

SUBMISSION TO END-OF-LIFE CHOICES INQUIRY

In this short submission I intend to comment on three topics which have commonly been raised in discussions of euthanasia and assisted suicide. In relation to the first two topics, only brief attention will be directed to some aspects of these which, I submit, commonly fail to attract the attention which they merit. The third, major, part of the submission will examine its topic in some more detail focussing on a feature which requires more attention than it usually receives.

The three topics which I wish to discuss are:

- 1) the moral issues raised by euthanasia and assisted suicide
- 2) the involvement of the medical profession
- 3) the experience in jurisdictions which have introduced euthanasia and/or assisted suicide

Moral issues raised in relation to euthanasia and assisted suicide commonly entail attempts to balance considerations of individual autonomy against the morality of the actions of an *individual* causing or contributing to the death of another person. A related issue which often fails to receive as much discussion could be characterised as one of **societal morality**. Specifically, should not the deficiencies of a society, insofar as they affect the lives of subpopulations, such as people living with disability, be included in the discussion when those deficiencies unfairly inculcate a preference for death as the only alternative. I have a particular interest in the welfare of people living with disability and will return to this subject when examining the third topic..

Involvement of the medical profession in the provision of euthanasia and assisted suicide services and its likely negative impact on the medical care of the community at large is frequently identified as an important consideration when any introduction of these services is under discussion. I have no doubt that this issue will be adequately explored by submissions from my professional colleagues. An aspect of the involvement of medical and other healthcare personnel in provision of these services which has become evident in jurisdictions which have legislated in favour of euthanasia is that most services are usually provided by a very small subpopulation of the profession. The expressed attitudes and practices of this subpopulation of practitioners may be cause for considerable concern, not necessarily foreshadowed in the enabling legislation. One situation in which things were not exactly as they seemed to be was the Belgian legislation which extended the availability of euthanasia to children under 12 years of age. This legislation, which evoked strong opposition from the profession at large was introduced at the specific behest of a group of paediatricians at the Queen Fabiola Hospital for the purpose of self-protection from prosecution in relation to their existing practices.

Experience in jurisdictions which have introduced euthanasia and/or assisted suicide. When predictions of the likely outcomes of any innovative practice are formulated in an ethical analysis, this is most commonly undertaken with the goal of determining whether the outcome benefits justify that practice and outweigh any

unfavourable features of that practice. In distinction from this common means versus ends ethical analysis, consideration of the outcomes of the introduction of euthanasia and/or assisted suicide within any jurisdiction has generally sought to predict whether outcomes will be as favourable as envisaged by advocates of that introduction or will include unanticipated and unacceptable consequences.

Following the introduction of assisted suicide and/or euthanasia in a number of jurisdictions during the last two decades, a substantial number of reviews of different aspects of the consequences have been published.. As referred to above, I have particular concerns about the implications for the Victorian disabled community of any legislation which could be introduced.

Any inferences drawn about the outcomes of an item of legislation can only be as valid as the data on which they are based. That data, in its turn, can only be as good as both the enforceable provisions governing its collection which have been incorporated in the original legislation and the diligence with which those provisions have been complied with by an adequately resourced regulatory body. Even the most cursory examination of the literature on the outcomes of assisted suicide and euthanasia in jurisdictions which have introduced either of these practices soon indicates the difficulty in formulating generalisations. I propose to select two jurisdictions as representative of the most apparently divergent outcomes of that introduction and then to proceed by comparing their respective stories.

As a starting point I suggest that **Belgium** has attracted the most attention among commentators critical of euthanasia as a jurisdiction in which adverse consequences have accumulated. On the other hand, the US State of **Oregon** has often been cited as an instance of the successful introduction of assisted suicide without adverse consequences by others supportive of the practice. Whilst neither of these jurisdictions has had the longest duration of legally accepted euthanasia practice, a distinction attached to Switzerland and the Netherlands, experience of the order of two decades provides adequate material for a comparison.

As a first basis for comparison, it is appropriate to take account of the nature of the regulatory systems which have been legislated to oversee euthanasia or assisted suicide in these two locations. The establishing legislation in both Belgium and Oregon provided for a body with oversight of euthanasia and assisted suicide respectively. In doing so, both jurisdictions, at least initially, exercised more responsibility than some have advocated.

For instance, the Falconer bill introduced into the UK House of Lords disposed of future regulation rather simply by specifying that safeguards were to be drawn up later by the Secretary of State; *who may, but is not required to, issue one or more codes of practice*. As regards the future, Falconer's bill indicated no more than that the Chief Medical Officer could *monitor the operation of the Act* were the bill to be enacted.

The **Belgian** legislation established a panel with the responsibility for determining whether doctors administering euthanasia were acting within the law. Since the enactment of legislation in 2002 and the more than 5000 occasions on which it has been applied, there has been no prosecution of a practitioner for malpractice. It is of more than passing interest that the government appointee to chair that panel, Dr Wim Distelmans, has also been the most prolific euthanasia practitioner in **Belgium**. He has also been the most prominent advocate of the extension of availability of euthanasia as will be mentioned below. This enthusiasm extended, in 2014, to his leading a study tour to Auschwitz, a strategy which alarmed some of his aficionados.

Oversight of the practice of assisted suicide in **Oregon** requires the annual release of the Official Oregon Report on the Operation of the Death with Dignity Act. The Report is dependent upon self reporting, on paper, by practitioners. There is no funding provision for investigation of practitioners. No penalties are applicable for failure to report an instance of assisted suicide, nor has any practitioner been prosecuted for failure to do so. The hard copy data on which each **annual report** is based is destroyed after the release of that report with no retention of any details. No practitioner has been charged with acting in a manner contrary to the law. .

There is general acknowledgement of substantial **under-reporting of euthanasia** cases in **Belgium**). Smets (2010) concluded, on the basis of extensive interviews, that unreported cases were less likely to involve consultation with a specialist palliative care practitioner. Whereas the legislated provisions require a second consultation with a palliative care specialist, if a patient expresses a concern about an inadequacy of such attention, this assistance does not appear to be available to any meaningful extent, at least in Belgium. Medical practitioners who intend to perform euthanasia undergo a 24 hour induction course. Of this period, 3 **hours** is set aside for briefing on palliative care. This token effort could be contrasted with the Australian situation in which a palliative care specialty is only acknowledged after 3 **years** training.

Both jurisdictions require the involvement of **two medical practitioners** for the acceptance of a request for euthanasia or assisted suicide. When there are indications that the patient may be depressed, there is a requirement for consultation with a psychiatrist or psychologist. In both jurisdictions, the role of second practitioner is likely to be filled by a member of a group with particular interest in, and professed enthusiasm for, euthanasia or assisted suicide. In **Belgium**, this is most likely to be the '**Life End Information Forum**'. ..In **Oregon**, the corresponding group is '**Compassion and Choices**' (originally the 'Hemlock Society') which undertakes this function. As an indication of the extent to which this has become the regular arrangement, during one period, a physician from this group acted as the second practitioner in 58 out of 61 consecutive assisted suicide applications.

A snippet of Australian data is available concerning the prevalence of depression among patients requesting, and receiving euthanasia. This is contained in an article reviewing the **Northern Territory** experience during the period before the enabling

Territory legislation was overridden. Of patients euthanased: *three were socially isolated and symptoms of depression were common* (Kissane 1998)

The number of reported cases of euthanasia or assisted suicide in each jurisdiction has increased steadily over the years since these procedures became available. The overwhelming majority of cases in **Belgium** have been confined to Flanders. The number of cases in specific years were: 2003 -235, 2011 – 1133, 2013 – 1807... Estimates of **non-voluntary** cases in which the patient had not given consent have been obtained by interviewing practitioners. Chambaere (2010) reported on this basis that, in 2010, 50% of the deaths attributable to euthanasia over a 5 month period in Flanders remained unreported. In **Oregon**, numbers have been considerably lower with 401 deaths over the first 10 years of availability of assisted suicide. In 2008, 88 prescriptions were written (not all of which would necessarily have led to a death).

Belgian practitioners, especially Wim Distelmans have not been reticent about releasing information identifying clients together with their reasons for choosing euthanasia.. There has been a substantial and ongoing broadening of the catchment beyond the original notions of ‘unbearable pain not responsive to analgesia and less than 6 months to live’. Examples of the most publicised cases have included those of 45 year old identical male twins with congenital deafness who opted to be euthanased when both started to become blind, a female who had undergone failed sex change surgery, another female with anorexia nervosa and a Nobel Laureate in his 90s who felt that he had nothing more to live for.

The occurrence of newsworthy cases such as the preceding should not divert attention away from a very much larger group of patients in respect of whom euthanasia outside of the originally professed situations has been performed. This has been publicly acknowledged by Wim Distelmans. In an interview published in the magazine *Humo* in March 2015, he indicated that: *at least 50 patients are euthanased each year for purely psychological reasons 2 to 3 % of the 1924 patients euthanased last year. They are in their 20s or 30s, they have been followed medically since they were children, they have a history of institutionalisation. We insist that the euthanasia occurs in the presence of the family. That is comfortable for the patient and it makes it easier for the family later.* The original notion of restriction of services to patients with terminal cancer and no more than 6 months to live is no more in Belgium.

The confinement of the practice of assisted suicide in **Oregon** to the originally espoused limits appears likely to be as fluid, if not as spectacular, as that in Belgium. According to the official Oregon report, the most frequent end of life concern cited by people requesting assisted suicide is not pain but ‘loss of autonomy’ (91.5%), followed by decreased ability ‘to engage in activities making life enjoyable’ (88.7%), ‘loss of dignity’ (79.3%), ‘losing control of bodily functions’ (50.1%) and ‘burden on family, friends/caregivers’ (40%), and only then ‘inadequate pain control or concern about it’ (24.7%), (in each case citing accumulated data for 1998-2013). It hardly requires any profound insight into medicine to realize that these concerns relate, in the first instance, to disability and increased dependence. The concern about feeling one is a ‘burden’ on others is significant, much more so than fear of pain (which, also, should not automatically be conflated with actual pain).

The report of Drum (2010) which cited the concerns listed above expressed concerns about the operation of the Death with Dignity Act. These are reproduced below.

Review of the empirical literature on DWD in Oregon reveals a number of potential concerns, including inadequate demographic profiling of DWD requesting patients with regard to disability, inadequate mental health evaluations, insufficient duration of physician-patient relationships, potential inaccuracy of the 6-month prognosis, and inadequate exploration of alternative treatment. Of greater concern is the lack of oversight of potential abuses of DWD. The DWD Act creates criminal liabilities for such acts as forging a request for DWD or exerting undue influence or coercing someone to request DWD but does not designate an agency to investigate potential abuses

An issue which has relevance to actual practice in both Belgium and Oregon is that of the identity of those in attendance when assisted suicide or euthanasia is accomplished. **Oregon** reports have revealed that in only 15.7% of cases was the prescribing physician present when the patient ingested the prescribed lethal medication. This obviously leaves the issue of coercion, especially by potential inheritance beneficiaries, as an uncontrolled risk. Whilst there has never been any form of disciplinary action taken against a prescribing practitioner in Oregon, suspicions about the circumstances applying **at the time of ingestion** have led to criminal charges. Belgian reports of unreported cases of euthanasia have indicated that it is common practice for a nurse to be instructed to administer the required medication in the absence of the prescribing doctor, a practice which nurses frequently do not appreciate.

As a natural successor to this, one might note the extent of compliance with the legislated regulatory mechanisms by the responsible authorities in the two locations. This could lead to some observations regarding the extent to which medical practice has conformed with the constraints contained in the legislation. In doing this I intend to direct particular attention to the risk that some sections of the respective communities have sustained, or are at imminent risk of sustaining, collateral damage .

The results of oversight of the practice of assisted suicide in Oregon are presented in the Official Oregon report on the Operation of the Death with Dignity Act. In the case of Belgium, this role is undertaken by a committee chaired, as mentioned above, by Wim Distemans. Perhaps unsurprisingly, the number of instances of investigation of the legitimacy of any instance of euthanasia in almost two decades is in low single figures.

The brief account provided above gives some indication of the **immediate** ‘side effects’ which have become apparent under existing legislation. The main thrust of this submission, however, is to direct the Committee’s attention to what might be termed ‘**second order**’ side effects. I use this term to categorise consequences which, while not necessarily foreseen at the time of the original legislation, may, with the passage of time, come to be strongly facilitated by the ongoing existence of legislation enabling euthanasia and/or assisted suicide. These consequences will not be the result of enthusiastic proponents such as Wim Distelmans noted above which might be somewhat crudely described as ‘euthanasia for anyone who wishes at some time to have it’.

Rather, my perception of ‘second order’ consequences refers to the interaction of an existing capacity for euthanasia juxtaposed with, and slotting into, other factors. The outstanding example of this combination in the previous century occurred when a well established penchant for euthanasia in the 1920s Weimar Republic interfaced in the following decade with a government hatred for several groups of citizens on the basis of ethnicity, religion, sexual orientation and disability. The interacting factor which, I believe, can increasingly be seen as capturing an established practice of assisted suicide or euthanasia is of course financial constraint on government budgeting. Disability care is expensive. Palliative care is expensive (that the organisation Human Rights Watch nominated palliative care as a human right in 2011 may not be as widely known as it should be). Decent care of a rapidly burgeoning aged population will become increasingly expensive.

To show my own hand, I was a member of the board of the National Brain Injury Foundation for 17 years and served as its chair for 12 of those years. We regularly encountered families who had been advised in relation to catastrophic brain injury to a son to ‘place him in a nursing home then walk away and forget him’. Individual stories can be much more informative than generalisations. Rather than present examples of these here, could I refer any interested Committee member to Chapter 3 of a monograph available as a free download from the ANU Press (<http://epress.anu.edu.au/titles/ted-freeman-and-the-battle-for-the-injured-brain>). These experiences were in the 1980s and 1990s so it is a little unsettling to have a Senate Committee proclaiming earlier **this** year that younger people should not be consigned to nursing homes (when will we ever learn?).

There have already been indications that an unholy alliance between health budgets and assisted suicide is developing in Oregon. The Oregon Department of Human Services: Public Health Division is responsible for oversight of the operation of the Death with Dignity program in addition to healthcare. In the course of testimony before a Californian Senate committee enquiring into a proposal to legalise assisted suicide the story of two identified Oregon patients, as it related to this Department, raised the issue of potential interaction of apparently unrelated issues. These named individuals, both with metastatic cancers, were informed that, whilst the Oregon Healthcare Plan would not pay for their prescribed chemotherapy, it would pay for assisted suicides. .

Some assessments of assisted suicide have changed significantly over the last 5 years. When Massachusetts was considering its implementation in 2012, among its supporters was a person who is regarded by many as the preeminent US bioethicist, Art Caplan.. In October, 2012 when the bill to legalise assisted suicide was under discussion, the New York Times carried an article by Ben Mattlin a 50 year old freelance journalist who had been severely disabled since birth by spinal muscular atrophy.

Mattlin’s article, written using a voice controlled computer, was headlined ***Suicide by Choice: Not So Fast***. Mattlin introduced his article with a reference to the imminent

vote: *Next week, voters in Massachusetts will decide on whether to adopt an assisted-suicide law. As a good pro-choice liberal, I ought to support the effort. But as a lifelong disabled person, I cannot.* He proceeded to detail all of the precautions incorporated in the legislation but, nevertheless, expressed his concern about the vulnerability which it could impose on some groups in the community. For instance, he referred to the 20,000 cases of elder abuse documented in the State during 2010. He alluded to the *porous border between coercion and free choice* and expressed his concern about *subtle coercive forces which emerge when physical autonomy is hopelessly compromised.* Mattlin then expressed his personal conviction that his own quality of life was perceived as untenable by others, especially doctors, with the response that: *I am more than my diagnosis and my prognosis.* His article concluded: *Advocates of Death with Dignity laws who say that patients themselves should decide whether to live or die are fantasizing. Who chooses suicide in a vacuum? We are inexorably affected by our environment. The deck is stacked!*

Fast forward 5 years and, several weeks before the writing of this submission, Art Caplan entered the medical publication arena to acknowledge the reversal of his previous position and to outline the reasons underlying his change. Writing in *JAMA Internal Medicine* in August 2015 Caplan acknowledged that he had strongly supported the Massachusetts bill in 2012. Nevertheless, he expressed strong concerns about the implications of the **developing trend** in use of euthanasia in Belgium: He posed the question: *Are the Netherlands and Belgium turning to physicians to solve what are essentially psychosocial issues?* He spelled out his concerns relating to the American situation in the following terms.

Although the euthanasia practices in the Netherlands and Belgium are unlikely to gain a foothold in the United States, a rapidly aging population demanding this type of service should give us pause. Physicians must primarily remain healers. There are numerous groups that are potentially vulnerable to abuses waiting at the end of the slippery slope—the elderly, the disabled, the poor, minorities, and people with psychiatric impairments. When a society does poorly in the alleviation of suffering, it should be careful not to slide into trouble. Instead, it should fix its real problems.

To conclude this submission, I refer back to the term **societal morality** used in introducing it. This relates to the rather basic principle that, as members of a decent society, we gain privileges but simultaneously should accept constraints on our personal options. In the context of the present discussion our striving for personal autonomy may, if uncritically accepted, come at a major cost to the most basic rights of others in our community. The regulation of society is replete with situations in which everyone will be subject to some constraints in the absence of which others may be exposed to harm. Proposals for everyone to have the right to assisted suicide represent but one, albeit novel, example of this. As Caplan has pointed out in his reappraisal of the situation, it is not his concern that the more florid examples of Belgian euthanasia practice might be duplicated in any country legislating to permit assisted suicide but rather that assisted suicide on the pattern existing in Oregon will impose a very substantial risk of non-voluntary termination of life of vulnerable subpopulations the

ongoing existence of which, with their inexorable increase in size, imposes substantial increasing costs upon governments.

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