Bioethics on the other hand has been defined as "a central aspect of medicine" concerning "the moral, legal, political and social issues raised by medicine, biomedical research, and life sciences technologies," in addition to its focus on "ethical issues relevant to clinical care." Commentators distinguish between three broad spheres of bioethics. The first is academic bioethics focusing primarily on how theoretical and practical aspects of medicine affect considerations such as special obligations or responsibilities of clinicians, what is valuable, good, right, etc. The second is public policy and law bioethics,

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JK. Mason and RA McCall Smith, Law and Medical Ethics (London, Dublin, Edinburgh: Butterworths, 1994) p. 3.

² Ibid pp. 5-6.

where concerns lie in how legal and extra-legal institutions can and should be involved in the regulation of clinical and research practices. The final sphere is clinical ethics which is directly related to helping improve patient care.³

21. The reality of dying, death, suffering and disease, the question of the value of human life in the face of this reality, and the problem of finding practical responses to this reality that are right or good or wise, are long standing issues for bioethics.

Framing the debate

- 22. Going back to the 13th century, Thomas Aquinas defended the prohibition against suicide on three grounds:⁴ (1) suicide is contrary to natural self-love, whose aim is to preserve us; (2) suicide injures the community of which an individual is a part; and (3) suicide violates our duty to God because God has given us life as a gift and in taking our lives we violate the divine right to determine the duration of our earthly existence.
- Of course, if suicide ought to be prohibited then assisting someone to suicide ought to be prohibited. Societal attitudes to suicide and homicide, and consequently the laws surrounding these matters, have undoubtedly been informed by, and trace their roots back to, the religious traditions of the Abrahamic faiths Judaism, Christianity and Islam.
- 24. For many centuries, and up until quite recently, the consensus position has been that assisted suicide and euthanasia are morally wrong, ethically wrong (prohibited under codes of professional medical ethics) and illegal. Obviously, this consensus is being challenged in some liberal democracies. The availability of euthanasia and/or assisted suicide in a small number of jurisdictions, most notably Switzerland, the Netherlands, Belgium, Luxemburg and in the states of Oregon, Washington and Vermont, is a reflection of the challenge to this consensus as well as a stimulus for on-going debates.
- 25. Many people have a perception of the long-standing religious influences on the legal status quo. Equally, it is often noted that part of the articulated resistance to a law change comes from those who remain connected to the various

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PA. Singer and AM. Viens, "Introduction," in *The Cambridge Textbook of Bioethics*, ed. PA. Singer and AM. Viens (Cambridge: Cambridge University Press, 2008) p. 1.

⁴ Aquinas 1271, part II, Q64, A5. NE

religious traditions. For this reason, many in our secular society see euthanasia and assisted suicide as an explicit rejection of a religious viewpoint, and seek to label those who argue against change as espousing a religious position no matter what their arguments. The truth is actually far more complex than this. The debate involves, among other things, the post-Enlightenment shift to a new world view and understanding of the person, such that there are now competing worldviews or narratives and understandings of the human person at stake.

- The debate about assisted-suicide and euthanasia is very much a debate about the adequacy and supremacy of differing worldviews or narratives, differing assumptions about human flourishing and different understandings of the human person. That this is the case is sometimes less than obvious for the fact that persons engaged in debating this issue use the same notions and terms (such as autonomy and dignity) without necessarily realising that they may mean different things. A particular feature of bioethics, as noted above, is its willingness and ability to tease out the solid philosophical foundations underpinning the different ways of making sense of the world that lead inevitably to differences in opinion about what is the right thing to do.
- While the discipline of modern day medical ethics has its roots firmly in the institutional expressions of hospitality and care offered by religious orders down through the centuries, it is now regarded as a secular discipline in its own right. Similarly, the relatively 'new' discipline of bioethics (1970s) is able to sustain its own arguments around end-of-life issues in a way that reflects its independence from religion while tolerating, and indeed being enriched by, the range of 'faith' positions from atheist to religious and everything in between that those who engage in this sphere bring to their deliberations.
- 28. I wish to make it plain that the evidence, argument and reasoning in this affidavit does not rely on religious commitments or premises. That rules out Aquinas's third ground. However, Aquinas' second ground, updated, has a prominent place.

J. J.C.

Language

- 29. Bioethics, influenced and connected as it is with philosophy, is always concerned with language and understanding and the intellectual frameworks that shape meaning. For that reason, attention to language is a logical first step.
- 30. The framing of a debate is of critical importance because it is the process by which we provide background meaning and structure the meaning of events particularly social ones.⁵ The most fundamental way in which we do this is linguistically. The language we draw on to define the key issues in a debate is critical because: "The categorisation of words creates instant bias toward one interpretation or another. Thus the words we choose not only reflect what we are trying to say, but also control meaning in and of themselves." From an ethical perspective, unambiguous and precise definitions are an essential first step in the process of critically analysing a practice.
- In the first statement of claim dated 20 March 2015 Ms Seales asked for orders for "physician assisted suicide" and "physician assisted death". In the second statement of claim dated 20 April 2015 the terminology (although not the defined meaning in the schedule to the document) was changed. Ms Seales' lawyers now use the terms "facilitated aid in dying" and "administered aid in dying" to refer to 'assisted suicide' and 'euthanasia' respectively. These terms do not represent common usage⁸ and nor (to the best of my knowledge over many years in addressing this issue) are they are recognised in the ethical, medical or legal literature.
- 32. These terms appear to be euphemisms, defined in the Concise Oxford Dictionary as the substitution of a mild or vague expression for one thought to be too harsh or blunt. The terms lack precision and clarity and are unhelpful in terms of the task of critically analysing the practices they supposedly refer to, not least because palliative physicians and others who provide care for patients at the end of life routinely facilitate and administer aid to those who are dying

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E. Goffman, Frame Analysis: An Essay on the Organisation of Experience (New York, Evanston, San Francisco, London: Harper Colophon Books, 1974)., quoted in M. Vamos, "Physician-assisted suicide: Saying what we mean and meaning what we say," Australian & New Zealand Journal of Psychiatry 46, no. 2 (2012).

Vamos, M. "Physician-Assisted Suicide: Saying What We Mean and Meaning What We Say." *Australian & New Zealand Journal of Psychiatry* 46, no. 2 (2012).

See DP. Sulmasy, "Killing and allowing to die: another look.," Journal of Law and Medical Ethics 26(1998).. See also KL. Tucker and FB. Steele, "Patient choice at the end of life: getting the language right," Journal of Legal Medicine 28, no. 3 (2007).

A Google search throws up no other usage of these terms save in the current case – Seales v Attorney General.

as part of their responsibility to provide such care; the sort of care that neither hastens nor postpones death.

- 33. Bioethicist Daniel Callahan describes the use of such terms as "organized obfuscation". The mischief is well demonstrated by a recent survey in Canada, (2013) carried out by Ipsos Marketing to assess what was understood by people asked about 'medical aid in dying' in the context of debates about the level of public support for euthanasia and physician assisted suicide. This survey showed one third of Quebecers interpreted the phrase 'medical aid in dying' as being a patient's request for lethal injection by a medical professional, while nearly 30% understood that it meant relieving symptoms through palliative care. Finally, nearly 40% of those surveyed associated it with a discontinuation of intensive medical treatment and assisted suicide.
- 34. The authors concluded: "It is therefore essential to clarify applicable terms and tangibly convey the true definition of euthanasia, and avoid using even vaguer expressions such as 'medical aid in dying'."
- I will, throughout this affidavit use the terms 'assisted suicide' and 'euthanasia' (and physician assisted suicide, where appropriate). These terms are well understood by the public and professionals alike and have the advantage of not blurring the critical practical and ethical distinction between what is currently ethical and legal (palliative care) and that which is unethical and currently illegal in New Zealand (assisted suicide and euthanasia).

What euthanasia and assisted suicide is (and is not)

A useful definition of the terms euthanasia and assisted suicide is recommended by the European Association for Palliative Care (EAPC) Ethics Task Force (2003): "Euthanasia is killing on request and is defined as: A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request. Physician-assisted suicide is defined as: A doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request." As well as being voluntary, acts of euthanasia may be non-voluntary (where the

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Ipsos Marketing, "Survey among the Canadian population about end of life issues," (Canada: Ipsos Marketing, 2013) p. 5.

European Association for Palliative Care Ethics Task Force. "Euthanasia and Physician-Assisted Suicide: A View from an Eapc Ethics Task Force." *Palliative Medicine* 17 (2003).

person is incapable of providing consent) or involuntary (where consent was capable of being given but not sought or not given).

- Health Professionals are not obliged to do everything possible to keep a person alive at all costs (vitalism). It is both bad medical practice and unethical to provide care to persons that is futile or when it is of limited benefit. Thus, health professionals often find themselves in a position of either withholding or withdrawing treatment. These actions are ethically distinct from acts of omission that constitute an intentional refusal to provide the necessaries of life as set out in Section 151 of the Crimes Act 1961, that is, acts that are carried out with both the intention and knowledge that a person will die. This distinction has been long recognised by the medical profession.
- 38. The ethicists Boudreau and Somerville note that the distinction is a workable one that health professionals make routinely, based on the circumstances in which an intervention is used and the precise nature of the intervention. "For instance, if a patient's symptoms can be controlled without sedation, yet they are sedated, and especially if the patient is not otherwise dying and food and fluids are withheld with the intention of causing death, this is clearly euthanasia." They further note: "Needing to discern the intention with which an act is carried out is not unusual. ... intention is often central in determining the ethical and moral acceptability of conduct, in general."
- 39. The EAPC Ethics Task Force notes: "None of the following should be seen as euthanasia ...:
 - withholding futile treatment;
 - withdrawing futile treatment;
 - -`terminal sedation' (the use of sedative medication to relieve intolerable suffering in the last days of life).
- 40. In explaining the notion of palliative sedation, the EAPC Ethics Task Force further underline the critical role of intention. "In terminal sedation the *intention* is to relieve intolerable suffering, the *procedure* is to use a sedating drug for symptom control and the successful *outcome* is the alleviation of distress. In

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JD. Boudreau and MA. Somerville, "Euthanasia is not medical treatment," *British Medical Bulletin* 106(2013), p, 3.

euthanasia the *intention* is to kill the patient, the *procedure* is to administer a lethal drug and the successful *outcome* is immediate death."¹²

- 41. The distinctions noted above are long-standing ones and are well accepted within the medical profession. In New Zealand and Australia it is wellarticulated within the ANZSPM Position Statement (2013) on The Practice of Euthanasia and Assisted Suicide: "(3) Good medical practice mandates that the ethical principles of beneficence and non-maleficence should be followed at all times. The benefits and harms of any treatments (including the provision of medically assisted nutrition and/or hydration) should be considered before instituting such treatments. The benefits and harms of continuing treatments previously commenced should be regularly reviewed. Withholding or withdrawing treatments that are not benefitting the patient, is not euthanasia. (4) Treatment that is appropriately titrated to relieve symptoms and has a secondary and unintended consequence of hastening death, is not euthanasia. (5) Palliative sedation for the management of refractory symptoms is not euthanasia."13 The withdrawing of treatment allows the person to effectively 'return to their dying'.
- Assembly held in Washington in 2002 in its position statement on euthanasia, the ethical stance taken with respect to euthanasia "does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness." The WMA Statement on Physician-Assisted Suicide, adopted by the 44th World Medical Assembly, Marbella, Spain, September 1992 and editorially revised by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005 likewise states: "Physicians-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession ... However the right to decline medical treatment is a basic right of the patient and the physician does not act unethically even if respecting such a wish results in the death of the patient."

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European Association for Palliative Care Ethics Task Force, "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force," *Palliative Medicine* 17(2003), p. 99.

ANZSPM "Position Statement on The Practice of Euthanasia and Assisted Suicide," http://www.anzspm.org.au/c/anzspm?a=da&did=1000948&pid=1383782594. NE

See http://www.wma.net/en/30publications/10policies/e13b/ NE

The concept of autonomy

- 43. The value of "autonomy" is often used to support physician assisted suicide as if this were a single unproblematic concept with a universally accepted meaning. See, for example, the Supreme Court of Canada in *Carter* at [2] where the Court frames the problem as balancing two "competing values of great importance"; the first, and the one clearly favoured by the Court, being "the autonomy and dignity of a competent adult".
- 44. Autonomy however, is not a univocal concept and has been understood in a number of different ways. The entry on "Personal Autonomy" in the *Stanford Encyclopaedia of Philosophy*, for example, has four accounts of autonomy.¹⁵
- 45. Autonomous persons are self-governing persons who are at the same time social beings existing in relationship with others and the world. The conceptual problem of autonomy turns on how to properly understand the complexity of that relationship.
- When it is used to support arguments in favour of legalising euthanasia and physician assisted suicide, the conceptual understanding that lies behind the use of the notion typically draws on just one such account although that is rarely acknowledged that relies on a particular set of (largely unquestioned) assumptions about the nature of values and rights. That account is then typically used to frame the debate in a way that effectively pits autonomy against notions such as the sanctity or inherent value of life or impact on the 'common good'. The Carter decision in Canada is a good case in point: "On the one hand stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable." 16
- 47. Ethically speaking this is both inaccurate and unhelpful in terms of a robust analysis. It amounts, analogously speaking, to saying that one side of the euthanasia debate has the monopoly on 'dignity' or 'compassion' when what is really at stake is different understandings of these concepts reflecting different worldviews or narratives. Noting that "the concept of autonomy now

J.K.

Buss, Sarah, "Personal Autonomy", The Stanford Encyclopedia of Philosophy (Winter 2014 Edition), Edward N. Zalta (ed.), URL = http://plato.stanford.edu/archives/win2014/entries/personal-autonomy/NE

¹⁶ Carter v Canada [2015] SCC 5 https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do. NE

pervades the whole of medical practice mirroring its general importance in contemporary moral philosophy" Mason and McCall Smith speak of "one view" of autonomy that "depends on the acceptance of an individualistic ethos which all may not share."¹⁷ In this account autonomy has come to mean that a person is entitled to do whatever they want and the self stands apart from the community and essentially knows no limits.

- 48. Mason and McCall Smith describe an alternative vision of autonomy qualified by the legitimate interests and expectations of others, one that includes a social dimension to life which is potentially enriching for the individual person. ¹⁸ In this alternative account of autonomy there is room for denying self-determination to others, including those whose determination to access assisted-suicide or euthanasia may be totally voluntary in the fullest sense of the word (truly 'volunteers'). ¹⁹
- 49. The current bias within our society towards an account of autonomy that draws on an individualistic ethos, and the associated problems associated with this account, are identified and affirmed by the Harvard philosopher Michael Sandel: "When science moves faster than moral understanding as it does today, men and women struggle to articulate their unease. In liberal societies, they reach first for the language of autonomy, fairness, and individual rights. But this part of our moral vocabulary does not equip us to address the hardest questions."²⁰

Choice is not the same as autonomy

50. Choice and autonomy are often, mistakenly, equated with each other. This is a mistake because it does not necessarily follow that enhanced autonomy flows out of increased choice. As Katrina George notes in an article exploring the gendered risks of euthanasia, it is not a matter of being incapable of deciding within a particular context but a matter of determining the real autonomy of people's decisions for death – a question of "how much real value, worth and

¹⁷ Mason and McCall Smith, Law and Medical Ethics p. 6.

¹⁸ Ibid

¹⁹ Ibio

M. Sandel, The case against perfection: Ethics in the age of genetic engineering (Cambridge, Massachusetts, USA: Belknap Press, 2007) pp. 9-10.

power these so-called choices have."²¹ Choice can be conformity when people "have little ability to determine the conditions of consent."²²

- Thus, while the legal availability of euthanasia or assisted suicide, should it come about, would rightly be described as an expansion of the legal choices currently available to persons in New Zealand, the key question that needs to be considered from an ethical perspective is the extent to which creating this new legal space will enhance or undermine real autonomy for all or some people. That is, the ability to make a choice, including whether a person possesses the legal competency to make a choice, is no guarantee that they are able to act in an autonomous way.
- 52. In other words: "The emphasis on an autonomous individual, free to choose ... irrespective of the life situation, is ... an ideal concept that does not always apply to the life situation of the terminally ill patients."²³

We all make choices within a historically, culturally and socially conditioned context

Grisso and Appelbaum (1998) emphasise the importance of context for persons coming to an informed decision about their medical situation: "The doctrine of informed consent has evolved over time to include three elements: 'disclosure of information by clinicians, within a context that allows for voluntary choice, made by a patient who is competent to decide." George, noting that the concept of increased choice has particular resonance with women who have historically struggled to win choice in their lives and control over their bodies, argues that there are "underlying forces which might animate women's decisions for death". These include "structural inequalities and disparities in power – most evident in women's experience of violence – and social and economic disadvantage and oppressive cultural stereotypes that idealise feminine self-sacrifice and reinforce stereotyped gender roles of passivity and compliance."

J.M.

²¹ K. George, "A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide," *Medical Law Review* 15, no. Spring (2007) p. 2.

Ibid p. 2. While George's comments are made specifically in the context of a discussion about the implications of legal assisted suicide and/or euthanasia for women, the insight is a generally applicable one.

W. Stronegger et al., "Changing Attitudes towards euthanasia among medical students in Austria," *Journal of Medical Ethics* 37, no. 4 (2011) p. 228.

Quoted in BM Sorger, "Decision-making capacity in terminally-ill cancer patients", ETD Collection for Fordham University (2005), http://fordham.bepress.com/dissertations/AAI3169403.

George, "A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide." p. 1.

²⁶ Ibid p. 2.

- While, as already noted, George's comments are made as part of a discussion about the impact of euthanasia and assisted suicide on women, the insight is generally applicable for all people who, for whatever reason, find themselves in a situation of disparity in power and social disadvantage. People with life-limiting illnesses and disabilities fit, without doubt, into such a category.
- 55. If you add to this the well-documented evidence that the impulse towards suicide is often ambivalent, sporadic, and influenced by mental illnesses such as depression,²⁷ there is justifiably very little confidence in the notion that that suicide is ever an exercise of autonomy.
- Canadian Physician René A. Leiva (MDCM CCFP) articulates well some of the underlying forces that characterise end-of-life decision making: "The troubles of human relationships within families become accentuated, and problems of physician error and abuse in an already stressed medical system abound. It would be difficult to ensure that the choice of suicide is freely made and adequately informed." All of which leads him to reiterate: "Amid these overwhelming fears, a free, autonomous decision about euthanasia is an illusion."

Assisted suicide and euthanasia are not acts of autonomy under any definition

Even putting aside the issue of true freedom of choice, assisted suicide and euthanasia, by their very nature, do not fall within any valid definition of autonomy in any event. As philosopher and bioethicist Daniel Callahan (PhD) points out: "Euthanasia is not a private matter of determination. It is an act that requires two people to make it possible, and a complicit society to make it acceptable." This highlights the social nature of such decisions. From an ethical perspective, both assisted suicide and euthanasia are most accurately described as acts of 'state-sanctioned killing'. It is logically incoherent, therefore, to argue that access to assisted suicide or euthanasia should be justified on the basis of individual choice when they require both the assistance of another or others and the authorisation of the state by way of an appointed

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²⁷ Cholbi, Michael, "Suicide", *The Stanford Encyclopedia of Philosophy* (Summer 2013 Edition), Edward N. Zalta (ed.), URL = http://plato.stanford.edu/archives/sum2013/entries/suicide/>. NE

R. Leiva, "We can do better than euthanasia—we must," Canadian Family Physician 56, no. 6 (2010).

D. Callahan, "When Self-Determination Runs Amok," in *Bioethics. An Anthology*, ed. Kuhse H and Singer P (Malden, MA: Blackwell Publishing, 2006).

'gate-keeper', whether that be a health professional or some other statesanctioned agent.

- In blunt terms, the proponents of euthanasia and assisted suicide based on the concept of autonomy take the already problematic proposition that autonomy means that a person is entitled to do whatever they want, and take it a step further. Their proposition is that the state's refusal to provide a person with something that they want becomes a denial of their freedom of choice, a denial of their right to autonomy.
- 59. The fallacy is obvious: if the exercise of my autonomy requires someone else to provide the option for me, then what is at issue is not my right to choose, but my 'right' to demand something from someone else. This is nothing to do with autonomy: it is to do with imposing my will on others and forcing another to accede to my wishes.
- Given that suicide is not prohibited in New Zealand, Ms Seales' claim is more properly seen as a claim for access to a privileged *means* of suicide: she is not asking just to have a lay person help her without fear of prosecution. Rather, she wishes to have access to drugs that are otherwise carefully controlled, and the comfort of medical involvement either at the prescribing stage (for physician assisted suicide) or at the time of administration of the drugs (for euthanasia). From the 'liberty' of suicide (although noting the considerable resources devoted to suicide prevention), we would move to a 'right' to have the state (and by implication society) condone and actively assist a person to take their own life in the manner of their choosing.

New Zealand's narrative(s)

61. Healthcare, like many other facets of our lives, is pervaded by metaphor and narrative. "Metaphor is shown to reflect and generate narratives related to what health is, what affects health and what can be done to improve health ... Metaphor and narrative are powerful constructs with positive and negative actual and potential outcomes." More specifically, our own perception of ourselves and our embodied place in the world is "continually created and

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See J. Talley, "Metaphor, Narrative, and the Promotion of Public Health," Genre 44, no. 3 (2011).

renegotiated through social and cultural agents, and shaped by the verbal and visual narratives individuals, families and institutions generate."³¹

This means that the concept of "illness narratives" must be thought about in an *active* way "as something collaboratively constructed by individual and collective voices, in the conversations between selves and culture." It follows from this that there are different narratives, different less because of our individual make-up and more because of our disposition towards a particular over-arching or 'master' narrative.

Clashing narratives

- In the New Zealand context, the dominant narrative is a 'Western' or 'Eurocentric' one, characterised by a strongly individualistic notion of the human person and the elevation of (a particular understanding of) autonomy and the closely related value of free choice. Commenting on this, and labelling it as a "reductive account of personhood", Lynne Bowyer of the Otago Bioethics Centre expands on its meaning: "an individual is said to be autonomous when she can make self-interested choices based upon her capacity for rational reflection, understood as a calculating, prudential activity that is unimpeded by the choices and actions of others."³³
- Also recognising the fact that the Western cultural tradition has privileged reason, reflection and individualism as important markers of identity, New Zealand psychiatrist Dr Chris Perkins notes: "Not all societies or all people in Western society hold the 'hypercognitist', individualistic view. We are more than our own, isolated, brains ... This [alternative] world view reminds us that humans are social creatures and our place in society is not just related to our personal efforts; we are part of a greater whole. Our community very much defines and identifies us."³⁴
- One of the deepest political debates lies in considering the proper relationship between the individual and the community in which they live. It is important to recognise there is a continuum of responses, not a simple binary choice, and

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M. Stoddard Holmes, "Embodied Storytellers: Disability Studies and Medical Humanities," Hastings Center Report 45, no. 2 (2015) p. 11.

³² Ibid p 14.

L. Bowyer, "Autonomy and dementia: what has been left unthought," The Nathaniel Report, no. 37 (2012) p. 5.

³⁴ C. Perkins, "Dementia, identity and spirituality," The Nathaniel Report, no. 36 (2012) p. 6.

that the particular response is significantly affected by the cultural context. Maori and Pasifika, for example, tend towards a community response, whereas Western political thought often emphasises an individualistic view. Even in the latter, however, it is important to acknowledge the range between starkly libertarian views of the autonomy of the hypercognitive individual, through nuanced versions of balancing individual and community rights and responsibilities, to a predominantly collective response. As discussed below, the vast majority of Western liberal democracies that have considered the balance between individual and community interests in this issue have upheld the community's overarching interest in prohibiting euthanasia and assisted suicide.

- 66. New Zealand researchers Malpas, Mitchell and Johnson confirm the existence of a strongly individualistic approach as well as more collectivistic approaches within New Zealand in a recent study which concludes, among other things, that the fear of becoming a burden is a significant motivating factor for those who support the availability of assisted suicide and euthanasia. They write: "It is important to note that all our participants identified as being of European descent. Thus we were unable to explore some of the particular issues of significance that may have arisen in the context of end of life decision-making for people who may have very different outlooks around dying and death. For instance, in communities where members have a more collectivist approach towards how decisions are made across the life span (as opposed to more individualistic approaches), support for medical hastening of death may be viewed very differently." ³⁵⁵
- As evidence of this, Malpas et al refer to an American study that "found that White older adults were more likely than Black older adults to discuss burden". They then conclude that the expression and meaning of burden differs according to ethnicity; "burden is expressed in different ways and

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P. Malpas, K. Mitchell, and MH. Johnson, ""I wouldn't want to become a nuisance under any circumstances"—a qualitative study of the reasons some healthy older individuals support medical practices that hasten death," New Zealand Medical Journal 125, no. 1358 (2012), emphasis added.

See Cahill E, Lewis LM, Barg FK, Bogner HR. You Don't Want to Burden Them. Journal of Family Nursing 2009; 15(3):295-317.

meanings that sometimes correspond to the experiences of particular ethnic groups".³⁷

- It is certainly the case that when people of a Māori or Pasifika cultural heritage speak out in opposition to assisted suicide and euthanasia, their views are anchored in very different understandings of the person, of the place of the elderly in society and of the obligation to show care to the sick and disabled than is presented through the dominant and reductionist Western paradigm. Thus, for example, Amster Reedy writes: "We bring people into this world, we care for them right from the time they are conceived, born, reared, in health, sickness and in death. The rituals still exist for every part of our lives we just need to have faith in our ancestors. Euthanasia is foreign to Māori and has no place in our society." 38
- Reedy's comments are an illustration of Stoddard Holme's insight that the recognition of community in a person's narrative can dismantle "the isolation of being ill". The same insight is a feature of the thinking of the Tokelauan, Samoan and Cook Island Pasifika groups. As Penehe Patelehio writes: "When someone is ill or dying, the idea of assisted-suicide or euthanasia is entirely foreign to us. There is no word in our language for this concept and consequently it does not enter into our thinking. The opportunity to care for and look after someone who is ill or dying/suffering is seen as a blessing even though it may present significant financial and other challenges. At such times the extended family and community networks come to the fore it is common for immediate and extended family and community members to visit, provide food, and massage and converse with the person who is ill. No-one would ever be left to die alone. Supporting the family and the person concerned through ongoing daily practical and emotional support enables the sick person to find

Malpas, Mitchell, and Johnson, ""I wouldn't want to become a nuisance under any circumstances"—a qualitative study of the reasons some healthy older individuals support medical practices that hasten death.".

Amster Reedy - Maori Tikanga Expert - Te Kawa of Marae (expert in ancient Maori rituals), Pukenga (many skills) Tohunga (teacher of Maori rituals) and Kaumatua (respected elder). At the forefront of Maori philosophy and as an expert in ancient Maori rituals, Amster provided advice to public and private sector agencies on tikanga, protocols and practices for over 20 years. Amster's iwi affiliations are with Aitanga-a-Mate; Putaanga; Tuwhakairiora; Uetohatu and Ngati Porou. (Personal communication with Dr John Kleinsman, Wednesday 16 November, 2011). NE

³⁹ Stoddard Holmes, "Embodied Storytellers: *Disability Studies and Medical Humanities.*", p. 12 (emphasis added).

ways to feel better and achieve the best possible quality of life during the latter stages of their life journey."⁴⁰

- Conversely, other narratives constructed to make sense of illness and disability may exacerbate the isolation of being ill, and it is my view that the contemporary Western tradition's account, which envisions illness and disability as essentially an individual tragedy, 41 does exactly this. The growing sense of social isolation being experienced by significant numbers of New Zealanders who are elderly is a sure expression of this. For example, the Auckland results of the New Zealand Longitudinal Study of Ageing (2012) show that over half of those questioned were lonely and nine percent described themselves as "severely" or "very severely" lonely.42
- 71. Within New Zealand, the existence of the traditional Māori and Pasifika narratives, expressed by the likes of Reedy and Patelehio, alongside the hypercognitist individualist perspective that sometimes characterises the dominant Western narrative, highlights a significant cultural clash. This should be seen as a critical issue when contemplating the wider societal impacts of making assisted suicide and/or euthanasia legally available in New Zealand.
- 72. To fail to take this into account would be to unilaterally privilege, after limited legal argument drawn mostly from Western philosophical and legal paradigms that (over) emphasise the idea of autonomy, a narrative around illness and care that clashed with the cultural understanding and practices of significant numbers of New Zealanders; a narrative that would undermine their rightful tikanga as well as potentially exposing those significant numbers of elderly who are already identified as 'lonely' to an *increased risk* of premature death by sanctioning suicide as a way of dealing with suffering and so making it more easily available and seemingly morally desirable.

The Treaty

73. In light of the Treaty of Waitangi principles of partnership, protection and participation, there must be serious concerns with a proposal to effect such a

P. Patelehio, "Euthanasia: A Pacific Island (Tokelauan/Samoan/Cook Island) perspective," *The Nathaniel Report*, no. 37 (2012), p. 8.

See Stoddard Holmes, "Embodied Storytellers: Disability Studies and Medical Humanities." p. 14.

See C. Waldegrave, P. King, and E. Rowe, "Aucklanders 50 and over: A health, social, economic and demographic summary analysis of the life experiences of older Aucklanders," (Auckland: Auckland Council, 2012) pp. 66-67.

significant change to the New Zealand medical and legal environment, when the rationale for such a change reflects a particular Western and individualistic narrative of human 'being' that conflicts with a traditional Māori cultural worldview.

- As noted above, a specifically Māori understanding is that persons are defined essentially through their relationships within and between their whanau, hapu and iwi; that is, as part of a community. This understanding is enshrined in a number of reports and has shaped a number of key social policies in New Zealand. For example, the preface to Puao-Te-Ata-Tu (The Report of the Ministerial Advisory Committee on a Māori Perspective for the Department of Social Welfare, 1988),⁴³ reads: "At the heart of the issue is a profound misunderstanding or ignorance of the place of the child in Māori society and its relationship with whānau, hapū, iwi structures".
- Puao-Te-Ata-Tu had a major influence on the development of the Children, Young Persons, and Their Families Act 1989 (CYPF Act). The Act includes the principles that, wherever possible: a child's or young person's family, whānau, hapū, iwi, and family group should participate in the making of decisions affecting that child or young person, and accordingly that, wherever possible, regard should be had to the views of that family, whānau, hapū, iwi, and family group"; and "the relationship between a child or young person and his or her family, whānau, hapū, iwi, and family group should be maintained and strengthened." The significance of this quote for the present issue is perhaps made more obvious if, in the preceding quote, the word 'child' is replaced with the word 'person', however the meaning is clear even without doing so.
- Of course, it is far from clear how a change to the law on assisted suicide and euthanasia that is argued on the basis of a particularly individualistic notion of the person would impact at the cultural level on the Māori collectivist understanding of the person. But that is the very point. To contemplate such a change in practice without proper consultation and reflection on the

See https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/archive/1988-puaoteatatu.pdf at p 7. NE

⁴⁴ See http://www.superu.govt.nz/web/māori-children-whānau/mauri-ora_cultural-identity.html

Children, Young Persons and Their Families Act 1989, section 5.

implications for Māori would amount to what Puao-Te-Ata-Tu defines as "the most insidious and destructive form of racism ... the outcome of monocultural institutions which simply ignore and freeze out the cultures of those who do not belong to the majority ... [the evolution of] National structures ... which are rooted in *the values systems and viewpoints of one culture only*". ⁴⁶

HARM

Assessing the 'risks' and 'benefits' and weighing them up is a standard approach to choosing between different options, and risk assessment lies at the heart of moral and ethical discernment. In ethical theory this generally involves a tension between the principles of beneficence and non-maleficence – doing good and avoiding harm. Careful consideration of the real and potential 'harms' is critical to a decision about the safety or otherwise of implementing a regime that allows euthanasia and/or assisted suicide.

Harmful narrative of care

- 78. I have outlined above the complex and diverse narratives of care in New Zealand, and noted that arguments in support of a change to the law on assisted suicide and euthanasia rely on a reductionist individualistic narrative.
- 79. From a bioethical perspective, the debate is appropriately defined in terms of a choice between two different narratives of care essentially a choice between two very different visions regarding the place of the elderly, the sick and the disabled in New Zealand society.
- 80. There is a widespread conception that pain is the main reason the terminally ill seek to hasten death, but research evidence indicates that it is less for reasons of inadequate pain relief that patients request euthanasia or assisted suicide but rather for reasons related to psychological and social concerns. These include depression,⁴⁷ feelings of hopelessness,⁴⁸ of disintegration and loss of

At paragraph 46, emphasis added.

Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al., "Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer," JAMA, (2000), 284:2907-11; Emanuel EJ, Fairclough DL, Daniels ER, et al., "Euthanasia and physician-assisted suicide: Attitudes and experiences of oncology patients, oncologists, and the public," Lanet, (1996), 347:1805-1810; Wilson KG, Chochinov HM, McPherson CJ, et al., "Desire for Euthanasia or Physican-Assisted Suicide in Palliative Cancer Care," Health Psychology (2007), Vol. 26 No. 3, 314-323; Van der Lee M, van der Bom JG, Swarte NB et al., "Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients," Journal of Clinical Oncology, (2005), Vol. 23 No. 27; Ganzini L, Goy ER, Dobscha SK, "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey," BMJ, (2008), 337: a1682; Smith KA, Harvath TA, Goy ER, Ganzini L, "Predictors of Pursuit of Physician-Assisted Death," Journal of Pain and Symptom Management (2015), Vol. 49 No. 3.

community, ⁴⁹ loss of dignity, ⁵⁰ loss of autonomy and ability to participate in activities that made life enjoyable, ⁵¹ and of being a burden to others. ⁵² The particular significance of the fear of being a burden as a reason for supporting "medical practices that hasten death" for "healthy older New Zealanders" is highlighted in studies by Malpas et al and McLeod. ⁵³

- This knowledge is not at all contentious. The pro-euthanasia doctor, Rob Jonquiere, who has recently toured New Zealand and who is described by the Voluntary Euthanasia Society as a "world expert", a "principal architect of the Dutch euthanasia legislation" and "one of the world's leading campaigners" for euthanasia and assisted suicide" readily admits that "the problem is not so much physical, but social and emotional." Explaining that further, he is on record as saying: "The elderly have feelings of detachment ... The elderly have feelings of isolation and loss of meaning. The elderly are tired of life ... Their days are experienced as useless repetitions. The elderly have become largely dependent on the help of others, they have no control over their personal situation and the direction of their lives. Loss of personal dignity appears in many instances to be the deciding factor for the conclusion that their lives are complete."
- 82. There is for me no other way to put this. Such attitudes to the elderly, not to mention those with disabilities, are quite simply offensive to many New

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Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA, "Attitudes of Patients with Amyotrophic Lateral Sclerosis and their Care Givers toward Assisted Suicide," *The New England Journal of Medicine*, (1998), Vol. 339 No. 14.; Chochinov HM, Wilson KG, Enns M, Lander S., "Depression, Hopelessness, and Suicidal Ideation in the Terminally Ill," *Psychosomatics*, (1998), Vol. 39 No. 4; Breitbart et al., op cit.

Lavery, JV, Boyle J, Dickens BM, Maclean H, Singer PA, "Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study," *Laneet*, (2001), Vol. 358, 362–367; Oregon Public Health Division, *Oregon's Death with Dignity Act*—2014, Table 1 at 5

http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/

Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M, "Dignity in the terminally ill: a developing empirical model," Social Science & Medicine, (2002), Vol. 54, Issue 3.

Oregon Public Health Division, Oregon's Death with Dignity Act—2014, Table 1 at 5 http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/.

Wilson et al., op cit; Oregon Public Health Division, *Oregon's Death with Dignity Act*—2014, Table 1 at 5 http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/.

See: Malpas, P, K Mitchell, and M Johnson. "I Wouldn't Want to Become a Nuisance under Any Circumstances' - a Qualitative Study of the Reasons Some Healthy Older Individuals Support Medical Practices That Hasten Death." New Zealand Medical Journal 125, no. 1358 (2012): 9-19; and McLeod, S. "Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician's view" Australian & New Zealand Journal of Psychiatry, 46(10), 936–945: "Contrary to what may have been predicted (and is perhaps assumed by the general public), people request assisted dying, if they have the legal opportunity to do so, because of psychosocial, and not physical, symptoms." (at 939)

See http://www.ves.org.nz/, accessed 1 May, 2015. NE

See Jonquiere, R. Fourth Annual Lecture to the Society for Old Age Rational Suicide, London, September 20, 2013 http://www.soars.org.uk/index.php/pages, accessed 2 March 2015.

Zealanders, in particular the tangata whenua and other Polynesian people. Jonquiere's comments and attitudes are, however, consistent with the inherent logic of the particularly individualistic narrative upon which the case for assisted suicide and euthanasia is typically constructed.

- 83. Jonquiere's 'compassionate' response to this is to advocate even more vociferously for these people to have the right to die. "The conclusion that life is completed is reserved exclusively for the concerned persons themselves ... They alone can reach the consideration whether or not the quality and value of their lives are diminished to such an extent that they prefer death over life." All of which leads him to the conclusion that it is "never for the state, society or any social system" to question or otherwise interfere in such a person's decision.
- As Looked at through a lens of social justice and inclusion, Jonquiere's analysis and conclusion is deeply disturbing. The intolerable situation that increasing numbers of elderly people find themselves in might be a direct result of neglect, ageism, abuse, ignorance, lack of funding for services, poor public policies or, worst of all, a lack of will to care from family and/or society. If assisted suicide or euthanasia were to become available in New Zealand, we would have a situation where the governing State might well be both complicit in their intolerable condition and complicit in their premature death.
- 85. Put bluntly, it raises the spectre of a society in which elderly people's deepest needs, their need to overcome isolation, neglect and the ignominy of feeling a burden, will be ignored in favour of making it easy for them to 'dispose of themselves'. Looked at like this, and looking beyond the (rare) individual hard cases which do exist, making assisted suicide and euthanasia available is as much about abandoning the foundational principles of an ethical and caring society as it is about abandoning particular individuals.
- 86. True 'death with dignity' occurs when a person's deepest physical, emotional, social, cultural and spiritual needs are met, when a person feels loved and cared for and feels included and valued no matter what. There is potentially a huge social price to pay for legalising state-sanctioned killing, one that would be counted in lives prematurely ended because of a sad perception by persons that

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they were 'past their used by date' and had become a burden – literally 'useless eaters'.

Harmful collision of law and ethics

- 87. It is important to understand that Ms Seales is not seeking to authorise her own actions: to put it very bluntly, anyone in New Zealand is at liberty to commit suicide. Even if another person commits an offence in assisting them, or in killing them at their request, the person who receives assistance will have done nothing contrary to the criminal law.
- 88. Ms Seales' claim is essentially on behalf of her GP: the law change she is seeking is to excuse her GP from criminal liability. In other words, this case is framed in such a way that it is actually about the practice of medicine in New Zealand.
- 89. The separation of curing from killing in the Western medical tradition goes back to the time of the Greeks and specifically to Hippocrates, to whom is attributed the Hippocratic oath. The oath includes: "I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan ..."
- 90. There also exists a very similar treatise on ethics that comes out of the eastern medical tradition, attributed to the great Chinese physician Sun Simiao who in the 6th Century wrote: "Human life is of paramount importance, more precious than a thousand pieces of gold."⁵⁷ It is, in other words, a tradition going back thousands of years across diverse cultures.

Law should not undermine medical ethics

91. To change the law allowing the State to sanction in advance the death of certain groups of people would be, by itself, a massive break with long-standing societal views and the legal tradition within New Zealand. To impose that role onto doctors and nurses, without any regard for the views of the medical profession in New Zealand and world-wide, would be quite something else. Euthanasia and assisted suicide is against the professional Codes of Ethics of the World Medical Association, the New Zealand Medical Association, the Australian and New Zealand Society of Palliative Medicine,

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See http://www.nlm.nih.gov/hmd/greek/greek_oath.html. NE

See http://www.chinesemedicalnews.com/2012/12/china-reveres-author-of-its-first.html. NE

Palliative Care Nurses New Zealand, the Health Professionals Alliance and Christian Medical Fellowship.

- 92. In the first instance this is a question of respect for the integrity of the medical profession and the importance of the law respecting (and not acting to subvert) the ethical judgments made by the profession. This objection is not overcome by asserting that there are individuals within the medical profession, either doctors or nurses, who would be prepared to undertake such actions in particular circumstances. At any point in time the ethics of any profession can never be reduced to the particular views of some of its members, especially when the majority of health professionals are opposed to any involvement.
- 93. The willingness of a few members of a profession to act in a particular way does not provide a mandate for unilaterally over-riding the long-standing ethical policies of that profession that exist independently of the law. The question of the State granting its citizens access to assisted suicide or euthanasia and the question of who might carry it out are two very separate questions and need to be considered quite separately.
- 94. The fact that assisted suicide and euthanasia, in the small number of jurisdictions where it exists, happen to sit within the medical profession is attributable to a failure at the time to thoroughly explore the *desirability* of this situation, or even to recognise it as an important question. It was undoubtedly influenced by the fact that, in the Netherlands, it was the efforts of a small number of doctors willing to break the law, including by his own admission Dr Rob Jonquiere,⁵⁸ that brought the issue into the public and political arena by way of a number of high-profile court cases.
- 95. It is quite understandable that the dynamics by which the Dutch introduced their current system pushed any strong thoughts about whether this was in fact the most appropriate scenario into the background. In addition, Jonquiere has also acknowledged that a focus on the medical profession was a deliberate strategic ploy by pro-euthanasia activists to successfully change the law. In a 2013 lecture he described how the campaigners in The Netherlands originally wanted to argue for euthanasia on the grounds of 'self-determination' (that is, on the basis of unfettered personal choice and without needing to fulfil any

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New Zealand Listener March 2015 Macfie, "Live and let die," at p. 30.

particular conditions such as being terminally ill) - effectively euthanasia-on-demand. However, it was deemed necessary at the time for doctors to be involved in order to gain public acceptance.⁵⁹

- 96. The association of assisted suicide and euthanasia with medicine in order to sanitize the process is also noted by others.⁶⁰
- 97. Objections to the involvement of the medical profession are becoming a more noticeable feature internationally. As noted in a recent letter to the Editor of the Times signed by 28 physicians and doctors (including the President of the Association for Palliative Medicine of Great Britain and Ireland, and the National Director for Hospice Care Hospice UK): "Doctors want no part in assisted suicide."61 The signatories write in response to an earlier editorial and state: "You are right to state [in your Editorial column⁶²] that doctors are in no position to judge whether patients who might request lethal drugs for suicide under an "assisted dying" regime meet the (rather vague) criteria suggested. In these days of the multi-partner GP practice, doctors often know little of their patients beyond the consulting room. Home visits, in which a doctor might just get a glimpse of unseen pressures on the frail and the elderly, are now the exception. With four out of five doctors unwilling to have anything to do with physician-assisted suicide, patients seeking lethal drugs would in most cases end up being assessed by a handful of referral doctors who knew nothing about them. Quite apart from these practical issues, there is the important ethical question of whether physician-assisted suicide can be reconciled with medicine's cardinal principle of 'do no harm'. Why are those who want to change the law so insistent that assisted suicide should be embedded in clinical practice? Perhaps it is thought that placing such practices within healthcare will help to commend them to a sceptical parliament and public. We do not believe any convincing case has been made for changing the law. But we are clear that, if assistance with suicide were ever to be legalised, it should be kept well clear of healthcare."

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See Jonquiere, R. Fourth Annual Lecture to the Society for Old Age Rational Suicide, London, September 20, 2013 http://www.soars.org.uk/index.php/pages, accessed 2 March 2015.

See for example Boudreau, JD and MA. Somerville. "Euthanasia Is Not Medical Treatment." *British Medical Bulletin* 106 (2013): 45-66 p. 46.

See http://www.thetimes.co.uk/tto/opinion/leaders/article4401990.ece, accessed 7 May 2015. NE

⁶² See http://www.thetimes.co.uk/tto/opinion/leaders/article4401990.ece, accessed 7 May 2015. NE

- 98. This issue also features in the recently released report of the Committee of the Scottish Parliament on the Assisted Suicide (Scotland) Bill, in a section headed "The role of the licenced facilitator". 63
- 99. The fact that, for many people, the primary motivations for requesting assisted suicide or euthanasia are related to existential reasons, rather than physical suffering, also takes such requests outside of the areas of specific medical expertise of health professionals. In particular, keeping in mind the potential dangers of patient 'coercion' that are universally recognised by opponents and proponents alike, health professionals, including GP's, are, once again, not trained to detect such. This of course begs the question of whether such coercion can be reliably detected by anyone.
- Support for withdrawing health professionals from State endorsed euthanasia and assisted suicide is also increasing from euthanasia advocates, including Rob Jonquiere. In his Fourth Annual Lecture to the Society for Old Age Rational Suicide in 2013 he states: "Another consideration being discussed now [in the Netherlands] is the possible introduction of 'counsellors in dying'. Starting end-of-life discussions, when severe suffering is caused only by illnesses, Dutch doctors occupy the central position with the present euthanasia law. When such suffering is no longer the only criterion, it is advisable that perhaps a new category of non-medical professionals could be entitled to give assistance such as 'counsellors in dying'."
- 101. The terminology used by the plaintiff in the current case (medically facilitated and medically administered aid in dying), shows a failure to appreciate that the question of whether assisted suicide and euthanasia should be lawful is separate from who should carry out such actions.

Law should not undermine ethical clinical practice

In the second instance, and integral to the ethical position taken by the practitioner groups named above, it is a matter of realising that there are very real negative practical consequences for the therapeutic relationship based on an inherent conflict of interest on the part of the health professional. These arguments are well-articulated by eminent health practitioners around the world and in New

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Health and Sport Committee, "Stage 1 Report on Assisted Suicide (Scotland) Bill".

See Jonquiere, R. Fourth Annual Lecture to the Society for Old Age Rational Suicide, London, September 20, 2013 http://www.soars.org.uk/index.php/pages, accessed 2 March 2015.

Zealand, including Margaret Somerville. Somerville, in a joint article with Boudreau, argues strongly that in instances where it is allowed assisted suicide and euthanasia should be carried out by 'thanatologists' rather than health professionals so that it did not encroach on the physicians' mandate to heal.⁶⁵

103. Professor Robin Taylor of Otago University New Zealand has also opined: "the arguments in favour of ending the life of a sufferer as a means of eliminating suffering are fundamentally flawed, even though they may be subtly tempting. … the relationship between doctors and their patients would be irrevocably changed, especially for the elderly, if legislation to facilitate assisted suicide were to be enacted."

Law should not engage in judging the value of lives

- Bioethicist Daniel Callahan observed that: "Apart from depression (the main statistical cause of suicide), people commit suicide because they find life empty, oppressive, or meaningless. Their judgement is a judgement about the value of continued life, not only about health (even if they are sick). Are doctors now to be given the right to make judgements about the kinds of life worth living and to give their blessing to suicide for those they judge wanting? What conceivable competences, technical or moral, could doctors claim to play such a role? Are we to medicalize suicide, turning judgements about its worth and value into one more clinical issue? Yes, those are rhetorical questions ... It is not medicine's place to determine when lives are not worth living or when the burden of life is too great to be borne. Doctors have no conceivable way of evaluating such claims on the part of patients, and they should have no right to act in response to them." 67
- 105. As noted in recent commentary in the Wall Street Journal a "fundamental premise of medicine is the vocational commitment of doctors to care for all people without doubting whether any individual is worth the effort. That means doctors will not hold back their ingenuity and energies in treating

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Boudreau, JD., and MA. Somerville. "Euthanasia Is Not Medical Treatment." *British Medical Bulletin* 106 (2013): 45-66.

The New Zealand Herald, 10 December 2012, J. Gibb, "Professor speaks against voluntary euthanasia," available at http://www.nzherald.co.nz/nz/news/article.cfm?c id=1&objectid=10853031

⁶⁷ Callahan, "When Self-Determination Runs Amok." p. 385.

anyone, rich or poor, young or old, prominent or socially insignificant, curable or incurable."68

- 106. In other words, at the core of the medical profession is a commitment to be totally non-judgemental. This explains why, in times of war, doctors are called upon to treat the 'enemy' in the same way they would treat their own soldiers. From an ethical perspective this is yet another way in which the involvement of health professionals as the agents of assisted suicide and euthanasia would undermine their profession.
- 107. As John Keown puts it: "Clearly, once the law abandons the bright line prohibition on any intentional ending of patients' lives, it enters a fuzzy world of arbitrary judgments about whose lives are, or are not, 'worth living'. It is not surprising that disability groups in general strongly oppose legalization."
- 108. He refers to a letter from disability groups in the United Kingdom and United States which opposed a proposal to relax the law, stating: 'We are like society's 'canaries in the coalmine' who can often see the dangers of potentially discriminatory legislation before others, as it impacts on us even before the deed is done. We are scared now; we will be terrified if assisted suicide becomes state-sanctioned."⁶⁹
- 109. What is needed instead is a concerted effort to help all people to feel valued and connected and, as bioethicist, moral philosopher and theologian Richard McCormick warned in 1981, to avoid a slide into a functional assessment of people: "Our treatment of the aged is perhaps the sorriest symptom of this. The elderly are, it can be argued, probably the most alienated members of our society. 'Not yet ready for the world of the dead, not deemed fit for the world of the living, they are shunted aside. More and more of them spend the extra years medicine has given them in 'homes for senior citizens,' in chronic hospitals, in nursing homes waiting for the end. We have learned how to increase their years, but we have not learned how to help them enjoy their days.' Their protest is eloquent because it is helplessly muted and silent. It is a

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The Wall St Journal (2015) P. McHugh, "Dr Death Makes a Comeback: Legalizing physician-assisted suicide is receiving fresh support, but doctors should think twice before signing on" http://www.wsj.com/articles/paul-mchugh-dr-death-makes-a-comeback-1421970736.

J. Keown, "A Right to Voluntary Euthanasia? Confusion in Canada in Carter," Notre Dame Journal of Law, Ethics & Public Policy 28, no. 1 (2014) p. 26.

protest against a basically functional assessment of their persons. 'Maladaptation' is a term used to describe *them*, rather than the environment. Hence we intervene against the maladapted individual rather than against the environment."⁷⁰

110. Legalising assisted suicide or euthanasia is contrary to the state's responsibility to uphold respect for life for all persons. This principle is a key factor in what binds us as a society and motivates us to care, in particular to care for those who are most vulnerable, including the seriously ill, disabled persons and persons with mental illnesses.

Harm to the vulnerable

- 111. The potential for harm to vulnerable individuals and groups is significant and complex. There are issues around true freedom and consent, issues around the inherent harm arising from society drawing a distinction between lives that are worth living and lives that are not, issues around the impact on end of life care and the doctor/patient relationship, issues around scope and restrictions (what is referred to as 'bracket creep' or the 'slippery slope'), issues around the impact on policy and funding decisions, issues around the impact on suicide prevention programmes, and the list goes on.
- In this affidavit I briefly touch on some of these issues. I do not address the majority: this would not be possible in the time available, and many of these require other fields of expertise. More importantly, these are issues where very many other views are required, including experts, commentators, advocates and those whose lived experience will be significant in informing understanding.
- 113. It is also important to clearly state the nature of the harm that we are talking about in this context. Failure here means death: this is not a policy measure where a certain margin for error can be accommodated. If one person is coerced or pressured into taking the option of euthanasia or assisted suicide, that is a person wrongfully killed by the law. This is one reason why an absolute prohibition is so important: what is at issue is the right to life (and

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See R. McCormick, How Brave a New World?: Dilemmas in Bioethics (Washington: Georgetown University Press, 1981).

the right to equal recognition of the value of their lives) of many vulnerable people.

The nature of vulnerability

- 114. Koffman et al make the point that vulnerability is a poorly understood concept, often (narrowly) aligned to autonomy and consent that is, "usually referring to *individuals* with limited cognitive abilities or diminished autonomy." They make the point that "this definition does not adequately engage with the context (social as well as medical) ...". Drawing on Kipinis, they highlight a more robust taxonomy of vulnerability that includes (i) communicative vulnerability, represented by participants impaired in their ability to communicate because of distressing symptoms; (ii) institutional vulnerability referring to participants who exist under the authority of others; (iii) deferential vulnerability, including participants subject to the informal authority or independent interests of others; (iv) medical vulnerability, referring to those with distressing medical conditions; and (v) social vulnerability, including participants considered to belong to an undervalued social group.
- 115. While the particular research undertaken by Koffman et al in south London found that participants from the prominent ethnic groups populated all these domains, "those who were black Caribbean were more present among the socially vulnerable." There are many who, in their discussion of the risks assisted suicide and euthanasia present for vulnerable persons, fail to take account of the broader understanding of vulnerability in particular social vulnerability because their starting point is an overly narrow understanding of the concept of vulnerability.
- 116. Hirini Kaa, drawing on his own experience and knowledge of working with largely Māori communities in isolated areas of New Zealand, highlights the impact of contextual and societal constraints on choices and their potential to lead to decisions that are incompatible with more deeply held cultural values. In particular he flags the real danger that the availability of assisted suicide or euthanasia would have on the values, systems and viewpoints of Māori as well

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J. Koffman et al., "Vulnerability in palliative care research: findings from a qualitative study of black Caribbean and white British patients with advanced cancer," *Journal of Medical Ethics* 35, no. 7 (2009) p. 440 (emphasis added).

⁷² Ibid

as other groups of people who find themselves in a similar position because of financial and other constraints.

- 117. Kaa writes: "The problem is, what is 'choice'? For the middle class advocates who have been pushing this issue, 'choice' is a wonderful thing. Shall I lie here in pain, or choose to end the struggle now in the love of my family? Good stuff, beautiful stuff. But what I also know will happen is that those on the margins will have less 'choice'. When their whanau can't afford the petrol to come and visit them in hospital, when they don't like the nurses and doctors, when the power bill is due at home, when you are whakama (ashamed) of your situation - you name it, the problems mount up for poor sick people far beyond the medical. I know this well from my whanau experience and my experience as a minister in these situations. Then, the 'choice' becomes much clearer. And what doctor will say 'actually, your choice is influenced too much by your poverty?' The coercion of poverty is subtle. Every day the medical profession, with the best intentions, make choices around the treatment of patients which essentially are based on socio-economic reasoning as much as the medical. 'Due to the lack of resources we won't treat that aging Māori who smokes and is obese...' - and we accept that brutal choice as a society"73
- 118. There is consistent recognition in the literature that the "deadly impact of legalizing assisted suicide would fall hardest, whether directly or indirectly, on socially and economically disadvantaged people who have less access to medical resources and who already find themselves discriminated against by the health care system. Particularly at risk are individuals in poverty, people of colour, older adults, people with progressive or chronic conditions, the disabled, and people with terminal illnesses". 74
- 119. Conversely, research which suggests that 'the vulnerable' won't be adversely affected, including the oft quoted Battin study, 75 is at best contentious and now significantly outdated. 76 With respect to our own situation, all such evidence is

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H Kaa, "Euthanasia: no choice for Maori," (2012), http://revtalk.co.nz/2012/07/euthanasia/.

See, for example, P. Longmore, "The resistance: the disability rights movement and assisted suicide," in Why I burned my book and other essays on disability, ed. P. Longmore (Philadelphia: Temple University Press, 2003) at p5.

MP. Battin et al., "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups," *Law, Ethics and Medicine* 33(2007).

See, for example Finlay, I G and R George (2011) "Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the Impact on patients in vulnerable groups—another perspective on Oregon's data" Journal of Medical Ethics 37: 171-4.

ultimately inadequate because it does not take account of the unique and distinct New Zealand social and cultural context, including the problems relating to economic disparity.⁷⁷

The elderly

- There is a widespread perception that irremediable pain is the main reason why people seek access to euthanasia and assisted suicide (and indeed, this appears to be the assumed justification for allowing access in the surveys undertaken to date). As I discuss in some detail above, this is not correct. Research evidence indicates that the main reasons people favour euthanasia are not related to extreme physical pain but to such things as loss of autonomy, feelings of being a burden and dependency on others, decreasing ability to participate in activities that made life enjoyable, fear of losing control, and social isolation. Financial concerns are also becoming a feature in requests in Oregon.⁷⁸
- Malpas et al in a 2012 letter to the NZMJ (in relation to their study on the reasons why people support euthanasia in New Zealand) note: "A person may wish to end their life at a time of their choosing rather than using their financial resources to sustain a life which they no longer value, preferring rather to leave that money to benefit others (either in the community or their own families)..."
- As Greene points out in the context of the current debate in California, when the symptom driving requests for assisted suicide is psychological distress, such as depression and fears of dependency, helplessness and becoming a burden, 'the standard of care ... is not a lethal dose of barbiturates' Aside from the implications of these findings for those involved in palliative care, as well as for families and friends of the terminally ill, they also highlight that those groups in

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The Scottish Select Committee report of April this year expressed the same point well: "The Committee considers that experience from other jurisdictions, although informative, cannot be regarded as evidence either in favour ... or against ... not only because none of the existing regimes is directly equivalent ... but because each cultural context is distinct, so that experience from one jurisdiction cannot be extrapolated straightforwardly into another." Stage 1 Report on Assisted Suicide (Scotland) Bill 30 April 2015 at 297.

Oregon Public Health Division, Oregon's Death with Dignity Act—2014, Table 1 at 5
http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf

Malpas et al Response to Dr Sinead Donnelly's 'Debate on euthanasia', 10 August 2012, NZMJ Vol 125, No. 1359

Greene, HR. Letter to the council on ethical affairs, California Medical Association. Available at http://dredf.org/assisted_suicide/greene.shtml

society who already experience being a burden, or the loss of community or loss of autonomy are more vulnerable. One of these groups is the elderly and in New Zealand there is evidence that this group is particularly at risk from these pressures.

- Several studies have established that loneliness is a significant problem for the elderly in New Zealand: an Auckland Council commissioned study found that 9 percent of Auckland residents aged over 50 were severely lonely, and 44.5 percent moderately lonely;⁸¹ a study investigating the rate, degree and impact of loneliness in a sample of 332 older community-dwelling New Zealanders found more than half of the sample (52 percent) was found to be lonely to some extent with 44 percent being moderately lonely and 8 percent severely lonely;⁸² and the New Zealand Longitudinal Study of Aging described a minority of participants as 'not lonely' (48.8 percent); the rest were considered 'moderately lonely' (41.2 percent); 'severely lonely' (7 percent); and 'very severely lonely' (3 percent).⁸³
- 124. People who feel neglected, undervalued and invisible can understandably perceive themselves as a burden and will want to do the 'right' thing, especially when there are growing pressures on families/spouses who are caring for a loved one and growing economic pressures on providing funding for health care and care for the aged. The elderly, like those with disabilities, are subject to a public opinion that questions the usefulness of people who are 'not contributing' to society and are 'swallowing up' health and other resources.
- 125. There is evidence that some groups of the elderly suffer high rates of depression. In the New Zealand LiLACS longitudinal study, which recruited 421 Maori aged 80-90 years and 516 non-Maori aged 85 years living in the Bay of Plenty and Rotorua districts, the prevalence of depression (measured by the Geriatric Depression Scale) was reported as ranging from 22 percent for Maori men and 23 percent for non-Maori men to 26 percent for non-Maori women

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[&]quot;Aucklanders 50 and over: A health, social, economic and demographic summary analysis of the life experiences of older Aucklanders" Prepared for the Anckland Council, Research, Investigations and Monitoring Unit by: Charles Waldegrave and Peter King of the Family Centre Social Policy Research Unit and Elizabeth Rowe of Elizabeth Rowe Consulting, 2012.

La Grow S, Neville S, Alpass F, Rodgers V, "Brief Report. Loneliness and self-reported health among older persons in New Zealand Australasian Journal on Ageing", Vol. 31, No. 2, June 2012: 121–123. NE

Noone, J, Stephens, C "Social integration, health and quality of life," Summary report for the New Zealand Longitudinal Study of Ageing, (2014), Palmerston North: Massey University. NE

and 30 percent for Maori women.⁸⁴ While the New Zealand Mental Health Survey indicates that those over 65 years have proportionately lower rates of depression than other age groups, this is also the age group where terminal illness is most common. In addition, physical health generally declines with age which has consequences for social functioning and emotional role functioning.⁸⁵

- While there are no population-based studies of elder abuse in New Zealand most research estimates 2 to 5 percent of the older population may be victims of elder abuse. The proportion increases dramatically when the person is dependent on carers, where studies estimate almost a quarter of older people who are dependent on careers have reported suffering "significant psychological abuse". The proportion increases dramatically when the person is dependent on careers have reported suffering "significant psychological abuse". The proportion increases dramatically when the person is dependent on careers have reported suffering "significant psychological abuse".
- 127. Similarly, Age Concern reports that it receives more than 1,500 confirmed referrals each year of older people facing abuse or neglect.⁸⁸
- 128. It is reported that elder abuse most commonly involves family members, with sons and daughters making up 40 percent, and spouses or partners 15 percent of abusers. Financial elder abuse is reported as being the second most frequently reported form of abuse, and that sons and daughters are the most frequent perpetrators of financial elder abuse. In October 2010 The Press newspaper (Christchurch) reported that: "Elderly people are more vulnerable since the Canterbury earthquakes, with more abuse and neglect incidents reported."

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Teh R, Kerse N, Kepa M, et al. "Self-rated health, health-related behaviours and medical conditions of Maori and non-Maori in advanced age: LiLACS NZ". NZMJ, (2014), Vol. 127, No. 1397. NE

Budge C, Stephens C, Stichbury C, "Health," Summary report for the New Zealand Longitudinal Study of Ageing, (2014), Palmerston North: Massey University. P. 11. NE

⁸⁶ Glasgow K, Fanslow JL "Family Violence Intervention Guidelines: Elder abuse and neglect," (2006). Wellington: Ministry of Health.

Cooper C, Selwood A, Livingston G "The prevalence of elder abuse and neglect: a systemic review" (2008) 37 Age and Ageing 151 at 158

⁸⁸ http://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ Public/Elder Abuse and Neglect.aspx NF.

Glasgow K, Fanslow JL, "Family Violence Intervention Guidelines: Elder abuse and neglect," (2006). Wellington: Ministry of Health.

Davey JA, McKendry J, "Financial abuse of older people in New Zealand," Institute of Policy Studies, Working Paper 11/10. November, 2011. Wellington: Victoria University of Wellington.

See http://www.stuff.co.nz/national/christchurch-earthquake/7874541/More-cases-of-elder-abuse-reported-after-earthquakes. NE

- 129. Reports from the 2001 Census show that there were 450,426 people aged 65 and over living in New Zealand, which means there could be between 9008 (2 percent) and 22,520 (5 percent) older New Zealanders suffering some form of abuse and neglect. It is estimated that only 16 percent of the actual number of abuse incidents reach service agencies. 92
- 130. The social context for the elderly in New Zealand then is one where many are already experiencing neglect and abuse, where their value to society is under question, and where many experience depression, loneliness and isolation. This context clearly puts them at risk of coercion by families and others, as well as their own feelings of being a burden, to choose to hasten the end of life. Introducing euthanasia and assisted suicide in New Zealand has a very real potential to place the elderly in an even more precarious position of having to justify carrying on living.
- 131. Despite our best attempts we have not been able to protect our elderly and vulnerable from abuse. Similarly, the figures for abuse by family and carers of the disabled is a significant issue in New Zealand, as highlighted by the evidence filed on behalf of Not Dead Yet Aotearoa. Again, despite our best attempts with regulations and social support services, we have not been able to full protect this highly vulnerable group of people.
- 132. The availability of state-sanctioned 'mercy killing' in this environment will create additional pathways for abuse and neglect, and put at risk the lives and security of these highly vulnerable groups.

NZ's high suicide rate

The Ministry of Health's most recent figures for suicide show that a total of 478 people died by suicide in New Zealand in 2011, which equates to 10.6 deaths per 100,000 population (age standardised).⁹³ One of our highest risk groups are men over the age of 85 (33.5 per 100,000⁹⁴).

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⁹²https://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ_Public/Elder_Abuse_and_Neglect.aspx# howmuch

Ministry of Health, "Suicide Facts: Deaths and intentional self-harm hospitalisations 2011," 27 January 2014. Available at: http://www.health.govt.nz/publication/suicide-facts-deaths-and-intentional-self-harm-hospitalisations-2011. NE

Cheung G, Casey J, "Few older people in New Zealand who commit suicide receive specialist psychogeriatric services," *Australasian Psychiatry*, (2014), Vol 22(4): 386–389. NE

- 134. The rate for 15-24 year olds was 19.3 deaths per 100,000. For Maori youth, the suicide rate for 2011 was 36.4 per 100,000 Maori youth population 2.4 times higher than that of non-Maori youth (15.1 per 100,000 non-Maori population). The rate of youth suicide is higher in New Zealand than in most other countries for which comparative data is available. 96
- The Ministry of Health describes protective factors for suicide as: access to community and health resources, social connectedness, and the capacity to cope with life's difficulties. As risk factors, it lists: mental health issues, exposure to trauma (e.g., disaster, family violence, abuse), a lack of social support (e.g., living alone) and experiencing stressful life events (e.g., chronic pain, discrimination, bullying, relationship conflict, job or financial loss). Cheung describes the risk factors for late-life suicide as 'older age, male gender, living alone, bereavement (especially in men), psychiatric illness (depression, previous suicide attempt), physical illness (pain) and social disconnectedness'. 97
- There has been a concerted effort on the part of government over a number of years to reduce the rates of youth suicide. The New Zealand Suicide Prevention Strategy 2006-2016 builds on work that started in 1992 because of concern about New Zealand's high rate of youth suicide. There are a range of factors that have been implicated in youth suicide and it is generally agreed that the approach needed is one that addresses both individual and population level factors. While individual factors such as mental health, particularly depression, are closely linked with suicide, a number of social effects have also been linked to suicide, especially youth suicide. One of these is the effect of 'contagion'.
- 137. The notion of suicide contagion is a well-established phenomenon and describes the links between media coverage of suicide and youth suicide, 98 as well as that between parental and offspring suicidal ideation and suicide

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⁹⁵ Ministry of Health, op cit. NE

Ministry of Youth Development, "Youth Statistics. A Statistical Profile of Young People in New Zealand: Suicide," available at: http://www.youthstats.myd.govt.nz/indicator/healthy/suicide/international.html NE

Cheung G, "Suicide in Older People: What We Know, and, is it Preventable?" PowerPoint Presentation August 20, 2014.

Crepeau-Hobson MF, Leech NL, "The Impact of Exposure to Peer Suicidal Self-Directed Violence on Youth Suicidal Behavior: A Critical Review of the Literature," Snicide and Life-Threatening Behavior, 44 (1) February 2014. NE Sisask, Merike, and Airi Varnik. "Media Roles in Suicide Prevention: A Systematic Review." International Journal of Environmental Research and Public Health 9, no. 1 (2012): 123-38 NE

attempts.⁹⁹ It has been found that the relative risk of suicide following exposure to another's suicide is two to four times higher among 15-19 year olds than among other age groups.¹⁰⁰ Haw et al have described 'suicide clusters', where a number of suicides occur over a restricted time period and are linked to actual or fictional suicides, or over a small geographical area over a brief period of time¹⁰¹. It is generally held that clusters are caused by contagion and Haw et al note adolescents and young adults are most at risk of being part of a suicide cluster. There is considerable evidence that being exposed to the suicide or suicidal behaviour of another can also increase the risk for suicide¹⁰².

- 138. Two main concerns are immediately apparent in terms of the impact on people who may be at increased risk of suicide, and particularly those with mental illnesses, including depression.
- 139. First, for those who found themselves 'within scope' of a law that permitted access to euthanasia and assisted suicide, suicide prevention measures are simply erased. There is no coherent basis upon which this group can be supported or dissuaded from suicide when the concurrent message is that suicide is 'rational' and an appropriate response to their suffering.
- 140. At particular risk here are of course the disabled and the elderly, noting that in those jurisdictions where assisted suicide or euthanasia is legal it is becoming more obvious that 'multiple conditions' (including conditions of old age) are sufficient to meet what ever limiting criteria is in place.
- 141. The complexities of care in this context are difficult to imagine: what, for example, would be the legally appropriate response to suicidal behaviour in custodial settings or in the compulsory treatment regimes when the person at risk is 'in scope'?

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Goodwin R, Beautrais AL, Fergusson DM, "Familial transmission of suicidal ideation and suicide attempts: evidence from a general population sample," *Psychiatry Research*, (2004), 126(2): 159–65.

Haw, C, Hawton K, Niedzwiedz C, Platt S, "Suicide Clusters: A Review of Risk Factors and Mechanisms," Snicide and Life-Threatening Behaviour, (2013), 43(1): 97-108.

¹⁰¹ Ibid.

¹⁰² Crepeau-Hobson, op cit.

- 142. Second, even for those currently 'out of scope', the legalization of assisted suicide will inevitably compromise suicide prevention programmes and endanger those with serious mental illnesses.
- 143. Legalisation will result in the introduction of competing paradigms: the concept of 'rational' suicide, for those who find their lives intolerable and not worthwhile, will be in direct conflict with the fundamental goal and message of suicide prevention programmes.
- 144. The suggestion in some commentaries¹⁰³ that there is a clear distinction between those whose suicides should be prevented and those for whom suicide is appropriate (on the basis that the latter are 'rationally' hopeless because they know that they will not recover from their condition) is not supportable. For a start, many mental illnesses are a permanent diagnosis, and those individuals 'rationally' face a lifetime of struggle and pain, that cannot be wholly eliminated even with the best treatment and support.¹⁰⁴
- 145. More significantly, for the depressed and those in existential pain, the distinction will be meaningless to them. The message will be that society condones and endorses the concept of rational suicide for those who consider that their lives are intolerable and not worthwhile. Technical limitations as to who is currently allowed to access the lethal drugs will be perceived as just that: technical. The core message that suicide is a rational and approved option for those who are suffering is the harm.
- As far as I am aware there have been no studies on the impact of legalisation of euthanasia and assisted suicide on suicide rates in the general public. For most jurisdictions, the time period since introduction would be too short in any event to give any meaningful picture.
- 147. However, there is a recorded simultaneous rise in general suicides (ie suicides occurring outside the euthanasia and assisted suicide regimes) in Oregon and the Netherlands.

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See for example Andrew Geddis "How to win a death with dignity" http://pundit.co.nz/content/how-to-win-a-death-with-dignity

Indeed Rob Jonquiere is reported in the New Zealand Listener in March 2015 as supporting euthanasia for this group on these grounds. As he puts it: "These [people with chronic depression] are deeply ill people. They are not terminally ill but they can suffer enormously knowing it will never go away and they might live with it for 20 or 30 years. You could say they are suffering even more than a cancer patient who knows he is going to die anyway." Macfie, "Live and let die," New Zealand Listener March 2015

- 148. A 2012 report by the Oregon Health Authority found: 105
 - In 2010, the age-adjusted suicide rate among Oregonians of 17.1 per 100,000 was 41 percent higher than the national average.
 - 148.2 The rate of suicide among Oregonians has been increasing since 2000.
 - Suicide rates among adults ages 45-64 rose approximately 50 percent from 18.1 per 100,000 in 2000 to 27.1 per 100,000 in 2010. The rate increased more among women ages 45-64 than among men of the same age during the past 10 years.
- 149. The report concluded, without apparent irony, that: "Suicide is one of Oregon's most persistent yet largely preventable public health problems. Suicide is the second leading cause of death among Oregonians ages 15-34, and the 8th leading cause of death among all Oregonians in 2010. The financial and emotional impacts of suicide on family members and the broader community are devastating and long lasting."
- 150. In 2013, Statistics Netherlands recorded that "The suicide rate has grown dramatically over the past five years." In 2008, a total of 1,353 people committed suicide in the Netherlands versus 1,753 in 2012, that is, an increase of 30 percent. 106

The terminally ill and others 'in scope'

- I am aware that other witnesses are addressing the harms this proposal will bring to the terminally ill. I wish to touch on only a few aspects of this, relating to the concept of 'comfort', and supporting the views of the palliative care experts that access to the option of assisted suicide may lead some people to die earlier than they would have if they had been fully supported through the initial stages of their diagnosis.
- There is an argument put forward that the availability of euthanasia contributes to people's 'peace of mind' and provides 'comfort'. Support for this is inferred

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Oregon Public Health Division "Suicides in Oregon: Trends and risk factors – 2012 report"

http://public.health.oregon.gov/DiseasesConditions/InjuryFatalityData/Documents/NVDRS/Suicide-in-Oregon-report.pdf

http://www.cbs.nl/en-GB/menu/themas/dossiers/allochtonen/publicaties/artikelen/archief/2013/2013-3995-wm.htm NE

from the percentage of the people who receive lethal prescriptions in Oregon but do not end up using them. As far as I am aware, this is pure speculation, and no studies have been undertaken as to why people chose not to use the prescription, or whether the existence of the option was a 'comfort' or a source of distress. It is possible to hypothesise both.

- 153. Further, if those who did not use the prescription can be inferred to have made that decision because they had found 'peace of mind', there is no reason to conclude that it was the presence of the drug that caused that. People may have found 'peace of mind' through other means, including the support of family and/or high quality palliative care, remembering that the goal of palliative care is to attend to people's suffering and needs; emotional, psychological, social and spiritual as well as physical needs.
- 154. Granting people access to lethal medication is a dangerous way of providing 'comfort' or peace of mind. It is also unnecessary in the New Zealand context: palliative care provides a highly effective, ethical and socially enhancing way of achieving this. Good palliative care physicians and their teams do this all of the time as part of their daily work.
- 155. Even if we accept the idea that allowing assisted suicide or euthanasia will mean some people will live longer than they otherwise might have (because otherwise they would have committed suicide earlier), from an ethical perspective there is something inherently contradictory about offering (state-sanctioned) suicide (or euthanasia) as a way of preventing suicide.
- 156. The following autobiographical story (used with the permission of the author who subsequently died in April 2013, six months after writing this letter and with the permission of his surviving family) serves to illustrate the reality of this:

"I am a patient with terminal cancer. I have kidney cancer which has spread to the bone. One of my tumours on the lower spine has 'eaten up' the L3 vertebra, causing it to fracture and collapse on itself. I have another huge tumour on the rear right pelvic bone. This bone has also been eaten and a portion is 'not there'.

I have had ups-and-downs throughout my cancer journey, leading to hospitalisation and day stays in the Acute Care Oncology ward. When my condition was diagnosed I was told the prognosis was not good. I was told that I didn't have much time left and to get my affairs in order.

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The pain I've had is hard to describe. Many a time even my morphine fix didn't help. During the early days, when I was going through intense pain spasms, I would have asked to be euthanised if I had the option. If I did not have much time left, why spend it suffering and in excruciating pain? If I had been able to make that choice, I wouldn't be here today writing my story.

But that was a phase and not the whole story. While we are in pain, we are not really in control of ourselves and our thinking. Remove the pain and, boy, we all want to live on, no matter what our individual conditions are.

With a lot of support and high quality treatment from our health services led by my oncologist, with excellent pain management from hospice and care and support from my dear family and friends, I have been able to fight my way through such times.

That fight has not always been easy but today, more than a year and a half later, I'm in a much better space. I have been able to do things I would never have thought possible. I have travelled to Amsterdam to see my very first grandchild. I've been able to celebrate my son's wedding and dance at the reception too. I've been able to live the best quality of life that's possible. I've learnt to live one day at a time and to enjoy each day.

Had I chosen euthanasia, none of this would have happened. If regret was possible, I would have regretted such a decision. Here in New Zealand we are blessed with a fantastic support system. I had no idea at the time what support and services were available. I would have taken the easy step and quit the world, even though I am not known as a quitter.

The point I'm making is that even the best of doctors can get things wrong. We as patients can get things wrong. While once I could have been a strong advocate for euthanasia, my life experience has turned me into a strong opponent of euthanasia. I am strongly opposed to the introduction and passing of the euthanasia bill in New Zealand because it will unnecessarily cut short people's lives — even strongminded people like me.

I do wonder if advocates for euthanasia truly have the patient's best interests at heart. There can be a number of motivating factors for euthanasia. They may be thinking the terminal patient is a burden on resources, or they may be care-givers exhausted by the struggle, or they may simply be motivated by compassion.

But now, after what I have been through, I see things very differently. I don't see euthanasia as a choice that is ever in my best interests. I am an outpatient at a Hospice in Auckland. Every time I go there and meet other patients, I get the feeling that we all want to fight on. There has not been a single occasion when I have heard any patient say they wished they could die. It is human nature to survive and fight against all odds. We are made to live.

I strongly believe euthanasia should not be legal. It is not simply that we shouldn't make a decision about someone else's life. For a whole host of reasons related to the vulnerability that illness brings, we are not qualified to make decisions about our own life. Even with all the knowledge and experience medicine can offer, we are still not in a position to know with any certainty what lies in the future for us. I know this from my own experience.

I am only alive to tell my story because euthanasia is illegal; because my doctors and I had to look for other options. I have been touched and humbled by the outpouring of love and support I have received from so many around me. These

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last eighteen months have opened my eyes to the true meaning of life. I want to live it!

- 157. Many people, having to the forefront of their minds the tragic (and very rare) 'hard cases', are moved with compassion and fail to see why euthanasia or assisted suicide should not be allowed. What is often not realised is that in none of the jurisdictions where euthanasia or assisted suicide is allowed is it limited to just these very rare cases of intractable pain. Nor are the orders sought in this case so limited. Ms Seales' orders would allow people to 'self define' intolerable suffering, and the examples she refers to in her statement of claim are wide, encompassing loss of mental faculties, loss of physical independence, seizures, loss of memory, loss of mobility and personality and behavioural changes. Similarly, the regime supported by the Voluntary Euthanasia Society would have very broad application.
- What appears to be inevitable in any regime is that much larger numbers of people will start requesting assisted suicide or euthanasia than the few and exceptional first cases that may have been instrumental in bringing about a change in the law. What is legal becomes tolerated and then becomes the norm such that people have to justify why they would not want to avail themselves of this option. This trend is evident in the escalating numbers of people accessing assisted suicide in Oregon and accessing euthanasia in the Netherlands and Belgium.¹⁰⁷
- 159. Robert Preston from the UK Think Tank Living and Dying Well¹⁰⁸ puts it well: "The point is that legalisation doesn't just reproduce the status quo in legal form. There is an understandable tendency to look with anguish and compassion at a small number of high-profile cases that attract media attention and to assume that changing the law would simply allow these cases to proceed without legal objection. The reality is not like this. Experience shows that

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See discussion below under the heading "Other jurisdictions do not demonstrate safety"

See http://www.livinganddyingwell.org.uk/about/what-we-do . "Living and Dying Well was formed in 2010 to research the serious evidence surrounding these issues, to apply clear thinking to them and to publish the results. We produce regular reports on specific aspects of the end-of-life debate and we hold seminars from time to time on topical issues. We also provide speakers for debates in universities and other bodies and we participate in conferences and seminars. Our aim is to ensure that the information that reaches Parliament and the public on these often-contentious issues is grounded in hard evidence and rigorous analysis rather than in spin and sensationalism. To this end, in addition to our periodic reports, we offer a website containing a wide range of factual material and comment on issues of the day."

enabling laws have a tendency to encourage the acts they enable - because they change the law's underlying social message." ¹⁰⁹

- 160. Recent commentary from the Netherlands on this issue should not be ignored.

 The Dutch academic and ethicist, Professor Theo Boer, has sounded a strong warning.
- In 2003 Professor Boer, evaluated the 'slippery slope argument' ("the contention that any form of legalization of voluntary euthanasia will inevitably go from bad to worse, from euthanasia in the case of terminal diseases to assisted suicide under much broader conditions, to more requests, to misuse, to nonvoluntary or even involuntary euthanasia and, eventually, to an erosion of the roots of our public morale.") He concluded that the Dutch experiences in the process of legalizing euthanasia justified some caution, but his expectation was that the Dutch euthanasia law would result in relatively low levels of death.¹¹⁰
- In 2012 Professor Boer published a paper analysing 1,200 reports submitted to one of the five Regional Review Committees on Euthanasia in the Netherlands in the years 2005-09. He noted the legal and professional safeguards to euthanasia but concluded that despite some concerns "and despite the fact that euthanasia remains a morally problematic death, however, the Dutch euthanasia practice can be described as morally solid."
- In 2015, however, Professor Boer spoke against the Assisted Dying Bill being considered by the United Kingdom House of Lords because of the relentless rise in the number of reported deaths under the Dutch regime. His statement included the following warning: "I used to be a supporter of the Dutch law. But now, with twelve years of experience, I take a different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have

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Personal correspondence between Robert Preston and the writer, December 2012. NE

[&]quot;After the Slippery Slope: Dutch Experiences on Regulating Active Euthanasia", Journal of the Society of Christian Ethics, 23/2 (2003): 67-83 NE

Boer, Theo A, "Euthanasia in a Welfare State: Experiences from the Review Procedure in the Netherlands", *Philosophy Study*, Volume 2, Number 1, January 2012, pp. 51-63 at 51. NE

Reported in full at "Don't make our mistake: An assisted suicide bill goes to Lords, Dutch Watchdog who once backed euthanasia warns UK of 'slipery slope' to mass deaths', *The Mail*, May 7 2015, at http://www.dailymail.co.uk/news/article-2686711/Dont-make-mistake-As-assisted-suicide-bill-goes-Lords-Dutch-regulator-backed-euthanasia-warns-Britain-leads-mass-killing.html

better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort? Before these questions are answered, don't go there. Once the genie is out of the bottle, it is not likely to ever go back again."

OTHER JURISDICTIONS DO NOT DEMONSTRATE SAFETY

- 164. Professor Boer's warning above is illustrative of the weakness of claims that the experiences of other jurisdictions demonstrate the 'safety' of assisted suicide and euthanasia.
- As I outlined above, the 'safety' concerns, in terms of preventing serious harm to vulnerable people, are complex and wide ranging. Many of the risks are simply inherent in any regime that allows assisted suicide or euthanasia, and cannot ever be mitigated or eliminated by 'regulatory controls'. The impact on the lives of the disabled is a primary example of this harm. Similarly, the impact on medical ethics and the clinical practice of palliative care, as well as on suicide prevention initiatives.
- 166. Even aside from that fundamental problem, the evidence from the jurisdictions does not demonstrate that effective regulatory controls are possible. Other witnesses are addressing this in more detail, but I wish to note some aspects that are of particular concern in light of the issues that I have discussed above.

The Netherlands

Weak oversight

- 167. The regime in the Netherlands is not structured to provide adequate oversight: lack of identified problems does not equate to full compliance, or indeed lack harm.
- 168. The 2013 report of the Dutch Regional Euthanasia Review Committees exemplifies the problem of weak oversight. For example, the Report records:

The committees again made great efforts to reduce the backlog of the past years. In most cases they succeeded. In the more complex cases, however, such as euthanasia for patients suffering from a mental disorder or dementia, exceeding the time limit is often unavoidable. Before a committee reaches its final decision, the

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¹¹³ Regional Euthanasia Review Committees Annual Report 2013.
http://www.euthanasiecommissie.nl/Images/Annual%20report%202013_tcm52-41743.pdf

members of all committees almost always hold a plenary discussion about such cases, aimed at harmonizing their views. It is usually not possible to complete the plenary discussion and reach a decision within the statutory time limit of 2×6 weeks.

169. The report was at pains to emphasise that "If the physician gives an account of the entire decision-making process in his notification, he may not be required to answer further questions at a later stage." The report goes on:

The committees are aware that such an interview with a committee is burdensome for the physician. It often requires the physician to relive a complex and distressing process months after the fact, and the physician often feels as if he is being called to account by the committee.

Weak compliance criteria

- 170. More critically, the Committee Reports reveal a concerning approach to what is considered to be within the parameters of compliance with the law. For example, the 2012 Report sets out a number of examples where the criteria were found to be complied with, including:¹¹⁴
 - 170.1 An 80 year old woman with advanced dementia and paranoid delusions, who had not made a specific request or left an advanced directive. Her request was inferred from prior discussions about euthanasia.
 - 170.2 A woman in her 80s with 'multiple geriatric syndromes' who "did not want to get any older or more decrepit" and who "was afraid that something might happen that would make her lose control over her life, such as a stroke or a fall resulting in fractures."
 - A physically disabled man in his 70s, suffering a severe infection. The independent physician did not speak with the patient "who was drowsy and unresponsive due to the administration of analgesics", but instead relied on "information obtained from the patient's attending physician and family members which revealed that the patient had specifically requested euthanasia the day before". The man had signed an advance directive "some years" earlier.

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Regional Euthanasia Review Committees Annual Report 2012. http://www.euthanasiecommissie.nl/doc/pdf/JV.RTE2012.engelsDEF2_39100.pdf

- 171. The 2012 Report also discloses that in that year 42 people with dementia were euthanized, and 14 people with mental illness. All euthanasias were considered to be compliant with the 'due care' requirements.
- 172. The 2013 Report records that in that year 97 people with dementia were euthanized, and 42 with mental illness. All were found to be handled with 'due care'.
- 173. In that Report, the Committee records that of the 42 persons with mental illness, the notifying physician (ie the doctor who approved the euthanasia) was a psychiatrist in only 14 cases. The Report simply records:

The committees have established that there appears to be an increase in willingness among physicians to carry out euthanasia and assisted suicide in cases involving a mental disorder.

- 174. The 2010 Government publication "Euthanasia Q and A" similarly records that euthanasia for long term psychiatric patients in some cases "may be permissible under the Act, so long as all the other due care criteria has been fulfilled".
- 175. The 2013 Report also discusses the 'due care' principles for 'decisionally incompetent' patients who are 'no longer capable of expressing his [or her] wishes'. The Report emphasises (in bold) that the independent physician is expected to see the patient.
- The 2013 Report also gives an example of a case where the independent physician had been consulted by the attending physician two years before the patient was euthanized: "At the time, the patient had not yet actually made a specific request for euthanasia, nor was he suffering unbearably." The Committee's concern that the independent physician did not see the patient again before the euthanasia occurred was allayed because the physicians "were able to convince the committee that the chances of the independent physician reaching a different conclusion [had he seen the patient] were zero."

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Netherlands Ministry of Foreign Affairs, FAQ EUTHANASIA 2010, The Termination of Life on Request and Assisted Suicide (Review Procedures) Act in practice. http://www.patientsrightscouncil.org/site/wp-content/uploads/2012/03/Netherlands Ministry of Justice FAQ Enthanasia 2010.pdf

- 177. The regime in the Netherlands specifically allows euthanasia for children aged from 12 15 with parental consent. Euthanasia of newborns "suffering extreme pain and discomfort" is also permitted. Rob Jonquiere was reported recently in the New Zealand Listener explaining the regime for euthanising children below the age of 12, as follows: "We have had situations where paediatricians were confronted with severely handicapped newborn babies and they designed a protocol that follows more or less the same criteria as the euthanasia law ... but it is a completely different protocol and doctors report to a different committee."
- 178. The 'safeguards' in the Netherlands are not designed to adequately protect the vulnerable. Evidence of compliance with them cannot be taken as evidence of an 'effective' regime.

Normalisation

179. From the 2012 and 2013 Reports it is apparent that the number of 'notifications' of euthanasia and assisted suicides is increasing at a significant rate, from 2,331 deaths in 2008 to 4,829 deaths in 2013.

Belgium

- 180. The reports from Belgium show similar issues. 118 The overall rate of euthanasia is reported as having increased by 89% in four years, and as at 2013 represented 1.7% of all deaths in Belgium. Of particular note, 13% of those euthanized were not expected to die in the short term, including those with non-terminal conditions, including neuropsychiatric disorders. Sixty-seven people with neuropsychiatric disorders were euthanized in 2013, with the figures showing a steady annual increase from 3 in 2005.
- 181. In February 2014 Belgium legalised euthanasia for children, with parental consent.

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¹¹⁶ Ibid

The New Zealand Listener, 12 March 2015, McFie Live & let die <www.listener.co.nz/current-affairs/social-issues-current-affairs/live-let-die>

This information is taken from the European Institute of Bioethics report "Belgian Euthanasia increases by 89% in four years" 15/09/2014, reviewing the Sixth biennial report from the Federal Committee on Oversight and Enforcement, covering the years 2012- 2013: http://www.ieb-eib.org/en/document/belgian-euthanasia-increases-by-89-in-four-years-382.html

Oregon

Weak safeguards and oversight at prescription stage

- Euthanasia is illegal in Oregon. Assisted suicide is available, and requires the person to make two oral requests separated by at least 15 days, and a written request. The attending physician must refer the patient to a consulting physician for confirmation of the medical diagnosis and that the patient is acting voluntarily in requesting the prescription. The physician then completes a compliance form, which is in a tick box format. The prescription must be issued within 48 hours of the written request.
- 183. The physician files the form with the Oregon State Public Health Division. If the form is correctly completed, the physician is assumed to have complied with his or her obligations.
- The table in the Oregon Public Health Division report *Oregon's Death with* Dignity Act 2014 shows the steady rise in prescriptions each year, from 24 in 1998 to 155 in 2014. The Report also records an increase in patients without private health insurance opting of euthanasia (in 2014 60.2%, compared with 35.5% in previous years). It states that the three most frequently mentioned end-of-life concerns were loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%). Other concerns recorded are "burden on family/friends/caregiver" and "financial implications of treatment". 121
- 185. The 'safeguards' in Oregon are simply not designed to protect vulnerable groups from the risks and harms that I have outlined above. The fact that the safeguards (which are provided on a self reporting basis) are apparently not being infringed cannot be taken as evidence of effective protection for the vulnerable.

Absence of any safeguards or oversight at time of administration

186. A critical concern with data from Oregon is that the 'safeguards' are placed around the issuing of the prescription only. There is no supervision or

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Death with Dignity Act 1997 s 3.01(d). Three of the 105 patients prescribed in 2014 were referred for such an assessment: Oregon Public Health Division report "Oregon's Death with Dignity Act – 2014"

Oregon Public Health Division Death with Dignity; Patient Request form and Attending Physician form http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/pasforms.aspx

Oregon Public Health Division, Oregon's Death with Dignity Act—2014

reporting requirements relating to when the drug is administered, other than that the person has died. As the 2014 report records, a revision in 2010 means that: "The new procedure accepts information about the time of death and circumstances surrounding the death only when the physician or another health care provider was present at the time of death." As a result, only 20 of the 105 deaths in 2014 were the subject of any report on the circumstances of the death. 122

- 187. The decision to ask for a prescription of a lethal drug on the basis that it might be wanted later is self evidently a different decision, and a far less serious and permanent decision, from the decision to actually take the drug.
- 188. There is no required oversight or visibility of what happens when the drug is taken.
- As the Oregon reports show, significant periods of time may pass before the person dies. There is no visibility of their mental state at the time they take the drug, whether they are depressed, or even fully rational. There is no assessment of whether the whether the decision to take the drug was subject to any sort of pressure or coercion. Indeed, there is no way to even assess if the drug was taken voluntarily at all.
- 190. The reality of the regime in Oregon is that once a person voluntarily accepts a prescription for a lethal drug, they step outside the protection of the law: their premature death will be assumed to be as a result of a fully competent and entirely voluntary decision and no inquiry will be made (unless one assumes there are obvious signs of physical violence at the time of death).
- 191. Given New Zealand's significant problem of abuse of the elderly (often by family members) and the disabled in care, which continues despite the policy, social services, community and regulatory initiatives to prevent it, the prospect of such a regime operating here is chilling.

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Oregon Public Health Division, Oregon's Death with Dignity Act—2014

A CONSENSUS FOR CHANGE IN NEW ZEALAND?

- 192. There is no proper basis to conclude that New Zealand society, in all its diversity, has a clear view that it is appropriate to change the law to allow assisted suicide and euthanasia.
- 193. The New Zealand Parliament has twice rejected legislation that would authorise assisted suicide or euthanasia, in 1995 and 2003. Further, Iain Lees-Galloway MP is on recent public record as saying that "after speaking with MP's around the House" he had come to the view that there was insufficient parliamentary support in the new parliament for bringing back Maryan Street's 'End of Life Choice Bill (16 December 2014).¹²³

Public polls are problematic

- 194. It is often reported that polls have shown that 60-70% of New Zealanders support the legalisation of euthanasia, leading Horizon researchers to conclude that "Supporters of end of life choice ... form a strong majority" in New Zealand and the Voluntary Euthanasia Society (VES) to state that "most New Zealanders support aid-in-dying legislation."
- 195. This is not the correct conclusion to draw from these polls. For example, it is clear that the "majority support" shown in the 2012 Horizon Poll referred to by VES is premised on the need for, and belief in the effectiveness of, strict controls. The poll results reveal this: "The need for strict controls, like those measured in the survey, is demonstrated by support for them exceeding support for end of life choice overall." As far as the 2012 Horizon poll goes, therefore, the more adequate and honest conclusion to draw is that 62.9% of New Zealanders believe in receiving medical assistance to end their life on the assumption that harms to others can be prevented by strong and effective safeguards. Even a

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See http://www.stuff.co.nz/manawatu-standard/news/64192672/Bill-euthanised-over-little-support-in-House. NE

See "Legalisation of Euthanasia in New Zealand: Surveys in New Zealand" at http://policyprojects.ac.nz/jasonrenwick/surveys-in-new-zealand/ NE

See, for example, Horizon Research, "New Zealanders' views on End of Life Choices," (Auckland, New Zealand 2012 at http://www.horizonpoll.co.nz/attachments/docs/horizon-research-end-of-life-choices-survey--1.pdf, accessed 1 May 2015.

See http://www.ves.org.nz/, accessed 1 May 2015. NE

Horizon Research, p. 4, emphasis added.

cursory scan of the international evidence shows that the assumption that effective safeguards are possible is, at best, a contentious one.¹²⁸

- 196. My view is that, properly weighed, the evidence points towards the practical impossibility of implementing adequate safeguards, and further, that many of the harms (such as to the disabled) are inherent, and cannot be addressed by 'safeguards' at all. That being the case, a truer indication of support for euthanasia or assisted suicide would be gained if survey questions made it clear that there is at least uncertainty if not impossibility that strict controls can be secured. A number of polls run overseas have shown that people's willingness to support such practices diminishes in the face of more information about the dangers and complexities of assisted-suicide and/or euthanasia regimes. 129
- 197. Then again, another alternative question might be: 'Would you support mentally competent adults in New Zealand being able to receive medical assistance in ending their life if they are suffering from a terminal illness or an irreversible physical or mental medical condition if there were genuine alternatives that meant such persons did not have to suffer from pain or unbearable suffering?' Or for reasons unrelated to physical suffering? Emanuel et al note, for example, that people's responses change according to the amount of detail they are given about the personal circumstances the proportion of the general public who agreed with euthanasia for unremitting pain was 66% but this dropped to 49.2%, 36.2% and 29.3% respectively for the categories "functional debility", "burden on family" and "view life as meaningless". 130
- 198. It is also to be expected that there would be a difference in people's responses if they were asked how they felt about the availability of euthanasia and assisted suicide in cases of irreversible psychiatric illnesses or intellectual disabilities as well as or separately from cases of irreversible physical conditions.
- 199. The only sure conclusion to be drawn about the 2012 Horizon poll is that New Zealanders are compassionate people who want to address suffering.

SA

See the discussion above, and further, for example, M. Golden and T. Zoanni, "Killing us softly: the dangers of legalizing assisted suicide," *Disability and Health Journal* 3, no. 1 (2010); Dr David Jeffrey quoted in Health and Sport Committee, "Stage 1 Report on Assisted Suicide (Scotland) Bill"

ComRes, "Care - Assisted Suicide Poll," (United Kingdom2014). at http://www.comres.co.uk/wp-content/themes/comres/poll/Care_Assisted_Suicide_Poll_July_2014_(with_summary_table).pdf

JE. Emanuel et al., "Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public.," The Lancet 347(1996)..

- 200. Moreover, various overseas polls show that people's willingness to support the legalisation of assisted suicide and/or euthanasia changes depending significantly on the language employed in the questions. "70% of Americans [are] in favor of allowing doctors to hasten a terminally ill patient's death when the matter is described as allowing doctors to 'end the patient's life by some painless means.' At the same time, far fewer 51% support it when the process is described as doctors helping a patient 'commit suicide' and only 45% of respondents support 'doctor assisted suicide'." ¹³¹
- 201. Further, it has been shown that many people who indicate their support for assisted suicide and/or euthanasia do not understand the distinctions between withholding and withdrawing treatment. When terms such as "medical aid in dying are used" the confusion is even greater. The 2013 Canadian survey above is a telling example: on the basis of the responses to that survey, the majority of people supporting "medical aid in dying" thought they were endorsing palliative care or the right to discontinue intrusive medical treatment. These insights cast significant doubts on the usefulness and accuracy of the various New Zealand polls.
- Most importantly, as discussed above, the issues around euthanasia and assisted suicide are complex and not necessarily well understood, and certainly are not accommodated within a brief polling question. What is apparent from the legislative experience overseas (discussed below) is that in almost every case where the issues are fully considered the proposal is rejected.
- As Professor Adhar concluded in his 2014 report on the legalising euthanasia and assisted suicide in New Zealand: "Voluntary euthanasia and physician-assisted suicide is a complex and challenging subject ... The arguments in favour of legalizing VE and PAS initially appear convincing. We should respect people's personal autonomy and free choice, euthanasia is a compassionate response to unbearable suffering, it has worked well in those nations that have implemented it, and so on. But on closer analysis the arguments for VE are less persuasive ..."

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Gallup, "U.S. Support for Euthanasia Hinges on How It's Described," (Washington2013). at http://www.gallup.com/poll/162815/support-euthanasia-hinges-described.aspx

Professor Rex Adhar, Faculty of Law at the University of Otago "Killing me softly: should euthanasia be legalized" Report to Family First New Zealand 2014.

New Zealand's position is consistent with the vast majority of the rest of the world

While proponents of assisted suicide and euthanasia for New Zealand routinely refer to the small minority of countries or states that allow their citizens access to euthanasia or assisted suicide, in fact many more jurisdictions have considered and voted down such proposals. Even if following other jurisdictions was an appropriate approach for New Zealand to take, given our unique culture and particular social issues, international experience actually points to a much stronger argument against its introduction.

205. Over the last 20 years a few jurisdictions have allowed some form of euthanasia or assisted suicide. It is important to note, however, that these are a tiny minority, and that in most jurisdictions in the world euthanasia and assisted suicide remain unlawful. Further, in most jurisdictions where a euthanasia or assisted suicide bill has been proposed, it has been rejected.¹³³

206. Two observations can be made about the history of legislative proposals. First, in the vast majority of cases, legislators who are exposed to the full breadth of the competing arguments reject the proposal.

207. Secondly, the proponents of such legalisation do not accept rejection: there is always another attempt. There appears to be little acceptance that the concerns which lead to the repeated rejection of the proposal have any validity, but rather continued (failed) attempts to change the law are themselves cited as somehow demonstrating support for "inevitable" change.

208. In the time available, I have been able to collate the following summary of recent legislative responses to proposals to change the law to allow euthanasia and assisted suicide.

Australia

Australia's Northern Territory became the first place in the world to legalise euthanasia with the passing of the Rights of the Terminally Ill Act in 1995. The legislation allowed a physician in defined circumstances to comply with a request from a patient that the physician end the patient's life or assist the patient to end his or her own life.

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For a wide ranging survey, although now somewhat dated, see John Keown, Euthanasia, Ethics and Public Policy: An Argument Against Legislation, Port Chester, NY, USA, Cambridge University Press 2002.

The Act was repealed in 1997 by the Australian Senate after it had been considered by the Senate Legal and Constitutional Legislation Committee. Amongst other issues, the Committee's terms of reference required it to consider the impact on, and attitudes of, the Aboriginal community. During the course of the inquiry, a major concern emerged whether the Northern Territory legislation might impact on the willingness of Aborigines to access medical services, given their cultural beliefs and customary laws and was therefore a significant threat to Aboriginal health. The Committee found that Aboriginal communities supported the repeal of the Rights of the Terminally Ill Act.

211. There have been a number of failed attempts to legalise voluntary euthanasia in Australia:

Medical treatment (Amendment) Bill 1995 (ACT);

Euthanasia Referendum Bill 1997 (ACT);

Rights of the Terminally Ill Bill 2001 (NSW);

Voluntary Euthanasia Trial (Referendum) Bill 2002 (NSW);

Voluntary Euthanasia Trial (Referendum) Bill 2003 (NSW);

Rights of the Terminally Ill Bill 2003 (NSW);

Rights of the Terminally Ill Bill 2010 (NSW);

Rights of the Terminally Ill Bill 2010 (NSW);

Rights of the Terminally Ill Bill 2011 (NSW);

Rights of the Terminally Ill Bill 2013 (NSW);

Medical Care (Advanced Consent for End of Life Treatment) Bill 2014 (NSW);

Voluntary Euthanasia Bill 1995 (SA);

Voluntary Euthanasia Bill 1996 (SA);

Dignity in Dying Bill 2001 (SA);

Dignity in Dying Bill 2001 (SA);

Dignity in Dying Bill 2003 (SA);

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The Commonwealth of Australia, Senate Legal and Constitutional Legislation Committee, *Euthanasia Laws Bill 1996*, March 1997 (p. ix).

¹³⁵ At paragraphs 9.14 -9.17.

Dignity in Dying Bill 2005 (SA);

Voluntary Euthanasia Bill 2006 (SA);

Voluntary Euthanasia Bill 2007 (SA);

Voluntary Euthanasia Bill 2008 (SA);

Consent to Medical Treatment and Palliative Care (Voluntary Euthanasia) Amendment Bill 2008 (SA);

Voluntary Euthanasia Bill 2010 (SA);

Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010 (SA);

Consent to Medical Treatment and Palliative Care (End of Life Arrangements) Amendment Bill 2010 (SA);

Criminal Law Consolidation (Medical Defences - End of Life Arrangements) Amendment Bill 2011 (SA);

Voluntary Euthanasia Bill 2012 (SA);

Ending Life with Dignity Bill 2013 (SA);

Dying with Dignity Bill 2009 (Tas);

Voluntary Assisted Dying Bill 2013 (Tas);

Medical Treatment (Physician Assisted Dying) Bill 2008 (Vic);

Voluntary Euthanasia Bill 1997 (WA);

Voluntary Euthanasia Bill 1998 (WA);

Voluntary Euthanasia Bill 2000 (WA);

Voluntary Euthanasia Bill 2000 (WA);

Voluntary Euthanasia Bill 2002 (WA);

Voluntary Euthanasia Bill 2010 (WA);

Euthanasia Laws (Repeal) Bill 2004 (Cth);

Australian Territories Rights of the Terminally Ill Bill 2007 (Cth);

Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 (Cth);

A comprehensive report in response to the Tasmanian proposals in 2013 is illustrative of the level of controversy around this issue in Australia. 136

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Voluntary Euthanasia and "Assisted Dying" in Tasmania: A response to Giddens and Mckim.136 (October 2013) by Hannah Graham and Jeremy Prichard.

213. The Senate Legal and Constitutional Affairs Legislation Committee of the Commonwealth of Australia last year considered a draft exposure bill (prepared by an individual senator and not yet before the Senate). The Committee reported in November 2014, recommending that more work be undertaken if the Bill was to proceed any further.¹³⁷

Westminster

- 214. The Lords Select Committee on Medical Ethics (1992-1994) was established to consider the ethical, legal and clinical implications of life-shortening actions. Their report in 1994 rejected any change in the law on assisted suicide. The Government accepted this recommendation.
- 215. Lord Walton outlined the content of the report: 139 "Little did I think, as our task began, that it would be possible to achieve unanimity. I was only too well aware of the wide range of religious and ethical opinion represented on the Committee and of the many entrenched differences of opinion on the topics that we were required to consider which had been exposed in the media in the past few months and years. But, in the end, although there was a single important issue on which we disagreed, we did not find it necessary to divide as we concluded that that particular point, to which I shall refer later, need not be decided. Hence it is with very great pleasure that I am able to present a unanimous report to the House."
- On euthanasia he said: "Ultimately, however, we concluded that such arguments are not sufficient reason to weaken society's prohibition of intentional killing which is the cornerstone of law and of social relationships. Individual cases cannot reasonably establish the foundation of a policy which would have such serious and widespread repercussions. The issue of euthanasia is one in which the interests of the individual cannot be separated from those of society as a whole."

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Report of the Senate Legal and Constitutional Affairs Legislation Committee on the Medical Services (Dying with Dignity) Exposure Draft Bill 2014

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Dying_with_Dignity/Report

Select Committee on Medical Ethics. Report. London: HMSO, 1994. (House of Lords paper 21-I).

House of Lords Debate 09 May 1994 vol 554 cc1344-412. http://hansard.millbanksystems.com/lords/1994/may/09/medical-ethics-select-committee-report

- 217. Lord Walton said that the Committee concluded that "it would be virtually impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law in the United Kingdom could not be abused. We were also concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death."
- Between 2003 and 2006 four bills promoted by Lord Joffe were rejected by the House of Lords. The House of Lords Select Committee reported on the Assisted Dying for the Terminally Ill Bill in 2005. Because of time constraints (the Bill was not to progress in the current session) the Committee decided to report only on the evidence received and make recommendations on how the matter should be handled if the bill proceeded in the next session, "rather than ruling on the acceptability or otherwise" of the bill. The recommendations included: "in the event that such a bill should be brought forward, those responsible for framing it should give serious consideration to a number of key issues which have emerged during the course of our inquiry and which, we believe, lie at the heart of the debate on this subject."
- 219. The House of Lords has recently considered a further proposal, the Assisted Dying Bill proposed by Lord Falconer in 2014. The bill was allowed to go into abeyance at the end of the Parliamentary session prior to the general election this month. The debate in the House of Lords demonstrates the high level of controversy surrounding this proposal in the United Kingdom.¹⁴¹
- 220. I understand that the High Court has recently given approval for a disability rights group to bring a judicial review of the 2013 relaxation of the DPP prosecution guidelines on mercy killings.¹⁴²

Scotland

221. The select committee of the Scottish Parliament reported back on the non government Assisted Suicide (Scotland) Bill on 30 April 2015, with the majority concluding that they did not support the general principles of the

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House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the Terminally Ill Bill [HL] Volume 1: Report, 2005. http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf

See for example the debate in the House of Lords at the second reading on 18 July 2014 http://www.publications.parliament.uk/pa/ld201415/ldhansrd/text/140718-0001.htm#14071854000545

http://www.bbc.com/news/uk-32502800 NE

Bill. 143 The Committee unanimously concluded that the bill contains significant flaws.

222. Most of the 886 submissions on the bill were in favour (73 percent in favour, 24 percent opposed, 3 percent neutral¹⁴⁴). The Committee's report illustrates the common pattern that committees that have the opportunity to consider the full range of arguments and evidence generally come to the conclusion that euthanasia and assisted suicide should remain unlawful.

United States of America

- 223. Euthanasia is not legal in any state in the US.
- 224. Physician-assisted suicide bills are regularly and repeatedly proposed and rejected in individual states. There are 23 bills across various states under consideration this year. In California, for example, the End of Life Option Act is the seventh attempt to introduce assisted suicide since 1994. Similarly, in April the Connecticut General Assembly's Judiciary Committee considered and rejected an assisted suicide bill for the third time in three years.
- 225. The Tasmanian Report,¹⁴⁵ for example, records that in the USA, between January 1994 and March 2011, there were 122 legislative attempts to legalise assisted suicide euthanasia in 25 states. Two succeeded (Oregon and Washington), while the remaining 120 attempts were defeated or withdrawn.
- 226. Three states now have legislation permitting physician-assisted suicide (Oregon in 1997, Washington State in 2009 and Vermont in 2013), while courts in two other states (Montana in 2009¹⁴⁶ and New Mexico in 2014¹⁴⁷) have made rulings enabling it.
- 227. Physician assisted suicide remains illegal in 45 states.

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Health and Sport Committee, Stage 1 Report on Assisted Suicide (Scotland) Bill, 6th Report, Session 4 (2015) at paragraph [318].

Michelle Rostant-Bell, Analysis of submissions of evidence on the Assisted Snicide (Scotland) Bill, at p. 1. (Commissioned by the Scottish Parliament Health and Sport Committee.) Downloaded from the Scottish Parliament website at www.scottish.parliament.uk, on 3 May 2015. NE

Voluntary Euthanasia and "Assisted Dying" in Tasmania: A response to Giddens and Mckim.145 (October 2013) by Hannah Graham and Jeremy Prichard.

Patients Rights Council website at www.patientsrightscouncil.org/site/montana; accessed 7 May 2015.

Patients Rights Council website at http://www.patientsrightscouncil.org/site/new-mexico; accessed 7 May 2015.

Conclusion

- An interpretation of the Crimes Act which would have the effect of erasing the "bright line" of New Zealand's prohibition against euthanasia and assisted suicide is fraught with ethical and practical difficulties.
- 229. It would be a fundamental challenge to the ethics of the medical profession.
- 230. It would privilege a particular, and inadequate, narrative regarding the place of the elderly, the sick and the disabled, without reference to the wider views of the society being so re-defined.
- It would compound the risk of abandonment, discrimination and abuse already faced by vulnerable people such as the elderly, the disabled and the mentally ill. It would be naive to imagine that such abuse will not continue into this arena, or that regulatory controls of any design could ensure that they would never be exposed to discrimination, pressure, coercion or even force. To expose our most vulnerable groups to this risk, with such a final fatal consequence, is unnecessary and dangerous. It would be to promote the interests of the strong at the expense of the weak.

SWORN

at Wellington this 12th day May 2015

before me:

Varsha Budhia

John Henry Marinus Kleinsman

A (Deputy) Registrar of the High Court of New Zealand