VOLUNTARY EUTHANASIA AND 'ASSISTED DYING' IN TASMANIA: A RESPONSE TO GIDDINGS & McKIM

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EXECUTIVE SUMMARY

This paper provides a consolidated response to the Honourable Lara Giddings (MP) and the Honourable Nick McKim (MP), offering analysis and critique of their 'Voluntary Assisted Dying – A Proposal for Tasmania' (2013) paper. Their paper puts forward a radical proposal that, if legislated, would make Tasmania one of a very small number of jurisdictions in the world to legalise voluntary euthanasia and assisted suicide.

From close examination of their paper and proposed model, it is argued that while a number of their claims are evidence based, others are unsubstantiated. Their claims often represent one perspective or type of response to complex issues and questions – the answers to which may never be agreed upon by relevant stakeholders.

This paper draws on international literature as well as insights from well-credentialed Tasmanian practitioners to analyse Giddings and McKim's (2013) representation of what has (and has not) happened elsewhere and to critique their bid for euthanasia law reform in Tasmania.

We conclude that the paper produced by Ms Giddings and Mr McKim does not constitute a compelling evidence-based case for changing the law. The risks of proceeding with the model that they propose are not justified.

The euthanasia debate is as complex as it is controversial, and yet it is not new. The transition between life and death, and the presence or absence of intervention and assistance (who, how, why, in what circumstances) in that process, is of intrinsic interest and importance to law makers. The euthanasia debate is, in essence, a debate not only about the purported 'right to die' but, importantly, whether doctors should be in certain circumstances authorised to kill their patients or to assist their suicide (see Jackson & Keown, 2012; Putnam, 2009). Ms Giddings and Mr McKim's proposal refers to these scenarios as collectively 'voluntary assisted dying'. In this paper the terms 'voluntary euthanasia' and 'assisted suicide' are used, which is consistent with the terminology of the bulk of the literature in this field.

Ms Giddings and Mr McKim are very clear in approaching this as individual private members. Nonetheless the views of significant Tasmanian political figures on such a complex topic warrant close scrutiny and deep reflection. Indeed, Giddings and McKim (2013) call for community engagement and it is in this spirit of respectful democratic debate that the following response is made. To be clear, this paper involves the analytical critique of ideas, issues and proposed law reforms, not people or their respective political parties. By framing the issues here in an academic way, it is hoped that ongoing public conversations can be further stimulated, inclusive of different stakeholders and diverse views.

The critique that follows highlights two substantial issues with Giddings and McKim's (2013) paper and proposed model. A number of the claims that they make inappropriately imply concrete facts (i.e. sentiments along the lines of "the evidence has spoken" and "our research shows…") without acknowledging the depth of international contention on certain topics.

Secondly, significant amounts of empirical evidence and alternative academic and professional perspectives have been understated or omitted in their paper. That evidence, along with the implications, paradoxes and questions that emerge for the Tasmanian context, is considered in this response. We look at what is being proposed and what is missing. In particular, we analyse what is missing from Giddings and McKim's (2013)

portrayal of the legalisation of voluntary euthanasia and assisted dying in jurisdictions, including the Netherlands, Belgium and Oregon.

Summary of the Key Issues

In response to the Giddings and McKim (2013) paper and model, some of the key issues and concerns raised here include:

- **Multiple formal bodies have considered and rejected voluntary euthanasia and assisted suicide:** Worldwide there have been multiple commissions, committees, panels, and parliamentary inquiries that have carefully considered and *decided against* the legalisation of voluntary euthanasia and assisted suicide (Jackson & Keown, 2012). For example, in the USA alone, between January 1994 – March 2011, there were 122 legislative attempts to legalise forms of euthanasia in 25 states. While Oregon and Washington have legalised it, the other attempts have been defeated or withdrawn (Patient Rights Council, 2011). It is still illegal in Australia and most of the world.

- **Where legalised, there is evidence of 'safeguards' being ignored:** In the Flanders region of Belgium approximately *half* of euthanasia cases are not formally monitored as doctors do not report them to authorities. The rate of underreporting in the Netherlands appears to be between 20%-23%. Also, in Oregon the 'safeguard' of referral to a psychiatrist for mental health assessment to consider issues of competency and informed consent dropped from 31% of patients in 1998 to 2% of patients in 2012. Yet, some research has indicated moderately high rates of depression among Oregonian Death With Dignity Act patients (Ganzini *et al.*, 2008).

- **Where legalised, there is evidence of vulnerable people being euthanased without their explicit request and informed consent:** This occurs in the Netherlands, Belgium, and Oregon, and the list of vulnerable patients being euthanased (with or without their consent) include infants and children, disabled people, people who are economically disadvantaged, and people with a mental illnesses. In Oregon, there are documented cases of the State suggesting to financially disadvantaged people that physician assisted suicide was a 'treatment' option after their request for other options (e.g. cancer treatment) was denied (Page, 2009).

- **There are risks of voluntary euthanasia and assisted suicide negatively impacting on the role of the doctor-patient relationship:** Giddings and McKim (2013) claim that there will be no negative impact on the doctor-patient relationships. Many academic journal articles take the opposite view. Doctors and medical associations around the world have expressed their concerns and opposition to voluntary euthanasia and assisted suicide for multiple reasons; the Australian Medical Association (Tas.) (2009, 2013) is one of the most prominent critics of Giddings and McKim's (2013) paper and proposed model.

- **Doctors, health care workers and family members may suffer unforeseen stress after being involved in voluntary euthanasia and assisted suicide:** There is research that has found that some people who have been involved with voluntary euthanasia and assisted suicide may have mixed feelings or be emotionally and psychologically burdened by the experience after the fact (for example, see Campbell & Black, 2013; Stevens, 2006; Haverkate *et al.*, 2001).

- **If legalised, the eligibility criteria for who can access voluntary euthanasia and assisted suicide is open to contest and risks being expanded to include vulnerable people:** This is referred to as 'bracket creep' and is the subject of discussion in the 'International Evidence and History Re-Visited' section.

- **Many disability advocates and organisations around the world oppose euthanasia and assisted suicide:** They argue against it on a number of grounds, but first and foremost because it has adverse implications for people with disabilities whether or not they are eligible for voluntary euthanasia and assisted suicide. The implication that some people are 'better off dead' and that 'some lives are not worth living, phrases which have been used internationally in euthanasia debates, are potentially offensive and stigmatising to those who live with the same or similar symptoms and conditions. This is discussed on pages 17-18 of our paper.

INTRODUCTION

This paper considers Giddings and McKim's (2013) paper and proposed model by focusing on a series of specific but inter-related contexts:

- Academic issues and critiques
- Medical and bioethical issues and critiques
- Legal and criminological issues and critiques
- Social and political issues and critiques

By their very nature, these contexts and categories are not mutually exclusive but instead inform each other. It is important to note, however, that the scope of this response is bounded and prioritised, limiting discussions and critique to the key issues. We make no claims of having universally and comprehensively surveyed all of the literature, nor is it reasonable or commonplace to expect that in the format of a response.

Defining Meaning and Key Terms

Multiple terms are used in this field, such as 'voluntary assisted dying', 'dying with dignity', 'therapeutic homicide', 'therapeutic killing' (Flegel and Fletcher, 2012; George, Finlay & Jeffrey, 2005), 'physician assisted suicide', and 'mercy killing'. Key terms used in this paper are defined in Table 1.

Table 1: *Terms and definitions*

Term	Meaning
Voluntary euthanasia (VE)	Actions taken by medical professionals with the primary intention of causing a patient's death with the patient's request and informed consent.
Physician-assisted suicide (PAS)	A suicide which is aided by a medical professional who intends to aid or knows they are aiding the suicide.
Non-voluntary euthanasia (NVE)	Actions taken by medical professionals with the primary intention of causing a patient's death without the patient's request or without informed consent.

A RESPONSE TO GIDDINGS & MCKIM

Throughout this response, we will refer to Lara Giddings (MP) and Nick McKim (MP) as 'Giddings and McKim', as is tradition in academic responses to papers by other authors.

In their paper, Giddings and McKim (2013) accurately outline certain key findings and recommendations from recent commissions and reviews from Quebec, Canada and the UK regarding voluntary euthanasia and assisted suicide. They quote large portions of individual submissions and viewpoints from those commissions and reviews throughout their paper. In addition to this, they provide appendices of numerical data and operational statistics from Oregon and the Netherlands.

Giddings and McKim also extensively draw upon two Australian pieces – an academic journal article by Bartels and Otlowski (2010) and the background paper by White and Willmott (2012) published by *Australia21*.

However, to conclude on the basis of these five sources that the euthanasia debate is settled is expeditious. Among other things, this paper seeks to demonstrate that: the euthanasia debate has many complex and unresolved dimensions; data do indeed exist that do not support the legalisation of euthanasia; and recent judicial consideration of central issues in the debate have not supported the case for legalisation.

Academic Issues and Critiques

It is reasonable to expect proponents of law reform to present thorough investigation of the issues and empirical evidence. While Giddings and McKim (2013) strongly assert that this is what they have done, closer analysis unearths some limitations in their paper that can be outlined here.

The Giddings and McKim (2013) paper is not as well researched as the authors intimate. It is not clear why readily available and recent sources have been omitted from their paper. Examples include Jackson and Keown (2012), Downie, Chambaere, and Bernheim (2012), Quill (2012), Werren, Yuksel, and Smith (2012) and Gill (2010), among many others.

In addition, the standard that Giddings and McKim (2013) set for acceptable research are applied inconsistently. For example, Giddings and McKim rejecting as unreliable or invalid 'unsubstantiated anecdotes' from those who argue against law reform (2013: 20). Surely then, this applies to the 'heart wrenching stories of people suffering at the end-of-life because of their symptoms' (2013: 16) that they and others use to support their rationale? It seems inconsistent that the favourable anecdotes and stories of doctors, carers, patients and their families testifying to the international committees and reviews are quoted extensively in the Giddings and McKim (2013) paper, and yet the opinions, anecdotes and stories of others with alternative or opposing views somehow do not count. The voluntary euthanasia and assisted suicide debate is full of stories and subjectivities (for more, see Kamisar's (1998) reflections on 'the problems presented by the compelling heart-wrenching case'). In an academic context, qualitative data and peoples' experiences are treated with caution but are not rejected as 'unsubstantiated anecdotes'. Rather they can be viewed as a valuable form of information, alongside statistics and other forms of evidence and knowledge. Furthermore, in the political context of Tasmania as a democracy, it is unclear why the stories and subjectivities of some should be rejected as unsubstantiated anecdotes, while those of others are accepted as valid reasons why the law and social norms need to change.

Another example is their rejection of claims that are dependent on 'poor quality information, particularly information from the 1990s but also pre-2009, that is now well out of date and does not reflect any of the changes that have occurred following legislative reform and recent reviews' (2013: 19). It is unclear, outside of political reasons, how and why the world and the issues have changed considerably since 2009. This particular year is not a standard cut-off or threshold in academia, nor is it necessarily reflected as a meaningful date in the deliberations of the various relevant committees and panels elsewhere.

The authors (2013: 19) refer to 'many years' of experience and evidence from jurisdictions that have legalised voluntary euthanasia and physician assisted suicide (e.g. in Oregon since 1997 and in Belgium since 2002) and yet claims made by opponents and others that use evidence and experience pre-dating 2009 is 'now well out of date.' In the Giddings and McKim (2013) paper, 84 of their endnotes and just under half (24/54) of the references in their bibliography refer to literature and legislation that pre-date 2009. Furthermore, in the Bartels and Otlowski (2010) article that Giddings and McKim (2013) cite frequently, no books or journal articles from 2009 or more recently are referenced; instead, the Bartels and Otlowski article largely cites sources from the 1970s – 1990s. This issue is not of particular concern to us here, as we recognise the Bartels and Otlowski (2010) article as a useful academic contribution irrespective of what year its references date from. These are, however, examples of rules and standards being applied to opponents of voluntary euthanasia and assisted suicide as grounds to reject their views which are not consistently applied to supporters and proponents.

Considering what else is missing raises the question of why the Australian example of the Northern Territory is largely omitted, yet overseas examples are featured throughout? On this, we concur with their statement about the absence of critically relevant information and that 'what is missing is just as important as what is included' (2013: 19). The authors of the Australia21 papers discuss the Northern Territory laws and data alongside those from overseas jurisdictions (see White & Willmott, 2012; Douglas, Willmott & White, 2013), so it remains unclear why Giddings and McKim have not done so? One possible reason is that the *Rights of the Terminally Ill Act* in the Northern Territory (NT) was repealed in 1997 – less than a year after coming into effect – through the actions of the Australian federal parliament (Plattner, 1997). Another possible reason is the problematic implications of the research finding that 'symptoms of depression were common' among NT patients seeking help to end their lives (Kissane, Street & Nitschke, 1998: 1097).

Their paper does not define some important terms (mentioned throughout this paper), while others are defined loosely. It is to issues of contested definitions to which we now turn.

MEDICAL & BIOETHICAL ISSUES AND CRITIQUES

Define 'terminal'

One of the issues in Giddings and McKim's (2013) paper is the notion of terminal illness and whether or not it should take into account life expectancy, actual and anticipated suffering, and quality of life. The international literature suggests diversity and ambiguity in the definition of 'terminal' and 'terminally ill', a point which is well illustrated in the examples given below and in a more detailed analysis by Hui and colleagues (2012: 588), where 'terminally ill' is defined as:

- 'a life expectancy of six months or less' (Meghani, 2004)
- 'less than six months to live' (Babgi, 2009; Schroepfer & Noh, 2010)
- 'life expectancy less than three months' (Proot *et al.*, 2004)
- 'patients with an anticipated prognosis of three months or less' (Napolskikh *et al.,* 2009)
- 'the term 'terminal' should be used to describe a dying patient, with a short life expectancy of a few days to a week' (Rogg *et al.*, 2006: 277).

To add to the confusion, 'end of life care' can be understood to be anywhere from one to two years of life expectancy through to 'the last few hours or days of life' (The European Association for Palliative Care 2009 cited in Izumi *et al.*, 2012: 609).

Rogg, Graugaard and Loge (2006) conducted a survey of 968 Norwegian physicians, where respondents were asked to define 'terminal' in expected number of weeks left to live. The results showed that, on average, Norwegian physicians expect a 'terminal' patient to have 3.6 weeks to live, with the majority (83.5%) restricting the definition of 'terminal' to the last 2-4 weeks of a patient's life (Rogg *et al.,* 2004: 273).

In Oregon and in Washington under their respective laws, a patient must be living with a terminal illness that will lead to death or be reasonably expected to lead to death within six months (Oregon Health Authority, n.d.; Washington State Department of Health, n.d.). Whereas, the Australian Medical Association (AMA) (2007) defines 'terminal illness'

within the timeframe of 'within a few months at most':

> 'An illness which is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will inevitably result in death within a few months at most. Terminal phase of a terminal illness is defined as the phase of the illness reached when there is no real prospect of recovery, or remission of symptoms (on either a temporary or permanent basis).'

Others have systematically analysed the varying definitions and lack of consensus in the international literature surrounding the terms 'terminally ill', 'palliative care' and the implications and challenges that arise in the midst of ambiguity about who might be defined as a palliative care patient (see Mitchell *et al.*, 2013; Hui *et al.*, 2012; Izumi *et al.*, 2012; Van Mechelen *et al.*, 2012).

In mid-2103, this exact issue arose in the UK in new critique of Lord Falconer's assisted dying bill (currently under consideration by Parliament there) by academics from the University of Oxford. Sheehan, Dunn and Horn (2013) state that the bill 'smacks of compromise' because of 'poorly defined and articulated' concepts, arguing that 'it is neither adequate nor coherent in its current form.' They consider the issues and limitations of the bill centre on the lack of clarity in what counts as a terminal illness, saying that 'there looks to be no good reason for the "six months to live" limit'. They instead call it 'arbitrary' and in conflict with the recommended 12 months to live in the final report of the Commission on Assisted Dying.

Sheehan, Dunn and Horn (2013) highlight the inconsistencies and ethical problems that arise when laws use vague language and broad categories to define key issues (e.g. terminal illness) while, at the same time, strictly limit eligibility and availability through short arbitrary timelines and other strict criteria. In arguing that Lord Falconer's bill needs to be clearer, they conclude that 'concepts are defined in ways that don't stand up to scrutiny, and moral judgments are imposed in ways that diverge from the main reasons given to support changes in the law.' This conclusion must apply largely to the terms put forward by Giddings and McKim (2013) because of their similarity to the terms used by Lord Falconer.

Healer, Helper, Killer? The Role of the Doctor and Potential Risks for Doctor-Patient Relationships

In considering the role of the doctor, Giddings and McKim (2013: 22-23) take a selective view of the perspectives and practices involved. They 'believe that those arguing against voluntary assisted dying law reform have failed to substantiate perceived threats… to the role of the doctor or to the doctor-patient relationship' (2013: 9). They go on to state that:

> A further fear expressed about the role of the doctor in a legislated system of voluntary assisted dying is the damage that could be caused to the relationship of trust between a doctor and his or her patient, should a doctor actively participate by providing assistance. We are not aware of any evidence that this damage has occurred as a result of voluntary assisted dying legislation that has now been in place for many years. In fact, there are indications that it has not occurred (Giddings & McKim, 2013: 22).

Yet they do not address the local and international literature on the diversity of professional opinions amongst clinicians (see Somerville, 2003; Dobscha *et al.*, 2004; George *et al.*, 2005; Girbes, 2005; Saunders, 2008; Gamester & Van den Eynden, 2009; Nitschke & Stewart, 2011; Pereira, 2011; McLeod, 2012; Scher, 2012; ABC News 2013a, 2013b) as well as the concerns that have been raised by clinicians and scholars about the negative impact of legalising voluntary euthanasia and assisted suicide on the role of the doctor and on patient care (see Foley, 1997; Hendin & Foley, 2008; Varghese & Kelly, 2001; Stephenson, 2006; Cooling, 2009; Dunne, 2009; Lowenthal, 2009; Saunders, 2010; Randall & Downie, 2010). Some of the findings of these studies certainly sit in tension with Giddings and McKim's (2013) claims because they demonstrate that large numbers of professionals may oppose voluntary euthanasia and assisted suicide.

Indications of mixed feelings and mixed results can be seen the work of Dobscha and colleagues (2004). They studied physicians in Oregon who had received requests for assisted suicide in the years after the Death with Dignity laws were enacted. In investigating doctors' perspectives on the opportunities and benefits as well as the costs,

challenges and negative impact on them, the study found that:

> Requests for assisted suicide had a powerful impact on physicians and their practices. Physicians often felt unprepared, and experienced apprehension and discomfort before and after receiving requests. Prominent sources of discomfort included concerns about adequately managing symptoms and suffering, not wanting to abandon patients, and incomplete understanding of patients' preferences, especially when physicians did not know patients well. Participation in assisted suicide required a large investment of time and was emotionally intense. (Dobscha *et al.*, 2004: 451).

The opposition of significant proportions of the medical fraternity has been an influential factor in jurisdictions that are considering or have rejected proposed law reforms. In the UK, national survey research shows that most doctors *do not* support voluntary euthanasia or physician-assisted suicide (Seale, 2006, 2009). In addition, Seale (2006, 2009) discounts the argument that so many doctors hold such views out of fear of legal liability. The finding that doctors are largely opposed to voluntary euthanasia is again upheld in a systematic literature review by McCormack and colleagues (2011), who used meta-analytic methodology to analyse empirical research of doctor's views of these issues over a period of 20 years. They found that across the research studies reviewed, the majority of UK doctors oppose active voluntary euthanasia and physician-assisted suicide.

More recently, the Canadian Medical Association (2013: 357) conducted a survey completed by 2,125 of its members, finding that 'only 20% would be willing to participate if euthanasia is legalised in Canada, while twice as many (42%) would refuse to do so. Almost a quarter of respondents (23%) are not sure how they would respond, while 15% did not answer.' The statistics were similar for physician assisted suicide, with 16% of respondents reported that they would be willing to participate, while 44% indicated that they would refuse to do so.

In summary, the professional and personal perspectives of doctors are mixed and varied, with fairly consistent majorities opposing voluntary euthanasia and assisted suicide.

Paradoxically, Giddings and McKim (2013) willingly refer to the Australian Medical Association's (AMA) Code of Ethics (2006) as being more relevant and replacing the Hippocratic Oath, and yet they ignore or omit the policy positions and the current publicly expressed views of representatives of the AMA. The perspectives of the professionals tasked with the practice of voluntary euthanasia and assisted suicide are considered highly relevant, and worth exploring in detail here. In response to a question about the views of the AMA and doctors in Australia, Dr. Andrew Pesce (2010), president of the Australian Medical Association in 2010, in an interview with the ABC offered a considered response, summing up a policy position and set of beliefs that does not supporting voluntary euthanasia or physician assisted suicide:

> Our response is rooted, I suppose, in our very strongly held values that our duty is to preserve and promote life, not walking away from our obligations to provide care for patients, even those that are dying. Even though there are always examples at the margins, I think our current system allows doctors to do that reasonably well (Pesce, 2010).

Dr. Christopher Middleton (2012), then chairman and now ex-officio chair of the council of the Tasmanian branch of the AMA, in an interview with the ABC in 2012 also opposed voluntary euthanasia, saying that legalising euthanasia would compromise the doctor's role as healer. Opposition to voluntary euthanasia and assisted suicide has consistently been the position of the AMA Tasmania (2009; 2013), whose most recent response to Giddings and McKim (2013) employs strongly worded censure to convey the gravity of concern:

> We are extremely disappointed in the arguments set forth in the Consultation Paper in relation to the role of the doctor (pages 22-23)… You fail to inform the Tasmanian public, and others, that the majority of national medical associations and medical organisations around the world continue to oppose doctors' involvement in assisted dying. Further, you claim that trust in the doctor-patient relationship will not be undermined should doctors participate in assisted dying but you only provide one citation to support this claim (page 22). We believe that to fundamentally change the role of the doctor as one who supports life to one who takes life will have profound, unpredictable effects on the perception and practice of medicine. Whilst we acknowledge the efforts put in to developing your Consultation Paper, we find it does not openly and objectively invite opposing views and opinions, which is contrary to the democratic process by which we

> live, nor does it sufficiently support its own arguments in relation to the role of the doctor. (Australian Medical Association (TAS), 2013: 2-3)

The AMA Tasmania (2013: 1) is categorical in its position: 'medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life (this does not include the discontinuation of futile treatment).' In keeping with this, other state and territory branches of the Australian Medical Association have also been active in opposing the legalisation of voluntary euthanasia and assisted suicide, for example South Australia (AMA SA, 2011) and Western Australia (Barich, 2010). The Australian Medical Association's position is backed up with reference to the position statements, codes of practice and codes of ethics of medical associations around the world (see, for example, World Medical Association, 2005; British Medical Association, 2013; Canadian Medical Association, 2007; New Zealand Medical Association, 2013; American Medical Association, 1996a, 1996b).

In summary, these positions and statements not only warrant further consideration and consultation, they directly contradict Giddings and McKim's (2013) portrayal of opponents of voluntary euthanasia and assisted suicide as a relatively ill informed group of lay citizens.

Supposed Benefits for Tasmania

Giddings and McKim (2013: 28-29) make some strong claims about the benefits and outcomes of their proposed model, stating that 'the model we have developed is designed to achieve a number of other positive outcomes, including:

- Encouraging frank and open conversations that improve the provision of information and communication between the doctor and the patient around end-of-life expectations. This is likely to improve doctor-patient relationships.
- Helping patients gain a better understanding of the different care and treatment options they have available to them. This will assist the patient to have their fears allayed and help address any misunderstandings.
- Providing a greater understanding and awareness of the role and scope of palliative care and how it can help the patient.
- Increasing awareness and reinforcing of the legal rights of Tasmanians to make important choices about their health and personal care. These choices include the right to refuse medical treatment or to withdraw from medical treatment, to make wills, appoint an Enduring Guardian, give someone they trust Power of Attorney, and make an Advance Care directive.
- Providing legal and professional guidance and support doctors who receive requests from their patients for assistance to die and who want to respond legally and responsibly to provide such assistance in line with their ethical and professional judgment.
- Providing legal and medical professional oversight of end-of-life decision-making with careful monitoring and ongoing review.
- Improving respect and acceptance of the law by aligning it more closely with community opinion and expectations.'

In relation to the first four claims, it is expeditious to say that the proposed model will improve these things, especially without substantiating what is meant in terms of the implied significant issues in current medical practice. There is nothing to stop Tasmanian doctors communicating clearly and providing clear and accurate information to their patients about available treatment options (including 'frank and open conversations') under Tasmanian law as it currently stands. In fact, it is part of a doctor's professional duty of care to do these things, irrespective of whether voluntary euthanasia and assisted suicide is legalised.

In making these claims, Giddings and McKim have not sufficiently demonstrated (a) that there are identifiable and substantiated issues in Tasmanian patients not being informed or being misinformed of their legal rights, or (b) *how* their proposed model will increase the awareness and autonomy of Tasmanian patients to exercise these rights, as they are already available and therefore do not necessitate or provide any additional rationale for law reform.

Similarly, awareness and understanding of the role and scope of palliative care in Tasmania already exists, and can, if needed, be strengthened in ways that are independent and irrespective of any proposed model or legislation. Therefore, if Giddings and McKim are aware of systemic issues of professional malpractice amongst doctors or failures in duty of care to provide accurate and clear information or to support patient rights, they need to substantiate these concerns and to work with the relevant authorities and the Tasmanian medical fraternity to remedy the issues they imply exist. The probable result is that such issues, if proven, will

likely be addressed through professional and workforce development mechanisms that do not require the legalisation of voluntary euthanasia or assisted suicide.

Regarding the latter three claims in Giddings and McKim's list, Tasmanian doctors should already have access to legal and professional guidance regarding any matter of practice, and should comply with routine professional protocols, clinical guidelines and systems of monitoring and review in providing any form of healthcare to patients, end-of-life or otherwise. There are a number of organisations that offer information and advice to stakeholders, as well as careful monitoring and oversight, to ensure high standards of professional practice and regulated professional accreditation. These organisations include the Australian Health Practitioner Regulation Agency (AHPRA), the Australian Commission on Safety and Quality in Health Care, the Australian Medical Association (AMA), Tasmania Medicare Local and the GP Tasmania network, the Tasmanian Department of Health and Human Services, Advocacy Tasmania, the Health Complaints Commissioner and Ombudsman Tasmania.

The only aspect of this list that does not currently exist is the legal option for doctors to provide assistance to patients who seek voluntary euthanasia or physician assisted suicide. The final claim about 'improving respect for and acceptance of the law' is vague and seems to suggest moderate prevalence of disrespect for the law as it currently stands and homogenous 'community opinion'. This statement does not adequately recognise and appreciate the plurality, diversity and complexity of social attitudes that exist in the Tasmanian population in this area.

The paper and the authors' respective contributions to the public record continually assert that the weight of public opinion is behind them in legalising voluntary euthanasia and assisted suicide. They cite opinion polls to support that their proposal has the backing of the Tasmanian public and argue that 'the case for legalising reform has continued to strengthen' (Giddings & McKim, 2013: 1) since 2009. Two overarching points need to be made in response to their claims. Firstly, their claims of the weight of public opinion need to be better substantiated, not only through opinion polls but through more thorough research. Their claims are contested. There was doubt cast over the opinion polls conducted in Tasmania during the last attempt at law reform, and this doubt has not been suitably averted. McGee (2011a), a legal scholar from the Queensland University of Technology, criticised Giddings and McKim's claims at the time of public support for the Dying with Dignity Bill because those claims were based on a survey with methodological problems, confusing terminology and oblique conceptualisation. He suggests that the poll figure of 80% of Tasmanians saying they do support euthanasia could be misleading because of unclear specification of what is involved in this umbrella term (McGee, 2011b). Based on these criticisms, the counter-claim could be made that, if the Tasmanian public is actually well informed on the issues, and the *details* of the practices (and in what circumstances) that they are being asked to support, the research statistics and qualitative feedback from the local public may become richer.

Secondly, opinion poll results bear limited relevance to the quality of the specific model (and accompanying Bill) being proposed by Giddings and McKim. A "yes" in principle does not equate with informed consent and unmitigated support for the details and practices they are putting forward. It is anticipated there are people who may support the case for law reform, but concede the issues with or oppose the model that Giddings and McKim have put forward.

But perhaps the most important point to make about opinion poll results is that consensus views can be wrong. For example, it is probable that a majority of Tasmanians support paying less tax or significant reductions to politicians' wages. Of themselves, such majority opinions would be unlikely to affect policy because they would not be treated as a sole justification. Pro-euthanasia advocates might distinguish our examples. They might argue that popular opinion on euthanasia is different because it is about individuals' rights over their own bodies – in other words individuals' right to autonomy and their right to die. However, where rights are concerned the euthanasia debate is not just about individuals' 'right to die'; axiomatically it includes generating an obligation or burden to cause or assist death (Putnam, 2009). This paper questions the value of opinion polls on this latter issue – given the complexity of such an enduring and extraordinary obligation on the state.

CRIMINOLOGICAL, LEGAL & SOCIOLOGICAL ISSUES

Understanding 'The Case Against' – The Diversity of Opponents

Giddings and McKim (2013: 2) use strong language to describe those with differing perspectives to theirs, describing opponents as 'fearful', 'inaccurate', illogical and 'unscholarly'. The discussion of the 'case against' legalising voluntary euthanasia and assisted suicide in Giddings and McKim's paper is very short. In order to remedy this, and complement and add to what White and Willmott (2012) have already said in outlining 'the case against', it is worth briefly noting the highly cited conclusions of Professor Yale Kamisar (1958, 1995, 1996a, 1996b, 1998, 2008, 2012).

- Associating voluntary euthanasia and assisted suicide with 'dignity', compassion and human rights wrongly implies that critics and opponents are somehow *against* these things, which is an inaccurate and misleading construction of 'the case against.' Critics and opponents are diverse, and often hold firm beliefs around promoting 'a good death';
- Many who support 'the case against' voluntary euthanasia and assisted suicide defend the important distinction between killing versus letting die (refusing or stopping treatment);
- Calls for legalisation are often founded on the unsubstantiated claim that 'physicians are doing it anyway' and that this is secretly common. Counterarguments point out the illogical nature of introducing new laws with 'safeguards' to a field of practitioners who are by the same argument breaking current criminal laws, the extent of which is under-researched. Additionally, criminal convictions (as a final result of monitoring and sanctioning) of doctors who break the law are rare. So how and why would this dramatically change with legalisation of euthanasia and assisted suicide?
- Voluntary euthanasia and assisted suicide, in practice, tends to extend beyond people who are 'terminal' to encompass other forms of suffering. Kamisar (1997: 128) argues that others can and will gain access to assisted suicide, 'To argue that suicide is plausible or understandable in order to escape intense physical pain or to end a physically debilitated life *but for no other reason* is to show oneself out of touch with the depth and complexity of human motives.'
- Media reporting and public debate about voluntary euthanasia can become too focused around actual and hypothetical individualised cases, usually sad and tragic stories, to the detriment of properly understanding the societal consequences of legalising the practice. The 'heart wrenching compelling case' affects how people respond to opinion polls, but is in danger of ignoring the wider social context and costs. Public policy cannot be made for one – it is made for all, even in the presence of eligibility criteria.

More of the issues encompassed within 'the case against' are covered in the 'International Evidence and History Re-Visited' section of this paper.

> 'Legalising 'assisted dying' places a huge burden on the vulnerable… We should not worsen the situation for the vulnerable by making it easy to point them to the door. Laws are written for all of us in all situations – not just for the unusually independent. Legalising 'assisted dying' amounts to adopting a principle of indifference towards a special and acute form of vulnerability: in order to allow a few independent folk to get others to kill them on demand, we are to be indifferent to the fact that many less independent people would come under pressure to request the same.'
>
> Onora O'Neill (in Jackson & Keown, 2012: 93)

The Potential for Elder Abuse

Giddings and McKim (2013: 2) assert that they 'have not been able to find any sound evidence that there is a heightened risk for people who may be vulnerable due to their age, disability, mental illness or isolation as a result of assisted dying legislation.' Others have been more cautious. For instance, in relation to the Swiss context, the European Court of Human Rights stated that "the risk of abuse inherent in a system which facilitated assisted suicide" should not be "underestimated" (Registrar of the European Court of Human Rights, 2011: 3). Similarly, White and Willmott (2012), prominent academics and activists for the introduction of voluntary euthanasia and assisted suicide laws in Australia, acknowledge the limitations of safeguards and the potential risks for vulnerable people:

> It would be difficult, if not impossible, to ensure all of the legislative requirements relating to eligibility are satisfied in all cases. Of particular concern may be the ability to ensure that the request to die was given voluntarily. A person approaching the end of his or her life who relies heavily on others for all aspects of living may be pressured to end his or her life. Such pressure may not necessarily be overt, and may be exerted in subtle ways. Nevertheless, this may result in the fact that the request to die cannot be regarded as having been made voluntarily. This inability to ensure that safeguards are observed means there is potential for abuse in that a person who does not fall within the ambit of the legislation may be killed. Vulnerable individuals in our society, such as the sick, the elderly and those living with disabilities, will be at risk. (White & Willmott, 2012: 18)

Prichard (2012) came to the same conclusion but after reviewing the growing body of literature on the dynamics of elder abuse. Among other sources, Prichard (2012: 617) pointed to qualitative case studies of elder abuse to highlight the strength and subtlety of psychological control that elderly people may experience:

> 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.

Using the elder abuse literature, Prichard also argued that psychological pressure – unintended or intended – in the euthanasia context would be very difficult to measure with purely quantitative studies. Citing Materstvedt (2009), Prichard described the need for carefully designed qualitative studies of pressure in systems of legalised euthanasia. As Prichard noted, only one such qualitative study has been published. Interestingly, that study did record one case where apparently a patient had been pressured into requesting access to euthanasia (Norwood, Kimsma, & Battin, 2009).

Prichard (2012: 620) concluded that the study of pressure in the context of euthanasia is "in its infancy". In this context it seems much more likely that the absence of what Giddings and McKim call 'sound evidence' on vulnerability reflects the paucity of research on the topic, rather than an indication that legalised euthanasia systems are risk-free for marginalised groups.

The issue of pressure is complex. It is feasible that pressure could be experienced in a variety of ways, including a patient's sense that applying for access to an euthanasia system is the 'right thing to do'. On this note it is important to consider data from the physician-assisted system in Oregon. Oregon Public Health's annual reports 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 2. 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, what do these data suggest about the social support and care afforded the elderly in the Oregon system? Issues such as these were not touched upon by Giddings and McKim (2013).

One of the recurrent issues in this area is the poor conceptualisation and lack of definition and consensus of 'vulnerability' and, also, 'unbearable suffering.' The Giddings and McKim (2013) paper does not define 'vulnerability', in fact, that exact word does not appear in their paper at all. People are described as 'vulnerable' here and there, without due conceptualisation and theorising of what is meant by that. Yet bioethicists, social scientists and criminologists alike underscore the importance of defining vulnerability and supporting it in all its forms (Dodds, 2007; Rogers *et al.*, 2012; Bartkowiak-Théron & Asquith, 2012; Graham, 2011, 2012). It is going to be extremely hard to safeguard what is not properly understood, especially in terms of recognising and supporting marginalised, 'hidden populations' and at-risk individuals.

> 'The opposition being mounted by disability advocates is rooted in the realities of the disability experience. Advocates who have worked with newly disabled individuals, or who may remember their own experiences are deeply concerned about the impact legalisation would have on people who may be struggling with difficult personal adjustments and, not infrequently, with rejection and loss of hope. The annals of the disability rights movement are punctuated with stories of individuals who "just wanted to die" before coming to realise they could still lead good, contributing lives. Advocates worry that some people would never get to that realisation if assisted suicide becomes legal. People who have personal histories of trauma… would be particularly vulnerable.'
>
> James McGaughey (2013), Executive Director, Office of Protection and Advocacy for Persons with Disabilities, Connetcticut Government

Many Disability Advocates Oppose Euthanasia and Assisted Suicide

The Giddings and McKim (2013) paper and model draws clear links between a person's quality of life and notions of dignity and autonomy. In essence, the argument goes that, in the event of 'poor quality of life' and unbearable or intolerable suffering, people who are eligible should be able to choose voluntary euthanasia and assisted suicide. This argument is not unique to the Tasmanian paper and model, and has been debated and critiqued more widely in the international literature, briefly summarised here. Associating worth with dignity and autonomy can have dangerous ethical ramifications.

The most powerful criticisms of this argument are raised by disability rights advocates and people with

disabilities (Newell, 1996; Haller & Ralph, 2001; Davis, 2004). In the United States, numerous disability organisations have opposed state attempts to legalise euthanasia and assisted suicide. These organisations include the National Council on Disability, the American Association of People with Disabilities, the National Spinal Cord Injury Association, the Disability Rights Education and Defense Fund, the World Institute on Disability, and Not Dead Yet (McGaughey, 2013).

Golden and Zoanni (2010) strongly argue against it on a number of grounds, but first and foremost because it has adverse implications for people with disabilities, whether or not they are eligible for or considering voluntary euthanasia or assisted suicide. The implication that some people are 'better off dead' and that 'some lives are not worth living', phrases which have been used in discussions in places such as the Netherlands and jurisdictions around the world debating euthanasia, are potentially offensive and stigmatising to those who live with the same or similar symptoms and conditions. British paralympian and Baroness Tanni Grey-Thompson (MBE) explains some of the issues that concern her and other people with disabilities:

> 'Legalising assisted dying for terminally ill people reinforces prejudices for people with disabilities. Terminal illness and physical disability aren't, of course, the same thing – many people with disabilities aren't terminally ill. But terminal illness can often bring with it disability of one kind or another and it's not a big step in popular perceptions to see the two in some way linked. That's why the majority of people with disabilities, including me, are afraid of a law that would offer a lesser standard of protection to seriously ill people than to others' (Grey-Thompson, 2013)

In addition to this, Coleman (2000, 2010) and the Not Dead Yet national disability rights organisation in the United States argue that assisted suicide laws create a discriminatory double standard for who is the focus of suicide *prevention* and who has access to suicide assistance.

Feminist Perspectives: The Gendered Risks of Voluntary Euthanasia and Assisted Suicide

The focus of concern in this section particularly relates to the experiences of women, while also recognising at the same time the importance of understanding the experiences and perspectives of men. There is an emerging literature that raises concerns about the wellbeing and rights of women and the need to consider the impact of sex and gender on decisions regarding and circumstances surrounding the end of life and hastening death (see Osgood & Eisenhandler, 1994; Callahan, 1996; Wolf, 1996; Raymond, 1999; Canetto & Hollenshead, 2000, 2001, 2002; Parks, 2000; Platt, 2000; Allen, 2002; George, 2007), as well as broader coverage of issues of ageing, autonomy, gender oppression and injustice in healthcare provision at the end of life (Dodds, 2005).

The prevalence of gendered violence (especially intimate partner violence) and, in this the disproportionate victimisation of women, in Australia is concerning – one in three Australian women have experienced physical violence since the age of 15 (COAG, 2012: 2). It is vitally necessary to carefully consider the potential for gendered violence and familial control to be directly or subtly influential, if not implicated, in matters of the 'voluntary' assisted death of women. Where there has been coercion, control and gendered violence in a woman's life, the nature of which may often be kept hidden and secret from others (including in professional and personal relationships) in her life, it is important to ask whether this might be a factor in a woman's death.

George (2007) uses a feminist lens to critically analyse a 1996 national survey of euthanasia and physician-assisted suicide on the United States by Meier *et al.* (1998). Her observations on the gendered risks to women are relevant:

> The results of this 1996 US study are a challenge to the autonomy of decisions for assisted death and decisions for euthanasia in particular…. For the women in this US study, the rhetoric of choice rings a little hollow. Compared to men, women died in circumstances where their requests are less likely to be explicit, less likely to be at their personal request and more likely to be initiated by family

> members or partners. The euthanasia cases were also characterised by weaker doctor-patient relationships: in 12% of cases, the physician had known the patient for less than four weeks (Meier *et al.,* 1998). Thus, the women considering whether to end their lives were also less likely to have the benefit of an established relationship with their physician (George, 2007: 6).

On a separate but related note (making the important distinction between 'mercy killing' as different from voluntary euthanasia), she identifies what she calls 'striking correlations between patterns of male violence against women and the mercy killing of women' (George, 2007: 11-14). In her overall analysis of the realities of women's autonomy and opportunities for meaningful choice in matters of voluntary euthanasia, physician assisted or otherwise, George (2007: 8-9) concludes that 'for some women, the decision for death may be a 'non-choice', induced by controlling influences that subvert women's autonomy at the end of life.' She calls for closer scrutiny of the gendered risks to women of physician assisted suicide and euthanasia, saying that when women do decide to carry through with these things 'we need to ask *why* they make that decision' (pg 18, emphasis in the original), warning that some women will encounter unique risks, control, domination and pressures that are not currently well researched or understood in these specific matters of life and death.

The words 'gender' and 'women' are not mentioned at all in Giddings and McKim's (2013) 108 page paper. In light of the feminist scholarly literature briefly raised here, these are important issues that warrant more sophisticated consideration in the Tasmanian context than has occurred to date. Feminists are likely to take diverse standpoints on the issue, some in support and some against, yet feminist scholarship may be helpful in at least considering the experiences and perspectives of women at the end of life. Gender responsive healthcare and service provision matters. If there is the potential for gendered risks in legalising voluntary euthanasia and assisted suicide, then this necessitates public acknowledgment and further empirical research.

INTERNATIONAL EVIDENCE & HISTORY RE-VISITED

'Slippery Slope' Arguments and Risks of 'Bracket Creep': Evidence from Other Countries

There are cogent arguments for the existence of the so-called 'slippery slope', including the potential to shift from voluntary euthanasia and assisted suicide to the normalisation and routine practice of non-voluntary euthanasia. There are also risks of 'net widening', 'bracket creep' and shifts from strict eligibility criteria to broad eligibility criteria, resulting in mixed messages and potentially serious risks for vulnerable people (Foley, 1997; Amarasekara & Bagaric, 2004; Golden & Zoanni, 2010; Jones, 2011; Jackson & Keown, 2012; Finlay & George, 2011; Pereira, 2011; Prichard, 2012; Schadenberg, 2012; Titterington *et al*., 2013; cf Kerridge & Mitchell, 1996; Shariff, 2012; Lewis, 2007a, 2007b). Similar philosophical, social and medical perspectives and concerns have been expressed in the Tasmanian context in public opinion and submissions to the recent and current bids for euthanasia law reform (see, for example, Giselsson, 2009, 2013; Malpas & Lickess, 2009; Smith, 2013).

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 widespread:** 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 legalisation of euthanasia should simultaneously consider developing a policy facilitating the due care and reporting obligations of physicians.'
- **More generally, significant increases in use of deep continuous sedation in treatment of dying patients have been observed:** In the Flanders region of Belgium between 2001 and 2007, the practice of deep continuous sedation (sometimes called 'terminal sedation') increased from estimates of 8.2% of all deaths to 14.5% of all deaths (Bilsen *et al.*, 2009). On a related note, this trend was also observed in the Netherlands, where rates went from an estimated 5.6% of all deaths in 2001 (prior to euthanasia being legalised in 2002), to 12.3% of all deaths in 2010 (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 & Suvalescu, 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.

The Netherlands: Evidence of Non-voluntary Euthanasia for Vulnerable Patients and the 'Dark Figure' of Euthanasia

Interestingly, and much like the example of Belgium, the paragraphs that follow are a good illustration of the differences between euthanasia as policy and euthanasia in practice. As Giddings and McKim (2013) continually refer to the Netherlands throughout their paper and base substantial portions of their proposed model on that of the Netherlands, the Dutch experience warrants close scrutiny here. It seems that some important issues are missing from Giddings and McKim's (2013) analysis that relate to the Netherlands. These relate to concrete examples of 'bracket creep'.

The 'dark figure' of crime is a well-known metaphor in criminology to describe the real extent of crime (outside of or beyond official statistics) that remains undetected and/or unreported or underreported (see White & Perrone, 2010: 27). In this, the role of criminological and sociological research is to supplement official statistics, which are limited, through a range of other measures to gather a real picture of the issues and to counteract the problem of omission and underreporting. Although in a different context, this 'dark figure' metaphor can also be used to describe the phenomenon of hidden euthanasia in the Netherlands. This issue has been raised since the legalisation of euthanasia there, with Sheldon (2003: 1164) alerting readers of the *British Medical Journal* to a Dutch Government study which found that 'only half of Dutch doctors report euthanasia.' Lower figures have since been put forward. In 2010, it is estimated that 23% of euthanasia cases were not reported to euthanasia review committees in the Netherlands (Onwuteaka-Philipsen *et al.*, 2012: 6). Underreporting rates in Flanders, Belgium, appear to be higher; available evidence suggests that only one out of two euthanasia cases is reported (Smets *et al.*, 2010).

Giddings and McKim (2013: 44) suggest that there are numerous cases in the Netherlands where the first attempt at assisted suicide may have failed, and required doctors' intervention to hasten death. Citing a 2010 annual report from the Dutch Regional Euthanasia Review Committee, there appear to be 44 cases involving a combination of both assisted suicide *and* euthanasia, but very little is known about how and why this occurred. They conclude that 'it is reasonable to assume that in some cases the doctor was required to intervene and perform euthanasia if the patient's attempt at assisted suicide was not successful' (Giddings & McKim, 2013: 44). In light of the under-reporting mentioned earlier, this is concerning. A lot more needs to be known about 'assisted suicide fail rates' in other jurisdictions and how these are recognised and

responded to, both immediately with individual patients and structurally in terms of law and healthcare. For example, Oregon annual reports provide statistics of cases of patients regaining consciousness after an 'assisted suicide' attempt, with some living for days and even months after and being listed as dying of other causes (Oregon Public Health Division, 2011, 2012, 2013).

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.' In this vein, Pitcher (2010) raises the pertinent question of 'how do around 1,000 people come to be put to death in Holland per year without having made a request to die?' The answer from a representative of the Dutch Ministry of Health is troubling:

> 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)

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 legalisation 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.

Still greater concerns arise when it is understood what is now acceptable ethical practice in the Netherlands after the introduction of the 'The Groningen Protocol' (Verhagen & Sauer, 2005). The grounds for euthanasing an infant through 'post-birth abortion' or 'neonatal euthanasia' have now been documented to extend to doctors hastening death because of severe disability and suffering, as well as the capacity to 'deliberately end the life of physiologically stable newborns with lethal drugs that would not otherwise have died' (Verhagen, 2013: 293). The extent of actual practice is unknown as there are significant issues with underreporting; even an advocate of this practice and architect of the protocol, Verhagen (2013) estimated that only 15-20% of neonatal euthanasia cases are reported. The Royal Dutch Medical Association (the 'KNMG') (2013) have recently estimated that palliative care and infant euthanasia could be relevant to the end of life care and deaths of approximately 650 Dutch infants a year, issuing medical guidelines relating to these practices.

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 legalisation 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.

Tolle and colleagues (2004) conducted extensive research on the characteristics and demographics of dying Oregonians considering physician assisted suicide. Within this, they found that mental illness and psychological symptoms were implicated as factors in thinking about and wanting assisted suicide:

> The role of pain and psychological symptoms on PAS consideration is controversial. Pain has been associated with a desire for hastened death (Chochinov *et al.*, 1994), but most researchers emphasize the greater contribution of depression and/or hopelessness (Ganzini *et al.*, 2002). We found that greater overall symptom distress independently predicted personal consideration of PAS. Those who considered PAS also were reported

> to experience a higher number of symptoms, with pain and sadness most strongly associated with PAS consideration (Tolle *et* al., 2004: 116).

In the years after this research was published, other researchers began conducting studies about the role of mental illness and its links with people seeking voluntary euthanasia and assisted suicide.

In 2008, a much cited article in the prestigious *British Medical Journal* brought this issue to the fore. Ganzini, Goy and Dobscha (2008) conducted a cross-sectional survey in Oregon to determine the prevalence of depression and anxiety in terminally ill patients pursuing assisted suicide.

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.'

The authors of this paper examined the official statistics in the annual reports from Oregon Public Health – see Table 3 – to assess referrals for psychiatric evaluation. It would be reasonable to suggest that in recent years, when less than 4% of Death with Dignity Act patients were referred to a psychiatrist, that the prevalence of mental illness and psychiatric symptoms remain largely unknown and unmonitored. Martyn and Bourguignon (2000) have criticised Oregon's data collection and regulation in this area in detail.

Table 3: *Percentage (%) of Oregonian Death with Dignity Act (DWDA) Patients Referred for Psychiatric Evaluation – Trends Over Time*

Year	Percentage (%) DWDA patients referred for psychiatric evaluation
1998	31%
1999	37%
2000	19%
2001	14%
2002	13%
2003	5%
2004	5%
2005	5%
2006	4%
2007	0%
2008	3%
2009	0%
2010	1%
2011	1%
2012	2%

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

This data and the other empirical studies from the literature discussed here provide evidence that the legal safeguards in Oregonian law may not protect vulnerable people with a mental illness and, in some cases, may have been deliberately breached. There are also concerns that 'bracket creep' may occur by officially expanding the eligibility criteria and laws to allow people with a mental illness to access assisted suicide. Both Giddings and McKim (2013:

35) and Lewis and Black (2012) acknowledge that there have been lobbying attempts and campaigns, as well as proposed legislation, seeking to expand the Oregon Act to allow for patients with a mental illness to access physician assisted suicide. This attempt to expand the scope was recently voted down by the Oregon legislature. (Attempts have also been made to expand the Swiss system to incorporate suffering based on mental illness (Prichard, 2012).)

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).

In an article titled 'What's the Cost of Living in Oregon These Days? – A Fresh Look at the Need for Judicial Protections in the Death with Dignity Act', Page (2009) highlights two vignettes of vulnerable patients in Oregon. Page (2009) describes Barbara Wagner's story. She was a 64 year old, low income Oregon resident who learned that her cancer, after two years in remission, had returned. Her doctor wrote a prescription for a cancer treatment. In May 2008, Ms Wagner received a letter to inform her that the funding for her prescription had been denied. Instead, 'the Oregon Health Plan offered her funding for comfort care that included the option of lethal prescription. In response to the letter, Ms Wagner said "To say to someone, we'll pay for you to die, but not for you to live, it's cruel…"' (Page, 2009: 233).

In a very similar case, Oregonian resident Randy Stroup, aged 53, was uninsured and unable to pay for expensive chemotherapy. He was informed that his treatment under the Oregon Health Plan had been denied, and 'likewise, learned that the State would offer to pay for a lethal prescription' (Page, 2009: 233). In discussing Randy Stroup's case, Dr William Toffner, professor of family at Oregon Health and Science University, said '"It is chilling when you think about it. It absolutely conveys to the patient that continued living isn't worthwhile"' (Springer, 2008).

After much national and international publicity, both Ms Wagner and Mr Stroup subsequently had their medication and treatment requests reconsidered and the State offered to pay for their life prolonging treatment and palliative care if desired (Page, 2009). Page, however, concludes that these two stories reveal a truth about Oregon's Death With Dignity Act – 'its safeguards are inadequate' (Page, 2009: 233).

In summary, there is evidence from Oregon that contrasts sharply with the portrayal of best practice outlined by Giddings and McKim (2013). In particular, documented cases of people with a mental illness and people living with socio-economic disadvantage highlight that the safeguards in Oregon's Death With Dignity Act do not adequately protect vulnerable people.

Ireland: Euthanasia Law Reform is Against the Public Interest

Voluntary euthanasia and assisted suicide has recently been the subject of extensive debate in Ireland, due to a much publicised court case. The case was initiated by Marie Fleming, a 59 year old woman with multiple sclerosis who was immobile from the neck down. She wished to participate in assisted suicide and be allowed to die at home at a time of her choosing. Marie mounted a legal challenge to the constitutionality of Ireland's law that prevented her from being assisted to commit suicide. The High Court of Ireland in *Fleming v Ireland & Ors* [2013] IEHC 2 considered and rejected her claim. The court's judgment cited a number of issues and reasons which are summarised here:

- Competent adult patients already have the right to refuse medical treatment, even if this leads to death;
- Legalising or relaxing the ban on voluntary euthanasia and assisted suicide was 'inimical to the public interest';

- 'Any relaxation of the ban would be impossible to tailor to individual cases';
- 'The evidence from other countries shows that risks of abuse are all too real and cannot be dismissed as speculative or distant';
- 'One real risk attending such liberalisation is that even with the most rigorous system of legislative checks and safeguards, it would be impossible to ensure that the aged, the disabled, the poor, the unwanted, the rejected, the lonely, the impulsive, the financially compromised and emotionally vulnerable would not avail of this option in order to avoid a sense of being a burden on their family and society';
- 'The safeguards built into any liberalised system would, furthermore, be vulnerable to laxity and complacency and might well prove difficult or even impossible to police adequately';
- 'The Court further notes that the validity of other similar statutory bans has been upheld by the Canadian Supreme Court, the US Supreme Court, the UK Supreme Court and the European Court of Human Rights.'

In *Fleming v Ireland* the High Court of Ireland referenced the high profile Canadian case *Carter v. Canada* (Attorney General), 2012 BCSC 886. This is directly relevant here because Giddings and McKim (2013) refer to the Canadian case several times in their paper. The High Court of Ireland stated that, in reviewing the same available international evidence, it 'has drawn exactly the opposite conclusions.' The High Court summary of the judgment directly mentions some of the evidence and issues that have been covered in this paper as the reasons for the judgment and the rejection of Fleming's constitutional claim:

> 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. For these reasons, the Court rejects the constitutional claim.

Marie Fleming appealed this to the Supreme Court of Ireland, citing issues of discrimination relating to disability. On 29 April 2013, the Supreme Court of Ireland dismissed her appeal and upheld the judgment of the High Court (*Fleming v Ireland & Ors* [2013] IESC 19). The issues highlighted in *Fleming v Ireland* support broader international concerns regarding 'bracket creep' and a 'slippery slope' as well as underscoring the potential for undue risks for vulnerable people.

In summary, the alternative and additional international evidence and experiences presented here raise ethical questions about euthanasia law reform. They demonstrate why questions relating to 'bracket creep' remain. Such questions and the potential for serious risks and harms are not as unfounded as Giddings and McKim (2013) might suggest. If euthanasia is legalised in Tasmania it is highly likely that there will at some stage be debate about changes to and extension of eligibility criteria. 'Safeguards' do not effectively avert concerns about bracket creep, especially if social change is one of the main reasons cited as the grounds for euthanasia law reform in the first place.

CONCLUSION

Despite Giddings and McKim's (2013) confidence about euthanasia as a policy option for Tasmania, it seems to us that the case for voluntary euthanasia and assisted suicide in Tasmania is far from being made out.

A primary concern about Giddings and McKim's (2013) paper is that it appears to assess available evidence optimistically and from the perspective of euthanasia advocates. Our paper has attempted to explain that the few jurisdictions that have legalised euthanasia have complex legacies and fallible safeguards. It is unclear why these complexities have been understated in the Giddings and McKim (2013) paper.

Like others, we hold grave concerns about the mixture of roles and social messages entailed in legalising euthanasia, including those relating to the doctor-patient relationship as well as perceptions of Tasmanians with physical disabilities. We are equally concerned about the extension of eligibility requirements (e.g bracket creep), especially through reinterpretations of terms including 'poor quality of life' and 'unbearable suffering'.

Based on the evidence and experiences presented in this paper, we conclude that there are unjustifiable risks in proceeding with the euthanasia law reform proposed by Giddings and McKim (2013). Irrespective of the success or otherwise of their bid, much more research is needed to become better informed about the issues, processes and practices discussed in this paper, and how they can be best understood in the Tasmanian and Australian context. In the interests of fostering further knowledge exchange, we hope that others take up analysis and discussion of what we have presented here. More diverse voices and a wider range of community stakeholders need to be heard on this important issue.

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