



Lilian Topic,
Secretary,
Legal & Social Issues Committee
Parliament House,
Spring Street,
Melbourne VIC 3002

August 2015

Dear Ms Topic,

Reference: Inquiry into End of Life Choices.

Thank you for the invitation to make a submission to this inquiry.

HOPE congratulates the Victorian Parliament on initiating this inquiry. While we oppose the introduction of euthanasia and assisted suicide we hope that discussing these matters within the broader context of end-of-life issues will assist the Victorian Parliament in developing a clear understanding of not only the dangers inherent in such laws but also a vision and a plan for the development of health services where the needs of all Victorians are met.

The question of patient choice is an important consideration related closely, as it is, to the principle of informed consent. But choice is not simply a slogan. Consideration of the question of choice must also extend to the provision and availability of services to all Victorians on an equitable basis and, by extension, to all Australians. Without equal access to quality services is it likely that Victorians in rural communities, for example, will have the same 'choice' as their city counterparts?

Please feel free to contact me for any further information.

(per email)

Paul Russell – Director, HOPE: preventing euthanasia & assisted suicide Inc.

M: [REDACTED]

HOPE is a not-for-profit incorporated association. We are a coalition of groups and individuals who oppose the legalization of euthanasia and assisted suicide and support measures that will make euthanasia and assisted suicide unthinkable.

HOPE: preventing euthanasia & assisted suicide exists to build a well-informed broadly-based network of groups and individuals to create an effective social and civic barrier to euthanasia and assisted suicide.

Inquiry into End of Life Choices

TERMS OF REFERENCE

That pursuant to Sessional Order 6 this House requires the Legal and Social Issues Committee to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

Opening Comments:

The last occasion that an Australian Parliament looked at euthanasia and assisted suicide through an inquiry without having the context of a particular bill was in 1998 in Tasmania. HOPE believes that the Report to the Tasmanian Parliament should be adopted by this committee as a reference point. The question can therefore be asked: what has changed since 1998? Seventeen years on, we contend that the findings of that committee bear at least the same relevance and pose the same issues for Victoria.

FINDING 4: The Committee found that whilst individual cases may present a strong case for reform the obligation of the state to protect the right to life of all individuals equally could not be delivered by legislation that is based on subjective principles.

FINDING 7: The Committee found that the codification of voluntary euthanasia legislation could not adequately provide the necessary safeguards against abuse.

FINDING 10: The Committee found that the legalisation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the state to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia.¹

The principle of equal protection under the law is pivotal in terms of any discussion on euthanasia and assisted suicide, evoking, as the Tasmanian Report articulated, matters of justice in protecting 'the

¹ Community Development Committee Report on the need for Legislation on Voluntary Euthanasia, Tasmania 1998 http://www.parliament.tas.gov.au/ctee/old_ctees/reports/Voluntary%20Euthanasia.pdf

more vulnerable members of society'. Finding 10 juxtaposes the 'freedom to choose' against the notion of 'equal protection' and finds the latter to be a higher-order priority.

HOPE believes that justice and equity as understood and enunciated in human rights conventions places certain demands upon society in respect to the common good and that such demands include the protection of the basic rights of everyone in respect to their life and their person.

We believe that the prohibition on killing another human person or assisting them to kill themselves should remain in force.

If we accept that the law should not be changed, then perhaps we can focus the abundant sentiments of compassion evident on all sides of the end-of-life debate towards a renewed focus on palliative care and medical training to ensure that all Victorians and all Australians have the confidence that, if ever in need of such care, it will be available and delivered in such a way as to support their aspirations to die well.

Paul Russell
Director
HOPE: preventing euthanasia & assisted suicide Inc.

August 2015

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1. Executive Summary

Section 2: Advance Care Planning and Directives

- Reviewing the Victorian Advance Care Planning (ACP) system, we find that the current framework strikes a good balance. Completing an ACP with a doctor and reviewing a plan in the same manner makes very good sense.
- We are concerned about the possible inclusion of 'binding provisions' and note that in the current system, this is not necessary nor desirable. The absence of anything that is binding, we submit, also supports our suggestion that doctors should retain the right of conscientious objection.
- We conclude this section by observing the ACPs are problematic in circumstances where euthanasia or assisted suicide is possible.

Section 3: Rights talk

- We begin our observations about 'rights' by reflecting on the fundamental human rights to freedom and protection from harm and argue, from that point, that it is a matter of justice that any euthanasia and/or assisted suicide legislation advanced should also use the 'precautionary principle' to prove, beyond doubt, that no Victorian will ever be placed 'at risk' under such a law.
- We also discuss the false notion of a 'right-to-die' and then explore the consequences of a euthanasia and/or assisted suicide law in terms of the 'right' that it would create, concluding that it is 'rights talk' that would ultimately see the law extended in practice, in form, or both.

Section 4: Palliative Care

- Palliative Care in Victoria has been the subject of a recent and extensive report to the parliament. We conclude that more needs to be done in the Victorian community to increase the awareness and understanding of what palliative care is and what it can achieve as a matter of public good and human welfare.
- We also look at Palliative Care in places where euthanasia and/or assisted suicide is publicly available and observe that those seeking euthanasia in Belgium and The Netherlands are not necessarily accessing palliative care, that euthanasia is becoming an 'early intervention' rather than a 'last resort' (which we contend is the public perception).
- We look at the availability of services in Victoria and nationally and observe that access is nowhere near the levels recommended by peak bodies, particularly in rural Australia and we question how we could make euthanasia and/or assisted suicide available as a 'choice' when, for some, there may be no real choice at all.

Section 5: Informed Consent

- We look at the ideal that is informed consent in terms of the exercise of patient autonomy and conclude that the notion of 'choice' is illusory given that the ultimate decision making (or 'choice') belongs to the physician.

- We also explore the question of autonomy looking at its natural limits and the effect upon the rights and autonomy of others when said limits are breached.

Section 6: The problems with safeguards

- Safeguards and their effectiveness in terms of both containing the parameters of any euthanasia and/or assisted suicide law and in protecting the rights of patients is brought into question.
- We argue that the problems of subjective language, with prognoses, with problems in defining 'terminal illness', doctor shopping, the role of psychiatrists as gatekeepers and posthumous reporting all lead to the conclusion that safeguards are anything but 'safe'.

Section 7: The Risk of Abuse

- The expressed need for safeguards tells us that there are inherent risks in euthanasia and/or assisted suicide legislation – risks of abuse. That said abuse may result in death should create a pause for thought.
- We look broadly at the question of 'vulnerable persons' through the lens of Elder Abuse, risks of coercion and the voices of people living with disability.
- We look at the negative messages that society sends to the elderly and sick
- We cite the example of the problems with the Liverpool Care Pathway in the UK as evidence of the risk of slippage.
- We conclude that the risk of abuse is real and cannot be eliminated.

Section 8: The Suicide Connection

- Making the connection between suicide and euthanasia and assisted suicide is, perhaps, unremarkable. However, as we discuss and juxtapose the putative 'person on the ledge' with potential euthanasia and assisted suicide candidacy we conclude that there is a dissonance in the way each is treated and viewed.
- We also look at the question of suicide contagion and raise a cautionary note about the possible connection between euthanasia and assisted suicide and suicide ideation.

Section 9: Conclusion

- HOPE affirms our rejection of euthanasia and assisted suicide and argue that the role of the State of Victoria lies in the extension and promotion of Palliative Care services.

2. Advance Care Planning and Directives

The advent of advance care planning and the idea that a person could/should express their thoughts and requests about their preferred care plan is a relatively new phenomenon that seems to have grown side-by-side with the development of thought on the importance of informed consent in all kinds of decision making.

That people should hold some concern about their future health and, indeed, what their ultimate demise might look like is nothing new and entirely understandable. But it should be noted that fear of what the future might look like, either in contemplating a current prognosis or in less specific terms, about death and dying generally, is also recognised as one of the drivers in thinking about euthanasia and assisted suicide.

Such fears can be about possible pain and suffering; but they are more often fears about the unknown and a perception of future loss of autonomy.² Discussions about end-of-life planning with the goal of articulating and recording thoughts about choices and personal preferences supports autonomy and increases wellbeing by restoring or reinforcing a person's sense of control. We therefore welcome the provision of such instruments and all public education endeavours that assist in the knowledge that such efforts contribute to the well-being of all Victorians.

2.1 The South Australian model

The South Australian Government recently reformed its approach to advance care planning

Advance Care Directives Act 2013

An Act to enable a person to make decisions and give directions in relation to their future health care, residential and accommodation arrangements and personal affairs; to provide for the appointment of substitute decision-makers to make such decisions on behalf of the person; to ensure that health care is delivered to the person in a manner consistent with their wishes and instructions; to facilitate the resolution of disputes relating to advance care directives; to provide protections for health practitioners and other persons giving effect to an advance care directive; and for other purposes.³

This new Act of Parliament was followed by a new form and guide to completing an Advance Care Directive (ACD)⁴. This form takes a very broad approach to planning so as to include provision for a person to include preferences concerning living arrangements and even the care of pets. In terms of providing a person with a sense of control over their future circumstances, this is very welcome.

² See for example, the 2014 DWDA Oregon Report: "As in previous years, 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%)." Available at:

<http://www.livinganddyingwell.org.uk/sites/default/files/year17.pdf>

³ Advance Care Directives Act 2013 SA

http://www.legislation.sa.gov.au/LZ/C/A/ADVANCE%20CARE%20DIRECTIVES%20ACT%202013/CURRENT/2013_10.UN.PDF

⁴ See: http://www.advancecaredirectives.sa.gov.au/upload/home/Current_ACD_Guide.pdf

There are, however, risks attached to creating such an all-encompassing document. Whereas expressions of a non-binding nature (such as who might look after the cat) are unlikely to change much over time, the creation of expressions that are considered binding under an ACD, such as decisions relating to the refusal or withdrawal of treatment, may, change over time.

Given that an ACD, in South Australia may be completed at a time when the person does not have a life-threatening or life-shortening prognosis and, therefore, no specific knowledge about possible treatments, such directives are likely to be made without fully informed consent.

2.2 Victoria

By way of contrast, the Victorian enabling legislation, *The Medical Treatment Act 1998*, provides for the completion of a directive in consultation/discussion with a medical practitioner who provides witness to the completed document. It relates to a particular condition and is, therefore, much more likely to adequately reflect the person's wishes over time and over the progress of the particular condition.

Even here, however, there are pitfalls. For example: in the weeks and even months after being told of a diagnosis and/or poor prognosis, there is a likelihood of confusion and even depression as a person works through what is, after all, a life-shattering change. This would not be an ideal time to be considering making any directives.

The guide to completing an ACD in South Australia is an excellent, user-friendly form. However, its shortcomings, in being a general document rather than condition/event-specific, is such that it is not likely to be completed in consultation with a medical practitioner and, therefore, may be written in layperson's terms that could lack precise meaning. While the guide does provide examples of clear language and warns against generalities, the potential for confusing and ill-informed statements still remains.

While the extant Victorian regimen of working in consultation with a medical professional is, in our opinion, a better approach, we also observe that the system of completing, registering or revoking a 'Refusal of Treatment Certificate' seems, in comparison with South Australia at least, cumbersome and overly complex. Whereas a patient, under the South Australian scheme can verbally override any previous written statement to a medical professional, the extant Victorian scheme seems to demand a formal revocation.

2.2.1. Victorian proposed reforms

We note, in a pre-election promise, that the now Premier Andrews committed his new government to, 'new laws giving people clearer rights to set directives about the kind of medical care they would want in the event of future conditions such as cancer, brain damage or dementia'. *The Age* article added:

'At present, people can make orders for the treatment they want for an existing medical condition, but the guidelines around future illnesses lack clarity.'

*"We will legislate to change that," Mr Andrews said. "It just means people can be really clear about their medical conditions and the sort of care that they don't want administered well in advance."*⁵

We have already covered the problems with the idea of decisions made 'well in advance'. While the Victorian system may need updating, we urge the Victorian Parliament to conclude that, keeping in mind the possibility of anxiety etc., that decision making close to or in the event of the onset of a condition or disease is much more likely to reflect the true intentions of the person and is therefore much more likely to reflect and uphold the principle of informed consent. This is well covered in the Victorian Advance Care Planning document.⁶

We also urge the committee to grapple with the possibility that a binding directive may give voice to a suicide-driven directive by the refusal of ordinary care. There is a movement in some pro-euthanasia organisations in the USA towards promoting the idea of Voluntary Stop Eating and Drinking (VSED) through the refusal of nutrition and hydration in an ACD⁷ even in circumstances where the person has no underlying, life-threatening illness.

This is a deeply disturbing proposition that has a number of ethical facets that demand consideration.

While the act of suicide has been decriminalised, suicide is still something that society discourages and shuns. It is not a legal act and assisting in suicide remains an offence. A person who intends to self-harm and is a risk to himself or herself may be detained under Part 4 of The Mental Health Act 2014.

How, then, is a medical practitioner and any reformed law on Advance Care Directives to deal with the possibility that a person may deliberately design to endorse and ensure his or own premature death (suicide) through an expression in an ACD?

As mentioned earlier, depression is common in the weeks and possibly months after a person receives advice of a poor prognosis. It is entirely possible that, in a state of poor mental health, a person may decide to direct that he or she not be fed or watered so as to deliberately bring about their own death. And while nutrition and hydration may legitimately be refused by a competent person and such refusal may be honoured even if capacity is lost, the use of an ACD presupposes a condition such that there is an implied relationship between such refusal and an impending demise from a known ailment.

2.2.2. Binding provisions

In the South Australian model, directives on the refusal or withdrawal of medical interventions are made binding. However, the binding nature is contestable by the medical professional if he or she considers that 'the person who gave the advance care directive did not intend the provision to apply in the particular circumstances; or (b) the provision does not reflect the current wishes of the person

⁵ The Age, 16 Nov 2014. *Victorians to get a greater say in dying with dignity under Labor reforms.*
<http://www.theage.com.au/victoria/state-election-2010/victorians-to-get-a-greater-say-in-dying-with-dignity-under-labor-reforms-20141115-11nelp.html>

⁶ Advance Care Planning: Have the Conversation – A strategy for Victorian health services 2014-2018.

⁷ A FACT SHEET on VSED is available at The Patient's Rights Council website:
http://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED_Questions.pdf

who gave the advance care directive.⁸ The question here is how the medical professional will ever truly know unless there has been a prior opportunity for review. In some situations, for example an accident causing temporary loss of capacity, the distinction will be clear, (that is: the ACD would not apply) but this will not always be the case.

While making certain provisions of an ACD binding upon the attending medical professionals has a certain attraction in that persons completing an ACD will obtain peace of mind from such certainty, we consider that the risks associated outweigh the possible benefits. While the Victorian ACP strategy document uses the term 'Advance Care Planning' to also include 'Advance Care Directives' it is otherwise silent on the distinction and, to the reading of this writer, the entire document is framed in terms of planning.

2.3. An alternative

As an alternative approach, we suggest that a protocol be developed that will give rise to the creation of (or review of) an ACP at certain 'trigger points' in a person's relationship with their medical practitioner through certain 'life change events' where it would be appropriate to visit the issue. For example, whether an ACP exists or not, moving to an Aged Care facility would be a good time to consider either making or rewriting an ACP. We have noted that the time a diagnosis is made is probably not a good time, but it might be a moment where the medical practitioner could schedule a further appointment and review in coming months. The same could be said for any programmed hospital procedure. Again, the Victorian ACP strategy document describes this well.⁹

This approach has the advantage of recording plans that are far more likely to be fully informed and therefore more likely to reflect the true and lasting intentions of the person concerned. Given that the ACP would be completed cognisant of current circumstances, it is much more likely to contain directions that are appropriate, achievable, ethical and easy to understand.

2.4. Conscientious objections

The South Australian law also provides for any medical professional to be able to refuse to comply with any provision(s) in an ACP on conscientious grounds.¹⁰ While we agree with this provision, it is also problematic in some ways, particularly in consideration of the fact that writing the ACD in South Australia does not require any input from the medical professional and the first time said medical professional may become aware of its provisions could be in an acute setting.

HOPE does not support any requirement that would remove or compromise a medical professional's ability to refuse. We include here any suggestion that a refusing medical professional be bound to refer the person to another doctor. Again, the revision or completion of an ACP at or near the time when a medical procedure or other event might trigger the ACP should be sufficient for the medical professional and the person concerned to be able to work through any contentious matters.

⁸ Ibid. Section 36 (2)

⁹ Ibid. pp. 4, 24 & 25.

¹⁰ Ibid. Section 37.

2.5. Advance requests and euthanasia

In closing, it is perhaps worthy of note that, in The Netherlands, a euthanasia request can be made via an advanced care directive. This makes sense if the whole issue turns on the principle of autonomy and if euthanasia and assisted suicide are considered to be 'medical treatment'. However, this option, we contend, undermines the entire flimsy regimen of checks and balances in the Dutch (and any) euthanasia regime because the intent, the voluntary nature of the decision, whether the decision was fully informed and, indeed, whether the written request was made free from coercion, cannot be tested.

This will pose significant dilemmas if ever euthanasia and/or assisted suicide become legal. We will discuss later the question of autonomy and informed consent. We observe at this point that, if euthanasia and/or assisted suicide were legally available that a person completing an ACD would have every right to make such an advance request. How will medicine and the law deal with a binding directive of that nature in terms of assessment?

3. Rights talk

The right to life which the State is obliged to vindicate, is a right which implies that a citizen is living as a vital human component in the social, political and moral order posited by the Constitution. While it may be said that it is of the essence of certain types of rights, such as that of the right to associate, that they logically apply as a corollary a right to dissociate, that reasoning cannot be applied to all rights guaranteed by the Constitution. In particular the protection of the right to life cannot necessarily or logically entail a right, which the State must also respect and vindicate, to terminate that life or have it terminated. In the social order contemplated by the Constitution, and the values reflected in it, that would be the antithesis of the right rather than the logical consequence of it. Supreme Court of Ireland (2013)¹¹

Human Rights considerations in respect to euthanasia and assisted suicide, we argue, must protect vulnerable persons from abuse of their fundamental right to exist. We contend that euthanasia and assisted suicide place such people at risk.

Euthanasia and assisted suicide arguments talk about legislative 'safeguards' which confirms and acknowledges that such risks do exist. Without the inclusion of these supposed 'safeguards' we sincerely doubt that any legislature would seriously consider adopting a legal framework. (We will look at the ineffective nature of legislative safeguards later on.)

In terms of the fundamental right to exist – a right enshrined in international human rights treaties – we observe that such 'safeguards' need to be proven to be absolutely effective in protecting all citizens in all circumstances. Euthanasia and assisted suicide laws would be unlike any other legislative instrument on any of Australia's statute books. Not only is the intention death, any unintended consequences of the legislation's inability to adequately protect all Victorians may also result in death. Statutes can and often are later amended because of unforeseen consequences; but, rarely would such mistakes include death.

¹¹ Fleming v Ireland & ors [2013] IESC 19 (29 April 2013) available at <http://www.bailii.org/ie/cases/IESC/2013/S19.html>

3.1. The Precautionary Principle

HOPE believes that all parliaments should adopt the precautionary principle in respect to such legislation. This principle should put the onus of proof about the efficacy of such 'safeguards' squarely upon those proposing the regime who would need to provide certainty that no person would ever be at risk of the loss of their life in circumstances where they did not request it, where they may have been pressured into it or where their circumstances were such that they did not qualify. It is simply not enough to assert that the safeguards will work.

This is a high standard and one, no doubt, that some would claim is impossibly high and far higher than for any other legislative regimen. But, as we have observed, most legislation does not have such grave and final consequences. The Tasmanian inquiry found that no legislation could '*adequately provide the necessary safeguards against abuse*'. This risk of abuse needs to be the baseline when we talk about real human rights.

There are other implications of 'rights talk' that also need to be considered.

3.2. Is there a 'right-to-die'?

It has been argued, falsely, that a 'right to die' is the 'other-side-of-the-coin' of the 'right to life'. There can be no 'right to die' as death befalls us all. It would be akin to saying that there was a right to be affected by the laws of gravity. As the Irish Court observed, it is the antithesis of the 'right to life'.

The euthanasia and assisted suicide polemic often frames access to such laws in terms of a 'right to die'. But there should be no doubt that creating a euthanasia and/or assisted suicide legal regimen would create a 'right' (albeit a false one) in terms of the law: a right in prescribed circumstances for a citizen to be 'made dead', and a corresponding duty upon the state to provide for or to make available a legal framework for such deaths to take place.

*'The debate has changed. Euthanasia is no longer a last resort. It was originally seen as a law that gave doctors rights rather than patients. But we very frequently hear it discussed in terms of a patient's right to euthanasia.'*¹²

If access to euthanasia and/or assisted suicide is made available to a limited section of the community under certain circumstances and conditions, by what argument will the law be able to contain, over time, said parameters and restrictions if, as indeed will be the case, such access is considered to be a 'right'? The 'right' and principle that it is lawful and even desirable for doctors to kill people will already exist in law. That Rubicon crossed, all that would be left to decide is where next to draw the boundaries. Such is the case in the development of euthanasia for children in both Belgium and The Netherlands.¹³

¹² Professor Theo Boer. *Rise in euthanasia requests sparks concern as criteria for help widen* DutchNews July 3, 2015 <http://www.dutchnews.nl/features/2015/07/rise-in-euthanasia-requests-sparks-concern-as-criteria-for-help-widen/>

¹³ The Belgian state was amended in 2013 while the matter is currently being discussed in Holland.

3.3. Legal euthanasia and assisted suicide would become a 'right'

That a euthanasia law creates an understanding in the community that said law confers a 'right' of sorts should be entirely unremarkable. If a 'right' then there are corresponding entitlements to access to such a right. This is a well understood principle in politics. It is confirmed by the developments in Belgium and The Netherlands.

Dutch Professor and former member of the Dutch Euthanasia Evaluation Commissions, Theo Boer, in a recent address, observed the following:

"Undeniably, assisted dying for one group of patients leads to demands from others."

"Whereas in the beginning assisted dying was seen as a last resort, public opinion is shifting towards considering it a right, with a corresponding duty on doctors to act."¹⁴

Belgium's co-chair of its euthanasia evaluation commission, oncologist Dr Wim Distelmans, was quoted recently in the newspaper *De Morgen* as saying: "Choosing euthanasia is a fundamental human right and patient's right."¹⁵

Belgium seems to have been captured by this 'rights talk' even more so than its neighbour. We should consider, in the context of a society where euthanasia has been practiced lawfully for more than a decade, how a limited 'right' has progressed to being considered a 'fundamental right'; and, if a 'fundamental right' then what obligations are placed on the state to enforce and support it, as Boer observes.

Such obligations, or duties press upon the state and upon medical professionals. The state, in debating and passing a bill, accepts that it has obligations to provide for this 'right to die' and does so by creating a regimen. That, initially at least, such a regimen will be limited to certain persons only, is a given as already discussed. However, the 'right' it will have created is not simply a 'right for a few'. By the very nature of rights, the state will have created a 'right to die' which applies generally (to all) but which would be initially restricted to a few.

3.4. If a 'right' incremental extension is inevitable

Consider: If, as has occurred in Belgium, The Netherlands and recently proposed also in Oregon, we see, following the earlier passage of a euthanasia law, a new bill arguing for extending the criteria to, say, for the sake of argument, non-terminally ill people; will this new debate be about whether or not we should allow doctors to kill in some circumstances? No, that matter had already been decided in the affirmative in the previous debate. This new debate would simply revolve around arguments relating specifically to this new category of persons and the wording of an amendment bill.

The state, in breaching the bulwark that is the criminal code prohibition on killing in the first instance, will have created a 'right' that ultimately others, who fall outside the scope of the original enabling legislation, will want to claim for their own. Such claims will be compelling in the same way as are the

¹⁴ Boer, T. Address to HOPE2015 International Symposium, Adelaide May 2015

¹⁵ Original: "Kiezen voor euthanasie is een elementair mensen- en patiëntenrecht." See: <http://www.demorgen.be/wetenschap/-the-new-yorker-plaatst-vraagtekens-bij-belgisch-euthanasiebeleid-a2360909/>

stories that appear in our media currently pushing for this initial breach. Indeed, one can easily imagine that those original restrictions could be legitimately cited as discriminatory in such later debates.

But more than that, one can easily imagine doctors being pressured to 'bend the rules' out of compassion; even if only a little at first.¹⁶ The lines on parameters such as a prognosis of six months or less are indistinct at the best of times; as is a determination of the terminal nature of an illness.¹⁷ It would not be at all difficult for any doctor to make the criteria work for his or her patient. This is what Professor Margaret Somerville and Donald Boudreau call, 'The Logical Slippery Slope'.¹⁸

In her contribution to the debate that established this inquiry, the Hon Colleen Hartland MLC gave her personal views on euthanasia type legislation:

*"On a very personal note, I have pursued this issue over the last eight years because I think every competent adult should have the right to decide when they will die and how they will die."*¹⁹

Ms Hartland had previously advocated for a limited regimen for only those who were terminally ill, citing her party's policy²⁰ when speaking to her earlier motion on this same question.

We have no issue with this difference but simply observe that the 'every competent adult should have the right to decide when they will die and how they will die' is a logically consistent approach to this issue if one, indeed, is inclined to support the idea. It is virtually the same position as Exit International's head, Dr Philip Nitschke. If one accepts our argument about 'rights' then this approach is the inevitable extension of any limited legislative regimen.

This is precisely what has occurred. It is unavoidable.

4. Palliative Care

From the position statement of the *Australia and New Zealand Society of Palliative Medicine*:²¹

Palliative Medicine is the study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life.

¹⁶ The cited Dutch News article references a Royal Dutch Medical Association survey claiming: *The KNMG survey appears to give substance to Boer's fears on this point: it found that 70% of doctors who replied had felt under pressure to grant euthanasia, while 64% believed the pressure had increased in recent years.* <http://www.dutchnews.nl/features/2015/07/rise-in-euthanasia-requests-sparks-concern-as-criteria-for-help-widen/>

¹⁷ In extremis, many conditions that can be managed with good care and medical support may indeed become terminal if a patient refuses medication.

¹⁸ *Euthanasia and assisted suicide: a physician's and ethicist's perspectives.* Boudreau, J & Somerville, M. *Jnl of Medicolegal and Bioethics* 2014:4 1-12. Available at: http://noeuthanasia.org.au/documents/papers/MB-59303-euthanasia-and-assisted-suicide_071714-somerville-and-Bourdreau.pdf

¹⁹ LC Hansard Thursday 7th May 2015 page 1283

²⁰ LC Hansard Wednesday 15th April

²¹ Australia and New Zealand Society of Palliative Medicine. *Position Statement on the Practice of Euthanasia and Assisted Suicide* (2013). Available at <http://www.anzspm.org.au>

Palliative Care as defined by the World Health Organization is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; it

- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The purpose of this position statement is to state that:

(a) The discipline of Palliative Medicine does not include the practice of euthanasia or assisted suicide;

(b) ANZSPM endorses the **World Medical Association Resolution on Euthanasia, adopted by the 53rd WMA General Assembly, Washington, DC, USA, October 2002**, which states:

"The World Medical Association reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice, and

The World Medical Association strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions."

(c) ANZSPM opposes the legalisation of both euthanasia and assisted suicide.

4.1. Palliative Care and euthanasia

There have been claims heard from time to time that suggest that euthanasia and assisted suicide should be considered as part of palliative medicine. Such claims have ranged in argument from the assertion that euthanasia and assisted suicide are tools in palliative medicine for situations where 'all else fails' or, indeed, that the knowledge that such 'options' exist, provide a sense of control and well-being for the patient.

The former statement is certainly the position commonly taken in Belgium and Holland, even though, as we will discuss later, 40% of those who die by euthanasia do not access palliative care. The latter: that 'peace of mind' at having a euthanasia and/or assisted suicide option makes the inclusion of such practices palliative, is a subtle distortion. While there is plenty of anecdotal evidence to suggest that this may be the case, it is also true that good palliative care, without the euthanasia option, delivers the same outcome of 'peace of mind'.

4.2 Selling the Palliative Care message

Palliative medicine has developed significantly over the last decade and more. The relief of distress, symptom management, pain control and existential suffering are all addressed in services that take the patient-centred approach that characterises palliative care. Assurances from palliative care specialists that all pain can be dealt with, that excellent care is available, that a 'good death' is achievable seem, however, to have done little to ameliorate people's concerns about end-of-life as seen through the polls on euthanasia in recent years.

Submissions to this inquiry will, no doubt, include anecdotes from relatives of people who perhaps have not experienced such a level of care or who may be facing a difficult prognosis themselves. Their concerns are valid and should be heard. However, it would not be proper nor helpful to simply assume that because some people raise their experiences, difficult and heart-rending as they no doubt are, that euthanasia and assisted suicide is the solution. We need to be prepared to dig deeper, recognising the aphorism that 'hard cases make bad law', but also asking the harder questions about the availability of palliative care and the public perception of what good palliative care looks like and how it supports autonomy and patient choice.

Selling the idea and practice of palliative care is not easy. It may be said to be similar to the difficulties in developing the uptake of advanced care planning. No-one really wants to talk about nor hear about death until it insinuates itself into one's immediate future. *Palliative Care Australia*²² has some excellent resources and pamphlets available and commonly found in the brochure racks of medical surgeries; but who reads them? A little like a manufacturer's warranty, perhaps, we never read the details unless we need to.

We know, too, that a little knowledge is a dangerous thing. People know enough about palliative care to leap to the conclusion that to access palliative care will mean that death is imminent - that life as we know it is perhaps already gone and that all that remains is a battle with symptoms that may or may not be successful. But, as one palliative care specialist recently observed: *Palliative Care is not about dying; it is about living until you die.*

We must do more to address these misconceptions; to arrive at a place where palliative care support is embraced as a new travelling companion and an opportunity to be well cared for. We make this plea in the belief that a broader understanding of palliative care and its delivery will address people's natural concerns about loss of autonomy, loss of control, fear of pain etc. and thereby increase their sense of well-being. Euthanasia has been characterised as arising from the fears of the 'worried well'. It is an entirely justifiable outcome of public education to reduce such fears.

²² See <http://palliativecare.org.au/>

We are aware that *Palliative Care Victoria* and *Palliative Care Australia* actively promote greater understanding of their craft and services; but as already observed, people naturally tend to avoid such items in the pamphlet racks. Perhaps it is time for a multimedia promotion including mainstream advertising that sells the message about palliative care and end-of-life planning in Victoria. I am reminded of the very successful (it must have been because I remember it!) public campaign 30 years ago that used the slogan: *Cancer is a word, not a sentence*. Such an initiative on Palliative Care would enhance public wellbeing and should be considered.

4.3. Palliative Care in Belgium, Holland and Oregon

It has often been suggested that legal access to euthanasia and assisted suicide would ultimately mean a deterioration in palliative care. Precisely what this kind of statement actually means is unclear: does it mean less services, a poorer standard of care or, perhaps, a retardation of the development of integrated services? It could mean a claim to all or any of the above; the claim is unclear.

Certainly, as Professor David Kissane showed in the review of the operation of the *Rights of The Terminally Ill Act* for the nine months it existed in the Northern Territory, when euthanasia (or, as it occurred, physician assisted suicide) was the focus, general care for the particular person was poor.²³

It is difficult to offer a full assessment of palliative care in other places. Countries such as Belgium and The Netherlands have structured their services differently. And while Oregon's services are largely provided in the home setting, Belgium and The Netherlands have different mixtures of home care and outreach care as well as hospital based services.

While it is not possible or practical to attempt to compare these places and the services they provide we can advance that, in all three, palliative services rank highly either against other comparable countries (Europe)²⁴ or states (Oregon-USA)²⁵.

In terms of a relationship between palliative care and the existence of a euthanasia option, Professor Theo Boer observes the following in respect to the situation in The Netherlands:

*"My conclusion is that once assisted dying becomes available, the level of palliative care doesn't matter that much. What was once considered a last resort, now becomes a 'default' mode of dying for an increasing number of people."*²⁶

This point is echoed in his testimony to the *Legal and Constitutional Affairs Committee Inquiry: Medical Services (Dying with Dignity) Exposure Draft Bill 2014*²⁷ where he observed that euthanasia is on the way to become a 'default' mode of dying for cancer patients.

²³ Kissane, D W, 2002, "Deadly days in Darwin", in *The Case Against Assisted Suicide*, K Foley & H Hendin (eds), pp 192-209, Johns Hopkins University Press, Baltimore;

²⁴ See, for example: *EAPC Atlas of Palliative Care in Europe 2013* <http://www.eapcdevelopment-taskforce.eu/images/booksdocuments/AtlasEuropafulledition.pdf>

²⁵ See, for example: *USA Center for Advanced Palliative Care Report Card*. <http://reportcard.capc.org/home/OR/RC/Oregon>

²⁶ Boer T. Ibid.

²⁷ Appended to the HOPE submission to the same inquiry.

Boer's observations are well founded. In Belgium we also note similar developments. The existence of good palliative care does not mean, as is perhaps assumed in the euthanasia debate, that people will take the palliative option and perhaps only consider euthanasia, as Boer put it, as a last resort.

In April 2012, after 10 years of legal euthanasia in Holland, Eric van Wijlick, policy officer at the *Royal Dutch Society of Doctors* observed that, "Euthanasia has become the central point of conversation between a doctor and a patient who is suffering when it should be seen as a "last resort"."²⁸

If then, discussion about euthanasia in terms of a diagnosis is 'the central point of conversation' rather than a 'last resort' and if euthanasia is being viewed as a 'treatment' option, it stands to reason that some, if not most, people will, at the very least, consider euthanasia as a possible early intervention.

In terms of full disclosure and informed consent, when a doctor delivers a diagnosis and is asked the obvious question: 'what are my options?' he or she is duty bound to explain. (See section on Informed Consent)

In a recent letter to the Journal, *Bioethical Inquiry*²⁹, the authors reviewed the data provided by the *Belgian Federal Commission for the Control and Evaluation of Euthanasia* for the years 2012 and 2013. They concluded that, 'almost 40 percent of the patients who received euthanasia did not see a palliative care specialist nor interacted with a palliative care team.'

'We see that only 40 percent (1283 out of 3239) had a visit by a palliative care team, barely 12 percent (396 out of 3239) had a visit by a palliative care specialist, and just 9 percent, (307 out of 3239) were consulted by a psychiatrist.'

By contrast, the latest report on the operation of the Oregon assisted suicide act reports that of the assisted suicide deaths recorded in 2014, '(93.0%) were enrolled in hospice care either at the time the DWDA prescription was written or at the time of death.'

The Oregon assisted suicide act prescribes that a person must have a 'terminal illness' and further describes that a 'terminal illness', for the purposes of the act, means 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.'³⁰

Access to Hospice care in America is also determined by a six-months-or-less prognosis:

*'Patients are eligible for the Medicare Hospice Benefit if a physician certifies that they are likely to die within six months if their underlying terminal disease follows its usual course.'*³¹

²⁸ see <http://www.newsinsurances.co.uk/euthanasia-rise-netherlands-belgium/0169486389>.

²⁹ Between Palliative Care and Euthanasia. Mortier et al. *Bioethical Inquiry* 22042015 available at: <http://link.springer.com/article/10.1007/s11673-015-9635-7>

³⁰ Oregon DWD Act. Available at: <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ors.aspx>

³¹ See, for example: The Hastings Center Report p:S27 http://www.thehastingscenter.org/uploadedFiles/Publications/Special_Reports/access_hospice_care.pdf

Yet Hospice enrolled patients, in the US model, need to make an invidious choice between curative and palliative care:

*'However, Medicare beneficiaries can access the hospice benefit only if they waive other routine Medicare benefits for their terminal illness that could prolong life. The line is often blurred between life-prolonging care and palliative care. If someone has emphysema and pneumonia, is treating the pneumonia palliative or life-prolonging? Of course, it is both. Unfortunately, the current Medicare statute presents a false dichotomy in which patients have to choose between hospice care and routine care for their terminal illness.'*³²

In the *Journal of Palliative Medicine* in 2008, Melissa Carlson and her colleagues observed that while hospice care in the US was on the increase, '60% of Americans die without hospice care':

*"There has been dramatic growth in the number of hospices in the United States, with more than 900 new hospices since 2000 (a 41% increase). However, only 39% of decedents in the United States in 2008 received hospice care and there is persistent evidence of disparities in hospice use by race/ethnicity, income, and education."*³³

We question how it is that while 39% of decedents in the USA received hospice care in the USA in 2008 (44.6% in 2011³⁴) that 93% of those who suicided in Oregon in 2014 (96.7% in 2011) using the provisions of their assisted suicide act were enrolled in hospice? We know that the pro-assisted suicide lobby organisation, Compassion and Choices (formerly the Hemlock Society), actively encourages people who seek their support in accessing assisted suicide to enrol in hospice. We could take the view that, in doing so, they provide a genuine public service.

However, there is an alternate view:

Toward this end, advocates often point to a statistic involving assisted-suicide deaths in Oregon. According to the state, approximately 86 percent of people who died by swallowing poisonous overdoses under the Oregon law were receiving hospice care at the time they committed assisted suicide. Promoters of such 'aid in dying' claim that this proves dying patients need the additional choice of a lethal prescription to ensure a 'good death' if hospice care does not suffice.

But there is another way to look at it. What advocates don't mention — and this is an issue about which the state bureaucrats seem utterly indifferent — is that most of Oregon's assisted suicides were facilitated in some way by people affiliated with the assisted-suicide advocacy group Compassion and Choices (formerly the Hemlock Society), either as end-of-life 'counselors' or as prescribing doctors after the patient's own physician refused to write a lethal prescription. This means that the patients in the hospice who committed assisted suicide under

³² *Effective Palliative Care Programs Require Health System Change* the Innovations Exchange Team <https://innovations.ahrq.gov/perspectives/effective-palliative-care-programs-require-health-system-change>

³³ *Geographic Access to Hospice in the United States*. Carlson MDA et al. *Journal of Palliative Medicine*. Nov 2010. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000898/>

³⁴ National Hospice and Palliative Care Organization statistical report. http://www.nhpc.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

Oregon's law most likely did not receive suicide prevention — either because the hospice team was not alerted to their patient's suicidal desire or perhaps the Oregon law has effectively shortcircuited the prevention response by hospice professionals.

In other words, rather than showing the need to expand hospice 'services,' Oregon demonstrates how assisted suicide actually interferes with the proper delivery of hospice services — at least as the hospice was envisioned by (Cicely) Saunders.³⁵

4.4. Palliative Care – equal access to quality services delivers real choice

ANZSPM acknowledges the significant deficits in the provision of palliative care in Australia and New Zealand, especially for patients with non-malignant life limiting illnesses, those who live in rural and remote areas, residents of Residential Aged Care Facilities, the indigenous populations and those from culturally and linguistically diverse backgrounds.³⁶

Palliative Care Australia (PCA) recommends that Palliative Care Specialists should be provided in Australia to the level of 1.5 full time equivalent (FTE) positions per 100,000 people.

*The Australian and New Zealand Society of Palliative Medicine (ANZSPM) say that: The ratio of 1.0 FTE Palliative Medicine Specialists per 100,000 population represents the *minimum number of Specialists for a reasonable provision of service.* (Emphasis added)*

Yet the Australian Institute of Public Welfare (AIHW) report, Palliative care services in Australia 2013, shows that the average availability is 0.4 FTE ranging from 0.3 to 0.5 in various states. (Table 7.3 below).³⁷

³⁵ Lawyer and activist, Wesley J Smith. Article: *Assisted Suicide and the Corruption of Palliative Care*. 2008. Available at: <http://noeuthanasia.org.au/documents/Wesley-J-Smith-Corruption-of-Palliative-Care.pdf>

³⁶ Ibid. ANZSPM Position Statement

³⁷ AIHW. *Palliative Care services in Australia 2013*. Downloadable at <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545131>

Nationally, there were 0.4 full-time-equivalent (FTE) specialist palliative medicine physicians per 100,000 population in 2011 (Table 7.3). The number of FTE specialist palliative medicine physicians per 100,000 population among the states and territories ranged from 0.3 in Victoria and Western Australia to 0.5 for New South Wales and South Australia. No FTE specialist palliative medicine physicians were recorded in the Northern Territory. The average hours worked varied across jurisdictions, ranging from 33.0 hours per week for Victoria to 46.6 hours per week for Queensland.

Table 7.3: Employed specialist palliative medicine physicians, average total hours worked per week, FTE and FTE per 100,000 population, states and territories, 2011

State or territory	Number of specialist palliative medicine physicians	Average total hours worked per week	FTE number	FTE per 100,000 population ^(a)
New South Wales	39	38.8	40	0.5
Victoria	19	33.0	17	0.3
Queensland	14	46.6	17	0.4
Western Australia	6	38.3	6	0.3
South Australia	7	42.4	8	0.5
Tasmania	n.p.	n.p.	n.p.	n.p.
Australian Capital Territory	n.p.	n.p.	n.p.	n.p.
Northern Territory	—	—	—	—
Total^(b)	92	39.5	95	0.4

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

(b) The number for each variable may not sum to the total due to the estimation process and rounding.

Note: FTE number is based on a 38-hour standard working week.

The variation in FTEs across Australia is significant and, at best, less-than half of the minimum recommended by ANZSPM and more than two-thirds less than the optimal level as described by PCA. Victoria, on par with Western Australia, has the lowest FTE at 0.3.

Euthanasia legislation will often include a statement to the effect that a medical specialist must inform a patient about palliative care and other treatment options when the matter of euthanasia is raised. Phrases such as: 'may be available', 'availability of ... options' and 'reasonably available' in respect to access to Palliative Medicine Specialists are, in reality, a cruel hoax. We certainly do have world's best practice services in Australia, but sadly, not even close to the level of access that might provide comments about 'availability' with defensible respectability.

The reality is, that for some citizens facing a difficult prognosis, where they live may mean that they do not have sufficient access to quality care. This does nothing to support patient choice. If you live in the Northern Territory or even in Victoria or Western Australia, 'availability' is not even close to being on par with New South Wales or South Australia. This is a matter of social inequity in every respect and creates a situation where, lacking a reasonable palliative option, a patient may become vulnerable to deciding to be killed by a doctor or to kill themselves with a doctor's support because they have a distinct lack of choice.

The social inequity is even starker in respect to regional and remote access:

Almost 9 out of 10 (85.9%) FTE specialist palliative medicine physicians worked mainly in the *Major cities* (Table 7.4) during 2011. Once population sizes for each remoteness area were taken into account, the FTE specialist palliative medicine physicians per 100,000 population was highest for *Major cities* (0.5), followed by *Outer regional* (0.3) and *Inner regional* (0.2) areas.

Table 7.4: Employed specialist palliative medicine physicians by remoteness area, average total hours worked per week, 2011

Remoteness area of main job	Number	Average total hours worked per week	FTE number	FTE per 100,000 population ^(a)
Major cities	79	39.2	81	0.5
Inner regional	8	42.8	9	0.2
Outer regional	5	39.2	5	0.3
Remote and very remote	—	—	—	—
Total^(b)	92	39.5	95	0.4

(a) Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2011 and are expressed per 100,000 population (see Appendix C).

(b) The number for each variable may not sum to the total due to the estimation process and rounding.

Note: FTE number is based on a 38-hour standard working week.

While recognising the attendant difficulties arising from the placement/availability of specialist services of any kind in remote parts of Australia it nevertheless remains that not every Australian has access to such service on an equitable basis and the availability of services for all Australians is well below the levels recommended by expert bodies.

We contend that, to bring into play a regimen of doctors killing patients and/or doctors assisting in patient suicide while such inequity exists and while access to services is well below the standard, is a failure of due care.

As Boudreau and Somerville observe:

It would also mean that to obtain informed consent to euthanasia, all reasonably indicated treatments would need to be offered and they would certainly include all necessary palliative care, in particular, fully adequate pain management. Many of those advocating for euthanasia posit euthanasia and palliative care as alternatives, but informed consent to euthanasia could not be obtained unless good palliative care was available.³⁸

And while the management of pain is only one facet of palliative medicine we wish to acknowledge a growing trend in medical and other literature for the consideration of pain relief as a right.

'The bioethical principle of justice, seeking the equitable distribution of health care, is the greatest challenge to inadequate pain management worldwide. However admirable the ideal of pain management as a universal human right, the reality is a world in which massive resource discrepancies preclude fulfilment of such a right. Thus, unequal access to pain relief

³⁸ *Euthanasia is not medical treatment*. Boudreau and Somerville. British Medical Journal 2013; 106:45-46 . available at: <http://noeuthanasia.org.au/documents/federal/inquiry/BMB-June-2013-Somerville-and-Boudreau-euthanasia-is-not-medical.pdf>

*is but one example of the broader problem of health disparities that arise due to inequities of socioeconomic status or from membership in a minority racial or ethnic group.*³⁹

While *Brennan et al* clearly have in mind disparities between Third World and Developing countries, it is nevertheless also the case that not every Australian enjoys the same access to quality services and support on an equitable basis.

At this point we wish to recognise and congratulate *Palliative Care Australia* for sponsoring a resolution passed by the *World Health Organisation's* Assembly in 2014:

*The resolution calls for countries to ensure that palliative care is a core part of health systems, that palliative care is embedded in the basic and continuing education and training for all health workers, and to ensure adequate access to pain medications.*⁴⁰

PCA's *National Palliative Care Consensus Statement*⁴¹ sets out their well-reasoned goals for end-of-life care. This is the agenda we should be adopting.

In terms of government policy on palliative care we wish to stress the obvious; that palliative care options – including an emphasis on home care – are far cheaper and deliver better outcomes for the patient and their family than any alternate forms of care.⁴²

In observing the USA hospice model of delivering palliative care, we stress that good palliative care is part of a continuum of care. Taking an option for palliation should not automatically exclude a patient from access to curative options – and vice versa. As we will discuss later, diagnoses and prognoses can be wrong. Such matters should be decided on a case-by-case basis.

5. Informed Consent

Informed consent means that you understand your condition and any proposed medical treatment. You have a legal right to be told any information that relates to your medical condition and treatment. Without this information, you are not able to make a fully informed choice and give valid consent for treatment.

Your doctor has a duty to explain your medical condition, the recommended treatment (including the other treatment options available) and the benefits, risks and possible

³⁹ *Pain Management: A Fundamental Human Right*. Brennan F et al. 2007 Journal of anesthesia-analgesia.

Available at: http://journals.lww.com/anesthesia-analgesia/Fulltext/2007/07000/Pain_Management_A_Fundamental_Human_Right.37.aspx

⁴⁰ Palliative Care Australia. Press Release: *Australia sponsors ground breaking palliative care resolution in Geneva*. Available at:

<http://www.palliativecare.org.au/Portals/46/media/2014/PCA%20Media%20Release%20-%20WHAResolution%20240114.pdf>

⁴¹ http://www.palliativecare.org.au/Portals/46/Palliative_Care_Consensus_Statement_final.pdf

⁴² See for example: *The Benefits of Palliative Care* Palliative Care Victoria.

<https://www.pcvlibrary.asn.au/download/attachments/2917913/Benefits+of+Palliative+Care.pdf>

*complications of the recommended treatment. This is essential so that you can make a decision.*⁴³

We have already observed some of the problems with informed consent in relation to Advance Care Directives and how the current Victorian scheme, where completing an ACP takes place with a medical professional's support and at an appropriate time, holds the benefit of being most likely to reflect fully informed consent.

Consent, in terms of a person's medical issues, is an ideal that recognises and endorses the right not to have something done to you which you did not want, the right to full information about any procedure or course of action and any alternatives, and the right to know the possible consequences arising therefrom and from the particular prognosis.

Arriving at a point in time where a person considers that he or she has all of the information, perhaps also any alternative or second opinion, is a process. It takes time. Given the significance of an informed decision, it is imperative that medical professionals have the time to devote to conversations with the patient and their family.

More than that, we endorse a consent regimen that includes in some way a requirement that the patient re-state the information and their decision to the medical specialist involved. The following anecdote, I think, describes a common enough problem:

*I recall in the passing of an elderly friend only this last year where a medical specialist asked him directly would he want to be resuscitated if there were any problems. He nodded in the affirmative. My wife, who knew him well and was aware that he had previously stated the precise opposite, gestured to him using hand signs indicating a CPR procedure. His eyes widened in horror and he let out a very loud and firm, 'No!' This was an assertive gentleman, completely lucid who was clearly momentarily confused about what was going on around him at his hospital bed at that time.*⁴⁴

In my role as director of HOPE over the last five years, I have taken numerous phone calls from people expressing concerns about their medical care or that of a loved one. As one might imagine, given the nature of my work, most concerns have been about suspicions that their relative was being euthanased. It pleases me to relate that most if not all concerns were easily put to rest by simply encouraging these callers to ask questions of those who are caring for them.

Consent and the relation of information to the patient and their families go hand-in-hand. Busy staff, shift changeovers, a patient not being able to relate fully what was discussed with their doctor to visiting family members etc. can all contribute to a sense of helplessness and concern. Problems of this nature are not easily overcome. However, we observe that the deliberate creation of a culture and policy where questions are welcomed and encouraged would serve the well-being of all concerned.

⁴³ Better Health Victoria, *Better Health Channel* website:

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Informed_consent_for_medical_treatment?open

⁴⁴ Personal Russell family story.

5.1. Informed Consent and euthanasia

As noted earlier, *Boudreau and Somerville* observe that, '*informed consent to euthanasia could not be obtained unless good palliative care was available.*'

We have also noted that in the Low Countries euthanasia is more and more being decided upon early in a disease trajectory and possibly without any direct experience of palliative care. We have also noted that people's understanding of what it means to be 'palliative' is largely negative which we believe may have an effect upon issues of consent.

Many euthanasia bills over the years in Australia rightly suggest that patients who would seek such a course must be given information about palliative care. More than that no-one can do; people cannot be forced to undertake palliative care or curative treatments. As observed, this is in contrast to the myth that euthanasia is a last resort option, after all else has failed. When those proposing euthanasia point out that palliative care is ineffective to some degree in a small percentage of cases, it tends to re-inforce this false 'last resort' idea.

In 2010 noted British Plastic Surgeon, Kayvan Shokrollahi, published a paper called: *Request for Treatment: the evolution of consent*⁴⁵ wherein he argued that consent for a procedure would be better served by the patient completing what he called a *Request for Treatment* form. In completing this form, the patient would need to adequately provide a written understanding, in their words, of the nature of the procedure, its aims and risks etc. This is perhaps worthy of some consideration.

His proposal would seem to cover requests for treatments or procedures and not refusals as such, but it does create, what we think, is an appropriate point of reflection on the notions of autonomy, choice and request in terms of euthanasia.

In terms of euthanasia, the notion of it being a person's (the patient's) choice is illusory. Understood correctly in terms as described by Kayvan Shokrollahi, a person may request euthanasia, but the decision or 'choice' remains that of the person committing the act (which is why euthanasia and assisted suicide laws protect the Doctor). Certainly, a person may, in a state where euthanasia has been made legal, decide that he or she wants death, but, in a greater sense than for any medical procedure, whether or not it ever occurs relies entirely upon the autonomous decision or 'choice' of the physician.

Consider: In a possible suite of procedures available (absent euthanasia), a person decides upon one particular course and relates that request to his or her physician. It may or may not have been the physician's preferred or recommended path; but, regardless, the physician accepts the request respecting the patient's decision. He or she need make no value judgement. He or she has laid viable and appropriate options on the table; the decision is the patient's.

Agreeing to a request for euthanasia is of a different order. There is implicitly much more to accepting a request. Whereas laying before a patient his or her options and accepting their judgement is supportive of patient autonomy, agreeing to an act of euthanasia upon a patient request is also making a tacit judgement about the value of that person's life.

⁴⁵ *Request for Treatment: the evolution of consent*. Annals of The Royal College of Surgeons of England. Mar 2010. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3025230/>

It can be compared to saying to a desperate person about to jump off a bridge when, after hearing out their woes and reasons for wanting to suicide: 'Okay, sure, jump!' The context is different, but the response is eerily similar. The patient is saying in one way or another: 'I don't want to face the difficulties that my prognosis entails and I can see no hope; I think I'd rather my life were over' and the doctor is effectively endorsing that sentiment.

No other procedure is likely to entail such a judgement. Is it any wonder that Dutch doctors can feel conflicted?

*The laws seem to have created a new conception of suicide as a medical treatment, stripped of its tragic dimensions. Patrick Wyffels, a Belgian family doctor, told me that the process of performing euthanasia, which he does eight to ten times a year, is "very magical." But he sometimes worries about how his own values might influence a patient's decision to die or to live. "Depending on communication techniques, I might lead a patient one way or the other," he said. In the days before and after the procedure, he finds it difficult to sleep. "You spend seven years studying to be a doctor, and all they do is teach you how to get people well—and then you do the opposite," he told me. "I am afraid of the power that I have in that moment."*⁴⁶

There are certainly 'powers' at play. As already observed, patients and patients' families can pressure a doctor and, as Wyffels observes, doctors can also influence patients. It is wrong to assume that any decision, be it the patient, the family or the doctor, in respect to euthanasia is not laden with all sorts of emotion and subtle and possibly unconscious suggestion. Decisions are not made in isolation.

The whole question of an autonomous decision is, at the very least, clouded. We don't ask an electrician to accept our direction as to where the red, green and blue wires go, even though we might direct where the power point is situated. In respect to any other procedure or course of action we place significant weight upon the experience and training of the medical professional. Yet we are expected to accept the premise that the decision to be made dead is solely that of the patient. This is clearly not the case.

Nor can it be said that doctors, as a class of persons, are any more or any less able to negotiate complex moral judgements than anyone else. They can and should bring their medical experience to the fore in advising on the best course of action for any medical matter, but the decision to kill is of a very different nature, further reinforcing the point that it has nothing to do with medicine.

But this medical experience is possibly compromised in a situation where euthanasia is a legal option. By convention and we expect also by law, a doctor in delivering a prognosis and then discussing options will be bound to lay out euthanasia as an option, even if, at that time, a patient was not sufficiently advanced in their prognosis to qualify (for example: had more than six months to live). This is perhaps part of the reason that the Dutch and Belgian regimes now see euthanasia as an 'early intervention' rather than a 'last resort'.

The choice in euthanasia, remains with the doctor. It is his or her autonomy that is the deciding factor and his or her judgement as to the value of a life.

⁴⁶ Aviv. R. *The Death Treatment* The New Yorker. June 22, 2015.

<http://www.newyorker.com/magazine/2015/06/22/the-death-treatment>

5.2. Autonomy properly considered

The exercise of autonomy is closely related to the principles of consent. Ensuring that a patient can exercise his or her autonomy is directly related to the ideal that providing a sense of control over the management of an illness promotes a sense of wellbeing.

But autonomy has natural limits. Such limits can be recognised as existing at the point where the autonomy of other persons, their rights and freedoms, are threatened. When the Tasmanian Committee, '*found that the legalisation of voluntary euthanasia would pose a serious threat to the more vulnerable members of society and that the obligation of the state to protect all its members equally outweighs the individual's freedom to choose voluntary euthanasia*' it was commenting on this reality. The law, therefore, in having a solemn duty to protect citizens, must not act in ways known to put the freedoms and rights of citizens in jeopardy.

In its deliberations on an assisted suicide bill earlier this year, the committee of the Scottish Parliament echoed the comments of the Tasmanian Parliament:

89. The Committee acknowledges that the principle of respect for autonomy is a qualified principle which is usually limited by the rights of others, by public safety considerations, and by the need to consider other principles and values.

90. If assisted suicide were to be permitted, robust safeguards would be required to protect the rights of others (for example, so that people with illnesses and disabilities would continue to feel valued and be provided with the support they need to live full lives, and so that healthcare professionals would not come under any pressure to be involved in the assisted suicide process). Safeguards to address public safety considerations would also be necessary. The issue of safeguards is considered at various points throughout the remainder of this Report.

91. Even if the rights of others and the safety of the public can be guaranteed, the principle of autonomy does not require that assisted suicide be permitted by law, since there may be other legal and ethical principles and values weighing in favour of maintaining the current prohibition

92. Therefore, the Committee is not persuaded that the principle of respect for autonomy on its own requires the legalisation of assisted suicide.⁴⁷

An argument based, as is sometimes heard, on the slogan 'my life – my choice' does not provide us with the full picture in relation to autonomy nor consent. As far as it goes, while we do not support it in any way, the slogan can be understood in terms of suicide. That is to say, when a person exercises his or her autonomy over their own existence without any coercion or encouragement from a third party.

⁴⁷ The Health and Sport Committee of the Scottish Parliament. 6th Report, 2015 (Session 4): Stage 1 Report on Assisted Suicide (Scotland) Bill. Available at: <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/88982.aspx>

Once a third party – be it an individual or the state – becomes involved, the relationship changes in some significant ways. Though a person may request euthanasia or assisted suicide under a legal regimen, it is no longer an autonomous act.

Autonomy, properly understood and considered, must be recognised as an important and 'higher-order' consideration; but not to the degree that it overrides other significant concerns such as public safety.

6. The problems with safeguards

In consideration of safeguards in terms of euthanasia we think of the 'checks and balances' that are designed to ensure the safety of vulnerable persons; that no-one suffers abuse, that proper procedures are observed. But the parameters of any bill; that is to say, the qualification regimes that attempt to contain the practice of patient killing to a certain cohort, can also be considered as a form of safeguard.

The question that must be resolved is: are they effective? Effective both in containing euthanasia and/or assisted suicide to the specified cohort (most likely terminally ill persons) and in ensuring that no persons are ever coerced or pressured into being made dead and that fully voluntary and informed consent is maintained in all cases.

US Lawyer and commentator, Wesley J Smith once observed that safeguards are really only there to make politicians and the public feel a little less concerned about passing legislation to allow people to be killed. Polemical? Perhaps; but the point is worth considering.

We have already observed that it is likely that no legislature would entertain such a law if it were 'open slather' and absent of such safeguards. And while those who propose such legislation may well only truly be seeking the limited remit expressed in their particular bill and may well be genuinely concerned to protect vulnerable people, we submit that such containment is not possible.

A former legislator once observed that the most common legislative instrument lodged in a parliament is an amendment bill. While not all such bills are about remedying an unforeseen consequence of extant legislation, many are of that character. The law is something of a blunt instrument when it comes to euthanasia and assisted suicide. It can never truly embody the best intentions of those that propose it nor those that support it. The observations made earlier that the Dutch and Belgian legislation was originally envisaged as being for a small cohort as a 'last resort' when it is now seen as an 'early intervention', points clearly to this reality.

6.1. Reliance on subjective language

Inevitably, some qualifying clauses in any legislation will include phrases that are subjective in nature. While the legislators may have a settled view and understanding of the intent of the law at that time, significant scope for other interpretations, particularly overtime as practice rather than theory become the dominant determinant, inevitably come into play.

Consider the qualifying clauses of the Dutch Law:

b. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;

d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;⁴⁸

Words such as 'unbearable' or 'hopeless' are commonly found in euthanasia bills as is the notion of 'reasonable'. Here also we see that the doctor is being asked to agree with the person's self-assessment that the 'suffering was unbearable'. This is entirely subjective and, we submit, is precisely the reason why euthanasia deaths are now being noted, more than a decade on, for reasons and circumstances not envisaged in 2001 and 2002 when the Dutch and Belgian laws were passed.

'Reasonable' in this context, is entirely without standard. Like the suffering of the patient, there is no standard against which 'reasonableness' can be measured.

Senator Richard Di Natale's 2014 draft bill also included the terms 'reasonable' and 'reasonably',

***terminal illness**, in relation to a person, means an illness which, in reasonable medical judgement will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the person, result in the death of the person.⁴⁹*

(c) the medical practitioner (the first medical practitioner) is satisfied, on reasonable grounds, that:

- (i) the person is suffering from a terminal illness; and*
- (ii) in reasonable medical judgement, there is no medical measure acceptable to the person that can reasonably be undertaken in the hope of effecting a cure; and*
- (iii) any medical treatment reasonably available to the person is limited to the relief of pain, suffering, distress or indignity with the object of allowing the person to die a comfortable death;⁵⁰*

This is not a criticism of Dr Di Natale; it is 'reasonable' to use that term in some instances where no possible other standard could be employed. However, subjective and unmeasurable terms simply do not lend themselves to the type of scrutiny and distinction that the principle of safeguards requires in euthanasia type laws.

Part of the problem also lies where a doctor might be questioned concerning a euthanasia or assisted suicide over some suspicion of error or foul play. 'Reasonableness' is a very low standard of proof in terms of the law and one, we submit, that cannot be effectively challenged. 'Reasonableness' may be a reasonable defence in law in other matters, but, as noted, we are dealing here with a unique type of law that involves making a patient dead.

Note also that the Dutch law does not mention 'terminal illness'. Neither does the Belgian law:

⁴⁸ Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002. Netherlands.

Taken from: http://www.patientsrightscouncil.org/site/wp-content/uploads/2012/05/Dutch_law_04_12.pdf

⁴⁹ Medical Services (Dying with Dignity) Bill 2014. Draft Exposure Bill. See: http://richard-di-natale.greensmps.org.au/sites/default/files/dying_with_dignity_medical_services_draft.pdf

⁵⁰ Ibid. Part 2, Section 12.

*The patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious or incurable disorder caused by illness or accident;*⁵¹

'Medical futility' relates principally to a treatment:

Medically, the concept of "futility," according to the American Medical Association, "cannot be meaningfully defined". Essentially, futility is a subjective judgment, but one that is realistically indispensable. There is consensus within the medical community that at specific times during the course of an illness some treatments are medically futile; consensus ends however, when attempts are made to formulate a fully objective and concrete definition. As a result, futility has been confused with interventions that are harmful, impossible and ineffective. Distinguishing futility from the concept of harmful and ineffective interventions has led to some clarity. In general, a medically futile treatment is

*an action, intervention, or procedure that might be physiologically effective in a given case, but cannot benefit the patient, no matter how often it is repeated. A futile treatment is not necessarily ineffective, but it is worthless, either because the medical action itself is futile (no matter what the patient's condition) or the condition of the patient makes it futile.*⁵²

Again we see the use of a subjective term that can only be understood or determined in relation to a particular patient at a particular time. Note that it is the treatments and not the condition that can be rendered futile. Having said that, at least conceptually, the term provides a sort of 'checklist point' that suggests that there is nothing remedial that can be done for the patient. It suggests that treatments may have been tried, but it could just as easily be taken to mean that there is no treatment that the patient agrees to; that there is nothing acceptable to the patient. Using an extreme example to make a point, an insulin dependent diabetic who deliberately ceased their injection regimen may trigger qualification under such a definition as perhaps they would under *Di Natale*.

This is perhaps clearer in the *Di Natale* definition of terminal illness: *without the application of extraordinary measures or of treatment unacceptable to the person, result in the death of the person*. We suggest that this expression is implied in the Belgian law; if not from inception, certainly in current practice.

Certainly the term 'cannot be alleviated' cannot exclude '*treatment unacceptable to the person*'. How else are we to understand the recent approval of euthanasia for a 24 year old Belgian woman who is not ill but suffering from suicidal depression?⁵³ This is a tragic situation that requires great care, support and possibly even protective restraint, but surely not euthanasia!

⁵¹ The Belgian Act on Euthanasia, May 2002. See: <http://www.ethical-perspectives.be/viewpic.php?TABLE=EP&ID=59>

⁵² Medical Futility: Legal and Ethical Analysis. Clark, P. AMA Journal of Ethics. May 2007, Volume 9, Number 5: 375-383. See: <http://journalofethics.ama-assn.org/2007/05/msoc1-0705.html>

⁵³ See: <http://www.demorgen.be/nieuws/laura-is-24-jaar-en-fysiek-gezond-ze-krijgt-deze-zomer-euthanasie-a2367037/29fjb5/> and <http://www.inquisitr.com/2196375/healthy-woman-die-doctor-assisted-euthanasia-suicidal-thoughts/>

6.2. The problem with prognoses

Many bills presented to Australian Parliaments over the years define the target cohort as people with a terminal illness that have a prognosis of less than six months to live.

Doctors readily admit the predicting the length of the trajectory of a terminal illness is guesswork. Guesswork based on experience, certainly; but we will all know of or will have heard of people who have supposedly 'defied the odds' and have either outlived the original prognosis significantly or who have experienced an unexplained remission.

This reality affects euthanasia and assisted suicide law in some significant ways.

Firstly, it must be acknowledged that the act of killing a patient who fits the criteria denies the possibility of other outcomes. The 'worst-case-scenario' of a disease trajectory is not everyone's experience nor is the timing of their ultimate death nor even the fact that the disease will cause their death.

Secondly, given this uncertainty, a doctor could easily certify that a patient had less than six months to live, who, by any other reckoning, would be expected to live significantly longer. He or she may simply rationalise that a month or two would make little difference. The trouble here is that such a small 'fudge' in the criteria is undetectable. Little 'fudges' can grow.

Thirdly, problems are known to exist in the determination that certain diseases are, in fact terminal. One example of this occurred during the operative period of the *Northern Territory's Rights of the Terminally Ill Act*. Kissane et al, mentions this as 'Case 4' for a person suffering from Mycosis Fungoides⁵⁴. They report that a physician saw the patient for the sake of providing the requisite second opinion and 'declined to certify that she was terminally ill'⁵⁵. Dr Nitschke describes the situation when he gave evidence before the Tasmanian Parliament in August 2009:

What we found in the Northern Territory was that people's decision about whether a person was terminally ill could largely be linked to whether they were supportive in principle to the question of whether a person had the right - in other words, whether or not they were philosophically on-side. We saw this in the case of the second patient who had an unusual skin condition called mycosis fungoides. A dermatologist, who was strongly hostile to euthanasia, insisted that she was not terminally ill. Another dermatologist, who was supportive of voluntary euthanasia, insisted that she was terminally ill. It seems that there was no difference in the dermatology - this is a skin disease - but there was a big difference in their attitudes to this issue, so putting medical professionals in this role leads to difficulty.⁵⁶

It is perhaps polemic to ascribe the two dermatologists' decisions as being based solely upon ideology and, as the literature describes this disease, variants and its progress can indeed be terminal in some cases.

⁵⁴ For a description of the disease see: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3699909/> Note that, in some circumstances and in some variants, the disease can become terminal.

⁵⁵ Kissane DW. Ibid. Case 4. P1100.

⁵⁶ Community Development Committee Parliament of Tasmania. Hansard 31st Aug 2009. P 101-102 <http://www.parliament.tas.gov.au/ctee/Transcripts/31%20August%2009%20-%20Hobart%20dwd.pdf>

More recently we note that the first person to die under Columbia's revived euthanasia legislation was refused euthanasia at the last moment by the attending physician who said that the patient was not terminal.⁵⁷ (Note: this matter is covered further under the heading *More than one doctor* in this section)

A prognosis of six months or less is a feature of the Oregon assisted suicide regime as already noted. Noted also, however, in the Official Oregon reports⁵⁸ for the last two years:

2014: Eleven patients with prescriptions written during the previous years (2012 and 2013) died after ingesting the medication during 2014.

2013: Eight (8) patients with prescriptions written during the previous years (2011 and 2012) died after ingesting the medication during 2013

Also from Oregon the story of Jeanette Hall who sought assisted suicide after her cancer diagnosis but was talked out of it by her doctor. Jeanette is still alive some 15 years later.⁵⁹

Then there is the chilling case of Pietro D'Amico who died by assisted suicide in Switzerland in 2013 after receiving a diagnosis that, after his death, was proven false by an autopsy.⁶⁰

Fourthly we need to consider the harsh reality that the definition of terminal illness cannot effectively exclude disability. The Canadian Supreme Court recently gave chilling voice to this reality when it struck down Canada's prohibition on assisted suicide:

*"a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or **disability**) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."*⁶¹ (emphasis added)

6.3. Blurred lines - disability

Craig Wallace from the disability advocacy group, *Lives Worth Living*, made a similar observation in his testimony before the Senate hearings on Senator Di Natale's draft euthanasia bill last year:

There is not some kind of clear dividing line between disability, illness and a medical condition which means that you can neatly quarantine the effect of the Bill to one set of people – unless you were to actually name the illnesses involved.

⁵⁷ See news report: http://elpais.com/elpais/2015/07/03/inenglish/1435925876_912720.html

⁵⁸ Oregon Reports are available at:

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>

⁵⁹ Jeanette Hall's story can be found at: <http://noeuthanasia.org.au/blog/1847-jeanette-hall-i-say-no-to-assisted-suicide.html>

⁶⁰ See news report here: <http://www.thelocal.ch/20130711/assisted-suicide-in-question-after-botched-diagnosis>

⁶¹ A summary of the Canadian Supreme Court decision in *Carter v Canada* 2015 can be found at: http://www.cmdscanada.org/my_folders/PAD/CarterDecisionSummary.pdf

The Bill defines terminal illness as one which, in reasonable medical judgement will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the person, result in the death of the person.

It also mandates that a person needs to experience pain, suffering, distress or indignity to an extent unacceptable to the person.

I am not satisfied that this would not apply to the people I represent on a reasonable reading.

For instance, I have known many people who have incurred high level spinal injuries and I would be concerned about how this kind of disability might be viewed within the Bill.

When does an illness become terminal? – Most medical practitioners would say that a disability like this shortens the lifespan. There is no clearly defined boundary between a shortened life span and a terminal illness.

What are extraordinary measures? – having a catheter or a diversion or a stoma or a ventilator or all of these, or any one of a number of interventions might fit this.⁶²

Because the principle of autonomy rightly empowers a person to refuse to accept or to cease medication or medical intervention, a person with a lifelong condition that, with medical support is not considered life threatening could, by refusing their medication, render themselves eligible for euthanasia and/or assisted suicide.

We may intuitively respond to such a scenario with the observation that this putative person is suicidal. Indeed. Medical professionals may arrive at the same conclusion and therefore move towards psychiatric support. The reality is that every person who will express a desire to die by euthanasia or assisted suicide is looking to precisely the same outcome: an early death. Euthanasia and/or assisted suicide laws will attempt to define circumstances in which society will agree.

6.4. More than one doctor

We have already noted that differences in opinion occur between medical professionals in respect to diagnosis and prognosis. The idea of a 'second opinion' is well understood as a patient's right in consideration of the diagnosis and prognosis and also in seeking to understand the treatment options available.

Most euthanasia and/or assisted suicide proposals include as a supposed safeguard the inclusion of a mandated second opinion; sometimes a third.

We submit that it is self-evident that only a very small number of doctors would be willing to be involved in euthanasia and/or assisted suicide.

⁶² See: <http://livesworthliving.com.au/?p=61>

As was the case with the euthanasia deaths of the Verbessem twins in Belgium⁶³, people facing a difficult prognosis who seek euthanasia and assisted suicide will seek to engage a medical practitioner who is known to support such an outcome; especially if they know that their treating practitioner is otherwise disposed.

In Oregon and Washington, the pro-assisted suicide group, Compassion & Choices provide a listing of doctors who support their objectives to prospective candidates. The following quote from the Press Release of *Physicians for Compassionate Care* in Oregon spells this out:

"One organization is responsible for 97% of the assisted suicide deaths this past year (2009). Compassion & Choices, the assisted-suicide-proponent organization, are authors of Oregon's physician-assisted suicide law and proclaim they are its steward. 78% (359/460) of all Oregon assisted suicide deaths are their cases. In the past two years they have been involved in 92% of Oregon's assisted suicides. They reported involvement in 53 of 60 deaths in 2008, and in 57 of 59 deaths in 2009. The Oregonian editorial board (local newspaper) correctly stated in 2008 that "a coterie of insiders run the [assisted suicide] program, with a handful of doctors and others deciding what the public may know." As is particularly evident for the 2009 year, they control the assisted suicide market; 97% (57 of 59) of physician assisted suicide deaths in 2009 were their cases! As was noted in The Oregonian in 2008, "the initials 'C & C' of this organization more properly reflect its repeated public behavior – that is, 'Conspiracy and Control' ".⁶⁴

Nor is it beyond the realms of the possible that a doctor who supports an act of euthanasia or assisted suicide would have in mind a number of colleagues whom he or she would know were likewise disposed for the sake of the certifying role or second opinion. This is not to say that these people would be willingly look to circumvent the intent of the law, but it would certainly be an easier process for busy medical professionals to know where to go and whom to go to.

Consider also the creation of 'Mobile Euthanasia Clinics' in The Netherlands. Minister Edith Schippers was quoted in the *UK Telegraph* as saying that mobile units "for patients who meet the criteria for euthanasia but whose doctors are unwilling to carry it out" was worthy of consideration. Professor Boer commented:

Under the name 'End of Life Clinic,' the Dutch Right to Die Society NVVE founded a network of travelling euthanizing doctors. Whereas the law presupposes (but does not require) an established doctor-patient relationship, in which death might be the end of a period of treatment and interaction, doctors of the End of Life Clinic have only two options: administer life-ending drugs or sending the patient away. On average, these physicians see a patient three times before administering drugs to end their life. Hundreds of cases were conducted by the End of Life Clinic. The NVVE shows no signs of being satisfied even with these developments.⁶⁵

⁶³ Marc and Eddy Verbessem were euthanized together in Belgium in December 2012 because they were going blind. They shared other medical issues. One report suggests that they took two years to find a service that would accommodate their euthanasia request. See:

<http://www.telegraph.co.uk/news/worldnews/europe/belgium/9801251/Euthanasia-twins-had-nothing-to-live-for.html>

⁶⁴ For more details see: <http://alexschadenberg.blogspot.ca/2010/03/2009-annual-oregon-physician-assisted.html>

⁶⁵ Boer T. Testimony. Ibid.

There is also a similar medical network in Belgium called LEIF, Life End Information Forum.⁶⁶

It is also worth considering, in the context of doctor shopping what a 'No' might mean. Of course, no doctor is obliged to provide euthanasia or assisted suicide, nor is there any compulsion to provide the confirmations as the second or third medical professional. But what would happen if a doctor or a psychiatrist provided a contrary opinion?

The second medical professional may only be required to confirm the diagnosis and prognosis; but what if he or she found differently? There is no obligation upon the first medical professional to accept this opinion; he or she may simply choose to ignore it and seek confirmation from another. Likewise, there is no obligation that a psychiatrist's view that the person was suffering a depression in relation to the illness be accepted.

This compromises the so-called safeguards and raises concerns about the transparency of the process. A repeated circle of referrals may also contribute to a dilution of objectivity. Attempts to deal with this by saying that the two or three attesting medical practitioners should not be related by blood, employment or part of the same medical practice is hardly sufficient. It cannot combat the natural associations of medical professionals that will form.

There would be no effective way to challenge such a development.⁶⁷

6.5. Psychiatrists as gatekeepers

Nor is the psychiatric referral anything like the 'safeguard' it is made out to be. It creates its own dilemmas.

The review of the operation of the *Rights of the Terminally Ill Act* (ROTI) that existed for a brief period in the 1990s in the Northern Territory includes some apposite discussion about the role and efficacy of the psychiatric assessment.⁶⁸

The authors observe that the psychiatric assessment was seen, by those who availed themselves of the process as, 'a hurdle to be overcome'. In one case it was noted that the patient withheld crucial information from the psychiatrist – seemingly out of fear that such knowledge might jeopardise the desired outcome. In another case the patient was already being treated for depression by other professionals. In the assessment for the sake of ROTI, there was no discussion or advice concerning whether or not the current drug regime was effective or whether psychotherapeutic management might have helped in that case. In a further case the assessment took place the morning that euthanasia was scheduled for the person.

The report also notes US studies that showed that only 6% of psychiatrists in Oregon thought that they could be competent gatekeepers for their legislation after only one consultation. Just as medical

⁶⁶ The New Yorker. Aviv R talks about LEIF in the context of Tom Mortier's mother and her euthanasia. Ibid.

⁶⁷ **Note:** two troubling examples of 'doctor shopping' can be found at the *Disability Rights Education & Defense Fund* website at <http://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/>

⁶⁸ Kissane DW. Ibid.

professionals are trained to 'heal or at least do no harm' psychiatrists are also about treatment and not gatekeeping.

As a post-script to the mentioned article's appearance in *The Lancet*, a letter to the editor in the December issue that year summarizes the problem with psychiatric assessment in such circumstances:

"Legislated Psychiatric assessment presumes that the role of the psychiatrist is solely that of making a psychiatric diagnosis or assessing so-called rationality; this ignores the role for assessment of the complex issues that contribute to the patient's suffering so as to formulate appropriate therapeutic interventions in the context of developing a trusting relationship. This is rarely achievable within one interview and the process involved does not lend itself to legislative intervention."

It is not hard to imagine that a patient convinced that they want to die by euthanasia or assisted suicide will attempt to project to any psychiatrist the image that they are not suffering from depression to any extent that would disqualify them.

Given that there is an opinion within the profession that one appointment is insufficient to make such a judgement, will the patient willingly accept a series of appointments or will they search for and find a psychiatrist who is happy to sign a certificate after only one consultation? As noted above, there will be some psychiatrists who will do so. But is that best practice and in whose interest?

Should it become known in medical circles (as it most certainly would do) which psychiatrists will or won't sign a certificate after one visit, it is likely that this gatekeeping role will be undermined by the exclusive use of such a psychiatrist.

Doctor shopping cannot be dismissed. It undermines and calls into question the efficacy of the involvement of two or more doctors in the process.

6.6. Safeguards and the Law

As we have seen above, there is an unavoidable subjective element in the expression of safeguards in any euthanasia and/or assisted suicide law. This alone, we argue, would make it difficult to prosecute any investigation into a wrongful death by euthanasia given an irrefutable claim to 'reasonableness'.

As we discussed earlier, a euthanasia law would be an effective exception to the Criminal Code provisions against homicide. That law will have created circumstances in which a doctor killing a patient would be lawful.

But what if a doctor did not properly report on a euthanasia death or chose not to report at all?⁶⁹ What if they were then challenged in some way concerning that death? What if he or she had not obtained the requisite opinions or not attested to the patient's consent?

He or she is allowed to kill. The statute defines the supposed parameters, the checks and balances – the safeguards; but what is the penalty for not observing them? The lack of reporting, for example,

⁶⁹ A reporting mechanism post mortem exists in both Belgium and the Netherlands and is a regular inclusion in Australian euthanasia bills.

could well be an oversight; but it could also be an attempt to hide a death that occurred without consent or because the patient did not qualify under the law. We believe that there would likely be little in the way of substantial evidence to sustain a charge of homicide. Euthanasia laws protect doctors, perhaps at the expense of patients.

Both Belgium and The Netherlands include in their laws the necessity of doctors formally reporting a euthanasia death to the relevant euthanasia commissions. This requirement is not being met.

For some, like Belgian Dr Marc Cosyns, euthanasia is a 'right' that need not be reported. In a joint interview in *De Standaard* in January 2014, Cosyns discussed his views with the joint head of the Belgian Euthanasia Review Commission, Dr Wim Distelmans:

This is the background to an astonishing admission made by Dr Cosyns in the course of their conversation. The journalist from De Standaard asked whether he reports the deaths he has caused through euthanasia to the Commission.

"No, not when it comes to our own patients," Dr Cosyns responded. "Everything I do is done on the basis of the law of patients' rights. We should not be required to give assurances that we did not intend to harm the person. Euthanasia is a normal medical procedure, as normal as the possibility of palliative sedation."⁷⁰

Dr Distelmans replies: "But Marc, you cannot ignore the criminal law." Yet nothing is done. No reprimand, no report.

This is entirely consistent with the behaviour of the *Belgian Euthanasia Evaluation Commission* which has yet to refer any euthanasia report for judicial review⁷¹; the *European Institute of Bioethics* going so far as to ask whether or not they have, 'become over the years a promoter of euthanasia'⁷².

A study published in the *British Medical Journal* in 2010⁷³ confirmed that only 52.8% of euthanasia deaths in the Flanders Region of Belgium were reported to the authorities (the Commission).

In this survey, doctors were asked about why they had not reported these cases.

"For 76.7% of these cases, physicians answered that they did not perceive their act as euthanasia, whereas for 17.9% they gave the reason that reporting is too much of an administrative burden, 11.9% that the legal due care requirements had possibly not all been met, and 9% that euthanasia is a private matter between physician and patient (8.7%). A small proportion (2.3%) did not report the case because of possible legal consequences."

⁷⁰ Report: Belgium and the majesty of the law. Mercatornet Careful! Blog. Jan 2014. Available at: <http://www.mercatornet.com/careful/view/13344>

⁷¹ See: European Institute of Bioethics 2014 Report: <http://www.ieb-eib.org/fr/bulletins/loi-sur-leuthanasie-incombe-t-il-a-la-commission-de-controle-dinterpreter-la-loi-272.html#sujet776>

⁷² See: <http://www.ieb-eib.org/fr/document/belgian-euthanasia-increases-by-89-in-four-years-382.html>

⁷³ Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. Smets et al. BMJ 2010;341:c5174 doi:10.1136/bmj.c5174
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2950259/pdf/bmj.c5174.pdf>

Adding those who thought that legal due care requirements had not been met to those who feared legal action it is possible to conclude that in *at least* 14.2% of these deaths were likely to have been outside the law; possibly more. It is also alarming that so many doctors appeared to have a poor understanding of euthanasia. The study concluded:

*"Consultation occurred in almost all reported cases, whereas it occurred in only half of all unreported cases. **This association was also found in the Netherlands, where the most important reason for not consulting was that the physician did not intend to report the case.** Physicians who intend to report a case seem to consult another physician and comply with the other requirements of the law, whereas physicians who do not intend to report a case appear to consult a physician only when they felt the need for the opinion of a colleague"* (emphasis added)

Smets et al summarizing:

*"As such legislation alone does not seem sufficient to reach the goal of transparency ("total" or a 100% transparency seems to be a rather utopian ideal) and to guarantee the careful practice of euthanasia"*⁷⁴

Deaths by euthanasia without request or consent have decreased in the Netherlands according to the official data in recent years, but in 2005 there were still 550 deaths without explicit request and in 2010 there were 310 deaths without explicit request.

However, a study published in *The Lancet* in 2012 concerning end-of-life practices in the Netherlands found that 23% of the euthanasia deaths were unreported.⁷⁵ In other words, like Belgium, the reporting system is not an effective safeguard and does not *guarantee the careful practice of euthanasia*.

The research points to many problems with reporting ranging from ignorance of what is and is not euthanasia to some clear evidence that some doctors knew they were operating outside the law. In respect to euthanasia acts not reported we think it right to observe that it is unlikely that any doctor who knowingly commits an act of euthanasia outside of the law would ever incriminate themselves by submitting a report attesting to the fact.

⁷⁴ **Note:** In respect to this and other studies noted both for and against euthanasia and dealing specifically with end-of-life decisions, the question of whether or not the data includes issues of 'double effect' mixed with possible cases of euthanasia without consent is not settled. Certainly, this study refers to these cases as euthanasia. However, the use of opioids rather than barbiturates in a majority of cases does call this into question.

⁷⁵ Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. Onwuteaka-Philipsen, Bregje D et al. *The Lancet*, Volume 380, Issue 9845, 908 – 915 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)61034-4/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)61034-4/abstract)

6.7. Incremental extension

*"...with respect to euthanasia, there is really no guarantee that the legal and administrative policies erected today, even if currently they functioned as intended, which is doubtful, will be as effective in a different cultural context decades hence."*⁷⁶

As earlier observed, the limit set on who does and does not qualify for euthanasia or assisted suicide, in law can be viewed as a 'safeguard' of sorts.

We have already discussed how a 'safeguard' on 'terminal illness' and a prognosis of, say, six months cannot effectively ensure that the law will only ever apply to an included definition and/or understanding of 'terminal illness' nor to the putative life expectancy.

In this section we discuss what *Boudreau and Somerville* called the 'Logical Slippery Slope' wherein the law itself is amended to include categories of persons that are excluded from access to euthanasia in the extant law.

As noted, the Belgian and Dutch laws were written broadly and, although the original intention may have only ever been for people who were dying and as a 'last resort' the practice, over time, has begun to explore and expand upon the breadth of the original legal wording.

Even so, in February 2014 the Belgian Parliament amended its 2002 enabling legislation to include children. Whereas the original act specified that 'the patient has attained the age of majority or was an emancipated minor'; the amendment included the possibility of euthanasia for minors with consent of the legal guardians. The child must have a terminal illness.⁷⁷

In The Netherlands, euthanasia of infants born with disabilities has been taking place outside the law but with tacit approval under what is known as 'The Groningen Protocol'. The Dutch law allows for euthanasia from the age of twelve in some circumstances.

The Groningen Protocol was developed by Dr Eduard Verhagen who gave a full explanation of this development in the *New England Journal of Medicine* in 2005:

*"To provide all the information needed for assessment and to prevent interrogations by police officers, we developed a protocol, known as the Groningen protocol, for cases in which a decision is made to actively end the life of a newborn."*⁷⁸

In this article, Verhagen explains the type of disabilities included, such as spina bifida.

In a paper prepared for the *International Federation for Spina Bifida and Hydrocephalus*, James E. Wilkinson notes the problems with this approach:

⁷⁶ Boudreau and Somerville. Ibid.

⁷⁷ See, for example: <http://www.smh.com.au/world/belgium-allows-euthanasia-for-terminally-ill-children-20140213-hvcb9.html>

⁷⁸ Eduard Verhagen, M.D., J.D., and Pieter J.J. Sauer, M.D., Ph.D. *N Engl J Med* 2005; 352:959-962 March 10, 2005 DOI: 10.1056/NEJMp058026 Available at: <http://www.nejm.org/doi/full/10.1056/nejmp058026>

First, the Protocol directs doctors to discriminate in their counseling based on the infant's disability. Second, predictions of a poor quality of life, a problematic concept to start with, are often not based on acceptable evidence but are rather a result of implicit stereotyping. This results in discrimination against and death of disabled newborns.⁷⁹

And now we note that the Dutch Parliament is actively considering revising their law to actively include child euthanasia under pressure from the *Dutch Paediatric Association* and Dr Verhagen.⁸⁰

Oregon's assisted suicide law is often looked to as providing a model of legislation where no 'slippery slope' or incremental extension has taken place. As we will note later, this is not the case. At this juncture we would simply point out that in Oregon there have been recent public discussions about expanding the law.

This year, a bill (House Bill 3337⁸¹) was drafted and presented to the Oregon Legislature that would change the prognosis qualification from six months to one year. *OregonLive* reported in April this year that the pro-assisted suicide lobby actually opposed the initiative on interesting grounds:

Then, the national Death with Dignity advocacy group joined the opposition. Steve Telfer, president of the board of the Portland-based Death with Dignity National Center, which helped create the original law, said politicians in Oregon shouldn't try to expand the law because that effort could jeopardize attempts to introduce physician-assisted suicide to other states.⁸²

As observed earlier, there is an inevitability about this kind of development given that the originating/enabling legislation had crossed the boundaries set by the criminal code, leaving any subsequent debate focussed only a rights based argument about who does or does not have access.

The fear Telfer expresses, that an extension of the law could 'jeopardize attempts' in other US states reflects the belief by some commentators that the Oregon law was hitherto deliberately held in check so as to advance that law as 'model legislation'. In all, something like 25 US states have looked at assisted suicide legislation in the last 10 to 12 months; none has been successful.

7. The Risk of Abuse

As pointed out earlier, the risk of abuse to citizens under any euthanasia and/or assisted suicide regime is a pivot point on which this matter ultimately turns. As a society, we should not be placing our citizens in known risk of harm from legislation, particularly when such risk involves loss of life.

Abuse can come in many forms and guises and is normally associated with the term 'vulnerable people'. This term lacks any precise definition but has a common understanding that suggests people who, for any number of reasons, are struggling to assert themselves, who feel powerless to influence

⁷⁹ Position Paper on the Disability Stereotypes, International Human Rights and Infanticide By James E. Wilkinson. <http://www.ifglobal.org/images/stories/groningen-d.pdf>

⁸⁰ See: Dutch paediatricians: give terminally ill children under 12 the right to die at: <http://www.theguardian.com/society/2015/jun/19/terminally-ill-children-right-to-die-euthanasia-netherlands>
⁸¹ <http://gov.oregonlive.com/bill/2015/HB3337/>

⁸² See: Legislator's promise to a dying friend: Death with Dignity amendment to help ALS, Alzheimer's patients fails. http://www.oregonlive.com/politics/index.ssf/2015/04/legislators_promise_to_a_dying.html

what is happening to them or who are being dealt with harshly by others with no opportunity for recourse nor justice.

As a society we seek to protect groups of persons whom it is acknowledged, are at risk. We think of children, the elderly and those experiencing mental illness amongst others.

But vulnerability can also be episodic. A trauma, changed circumstances, a threatening diagnosis, a mental health episode are amongst some of the factors.

It is wrong to assume that anyone in our society cannot at some time and in some circumstances become vulnerable.

As observed, it is these persons in these circumstances that have been continuously identified as being 'at risk' under any euthanasia and/or assisted suicide regime.

A good starting point for observations on this important issue is a study by *Battin et al* published in 2007 that concluded that vulnerable people were not over represented in the statistics from Holland and Oregon⁸³. Battin used the official data that shows that the elderly, women, those without medical insurance, those with a low educational status, the poor, racial and ethnic minorities and those with disabilities and chronic illness are not over-represented in the data, to conclude that there is no risk to vulnerable people inherent in legislation.

There are a number of assumptions made by Battin that should be of concern. Battin marks most of the aforementioned categories as 'vulnerable' and, secondly suggests by implication that those not in these cohorts are not vulnerable. These assumptions do not take into account the reality, as mentioned earlier, that anyone can become 'vulnerable' and takes no account of external factors or episodes. It is, in some ways, a stereotyping.

Finlay and George 'challenge the underlying assumptions and the methodology' chosen by *Battin et al*:

*However, their paper categorises vulnerability by reference to certain socioeconomic groups, relating to age, race, sex and economic and educational status, rather than by reference to emotional vulnerability and personality type, or other recognised markers of vulnerability among people seeking to end their lives, which exist across the spectrum of society.*⁸⁴

Battin provided testimony of her findings to the Irish High Court in the matter of *Fleming vs Ireland* in December, 2012 saying, according to a media report, that there was no evidence from studies in the US and the Netherlands that legalised assisted suicide led to abuse of vulnerable people such as the elderly, poor or disabled⁸⁵. In their judgement, later confirmed by the Supreme Court, the justices observed the contrary:

⁸³ See: http://press.thelancet.com/netherlands_euthanasia.pdf

⁸⁴ Finlay I, George R. *Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups - another perspective on Oregon's data*. J Med Ethics 2011 37: 171-174 Nov 2010 Available at: <http://www.livinganddyingwell.org.uk/sites/default/files/LDW%20-%20Research%20-%20Oregon%20-%20Finlay-George.pdf>

⁸⁵ See: *US expert on assisted suicide gives evidence in High Court case*. RTE News 11 Dec 2012 available at: <http://www.rte.ie/news/2012/1211/357867-marie-fleming-court/> accessed 13082014

It is true that there is one recent first instance Canadian decision (Carter v. Canada (2012)) in which a different view was taken. In that case, the Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and has drawn exactly the opposite conclusions. The medical literature documents specific examples of abuse which, even if exceptional, are nonetheless deeply disturbing. Moreover, contrary to the views of the Canadian court, there is evidence from this literature that certain groups (such as disabled neonates and disabled or demented elderly persons) are vulnerable to abuse. Above all, the fact that the number of LAWER ("legally assisted deaths without explicit request") cases remains strikingly high in jurisdictions which have liberalised their law on assisted suicide (Switzerland, Netherlands and Belgium) – ranging from 0.4% to over 1% of all deaths in these jurisdictions according to the latest figures - without any obvious official response speaks for itself as to the risks involved.⁸⁶

Two of Battin's colleagues (and occasional co-authors) confirmed evidence of 'vulnerability':

Study 1: Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. Ganzini, Goy, Dobscha. BMJ Aug 2008.⁸⁷

The study by Linda Ganzini examined the prevalence of depressed people asking for assisted suicide in Oregon. Ganzini had 58 participants who had requested assisted suicide. She found that 26% of the participants were depressed or had "feelings of hopelessness".

The study links the fact that depressed people who request assisted suicide in Oregon are not being referred for a psychiatric or psychological assessment (a requirement of the law). In 2007, 49 people who were reported to have died by assisted suicide in Oregon, none of them were referred for a psychiatric or psychological assessment.

Study 2: Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients. Van der Lee et al. JCO Aug 2005.⁸⁸

The study by van der Lee, et al, that found that people who were depressed or had "feelings of hopelessness" were 4.1 times more likely to request euthanasia. The study was conducted in the Netherlands through 2003. The study concluded that a depressed mood is an indicator for requests for euthanasia. This study is significant because van der Lee, who supports euthanasia, stated in her hypothesis: "their clinical impression was that requests for euthanasia were based on well-considered decisions and not depression in the Netherlands." They found otherwise:

"Our findings suggest that a depressed mood in the last months of life is associated with a higher risk for request for euthanasia."

None of the above should come as any surprise. A terminal diagnosis would set anyone back on their heels – even if only for a while. Suggestion or talk of euthanasia at these vulnerable times could have significant consequences.

⁸⁶ Fleming v Ireland. Ibid.

⁸⁷ Available at:

<http://www.bmj.com/content/337/bmj.a1682.full?ijkey=bc7d37e92efbfea7ce03a2d59bfd0c8b4623fa04&eaf>

⁸⁸ Available at: <http://jco.ascopubs.org/content/23/27/6607.full.pdf+html>

In Oregon, while the official data is published each year, providing at least some indication of problems with the system, the posthumous reporting and recordkeeping system is not accessible to scrutiny:

*The State does collect the names of patients in order to cross-check death certificates. However, the law guarantees the confidentiality of all participating patients (as well as physicians) and the Oregon Health Authority does not release this information to the public or media. The identity of participating physicians is coded, but the identity of individual patients is not recorded in any manner. Approximately one year from the publication of the Annual Report, all source documentation is destroyed.*⁸⁹

Elder Law advocate and Washington State Attorney, Margaret Dore, writing for the *Marquette Law Review* observes in respect to both the Oregon and the Washington statutes, that:

*Both Acts have an application process to obtain the lethal dose, which includes a written request form with two required witnesses. One of these witnesses is allowed to be the patient's heir, who will benefit from the death. Once the lethal dose is issued by the pharmacy, there is no supervision over its administration. The death is not required to be witnessed by disinterested persons. No one is required to be present.*⁹⁰

The opportunity for abuse of vulnerable people is evident in the Oregon statute and practices. We have already noted the problem with depression and prescribing doctors not seeking psychiatric evaluation.

Note: Anecdotes pointing to possible abuse and problems with the Oregon law are linked below.⁹¹

7.1 Elder Abuse

The sense that one is a 'burden' is noted in the Oregon official statistics as being a factor in a decision to die by assisted suicide in 40% of cases.⁹²

Concern about 'being a burden' is a commonly heard comment amongst our elderly. Sadly, it is also occasionally reinforced in our media; particularly in advertisements selling funeral insurance plans.

*"Elder Abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person"*⁹³

Elder Abuse, we argue, is a valid reference point for the consideration of why the protection of vulnerable people needs to include rejection of euthanasia and assisted suicide.

Most often thought of in terms of financial abuse, it is also recognised as being manifest in psychological, physical, sexual, social abuse as well as neglect.⁹⁴

⁸⁹ Oregon Health Board Q & A on the assisted suicide act. See:

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/aqs.aspx>

⁹⁰ Marquette Law Review. Dore. M. "DEATH WITH DIGNITY": A RECIPE FOR ELDER ABUSE AND HOMICIDE (ALBEIT NOT BY NAME) May 18, 2010. p387-401. Available at:

<https://choiceisanillusion.files.wordpress.com/2014/01/dore-marquette-law-review-article.pdf>

⁹¹ Link: http://courses.washington.edu/lsl434/documents/14_Oregon_abuses.pdf

⁹² Oregon Reports. Ibid. 2014.

⁹³ Definition. Elder Abuse Prevention Unit website: <http://www.eapu.com.au/elder-abuse> accessed 24072015

⁹⁴ Ibid.

Recently the *Victorian Royal Commission into Family Violence*⁹⁵ heard some disturbing evidence regarding abuse of elders by their children. The *ABC News* report⁹⁶ on evidence provided to the Commission quoted manager of *Seniors Rights Victoria*, Jenny Blakey, who said that abused parents often resisted reporting the abuse because they wanted to protect their children:

"If it's an adult son or daughter, the parent can often be very reluctant to disclose [abuse]," she said.

"There's a sense of shame, there's a sense of embarrassment, there's a sense of wanting to help or support the son or daughter, or protect them.

"There's a reluctance to engage the police."

The commission heard 40 per cent of elder abuse was perpetrated by adult sons, and 26 per cent by adult daughters.

Ms Blakey said elderly victims were also held back from going to police out of fear of becoming isolated.

"There is this sense of 'you need to look after me, you're my parent, you're going to die and haven't got much longer to live, so therefore the money ... [it's] better, that I have it'," Ms Blakey said.

Experts also believed the problem was significantly under-reported. This stands to reason as explained in the article. A socially isolated and abused elderly person is very likely to question their own intuitive judgement and likely also to have little if any opportunity to complain or cry for help. A recent fraud report by *KPMG UK* highlighted the problem:

*"Fraudsters in the family are abusing their intimate knowledge and close connections to steal from partners and parents. People are living longer, and we are seeing examples of people who are choosing to remove uncertainties about when or if they will get their inheritance by fraudulent means. It's also likely these cases are just the tip of the iceberg – frauds of this nature often go unreported as embarrassed victims seek to 'keep it in the family' and 'forgive and forget'."*⁹⁷

HOPE believes that euthanasia and assisted suicide could create opportunities for the ultimate in Elder Abuse; the death of a relative who is pressured into accepting being made dead or who perhaps even willingly takes that alternative as a way out of the cycle of abuse. The *UK Disability News Service* recently noted that the same *KPMG* report has similar negative consequences for people living with disability.⁹⁸

⁹⁵ Royal Commission into Family Violence <http://www.rcfv.com.au/About-Us>

⁹⁶ ABCNews online: *Royal Commission into Family Violence: Abuse of elderly under-reported by victims due to 'embarrassment, shame'* available at: <http://www.abc.net.au/news/2015-07-16/royal-commission-abuse-of-elderly-is-under-reported-by-victims/6625230>

⁹⁷ KPMG UK Report: *Fraud up, and it's becoming a family affair*. Available at: <http://www.kpmg.com/UK/en/IssuesAndInsights/ArticlesPublications/NewsReleases/Pages/fraud-up-and-its-becoming-a-family-affair.aspx>

⁹⁸ *Family fraud 'explosion' highlights fears of assisted suicide opponents*. DNS Aug 7, 2015. Available At: <http://www.disabilitynewsservice.com/family-fraud-explosion-highlights-fears-of-assisted-suicide-opponents/>

It is, perhaps, not entirely accurate to characterise all Elder Abusers as selfish, cruel and bent on an early access to an inheritance. A study released on the 23rd of July this year researching homicidal ideation in carers of people suffering from dementia should create some pause for thought.

O'Dwyer *et al*, in an earlier study concerning *Suicidal ideation in family carers of people with dementia* noted a comment about homicidal thoughts towards their relative from one respondent. Their follow up study, *Homicidal ideation in family carers of people with dementia*⁹⁹ included interviews with 21 carers. Two participants reported 'active homicidal thoughts', four acknowledged what the researchers call 'passive death wishes' while 13 'who had not contemplated homicide understood how other carers could', citing factors such as compassion, frustration, lack of support and a 'sense that the caregiving role was never ending'.

The researchers did not use the terms 'euthanasia' or 'assisted suicide' in the interviews, yet four carers 'couched their responses in terms of euthanasia' while all four denied any direct homicidal intent.

Four participants also reported verbally and physically abusing the person they were caring for.

While the persons being cared for had dementia and would not, therefore, be likely candidates for euthanasia (given concerns about consent) it is worthy of note that pressures do exist in the carer role that potentially could become influential in a decision on euthanasia and/or assisted suicide.

This may well be amplified in a situation where euthanasia and/or assisted suicide were legally available through an advance care directive as is possible in The Netherlands¹⁰⁰.

7.2. Coercion

The problem of coercion cannot be eliminated by simply creating a clause in a euthanasia or assisted suicide bill that requires some attestation that the person is not under some form of duress regarding a decision to be made dead.

Coercion may be subtle. It may simply be part of a person's sense of being a burden amplified by their experience as a patient.

Active coercion has been noted by Dutch Professor Theo Boer who reviewed thousands of case files as part of the Dutch review commission. He made these comments recently in an interview for *DutchNews*:

Asked how often he saw evidence of pressure from the family, he said: 'It's hard to say, but at a rough estimate I would say the family is a factor with one in five patients. The doctor doesn't want to put it in the dossier; you need to read between the lines.'

*'Sometimes it's the family who go to the doctor. Other times it's the patient saying they don't want their family to suffer. And you hear anecdotally of families saying: "Mum, there's always euthanasia".'*¹⁰¹

⁹⁹ O'Dwyer ST *et al*. *Homicidal ideation in family carers of people with dementia* (2015) *Aging and Mental Health*. Available at:

<http://www.tandfonline.com/doi/abs/10.1080/13607863.2015.1065793?journalCode=camh20#abstract>

¹⁰⁰ 97 Dutch people with dementia were euthanased in 2013. See official report:

<https://www.euthanasiecommissie.nl/overdetoetsingscommissies/jaarverslag/default.asp>

¹⁰¹ Article: Pressure on patients is cause for concern: euthanasia expert. *DutchNews*. July 3, 2015. Available at:

<http://www.dutchnews.nl/news/archives/2015/07/pressure-on-patients-is-cause-for-concern-euthanasia-expert/>

In evidence given before the Scottish Parliamentary committee concerns about coercion were also noted:

186. Professor David Jones pointed out that people are vulnerable, not just to coercion, but to "influence", which is wider. He noted that individuals may be influenced in the direction of suicide by a range of factors including their own subjective sense of being a burden; this is a concern which was also raised by a number of witnesses in different evidence sessions.¹⁰²

These concerns are highlighted by a recent anecdote from Vermont where assisted suicide is legally available:

True Dignity has spoken with the family of a 90-year-old Medicaid patient who felt pressured by caregivers in the facility where she was admitted for recovery from a fall. The patient did not have a terminal diagnosis.

According to Beth Neill, clinicians at the Berlin Health and Rehab Center informed her mother at regular intervals during her 4-month stay there that she had a "right" to use Act 39, and that, "She didn't even have to discuss it with her family." It was the act of repeatedly bringing up Act 39 as a health care "option" that caused her mother to feel pressure, and not overt efforts by clinicians to convince her to request the lethal prescription, Neill said. However, she said her mother made it clear she wanted nothing to do with Act 39 and was disturbed that staff re-introduced the topic repeatedly.

Neill notes that her mother was, and is, in otherwise surprisingly good health for her age, and would not have qualified for Act 39, as the extended stay in Berlin Health and Rehab was strictly for help recovering from her fall.

Neill was not made aware of the situation at Berlin Health and Rehab until after her mother had already been moved to assisted living at a Northfield facility, where she currently resides. When she did hear of it, "It blew my eyebrows off," she said.

According to Neill, the staff at the Northfield facility informed her that her mother had reacted strongly when they began to discuss care options. "Mom thought they were going to start talking about Act 39, the way they did at Berlin (Health and Rehab), and she blew up at them. She said, 'I don't want anyone talking to me about killing myself.'"¹⁰³

Was this simply a matter of medical staff trying to come to terms with how to talk to patients properly about the assisted suicide option or was it something more sinister, such as wanting to be rid of a 'bed-blocker'? We do not know. All we can conclude is that coercion can come in many forms and guises, is not always malicious in intent, but clearly can have an influence over a patient's thinking and actions.

This re-enforces the point that decisions about euthanasia and/or assisted suicide are rarely if ever totally free from influence of one kind or another.

7.3. Societal pressure

Nor should we dismiss the negative messages on aging and illness that our society inadvertently visits upon our elders.

¹⁰² The Health and Sport Committee of the Scottish Parliament. Ibid.

¹⁰³ From the TrueDignityVermont website available at: <http://www.truedignityvt.org/from-the-netherlands-to-vermont-patients-under-pressure-to-die/>

By way of recent example, the Northern Territory Health Minister, John Elferink openly discussed 'canvassing support for cutting seniors' funding' in health that 'has been coming "at the expense" of children'. The ABC News reports also cited support for his thinking from an economist and even the AMA in the Northern Territory.¹⁰⁴

While the latter raised the issue of an aging population and the health budget in more moderate and general terms, Elferink said: *"I suspect if you spoke to somebody who, ... for arguments sake, had end-stage renal failure and said: 'We can continue treatment but by discontinuing treatment your grandchildren would have a better opportunity'.*

"Many of those old people would say 'Yeah I accept that'."

End of life issues should never be discussed in such offensive terms. It amounts to putting pressure on vulnerable people and, as is often observed with euthanasia and assisted suicide, could be conceived as creating a 'duty-to-die' in the minds of the elderly, sick or disabled.

That this is perceived in such terms was made obvious by one elderly and ill Territorian in reply:

"Let's see how [Mr Elferink] feels when he gets to that age," Mr Morphett said.

"What's he going to do, stand in front of a firing squad with the rest of the 65-year-old members of the community? What do they do, do they march all these people out like they did in the holocaust?"

Certainly we need to continually evaluate the health budget against pressing needs and seek always to provide the best of care to all in what are challenging times. It is not so much that people will perceive such comments as precipitous and the dawn of an era where films such as *Logan's Run* or *Soylent Green* might be seen in hindsight as prophetic. It is more about the reinforcement of thoughts of abandonment and fear; fears which may actually be driving people towards accepting the invitation and subtle sales and marketing of groups like Exit International.

7.4. Disability

As Craig Wallace from *Lives Worth Living* observed in respect to the *Di Natale Bill* and people living with disability, *'I am not satisfied that this would not apply to the people I represent on a reasonable reading'.*

In the media attention often given to people who claim to want euthanasia or who are preparing to suicide because of some presenting illness, it is common to read or hear sentiments attached to their concerns that describe the kind of circumstances that some people living with disability experience daily. Fears such as the loss of ability to do certain things, fear of needing someone to assist with toileting, feeding, cleaning etc. are regularly cited as reasons for wanting to die.

What effect do these kind of references have on people who need support for these kind of issues because of disability?

English Peer, Baroness Jane Campbell of Surbiton told the *House of Lords* last year, in relation to Lord Falconer's assisted suicide bill: 'Disabled and terminally people are rightly frightened that it (the bill) puts them at risk.' She added:

¹⁰⁴ See ABC News online: *Economist, doctor back NT Minister's call for debate on funding for elderly health care* <http://www.abc.net.au/news/2015-08-21/support-for-nt-ministers-comments-on-funding-for-elderly-debate/6715348> Accessed 26082015

Outside this building, there are people sitting in wheelchairs with terminal conditions saying, 'No, this is not about choice—this is not about me asking.' They have often felt so low that they felt that they had no options. They could have taken advantage of this Bill, because they have a terminal illness.

But people with terminal illnesses in the disability community say we should slow down and think again. We have to listen to them. Do not tell me that this is not about disabled people. It is very much about us because we are the people with experience of these issues. Many of those campaigning for this measure have not experienced these issues. They are people in control of their lives. They are people who fear becoming what they see us as.¹⁰⁵

Disabled actress, comedian and star of the UK Crime series, *Silent Witness*, Liz Carr, spoke out recently in the Westminster Parliament against assisted suicide:

"I am terrified by this Bill. I am terrified because as a disabled person I have experienced first-hand how poorly our society values disabled people. It's the same with elderly people.

"I'm always being told, 'If I was like you I'd kill myself'. 'If I was like you I'd want to die.' There are people who sincerely believe that people like me are better off dead.

"But I don't want to die. And to talk about choice when so many vulnerable and disabled people do not have a choice about basic care, housing and support is to put us in a very dangerous position indeed.

"This is really serious. It's about life and death. If this Bill becomes law some disabled and vulnerable people will be subjected to exploitation and abuse and will die as a result."¹⁰⁶

Dr Kevin Fitzpatrick OBE, co-convenor of *NotDeadYetUK* sums the situation up well by quoting a comment raised online in discussing euthanasia and assisted suicide:

As one subscriber to a recent online discussion expressed it:

'It is not always about pain. It is also about being decrepit, disabled, incapable of taking care of oneself anymore, getting blind, getting incontinent, becoming an object of disgust and pity for those in charge of cleaning you up and feeding you. Who wants to go through all that when there is an easy way out?'

There it is: all of it. Becoming an object of disgust and pity for others, being 'decrepit, disabled' – and when the 'easy way out' is to hand.¹⁰⁷

We need always to be aware of subtle and not-so-subtle messages; intended or otherwise.

¹⁰⁵ Report on address to The Lords. Baroness Campbell. Available at: <http://noeuthanasia.org.au/blog/2198-it-is-a-bill-for-the-strong-at-the-expense-of-the-weak-baroness-jane-campbell.html>

¹⁰⁶ Report on this event at: <http://www.notdeadyetuk.org/notdeadyet-news.html>

¹⁰⁷ Blog story: *Disability discrimination to death – the unthinking final solution proposed by non-disabled people*. At: <http://hopeire.com/disability-discrimination-to-death-the-unthinking-final-solution-proposed-by-non-disabled-people/>

7.5. Slippage – when person centred care is replaced by protocol

Even the best intentions and a sound plan can go wrong; in this case, horribly wrong.

In the late 1990s, the Royal Liverpool University Hospital and Liverpool's Marie Curie Hospice developed what became known as the *Liverpool Care Pathway* or LCP, as a tool to help doctors and nurses provide quality end-of-life care in the last few days of life. Originally intended for cancer patients, it was soon adopted more broadly across the UK in hospitals, aged care facilities etc.

I heard two clinicians give a rousing tick of approval to the LCP in Edinburgh in 2012. Both were involved in the care of cancer patients and both had a high level of expertise. Even at that time, however, significant disquiet was being heard around the UK as stories of abuse and poor care resulting from the use of the LCP began to surface in the media.

The UK government instigated a review of the LCP in 2013 which recommended that the LCP should be "phased out over the next 6-12 months and replaced with an individual approach to end of life care for each patient". The Independent Review summarized (in part) that:

"..it is clear to us, from written evidence we have received and what we have heard at relatives' and carers' events, that there have been repeated instances of patients dying on the LCP being treated with less than the respect that they deserve. It seems likely that similar poor practice may have taken place in the case of patients with no close relatives, carers or advocates to complain, or where families have not felt able or qualified to question what has taken place. This leads us to suspect this is a familiar pattern, particularly, but not exclusively, in acute hospitals. Reports of poor treatment in acute hospitals at night and weekends – uncaring, rushed, and ignorant – abound.

*"Where care is already poor, the LCP is sometimes used as a tick box exercise, and good care of the dying patient and their relatives or carers may be absent. Whether true or not, many families suspected that deaths had been hastened by the premature, or over-prescription of strong pain killing drugs or sedatives, and reported that these had sometimes been administered without discussion or consultation. There was a feeling that the drugs were being used as a "chemical cosh" which diminished the patient's desire or ability to accept food or drink. The apparently unnecessary withholding or prohibition of oral fluids seemed to cause the greatest concern."*¹⁰⁸

There is no doubt, as the Independent Review makes very clear, that the LCP itself was an excellent tool in helping to ensure patients received the best of care at the end-of-life. The caveat is: *when used properly*. Like any tool, it works best in the hands of an appropriately skilled person.

Clearly what developed overtime was this 'tick-box', 'one-size-fits-all' interpretation and application by junior staff with little or no training and in circumstances where it may not have been appropriate.

¹⁰⁸ MORE CARE, LESS PATHWAY A REVIEW OF THE LIVERPOOL CARE PATHWAY.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

It is an example of where even with the very best of intentions a regimen can fall into inappropriate use with devastating consequences; such 'slippage' becoming perhaps routine and creating or reinforcing a culture of poor care standards. We observe that this is also a very real risk attached to any euthanasia or assisted suicide regime.

By way of example, a 2007 study of deaths in Belgium reported that in 12% of the cases reviewed, it was nurses who had given the 'life-ending drugs in some of the cases of euthanasia'. In 45% of those deaths, euthanasia was administered without explicit patient request. The Due Care provisions of the Belgian Act insist that the euthanasia request must be discussed with the nurses involved. However, nurses are not permitted to enact euthanasia.¹⁰⁹

8. The suicide connection

*So what should our response be to suffering? As a culture do we reach a helping hand to our neighbor on the bridge? Or do we redefine "helping" as pushing them off? Do we even pretend to ourselves that pushing them is the "compassionate" thing to do?*¹¹⁰

As Boudreau and Somerville warn: "One must be wary of euphemisms because they dull our moral intuitions and emotional responses that warn us of unethical conduct;" what they summarize as 'legalizing euthanasia through confusion'.¹¹¹

We must call a spade a spade if we are to give the matter of euthanasia and assisted suicide due consideration. Euthanasia involves, by commission or omission, an intentional act designed to make a person dead. It is killing. Assisted suicide is an act or acts that assist people to kill themselves: suicide.

We must not confuse the idea of compassion, a wholesome and good motive, with the intention to kill or to help someone kill themselves. Compassion is evident on both sides of this debate.

Compassion is meant to motivate us to respond in some way; to help.

The question is whether or not as a society we want to consider ending suffering by ending the sufferers.

With euthanasia and assisted suicide we are presented with 'options' that in essence act upon a decision by a person that they want to be made dead. We ask: what's the difference between the putative person on the ledge and someone facing a difficult prognosis?

¹⁰⁹Els Inghelbrecht et al. *The role of nurses in physician-assisted deaths in Belgium*. CMAJ June 15, 2010 vol. 182 no. 9 905-910. Available at: <http://www.cmaj.ca/content/182/9/905.full>

¹¹⁰ Blogger Jessica Rodgers a reflection entitled: *Whom Do We Mourn?* At: <http://noeuthanasia.org.au/blog/2278-whom-do-we-mourn.html>

¹¹¹ Boudreau & Somerville. *Euthanasia and assisted suicide: a physician's and ethicist's perspectives*. Jnl of Medicolegal and Bioethics 2014:4 available at: <http://noeuthanasia.org.au/documents/federal/inquiry/Boudreau-and-Somerville-pespectives-on-euthanasia-Jul-2014.pdf>

Both are facing a crisis. Both will have 'rationalised' their circumstances to the point where they see no other option.

As differences we could note that perhaps the person on the ledge is young and otherwise well while the candidate for euthanasia or assisted suicide is suffering physically. We are being asked to see these as essential differences; to define the life of the first as worth living and, the second, not so. We expect that the first may have a long life ahead of them, but not so the second; but we really don't know in either case. We offer counselling to the first and death to the second.

While we can see, perhaps, that both have 'rationalised' their decisions we judge the first as being an errant judgement while we will easily accept the thoughts of the latter.

We are making judgements. Judgements that are discriminatory and, in essence, ableist and/or ageist. We are determining a higher value on the life of the younger person and a diminished value on the aged and those disabled by illness. We want to stress to the former that there is hope while viewing the latter as hopeless.

The committee of the Scottish Parliament commented on the relationship between assisted suicide and suicide prevention:

277. The Committee acknowledges that discussion of the current Bill forms part of "how we talk about suicide".

278. There appears to be a contradiction between a policy objective of preventing suicide, on the one hand, and on the other, legislation which would provide for some suicides to be assisted and facilitated.

279. The Committee notes that, unless assisted suicide is to be made freely available to all, any legislation permitting it must identify eligibility criteria. Where legislation to permit assisted suicide exists alongside a wider policy of suicide prevention, the eligibility criteria in the legislation serve to differentiate between circumstances in which suicide is to be regarded as a tragedy and prevented wherever possible, and circumstances in which suicide is to be regarded as a reasonable choice, to be facilitated and supported.

280. The Committee is concerned that this has the potential not only to undermine the general suicide prevention message by softening cultural perceptions of suicide at the perimeters, but also to communicate an offensive message to certain members of our community (many of whom may be particularly vulnerable) that society would regard it as 'reasonable', rather than tragic, if they wished to end their lives.¹¹²

In Australia, there is plenty of evidence to suggest that the public advocacy for suicide by Exit International is drawing those who are not ill nor of advanced age towards suicide.

A recent report in *The Melbourne Age* newspaper noted this phenomenon:

¹¹² The Health and Sport Committee of the Scottish Parliament. Ibid.

New data from the national coronial information system shows 120 people died by taking Nembutal – dubbed the "peaceful pill" – between July 2000 and December 2012.

'The number of deaths from the drug reached a high of 24 in 2011, compared with nine in 2001. In 2012, there were 17 deaths. However, there may be more as the data obtained by Fairfax Media does not include cases before the coroner.'

*'The deaths included one person under the age of 20, 11 people in their 20s and 14 people in their 30s.'*¹¹³

That's 22% of all Nembutal deaths over a little over 11 years being suicides of persons under 40 years of age and 10% under 30 years. The data does not include deaths still under investigation.

In June this year the media began to report that a 24 year old Belgian woman known as 'Laura' had been approved for euthanasia due to persistent suicidal thoughts. She is otherwise not ill. In an article published by *Inquisitr*, the reporter notes how 'Laura' first came to consider euthanasia:

*Due to these issues, she began seeking treatment in a psychiatric institution over the last three years. Laura says she first began considering euthanasia when she became friends with another woman named Sarah, who also ended her life about a year and a half ago. Now, Laura is also a candidate for euthanasia for psychological reasons, which is when a patient is in mental pain and wants to die.'*¹¹⁴

Though not stated, it is nevertheless a reasonable assumption in the circumstances to conclude that this woman named 'Sarah', died by way of euthanasia or suicide.

To our knowledge, there is no sociological data from places where euthanasia and assisted suicide has been legalised that provides empirical proof of the connection between euthanasia and assisted suicide and an increase in that practice and/or suicide generally. There is, however, significant concern about the suicide contagion phenomenon, particularly amongst young people.¹¹⁵

8.1. A cautionary tale

There are also cautionary notes that serve as a point of reflection upon the development of the notion that some suicides are okay and, perhaps even 'heroic'.

Minnesota Citizens Concerned for Life developed a discussion paper in May this year reviewing the assisted suicide phenomenon in the USA and focussing on the possible contagion or *Werther Effect*.

There is no direct causational relationship established here as the author readily admits. Generally speaking, it appears that there are only a handful of studies dealing with E & AS and possible

¹¹³ Report: *Young people opt for euthanasia drug as overall number of deaths grows*. The Age July 12, 2015. Available at: <http://www.theage.com.au/national/health/deaths-from-euthanasia-drug-on-the-rise-20150712-gia76j>

¹¹⁴ Article: *Healthy Woman Will Die By Doctor-Assisted Euthanasia Over Suicidal Thoughts*. Inquisitr. June 24, 2015. Available at: <http://www.inquisitr.com/2196375/healthy-woman-die-doctor-assisted-euthanasia-suicidal-thoughts/>

¹¹⁵ See, for example: *Suicide Can Be Contagious Among Teens*. May 22, 2013. Medical News Today. Available at: <http://www.medicalnewstoday.com/articles/260836.php>

contagion. We submit, however that such observations should not be summarily dismissed simply on the basis that no empirical evidence nor formal connection has been established. While the question is ripe for sociological research, any studies that may be undertaken will be after the harm is done if, indeed, the principle postulated is proven correct.

The paper quotes a Canadian doctor colleague, Dr Will Johnston referring to the media frenzy that followed the planned assisted suicide death of Brittany Maynard throughout 2014:

"I hospitalized a young suicidal patient 10 days ago who told me how he had done an Internet search for suicide drugs after watching the slick video glamorizing Brittany which was produced by the Hemlock Society (now Compassion & Choices)."

The article quotes him further:

"The social threshold of inhibition against suicide has been steadily eroded by the rhetorical strategy of calling for an endorsement of suicide in hard cases through labeling such endorsement [as] compassionate," he said. "The Brittany Maynard tragedy is a prime example of this."...

"We see how suicide contagion works when the media admire the suicidal person and speak of suicide as a form of heroism," Johnston said.¹¹⁶

A similar effect was noted by researchers looking into 'Exit suicides' in Switzerland pre and post the publicised double Exit suicides of a prominent Basle couple in 1995. Looking at the data for the corresponding periods prior and post the publicity surrounding the deaths, the researchers noted that Exit deaths quadrupled in the second period.¹¹⁷

We would stress that the precautionary principle and the possibility that such laws have, *'the potential not only to undermine the general suicide prevention message by softening cultural perceptions of suicide at the perimeters, but also to communicate an offensive message to certain members of our community (many of whom may be particularly vulnerable) that society would regard it as 'reasonable', rather than tragic, if they wished to end their lives'* should create, at the very least, significant concern.

8.2. Public Policy – creating a pause

The law, as it stands, that prohibits killing and prohibits assisting in suicide is meant to provide a pause, as are the taboos around suicide generally. In suicide we can understand that the person is struggling with the human instinct to preserve life in the face of what they might see as overwhelming and desperate circumstances; a pause that, we would always hope, holds them back from the edge.

The prohibition on killing creates a pause for the doctor who may find themselves having been asked to kill their patient. Again, a pause that we trust will motivate them to support their patient, to seek to allay their fears and to deal with their issues. We would never say to the person on the ledge, 'your

¹¹⁶ Stark. P. *How assisted suicide advocacy and legalization threaten the lives of vulnerable people*. May 2015. White Paper: Minnesota Citizens Concerned for Life. Available at: <http://www.mccl.org/document.doc?id=724>

¹¹⁷ Frei, A., Schenker, T et al. (2003) *The Werther Effect and assisted suicide*. *Suicide and Life Threatening Behaviour*, 24, 326-333.

troubles are insurmountable; go ahead and jump!' Why then would we want to say something of a similar nature to the sick person? Could we not be accused of abandonment?

This, we submit, is the significance of the research by *Kissane et al* in reviewing the operation of the Northern Territory legislation. If euthanasia is the outcome sought and planned, there is perhaps little impetus to pursue other options.

Just as with the person on the ledge, we know that the underlying issues of the medically ill person can be dealt with. We know from research that they are largely not about pain, but fears about loss of autonomy, perceived loss of dignity and a sense of becoming a burden.

These are very real concerns, no less real than those of the person on the ledge. How is it that we should be so committed to dealing with the fears and anguish of one and so ready to accept without question that the issues of the other cannot also be ameliorated? We know that good care that considers the whole person, not just the illness, can achieve that.

9. Conclusion

"We try to formulate pathways and guidelines and mathematical predictors of life expectancy and discharge destination. But no algorithm or flow chart can accommodate the messy intricacies of dying. No pathway can decide which life is worth living.

"We cannot monetise, corporatize and streamline our individual demise, and we must protect the vulnerable: those who feel they are a burden, that their living has become a burden – those whom other people feel are a burden." Karen Hitchcock, Dear Life – on caring for the elderly¹¹⁸

We recognise that compassion motivates everyone who has made any submission to this inquiry, no matter what subject matter under the terms of reference they have focussed upon. People are likewise motivated on both sides of the euthanasia and assisted suicide debate.

The question arising from that motivation is: 'How do we care?' It is about intentions and the role, if any, of the State of Victoria in facilitating such intentions.

Parallel are considerations of whether or not such intentions are defensible from a justice and public safety perspective; the primary function of government being the protection of all citizens. The further questions are therefore about whether or not the intentions serve the common good and whether or not the State has a role to play.

We believe the State of Victoria has a valuable and primary role to play in enhancing public well-being and health through efforts to extend and improve palliative care and in the promotion of these services to the public. No Victorian should be left unsupported in their need.

There are valuable messages that the State of Victoria can deliver that supports and enhances a sense of wellbeing, support and care.

¹¹⁸ Quarterly Essay. Issue 57 March 2015.

There will always be those who decide not to avail themselves of palliative and other supports. That is a valid choice. But it should not be able to be said that people who make such a choice do so in ignorance of what is available and its potential efficacy. That would be a tragedy.

That some may still choose another path is up to them. But such choices create no further responsibility upon good government. It is not and should not be an argument for state-facilitated killing or help for people to suicide.

The criminal code prohibition on homicide has stood the test of time; likewise the prohibition on helping people to suicide. They are like a dam-wall that is an effective bulwark creating and endorsing protection for all.

HOPE views any legalisation of euthanasia or assisted suicide as a breach of that wall. The consequences of such a breach have been explained and, extending the metaphor, any breach inexorably weakens the whole wall over time.

Thank you,

Paul Russell
Director
HOPE: preventing euthanasia and assisted suicide Inc.

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Lilian Topic,
Secretary,
Legal & Social Issues Committee
Parliament House,
Spring Street,
Melbourne VIC 3002

1st December 2015

(per email)

Dear Members of the Committee,

Please accept this letter as an addition to my submission of the 31st of August (# 926) concerning matters raised in respect to myself and the HOPE organisation by Mr Neil Francis of *Dying for Choice* both in his submission (#962) and in his evidence given before you on the 21st of October 2015.

I understand Mr Francis has made the same or similar claims in regards to myself on a number of occasions and in a number of fora. With your indulgence, I seek to take this opportunity to correct the record and to provide additional information published more recently that may be of interest in your deliberations.

Mr Francis first raised claims that I had adopted the view that the suicide data in Oregon had a causal relationship with the existence of assisted suicide in that place, in a debate in Launceston (to which he refers).

Very much a 'gotcha' moment, I considered his claims at the time as a coarse 'ad hominem' debating strategy (creating the inference that, Russell is wrong here, so why would you trust anything he says). I could not recall the reference and the context of the article and had no way of checking at the time. As I had no desire to dignify the strategy, I ignored it.

Mr Francis confirmed to you that he made the same claim in a video recording he made for South Australian MPs in 2013. A number of MPs contacted me personally about the video and I responded to them in person. I also contacted the Oregon doctors mentioned in the video (and in Francis' submission) in regards to his claims about their comments in that same video (see below).

Mr Francis also draws into the question of 'correlation vs causation' two of my colleagues and a few articles which he claims shows that we are making false claims in respect to suicide in Oregon USA. Francis claims that I have said, *'that there is suicide contagion in Oregon because the data since 2000, he says — here is 2000 — the law came into effect in 97. Since 2000 the general suicide rate in*

Oregon has been increasing markedly, and he suggests that that is a result of suicide contagion' (Hansard from Committee Hearing).

I have not made such a claim and neither have my colleagues whom Mr Francis mentions. We are consistent in this approach. Mr Francis correctly points out in respect to Oregon, the rate of unemployment is likely to be a significant factor in the rise in suicides. I accept that there are other factors at play in the Oregon statistics.

All I have ever done is to occasionally, in context, note the Oregon suicide data and note the possibility that the existence of assisted suicide laws may have had an effect on the data given that one of the noted characteristics in suicide is the person having known or known about someone else who died by suicide. This is a reasonable question to ask and one, we hope, that sociologists may, in time, attempt to come to terms with more fully.

The original 'offending' quote mentioned by Mr Francis is, contrary to his advice, available on my website. In a post entitled: *The Nitschke Travelling Road Show*, I discussed the work of Exit International and attacked its modus operandi. Mr Francis quoted a comment of concern for youth:

And what of our youth? What do we think happens in the minds of troubled teenagers when they hear the message that rings loud and clear in Nitschke's sales pitch that some people are "better off dead"? In Oregon following the introduction of doctor-assisted suicide, suicide by other methods went up and not down as predicted. This is consistent with suicide contagion or clusters.ⁱ

The claim that the Oregon suicide rate went up is true. It was argued in Oregon during the debate around the original plebiscite and the subsequent Dying with Dignity Bill that assisted suicide would reduce the general suicide rate (the sick and dying opting for less violent suicides via the assisted suicide Act). It did not. To say that this is 'consistent with suicide contagion or clusters' is simply a reflection; it is not a claim to causation.

Francis also raises my re-post of Washington Attorney, Margaret Dore's article: *Assisted suicide: Is there a suicide contagion effect?*ⁱⁱ He claims Dore argues only in the affirmative. Dore's main concern is the campaign promotion of a pro-assisted suicide organisation and the risk that such promotion could create suicide ideation in vulnerable people. It is a cautionary. She notes, as does Mr Francis, that the suicide rate in Oregon began rising after an historic low in 2000.

While this historic low in suicides was noted across the USA and while the Oregon suicide figures were, otherwise, always above the national average (mostly in parallel with them), post 2000, the suicide rate in Oregon did increase against the national average. Noted at 37% above the national average in 2007, the 2010 data showed an increase to 41%, and 42% in 2012 for an age adjusted suicide rate of 17.7 deaths per 100,000.ⁱⁱⁱ

Mr Francis also refers to an article entitled: *Canadian study proves that "suicide contagion" exists – more work needs to be done*^{iv} which he wrongly attributes as being written by me. Author, Alex Schadenberg refers to a study done in relation to youth suicide in Canada. The only commentary the author makes is to note that, 'The Euthanasia Prevention Coalition (EPC) is concerned with the connection between suicide and assisted suicide.' and 'The EPC urges researchers to do a study on the relationship between suicide, assisted suicide and the promotion or normalizing of assisted suicide upon the rate of suicide.'

Indeed, since Mr Francis' original submission to your Inquiry and nearly two weeks prior to his attendance at your hearings on the 21st October, the USA Southern Medical Association Journal published a study called: *How Does Legalization of Physician-Assisted Suicide Affect Rates of*

Suicide?^v The study's authors looked at all the data available from US states, looked at the assisted suicide data and, after controlling for *a range of demographic and socioeconomic factors* and including *state-specific time trends*, noted that, contrary to suggestions, there is clearly no reduction in the general suicide data as a result of the inclusion of legal Physician Assisted Suicide. They also noted a positive association in the relationship between PAS and nonassisted suicide but said that it was, 'no longer statistically significant', after controlling for state specific trends.

The authors conclude that: *Legalizing PAS has been associated with an increased rate of total suicides relative to other states and no decrease in nonassisted suicides. This suggests either that PAS does not inhibit (nor acts as an alternative to) nonassisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals.*

This is but one study and a complicated one at that. We look forward to more research being done in this area. Even with this study the authors only observe 'relationships' and do not venture into speculation on possible causation.

Additionally, I take exception to Mr Francis continuing to refer to HOPE as 'Australian Family Association's anti-assisted-dying blog'. HOPE began in 2010 and, for a few short months, we acknowledged the Australian Family Association's support in working with me to create HOPE as a campaign to oppose a bill in South Australia at that time (via the inclusion of their logo on our website). Since then, for nigh on five years, HOPE has been a stand-alone, single issue organisation with no affiliation to any auspicing organisation. Our website has, since that time noted that: *HOPE: preventing euthanasia & assisted suicide is a coalition of groups and individuals who oppose the legalization of euthanasia and assisted suicide and support measures that will make euthanasia and assisted suicide unthinkable.*^{vi}

Mr Francis' continued association of HOPE with the AFA seems to be an attempt to foster some sort of negative association. I'm not sure which of us benefits or loses from this false association! Given Mr Francis' interest in this subject, I would find it difficult to accept that he is not aware of the reality.

I commented earlier in relation to claims made by Mr Francis in a video directed at Members of the South Australian Parliament in 2013. On reflection, had I commented publicly and corrected the record at that time, perhaps I would not be writing this letter to you now. I had the occasion at that time in 2013 to check the video claims and comments attributed to an Oregonian Doctor, Bill Toffler by contacting him. He replied to me as follows:

Toffler (email 4/10/2013):

Dear Mr. Russell,

I've had the opportunity to view the youtube video of Mr. Francis. In response, I offer the following.

His truncated video clip includes a comment I made about the research concept that is challenging (if not impossible) to prove cause and effect. It was NOT an admission that there is not a slippery slope. The clip is taken entirely out of context.

It is not my intention to provide any sort of defence for any of my colleagues in respect to any or all of Mr Francis' other claims (although I know well enough the situations described). I am sure those concerned can do that for themselves. I would note, however, that it would not be appropriate to consider their silence as agreement.

I thank you for the opportunity to make these comments in my own defence by way of correction and, hopefully, in assistance to the Inquiry.

I wish you well with your deliberations.

Yours sincerely,

Paul Russell

Director, HOPE: preventing euthanasia & assisted suicide Inc.

[REDACTED]
[REDACTED]
[REDACTED]

HOPE is a not-for-profit incorporated association. We are a coalition of groups and individuals who oppose the legalization of euthanasia and assisted suicide and support measures that will make euthanasia and assisted suicide unthinkable.

HOPE: preventing euthanasia & assisted suicide exists to build a well-informed broadly-based network of groups and individuals to create an effective social and civic barrier to euthanasia and assisted suicide.

ⁱ See: <http://noeuthanasia.org.au/blog/128-the-nitschke-travelling-road-show.html>

ⁱⁱ See: <http://noeuthanasia.org.au/blog/2155-assisted-suicide-is-there-a-suicide-contagion-effect.html>

ⁱⁱⁱ See: *Suicides in Oregon: Trends and Associated Factors 2003-2012*. Available at: <https://public.health.oregon.gov/DiseasesConditions/InjuryFatalityData/Documents/NVDRS/Suicide%20in%20Oregon%202015%20report.pdf>

^{iv} See: <http://noeuthanasia.org.au/blog/1658-canadian-study-proves-that-the-suicide-contagion-exists-more-work-needs-to-be-done.html>

^v Available at: <http://sma.org/southern-medical-journal/article/how-does-legalization-of-physician-assisted-suicide-affect-rates-of-suicide/>

^{vi} See: <http://noeuthanasia.org.au/about-us.html>