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The right to death with dignity -A basic human right The experience in Australia **Annmarie Lumsden Director, Northern Territory Legal Aid** Australia

History of legislative reform in Australia



- In Australia's federal legal system the six States and two Territories each have the power to make laws with respect to euthanasia
- In 1995, the Northern Territory was the first jurisdiction in the world to enact legislation allowing voluntary euthanasia (as it was then called)
- Nine months after the *Rights of the Terminally III Act 1995* (NT) commenced operation, the Commonwealth government overturned the Act using its power to make laws with respect to the Territories

History of legislative reform in Australia



- In November 2017 the State of Victoria passed its *Voluntary Assisted Dying Act 2017* (Vic), which became operative after an 18 month implementation period, in June 2019
- This law reform process was led by the government with the personal support of key politicians
- Laws that legalise voluntary assisted dying, or VAD, have been passed in all Australian States. VAD remains illegal in our two Territories - the Northern Territory and the Australian Capital Territory

Nature of Australian VAD laws



- The Australian VAD models are narrow and conservative the eligibility criteria tightly constrain an individual's access to VAD
- In Australia, voluntary assisted dying is the assistance provided by a health practitioner to a person with a terminal illness, disease or medical condition to end their life
- VAD includes both:
 - self-administration, where the person takes VAD medication themselves, and
 - practitioner administration, where the health practitioner administers the VAD medication to the person

Voluntary Assisted Dying Act 2017 (Vic) Eligibility criteria



- To be eligible for VAD the person must:
 - be aged 18 years or more, and
 - be an Australian citizen or permanent resident who has been resident in the State for at least 12 months when they first request VAD
 - have decision-making capacity in relation to voluntary assisted dying, and retain that capacity throughout the process of seeking VAD

Voluntary Assisted Dying Act 2017 (Vic) Eligibility criteria- capacity



- A person has decision-making capacity if they are able to:
 - understand the information relevant to the decision to access VAD and the effect of the decision
 - retain that information
 - use or weigh the information as part of a decision-making process, and
 - communicate their decision in some way, including by speech, gestures or other means
- A person is presumed to have decision-making capacity
- Mental illness does not necessarily mean a person lacks capacity

Voluntary Assisted Dying Act 2017 (Vic) Eligibility criteria- medical condition



- The person must be diagnosed with a disease, illness or medical condition that is:
 - incurable, and
 - advanced and progressive, and
 - is expected to cause death within weeks or months, not exceeding 6 months, or 12 months for neurodegenerative conditions, and
 - is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.
- A person is not eligible only because of mental illness or disability

Voluntary Assisted Dying Act 2017 (Vic) What medical conditions meet criteria



- Analysis of whether the following nine medical conditions can provide an individual with access to VAD:
 - 1. colorectal cancer
 - 2. motor neurone disease
 - 3. chronic obstructive pulmonary disease
 - 4. chronic kidney disease
 - 5. Alzheimer's disease
 - 6. anorexia
 - 7. frailty
 - 8. spinal cord injury, and
 - 9. Huntington's disease

Voluntary Assisted Dying Act 2017 (Vic) What medical conditions meet criteria



Medical conditions which could possibly provide access to VAD in		
Victoria		
Colorectal cancer	Yes, by later stages and once death is expected within 6 months	
Motor neurone disease	Yes, by later stages and once death is expected within 12 months, provided capacity is retained	
Chronic obstructive	Yes, by later stages, provided capacity is retained. Uncertain trajectory may present challenges of prognostication of death expected within	
pulmonary disease	12 months	
Chronic kidney disease	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges of prognostication of death expected within 12 months	

Voluntary Assisted Dying Act 2017 (Vic) What medical conditions meet criteria



Medical conditions for which access to VAD in Victoria is very unlikely

Alzheimer's disease	Very unlikely because it is very unlikely capacity would be retained when death expected within 12 months
Anorexia	No, because a mental illness. Remote possibility for severe cases on basis of a sequelae of prolonged starvation, provided capacity retained
Frailty	No, because no single medical condition will cause death
Spinal cord injury	No, because a disability

Voluntary Assisted Dying Act 2017 (Vic) Safeguards – request and assessment



- The law requires at least three requests from an eligible patient and assessments by at least two medical practitioners the coordinating medial practitioner and the consulting medical practitioner
- The medical practitioners must have completed training approved by the Secretary of the Department of Health and Human Services including on identifying and assessing risk for abuse or coercion
- The consulting medical practitioner must refer the person to a specialist where unable to determine capacity, or whether the medical condition meets the eligibility criteria, and they may adopt the specialist advice

Voluntary Assisted Dying Act 2017 (Vic) Safeguards – request and assessment



- Within 7 days both medical practitioners must record their assessment on a report form and provide it to the Voluntary Assisted Dying Review Board established under the Act
- When assessed as eligible to access VAD, the person must make a written declaration which must be signed by two witnesses and the coordinating medial practitioner
- The coordinating medial practitioner must apply for a selfadministration or a practitioner administration permit, which must be approved by the Secretary of the Department of Health and Human Services

Voluntary Assisted Dying Act 2017 (Vic) Safeguards – additional



- Registered health practitioners cannot initiate a discussion about VAD with a patient. To do so is unprofessional conduct within the meaning of the Health Practitioner Regulation National Law. However, health professionals can provide VAD information if a person requests it
- 2. Strict protocols govern the prescription, dispensing and disposal of VAD medication
- 3. Any unused or remaining VAD medication must be returned to a pharmacist at the dispensing pharmacy

Voluntary Assisted Dying Act 2017 (Vic) Safeguards – additional



- 4. It is an offence for anyone to induce another person to request VAD or to induce self-administration of the VAD medication
- 5. A Voluntary Assisted Dying Review Board provides oversite for the operation of the VAD scheme. Its powers include:
 - reporting to Parliament on the operation of the Act and any recommendations for improvement of the scheme
 - conducting analysis and carrying our research
 - consulting and engaging with community groups and government agencies with an interest in VAD, and
 - providing advice and reports to the relevant Minister and Secretary of the Department about the operation of the Act

Voluntary Assisted Dying Act 2017 (Vic) Access to VAD is challenging



- The complex Victorian VAD law and system make patient access to VAD challenging. Key problems include:
 - doctors are not allowed to raise the topic of VAD with patients
 - the need to obtain a government permit to access VAD, and
 - the complexity of the administrative process when applying for VAD.
- VAD laws and systems must meet intended policy goals of allowing access VAD to people who meet eligibility criteria, and find the balance of patient and community safety without being overly burdensome
- Legislation in Australia has some way to go to achieve this.