

NTVES POSITION STATEMENT

PRINCIPLES FOR A VOLUNTARY ASSISTED DYING LAW

The VAD laws in all Australian states have been passed with trepidation by well-intentioned MP's who opted to minimise the numbers of people that might choose to exercise the option of VAD. The view seemed to be that success would be demonstrated by how few people used the law to die. The contrary is true.

The driving objective in allowing a citizen access to the means of a tranquil death is to relieve unbearable suffering.

At the end of the day, when all the states and territories permit VAD, the judgement of which has the best law will not be the one with the most restrictive regime, or the most safeguards. It will be the one which has the most liberal, least complicated access for those deemed eligible. It will also prevent anyone who is not eligible from unwillingly or inadvertently gaining access and enshrine the right not to participate without penalty.

The fundamental principle of a law that legislates for voluntary assistance to die is that a person who has intolerable and unrelievable suffering, has a right to request assistance from a doctor to die, and the doctor has the right to provide or decline such assistance.

DEFINITIONS

Terminal illness

- (i) An illness that will, in the normal course and without the application of extraordinary measures, result in the death of the patient.
- (ii) in reasonable medical judgment, there is no medical measure acceptable to the patient that can reasonably be undertaken in the hope of effecting a cure; and
- (iii) any medical treatment reasonably available to the patient is confined to the relief of pain, suffering and/or distress with the object of allowing the patient to die a comfortable death (per NT Rights of the Terminally Ill Act).

Advanced incurable illness (All) is defined as a severe permanent illness with no predictable timeframe to death, which causes persistent intolerable suffering, where

no effective treatment is available and acceptable to the person to alter the course of the illness, or to relieve the suffering.

Intolerable suffering is defined as physical and/or mental suffering that is intolerable to a person. The definition of suffering should contain the words anticipation and expectation (per Tasmania).

Unrelievable suffering is defined as physical and/or mental suffering that is unrelievable by any treatment available and acceptable to the person.

ELIGIBLE PERSONS

There are three categories of person with intolerable and unrelievable suffering who may make a request for assisted dying.

1. Persons diagnosed with a terminal illness (injury or medical condition).
2. Persons with an advanced incurable illness (injury or medical condition).
3. Persons with dementia who have completed an advance directive and appointed an attorney when they are competent.

OTHER CONDITIONS FOR ELIGIBILITY

1. The person is at least 18 years of age.
2. The person is making an informed decision, and has adequate information re diagnosis, prognosis, and treatment available including palliative care, and the implications of their request.
3. Only the person can initiate the request and is assessed to be acting voluntarily without coercion.
4. The person has made a well-considered and repeated request and has not withdrawn the request despite having been advised at each stage of the process that the request can be withdrawn at any time.
5. The person is competent to make end of life decisions for himself/herself.

ADDITIONAL REQUIREMENTS FOR ADVANCED INCURABLE ILLNESS

If the person requesting assistance has an advanced incurable illness, (not terminal), the person must be assessed by a qualified psychiatrist as competent to make an end of life decision considering the conditions causing the person's suffering and treatment options available to relieve their suffering.

ADVANCE DIRECTIVE AND DEMENTIA

There is strong support in the community for a person to be able to request voluntary assisted dying in advance care planning documents, so that assisted dying could take place after the person has lost capacity. Submissions to all state VAD inquiries advocated this be provided for; however no state has accepted the challenge. Our society has long accepted that doctors, in consultation with family members, can lawfully remove life support where no hope of recovery exists, without the patient's consent. One can also give an enduring power of attorney in advance care planning documents to make life critical decisions in the event competence is lost. It is time for legislators to embrace the issue and devise an acceptable regime.

Reference provisions in Canadian legislation where a person with dementia has been found to be eligible for VAD, they can exercise the final consent waiver provision of the Criminal Code and make arrangements for VAD to be provided after they lose decision-making capacity.

AGE

It is understood that minors are currently involved in decisions about consent or refusal of lifesaving medical treatment in Australia.

NTVES believes the concept of 'mature minor' should be developed to allow persons under 18 years old to access VAD where they are otherwise eligible, subject to additional provisions including being 'Gillick competent'. Additionally, provisions might include parental approval and possibly a special tribunal with relevant expertise may be appropriate.

NATURE OF ASSISTANCE TO BE PROVIDED

The nature of the assistance to be provided and who will administer the VAD substance should be negotiated between the person and their doctor.

Wide options for self-administration or doctor administration should be allowed including oral, IV, (including self-activated IV) and PEG.

OTHER ISSUES

NTVES supports elements of what has been termed 'The Australian Model' emanating from the laws passed in all Australian states in the past 5 years.

While each state law differs, there is commonality in areas such as minimum age - 18 years, a terminal diagnosis, acting voluntarily without coercion. Only the patient can apply, assessment by at least two health practitioners, multiple witnesses, and anyone can refuse to participate. An oversight body is established.

We agree all of those provisions are required in a responsible VAD law; however we oppose other provisions such as timeframes to expected death, a final approval permit, and cooling off periods.

We support health practitioners being able to initiate discussion on all end-of-life options. Neither health practitioner should have to be a specialist; however referral is required if there are doubts about diagnosis or prognosis.

Considering the Territory's small population, demography and corresponding small pool of medical professionals, it is recommended that a VAD regime be restricted to Territory residents. This will be of greater importance if the Territory adopts a less restrictive regime than any of the states. If no residential restrictions apply, the potential impact of interstate and international applicants needs consideration.

ATSI CONSIDERATION

NTVES acknowledges that many Territory First Nations people who retain strong attachment to ancient traditional customs and lifestyle are likely to find voluntary assisted dying hard to comprehend, and as a result oppose the concept.

Special consideration needs to be given to an education program to explain that no person has anything to fear from VAD as it can only be initiated by an individual acting voluntarily without coercion.

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NTVES