

**Inquiry into the exposure draft of the  
Medical Services (Dying with Dignity) Bill 2014**

**A submission to the Legal and Constitutional Affairs Legislation Committee**

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## Overview

I am grateful to the Legal and Constitutional Affairs Legislation Committee for its invitation to provide a submission addressing the terms of reference regarding the Medical Services (Dying with Dignity) Bill 2014. I am a criminologist and I lecture in criminal law at the University of Tasmania.

The Bill concerns legalizing means by which patients under certain circumstances can be assisted to suicide, or voluntarily euthanized (s 5(2)). The primary problem with the draft Bill is that it assumes that legalization is a good policy; no accompanying documents or materials exist to explain why this is the case, which is strange given how extraordinarily complex the topic of euthanasia is. For a 2013 overview of many critical issues facing this debate, Graham and Prichard's (2013) submission to the Tasmanian Parliament is attached.

My hope is that the committee will conclude that the case the legalization is not made out. It is not clear exactly what problems this Bill is intended to address, or whether these problems could be dealt with in other ways that entail much lower levels of risk.

## The right to die & use of the word 'dignity'

If any rationale for legalization is provided at all it is evident in section 3 of the Bill – “to recognise the right of a mentally competent adult... to end his or her life peacefully, humanely and with dignity.” The right to die argument, often forwarded by a pro-euthanasia advocates, is problematic because even if a right to die (or to suicide) exists, this does not axiomatically generate an obligation to cause or assist death (see Box 1).

**Box 1. Issues relating to the right to die: extract from Prichard J (2012) Euthanasia: A Reply to Bartels and Otlowski, 19 *Journal of Law and Medicine* 610: 611**

Putnam, a medical ethicist sympathetic to the pro-euthanasia perspective, nonetheless suggests that euthanasia advocates mistakenly rely upon the autonomy principle. This is because the right to die, which she accepts exists, cannot impose a burden on anyone to assist in an individual's death:

“[T]he much-invoked right to die is best supported by the Argument from Autonomy, but ... any right to die is still a fairly limited right because the Argument for Assistance is so unpromising. Whether there might be some – perhaps even many – cases in which the right thing to do would be to assist a dying patient who seeks to die painlessly, whether this is what doctors ought to do under certain conditions, are matters that cannot be deduced from a dying patient's right to die” [Putnam C, “What Kind of a Right is the ‘Right to Die?’” (2009) 4 *European Journal of Mental Health* 165: 179.]

Others, like Professor Yale Kamisar, have commented on the subtext involved in the use of the word 'dignity' by legalization advocates. Yale has argued that it wrongly implies that opponents are somehow against dignity, when “opponents

are diverse, and often hold firm views around promoting ‘a good death’” (Kamisar, 2012: cited in Graham & Prichard, 2013: 13). These views apply also to the language used in the Bill.

## Access criteria: the definition of terminal illness

The Bill proposes a model for people with “terminal illnesses”, which is defined to mean “an illness which... will... result in death”, including “disease, injury and degeneration of mental or physical faculties” (s 4). This definition clearly encompasses dementia.

The Bill is slightly inconsistent in its references to the causative link between the illness and death. As noted, s 4 refers to an illness which “*will* result in death”. Similarly, the Certificate of Request attached to the Bill refers to an illness which “*will ultimately* result in my death”. However, the language of s 12(1)(d) is less certain about causation because it requires a medical practitioner to confirm that the patient is “*likely* to die as a result of the illness”.

These sorts of access criteria have always presented challenges to different models of euthanasia/assisted suicide. A Catch-22 of sorts exists regarding eligibility and terminal illness. On the one hand, such models are intended to alleviate suffering and are motivated by compassion, combined with notions of personal autonomy. This would suggest that anyone who is suffering intolerably and who wants to die ought to be able to access the system regardless of whether their illness is terminal. In other words, surely a person experiencing intolerable suffering, but who does not have a terminal illness, should have access to euthanasia/assisted suicide when – unlike a patient with a terminal illness – their condition may continue for many years or decades? What is worse: 30 months or 30 years of suffering? On the other hand, legalization proponents have – initially at least – been cautious about broad access criteria which do not include a terminal illness. This is because of, among other things, concerns about protecting vulnerable groups.

The Netherlands’ model was originally introduced many years ago with terminal illness being an essential access criteria. Policy and practice has since been broadened to include people without terminal illnesses as indicated in this quote from the Dutch Ministry of Health:

There are some cases in which it is not careful euthanasia, but in most cases are people who are not able to make a request because they are not seen as able to make a request – for instance, people who are suffering from a psychiatric disease or people who are in a coma. Also, newborn babies are not capable of making a request (Keizer, 2005 cited in Pitcher, 2010: 66).

Similarly, after the introduction of the ‘The Groningen Protocol’ it is possible in The Netherlands for practitioners to ‘deliberately end the life of physiologically stable newborns with lethal drugs that would not otherwise have died’ (Verhagen, 2013: 293).

If the Bill is to be introduced it should *not* restrict access to terminal illness because it is illogical to limit the system only to people whose life expectancy does not extend far. The other option – simpler and safer from a policy perspective – is not to introduce the Bill at all.

## **Mental illness & age**

The Bill's access criteria does encompass 'degeneration of mental ... facilities' that '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' (s 4). On plain reading this section seems to be directed towards dementia and related mental conditions, providing they result in death. However, there are well-documented cases where people with non-terminal mental illnesses have argued for access to euthanasia/assisted suicide systems, such as bipolar affective disorder which was raised in the Swiss context (*Haas v Switzerland*, Registrar of the European Court of Human Rights, "Switzerland Cannot be Criticised for Not Having Assisted a Suicide", Press Release 040, 20 January 2011). As noted, The Netherlands's system is open to other types of non-terminal mental illnesses and a similar situation exists in Belgium (Prichard, 2012).

By limiting access to mental illnesses which lead to degeneration of mental facilitates and ultimately death, the Bill appears to be discriminating against people with non-terminal mental illnesses whose level of suffering might be equal to or great than that experienced by dementia patients. On the other hand, if the Bill was not introduced at all many complex policy issues can be circumvented, including how a euthanasia/assisted suicide system would impact on initiatives such as beyond blue and suicide prevention programs.

Very similar arguments can be mounted against the Bill regarding its restriction to those aged over 18 years of age, given that The Netherlands has lowered the age of consent to people aged 12 years or older (Vrakking et al., 2005). In Australia, why should Gillick-competent adolescents be excluded from the system?

## **Bracket creep & problems with safeguards**

If the supporters of the Bill are convinced that its model ought to be restricted to adults, terminal illnesses and only terminal mental illnesses, how confident are they that it will remain so over the long term? If passed, the legislation could not ensure that it could maintain this situation decades from now. The experience from other jurisdictions has been that over time the systems tend to be broadened – not narrowed – often as a result of lobbying, political pressure or judicial rulings.

It is good that the Bill has set out procedures to attempt to safeguard patients, including multiple medical opinions, checks to assess voluntariness,

requirements for record-keeping, time delays and so forth. However, the experience in countries with legalized euthanasia/assisted suicide indicates that just as formal policy expanded so to has practice. This prompts the question as to how the Bill, if passed, would ensure the maintenance of its proscribed practice standards across regions of Australia and over time? What resources will be needed to monitor practice standards and, if necessary, investigate misconduct? The following extract explores bracket creep and the degree to which practice ignores safeguards in other jurisdictions (see Box 2).

**Box 2. Issues relating to bracket creep and failing safeguards from Graham & Prichard (2013), attached.**

The debate about 'safeguards', slippery slopes and evidence of impact on vulnerability has been played out in public debate and academic analysis in North America and Europe (see Avila, 2000; Battin et al., 2007; cf Finlay & George 2011). Concerns and questions have also been raised closer to home. In their consideration of Australian and Italian end of life law, Australian academics Faunce and Townsend (2012: 173) speak of the risks of changes in policy and practice arising because of political and economic pressures on the state: 'regardless of the ... importance of respecting individual patient rights in end-of-life decision-making, the financial constraints upon governments to care for an ageing population will increasingly provide consequentialist interest... in permitting physician assisted suicide when requested by competent, non-depressed patients with a terminal illness who have already received reasonable palliative care.' This contextualises discussions of individual patient rights against the backdrop of broader economic and political imperatives.

At the other end of the spectrum, Dr Philip Nitschke, the leading proponent of euthanasia and one of the few doctors to have been involved in its state-endorsed practice in Australia, openly states that the campaign to extend the remit of voluntary euthanasia and assisted suicide is already well underway. He says 'in the intervening 16 years since the Northern Territory Rights of the Terminally Ill Act came and went, the debate on voluntary euthanasia has been extended beyond those who are terminally ill, to include the well elderly for whom rational suicide is one of the many end of life options' (Nitschke cited in Douglas, Willmott & White, 2013: 25). This type of public lobbying is an example of what may occur to an even greater extent if voluntary euthanasia and assisted suicide are legalised. What Philip Nitschke proposes is an example of the risks of 'bracket creep.'

**Belgium: Evidence that 'Safeguards' are Fallible and May Be Ignored**

In Belgium, euthanasia was legalised in 2002. Closer examination of both official statistics (i.e. reported cases and documented practices) and research into unreported cases and actual practices in Belgium highlight that concerns about unprofessional practice at an individual level and 'bracket creep' at a societal level are well founded. Research and analysis by Bilsen and colleagues (2009), Chambaere and colleagues (2010), Inghelbrecht and colleagues (2009, 2010) and Smets and colleagues (2010) show that:

• **Non-voluntary euthanasia can and does happen:** There is consistent evidence from Belgium showing that a significant number of patients were euthanased without their explicit request or competent, informed consent. The study by Chambaere and colleagues (2010) shows that, in the Flanders region of Belgium, 32% (n = 66) of assisted deaths were done without the explicit request or consent of the patient. Of the 66 deceased non-voluntary euthanasia patients, approximately 46 of these were comatose at the time of assisted death, and 14 had dementia. An earlier article by Bilsen and colleagues (2009: 1120) identified the characteristics of deceased non-voluntary euthanasia patients in the Flanders region of Belgium as 'mostly older, incompetent patients; patients with cardiovascular diseases or cancer; or patients dying in hospitals.'

- **Vulnerable patients were euthanased without their explicit request:** Following on from the first point, ‘most of the euthanasia deaths without explicit request were done to people who did not and could not request euthanasia at the time of death... The demographic group of patients euthanized without explicit request “fits the description of “vulnerable” patient groups at risk of life-ending without request”’ (Schadenberg, 2012: 14). This is especially concerning given that Belgian people who died by euthanasia without explicit request were more likely to have had a cure as their goal of treatment in the last week prior to their death.
- **Nurses have illegally administered euthanasia drugs to patients without their explicit request, mostly without a doctor present:** (Chambaere et al., 2010: 897; Inghelbrecht et al., 2010; Smets et al., 2010). In Belgium, the euthanasia law only allows physicians to perform the act (Inghelbrecht et al., 2010). However, worryingly, the Inghelbrecht (2010: 905) study of the role of nurses showed that ‘The life-ending drugs were administered by the nurse in 12% of the cases of euthanasia, as compared with 45% of the cases of assisted death without an explicit request. In both types of assisted death, the nurses acted on the physician’s orders but mostly in the physician’s absence.’ Inghelbrecht and colleagues (2010: 909) concluded that ‘the current law (which does not allow nurses to administer life-ending drugs) and a control system do not prevent nurses from administering life-ending drugs.’ In another study, Inghelbrecht and colleagues (2009) found that Belgian paediatric intensive care nurses administered life-ending drugs to children to hasten death, with or without a doctor present. This is illegal but Belgian law reform to allow child euthanasia is currently being discussed.
- **Family members’ wishes may influence the practice of euthanasia without explicit request:** Euthanasia ‘without explicit request was most often to reduce the burden on the family or because they did not want to needlessly prolong the life of the patient’ (Schadenberg, 2012: 14). Chambaere and colleagues (2010: 900) raise this as a concern due to the potential for ‘conflict of interest’ and the violation of patients’ rights.
- **Under-reporting appears common:** Research by Smets and colleagues (2010: 5174) in the Flanders region of Belgium shows that ‘only one out of two euthanasia cases is reported to the Federal Control and Evaluation Committee. Most non-reporting physicians do not perceive their act as euthanasia. Countries debating legalization of euthanasia should simultaneously consider developing a policy facilitating the due care and reporting obligations of physicians.’ [More recent data suggest that underreporting is about 20% of cases (Onwuteaka-Philipsen et al, 2012)].

In late July 2013, Belgian oncologist Dr Benoit Beuselinck publicly voiced his professional and personal concerns in the Australian media, saying ‘For me and several of my colleagues, the euthanasia law has been bad for Belgium: the patients are finding less humanity, the doctors have more difficulties in their daily work and finally, I think the image of our country is suffering... In my practice it occurred that some family members thought we were euthanasing a patient without her demand. Another patient refused to go to a hospice, because he thought that palliative care would automatically mean euthanasia. A colleague even received a false demand for euthanasia, written by a son on behalf of his father’ (Doherty, 2013).

An emerging issue for bioethicists and practitioners in Belgium and elsewhere is that of organ donation and ‘procurement’ from voluntary euthanasia and assisted suicide patients. There already have been cases where the patients’ euthanasia became a surgical procedure, prior to and/or shortly after, involving a wider team in procuring the organs (Ysebaert et al., 2009). This is an issue we wish to flag here, however, it is too complex to analyse in any depth except to say that there are philosophical and practical boundaries that start to be blurred.

More radically, and in the international context that is beyond Belgium, bioethicists Wilkinson and Savulescu (2012: 41) have already hypothesised that ‘organ donation euthanasia’ – that is, removal of organs, such as the heart, which causes death - would be a ‘rational improvement’ and way of increasing transplant supply. They pose the question: ‘why should surgeons have to wait until the patient has died as a result of withdrawal of life support or even simple life prolonging medical treatment?’ They suggest a ‘viable’

alternative would be to anaesthetise patients and hasten death by the process of removing organs from their body (Wilkinson & Suvaescu, 2012: 41). Of course, they suggest some safeguards around this proposal, however, the suggestion of seeing euthanasia as a vehicle and opportunity for organ donation raises complex ethical and practical questions. Collectively these sources paint a more troubled account of the Belgian experience than intimated by Giddings and McKim (2013). The same appears to be true with respect to the Netherlands.

#### **Dutch Neonatal Euthanasia**

In his analysis and rebuttal of arguments for the decriminalisation of euthanasia and assisted suicide, John Keown (Jackson & Keown, 2012: 100-101) uses the example of the Netherlands to argue how legalising such practices no longer becomes a private matter concerning only a few highly autonomous patients, but instead 'it clearly has profound ramifications for the wellbeing of all patients who might be judged 'better off dead', not least those who are unable to refuse it.' ...

The Netherlands has attracted criticism for its approach to euthanasia of people with a mental illness (Kissane & Kelly, 2000). Giddings and McKim (2013: 33) concede that there are reported cases of patients with a mental illness or disorder accessing voluntary euthanasia or assisted suicide under the Dutch model; however, in their paper they arguably understate the extent to which this occurs.

The 'slippery slope' argument from voluntary to non-voluntary euthanasia and from competent to vulnerable and incompetent patients has received some credence from other quarters. Ardent defender of euthanasia in the Netherlands, Professor John Griffiths, himself concedes the link between the legalization of voluntary euthanasia and the process of legalising non-voluntary euthanasia of vulnerable people, in this case infanticide or what the Dutch call 'neonatal euthanasia' for infants:

"The applicable norms in the Netherlands have assuredly changed in the direction of open acceptance of the legitimacy of termination of life of severely defective newborn babies... [T]he influence on these changes of the way euthanasia had earlier been legalised and regulated is obvious. In this sense, one might speak of a normative slippery slope." (Griffiths et al., 2008: 252 cited in Jackson & Keown, 2012: 100).

Laing (2013: 339) also reaches this conclusion of the existence of a clear 'slippery slope' in her critique of infanticide and the approach of 'eliminating suffering by eliminating the sufferers' in the Netherlands.... The killing of terminally ill or disabled infants, or just those with a prognosis that is 'very grim' (Verhagen, 2013: 293) has attracted strong criticism (see Kon, 2007, 2008; Kodish, 2008; Jotkowitz et al., 2008; Chervenak et al., 2009; Laing, 2013).

#### **Child Euthanasia in the Netherlands**

Euthanasia is also relevant at the other end of childhood. In the Netherlands, the age of consent regarding voluntary participation in euthanasia has been lowered to allow children aged 12 years or older to consent to being euthanased, providing their parents also consent. Documented cases of physician-assisted dying for children in the Netherlands include: a 16 year old with an autoimmune disease, an 18 month old child with epilepsy and a progressive neurodegenerative disease, and a 13 year old with leukaemia (Vrakking et al., 2005). The extension of euthanasia to children and infants may not be isolated to the Netherlands for much longer since the legalization of similar practices are being considered in Belgium (Pousset et al., 2011; De Morgen, 2013). There are, however, research findings that indicate that neonatal euthanasia is already occurring in the Flanders region of Belgium at rates similar to the Netherlands, (Vrakking et al., 2007). It is important to emphasise that (a) Giddings and McKim (2013) acknowledge the developments described above concerning children and (b) their proposed model does not include minors. The point we want to underscore is that over time significant 'bracket creep' has indeed occurred in the Netherlands, as it has in Belgium. There can be no assurances that, if legalised, euthanasia systems in Tasmania or Australia would not also extend their scope over time.

### Oregon: Insufficient Protection for Protect People with a Mental Illness and Financially Disadvantaged People

Physician assisted suicide (PAS) has been legally available in Oregon since 1997. According to the Oregon Public Health Division (2012), since 1997 when the law was passed, a total of 1,050 people have received prescriptions for lethal drugs and 673 patients have died from ingesting medications prescribed under Oregon's Death With Dignity Act. Giddings and McKim (2013) and others (White & Willmott, 2012) have provided their own detailed analysis of past and present laws and practices in Oregon, upholding it as a positive example of how assisted suicide laws can be safely and successfully implemented. However, they have not sufficiently recognised two important issues in protecting or failing to protect vulnerable people. The first issue relates to how legalising voluntary euthanasia and assisted suicide affects people with a mental illness and those experiencing psychological distress. The second issue arises from examples of what some might consider unethical decision-making and a failure of duty of care on the part of Oregonian health authorities in the cases of vulnerable patients.

Levene and Parker (2011: 205) explain why mental illness in general, and depression and anxiety in particular, are of particular interest and concern. They highlight the fact that depression is 'potentially reversible' and 'may affect the patients' competency' as well as their own assessments of the quality of their life and their desire to live. They recommend that, because depressed patients and other patients with a mental illness are considered a vulnerable population, 'their request for death may be part of their illness, with the correct response being treatment rather than assistance in dying' (Levene & Parker, 2011: 205). Giddings and McKim's (2013: 32) proposed model suggests that people with depression or other psychiatric or psychological disorders would be ineligible for voluntary euthanasia and assisted suicide. Yet, evidence from Oregon suggests that such safeguards will not stop patients with depression successfully accessing assisted suicide (Schwartz, 2004; Hamilton & Hamilton, 2005). These issues warrant further consideration in the paragraphs that follow.

Importantly, Ganzini and colleagues (2008) found that, among terminally ill Oregonian patients who participated in their study:

1. Of those who requested physician assisted suicide, one in four had clinical depression;
  2. Of those who received a prescription for a lethal drug, one in six had clinical depression.
- While acknowledging that the majority of patients in their study did not have depression, they (2008: 1) concluded that 'the current practice of the Death with Dignity Act may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug.'

In the same year, Hendin and Foley (2008) published details of six cases of vulnerable patients who were euthanased. Their analysis suggested that safeguards were being ignored by doctors, especially in cases where the patient had a mental illness, and that the Oregonian Death with Dignity Law does not protect vulnerable patients.

In light of this and other research studies, Levene and Parker (2011) conducted a systematic review of the prevalence of depression in granted and refused requests for euthanasia and assisted suicide in Oregon and the Netherlands. They expressed concern about the capacity of psychiatrists to confidently assess the existence and role of mental illness in the case of patients requesting physician assisted suicide (PAS), citing research that 'only 6% of Oregonian psychiatrists felt they could assess whether psychiatric factors were affecting a patients' judgment in a PAS request during a single consultation' (Levene & Parker, 2011: 210). They (2011: 210) concluded that 'up to half of all patients requesting euthanasia/ physician assisted suicide may show symptoms of depression.'

However, it should be noted that the system in the Netherlands was expanded in 2002 to permit access to euthanasia on the basis of psychiatric illness, providing the patient is suffering hopelessly and unbearably (Pereira, 2011). A similar situation exists in Belgium.



The second issue warranting brief mention here is the risks of legalising voluntary euthanasia and assisted suicide to people living with socio-economic disadvantage and poverty, who are typically considered a vulnerable group in society. Research on Oregon and the Netherlands by Battin and colleagues (2007) (whom Giddings and McKim (2013) cite extensively) concluded that people on low incomes and from socio-economically disadvantaged backgrounds were not at heightened risk in terms of voluntary euthanasia and assisted suicide. This has since been challenged by Page (2009) and Finlay and George (2010).

## Is non-voluntary euthanasia already happening in Australia?

One of the arguments legalization proponents advance is that Australian doctors are already practicing forms of non-voluntary euthanasia at a higher rate than occurs in The Netherlands. The following extract offers counter arguments to this view.

**Box 3. Non-voluntary euthanasia rates in Australia: extract from Prichard J (2012) *Euthanasia: A Reply to Bartels and Otlowski*, 19 *Journal of Law and Medicine* 610: 611-13**

Bartels and Otlowski note that quantitative research findings indicate that some countries like Australia may have higher rates of non-voluntary euthanasia than do some other countries where euthanasia is regulated, such as The Netherlands. On this basis, the authors infer that restrictive euthanasia policies offer less protection for patients, which implies that lack of regulation causes, or at least contributes to, the higher rates of non-voluntary euthanasia in Australia. This may be because with legalization comes openness, peer review, guidelines and various safeguards that reduce the risks of non-voluntary euthanasia and inadequate assessments of patient competency.

However, some authors have pointed to research findings that do not support this view. Chief among these is that there are countries, other than Australia, where euthanasia has not been legalised, which appear to have lower rates of non-voluntary euthanasia than The Netherlands. These countries include Italy, the United Kingdom and Sweden. [Lewis P, "The Empirical Slippery Slope from Voluntary to Non-voluntary Euthanasia" (2007) 35(1) *Journal of Law, Medicine and Ethics* 197.] More generally, Lewis, and others, encourage caution in comparing countries insofar as euthanasia research is concerned. In part this is because of differences in health care and legal systems as well as cultural dynamics.

Of course, assessing the impact of legalization on non-voluntary euthanasia could involve a single country with an A-B design, where A represented pre-legalization data and B post-legalization data. Evidence of a significant reduction in non-voluntary euthanasia post-legalization would constitute, according to Lewis, the "best evidence" on this issue. Some research of this sort has been conducted on the Belgian euthanasia system, which was legalised in 2002. Bilsen et al compared the responses of physicians who had certified deaths in 1998 (N=1,925), 2001 (N=2,950) and 2007 (N=3,623). Physicians reported ending a patient's life without an explicit request in 3.2% of deaths in 1998, 1.5% in 2001 and 1.8% in 2007. This has been read to mean that the prevalence of non-voluntary euthanasia decreased after legalization. Yet, since the decrease occurred before legalization, as indicated by the 2001 figure, it seems difficult to conclude that legalization caused the reduction. Future research is required on this issue, particularly since others have queried the accuracy of Belgian physicians in correctly labelling and reporting euthanasia cases.

Regarding Holland, there is a lack of baseline data and consequently the impact of legalization in that country cannot be assessed with confidence insofar as non-voluntary euthanasia is concerned. Although proponents of euthanasia suspect that legalization in The Netherlands reduced non-voluntary euthanasia, it is nonetheless feasible that legalization was not the cause of the reduction (as evidenced by the Belgium data). Alternatively, non-voluntary euthanasia rates in The Netherlands may not have changed at all from the pre- to post-legalization periods. This notion is supported by the fact that, as noted above, three European countries that have not legalised euthanasia appear to have lower rates of non-voluntary euthanasia than The Netherlands. The factors – cultural, systemic or otherwise – that worked to keep non-voluntary euthanasia comparatively low in Italy, the United Kingdom and Sweden may equally have operated in The Netherlands in the pre- and post-legalization periods. In fact, it would be beneficial if future research better identified those factors in Italy, the United Kingdom and Sweden. Such research might unveil other policies that Australia could employ to reduce its seemingly high rate of non-voluntary euthanasia. Legalisation may not be the only policy option insofar as tackling non-voluntary euthanasia is concerned.

### **Pressure to request access and elder abuse**

It is difficult to directly measure the prevalence with which patients experience indirect or direct pressure to ask for euthanasia or assisted suicide. Direct pressure, being a hidden phenomenon, is hard to detect and the sorts of interpersonal dynamics that underlie direct pressure may also make victims reluctant to talk about their experiences openly. The work being done to research pressure is in its infancy.

Regarding indirect pressure it is useful to view Oregon Public Health's annual reports, which contain statistics on numbers of patients who noted that part of their motivation to request euthanasia was because they felt 'a burden on family and friends'. These statistics are illustrated in Table 1. It should be highlighted that these only represent occasions where patients expressed their concern to physicians *without prompting*; the physicians then recorded and reported this.

**Table 2: 'Burden to Family and Friends' as an End of Life Concern Reported by Death with Dignity Act Patients to Oregon Physicians – Trends Over Time**

Year	Percentage (%) citing this concern
1998	12%
1999	26%
2000	63%
2001	24%
2002	37%
2003	38%
2004	38%
2005	42%
2006	43%
2007	44%
2008	33%
2009	25%
2010	26%
2011	42%
2012	57%

Sources: Oregon Public Health (2001; 2002; 2003; 2004; 2005; 2006; 2007; 2008; 2009; 2010; 2011; 2012; 2013).

Importantly, in most years between 1998 to 2012 more than one in three patients in the euthanasia system apparently perceived themselves as a 'burden' to family and friends. It may be that only a fraction of these patients requested euthanasia *primarily* because they perceived themselves as a burden to others. But even if that is the case, the data are concerning.

It has been argued that the growing literature on 'elder abuse' ought to be consulted to better understand vulnerability. As Prichard (2012: 615-18) notes, this broad term encompasses neglect as well as emotional, psychological, physical, financial and even sexual forms of abuse of elderly people by others in a relationship of trust.<sup>1</sup> Many victims will experience more than one form of abuse.<sup>2</sup> Elder abuse is a phenomenon that is evidently gaining attention

<sup>1</sup> Hazzlewood J and Orpin P, "Vulnerability In Elderly Community Care Clients: a Literature Review" (Department of Rural Health, University of Tasmania, Sandy Bay, 2007). Note Schiamberg et al.'s ecological model for understanding dimensions of abuse in residential institutions; Schiamberg L, Barboza G, Oehmke J, Zhang Z, Griffore R, Weatherill R, von Heydrich L and Post L, "Elder Abuse in Nursing Homes: An Ecological Perspective", (2011) 23 Journal of Elder Abuse 190.

<sup>2</sup> Ellison S, Schetzer L, Mullins J, Perry J and Wong K, *The legal needs of older people in NSW* (Law and Justice Foundation of NSW, Sydney, 2004).

internationally among psychologists, lawyers, criminologists and epidemiologists.<sup>3</sup>

The prevalence of elder abuse is difficult to gauge. Like many other types of antisocial or criminal behaviour, victims may be reluctant to report elder abuse. Gibbs and Mosqueda suggest this may be because they: are ashamed and embarrassed; worry that their complaint will not be taken seriously; or fear some sort of reprisal from perpetrators (who may be their primary carers).<sup>4</sup> It has also been suggested that some victims may experience a state of learned helplessness, where they become resigned to unacceptable behaviours because of a perceived personal inability to change their situation.<sup>5</sup> Finally, cognitive disorders, including dementia, may mean that victims cannot recall or are not aware of abuse.<sup>6</sup> Logically, some of these issues will affect future studies which attempt to estimate the prevalence of pressure on patients.

Cooper, Selwood and Livingston's systematic review of prevalence studies found that 6% of elderly participants reported significant abuse in the preceding month.<sup>7</sup> Sixteen per cent of long-term care staff admitted having ever committed significant psychological abuse. In an American study of people aged 57-85 years of age (N=3005), some participants reported that in the preceding year they experienced financial exploitation (3.5%) and physical mistreatment (0.2%).<sup>8</sup> Fewer (2.6%) participants in an UK study (N=2111) reported abuse, the two most commonly reported forms being neglect (1.1%) and financial exploitation (0.6%).<sup>9</sup> One study of older people in South Australia (N= 1158) found that 2.7% reported having experienced elder abuse; extrapolating this finding the researchers suggested that the national rate might fall between 1.9% and 3.9% of the elder population.<sup>10</sup> Garre-Olmo et al.'s Spanish study (N=676) suggested

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<sup>3</sup> Brank E, "Elder Research: Filling an Important Gap in Psychology and Law", (2007) 25 Behavioural Sciences and the Law 701; Culley D and Sanders H, "Exploitation and Abuse of the Elderly During the Great Recession: A Maine Practitioner's Perspective", (2010) 62(2) Maine Law Review 430; Gibbs L and Mosqueda L, "Elder Abuse: a Medical Perspective", (2010) 6(6) Aging Health 739; Dong X, Simon M, Mendes de Leon C, Fulmer T, Beck T, Hebert L, Dyer C, Paveza G and Evans D, (2009) 302(5) Journal of the American Medical Association 517; Kinnear P and Graycar A, "Abuse of Older People: Crime or Family Dynamics?", (1999) 113 Trends and Issues in Crime and Criminal Justice 1.

<sup>4</sup> Gibbs and Mosqueda; Ellison, Schetzer, Mullins, Perry and Wong,. See also Kinnear and Graycar.

<sup>5</sup> Gibbs and Mosqueda, at 14-15

<sup>6</sup> Gibbs and Mosqueda.

<sup>7</sup> Cooper C, Selwood A and Livingston G, "The Prevalence of Elder Abuse and Neglect: a Systemic Review", (2008) 37 Age and Ageing 151.

<sup>8</sup> Laumann E, Leitsch S and Waite L, "Elder Mistreatment in the United States: Prevalence Estimates From a Nationally Representative Study", (2008) 63B(4) Journal of Gerontology 248.

<sup>9</sup> Biggs S, Manthorpe J and Tinker A, "Mistreatment of Older People in the United Kingdom: Findings from the First National Prevalence Study", (2009) 21 Journal of Elder Abuse and Neglect 1.

that the most common forms of abuse were neglect (16%), followed by psychosocial abuse (15%), financial abuse (4.7%) and physical abuse (0.1%).<sup>11</sup> Recent qualitative reports from some American lawyers have suggested an apparent increase in financial exploitation of elderly people in the aftermath of the global financial crisis.<sup>12</sup> If accurate, this implies: (a) that rates of elder abuse may fluctuate; and (b) different forms of elder abuse may have distinct risk factors.

Certainly Garre-Olmo et al found that, for example, psychological abuse was positively associated with social isolation and frequent bladder incontinence, whereas financial abuse was associated with marital status and being aged over 85 years.<sup>13</sup> This topic awaits future research. In general terms, risk factors for elder abuse include: impaired cognitive and physical functioning; social isolation; lack of autonomy; financial costs of caring; ill-suited primary carer; high carer stress; and concerns over carer health.<sup>14</sup>

Taking these findings into account, it could be concluded that euthanasia/assisted suicide may be safe for socially connected, financially independent individuals with high autonomy and self-efficacy. Norwood et al.s' qualitative study, for instance, referred to a patient who had been active and healthy until a heart attack, after which he was attended to by six family members and a GP who had known the family for many years.<sup>15</sup> More generally, data from Oregon's physician assisted suicide system indicate there has been an overrepresentation of patients accessing the system who have insurance and higher educational status, which the researchers suggested were indicators of affluence.<sup>16</sup>

However, circumstances may be entirely different for isolated patients with low self-efficacy who represent an unwanted burden to their carers, some of whom may benefit financially from the death of the patient (even just in a reduction of financial pressure). Patients in such situations may conceivably meet eligibility criteria, including capacity to consent, having a terminal illness and lack of clinical depression. But their primary motivation for requesting access may be, by way of example: a feeling that it is the sensible option for all concerned; that

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<sup>10</sup> Cripps D, Biven J, Northey J and Rigger P, "Abuse of Older People: Issues for Lawyers" (2002) 1 Elder Law Review 14.

<sup>11</sup> Garre-Olmo J, Planas-Pujol X, Lopez-Pousa S, Juvinya D, Vila A and Vilalta-Franch J, "Prevalence and Risk Factors of Suspected Elder Abuse Subtypes in People Aged 75 and Older", (2009) 57(5) Journal of the American Geriatrics Society 815.

<sup>12</sup> Culley and Sanders.

<sup>13</sup> Garre-Olmo, Planas-Pujol, Lopez-Pousa, Juvinya, Vila and Vilalta-Franch.

<sup>14</sup> Hazzlewood and Orpin, n 31; Garre-Olmo, Planas-Pujol, Lopez-Pousa, Juvinya, Vila and Vilalta-Franch, n 41; Gibbs and Mosqueda.

<sup>15</sup> Norwood, Kimsma and Battin.

<sup>16</sup> Battin, van der Heide, Ganzini, van der Wal and Onwuteaka-Philipsen.

their carers/family – well intentioned or otherwise – have convinced them it is for the best; or that there are no other options. The following comments were made in a Tasmanian study of elderly people. They show the subtlety of psychological control that elderly people can be vulnerable to.

He knows he can do with me what he likes, because there is no one here to help me, and I can't cope with it very well. We sit in the dining room chair to chair, and he never spoke to me for 7 weeks. He said I hadn't been a mother, I'd been an enemy. I don't know how he got like this.

Now I am like this, I am nothing, worth nothing anymore. I can't do much, my house looks terrible ... it's very, very difficult. He makes me responsible for everything that is happening to him now, that it's all my fault, but I can't, I can't cope with it, but I haven't done anything to him. I just helped and helped and helped, and paid and paid and paid.<sup>17</sup>

### **Criminal sanctions as safeguards: ss 21 and 22**

The Bill foreshadows the risk of pressure, particularly through creating an offence of procuring – through deception or improper influence – the signature or witnessing of a Certificate of Request (s 22), punishable with a five year prison sentence.

A few questions come to mind about how this law would this affect behaviour in reality and what would constitute “improper influence” (see Prichard, 2012: 627-18). Carers and/or family members who sought to convince a patient that euthanasia (or assisted suicide) was the right option may not view their behaviour as “improper”, despite the fact that it could constitute considerable pressure.

In the presumably rarer cases where individuals had improper motives, arguably the law would have little deterrent effect. The elder abuse literature would suggest that various sorts of protracted psychological tactics could be employed to wear a patient down, exacerbate feelings of isolation et cetera that increased the likelihood that a patient viewed euthanasia/assisted suicide as an inevitability, or a sensible option, or an escape. Arguably this could be done without much risk of detection, or it could be carried out with a prepared plausible explanation so that – in the absence of witnesses or tangible evidence – even if the pressure was detected it could easily be denied. Indeed, psychological pressure may include convincing a patient to keep conversations secret, for instance on the basis that “others may not understand what we have been discussing” and “you could get me in trouble with the law”.

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<sup>17</sup> Marsh.