



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

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: 112

Date Authorised for Publication: 29/3/18

Date Amendment Authorised: 30/5/18

**SUBMISSION TO THE SELECT COMMITTEE ON
END OF LIFE CHOICES IN THE ACT
BY 12 SENIOR CITIZENS**

18 February 2018 (amended 25 May 2018)

The Secretary
Select Committee on End of Life Choices in the ACT
Legislative Assembly for the ACT
GPO Box 1020
CANBERRA ACT 2601

Dear Secretary

We wish to make this submission for consideration by the Select Committee. We applaud the undertaking of the work of the committee because it may eventually lead to provisions for an end of life option that meets the unsatisfied needs of many people who at some time in the future would want to end their life quickly, peacefully, humanely and with dignity.

Our responses to the six terms of reference are as follows.

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

The current practices utilised in the medical community definitely do NOT meet the needs of many persons in the ACT for the following reasons:

- (a) For people who are residents in the ACT, the end of life options are: travel to a country in which there are legal provisions for voluntary euthanasia; dying at the end of a palliative care program at home and/or in an institution; or suicide.
- (b) Travelling to another country to undertake voluntary euthanasia (e.g. Switzerland) can be impracticable for many people: it can be impossibly trying for people who are seriously ill, very frail or disabled; it is extremely expensive; and some people may not be able to satisfy all the pre-conditions that apply.
- (c) Palliative care in a home situation and/or in a subsequent institutional situation is an end of life strategy that meets the needs of some people. However, many others do not regard it as being acceptable as an end of life option because of the risk of having a "bad death". They feel that even under the best possible palliative care it may well be that they will experience one or more of the following conditions over a period of weeks or days: protracted periods of pain or discomfort; indignity (relating to inability to eat without assistance and/or to clean and toilet oneself); inability to communicate fully; periods of semi-consciousness or coma; and what can be perceived to be pointless suffering.
- (d) Many people seek means of achieving a "good death" (as defined below in section 5 of this submission) via voluntary euthanasia. One such means is taking a drug that is fast-acting, painless, peaceful and with an assured outcome. Such drugs are used in European jurisdictions that have provisions for voluntary euthanasia. However, import of or possession of such drugs in Australia and the ACT is illegal. Administration of or provision of such drugs by a medical worker, doctor or any other person to achieve the death of a person is also illegal and not sanctioned by professional associations. What many people seek is the option of legally acquiring such a drug via prescription for self-administration, or the legal administration of such a drug by a suitably qualified medical worker at the re-

quest of the person. In both situations, many people seek to be able to take the drug at a time and location of their choosing, with support and comfort being provided legally by friends and carers.

- (e) For people who regard palliative care being an unacceptable end of life option, non-availability of such drug that they could use to end their own life in a "good death" can lead to consideration of alternatives. The literature available indicates alternatives such as: ingestion of drugs that have been prescribed for treatment of specific medical conditions; ingestion of poisonous chemicals; use of drugs purchased from overseas; asphyxiation or hypoxic death through use of car exhaust gas, or some other gas; hanging oneself. However, these are inadvisable alternatives with grave risks. Implementation could be ineffective and lead to very bad outcomes such as painful or prolonged death, or failure to achieve the desired result but with additional impairment to health. The purity and composition of drugs bought overseas cannot be assured and importing or possessing such drugs is illegal.
- (f) In spite of the potential dangers and risks, we understand that some people may wish to acquire the means of undertaking suicide with the intention of use in the future while they are still physically able to do so. That could lead to a person ending their own life needlessly early. In contrast, if a person knows that at an appropriate time in the future, they could have access to a legally sanctioned drug that would guarantee a "good death", that would give them the peace of mind to carry on until life becomes unbearable.
- (g) Providing assistance to a person who commits voluntary euthanasia is illegal. This means that providing comfort or support to such a person during the end of life act could lead to a significant fine and/or imprisonment or other sanctions. Such a person may then experience a sad, lonely and undignified death. The law needs to be changed so that it is not illegal for someone to provide comfort, support and assistance to a person who is voluntarily ending their life.

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

Many professionally developed, well-designed sample surveys have been undertaken in Australia in past years to ascertain views on voluntary euthanasia. These surveys consistently demonstrate that a large majority of citizens support the concept of voluntary euthanasia in some form or another. This is certainly the case in respect of voluntary euthanasia for people who have a terminal illness and a short time to live. However, we believe that a majority of citizens and certainly many senior citizens would endorse the concept of voluntary euthanasia being available to people who do not have a terminal illness and/or who have more than, say, 12 months to live.

We believe that a well-designed sample survey should be undertaken in the ACT to determine constituents' views on voluntary euthanasia in a number of circumstances. It can be safely assumed that the proportion of people in support of voluntary euthanasia for people with a terminal illness and/or a short time to live would be at least equal to that found consistently in past surveys (in the order of 75% to 85%). However, if such a survey were to be undertaken it should also canvas views on making voluntary euthanasia available to people who do not have a terminal illness or a short time to live, but who meet the access criteria specified below in section 4 (a) of this submission.

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

In the past, opponents of voluntary euthanasia and physician-assisted dying have identified a number of potential risks associated with their implementation. At this date, there are a considerable number of jurisdictions in which voluntary euthanasia has been implemented outside Australia. There have been many follow-up evaluation studies and research studies into the implementation of voluntary euthanasia in such jurisdictions. Those studies have demonstrated that the implementation of mandatory procedures, processes and guidelines have been very successful in negating the posited risks. If voluntary euthanasia were to be implemented in the ACT, the Government should study the procedures, processes and guidelines that have been applied in those jurisdictions and the results of studies into their effectiveness in negating risks. Branches of Dying with Dignity in the ACT, Victoria and South Australia are able to provide comprehensive information about such studies.

It is of particular significance that the "slippery slope" risk that opponents of voluntary euthanasia have posited has not materialised.

Similarly, the potential risk of elderly or otherwise vulnerable people being coerced into undertaking euthanasia has not been evidenced.

It should also be noted that analyses undertaken by a few seemingly authoritative figures who oppose voluntary euthanasia have misreported or misinterpreted some research studies.

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

At November 2017 provisions for euthanasia or assisted dying has been implemented in Canada, Belgium, Switzerland, the Netherlands, Belgium, Netherlands, Luxembourg, Germany, Japan, Colombia, and in the USA states of Washington, Oregon, Colorado, Vermont, Montana, Washington DC, and California. In Australia, Victoria has passed legislation for assisted dying. The legislation and consequential procedures, processes and guidelines developed in those jurisdictions provides a rich knowledge base that the ACT government should study when developing appropriate provisions for voluntary euthanasia in the ACT. That undertaking will benefit from the research and follow-up studies that have been undertaken in those jurisdictions.

The Victorian legislation is admirable in terms of voluntary euthanasia being made available for some deserving people. However, the legislation in Victoria has at least two major shortcomings which must be avoided in provisions that may be made for the ACT:

(a) **The Victorian legislation will preclude voluntary euthanasia from being made available to many people who believe that they have a need for it and a right to it.**

One of the preconditions for accessing provisions for voluntary euthanasia in Victoria is that the person must have a terminal illness. **We believe that having a terminal illness should not be a prerequisite for access to voluntary euthanasia.** For many people this is an inappropriate criterion. Many people may not have a terminal illness, but desire to end their life because of circumstances such as these: they suffer from untreatable chronic pain or ongoing debilitating untreatable ill-health; they have an intolerable medical condition for which medical treatment has failed to be effective; they have crippling disabilities or a medical or personal condition that is intolerable; they are no longer able

to undertake activities that make living worthwhile to them; or for other rational reasons they are simply "tired of life" and wish to end their life.

The Victorian legislation also requires that the person has only 6 months left to live. We understand that time may be set at 12 months. However for many people 12 months will be regarded as being an inordinately short period of time. **We believe that there should be no "time left to live" qualification for access to voluntary euthanasia.**

In contrast to the Victorian qualifications we believe that there should be access to provisions for voluntary euthanasia to be undertaken at a time of a person's own choosing providing that the person meets all these criteria:

- They have fully competent decision-making capacity.
- Their decision to end their life has been made after they have undertaken a full consideration of advice from health care professionals concerning all relevant possible treatments relating to health and well-being.
- Their decision to end their life is one that has been arrived at and declared for a period of time that ensures that the decision is not transitory in nature and is made after full consideration of all end of life options, including palliative care.
- The decision is totally voluntary and not a consequence of coercion.
- They are 18 years or older and have a disease, illness or medical condition for which there is no prospect of improvement and which results in unbearable suffering that cannot be relieved in a manner and to the extent that the person considers tolerable; or they are 70 or more years of age.
- Their normal place of residence is in any Australian jurisdiction.

(b) **The Victorian legislation reflects a "medical model" rather than a model that reflects that decisions about end of life choices should be made by the person her/himself**

The Victorian legislation reflects a "medical model" involving evaluations and decisions about appropriateness, location and timing of voluntary euthanasia being made by medical professionals. **In contrast, we believe that it should be the individual's right to decide how, when and where and in what circumstances they end their life.** Such a decision should be made after consultation with relevant health professionals but not by the health professionals.

5. Any other relevant matter

In any jurisdiction, the provisions for end of life options should reflect the needs of the general adult population, rather than being based on the needs of only people who have an incurable illness and a very short time to live.

If a person wishes to end their life through palliative care, that should be available to them and at a time that meets their needs. However, people who believe that provisions for and procedures during palliative care are inadequate or inappropriate for them should be able to end their life with a **"good death"** via voluntary euthanasia when their quality of life falls to a level that is no longer tolerable to them.

We believe that a “good death” has these qualities:

- The decision about the timing, location and manner of ending life is made by the person concerned after consultation with relevant health professionals.
- The person is able to end their life at a date of their own determination and without regard to length of life expectancy.
- The person can end their life at the date of their choice even if they do not have an “incurable” or “terminal” illness.
- The person can end their life at a location of their choice. That may be in their own home or at a hospital or palliative care facility, or elsewhere as they may decide.
- The person can end their life by taking or being administered a drug that ends life easily, quickly, peacefully, painlessly and without discomfort or distress. Such a drug must be one that has been proven to achieve those outcomes reliably. The drug may be taken by the person or administered by a suitably qualified health worker at the person's request.
- If the person chooses to have assistance or comfort from friends, relatives or other people when they end their life, that should be legal.

Date of preparation: 18 February 2018 (Amended 25 May 2018)

Submitted on behalf of 12 citizens by Michael Thomas Boesen

Email: [REDACTED]

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SUBMISSION TO THE SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

by 12 PEOPLE

The Secretary

Select Committee on End of Life Choices in the ACT Legislative Assembly for the ACT

GPO Box 1020

CANBERRA ACT 2601

Dear Secretary

We would like to make this submission for consideration by the Select Committee. This submission addresses only the fifth of the Committee's Terms of Reference.

5. Any other relevant matter

We are aware of the view held by some people that if provisions enabling voluntary assisted dying are legislated, it would be inappropriate for people suffering from depression to have access to such provisions. The arguments advanced in support of such a restriction are of this nature: there are treatments (e.g. drugs, other medical procedures, counselling, psychiatric treatment) that can be used to cure or to manage depression; and a person with depression lacks "decision-making capacity".

However, we believe that depression can be a consequence of a person having an intolerable quality of life because of other chronic illnesses. For instance, afflictions such as ALS, MS, CFS and various other chronic illnesses may result in an intolerable quality of life and that is the cause of the depression. Treatment for depression amongst people with such health problems may not lead to their quality of life being remediated to an acceptable level.

In addition, for some people with depression, the treatments available may have side effects that in the opinion of the patient, are intolerable and resulting in an unacceptable quality of life.

Our view is that the existence of a condition that has been ascribed as being "depression", or taking drugs that have been developed for treatment of depression should not preclude a person from access to provisions for voluntary assisted dying, providing that:

- the person has consulted appropriate medical practitioners about the probable causes of their depression and options for treatment and has a good understanding about causes and treatments; and
- after giving full consideration to and/or trial of treatment options that are available, the person does not wish to undertake any further treatment for depression; and
- legally, the person has "decision-making capacity".

Submitted on behalf of 12 people by Peter Atcherley

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