

REPLY to Questions on Notice

to the

Joint Select Committee on End of Life Choices

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by

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Dear Chairman

Re: Joint Select Committee on End of Life Choices

Thank you for the opportunity to respond to the Questions on Notice from public hearing of 8 March 2018, please find attached our response.

Question 1,2,3,6,9,10,11 – will be addressed in Mr Eastwood letter attached.

Question 4. I thought this question was addressed within the submission.

Question 5: Hon Robin Chapple MLC noted (on page 5 of the transcript) the notion that palliative care can relieve suffering for the terminally ill, as a statement, is a bit too broad. Do you have any comments on that?

Part of the confusion in current discussions about suffering of the terminally ill is due to confusion between the phenomenon of existential suffering, which is a difficult but rare experience at the end of life, and the experience of pain and other symptoms which are often given the label of 'suffering' in the end of life context.

Regarding physical symptoms, there is no doubt that the involvement of palliative care for terminally ill patients can reduce suffering, as the medical specialty of Palliative Medicine involves training in symptom control as a major part of the syllabus. Take, for example, pain control. Andrew Denton made the bold statement 'But no one dies without severe pain do they?' in his submission to the Health Select Committee in New Zealand last year. There are very few studies that address the question: what proportion of all cases of terminal suffering (most commonly thought of as pain) does good palliative care fail to control? Allegedly quoting from the University of Wollongong's Health Service Unit (actually the Australian Health Services Research Institute) that co-ordinates information from most of the palliative care units in Australia, Denton wrote: "(The data) show that one fifth of those in the last 24 hours of life died in moderate to severe pain despite the best efforts of palliation." [i] This is exactly the story that advocates for legalisation from Belgium, the Netherlands, Oregon and Washington States and Canada. And it is not true in New Zealand or Australia.

There are two problems with Denton's statement. One is that the data collected and presented by the Health Services Research Institute is, for epidemiological purposes, based on 'phases' in a patient's clinical course rather than days or hours of survival. A patient may pass through several 'phases' during their time in palliative care. The patient is designated "terminal" when they are considered to be close to death.

The second problem lies in his vastly inflated estimate of the number of people who die in pain. The Australian data actually show that 3.6% of patients in this category which typically has a duration of two days have moderate to severe pain at the beginning of the phase. But the benchmark for managing pain of this intensity is that in 60% of cases the patient's pain should have been reduced to mild or absent during the terminal phase.

Most palliative care units meet or are very close to meeting that standard. Thus at most 2 patients in 100 would be experiencing difficult pain symptoms at the end of their terminal phase. This is empirical data not guesswork or hearsay.[ii] Moreover the figure is consistent with another recent publication which supports this much less dramatic conclusion.[iii]

This study of approximately 24 000 palliative care patients was, according to its authors “designed to analyse routine assessments recorded when a patient was documented as likely to die in hours to days, to determine the prevalence, intensity and associations of physical symptoms.” It has the advantage of being a prospective rather than retrospective study. Its research team concluded that: “it is possible to conclude (from our study) that the majority (of those diagnosed as dying) were either not highly symptomatic at the time they were assessed as dying or were well palliated or both. Only 4.2% were documented as experiencing severe pain that urgently required attention[iv]” NOT ‘that could not be controlled’. They went on to say that the “data provide clinicians with sufficient confidence to honestly reassure people that for the majority the final stages of life are not likely to be complicated by unbearable or unmanageable pain.”[v]

Regarding existential suffering, the treatment for such distress is spiritual care, (vi) which has always been a feature of palliative care. (vii) It is in the early stages of being introduced into the medical mainstream as a preventative and therapeutic option and early interventions look promising. (viii) However, it is noted that existential distress is not actually a biological problem, and therefore does not require a medical answer.

[i] Denton A. 2017. Voices from the front line. A submission to New Zealand Parliament’s Select Committee inquiry into ending one’s life in New Zealand. In support of the petition by Maryan Street and 8974 others. P.6.

[ii] Connolly A, Bird S, Allingham S et al. (2016) Patient outcomes in palliative care in Australia. National Compendium Report January - June 2016. Palliative Care Outcomes Collaboration. Australian Health Services Research Unit, University of Wollongong, NSW Australia. Web Site: www.pcoc.org.au.

[iii] Clark K, Connolly A, Clapham S et al. Physical symptoms at the time of dying was diagnosed: a consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care. *J. Pall. Med.* 2016;19 (12): 1288 –1295. doi:10.1089/jpm.2016.0219.

[iv] The emphasis is on needing urgent evaluation and attention, not on the failure of medication to ameliorate the symptoms.

[v] Clark K et al 2016. Op cit.

(vi) Best, Megan, Lynley Aldridge, Phyllis Butow, Ian Olver, and Fleur Webster. 2015. 'Conceptual Analysis of Suffering in Cancer: a systematic review', *Psycho-Oncology*, 24: 977-86.

(vii) Sepúlveda, Cecilia, Amanda Marlin, Tokuo Yoshida, and Andreas Ullrich. 2002. 'Palliative care: the World Health Organization's global perspective', *Journal of Pain and Symptom Management*, 24: 91-96.

(viii) Breitbart, W., et al. (2010). "Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial." *Psycho-Oncology* 19: 21-28.

Question 6.

Refer to Mr Eastwood response:

Question 7: In relation to argument against euthanasia in the media, and specifically that there is a negative social consequence from the legislation of end-of-life choices or euthanasia, could you identify what they area?

NEGATIVE SOCIAL CONSEQUENCES FROM LEGISLATION OF EUTHANASIA

Arguments supporting euthanasia laws presuppose a world of ideal hospitals, doctors, nurses and families. But we don't live in an ideal world. We live in a world where humans make mistakes and have selfish motives. For this reason, legalisation of euthanasia holds a number of risks.

1. COERCION

Sadly, the prospect of inheritance brings out the worst in many people. The NSW Government released a report on Elder Abuse in 2016. The Committee found evidence that elder abuse is a significant and growing problem in our community. Financial abuse emerged during the inquiry as a substantial problem demanding urgent action on the part of government. The report refers to claims that the law as it stands provides insufficient safeguards against financial abuse, that it does not treat many forms of financial abuse as criminal, and indeed, that the law itself is significant enabler of abuse. A need for increased awareness of financial abuse was noted. See the report here: [https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report44 -Elder abuse in New South Wales.pdf](https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report44-Elder%20abuse%20in%20New%20South%20Wales.pdf) In June 2017, the Australian Government Attorney-

General's Department launched the Australian Law Reform Commission's (ALRC) report on elder abuse: Elder Abuse – A National Legal Response. <https://www.attorneygeneral.gov.au/MediaReleases/Pages/2017/SecondQuarter/Building-the-national-response-to-elder-abuse.aspx>

It also found that elderly persons are victims of financial fraud. It recommended that a national register of enduring powers of attorney be established to prevent greedy children from using the document as a "licence to steal" from their elderly parents. The paper notes that "the potential for pressure and coercion in setting up the instruments" [the powers of attorney appointing children to act on their parent's behalf] and that "early inheritance syndrome" is on the rise. "With Australians living longer than ever before, the ALRC inquiry heard many examples of children who were impatient to get their hands on their parents' money and tried to claim their inheritance before they were entitled to it." While the exact prevalence of elder abuse is not established in NSW, the ALRC reported that "at the international level, the WHO (2015) recently reported that estimated prevalence rates of elder abuse in high-or middle-income countries ranged from 2% to 14% ... and that the perpetrators are likely to be related to the victim...[and] one study suggests that neglect could be as high as 20% among women in the older age group (Australian Longitudinal Study on Women's Health, 2014). Older women are significantly more likely to be victims than older men, and most abuse is intergenerational (i.e., involving abuse of parents by adult children), with sons being perpetrators to a greater extent than daughters." The report is accessible here:

http://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf

What has this got to do with euthanasia? A portrayal of the mixed motives for family support of euthanasia was the topic of the winning short film in this year's Tropfest festival, 'The Mother Situation'. We cannot be sure that euthanasia, once legalised and socially accepted would remain voluntary. Vulnerable and burdensome patients may be subtly pressured to request termination of their lives, even though they don't really want to. There is no way to police this type of coercion, which may be unconscious on the part of relatives.

2. INCREASED COMMUNITY SUICIDE RISK

Legalisation of euthanasia sends a message to the community that suicide is a reasonable response to hardship in life. In The Netherlands, unassisted suicide rates have risen to an all-time high: Laws, once passed, have an educative influence – they mould social attitudes. We already have a problem with suicide in Australia.

Proponents of assisted suicide have claimed that providing the elderly, terminally ill with a legal lethal dose of drugs to facilitate assisted suicide will reduce the incidence of other forms of suicide among this group and, because, it is claimed, many of those for whom the lethal dose is prescribed may never take it, actually decrease the overall suicide rate. This hypothesis has been subjected to careful scrutiny in an important study² by David Albert Jones and David Paton comparing trends in suicide rates in those states of the United States which have legalised assisted suicide compared to those which have not.

The study, which controlled for various socio-economic factors, unobservable state- and year effects, and state-specific linear trends, found that legalizing assisted suicide was associated with a 6.3% increase in total suicides (i.e. including assisted suicides). This effect was larger (14.5%) in the over 65s (14.5%, CI = 6.4%, 22.7%). Introduction of legalised assisted suicide was not

associated with a reduction in non-assisted suicide rates, nor with an increase in the mean age of non-assisted suicide. The conclusion is that assisted suicide either does not inhibit (nor acts as an alternative to) non-assisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals. The latter suggestion would be consistent with the well-known Werther effect of suicide contagion.³

The NSW Suicide Prevention Strategy 2010-2015 observes that: Suicide and attempted suicide are human tragedies with many contributing factors. These acts often occur in circumstances of hopelessness and despair, with there frequently being no single cause and no simple solution. There would be few families in NSW that haven't been touched in some way.⁴ Like any other suicide, assisted suicide can profoundly affect surviving family members and friends. A recent study found that about 20% of family members or friends

who witnessed an assisted suicide in Switzerland, where assisted suicide is legal, subsequently suffered from full (13%) post-traumatic stress disorder or subthreshold (6.5%) post-traumatic stress disorder.⁵

Risks to those living in rural and remote areas will have proportional increase in risk due to the lack of mental health resources in those jurisdictions. (See NSW report on mental health in rural areas).

Furthermore, in Canada, where EPAS has recently been legalized, the new euthanasia laws are perplexing doctors who have to deal with suicide attempts. According to the

National Post, there have been a number of reports of doctors who refused to treat people who had tried to kill themselves. In the case of poisons, remedies were readily available.

Quebec's College of Physicians has issued an ethics bulletin which says that last year, "in some Quebec hospitals, some people who had attempted to end their lives through poisoning were not resuscitated when, in the opinion of certain experts, a treatment spread out over a few days could have saved them with no, or almost no, after-effects."

However, the bulletin says that this approach is mistaken: "If there is a life-threatening situation, you have to do whatever is possible to save a life, then you treat the underlying cause ... From a moral point of view, this duty to act to save the patient's life, or to prevent him from living with the effects of a too-late intervention, rests on principles of doing good and not doing harm, as well as of solidarity. It would be negligent not to act." Bernard Mathieu, president of the 500-member Association of Quebec Emergency Physicians, said

that the new euthanasia law had probably confused some doctors. "It's possible it has confused doctors a little bit," he said. "Patients are being given the right to no longer live, and doctors are even being asked to help them in certain cases." It is not known whether these patients would have been grateful that their lives were saved, as is often the case with attempted suicide.

1 Example: Victorian Suicide Prevention Framework 2016–25, July 2016, p. 6,
<https://www2.health.vic.gov.au/Api/downloadmedia/%7B20D93A86-861E-4711-AA07-AFCA8B411504%7D>

2 Jones, David Albert and Paton, David (2015) How does legalization of physician assisted suicide affect rates of suicide? *Southern Medical Journal*, 180(10). pp. 599-604.
<http://eprints.nottingham.ac.uk/31805/1/Suicide%20US%20SMJ%20pre-publication.pdf>

3 Niederkrotenthaler T, Herberth A, Sonneck G. [The "Werther-effect": legend or reality?]. Article in *German, Neuropsychiatrie*, 2007;21(4):284-90, cf. Niederkrotenthaler T, Sonneck G, "Assessing the impact of media guidelines for reporting on suicides in Austria: interrupted time series analysis", *Australian and New Zealand Journal of Psychiatry*. 2007 May;41(5):419-28.

4 NSW Suicide Prevention Strategy 2010–2015, Sept 2010, p. 1,
<http://www.health.nsw.gov.au/mentalhealth/programs/mh/Publications/suicide-prev-strategy.pdf>

5 B. Wagner et al. "Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide", *European Psychiatry*, 2012; 27:5422-6

3. DISCRIMINATION AGAINST DISABILITY

All disability groups in Australia oppose legalization of assisted suicide. They are concerned that a change in the law may lead to devaluation of the lives of the disabled. The reasons given for requesting assisted suicide in Oregon are not primarily to do with pain (only 26.4%) but rather (only 26.4%) with concerns about loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (89.7%), loss of dignity (77%), loss of control of bodily functions, such as incontinence and vomiting (46.8%) and the physical or emotional burden on family, friends, or caregivers (42.2%).¹ These are all disability issues. The entirely subjective notion of suffering being proposed in the model for Victoria would allow assisted suicide for a similar set of concerns. This set

of concerns reflects the day to day realities of life for many people living with disabilities of various kinds. If we legalise assisted suicide for incontinence, a loss of ability to engage in one's favourite hobby, a need to have others take care of your physical needs, a loss of mobility and so forth what is the take home message for those Victorians who live with these challenges every day? Are we saying they would also be better off dead?

The late Stella Young, comedian, writer and disability activist, wrote on the implications of legalising assisted suicide for people living with disabilities:

As a disabled person, I'm accustomed to conversations about quality of life and dignity. Specifically, I'm accustomed to assuring people that my life is worth living. I'm short statured, a wheelchair user, and I frequently have bone fractures. All the visual cues that make me 'the other' are front and centre. People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong. I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?". What we as a society think we know about what it means to live as a disabled person comes from cultural representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories. Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors might know about our biology, but it doesn't mean they know about our lives. Media reports on assisted dying feed these misconceptions. ABC News reported this week on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving to Tasmania if the Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand, my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."

The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.

Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and

assisted suicide talk about wanting to avoid the pain and suffering that often comes with imminent death. But more often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and

independence.²

The proposed model suggests making assisted suicide available to people with a 'terminal illness'; defined in the draft bill as 'less than 12 months to live.' However, the prognosis would take account of which treatments are "acceptable to the person". On this basis various condition that are not in themselves terminal may be considered as terminal for the purpose of offering assisted suicide if the person decides to forego an effective, available treatment for whatever reason. This approach poses a severe risk to people following an

initial acquisition or diagnosis of a condition that may involve a considerable level of disability.

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives. However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period [generally] required by assisted suicide proposals. People with new diagnoses of terminal illness appear to go through similar stages. In that early period

before one learns the truth about how good one's quality of life can be, it would be all too easy, if assisted suicide is legal, to make the final choice, one that is irrevocable. Dr. Richard Radtke, a well-known retired academic oceanographer in Hawaii, provides one such example. Dr. Radtke has had a very disabling form of muscular sclerosis for over 25 years. In the period after his diagnosis, doctors often classified him as terminally ill. He experienced

severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it and died long ago. Today, still with an extremely limiting disability, he has retired from a successful academic career, is a happily married father, remains the president of a charitable foundation, and is grateful for the length and varied experiences of his life. How many such individuals is our society prepared to sacrifice as the collateral damage from the legalization of assisted suicide?³

CONCLUSION

Legalising assisted suicide poses a direct threat to the lives of some people with disabilities who may be assessed as eligible to request it. Doctors are more likely to agree that they are "better off dead" and to miss signs of depression or coercion. Legalising assisted suicide for being a burden, incontinence and loss of ability to enjoy activities trivialises issues faced daily by persons living with disability and demeans their courage in facing the challenges of life.

1 Oregon Public Health Division, Oregon Death With Dignity Act: Data Summary 2016, Table 1.

Characteristics and end-of-life care of 1,127 DWA patients who have died from ingesting

a lethal dose of medication as of January 23, 2016 [sic = 2017], by year, Oregon, 1998-2016,

p.10,

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

2 Stella Young, "Disability a fate worse than death?", Ramp Up, 18 Oct 2013,

<http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm>

3 Marilyn Golden, Why assisted suicide must not be legalized, <https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>

4. EROSION OF THE ROLE OF THE DOCTOR

Assisted suicide directly contradicts the purpose of medicine. It directly contradicts physicians' long-standing profession, which is to maintain solidarity with those who are sick and debilitated. It's not just bad medicine; it's the antithesis of medicine. When a physician is intentionally hastening a patient's death or cooperating with a patient so that the patient can take her own life, that physician has already slid down a terribly long slope. That physician is already detached from centuries of professional railings and boundaries that physicians have maintained so that patients can entrust themselves to physicians when they cannot care for themselves. The physician has already given up

the commitment to the patient's health, to the good of those who are sick. He's already given up a historic commitment to not give a patient a deadly remedy that would cause their death even when the patient implores them. The physician has already decided implicitly that their obligation is primarily to satisfy the patient's wishes, not to seek the good of the patient with respect to health. That's a long slope that the physician has already traveled down to get to that point. Introduction of assisted dying means that the doctor can no longer always be guaranteed to be a protector of life. Having VAD is a fundamental change in the doctor-patient relationship with killing a patient being now an option: erosion of trust and fear around disclosure of depression and suffering will become more common.

Question 8: Are there any other aspects of concern that you believe create the slippery slope in what might be defined legislation?

CREATION OF THE SLIPPERY SLOPE

There are two ways in which slippery slopes can develop following legalisation of euthanasia and assisted suicide (EPAS). One is by increasing the frequency with which it occurs, (EPAS legislation usually being passed on the understanding that only a small proportion of the population will desire to access it). Secondly the slippery slope is realised by widening the criteria of who is eligible to access the legislation. Both are known to occur in legalisation of EPAS. In all jurisdictions, the number of deaths due to EPAS increases over time, and the eligibility criteria is widened. This includes Oregon, which is widely considered to be the model which Australian legislation should emulate.

1. Increased frequency

In July 2012 The Lancet published a meta-analysis study concerning euthanasia and end-of-life practices in the Netherlands in 2010 including a comparison to the previous meta-analysis studies that were done in 2005, 2001, 1995 and 1990. (Onwuteaka-Philipsen et al. 2012) It shows an increase in the proportion of euthanasia deaths over the time studied, including dementia patients. The annual reports of the Oregon Death with Dignity Act show a similar gradual increase in the number of deaths each year since the legislation was introduced.

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx>

2. ABUSE

Another risk is that doctors may not be able to resist the extension of euthanasia to those who don't, or can't, consent to termination of their lives. Proponents of euthanasia will tell you that legal guidelines will prevent this happening. But if you examine the jurisdictions where euthanasia has been legalized, you can't be so sure.

In the Netherlands, euthanasia was legalised in 2002 after 20 years of widespread practice under legal guidelines.

- By the time the law had passed, the courts had already legitimized the death of patients who were not terminally ill.
- Patients who are not mentally competent are euthanized.

- Adolescents aged between 12 and 18 can be killed with the consent of their parents.
- Early in 2005 a Dutch hospital published their guidelines in *The New England Journal of Medicine* on how to kill disabled newborns. (Verhagen and Sauer 2005) Under this amendment of the law, it is not only the anticipated suffering of the child that is taken into consideration, but also anticipated suffering of the parents can justify its use.
- The Dutch are currently debating whether euthanasia should also be allowed for children 1-12 years old, as is the case in nearby Belgium.
- They are also debating the need to allow the elderly to be euthanased when they are 'tired of life'.

In July 2012 *The Lancet* published a meta-analysis study concerning euthanasia and end-of-life practices in the Netherlands in 2010 including a comparison to the previous meta-analysis studies that were done in 2005, 2001, 1995 and 1990. (Onwuteaka-Philipsen et al. 2012) It indicated that in 2010, 23% of the euthanasia deaths were unreported in the Netherlands, which was an increase from 20% in 2005. It shows an increase in the proportion of euthanasia deaths over the time studied, including dementia patients.

Of more concern, there has been an increase in the number of hastened deaths without discussion with the patient, their family or other physicians. Regular surveys have shown that around 1,000 patients a year are killed without their knowledge or consent.

Similarly in Oregon, USA, abuses have been reported in terms of mentally ill patients accessing lethal medications, and not being referred for psychiatric review, contrary to safeguards in the legislation. (Hamilton and Hamilton 2005)

An added risk in the Oregon model is lethal medication administered to patients against their will, once they are at home. With no requirement for the doctor to be present at the time of death, there are recorded cases of patients receiving medication at the hands of others, rather than the medication being self-administered at the timing chosen by the patient.

Onwuteaka-Philipsen, Bregje D., Arianne Brinkman-Stoppelenburg, Corine Penning, Gwen J. F. de Jong-Krul, Johannes J. M. van Delden, and Agnes van der Heide. 2012. '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', *The Lancet*, 380: 908-15.

Verhagen, Eduard, and Pieter J.J. Sauer 2005. 'The Groningen Protocol — Euthanasia in Severely Ill Newborns', *New England Journal of Medicine*, 352: 959-62.

N. Gregory Hamilton and Catherine Hamilton, "Competing Paradigms of Responding to Assisted-Suicide Requests in Oregon: Case Report," presented at the American Psychiatric Association Annual Meeting, New York, New York, May 6, 2004. (<http://www.pccef.org/articles/art28.htm>)

Question 9, 10, 11

Refer to Mr Eastwood response:

