



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

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## Submission Cover Sheet

### End of Life Choices in the ACT

**Submission Number: 367**

**Date Authorised for Publication: 19/4/18**

## Submission to Select Committee on End of Life Choices in the ACT

**This is a personal submission addressing the first 4 points and the 6th point identified in the call for submissions. In order to achieve a more concise format, references to issues raised in the submission have not been included but will be provided to any Committee member who is interested in seeking additional information.**

### **1. Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;**

A person has the right to exercise a preference not to receive treatment which is offered by a medical practitioner. This does not represent a change in attitudes to 'managing end of life' and has been a longstanding option available in medical practice. The exercise of this option should be preceded by an appropriate explanation, provided by the practitioner, detailing what treatment is potentially available and what its outcomes, positive and negative, are likely to be

. That withholding or cessation of any procedure at a patient's request may invariably lead to death does not invalidate such a request. A common request, namely for withdrawal of renal dialysis, invariably has this outcome. In some instances, withdrawal of a treatment may necessitate the introduction of an additional form of treatment in order to spare a patient avoidable distress during withdrawal. The provision of anaesthesia at the time of a requested withdrawal of artificial ventilation in a person unable to breathe spontaneously is necessary. **Withholding** this would be utterly unethical. Withdrawals of measures such as dialysis and ventilation at a patient's request, because of their intrinsically burdensome nature, are certainly not equivalent to the notion of 'assisted dying' used, as it invariably is, as a euphemism for assisted suicide.

The tendency of some practitioners, and some institutions, to proceed relentlessly with treatment, even though this is patently of little benefit to a patient, is likely to have fuelled some of the agitation for 'assisted dying'. Vitalism, as parodied in enthusiasm to 'keep going until rigor mortis sets in', has no place in good medical practice.

Another frequently discussed procedure, which is also prone to be mistakenly equated with 'assisted dying', is the implementation of therapy, **with the intention of alleviating a patient's symptoms**, which may inadvertently hasten death. In such a situation, provided that the **genuinely intended outcome** is symptom relief, even whilst recognising the possibility that death may occur, differs fundamentally from undertaking measures which are primarily **intended** to cause death. Historically, this situation in which the possibility of unintended death exists has, most commonly, been associated with opiate administration. A dose which provides relief from suffering for one patient may be potentially lethal for another.

The situation adverted to in the preceding paragraph, generally described as ‘the doctrine of double effect’, although one of the hardy perennials of bioethics, is rapidly ceasing to have relevance for the practice of ‘assisted dying’. For example, the specified protocol for ‘assisted dying’ in Canada can require sequential administration of up to 3 pharmaceutical agents, namely an anaesthetic agent to obviate the distress consequent upon cessation of breathing, a muscle relaxant to halt respiration and, if necessary, a third agent to arrest cardiac function (this trio closely resembles the US protocol employed in capital punishment).

There is only one intent, and one outcome, in this sequence. In a quaint twist to medical terminology, the use of opiate overdose to guarantee death has now come to be condemned by some practitioners as ‘medical malpractice’ on account of its inherent unreliability. The applicability of the doctrine of double effect is diminishing.

In recent decades, a patient’s preference in relation to treatment, or its withholding, may have been indicated in an advance directive prepared at an earlier time and available to those medical personnel responsible for providing treatment. A caveat applicable when complying with a contemporary request concerns the person’s decision making capacity at that time. If this is judged to be significantly impaired, and an advance directive is not available, information from a ‘significant other’ based on previous oral communication provided by the patient may be adequate in deciding about treatment, or the withholding thereof.

In the situation in which a surrogate decision maker is expressing a preference, on behalf of another, which entails foregoing a treatment which is considered to be medically indicated (for example, a blood transfusion) recourse to a legal intervention may be indicated.

Given the possible context in which question 1 has been introduced, namely that of omitting treatment, including palliative care, as a prerequisite to requesting assisted suicide (categorised disingenuously in some jurisdictions, such as Victoria, as ‘assisted dying’) it behoves one to be aware of the history of ‘bracket creep’ in relation to the limits to autonomy in jurisdictions such as Belgium and the Netherlands.

When medical assistance to end life, either by assisting at suicide or by undertaking euthanasia, was originally legalised in Benelux jurisdictions, a patient’s right to decline treatment, as discussed above, could not be then presented as creating the situation of the unavailability of a suitable treatment. This restriction was imposed to prevent a patient from rejecting treatment for the purpose of generating *a prerequisite for assistance with suicide or euthanasia*. In the absence of this restriction, having achieved this stage, the patient could then invoke autonomy for a second time. Subsequent legislation adjusted the situation by removing the inconvenient prohibition.

As implied in question 1, consideration of the place of palliative care is integral when one sets out to formulate a holistic description of end of life care. Apart from a small number of well publicised individuals, most Australian palliative care specialists have been

emphatic in rejecting the notion that there exists a natural 'continuum' from palliation to assisted suicide or euthanasia. My reading of arguments for providing legal access to assisted suicide and/or euthanasia suggests that a fundamental motivation underlying such advocacy is that of personal autonomy. Nevertheless, the most persuasive and most frequently used, presentation of this argument is based on genuinely distressful accounts of the deaths of loved ones by family and friends of the deceased individual. I certainly have no wish to question the sincerity of many of these accounts.

Given their sensitive nature, it would often be offensive and distressing to those families and friends were a detailed assessment of the adequacy, or otherwise, of the *management*, as distinct from the *medical treatment*, of the dying person to be undertaken. This avoidance, however, runs directly counter to the invariable approach to any other medical situation in which the adequacy of a particular approach is questioned. To assume automatically that a fundamentally different approach to management of future, similar situations is indicated, without meticulous scrutiny of the earlier events, is never an acceptable solution. That scrutiny would entail, in the first instance, analysis of the quality of the management that had been provided, of the extent to which this matched 'best practice', of the accessibility to that practice, of the performance of the attending medical personnel and of much more.

Legislation to decriminalise assisted suicide and/or euthanasia in overseas jurisdictions has often been accompanied by promises to introduce complementary legislation to upgrade palliative care availability. In practice, these promises have often remained just that. While palliative care budgets may not have decreased after the passage of decriminalisation legislation, they have commonly failed to keep pace with increases in health care budgets.

Good palliative care entails considerably more than adequate pain relief although the two issues are sometimes conflated. The reasons given by patients seeking assisted suicide in Oregon during 1998-2003 were loss of autonomy (91.5%), decreased ability to engage in activities making life enjoyable (88.7%), loss of dignity (79.3%), loss of control of bodily functions (50.1%) burden on family (40%) and, last of all, inadequate pain control *or concerns about it* (24.7%). An effective response to these reasons clearly requires much more than medical assistance. Comprehensive contributions from nurses, social workers, ward staff and psychologists to support the patient have to be accompanied by support for involved family members. Perhaps the best illustration of what palliative care *is* can be provided by noting what it is *not*. A 24 hour training course provided by a group committed to assisting with suicide and providing euthanasia in the Netherlands includes 3 hours training in palliative care (Australian accreditation as a palliative care specialist requires several years practice).

*Concern* about loss of autonomy, especially in anticipation of that loss, appears to arise considerably more often than actual loss. It could be argued that many substantial limitations to personal freedom exist in the community at large for the benefit of other members. Organised opposition to them on the part of autonomists is perhaps best illustrated currently by anti-vaxxers.

## 2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

As with any issue, community views on the desirability of ‘assisted dying’ will be largely influenced by that community’s understanding of details of the issue including, especially, the extent of respondents’ comprehension of the terms used in the survey. In its turn, that comprehension may be at the mercy of the precise wording of the questions and this, in its turn, is likely to reflect the beliefs of those responsible for commissioning and funding the survey

The above caveats are widely recognised as is their influence on any results. The Gallup organisation has conducted surveys of US community attitudes to assisted suicide and euthanasia on an annual basis since 2003 as part of its Values and Beliefs survey project. These surveys have placed particular emphasis on the manner in which the terminology selected in the questions determines the outcome of any poll. In a report of the outcome of a survey undertaken between May 2 and May 7 released on 29/5/2013, it was found that:

*70% of Americans were in favor of allowing doctors to hasten a terminally ill patient's death when the matter is described as allowing doctors to "end the patient's life by some painless means." At the same time, far fewer -- 51% -- support it when the process is described as doctors helping a patient "commit suicide"*

The 2013 survey involved more than 1500 participants and its error margin was calculated at 3%. The report on the survey also noted that:

*Gallup's question with the softer description of euthanasia -- calling it "ending a patient's life by some painless means" -- also specifies that both the patient and his or her family requested it. The "suicide" version says the patient requests assistance from a doctor, without referencing other family members.*

An international ‘right to die’ survey has canvassed suggestions of new, more convenient, words to avoid the use of distressing terminology. The Survey Monkey affords such an opportunity to understand the position of right to die advocates, without misrepresentation. Offerings submitted to the Monkey included *self deliverance humane self-chosen death, dignicide* and *rational suicide*.

Some assistance from Dr Thomas Bowdler to insulate the community from the insensitivity of the ‘suicide’ word is sought – will ‘assisted dying’ suffice? A final point worth considering in relation to contemporary Australia has been the lack of any public response from suicide prevention organisations. Perhaps the risk of ‘assisted dying’ being conflated in the community’s mind with suicide doesn’t bear contemplation?

### **3. Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;**

**Two general categories of people** in the ACT could be placed at risk were assisted suicide to be decriminalised. The **first category** includes individuals who may be subject to pressure to utilise the procedure or who, even in the absence of *direct* pressure, may feel obliged to avail themselves of the procedure, or to undertake unassisted suicide, because of perceived obligations that others expect them to do so.

The two most vulnerable groups of people in this *first category* who will be at considerable risk of feeling obliged to accept assisted suicide for the sake of others, when this becomes available, are the *elderly* and those living with *disability*.

. As regards the elderly, the existing epidemic of elder abuse is at last being acknowledged in Australia. At present, this most frequently takes the form of financial abuse. A power of financial attorney granted by an elderly person has been frequently likened to a licence to steal or, more delicately, considered to represent permission for accelerated inheritance.

The implications of this attitude sufficed to persuade Art Caplan, arguably the preeminent US bioethicist and a committed 'pro choice' advocate, to reverse his earlier position and oppose assisted suicide legislation in Massachusetts. Caplan cited the 20,000 acknowledged instances of elder abuse in the state in 2010 and the statistic that more than half of euthanased Belgians were over 80 years of age as influential factors for him.

As regards people living with *disability*, statements from some very articulate public figures who come within this category should be read by anyone contemplating a jump onto the assisted suicide bandwagon. In the course of a House of Lords debate on euthanasia, Baroness Campbell, who has been wheelchair reliant from birth with spinal muscular atrophy, described the prevalent view of many people, expressed to her, that others who were severely disabled must surely wish for death.

The *second category* of people are those who may be, indirectly, placed at increased risk of undertaking *unassisted* suicide following the normalisation of suicide inevitable with legislated 'assisted dying'. Efforts to reduce the incidence of suicide in Australia (currently 8 cases/day) will inevitably be

compromised by any perception of such normalisation (try Googling suicide prevention programs in Belgium or the Netherlands). Devising quaint semantic fiddles and instituting ‘robust regulatory protocols’ have not succeeded elsewhere in their goal of sanitising ‘good’ suicide (aka ‘assisted dying’) with the aim of distinguishing it from the ‘bad’(unassisted) variety.

People in this second category include those groups in the Australian community already recognised as at increased risk of taking their own lives (suicide is now the commonest cause of death in Australians aged between 18 and 35). These people are currently targeted, with varying measures of success by Australian suicide prevention campaigns. For example, students are targeted by the ‘Headspace’ program. This contrast with the situation in the Netherlands where students are targeted by ‘Cafe Dead Normal’ an organisation which holds regular meetings at which participating students are encouraged to regard suicide as an entirely permissible life choice (no pun intended).

Some specific categories of recognised susceptible groups in the Australian community include:

**People suffering from depression.** The original legislation in Benelux jurisdictions and in Oregon mandated psychiatric or psychological assessment if depression was suspected in anyone seeking assisted suicide or euthanasia. Confirmation of a diagnosis of clinical depression required exclusion from access to assisted suicide or euthanasia. Such a requirement for assessment was removed when legislation was later adjusted in Benelux jurisdictions. With the further passage of time, depression has itself become *an acceptable reason* for assisted suicide or euthanasia. A requirement for assessment if depression is suspected remains in Oregon but is rarely observed.

**Indigenous people.** Suicide occurs at a substantially higher frequency in indigenous communities, often as clusters of cases. A similar situation prevails in Canada and, consequently, considerable work was required behind the scenes to secure the support of Indigenous MPs when euthanasia legislation was presented for parliamentary approval.

**LGBTI people,** especially those in the 18-35 age group remain at significantly higher suicide risk than their peers. This was frequently cited as a likely risk of conducting the same sex marriage plebiscite.

**Prisoners who have recently completed a custodial sentence** are at a much higher risk of suicide than the community at large.

*Ex service personnel recently returned from a combat zone* are similarly at risk. This issue is currently the subject of a federal parliamentary inquiry.

It is frequently argued, as in the Victorian Legislative Council Select Committee Report which set the scene for the 'assisted dying' legislation, that the availability of the assisted variety of suicide would reduce the incidence of the 'do it yourself' variety. Such a prediction has yet to be fulfilled in any jurisdiction in which assisted suicide or euthanasia has been decriminalised. The Victorian Select Committee quoted coronial testimony to the effect that the availability of 'assisted dying' would eliminate the occurrence of 'horrific' suicides among people who would qualify for 'assisted dying'. With due respect to the coroner, a great number of unassisted suicides, undertaken for whatever reason, are decidedly horrific. For instance, in a group of more than one hundred suicides in the Kimberly region, more than 90% involved hanging.

#### **4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme.**

Four aspects of the Victorian legislation which effectively decriminalised assisted suicide merit particular attention by the ACT committee.

The *first* of these relates to the manner of *regulation* of assisted suicide when the legislation comes into effect (in passing, it could be noted that it has become de rigueur that the noun regulation invariably be qualified as *robust*, an adjective profusely employed in the Victorian committee report and ensuing commentary) Promotional material relating to the Victorian legislation frequently proclaimed it to be the most rigorous in the world. While this may be so if one measures the weight of the paper required to accompany each instance of assisted suicide, the issue of *detecting and enforcing compliance* appears not to have made it into the legislation.

Notwithstanding the heavily formalised paper trail, there doesn't appear to be any requirement for an independent person to be present at the time of lethal ingestion (presence of a practitioner is mandated when ingestion of the material is not possible). Whilst there are efforts in the legislation to avoid coercion, it would seem likely that coercion at the time of ingestion has been overlooked. Given that there is a significant overseas incidence of patients ultimately deciding not to ingest the lethal agent to which they have been granted access, it would seem likely that encouragement/coercion of a patient, who was having second thoughts about proceeding to open the box and proceed would be feasible. Recall elder abuse.

As a way of evaluating the Victorian regulatory regime, consider the efficacy of a similar regime if it were to be the sole measure to achieve compliance in other government

regulated activities. For example, the declaration of an individual's taxable income to the Australian Taxation Office is the responsibility of that individual and, to that extent, whether he or she chooses to submit the paperwork is entirely a matter for his or her discretion. If one elects to refrain from submitting a declaration of income, is the ATO none the wiser? Well, not exactly, there are such a profusion of other sources of this information available to the ATO that ultimate detection of failure to lodge a report will, almost invariably, be detected with potential for dire consequences.

Returning to the question of compliance with the Victorian legislation, what safeguards are provided to guarantee that a participating practitioner complies with the legislation? Sure, the dispensing pharmacist is required to submit paperwork, but given that the preferred pharmaceutical options for assisting at suicide, as they are in the 'do it yourself' version, are likely to entail an overdose of a pharmacological agent which it's not too difficult to get around (witness the introduction of non-availability of over-the-counter opioids from February 1), the necessary prescription need not require notification of the anticipated assisted suicide.

Surely the death certificate will give the game away? But wait: the legislation requires that the practitioner falsify the certificate so that the cause of death is said to be the prevailing medical condition which motivated the patient to choose suicide. (There are some interesting nuances arising from this one relating to voiding life insurance policies)

The Victorian legislation envisages that, if a practitioner elects not to notify the authorities of an instance of assisting at suicide, others will oblige. Who? Perhaps the patient's family? This is possible if the family was not in agreement with the practitioner's actions and becomes aware of these after the event. Practitioners need to exercise caution. It is envisaged in Victoria that other practitioners will notify the authorities of their colleague's actions. Medical practitioners will certainly, on occasion, dob in a colleague, but consider the Victorian Select Committee's slant on this one. The Committee report refers to a published study which revealed that some 7% of practitioners interviewed in NSW *and the ACT* admitted to the researchers that they had undertaken measures intended to achieve the death of a patient. So much for 'robust regulation'.

A *second* aspect of the Victorian legislation which appears to fall short of 'best practice', if one chooses to apply this term to assisting with suicide, is its failure to require a psychiatric assessment if a patient is suspected of having clinical depression. As mentioned elsewhere, this requirement was originally incorporated in Benelux and Oregon legislation but was subsequently removed from the former and largely ignored in the latter. Published studies have reported that treatment of clinical depression affecting patients requesting assistance with suicide frequently results in withdrawal of the request. Experienced psychiatric practitioners have, furthermore, indicated that assessment of a patient's status in relation to depression often requires more than a single consultation.

A *third* feature of the Victorian legislation which has wider implications than are immediately apparent is the specification of a nominated interval for assisted suicide

eligibility, in this case 6 months, estimated survival interval within which a patient's death can be anticipated. Leaving aside the considerable imprecision frequently inherent in prognosticating about survival times when death is not probable within weeks, the origin of this specification is considerably more complex than is immediately apparent. The Victorian Select Committee report recommended this feature of the legislation and careful perusal of that report rather gives the game away. The estimate of 6 months was proposed to that committee in the course of its consultation with health authorities in Oregon. One could be excused for anticipating that this specification was based on collected opinions from a survey of practitioners experienced in end of life care. Far from it.

The Victorian committee was informed that the interval of 6 months was employed in Oregon because this was the period before anticipated death at which the relevant state regulations conferred eligibility for hospice care. Bureaucracy triumphs over clinicians once again. This origin of the survival estimate, based upon linkage to entitlement to a specific form of medical care sounds harmless enough. Subsequent incidents, however, have thrown that interpretation into doubt. More specifically, the legal availability of assisted suicide risks gradually entrenching a system in which expensive, but potentially beneficial, alternatives are not readily funded.

Two Oregonian patients testified to a Californian Senate inquiry into assisted suicide that their state health authority had declined them access to chemotherapy recommended by their medical practitioners, instead offering to fund assisted suicide. Some consolation prize!

There has been an increasing trend in North America for health providers and insurers to refrain from offering indicated therapy in favour of providing funding for assisted suicide (after all, the latter is much cheaper, so it's really a no-brainer). On a number of occasions, generalised prognostic implications of nominating timing for access to assisted suicide appear, at the same time, to be employed to curtail funding of therapeutic options offering prospects of improvement or cure.

The first instance to hit the US mass media related to two patients in Nebraska who were assessed by their medical practitioner as likely to benefit from *potentially curative* (albeit expensive) therapy. Their health insurer, however, declined to fund this, opting instead to pay for their assisted suicide (much cheaper). It would require enormous belief in the absolute altruism of health insurers anywhere not to react in similar fashion. As this submission is being written, in mid-March, a related news item came to attention. An Ontario man with an incurable neurological disease has commenced legal action against the health department for the right to choose his home healthcare team, rather than accepting its offer of MAD (the acronym used in Canada for medically assisted death).

A *fourth* subject of concern arises from Victorian Government attitudes to palliative care. The evolution of attitudes towards palliative care in Victorian government publications is revealing. The Select Committee report devoted considerable attention to palliative care commenting especially on its scarcity in rural communities. The report recommended an

increase in resources for palliative care in general and especially in access to it in rural communities (almost without exception, the decriminalisation of assisted suicide or euthanasia in overseas jurisdictions has been accompanied by proposals for increased allocation of funding for palliative care: almost invariably this has not been followed through).

By the time that the report on *implementation* of assisted suicide commissioned by the Victorian government appeared, the focus had shifted to the projected lack of access to assisted suicide in rural communities. Circumstances modify priorities.

## **6. Any other relevant matter.**

I submit that it would be naïve to consider the possibility of end of life legislation, and, for that matter any issue raising possibilities of ACT legislative initiatives, without some awareness of the practical consequences of comparable legislative changes within other jurisdictions. Whilst some inferences have been presented above about the likely consequences of the legislated changes which are to be implemented in Victoria, it is not feasible to evaluate with confidence the implications of these until they have been in operation for some time.

The jurisdictions in which decriminalization of assisting with suicide and euthanasia have been in operation for the longest period are those of the Benelux countries and the US state of Oregon. Whilst a detailed assessment of the operation of the original legislated provisions within these jurisdictions can readily be provided, it will not be included in this submission. Such an assessment would include the manner in which they have operated and the legislated adjustments which have brought the original legislation into accord with that operation (rather than adjusting the practical operation to conform with the original legislated intentions).

Whilst some account of differences between prevailing attitudes towards death in Belgium and Australia is appropriate, the *current* evolution of events in Canada is more applicable to Australia. Suffice it to say, at this stage, that the well publicised claims of commentators such as Andrew Denton that all is sweetness and light, based on his ‘research’ can only be categorised as ludicrous. From his description, it appears likely that his judgment was founded on the opinions of people with whom he spoke rather than on hard data.

Interpretation of a factual situation based on community perceptions of that situation can be quite misleading. Thus, there may well be substantial differences between typical Belgian attitudes towards death and suicide and prevailing attitudes in Canada. Such differences were accepted by the Canadian Supreme Court in *Carter v Canada*. The Court stated that, on account of historical differences between the two countries, conclusions about the likely outcomes of Canadian decriminalisation of euthanasia based on Belgian experience were ‘problematic’.

Consequently, it was inferred that Belgian experience was unlikely to be repeated in Canada. Once the Canadian legislation permitting Medical Assisted Dying had been in place for a year, with the frequency of the procedure considerably exceeding most peoples' expectations, Dr Ellen Wiebe, one of the most prolific practitioners, was reported as predicting that the Canadian rate would rise to about 5% of all deaths because of similarities of laws. Victoria could be worth watching.

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