

# Voluntary assisted dying

### Findings and recommendations

(Report No. 34)

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

Paper No. 5, 56<sup>th</sup> Parliament, March 2020

### This paper

This paper provides a summary of the findings and recommendations from Report No. 34 on voluntary assisted dying. The report is one of three reports and a volume of additional information from the Inquiry into Aged Care, End-of-Life and Palliative and Voluntary Assisted Dying.





Rockhampton public hearing, 17 July 2019.

### Inquiry terms of reference

On 14 November 2018, the Legislative Assembly referred an inquiry to the committee with the following terms of reference:

- 1. That the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee inquire into aged care, end-of-life and palliative care and report to the Legislative Assembly on:
  - a. the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems; and
  - b. Queensland community and relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.
- 2. That in undertaking the inquiry, the committee should consider:
  - a. in relation to aged care, the terms of reference and submissions made to the Australian
  - b. Government's Royal Commission into the Quality and Safety of Aged Care and, in recognising the Commission will occur in parallel, how to proactively work with the Commission to ensure an appropriate exchange of information to inform the conduct of the inquiry;
  - c. outcomes of recent reviews and work including Queensland Health's Palliative Care Services Review; and
  - d. the current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian Government's Inquiry into end-of-life choices, Voluntary Assisted Dying Act 2017 (Vic) and implementation of the associated reforms.
- That the committee report to the Legislative Assembly by 30 November 2019.

On 22 August 2019, the Legislative Assembly agreed to a motion that the reporting date for the inquiry be extended from 30 November 2019 to 31 March 2020.

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#### Definition of voluntary assisted dying

For the inquiry the committee defined voluntary assisted dying (VAD) as:

The administration by a medical practitioner, or self-administration by the person, of a lethal dose of medication, with that person's informed consent, with the intent of relieving pain and suffering by hastening death.

VAD schemes allow people suffering from a life-limiting illness to choose how and when they die.



### Context for the Inquiry

#### Voluntary assisted dying

People who have a life-limiting illness or who are suffering from a neurodegenerative condition and are seeking relief from prolonged suffering and discomfort, despite palliative care or other support they may be receiving, are currently unable to access VAD in Queensland. Although modern medicine recognises the principle of the autonomy of the patient, the options available to patients under these circumstances are somewhat limited. They include: refusal of medical treatment, refusal of food and/or hydration, palliative sedation and suicide. These options are further constrained by restrictions on what doctors can legally provide to their patients.

Two other Australian states and a number of other countries offer, or are preparing to offer, voluntary assisted dying (VAD) as a further end-of-life choice for people in these circumstances.

As part of its inquiry, the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (the committee) examined Queensland community and relevant health practitioners' views on the desirability of supporting and legislating voluntary assisted dying in Queensland. The committee also considered the necessary safeguards to protect vulnerable persons if a VAD scheme were to be legislated.

The committee's inquiry is the first inquiry into voluntary assisted dying in Queensland.

The committee's inquiry follows recent inquiries into voluntary assisted dying by the Victorian, Western Australian and New Zealand Parliaments. These inquiries have recommended that voluntary assisted dying be legislated with extensive safeguards, eligibility criteria and oversight to ensure protections against misuse.

The Victorian Parliament's Legal and Social Issues Committee recommended in 2016 a legal framework for assisted dying in that state. Victoria's voluntary assisted dying scheme, under their *Voluntary Assisted Dying Act 2017*, commenced in June 2019.

The Western Australian Parliament's Joint Select Committee on End of Life Choices reported in November 2018 with recommendations to establish an expert panel to develop legislation for voluntary assisted dying in that state. The Western Australian Voluntary Assisted Dying Bill was passed by both Houses of the Western Australian Parliament on 10 December 2019.

In April 2019, the New Zealand's Parliament's Justice Committee reported on a private members' Bill, the End of Life Choices Bill, introduced in October 2015. The End of Life Choices Bill was passed by the New Zealand Parliament passed on 13 November 2019.

At their general election in 2020, the New Zealand people will be asked to vote in a referendum on the introduction of voluntary assisted laws.

Outside of Australia and New Zealand, voluntary assisted dying, otherwise known as 'euthanasia' or 'medical assistance in dying', is lawful in a number of other countries including Luxembourg, the Netherlands, Belgium, Canada and in several states of the United States of America.





Brisbane public hearing, 13 September 2019.

#### <u>Inquiry process</u>

The committee undertook a range of activities to raise awareness of the inquiry and to assist groups and individuals contribute their views. These activities included distributing an issues paper, providing information about the inquiry to over 4,000 groups and individuals registered to receive regular email updates about the committee's work, advertising the inquiry and calling for submissions in major newspapers, and further advertising to raise awareness of hearings and forums for the inquiry.

The committee accepted 4,719 written submissions for the inquiry, conducted 34 public and private hearings and briefings for the inquiry and heard evidence from 502 invited witnesses. These included public hearings in regional centres along the state's east coast as well as Mount Isa, Longreach, Mossman and Palm Island. During the inquiry the committee also visited a cross section of residential aged care facilities, hospices and palliative care facilities.

As a case study for the inquiry, the committee resolved in August 2019 to investigate the sudden closure of the Earle Haven residential aged care facility at Nerang, and the standard of care provided to former residents at the facility. The committee held an additional seven hearings and briefings for the investigation, with 33 further witnesses appearing, and accepted ten further submissions.

### 41 hearings - 535 witnesses - 4,729 submissions





#### Recommendations

The following recommendations were agreed by the majority of the committee. For further information please refer to comments by committee members in the full report.

#### 1. Willmott and White draft legislation

The committee recommends the Queensland Government use the well-considered draft legislation submitted to the inquiry by Professors Lindy Willmott and Ben White as the basis for a legislative scheme for voluntary assisted dying.

#### 2. Limit eligibility to over 18s

The committee recommends that any voluntary assisted dying scheme in Queensland limits eligibility to adults aged 18 years or older.

# 3. Limit eligibility to Australian citizens ordinarily residing in Queensland

The committee recommends that any voluntary assisted dying scheme in Queensland limits eligibility to Australian citizens or permanent residents ordinarily resident in Queensland.

#### 4. Eligibility linked to diagnosis

The committee recommends that any voluntary assisted dying scheme in Queensland requires that, to be eligible to access voluntary assisted dying, a person must be diagnosed by a medical practitioner as having an advanced and progressive terminal, chronic or neurodegenerative medical condition that cannot be alleviated in a manner acceptable to the person, and that the condition will cause death.

# 5. No precise timeframes for a person's anticipated death

The committee recommends that any voluntary assisted dying scheme in Queensland should not propose precise timeframes for a person's anticipated date of death within which voluntary assisted dying may be accessed due to the complex, subjective and unpredictable nature of the prognosis of terminal illness.

#### 6. Eligibility limited to people with decisionmaking capacity

The committee recommends that any voluntary assisted dying scheme in Queensland limits eligibility to people with decision-making capacity.

# 7. Research into improving options for people who do not have decision-making capacity

The committee recommends that any voluntary assisted dying scheme in Queensland requires further research, consultation and examination to be undertaken with respect to improving end of life options for people who do not have decision-making capacity, particularly in relation to ensuring Advance Health Directives are fit for purpose and effective.

## 8. Assessments, qualifications, medications and protections from liability

The committee recommends that any voluntary assisted dying scheme in Queensland includes: controls on the qualifications required for participating practitioners; the requirement that two independent medical practitioners assess any person wishing to access voluntary assisted dying; rigorous governance of systems for prescribing, dispensing and disposing of any voluntary assisted dying medications; protections from liability for practitioners and patients participating in the scheme; and thorough documentation and reporting requirements.

#### 9. Education campaigns

The committee recommends that any voluntary assisted dying scheme in Queensland includes comprehensive education campaigns to inform health practitioners and the general public about the scheme, its eligibility requirements and the rights and responsibilities of health practitioners.

#### 10. Eligibility for people with mental illness

The committee recommends that any voluntary assisted dying scheme in Queensland provides that a person who is otherwise eligible to access the scheme not be rendered ineligible only because the person has a mental health condition, provided that the person has decision-making capacity.



#### 11. Medications not be specified

The committee recommends that any voluntary assisted dying scheme in Queensland does not limit or prescribe the medications that may be used for voluntary assisted dying.

# <u>12. Self-administration of substance or</u> administration by a practitioner

The committee recommends that any voluntary assisted dying scheme in Queensland stipulates that the coordinating practitioner may determine whether self-administration of the substance or administration by the practitioner is the method best suited to the patient.

#### 13. Insurance implications of VAD

The committee recommends that safeguards should be included in any voluntary assisted dying scheme in Queensland to ensure that participation in voluntary assisted dying does not nullify life insurance, funeral or health insurance held by a person accessing voluntary assisted dying.

#### 14. Counselling should not be mandatory

The committee recommends that any voluntary assisted dying scheme in Queensland does not require that every person seeking access to voluntary assisted dying receives counselling as a condition of their eligibility.

### 15. Assessment of applicants where doctors are not available

The committee recommends that the Minister should consider including flexibility in any voluntary assisted dying scheme in Queensland for applicants in rural and remote areas of Queensland where a doctor or second doctor are not available, to permit a registered nurse who meets the training and other requirements to participate in the scheme to assess an applicant for voluntary assisted dying and to administer the voluntary assisted dying medication.

# 16. Discussion to be instigated by the person wishing to access VAD

The committee recommends that any voluntary assisted dying scheme in Queensland stipulates that

discussion with a medical practitioner about accessing voluntary assisted dying can be instigated only by the person wishing to access voluntary assisted dying.

### 17. Conscientious objection rights for medical practitioners

The committee recommends that any voluntary assisted dying scheme in Queensland provides health practitioners who may have a conscientious objection to participating in voluntary assisted dying to opt not to participate, provided that the rights of the patients to access the scheme are also protected.

## 18. Accessibility of VAD where available doctors conscientiously object

The committee recommends that any voluntary assisted dying scheme in Queensland ensures that voluntary assisted dying is genuinely accessible to people with a life-limiting condition whose local doctor has a conscientious objection to voluntary assisted dying.

## 19. Establishment of a review body to oversight the scheme

The committee recommends that any voluntary assisted dying scheme in Queensland provides for the establishment of a review body similar to the Victorian Voluntary Assisted Dying Review Board to provide oversight of the scheme.

#### 20. Mandatory training of practitioners

The committee recommends that any voluntary assisted dying scheme in Queensland requires that health practitioners involved in administering or conducting assessments for voluntary assisted dying complete mandatory training developed by the Department of Health in conjunction with peak health professional bodies.

#### 21. Review of the scheme after 3 years

The committee recommends that any voluntary assisted dying scheme in Queensland includes a requirement that the scheme be reviewed within three years from the date of proclamation to ensure the legislation is effective and working appropriately.



### Summary of findings

## <u>Suicides in Queensland linked to terminal</u> and debilitating illness

Tragically, on average around once every four days, someone suffering from a terminal or debilitating condition suicides in Queensland. It remains an option of last resort for people to bring on the end of their lives. Most (62%) of these suicide victims are aged over 60 and almost three quarters (72%) are males.

Data compiled for the committee from the National Coronial Information System for the period 1 January 2016 to 31 December 2017 identified 168 notifications of death to a Queensland coroner where the deceased died as a result of intentional self-harm and suffered from a terminal or debilitating physical condition.

These suicide deaths are extremely tragic and shocking for the victims, the loved ones left behind, and for the first responders. The committee extends its sympathies to those who have been touched by these suicides.

#### <u>Community Views in support of Voluntary</u> Assisted Dying

Views on VAD across Queensland are diverse and polarised.

Of the submissions received from organisations and individuals in support of the introduction of VAD legislation, the most common reasons cited (in order of frequency from highest to lowest) were:

- individual choice and the right to selfdetermination at the end of life
- VAD is necessary for the relief of pain and suffering that cannot be relieved by palliative care
- VAD would provide dignity for the patient and less distress for their loved ones
- the morals of others should not prohibit access to VAD for those who seek it
- the current regulatory framework is not working.

The views of those submitters, reinforced by witnesses at the committee's hearings, expressed a strong desire for people to be able to exercise choice about the timing and manner of their death.

A significant number of inquiry participants supported VAD on the basis of personal autonomy or a person's right to choose how they died. Stakeholders also raised concerns that unbearable pain and suffering were not alleviated in some people at the end-of-their lives, and provided evidence about the loss of dignity during dying and the impact of seeing loved ones dying without dignity.

Many argued that the personal beliefs of those in the community who oppose VAD should not impinge on the rights of others who support it being legislated.

If there is a choice between a death accompanied by prolonged suffering and a death that is without such suffering, it appears from the submissions and other evidence presented to the committee that most Queenslanders would choose the latter.

Submitters also argued the current legal end-of-life choices are not meeting the needs of the terminally ill. In their evidence, submitters commented on:

- suicides involving the terminally ill
- people refusing food and hydration to hasten their death
- people travelling overseas to access VAD, and
- the possibility that doctors may already be providing VAD in an unregulated way without the patient's consent.

#### <u>Community Views opposed to Voluntary</u> Assisted Dying

For submitters who oppose VAD, the key reasons in order of frequency were:

- the sanctity of life should be respected/VAD contradicts religious beliefs
- the risk of coercion of vulnerable people, or that safeguards in the legislation would not





be sufficient to ensure all assisted deaths were voluntary

- introducing VAD would lead to a slippery slope enabling expanded eligibility or nonvoluntary euthanasia
- access to effective palliative care makes the need for VAD obsolete
- it would pose ethical problems for health professionals who may be required to administer VAD
- VAD sends the wrong message to people contemplating suicide.

A key argument presented in evidence to the committee for not supporting VAD is the inherent sanctity of life, and that VAD conflicts with religious beliefs about that sanctity at the most fundamental level.

Faith groups spoke passionately on these points in their submissions and other evidence to the committee. They argued the intrinsic worth of human life and their beliefs that death is a matter for God, and only God, and that any attempt to interfere in that process is immoral and an expression of defiance toward God.

A number of submitters contended that vulnerable people at the end of their life cannot be adequately protected from coercion by legislated safeguards and that, as a result, some VAD deaths would not be voluntary.

Many stakeholders who opposed VAD cited the slippery slope argument as a reason for not introducing VAD in Queensland. The slippery slope argument is, that once introduced, restrictions on VAD would eventually ease and eligibility would be expanded. Proponents of the argument also claim that expansion of VAD regimes leads to abuse and involuntary euthanasia. Stakeholders also highlighted the importance of addressing shortcomings in the delivery and resourcing of palliative care before VAD is introduced. Problems with the delivery of palliative care in Queensland and options to address these problems are discussed in the committee's Report No. 33 from this inquiry.

Others raised concerns about ethical problems for health professionals who may be required to administer VAD.

Stakeholders were also concerned that allowing VAD would send the wrong message to people contemplating suicide.

#### The views of health practitioners

A range of health practitioners provided evidence to the inquiry, including doctors, nurses, and personal care workers. Health practitioners were split on the desirability of introducing VAD legislation in Queensland.

Professional medical organisations differed in their stance on the issue of VAD. Some organisations representing health practitioners did not take a single position on VAD due to the diversity of views of their membership while others took a stance against legislating for VAD.

There were strong and, at times, polarised views shared by health practitioners who participated in the inquiry. Practitioners who expressed support for VAD cited a range of arguments for its introduction:

- the limits of palliative and end-of-life care to address pain and suffering
- the need for a more humane option at the end of life
- the need for people to have choice and autonomy at the end of their lives
- concerns about the legalities of palliative sedation and the under-treatment of patients
- the impact of pain and suffering experienced by the dying and terminally ill on their loved ones.

Medical practitioners opposed to VAD cited a range of arguments including:

- the greater benefits of palliative care
- concerns that VAD will interfere with doctorpatient relationships and may discourage patients from seeking medical treatment for lifeshortening illnesses



- risks that patients may seek to access VAD because of fear of dying and suffering rather than actual pain and suffering
- the potential for the scheme to be broadened in future (the slippery slope argument)
- impacts on vulnerable people and risks of VAD schemes being abused
- impacts on families and loved ones, and
- conflicts with messages of suicide prevention
- fundamental legal, philosophical and moral concerns.

#### <u>The committee's assessment of</u> <u>Queensland community and health</u> practitioners views on VAD

The committee found on balance, both the Queensland community and health practitioners were supportive of legislating for voluntary assisted dying in Queensland.

In regard to arguments raised against introducing VAD in Queensland, the committee found:

- people opposed to participating in VAD because of religious or other beliefs would have the choice to not access VAD which would be voluntary
- concerns raised about protections for vulnerable individuals can be addressed through safeguards and eligibility requirements, as has been demonstrated in other VAD schemes
- the view expressed by some faith groups about the spiritual benefits from suffering at the endof-life are not universally accepted, even within particular denominations, even within particular denominations
- there is no clear evidence that legalisation of assisted dying results in an inevitable move toward the erosion of safeguards and an increase of non-voluntary euthanasia, and
- temporary suicidal ideation is quite distinct from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.

#### Palliative care and voluntary assisted dying

Health practitioners and other inquiry stakeholders argued that palliative and end-of-life care services in Queensland need to be improved, and not devalued at the expense of voluntary assisted dying services. The committee agreed that palliative care needs to be adequately resourced and supported irrespective of whether VAD legislation is introduced.

Recommendations on palliative and end-of-life care are discussed in the committee's report for this inquiry, Report No. 33.

### Eligibility for a voluntary assisted dying scheme

In Australia and overseas, access to VAD is determined by a range of eligibility criteria, which reflect the need to balance appropriate safeguards with the accessibility of the scheme for those who are suffering.

Eligibility to access VAD can be grouped into the following four main categories:

- the age of the person seeking VAD
- the citizenship and residency status of that person
- the condition of the person
- the person's capacity for medical decision making.

The committee found although VAD is accessible to a limited number of children in some overseas countries, if legislation for VAD were introduced in Queensland, eligibility should be restricted to people 18 years of age or older.

In addition, eligibility should be restricted to citizens and permanent residents of Australia who are ordinarily resident in Queensland. The Victorian legislation and Western Australian legislation require a person to have been living in their respective states for at least 12 months at the time of their first request. However, a 12 month waiting period could exclude people with a rapidly progressive disease. The term 'ordinarily resident' should not be restricted.







In both the Victorian and Western Australian legislation, eligibility is restricted based on the condition of the person wishing to access VAD. While particular conditions are not specified, the illness or medical condition must have been assessed by a medical practitioner as likely to be the foreseeable cause of death in the following six months, or 12 months for a neurodegenerative condition. During the inquiry, evidence from health practitioners highlighted the practical difficulties in obtaining a prognosis and timeframe of progression of some medical conditions, such as motor neurone disease. The committee found that eligibility criteria should not prescribe specific timeframes within which death is likely to occur.

The committee found that in most jurisdictions, eligibility to access VAD is restricted to persons suffering from a life-limiting illness.

In relation to capacity, most jurisdictions require that a patient has decision-making capacity to consent to VAD. Opinion was divided on whether a person should be able to stipulate their wishes to access VAD in an Advance Health Directive, which can be acted upon if that person loses capacity. This complex issue requires further consideration as any decision to administer VAD must balances people's wishes with the need to ensure robust protections for vulnerable individuals and the medical practitioners who are providing VAD services.

#### Further safeguards for a voluntary assisted dying scheme

In the committee's view, the protection of vulnerable people from coercion is a critical issue for the design of any voluntary assisted dying scheme for Queensland. In addition to eligibility criteria for accessing VAD, further safeguards are required to protect vulnerable people.

A patient's access to voluntary assisted dying should be assessed at several stages through the process. A staged approach ensures that the patient's decisionmaking capacity is enduring.

If voluntary assisted dying is legislated in Queensland, it should include the following safeguards against coercion:

- strict controls on the qualifications required for participating practitioners
- the requirement that two independent medical practitioners conduct assessments prior to the applicant accessing the scheme
- rigorous governance for systems for prescribing, dispensing and disposing of voluntary assisted dying substances, and
- transparent review mechanism protections for liability for scheme participants.

should also require thorough Any scheme documentation and reporting at all stages of the assisted voluntary dying process and comprehensive education campaign for medical practitioners and the public.

The committee found that doctors should be prohibited from initiating discussions about VAD with their patients.

It is appropriate and prudent to require two practitioners to determine a patient's eligibility for voluntary assisted dying. To overcome the difficulty of access to two independent doctors in a rural or remote area, legislation for a voluntary assisted dying scheme in Queensland should allow flexibility such that a qualified nurse can undertake the assessment of applicants in rural and remote areas where a doctor or second independent doctor is not available to undertake the assessment and to administer the voluntary assisted dying medication if required. This would help to ensure people wishing to access voluntary assisted dying in rural and remote areas are not unfairly discriminated against.

The committee does not support the need to prescribe the specific substance to be administered as part of a voluntary assisted dying scheme in Queensland.

The committee concluded that there should be scope for the coordinating practitioner to determine whether self-administration of the substance or administration by the practitioner is the method best suited to the patient.

The committee found people should not be automatically excluded from VAD simply because they have been diagnosed as having a mental illness. Similarly, people with a mental illness diagnosis





should not automatically be considered eligible for VAD because of their illness. Their eligibility to access VAD needs to be considered on the same basis as anyone else seeking to access VAD.

The committee does not support the need to require that applicants seeking to access voluntary assisted dying must receive counselling to access the scheme. Counselling and support should, however, be available to anyone who requests it. The committee also notes the importance of bereavement counselling for loved ones of people accessing voluntary assisted dying.

It is important for protecting the financial interests of those accessing VAD that, any scheme legislated in Queensland include safeguards to ensure that participation in VAD does not nullify life insurance, funeral or health insurance held in the name of the person participating in VAD.

The committee supports the need for mandatory training approved by the government for practitioners and others to participate in a voluntary assisted dying scheme for Queensland.

There was strong support from stakeholders to ensure that medical practitioners would not be forced to participate in the VAD process. However the committee acknowledged this may cause practical difficulties due to the limited availability of practitioners in remote communities.

If VAD were legislated in Queensland, it would be imperative that the legislation ensured that VAD was genuinely accessible for ill people with a life-limiting illness regardless of their location and whether their local doctor conscientiously objects to participating in VAD.

# Implementation of a voluntary assisted dying scheme

The committee agrees that a review body similar to the Victorian Voluntary Assisted Dying Review Board should be established to oversight any voluntary assisted dying scheme for Queensland.

An implementation time period of up to 18 months may be required to set up any VAD scheme.

If VAD were legislated in Queensland, the implementation of the Victorian and Western Australian VAD schemes provide a basis for development of materials needed to guide both community members and medical practitioners for any Queensland VAD scheme.





Bundaberg public hearing, 16 July 2019.

The committee thanks all Queenslanders who attended its hearings and forums for the inquiry, and the hundreds of groups and individuals who came forward to share their views on voluntary assisted dying.

#### The committee



Aaron Harper MP (Chair)
Member for Thuringowa
(ALP)



Mark McArdle MP (Deputy Chair) Member for Caloundra (LNP)



Michael Berkman MP Member for Maiwar (GRN)



Marty Hunt MP
Member for Nicklin
(LNP)



Barry O'Rourke MP Member for Rockhampton (ALP)



Joan Pease MP Member for Lytton (ALP)

The Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee is a portfolio committee of the Legislative Assembly responsible for:

- Health and Ambulance Services
- Communities, Women, Youth and Child Safety
- Domestic and Family Violence Prevention, and
- Disability Services and
- Seniors.

### **Further information**

The reports, submissions to the inquiry, transcripts of hearings and briefings, tabled documents and other information published by the committee from the inquiry, are available from the inquiry page on the Parliament of Queensland website. Alternatively contact the committee's secretariat:

Email: health@parliament.qld.gov.au

Phone: 07 3553 6632 or 1800 504 022.

Website: www.parliament.qld.gov.au/health