

Attention: Principal Research Officer
Joint Select Committee on End of Life Choices
Legislative Assembly, WA Parliament

To the Chair and Members of the Joint Select Committee on End of Life Choices:

**Inquiry into the need for laws in Western Australia
to allow citizens to make informed decisions regarding their own end of life choices**

Submitter: Mary Aerts (private citizen)
23 October 2017

What we need and why

I write in strong endorsement of the need for good laws to allow voluntary assisted dying (VAD), and the right to request medical help to die quickly rather than slowly. All persons should have this choice available to them as they reach the inevitability of death. This is not choosing between life and death, but between different ways of dying.

If I become terminally ill, or develop a condition which would mean futile unbearable suffering or distress with no prospect of improvement, or (for me) if I lose all independence for even the most basic care, then I want the right to choose how and when my life will end.

I want this autonomous voluntary *choice* for my children and grandchildren and for all persons. We can all benefit from such laws, if only by the reassurance that the choice is available should we ever need it.

(I have used the broader term “suffering and distress” rather than just “pain” because, for example, respiratory distress can be more severe than some pain. Consideration also needs to be given those chronic conditions which may make life unbearable, as well as terminal illnesses.)

To have such means of peaceful death readily and legally available (with safeguards) and with a doctor’s assistance where necessary, would prevent many ineffectual attempts (often with severe consequences) and many successful attempts by violent or lonely and secretive means. Such events must be terrible for the person and leave many families distraught and often with a sense of shame.

The present non-availability of legal VAD also results in many cases of shortening of life when persons feel compelled to end their lives while still capable of doing so (but potentially before they really wish to cease life). If VAD with good safeguards and conditions were available, many people may continue to squeeze every sweet moment out of their lives, with confidence that voluntary euthanasia (assisted if necessary) remains an option. To give an example: I understand that a few years ago in WA, a woman with a chronic debilitating disease (who kept a diary shared with, and released by, a journalist after her death) wished to end her life peacefully by means of a suitable drug which she had obtained. Despite increasing distress and incapacity, she was hoping to attend her son’s graduation. She tried to hold out until after this event, but eventually felt she had to use the lethal drug while still able to administer it herself. Had VAD been legally available, she may have felt able to live several months longer and thus attend her son’s graduation.

My personal experience

As far back as I can recall, I have felt that the choice of a reliable and peaceful means to end one's life should be legally available to those who chose to avoid a continuing decline in health and dignity.

My direct observation of the final days of family members has been somewhat limited as most family is overseas. My mother died in recent years from long-term heart failure – suddenly but peacefully, with her care having been well-managed by her GP and, very importantly, according to her wishes.

My professional work has brought me at times into contact with dying patients. I was also aware, albeit back in the 1960s and 1970s (thank goodness we have moved on in our approaches!) of cases of determined withholding by doctors of information requested by a dying person about their condition or prognosis, sometimes due to direction from a spouse. This struck me as obstruction of the patient's rights and self-determination, and a basic lack of respect for the individual.

There was a particular incident some 30 odd years ago involving an elderly family friend suffering terminal cancer which first sharply focused my thoughts around voluntary euthanasia. This was the observation of the transition from her relaxed lucidity and apparent comfort (if with some euphoria induced by pain relief drugs), about a week or two before her death, into the final stage of deterioration and lack of pain control despite best practice hospital palliative care. I knew then that, if it were me, I would want the choice to die peacefully by some form of deliberate ending of life *before* the final stages of distressing deterioration occurred.

I have since then known personally, or known of, elderly people whose life has become so unbearable that they have ended/attempted to end their lives in manners not peaceful and very difficult for their families to watch. Some once-vital persons who led full lives well into very old age, have starved themselves to death over many weeks or have pitifully attempted to do so. VAD with good safeguards would offer other options.

Type of legislative change needed, protections and considerations

The safeguards and conditions to be applied to VAD legislation should be those that are necessary and sufficient without being overly bureaucratic.

Good regulation is that which is broad enough to allow good interpretation for the situation by the responsible professionals to achieve the intent of the law. Full use should be made of the comprehensive reports and resources from interstate and overseas on end-of-life choices and legislative practicalities. We have an opportunity in WA to judiciously select from the overseas and interstate models as we build our own sound model of VAD.

It is essential that VAD is a free choice without coercion, i.e. voluntary, and with information of all alternatives. There must be protection for all persons who do not want VAD. There should be no expectation because of the views of others. We need, importantly, to protect mentally ill persons who may have very treatable conditions.

I would also contend that VAD should be extended beyond just those who are competent at the time of requesting imminent VAD; if a person has lost competency/consciousness, and there is no reasonable likelihood of this being regained, then their wishes in relation to VAD at the last

competency/consciousness should be upheld. Conversely, any wish for VAD must be reversible at any stage by a competent person.

The role of the General Practitioner in particular is vital in applying end-of-life choices, including VAD with adequate safeguards.

Currently some doctors are assisting patients to die without legal protection or scrutiny, and this carries risk for themselves and for the community. Good VAD legislation would afford clarity and legal protection for doctors, and would also provide the right to have family and friends present (if one chooses) without a legal risk to them.

The current legal “double effect” method available to doctors of effectively ending a patient’s life (i.e. increase of certain painkillers to a point which may end a patient’s life without this being the primary intent) is inadequate, unreliable, not transparent, and decided by the doctor and/or family (i.e. not directly “voluntary” on the part of the dying person).

There must be protection for all doctors and other health professionals who do not wish to be involved in VAD for reasons of personal conscience. However, just as it is essential that no person is coerced (by family, health professionals or others) into VAD, it is also essential that no person is denied information on the availability of VAD. Hence doctors who do not wish to be part of VAD must be open about this to their patients and not block information of the availability of this choice. Some doctors may not be specifically against VAD in principle but may not wish to be involved in the administration themselves; they could, and should, refer on those patients who express the wish to explore this option.

I note that the proposed Victoria VAD Bill requires that the request for VAD comes from the patient and that the doctor does not initiate it. I understand that this is an attempt to prevent the doctor from providing any coercion to the patient, and to protect the doctor from any such accusation. However, it is necessary to ensure by some means that all persons are aware of their rights under any VAD laws and feel comfortable with raising the issues if they so desire with their doctor(s). This would need to be implemented by some appropriate means of health education.

There is much false scaremongering about supposed dangers from VAD provisions to persons who do not wish this for themselves. I will simply say here that the experience of countries/states with VAD options already in place (in the USA, Canada, and Europe) should be thoroughly assessed by the Committee, and using data and information which has not been distorted or given misleading interpretation.

However, there do appear to be some genuine fears and concerns, and these need to be addressed; e.g. protection of handicapped persons and endorsement of their value as persons; disabled people should in no way feel they *ought* to euthanase themselves.

In relation to the objection often raised of possible coercion into VAD by family members who are chasing an early inheritance: This would be elder abuse. Addressing *all* forms of elder abuse is urgently needed. Passive neglect can be just as much a form of elder abuse as any coercion to hasten death. Strong in-depth conversation around these very real issues is needed by our community. Respect of our elderly includes allowing full independent protected choices about end-of-life issues, including the availability of VAD.

Some objections to an elderly parent having access to voluntarily-desired VAD appear to me to be simply a denial to face the inevitable loss of a parent by the sons/daughters. The choice (as to

whether VAD or not) should be from the dying person; that is their human right of personal autonomy. Family members and their issues of farewell and grieving are important, but they should be secondary to the rights of the dying person.

Palliative Care

I endorse the availability of best practice palliative care for all who may need and want it, and support provision of adequate funds to achieve this and to further improve and extend the availability in WA. VAD must not be used to thwart the availability of good palliation; rather VAD should be available as an un-coerced option within good palliative care.

However, palliative care is not always able to satisfactorily control suffering and distress or meet the needs of all. Family members who have seen their loved ones helped by palliative care and who have also been greatly assisted themselves as a family at this time, tend to gratefully acknowledge this, but sometimes erroneously assume that their perceived good outcome can apply to all.

End-of-life directives and conversation

I welcome any promotion of the role of Advance Health Directives, Enduring Power of Attorney, and Enduring Power of Guardianship, so that these issues may become the “norm” for people to matter-of-factly address and update with informed decisions throughout their adult lives.

It is important in this context that all persons, particularly older persons but in fact all competent adults over 18, are encouraged to take the responsibilities of self-determination, and to have the continuing conversations with their loved ones about their wishes.

Thank you for the opportunity for discussion about end-of-life issues, voluntary assisted dying options and legal requirements. It has been estimated that most of the population now want some form of VAD as an available choice, so that a robust conversation is to be welcomed.

I urge you to ensure that good legislation for end-of-life choices and voluntary assisted dying (with safeguards) is drawn up and placed before Parliament.

Mary Aerts
23 October 2017