



# Voluntary assisted dying

**Report No. 34, 56<sup>th</sup> Parliament**  
**Health, Communities, Disability Services and**  
**Domestic and Family Violence Prevention Committee**  
**March 2020**

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

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### **Acknowledgements**

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## Abbreviations

AHD	Advance health directive
AHPRA	Australian Health Practitioner Regulation Agency
AMA	Australian Medical Association
AMAQ	Australian Medical Association Queensland
ANZSGM	Australian & New Zealand Society for Geriatric Medicine
ANZSPM	Australian and New Zealand Society of Palliative Medicine
APS	Australian Psychological Society
Belgian Act	<i>Loi du 28 mai 2002 relative à l'euthanasie.</i>
CHA	Catholic Health Australia
Committee	Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
DFADC	Doctors for Assisted Dying Choice
Dutch Act	<i>Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Wet van 12 April 2001, Staatsblad 2001, 194</i>
DWDQ	Dying with Dignity Queensland
DWDV	Dying with Dignity Victoria
EPAS	Euthanasia and physician assisted suicide
Inquiry	Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying
LSIC	Legal and Social Issues Committee (Victorian Legislative Council)
Luxembourg Act	<i>The Law of 16 March 2009 on euthanasia and assisted suicide</i>
MAID	Medical Assistance in Dying (Canada)
MND	Motor neurone disease
OHO	Office of the Health Ombudsman
NCIS	National Coronial Information System



NT	Northern Territory
Panel	Ministerial Expert Panel (Western Australia)
POQA	<i>Parliament of Queensland Act 2001</i>
Powers of Attorney Act	<i>Powers of Attorney Act 1998</i> (Qld)
QCAT	Queensland Civil and Administrative Tribunal
QNMU	Queensland Nurses and Midwives Union
RACGP	Royal Australian College of General Practitioners
RACP	Royal Australasian College of Physicians
RANZCP QLD Branch	Royal Australasian College of Psychiatrists – Queensland Branch
ROTI Act	<i>Rights of the Terminally Ill Act 1995</i> (NT)
SDM	substitute decision maker
VAD	voluntary assisted dying
WA VAD Act	<i>Voluntary Assisted Dying Act 2019</i> (WA)
Victorian Review Board	Voluntary Assisted Dying Review Board (Victoria)
Victorian VAD Act	<i>Voluntary Assisted Dying Act 2017</i> (Vic)
VPS	voluntary palliated starvation
VSED	voluntarily stopping eating and drinking
WA	Western Australia
WA VAD Bill	Western Australia Voluntary Assisted Dying Bill 2019
WA VAD Board	Western Australia Voluntary Assisted Dying Board
White and Willmott Bill	VAD Bill written by Professors Ben White and Lindy Willmott

## Glossary

Advance health directive	A formal way to give instructions about a person's future health care, which comes into effect only if the person's cognitive health deteriorates and the person become unable to make their own decisions (i.e. lose capacity to make decisions).
Capacity	A person's ability to: understand the nature and effect of decisions; freely and voluntarily make decisions; and communicate those decisions in some way.
Coercion	The compelling or forcing of a person to do, or refrain from doing, something.
End-of-life care	Care provided to a patient with a life-limiting illness during the last stages of life.
Euthanasia	The act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering.
Futile medical treatment	Treatment that no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate.
Neurodegenerative	Resulting in, or characterised by, degeneration of the nervous system, especially the neurons in the brain. For example, Parkinson's disease, motor neurone disease or Alzheimer's disease.
Palliative care	Healthcare that focuses on improving the quality of life and quality of care for people with a life limiting illness, and their families. It includes the prevention and relief of suffering, communication about goals of care, and the early identification, assessment and treatment of physical, psychological, emotional, social and spiritual symptoms.
Palliative sedation (terminal sedation)	The use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.
Slippery slope argument	If VAD laws were introduced, restrictions would eventually ease and eligibility would be expanded. Once the expansion happens the system would be more open to abuse and lead to non-voluntary euthanasia.
Voluntary assisted dying	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.

## Chair's foreword

As Chair of the Health Committee tasked with seeking Queensland's view on the desirability of a voluntary assisted dying scheme in our state, I give my heartfelt thanks to all of the thousands of people who participated in the inquiry.

The Inquiry we undertook was extensive. It included inquiring into the delivery of aged care, end-of-life and palliative care, which we have reported on separately. The decision to table the reports separately was made because of the importance and gravity of each of the topics.

This report is historic. No Bill for voluntary assisted dying has ever been introduced in the Queensland Parliament nor has any parliamentary committee inquired into its desirability. Our parliament can now consider and debate whether to legislate for a voluntary assisted dying scheme in Queensland based upon the recommendations in this report.

I would like to state upfront that this report reflects the views of the majority of Queenslanders who came before us, made thousands of submissions and often at times brought committee members to tears, reflecting the deeply personal, tragic stories of seeing loved ones suffer at end of life.

We also heard divergent views from those who oppose voluntarily assisted dying, and their reasons have been reflected in this report. We respect their views and thank them for sharing their concerns.

However, the majority of the committee voted to recommend a legislative scheme for voluntary assisted dying in Queensland.

Our committee received nearly 5,000 submissions, and had hundreds of people attend and express their views at 41 public hearing across the state. Many sought individual choice raised the need for individual choice for people at the end of their lives.

Many also raised the matter of capacity. Losing decision making capacity affects a person's right to have their wishes followed at end of life. This is why the committee has included a recommendation for more work to be done in relation to capacity and the legal framework that governs it, particularly Advance Health Directives.

As a former Paramedic, I know first-hand the difficulties faced by first responders when attending suicides. I understand the effects of suicide on families and loved ones. These are tragic and deeply upsetting situations.

We received information that every four days in Queensland, a person suffering a terminal illness takes their own life. This must stop. In my view, suicide should never be the only option for Queenslanders suffering at end of life.

I thank and acknowledge those submitters and witnesses who provided information and reflected on those suicides. This is just one of the many reasons the majority of our committee chose to support a recommendation for more choice for people suffering from an advanced progressive or neurodegenerative condition, through access to a voluntary assisted dying scheme.

There are so many people who came forward and shared their stories, from family members, carers, nurses, paramedics and doctors, those who provide such love and support through spiritual support, to medical groups and organisations the committee has reflected all views in this report. Words simply cannot express my thanks for their valued contributions. We finished this work better informed and filled with nothing but admiration for those who shared their stories.

I also thank Dying With Dignity and the Clem Jones Trust for their work to encourage informed public debate of voluntary assisted dying in Queensland.

Many stakeholders expressed views on potential safeguards that should apply to any model of voluntary assisted dying introduced in Queensland, and the committee made recommendations for a comprehensive set of safeguards to prevent coercion and protect vulnerable people.

The assistance provided by Professors Ben White and Lindy Wilmot warrants special acknowledgement. Their depth of knowledge and ability to assist the committee with international experts in countries where voluntary assisted dying has existed for years was of great benefit to the committee during its inquiry. The drafting of their sample Bill and explanatory notes is exemplary and, therefore, the first recommendation in this report is to introduce legislation for a voluntary assisted dying scheme in Queensland based on this sample Bill. The assistance of the professors was certainly deeply appreciated by the committee.

As Chair I would like to thank my fellow Members for the way they have worked together over the past 15 months. I would also like to thank and acknowledge other members who participated: Mr Jim McDonald MP, Member for Lockyer; Mr Sam O'Connor MP, Member for Bonney; and Ms Julieanne Gilbert MP, Member for Mackay, who substituted for committee members when they were unable to attend hearings. I also thank other members who attended the committee's hearings: Mr Chris Whiting MP, Member for Bancroft; Mr Trevor Watts MP, Member for Toowoomba North; Mr Michael Healy MP, Member for Cairns; Mr Scott Stewart MP, Member for Townsville; Mr Ted Sorensen MP, Member for Hervey Bay; Mr Stephen Bennett MP, Member for Burnett; Mr David Batt MP, Member for Bundaberg; Ms Brittany Lauga MP, Member for Keppel; Ms Jen Howard MP, Member for Ipswich; Mrs Charis Mullen MP, Member for Jordan; Mr Ray Stevens MP, Member for Mermaid Beach; Mr John-Paul Langbroek MP, Member for Surfers Paradise; Ms Meaghan Scanlon MP, Member for Gaven; and Mr Linus Power MP, Member for Logan.

I also acknowledge the work and support provided by the committee's secretariat and other staff within the Committee Office, the Parliamentary Reporters and the Parliamentary Library.

I commend the report to the House.



Aaron Harper MP  
**Chair**

## Recommendations

### **Recommendation 1** **105**

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.

### **Recommendation 2** **117**

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

### **Recommendation 3** **118**

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

### **Recommendation 4** **120**

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.

### **Recommendation 5** **120**

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.

### **Recommendation 6** **127**

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

### **Recommendation 7** **127**

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.

### **Recommendation 8** **132**

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.

### **Recommendation 9** **132**

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.

**Recommendation 10** **133**

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.

**Recommendation 11** **135**

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.

**Recommendation 12** **136**

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.

**Recommendation 13** **137**

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.

**Recommendation 14** **138**

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.

**Recommendation 15** **140**

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.

**Recommendation 16** **141**

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.

**Recommendation 17** **144**

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.

**Recommendation 18** **144**

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.

**Recommendation 19** **145**

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.

**Recommendation 20**

**146**

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.

**Recommendation 21**

**147**

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.

## 1 Introduction

### 1.1 This report

This report is one of three reports and a volume of additional information from the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee's (the committee's) Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying (the inquiry).

This report presents the committee's findings on aspects of the inquiry terms of reference that relate to voluntary assisted dying. The other publications from this inquiry are:

- *Report No. 30: Investigation of the closure of the Earle Haven residential aged care facility at Nerang*, tabled on 28 November 2019
- *Report No. 33: Aged Care, End-of-Life and Palliative Care*, and
- *Volume of additional Information* tabled with this report. This volume lists: the submitters to the inquiry; the briefing officers and witnesses who gave evidence at the committee's briefings and hearings for the inquiry; tabled documents; information provided in response to the committee's questions taken on notice at briefings and hearings; and the details of the committee's advertising and other activities to inform stakeholders for the inquiry.

### 1.2 Role of the committee

The committee is a portfolio committee of the Legislative Assembly which commenced on 15 February 2018 under the *Parliament of Queensland Act 2001* (POQA) and the Standing Rules and Orders of the Legislative Assembly.<sup>1</sup>

The committee's primary areas of responsibility are:

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

Section 92 of the POQA provides that, in addition to performing a general legislative scrutiny and parliamentary oversight role in relation to its primary areas of responsibility, a portfolio committee is responsible for dealing with any issue referred to it by the Legislative Assembly or under another Act.<sup>2</sup>

Section 93(2) of the POQA provides that a portfolio committee is to deal with an issue referred to it by the Assembly or under another Act, whether or not the issue is within its portfolio area.

Further information about the committee can be found on its [webpage](#).<sup>3</sup>

### 1.3 Inquiry referral and process

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

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<sup>1</sup> *Parliament of Queensland Act 2001*, section 88 and Standing Order 194.

<sup>2</sup> *Parliament of Queensland Act 2001*, section 92(2).

<sup>3</sup> Queensland Parliament, Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, <https://www.parliament.qld.gov.au/work-of-committees/committees/HCDSDFVPC>.



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 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;
  - b. outcomes of recent reviews and work including Queensland Health's Palliative Care Services Review; and
  - c. 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.
3. That the committee report to the Legislative Assembly by 30 November 2019.<sup>4</sup>

On 17 July 2019, the committee resolved to undertake an investigation into the sudden closure of the Earle Haven residential aged care facility at Nerang. This investigation was undertaken as part of the inquiry, but with a separate submissions process and hearings. The committee made 12 recommendations from that investigation for the Federal Government and the Queensland Government to implement. Further details can be found in the committee's Report No. 30, 56th Parliament: *Investigation of the closure of the Earle Haven residential aged care facility at Nerang (Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying)*.

On 22 August 2019, the Legislative Assembly agreed to extend the committee's reporting date for the inquiry from 30 November 2019 to 31 March 2020.

#### **1.4 Public awareness campaign**

The committee undertook a range of activities to raise awareness of the inquiry and to assist groups and individuals contribute their views.

On 14 February 2019, the committee published an issues paper for the inquiry<sup>5</sup> outlining the issues it would consider and the process for providing a submission.

Copies of the issues paper were distributed to Queensland public and private hospitals, residential aged care facilities, Members of Parliament and other stakeholders for aged care, health, communities, law and government.

The committee also provided information about the inquiry to over 4,000 groups and individuals registered to receive regular email updates about the committee's work.

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<sup>4</sup> Legislative Assembly, 2018, *Record of Proceedings*, 14 November, p 3477.

<sup>5</sup> Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 2019, *Paper No. 3, 56th Parliament, February 2019—Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying*.

The committee advertised the inquiry and call for submissions in major newspapers in February 2019. The committee placed further advertising to raise awareness of each of the public hearings and forums for the inquiry.

The details of the committee advertising and other work to raise awareness of the inquiry are included in the volume of additional information tabled with this report.

### **1.5 Submissions**

The committee announced the call for submissions on 14 February with a closing date of 15 April 2019. The committee continued to accept late submissions after the closing date.

In total, the committee accepted 4,719 written submissions for the inquiry. A list of submitters can be found in the volume of additional information tabled with this report and on the committee's website.

### **1.6 Briefings and hearings**

The committee conducted 34 public and private hearings and briefings for the inquiry, and heard evidence from 502 invited witnesses. These included public hearings across regional centres along the east coast of Queensland as well as Mount Isa, Longreach, Mossman and Palm Island.

The committee held an additional seven hearings and briefings for the Earle Haven investigation, with 33 further witnesses appearing.

A list of hearings, briefings and witnesses is provided in the volume of additional information tabled with this report.

### **1.7 Inspections**

The committee visited a cross section of residential aged care facilities, hospices and palliative care facilities during the inquiry. A list of these inspections is included in the volume of additional information for the inquiry.

## 2 Options for people with a life-limiting illness

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. These options include:

- **refusal of medical treatment** - It is a general principle of law and medical practice that people may refuse medical treatment.<sup>6</sup>
- **refusal of food and/or hydration** - An adult with capacity may refuse both artificial nutrition and hydration (for example, nutrition given through a tube into the person's stomach) and ordinary food and drink, and receive palliative care to relieve any suffering she or he experiences from dying due to a lack of food (nutrition) and water (hydration).<sup>7</sup>
- **palliative sedation** - Sedative medications may be used to relieve intolerable and refractory distress by the reduction in patient consciousness.<sup>8</sup>
- **suicide** - Attempted suicide is not a crime in Queensland;<sup>9</sup> although, it is unlawful for a person to aid or counsel another person to kill himself or herself.<sup>10</sup>

These options are further constrained by restrictions on what doctors can legally provide to their patients. Chapter 23 of Report No 33 from this inquiry examines the legal status of the refusal of medical treatment, the refusal of food and/or hydration and palliative sedation as part of end-of-life care. The following sections discuss suicide, which is not part of end-of-life care and remains an option where VAD is not available.

### 2.1 The law on suicide in Queensland

Attempted suicide ceased to be a crime in Queensland in 1979. However, aiding or counselling another person to kill himself or herself remains unlawful under Queensland's *Criminal Code Act 1899*.<sup>11</sup> A person convicted of that crime is liable to imprisonment for life.<sup>12</sup> As VAD is not available in Queensland, health professionals, family members and loved ones are legally unable to assist a person to end their life despite many instances where people have begged them for help.

### 2.2 People have ended their lives because of a life-limiting or debilitating illness

Some submitters to the inquiry described decisions by their loved ones to take their own lives. Ms Amy Nankivell described the death of her mother, who took her own life after suffering from multiple sclerosis:

*...my mum was forced to take her own life on 28/12/2011. She was suffering from a very aggressive form of MS. She had very little quality of life left, and was only a matter of days/*

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<sup>6</sup> Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, January 2018, p 104.  
[https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0026/813392/qh-gdl-462-2019.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0026/813392/qh-gdl-462-2019.pdf).

<sup>7</sup> Queensland University of Technology, *End of Life Law in Australia*, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

<sup>8</sup> Morita, Tatsuya et al, Definition of Sedation for Symptom Relief, *Journal of Pain and Symptom Management*, 2002, Volume 24, Issue 4, p 447.

<sup>9</sup> *Criminal Law Amendment Act 1979 (Qld)*, s 4.

<sup>10</sup> *Criminal Code Act 1899 (Qld)*, s 311.

<sup>11</sup> *Criminal Code Act 1899 (Qld)*, s 311.

<sup>12</sup> *Criminal Code Act 1899 (Qld)*, s 311.

*weeks/months off been [sic] permanently in a wheelchair and unable to feed/ bath herself. She was a[an] independent head strong lady who didn't like asking for help, and told us all she refused to be cared for or put in a home where her only choice then would be to starve herself.*

*We were aware of her plan and my step father helped organize the things she would require to end her life. Sadly but because of the law and the way it stands at the moment none of us could be with her at the time of passing. She died all alone and this is not right... my step father was still charged with assisting her 'suicide' (euthanasia!) after a lengthy court hearing he was eventually found not guilty. People should be allowed to make the choice for themselves to die, rather than suffer.<sup>13</sup>*

A submitter from Western Australia whose name was withheld, described the suicide of her husband who was suffering from Chronic Obstructive Pulmonary Disease. She explained the careful preparations he made to avoid prosecution:

*...made a brief video on our laptop explaining his reasons for wanting to die and making it quite clear that the decision was entirely his and exonerating his sons and me. To protect me further he wanted me to go shopping while he ended his life but I told him that, after 51 years of marriage, I wasn't going to let him die on his own.<sup>14</sup>*

Palliative care physician Dr Will Cairns told the committee about patients who ended their lives by suicide:

*Suicide is not illegal. What is illegal is making it into something peaceful and comfortable. I have seen patients who have suicided in very messy and unpleasant ways because they felt that the time had come for the end of their life.<sup>15</sup>*

Similarly, at the public hearing in Bundaberg, Dying With Dignity member, Ms Dianne Lange stated:

*I am in a position where I have seen and heard of a lot of people suiciding. I do not wish this to happen. If we brought in this law, this would save a lot of people from making that dreadful decision to commit suicide. It is happening and it is happening underground. The government must know about this huge number of people who are dying alone and who are in such an insidious position that this happens. It is just horrific.<sup>16</sup>*

## **2.3 People are pleading for help to end their lives**

The committee heard from submitters and witnesses about loved ones who were nearing death and had requested help to end their lives. Ms Maria McGregor made the following submission about the death of her mother:

*Her death was traumatic for her, for us (her family) and for the nursing staff because nobody was legally allowed to agree to her simple, personal request to be 'helped along'. Can anybody on your committee even begin to feel how horrible her death must have been? It was her life and her death but she was not allowed to have her death as she wanted it, peaceful, swift and surrounded by her loved ones. Surely no legislator has the right to deny the basic right of a human being to wish to die peacefully?<sup>17</sup>*

Mr Mark Herron, described the traumatic death of his brother-in-law Earl, who had made many requests for help to end his life. He submitted:

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<sup>13</sup> Submission E799

<sup>14</sup> Submission 173, p 2.

<sup>15</sup> Public hearing transcript, Townsville, 29 May 2019, p 9.

<sup>16</sup> Public hearing transcript, Bundaberg, 16 July 2019, p 24.

<sup>17</sup> Submission 103, p 1.

*All Earl's suffering and indignity were for nothing except a society's belief that he should not be able to end his life at a time of his choosing. Earl's distress in the final weeks of his life, and his constant requests to "end it" brought hospital staff including his oncologist to tears, and this is people who are supposedly inured to this type of end of life situation. Imagine the effect on relatives and friends witness his body decomposing and collapsing as they look on!*

*He had to starve/dehydrate himself to death to get release. I find this both utterly intolerable and terribly sad that we as a society do this to terminally ill people, and this is why I so strongly support VAD and thus demand this legislation.<sup>18</sup>*

Paul Bennet explained the distress caused by being unable to help a loved one in need who is suffering and wants help to die. He stated:

*... witnessing the ten-year slow and agonising death of a dear Parkinsons-affected cousin who, in the final two years of her pathetic "life" begged for our help in ending her life, and we were unable to help despite her pleading and constant weeping. Even if her feelings were not enough to soften the hardest heart we, her husband and I, were strongly affected by feeling guilty for not helping our loved one because of laws imposed by people we did not know, vote for, trust or value.<sup>19</sup>*

A submitter who asked for his name to be withheld described the death of his father-in-law as follows:

*[His] last week was hideous as he lost control of his body functions, he wasn't able to eat anything except soft food and drink through a straw. He was heavily drugged which further incapacitated him and his awareness of what was going on. He begged his son to end it for him on numerous occasions during his lucid periods. All we could do is be there with him to help him cope with what was happening to this once strong proud man.<sup>20</sup>*

Ms Jill Glover explained that when the pain became too much, her brother wanted to end his life.

*He had Pancreatic cancer, had fought a good fight for a year or so, had multiple tumours in his body, was doing well with palliative care up to a point, after a while drugs didn't help much, and he just wanted to end it, be away from the pain. I would have loved for him to be able to have his wish and die peacefully at home, as it was, he was very agitated and had to be in hospital.<sup>21</sup>*

At the Caloundra public hearing, Ms Barbara Leadbetter, a registered nurse, advised:

*I have been a registered nurse for a very long time—38 years—and I have worked in the aged-care industry for most of that time. I have personally witnessed hundreds of deaths. I have never heard a person ask to be kept alive when they are in severe pain, leaking bodily fluids, agitated, not knowing who their family are, but hundreds of times I have been begged, as have other staff around me, to assist these people to go. Why do we need to get to this stage where someone cannot choose when it is time to go?<sup>22</sup>*

Dr Timothy Porter, a general surgeon from Toowoomba, told the committee about the distress he experienced being unable to help his sister in her dying days:

*A lot of people get great comfort from the fact that they have something in the cupboard that they can use if they get desperate enough. I think in practice where it is provided overseas, more often than not they do not get to use it because their dying process is managed in a comfortable way and they never feel the need, but they are greatly reassured by having it there. At the same*

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<sup>18</sup> Submission E587.

<sup>19</sup> Submission 070, p 1.

<sup>20</sup> Submission 14, pp 1-2.

<sup>21</sup> Submission E032.

<sup>22</sup> Public hearing transcript, Caloundra, 3 May 2019, p 2.

*time my sister begged me—begged me—to kill her. She was really distressed. As I say, we had a specialist palliative care team with nurse practitioners readily available. It was a very difficult process. I found it very distressing that the only thing we had available to us was slightly more pain relief. It was a very awful experience.*<sup>23</sup>

Ms Corina Robinson, who works as an end-of-life doula told the committee about the death of one of her clients:

*In the last week before he died the pain was excruciating. I can sit here and tell you that if I had my time all over again I would be sitting here either convicted of murder or manslaughter, at the least as the law stands today, because he begged me so many times to pick up that morphine needle and inject the whole bottle into him. The night he died I had his relatives screaming at me to do something because the pain was so bad.*<sup>24</sup>

Similarly, a submitter whose name was withheld, explained his regret for not taking action:

*Taking no action is something I have to live with, and that I turned out to be not as good as a friend as what he thought I was. I should have done it, I should have assisted him. I saw no signs that he was affected by morphine when he asked me. I feel like I let him down, when he needed me the most. If it happened again, I would do it, regardless of the law.*<sup>25</sup>

## **2.4 People are planning to suicide in the absence of VAD**

The committee heard from people who had made plans for suicide in circumstances where they had a life-limiting illness or debilitating condition. Ms Margaret (Marj) Lawrence outlined her plan in her submission to the committee.

*When I am suffering intolerably and have no quality of life, I will be forced to end my own life if there is not a law in parliament that would allow doctors to prescribe medication that will end my life quickly and peacefully (just a few minutes with Nembutal – the drug of choice in overseas countries).*

*However, it will be hard on my family as they will not be allowed to be with me because of fear of being charged with murder. This means I will die alone and I will be joining the statistics of many people who end their own lives to escape the pain of dying.*

*The worst part of ending my life is that it has to be done whilst I am still able to do so. If it is left too long, I may not be able to help myself, as no one is allowed to assist me. I will die alone.*

*I cannot find words to describe the peace of mind I have in knowing I will not suffer at the end like my brother did, as well as three friends who also died, under horrendous circumstances from pancreatic cancer last year. Everyone should have access to this peace of mind.*

*Ideally, a law will allow me to die quickly and peacefully in palliative care, with my family and doctors by my side – as it should be – and my life will likely be extended because I will not have to end it before it is necessary.*<sup>26</sup>

Mr Gregory Gesch made a submission to the committee along similar lines:

*As for myself I do not wish to end life like this. Suicide is the only current option and one that I would need to take early to make sure I was still physically and mentally able to do it.*

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<sup>23</sup> Public hearing transcript, Toowoomba, 17 May 2019, p 15.

<sup>24</sup> Public hearing transcript, Bundaberg, 16 July 2019, p 14.

<sup>25</sup> Submission 288, p 1.

<sup>26</sup> Submission 40, p 3.

*This sounds so melodramatic but it is true. There are worse things than death and the way of dying is major amongst them.*<sup>27</sup>

A submitter whose name was withheld told of his father's plans:

*My father's current plan is to commit suicide, alone, before he becomes a burden to our family.*<sup>28</sup>

Mr David Bedford, a person suffering from a disability as the result of a motor vehicle accident, provided the committee with details about his plans to go to Switzerland to access assisted dying there:

*I'm a qualified chef but on the 13th of August 2002 I crashed my car into a pole driving home from work and became a high-level C2 incomplete quadriplegic.*

*I'm not going to go into detail about my life since then but I will say I want to be able to have control over when I end my life and for that reason I sought a company in Switzerland called Dignitas which gives access to people with a terminal illness or an incurable condition like my own to a doctor who can assist their suicide.*

*Being an incomplete quadriplegic means I fractured my neck at C2 just bruising my spinal cord which left me with limited movement below my neck and only slightly impairing my feeling.*

*This leaves me laying in bed most of the day as I can only sit up in my wheelchair for short periods due to bedsores. Still having most of my feeling means I get lots of pain due to bed sore wounds I got in intensive care and pain from just laying in bed for long periods.*

*I have a friend who works in patient transport who will be taking me to Switzerland, this will come at significant cost to me, I would like to be able to do this in my own country...*<sup>29</sup>

In a private briefing to the committee, Dr Sandy Buchman, President-Elect, Canadian Medical Association spoke about one of his patients, who would have ended his life if VAD had not been available to him.

*I will say that overall it is often less about physical pain management and physical symptom management in general and more about perhaps the psychological or existential suffering or fear of that suffering that patients may experience. I have a current case of a patient I saw last week. There is little in the way of physical support that modern medicine can provide for him as his condition declines. He actually told me very directly that, had it not been for our assisted dying legislation, he would have proceeded to suicide early, probably about three years ago, but the hope of the legislation has actually kept him there and is allowing him to receive the palliative care that we can offer him. Ultimately he is interested in assisted dying.*<sup>30</sup>

## 2.5 Impact of suicide on those left behind

Some inquiry stakeholders commented on the devastation caused by suicide, not only for the family and friends of the deceased but also for first-responders such as paramedics and police.

Mr Peter Vinnicombe expressed this view in his submission to the committee:

*...For people to have to turn to suicide by violent means is even more traumatic for those left behind. People who have been diagnosed with end stage cancer, sometimes after their 4th lot of remission and would rather shoot themselves to save their families witnessing their slow and painful deterioration.*<sup>31</sup>

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<sup>27</sup> Submission E110.

<sup>28</sup> Submission, 12, p 1.

<sup>29</sup> Submission E147.

<sup>30</sup> Private briefing transcript, 10 April 2019, p 4.

<sup>31</sup> Submission E171.

Similarly, Noel Hamilton submitted:

*If we really want a civilised society we should offer voluntary assisted dying to reduce the occurrence of suicide by hanging, shooting, suffocation and any other horrific means people are forced to take now, the ongoing effects of these gruesome suicides are ongoing and far reaching and could be greatly alleviated by legal and compassionate voluntary assisted dying.*<sup>32</sup>

At the public hearing in Hervey Bay, Ms Cecile Scherrer stated:

*Terminally ill people with irreversible health issues have much comfort when there is a choice available in the last stage of their life. They know they could use it but many never use it but it is available. Despite the expansion of palliative care, euthanasia fulfils a need amongst the increasingly ageing society. Nobody should need to live against their own will. Everybody should have a choice and option regarding all aspects of their own life. I hope and wish this law will come into effect so fewer people need to commit suicide all alone—often involving innocent people and leaving family members, truck and train drivers, paramedics, police et cetera with a trauma for the rest of their life.*<sup>33</sup>

In her submission to the inquiry, Ms Madeleine Luck-Grillon commented on the impact of suicide on those left behind:

*At the age of 83 my dear father took his life and I had to deal with his desperate action. Suicide traumatises the ones left behind for life.*<sup>34</sup>

Palliative care nurse and former paramedic Mr Phil Browne told the committee about his experiences as a first responder. He also commented on the plight of the family and loved ones in the event of a suicide.

*I attended two suicides where it was known that the person killed themselves because they had either a terminal or an advanced progressive incurable debilitating condition. Both patients were men with self-inflicted firearm blasts to the head.*

...

*This man had shot the rifle into his head, completely removing the top of his head.*

...

*Reading the man's suicide note was awful. He spoke of his love for his family and how he could no longer tolerate the symptoms he was experiencing in his terminal decline. The man's family found him - they were sobbing and absolutely inconsolable.*

*The other suicide involved a patient who[se] horrific brain injury from his gunshot had made him unconscious, but he was still alive on arrival at the Emergency Department. I knew his disastrous injuries were incompatible with life. I was relieved when I learnt this patient had later died in hospital, knowing there was no chance of him being left existing (not living) in a vegetative state in a hospital or nursing home bed.*

...

*I can't imagine how the families have coped knowing the desperation, fear and isolation their loved one felt before pulling the trigger. Plus, the families could have "survivor guilt", knowing they weren't there to comfort and support their loved one in their final desperate minutes.*

*How does the family move forward after this? And, how could the family even continue living in the same house where their loved one blasted their brains out?*

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<sup>32</sup> Submission E072.

<sup>33</sup> Public hearing transcript, Hervey Bay, 15 July 2019, p 28.

<sup>34</sup> Submission 706, p 1.



...

*In addition to the massive toll on family members - there is a huge emotional toll on emergency services responders. The utter devastation and sheer horror of these suicides still troubles me, as it does all Paramedics and Police who must attend these devastating scenes. The impact of these horrific and violent suicides on Paramedics and Police is cumulative and can become crippling, leading some excellent and highly skilled emergency responders to leave the job.*<sup>35</sup>

Similarly, former Police Officer, Mr Laurie Paul made the following submission:

*Whilst performing duties as a uniformed Scenes of Crime Officer in Townsville and Mt Isa, I attended many suicides and sudden deaths. However as a Detective Sergeant at the Kirwan Criminal Investigation Branch I was tasked to attend a suicide one evening in the Condon area. On arrival a uniform crew were in attendance and we were directed to the back yard shed. There lay an elderly gentleman who had suicided his elderly wife and family grieved for him upstairs.*

*The investigation determined that he had recently been advised that he had cancer and in his loving note to his wife of many years, outlined that he was of the view that he did not wish for her to suffer as he slowly died in front of her and that she would have to nurse him in the last years of their lives. This was wrong and a sad indictment on our society.*<sup>36</sup>

## **2.6 Suicides in Queensland linked to terminal and debilitating illness**

During the inquiry the committee heard from a number of witnesses who related personal accounts of people suffering from terminal and debilitating illnesses who took their own lives.

In Queensland, suicide is considered a violent or unnatural death and is, therefore, a reportable death which means it must be reported to the coroner.<sup>37</sup> Coronial data is compiled into the National Coronial Information System (NCIS), a national database managed by the Department of Justice in Victoria.

Data compiled for the committee from the NCIS 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.<sup>38</sup> The NCIS data showed that 125 of those 168 intentional self-harm deaths (74 per cent) were committed by males.<sup>39</sup>

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<sup>35</sup> Phil Browne, Medicines information from Australian MIMS with notes (7/11/19), pp 11-12, Tabled Paper, 15 July 2019.

<sup>36</sup> Submission 37, p 1.

<sup>37</sup> Queensland Courts, Reportable deaths, <https://www.courts.qld.gov.au/courts/coroners-court/coroners-process/reportable-deaths>.

<sup>38</sup> NCIS, *Data Report DR19-26: Intentional self-harm deaths of persons with terminal or debilitating physical conditions in Queensland, 2016-2017*, released July 2019.  
<https://www.parliament.qld.gov.au/documents/committees/HCDSDFVPC/2018/AgedCareEOLPC/cor-23Jul2019.pdf>.

<sup>39</sup> NCIS, *Data Report DR19-26: Intentional self-harm deaths of persons with terminal or debilitating physical conditions in Queensland, 2016-2017*, released July 2019.

**Table 1: Intentional self-harm deaths by age range where the deceased suffered from a terminal or debilitating physical condition, Queensland, 1 January 2016 to 31 December 2018.**

Age range (years)	Number	Percentage of notifications identified
<31	8	4.8
31–40	8	4.8
41–50	17	10.1
51–60	31	18.5
61–70	36	21.4
71–80	34	20.2
>80	34	20.2
<b>Total</b>	<b>168</b>	<b>100</b>

Source: NCIS, Data Report DR19-26.

*Note: Cases were included only where the deceased suffered from a terminal or debilitating physical condition (for example, terminal cancer, multiple sclerosis or paraplegia), or the investigating coroner noted the deceased's physical condition as a likely contributing factor to their intention to engage in self-harm.*

Table 1 presents the data for males and females combined by aged group, number and percentage of total notifications for the two years. The data also showed that, for those who suffered from a terminal or debilitating physical condition, the number of intentional self-harm deaths increased significantly in the older age brackets (see Table 1). The 168 Queensland suicide notifications identified by the NCIS represents on average around one notification every four days over the two years. Approximately 62 per cent of notifications were aged over 60.

Chapters 5 and 6 of this report include a summary of the views of submitters and witnesses that the introduction of voluntary assisted dying may send a wrong message to people contemplating suicide.

#### **Committee comment**

The committee notes that, consistent with trends in other jurisdictions, a significant number of Queenslanders facing terminal and debilitating illnesses are choosing to take their own lives.

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.

### 3 Legislating for voluntary assisted dying

This chapter provides an overview of the VAD schemes that were recently passed by the parliaments of Victoria, Western Australia and New Zealand as well as noting the scheme that previously operated in the Northern Territory. It begins by examining the definitions for VAD adopted for these schemes.

#### 3.1 Definitions

While undertaking this inquiry, the committee heard a number of terms used to define the act of consensually ending a person's life, such as assisted suicide, medical assistance in dying (MAID), euthanasia and VAD. Each of these terms lack a commonly-accepted definition. Professors White and Wilmott of the Australian Centre for Health Law Research at the Queensland University of Technology noted that:

*Both in Australia and overseas, the VE [voluntary euthanasia] and PAS [physician-assisted suicide] debates have been undermined by semantic ambiguity.*<sup>40</sup>

A number of stakeholders discussed definitions in their submissions.

The Australian Medical Association (AMA) defines euthanasia as 'the act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering'.<sup>41</sup>

Expanding on this definition, the Australian Human Rights Commission (AHRC) notes that euthanasia is sought not only by those suffering pain, 'but for other reasons such as changes in quality of life resulting from catastrophic physical injury and psychological factors associated with incurable diseases'.<sup>42</sup> The AHRC also states that the term 'euthanasia' does not refer to one particular practice, but is instead an umbrella term that covers a range of practices. These include:

- *Passive voluntary euthanasia – when medical treatment is withdrawn or withheld from a patient, at the patient's request, in order to end the patient's life;*
- *Active voluntary euthanasia – when medical intervention takes place, at the patient's request, in order to end the patient's life;*
- *Passive involuntary euthanasia – when medical treatment is withdrawn or withheld from a patient, not at the request of the patient, in order to end the patient's life;*
- *Active involuntary euthanasia – when medical intervention takes place, not at the patient's request, in order to end the patient's life.*<sup>43</sup>

Assisted suicide, or physician assisted suicide, differs from euthanasia in that the person who provides the assistance, such as a relative or doctor, does not perform the final act that causes the death. The death is caused by the person themselves, by their own action of committing suicide. For example, a doctor may prescribe the medication with the intention of assisting that person to die, but the person then uses that medication to commit suicide.<sup>44</sup>

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<sup>40</sup> Submission 1206, attachment 6, p 6.

<sup>41</sup> Australian Medical Association (2016) Euthanasia and Physician Assisted Suicide, AMA Position Statement, p. 1. <https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016>.

<sup>42</sup> Australian Human Rights Commission, Euthanasia, human rights and the law, Issues Paper, May 2016, p 3, [https://www.humanrights.gov.au/sites/default/files/document/publication/2016\\_AHRC\\_euthanasia\\_human\\_rights\\_law.pdf](https://www.humanrights.gov.au/sites/default/files/document/publication/2016_AHRC_euthanasia_human_rights_law.pdf).

<sup>43</sup> Australian Human Rights Commission, Euthanasia, human rights and the law, Issues Paper, May 2016, p 3,

<sup>44</sup> Queensland University of Technology, End of Life Law in Australia, Euthanasia and Assisted Dying, <https://end-of-life.qut.edu.au/euthanasia>.

The committee also considered the definitions adopted by recent parliamentary inquiries in Victoria, Western Australia and New Zealand. A summary of the definitions used in those inquiries is presented in Table 2 below.

**Table 2 – Definitions of voluntary assisted dying used in recent inquiries**

Victoria	Western Australia	New Zealand (uses the term 'assisted dying')
<p>Voluntary assisted dying means administering a medication for the purpose of causing death in accordance with the steps and process set out in law.</p> <p>Voluntary assisted dying must be voluntary and initiated by the person themselves, and it will usually be self-administered.<sup>45</sup></p>	<p>The administration of a voluntary assisted dying substance and includes steps reasonably related to that administration.<sup>46</sup></p> <p>The administration may be self-administration, or administration by a practitioner.<sup>47</sup></p>	<p>1. The administration by a medical practitioner of medication to the person to relieve the person's suffering by hastening death, or</p> <p>2. The self-administration by the person of medication to relieve their suffering by hastening death.<sup>48</sup></p>

Source: This table was compiled from information published by the Department of Health and Human Services (Vic), the Voluntary Assisted Dying Bill 2019 (WA), and the *End of Life Choices Act 2019* (NZ).

### **Committee comment**

After considering the views of submitters and the definitions from other recent parliamentary inquiries, the committee has defined the term voluntary assisted dying (VAD) for the inquiry 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.

## **3.2 Voluntary Assisted Dying Act 2017 (Vic)**

### **3.2.1 Committee Inquiry and Ministerial Advisory Panel**

In May 2015, Victoria's Legislative Council resolved that its Legal and Social Issues Committee (LSIC) would inquire into the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices.<sup>49</sup> The LSIC published its interim report in November 2015, where it shared the consultation process it had undertaken during its inquiry.<sup>50</sup> In May 2016, it published its final

<sup>45</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying, Overview, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>.

<sup>46</sup> *Voluntary Assisted Dying Act 2019* (WA), s 58(5).

<sup>47</sup> Western Australia, Voluntary Assisted Dying Bill 2019, explanatory memorandum, p 2, [https://www.parliament.wa.gov.au/Parliament/Bills.nsf/502E87F2E1B94E27482584A3003A757C/\\$File/EM%2B139-1.pdf](https://www.parliament.wa.gov.au/Parliament/Bills.nsf/502E87F2E1B94E27482584A3003A757C/$File/EM%2B139-1.pdf).

<sup>48</sup> New Zealand, *End of Life Choice Act 2019*, s 3.

<sup>49</sup> Parliament of Victoria, Legislative Council, Legal and Social Issues Committee, *Inquiry into end of life choices, Interim Report, November 2015*, p 1, [https://www.parliament.vic.gov.au/images/stories/committees/lisic/ELC\\_-\\_Presentations/LSIC\\_58-02\\_Report.pdf](https://www.parliament.vic.gov.au/images/stories/committees/lisic/ELC_-_Presentations/LSIC_58-02_Report.pdf).

<sup>50</sup> Parliament of Victoria, Legislative Council, Legal and Social Issues Committee, *Inquiry into end of life choices, Interim Report, November 2015*, pp 1-2.

report, where it recommended, among other things, that the Victorian Government introduce a legal framework providing for assisted dying.<sup>51</sup>

After the LSIC's report, the Victorian Government appointed a Ministerial Advisory Panel (the advisory panel) to develop voluntary assisted dying legislation.<sup>52</sup> In January 2017, the advisory panel published a discussion paper seeking stakeholders' views on a range of questions regarding VAD.<sup>53</sup> In May 2017, the advisory panel published an interim report, covering the main issues raised during its consultation process.<sup>54</sup> In July 2017, the advisory panel published its final report, which outlined a framework for a VAD scheme in Victoria.<sup>55</sup>

### 3.2.2 Passage of the Voluntary Assisted Dying Bill 2017

In September 2017, the Voluntary Assisted Dying Bill 2017 was introduced into the Victorian Parliament by then Minister for Health, the Hon Jill Hennessy MP.<sup>56</sup> The Victorian Parliament passed the Bill in November 2017 and the *Voluntary Assisted Dying Act 2017* (Vic) (the Victorian Act) commenced on 19 June 2019.<sup>57</sup>

The Victorian Act allows a person in the late stages of a disease to take medication prescribed by a doctor that will bring about their death at a time the person chooses. Among other criteria, the person must have an advanced disease that is expected to cause death within six months (or within 12 months for neurodegenerative diseases like motor neurone disease) and that is causing the person unacceptable suffering. Reports in August 2019 noted the passing of Ms Kerry Robertson from Bendigo in Victoria, the first person to access Victoria's VAD scheme.<sup>58</sup>

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<sup>51</sup> Parliament of Victoria, Legislative Council, Legal and Social Issues Committee, *Inquiry into end of life choices*, Final Report, November 2015, p xxxiv, [https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL\\_Report/LSIC\\_58-05\\_Text\\_WEB.pdf](https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf).

<sup>52</sup> Victoria State Government, Department of Health and Human Services, *Voluntary Assisted Dying Bill discussion paper*, <https://www2.health.vic.gov.au/about/publications/researchandreports/voluntary-assisted-dying-Bill-discussion-paper>.

<sup>53</sup> Victoria State Government, Department of Health and Human Services, *Voluntary Assisted Dying Bill*, Discussion paper, January 2017, <https://www2.health.vic.gov.au/Api/downloadmedia/%7B8E76600C-4B7F-4E6E-AC4F-FCE39350A815%7D>.

<sup>54</sup> Victoria State Government, Department of Health and Human Services, *Interim report of the Ministerial Advisory Panel: Consultation overview Voluntary Assisted Dying Bill*, May 2017, <https://www2.health.vic.gov.au/Api/downloadmedia/%7B799B1AB8-1F73-48D2-8718-E077375AF56B%7D>.

<sup>55</sup> Victoria State Government, Department of Health and Human Services, *Ministerial Advisory Panel on Voluntary Assisted Dying, Final Report*, July 2017, <https://www2.health.vic.gov.au/Api/downloadmedia/%7BA27EEE2F-02DE-44BF-8347-C901CF20B7E5%7D>.

<sup>56</sup> Parliament of Victoria, Voluntary Assisted Dying Bill 2017, [http://www.legislation.vic.gov.au/domino/Web\\_Notes/LDMS/PubPDocs\\_Arch.nsf/5da7442d8f61e92bca256de50013d008/CA257CCA00177A46CA2581A1007A8903/\\$FILE/581392bi1.pdf](http://www.legislation.vic.gov.au/domino/Web_Notes/LDMS/PubPDocs_Arch.nsf/5da7442d8f61e92bca256de50013d008/CA257CCA00177A46CA2581A1007A8903/$FILE/581392bi1.pdf).

<sup>57</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 2, [http://www.legislation.vic.gov.au/Domino/Web\\_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/\\$FILE/17-061aa%20authorised.pdf](http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/$FILE/17-061aa%20authorised.pdf).

<sup>58</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying Implementation Taskforce, *Voluntary assisted dying newsletter, Taskforce Implementation News, Farewell message from the Taskforce Chair, Julian Gardner*, August 2019,

Media reports stated that Ms Robertson's daughters had described her death as 'beautiful and peaceful'.<sup>59</sup>

### 3.2.3 Key features of Victoria's voluntary assisted dying scheme

Table 3 outlines key features of Victoria's VAD scheme.

**Table 3: Key features of Victoria's voluntary assisted dying scheme**

Feature	Explanation
What law allows	A physician can prescribe a lethal drug that the patient self-administers at a time of their choosing, unless they are physically unable to do so, in which case their doctor may assist. <sup>60</sup>
Eligibility	A patient must have an incurable, advanced and progressive disease, illness or medical condition, assessed by two medical practitioners to be expected to cause death within six months. For patients suffering from a neurodegenerative condition, the condition must be expected to cause death within 12 months. <sup>61</sup>
Level of suffering	Intolerable suffering that cannot be relieved in a manner the person considers tolerable. <sup>62</sup>
Medical opinion needed	Yes, two doctors needed. <sup>63</sup> The Voluntary Assisted Dying Review Board (the Board) will monitor all activity under the law and will receive reports from all health practitioners who participate. The Board will make sure that the Act is being complied with and will also monitor substance permit applications. <sup>64</sup>
Coercion prevention; ensuring informed decision	Patient needs to make a written declaration, witnessed by two independent individuals, confirming that they are making an informed, voluntary and enduring decision to access voluntary assisted dying. <sup>65</sup>
Information to be given to patient	Patient must be informed of, among other things: their diagnosis and prognosis; available treatment options and the likely outcomes of that treatment; available palliative care options and the likely outcomes of that care; the risks of taking a drug likely cause their death; and that they may decide at any time not to continue the request and assessment process. <sup>66</sup>
Residency requirement?	Yes, need to be an Australian citizen or permanent resident and have been living in Victoria for at least 12 months.

<https://www.vision6.com.au/v/47492/5705741/email.html?k=65URfUJVC-JPuEilgBGv-vu7ukN4lsgVcFykzkyiM>.

<sup>59</sup> 'Bendigo woman Kerry Robertson becomes first Victorian to use Voluntary Assisted Dying Act', *Australian Broadcasting Corporation*, 5 August 2019, <https://www.abc.net.au/news/2019-08-04/bendigo-woman-first-victorian-use-voluntary-assisted-dying-law/11382332>.

<sup>60</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>.

<sup>61</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>62</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>63</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>64</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>65</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>66</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 19(1).

Feature	Explanation
Access for under-18s?	No
Capacity needed when death occurs?	Yes – for practitioner administration. <sup>67</sup> For self-administration a person can take the substance at a time of their choosing if they are physically able to. <sup>68</sup>

Source: This table presents information compiled from the Voluntary Assisted Dying Act 2017 (Vic) and information published by the Department of Health and Human Services (Vic) about the voluntary assisted dying scheme.

### 3.2.3.1 *Process a patient must follow to access voluntary assisted dying*

If a patient wishes to access VAD, they must ask a health practitioner for information about it.<sup>69</sup> A family member or carer cannot request VAD on somebody else's behalf. This is to help ensure the request is voluntary and without coercion, and that the decision is the person's own.<sup>70</sup> In addition, a health practitioner can only talk about VAD if a patient asks them about it (and cannot initiate the discussion).<sup>71</sup>

After a person requests VAD, they are first assessed by a doctor (the co-ordinating medical practitioner) to ascertain whether the person is eligible to access VAD. If the co-ordinating medical practitioner considers the patient is eligible to access VAD, that doctor refers the patient to a second doctor (the consulting medical practitioner) where the patient is assessed independently. The doctors will make sure the person is making a fully informed decision and is aware of the available palliative care options.<sup>72</sup>

If the person wishes to proceed, they will need to make a written declaration that is witnessed by two independent individuals, confirming that they are making an informed, voluntary and enduring decision to access VAD.<sup>73</sup>

On receiving a final request, the co-ordinating medical practitioner will apply for a permit to prescribe a medication that the person may use to end their life at a time of their choosing. The person must administer the medication themselves, unless they are physically unable to do so, in which case their doctor may assist.<sup>74</sup>

<sup>67</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 64(1)(b).

<sup>68</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>.

<sup>69</sup> Victoria State Government, Department of Health and Human Services, *Community information about voluntary assisted dying*, April 2019, p.3, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>.

<sup>70</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>71</sup> Victoria State Government, Department of Health and Human Services, *Community information about voluntary assisted dying*, April 2019, p 3.

<sup>72</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview>.

<sup>73</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>74</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

No health practitioner or healthcare provider is obliged to participate in voluntary assisted dying.<sup>75</sup> If a health practitioner does not wish to participate in the VAD scheme and receives a request to do so, they must inform the patient of this within seven days of the patient's first request to access VAD.<sup>76</sup>

### 3.2.3.2 Access to voluntary assisted dying for people with a disability, mental illness or dementia

Having a disability or mental illness does not preclude a person from accessing VAD. People with disability or mental illness who meet the conditions to access VAD have the same right to access VAD as other people. They must have an advanced disease likely to cause death within six months (or 12 months for neurodegenerative diseases) and the ability to make and communicate a decision about voluntary assisted dying throughout the process.<sup>77</sup>

Having dementia is not sufficient reason for a person to access VAD, but a person diagnosed with dementia may be eligible if they meet all of the conditions, including having decision-making ability throughout the entire process. When dementia affects a person's ability to make a decision about VAD, they will not meet the conditions to receive assistance to die.<sup>78</sup>

### 3.2.3.3 Doctors' reporting duties

The co-ordinating medical practitioner is responsible for ensuring all the VAD forms are completed and must report these to the Voluntary Assisted Dying Review Board (VAD Review Board) through the voluntary assisted dying portal.<sup>79</sup>

The co-ordinating medical practitioner will also be responsible for applying for a permit, prescribing the voluntary assisted dying medications, and conducting the consulting assessment. They must independently satisfy themselves that the person meets each of the eligibility criteria.<sup>80</sup>

The consulting medical practitioner must also report their assessment to the VAD Review Board through the voluntary assisted dying online portal.

### 3.2.3.4 The voluntary assisted dying portal

The VAD portal is the platform where medical practitioners can:

- complete and submit all forms required for voluntary assisted dying, and
- apply for a self-administration permit or a practitioner administration permit to prescribe a voluntary assisted dying medication.<sup>81</sup>

<sup>75</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying – Overview.

<sup>76</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 23.

<sup>77</sup> Victoria State Government, Department of Health and Human Services, *Community information about voluntary assisted dying*, April 2019, <https://www2.health.vic.gov.au/Api/downloadmedia/%7B16E71848-1A55-4FA4-B5C5-293D659F62A3%7D>, pp 2-3.

<sup>78</sup> Victoria State Government, Department of Health and Human Services, *Community information about voluntary assisted dying*, April 2019, p 3.

<sup>79</sup> Government of Victoria, Department of Health and Human Services, *Co-ordinating and consulting medical practitioner information*, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/coordinating-consulting-medical-practitioner-information>.

<sup>80</sup> Government of Victoria, Department of Health and Human Services, *Co-ordinating and consulting medical practitioner information*.

<sup>81</sup> Victorian Agency for Health Information, Voluntary Assisted Dying Portal, <https://www.bettersafercare.vic.gov.au/about-us/about-scv/councils/voluntary-assisted-dying-review-board/voluntary-assisted-dying-portal>.



The VAD portal also offers the approved assessment training for medical practitioners who wish to be involved in offering VAD.

#### 3.2.3.5 *Role of the Voluntary Assisted Dying Review Board*

The Voluntary Assisted Dying Review Board (the Victorian Review Board) was established to review and monitor VAD activities in Victoria. Its responsibilities include:

- promoting and ensuring compliance with the *Voluntary Assisted Dying Act 2017* (Vic)
- reporting to the Victorian Parliament and referring any potential issues or breaches to the appropriate authorities
- collecting data about VAD, and
- providing information to the community while maintaining the privacy of individuals involved.<sup>82</sup>

The Victorian Review Board reviews all assessments and forms submitted for VAD retrospectively.

It does not:

- grant or refuse applications for VAD, or
- participate as coordinating or consulting medical practitioners in VAD assessments.<sup>83</sup>

In its first report for the period June to December 2019, the board reported the following operational statistics:

- 136 first assessments for eligibility were assessed
- 102 consulting assessments were conducted, of which 100 were assessed as eligible
- 52 deaths through voluntary assisted dying were confirmed
- Medication was self-administered in 43 deaths, and administered by a practitioner in 9 deaths
- 365 medical practitioners registered for training
- 83% of cases required forms to be returned for clarification or provision of missing eligibility information, and
- 100% of cases were assessed to be compliant.<sup>84</sup>

#### 3.2.3.6 *How a patient accesses the voluntary assisted dying substance*

The Voluntary Assisted Dying Statewide Pharmacy Service (Statewide Pharmacy Service) is responsible for providing medication to people who have been prescribed the medication after completing the request and assessment process under the *Voluntary Assisted Dying Act 2017* (Vic). The Voluntary Assisted Dying Statewide Pharmacy Service's role is to:

- liaise with the co-ordinating medical practitioner
- communicate with the patient
- dispense the prescription, and

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<sup>82</sup> Victoria Agency for Health Information, Voluntary Assisted Dying Review Board, <https://www.bettersafecare.vic.gov.au/about-us/about-scv/councils/vad-review-board>.

<sup>83</sup> Victorian Agency for Health Information, Voluntary Assisted Dying Review Board.

<sup>84</sup> Voluntary Assisted Dying Review Board, 2020, *Report of operations June to December 2019*, pp 3-6.

- provide the medication to the patient.<sup>85</sup>

The Statewide Pharmacy Service involvement commences after a permit has been approved by the Victorian Department of Health and Human Services and the prescription has been provided to the service by the co-ordinating medical practitioner. For patients that have been admitted to a Health Service, the Statewide Pharmacy Service will liaise directly with the co-ordinating medical practitioner whose responsibility will be to communicate with the appropriate health professionals at the Health Service involved in the care of the patient.<sup>86</sup>

To have a prescription dispensed:

- the prescription will be sent directly to the Statewide Pharmacy Service by the patient's co-ordinating medical practitioner
- the Statewide Pharmacy Service will dispense the VAD medication only when the patient directly requests it from the service, and
- the Statewide Pharmacy Service will visit the patient anywhere in Victoria to provide the medication and education regarding the VAD medication.<sup>87</sup>

### **3.3 Western Australia's Voluntary Assisted Dying Act 2019**

#### **3.3.1 Committee report into voluntary assisted dying**

In August 2017, the Western Australian Parliament appointed the Joint Select Committee on End of Life Choices (WA committee) to inquire into end-of-life choices. The committee's inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices ran for a year and received over 700 submissions. For the inquiry, the WA committee heard from over 130 witnesses at 81 hearings.

The WA committee tabled its report, *My Life, My Choice*, on 23 August 2018. The report reflected the broad community agreement about the importance of individual autonomy and choice over end-of-life matters. The committee recommended that the Western Australian Government introduce legislation for VAD and to have regard to the framework recommended in its report.<sup>88</sup>

Arising from the recommendations of the WA committee, a panel (the WA panel) was appointed to undertake consultation and develop legislation for voluntary assisted dying in Western Australia.<sup>89</sup> The WA panel received 541 submissions and heard from 867 participants during its consultation process.

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<sup>85</sup> Victorian Agency for Health Information, Voluntary Assisted Dying Review Board, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-services-information>.

<sup>86</sup> Victorian Agency for Health Information, Voluntary Assisted Dying Review Board.

<sup>87</sup> Victoria State Government, Department of Health and Human Services, Health services information, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-services-information>.

<sup>88</sup> Parliament of Western Australia, *My Life, My Choice*, The Report of the Joint Select Committee on End of Life Choices, August 2018, p xli.

<sup>89</sup> The Panel was chaired by Malcolm McCusker AC QC, former Governor of Western Australia. Panel members included senior palliative care physicians, two former Australian Medical Association (WA) Presidents, a former WA Chief Medical Officer and a former WA Chief Nurse.

The WA panel's final report provided the Western Australian Government with recommendations for the introduction of VAD legislation. The Western Australian Government considered all the panel's recommendations, but chose 'to adopt a cautious approach'.<sup>90</sup>

### **3.3.2 Passage of the Voluntary Assisted Dying Bill 2019**

The Western Australia Voluntary Assisted Dying Bill 2019 was introduced to the Western Australian Parliament's Legislative Assembly by Hon Roger Cook MLA, Deputy Premier and Minister for Health, Mental Health on 7 August 2019.<sup>91</sup> The Bill was passed with amendments on 10 December 2019.

The Bill received royal assent on 19 December 2019. Sections 1-3 of the *Voluntary Assisted Dying Act 2019* (the WA VAD Act) came into force on that date, while the remainder of the Act will commence on proclamation.<sup>92</sup> The explanatory notes foreshadowed up to 18 months will be required between the passage of the Bill and its commencement, to provide sufficient time to prepare for the implementation of the scheme, including the establishment of the Voluntary Assisted Dying Board.<sup>93</sup>

Table 4 outlines the Act's key features. Aspects of the scheme are discussed in more detail below.

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<sup>90</sup> Hon. Roger Cook MLA, Deputy Premier and Minister for Health, Mental Health, Parliament of Western Australia, Record of Proceedings, 7 August 2019, pp 5134a-5140a, [http://www.parliament.wa.gov.au/hansard/hansard.nsf/0/F890F1942320ACA048258466001B3035/\\$FILE/A40%20S1%2020190807%20p5134a-5140a.pdf](http://www.parliament.wa.gov.au/hansard/hansard.nsf/0/F890F1942320ACA048258466001B3035/$FILE/A40%20S1%2020190807%20p5134a-5140a.pdf).

<sup>91</sup> Parliament of Western Australia, Voluntary Assisted Dying Bill 2019 (WA), <https://www.parliament.wa.gov.au/parliament/bills.nsf/BillProgressPopup?openForm&ParentUNID=502E87F2E1B94E27482584A3003A757C>

<sup>92</sup> Parliament of Western Australia, Voluntary Assisted Dying Bill 2019 (WA).

<sup>93</sup> Voluntary Assisted Dying Bill 2019 (WA), Explanatory Memorandum.

### 3.3.3 Key features of Western Australia's voluntary assisted dying scheme

Table 4 Key features of Western Australia's voluntary assisted dying scheme

Feature	<i>Voluntary Assisted Dying Act 2019 (WA)</i>
What law allows	The co-ordinating practitioner may prescribe a voluntary assisted dying substance for the patient, to be self-administered in a sufficient dose to cause death. <sup>94</sup> The co-ordinating practitioner may also administer the prescribed a voluntary assisted dying substance to the patient. <sup>95</sup>
Eligibility	A patient must have at least one disease, illness or medical condition that is advanced, progressive and will cause death within six months or 12 months for a neurodegenerative medical condition. <sup>96</sup>
Level of suffering	Suffering that cannot be relieved in a manner that the person considers tolerable. <sup>97</sup>
Medical opinion needed	Yes – by two doctors: the coordinating practitioner and the consulting practitioner. <sup>98</sup> Practitioners must undertake training before completing an assessment of the patient. <sup>99</sup>
Coercion prevention; ensuring informed decision	The patient must make: <ul style="list-style-type: none"> <li>• an initial request,</li> <li>• a written declaration, and</li> <li>• a final request.<sup>100</sup></li> </ul>
Information to be given to patient	Among other things, the patient must be told: <ul style="list-style-type: none"> <li>• of their diagnosis and prognosis</li> <li>• available treatment options and the likely outcomes of that treatment</li> <li>• the palliative care and treatment options available to the patient and the likely outcomes of that care and treatment, and</li> <li>• the potential risks of self-administering or being administered a voluntary assisted dying substance likely to be prescribed for the purposes of causing the patient's death.<sup>101</sup></li> </ul>
Residency requirement?	Yes – must be an Australian citizen or permanent resident and have been ordinarily resident in Western Australia for a period of at least 12 months at the time of making the first request. <sup>102</sup>
Access for under-18s?	No. <sup>103</sup>
Capacity needed when death occurs?	Yes, for practitioner administration. <sup>104</sup> For self-administration, person can take the substance at a time of their choosing. <sup>105</sup>

Source: This table presents information compiled from the *Voluntary Assisted Dying Act 2019 (WA)*.

<sup>94</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 58(5).

<sup>95</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 59 (2).

<sup>96</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 16(1)(c).

<sup>97</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 16(1)(c).

<sup>98</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 17(2).

<sup>99</sup> *Voluntary Assisted Dying Act 2019 (WA)*, ss 15(b), 25.

<sup>100</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 15.

<sup>101</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 27.

<sup>102</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 16 (1)(b).

<sup>103</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 16(1)(a).

<sup>104</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 16(1)(d).

<sup>105</sup> *Voluntary Assisted Dying Act 2019 (WA)*, s 58(5)(d).

### 3.3.3.1 *Process a patient must follow to access voluntary assisted dying*

To access VAD in Western Australia, a person must make an initial request to a medical practitioner. If the practitioner accepts the request, they become the co-ordinating practitioner and must assess whether the person is eligible to access VAD. If the co-ordinating practitioner considers the person to be eligible for VAD, they must refer the person to another medical practitioner (the consulting practitioner) to independently assess whether the person is eligible for VAD.<sup>106</sup>

The person then makes a written declaration requesting VAD.<sup>107</sup> The written declaration must be witnessed by two people aged at least 18 years who are not ineligible witnesses.<sup>108</sup> For example, a person who is a beneficiary under the will of a patient is ineligible.<sup>109</sup>

The final request must generally be made at least nine days from when the first request was made. Exceptions to are allowed where the co-ordination and consulting practitioners are of the opinion that the patient is likely to die or lose decision-making capacity before that time.<sup>110</sup> However, the final request cannot be made on the same day as the consulting assessment.<sup>111</sup>

The WA VAD Act prevents a health care worker from initiating a discussion with a person about VAD unless the health practitioner also provides the person with treatment options and palliative care options as well as the likely outcome of choosing those options.<sup>112</sup>

### 3.3.3.2 *Access to voluntary assisted dying for people with a disability, mental illness or dementia*

The Act provides that patients are not eligible for VAD solely on the basis of a disability or mental illness diagnosis. However, having a mental illness or disability does not exclude a person from being an eligible applicant if they meet the eligibility criteria.<sup>113</sup>

The WA VAD Act also requires that the patient has capacity to be eligible for VAD.<sup>114</sup> This criteria would exclude many people suffering dementia from being able to access VAD.

### 3.3.3.3 *The role of the Voluntary Assisted Dying Board*

The Act establishes a Voluntary Assisted Dying Board (WA VAD Board) to monitor the operation of the Act. It is required to provide information to the Minister or CEO on the operation of the Act and to make recommendations for the improvement of VAD.<sup>115</sup> The Act also specifies that the WA VAD Board collects, uses and discloses information given to the board and conducts analysis and research of that information. In addition, the WA VAD Board is also required to refer relevant matters to the following bodies:

- the Commissioner of Police
- the Registrar of Births, Deaths and Marriages

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<sup>106</sup> *Voluntary Assisted Dying Act 2019* (WA), part 3.

<sup>107</sup> *Voluntary Assisted Dying Act 2019* (WA), ss 42-46.

<sup>108</sup> *Voluntary Assisted Dying Act 2019* (WA), s 43.

<sup>109</sup> *Voluntary Assisted Dying Act 2019* (WA), s 43(2)(a)i.

<sup>110</sup> *Voluntary Assisted Dying Act 2019* (WA), s 48(3).

<sup>111</sup> *Voluntary Assisted Dying Act 2019* (WA), s 48(2)(b).

<sup>112</sup> *Voluntary Assisted Dying Act 2019* (WA), s 10.

<sup>113</sup> *Voluntary Assisted Dying Act 2019* (WA), s 16(2).

<sup>114</sup> *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(d).

<sup>115</sup> *Voluntary Assisted Dying Act 2019* (WA), s 118.

- the State Coroner
- the CEO of Prisons
- AHPRA
- the Director of the Health and Disability Services Complaints Office.<sup>116</sup>

Depending on the conduct in question, the body will then be able to investigate the matter referred pursuant to its own legislation. For example, if the WA VAD Board refers a matter to the Coroner on the basis that the death is or may be a reportable death because the death was not in accordance with the WA VAD Act, the Coroner would be able to investigate the matter pursuant to the *Coroners Act 1996* (WA).<sup>117</sup>

#### 3.3.3.4 *How a patient obtains the substance to end their life*

The Act enables the CEO of the department administering the Act to authorise health practitioners to supply or dispose of the VAD substance.<sup>118</sup> The CEO is required to publish an up-to-date list of authorised suppliers and disposers on the department's website.<sup>119</sup>

Where the patient has decided to self-administer the VAD substance, the WA VAD Act authorises the coordinating practitioner to prescribe the substance and the patient to take it.<sup>120</sup>

Information about the supply and disposal of the VAD substance is recorded and supplied to the WA VAD Board. A number of safeguards apply to this process.<sup>121</sup>

#### 3.3.3.5 *Differences from the Victorian scheme*

Differences between the WA and Victorian VAD schemes largely reflect geographic and demographic differences between the two states. Western Australia is significantly larger in land area than Victoria and has more remote communities. Western Australia also has a proportionally larger Aboriginal population. According to White et al (2019) '... a few important differences suggest eligible people in WA seeking access to voluntary assisted dying will not have to navigate a process as complex as in Victoria'.<sup>122</sup>

Key differences between the Victorian and Western Australian schemes include:

- Under the Victorian law, self-administration (the person taking the medication themselves) is the default option. Practitioner administration (a doctor administering the medication directly) is only permitted where a person is physically incapable of self-administration or digestion;<sup>123</sup>
- In Western Australia the default requirement to self-administer the voluntary assisted dying substance is not limited to being physically unable to do so. Where a patient has concerns about

<sup>116</sup> Parliament of Western Australia, Voluntary Assisted Dying Bill 2019; explanatory memorandum, p 39.

<sup>117</sup> Parliament of Western Australia, Voluntary Assisted Dying Bill 2019; explanatory memorandum, p 39.

<sup>118</sup> *Voluntary Assisted Dying Act 2019* (WA) s 79.

<sup>119</sup> *Voluntary Assisted Dying Act 2019* (WA) s 79(6).

<sup>120</sup> *Voluntary Assisted Dying Act 2019* (WA) s 58.

<sup>121</sup> *Voluntary Assisted Dying Act 2019* (WA) ss 56, 57, 60, 61.

<sup>122</sup> B White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation*, 9 August 2019.

<sup>123</sup> *Voluntary Assisted Dying Act 2019* (WA) s 56 (2); B White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation*, 9 August 2019, <https://theconversation.com/was-take-on-assisted-dying-has-many-similarities-with-the-victorian-law-and-some-important-differences-121554>.

self-administration, the method most suitable for the patient is determined by the coordinating practitioner;<sup>124</sup>

- Nurse practitioners are permitted to administer the substance in Western Australia but not in Victoria;<sup>125</sup>
- When the patient makes a written declaration, two witnesses are required in both the Victorian and the Western Australian legislation. Family members are ineligible witnesses in the *Voluntary Assisted Dying Act 2019* (WA). In the *Voluntary Assisted Dying Act 2017* (Vic), family members are not necessarily ineligible witnesses but only one of the two witnesses may be a family member;<sup>126</sup> and
- The required experience of medical practitioners varies:
  - minimum of five years in Victoria for either the coordinating or consulting medical practitioner:
    - each coordinating practitioner must hold either a fellowship with a specialist medical college or be a vocationally registered general practitioner;<sup>127</sup> and
    - either the coordinating or consulting practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the patient.<sup>128</sup>
  - for coordinating and consulting medical practitioners in Western Australia, minimum of one year practice for specialists but 10 years practice for GPs.<sup>129</sup> There is a provision for the involvement of overseas-trained specialists with limited or provisional registration in Western Australia.<sup>130</sup>
- The Western Australian legislation does not prohibit health care workers from initiating the topic of VAD with patients, and imposes conditions on those discussions.<sup>131</sup>
- In Western Australia medical practitioners are not required to obtain a voluntary assisted dying permit, as in Victoria.<sup>132</sup>
- In Western Australia medical practitioners must notify the patient of their conscientious objection immediately.<sup>133</sup> In Victoria, practitioners are required to respond to the first request for VAD within seven days and do not need to provide information about the VAD process if they do not wish to.<sup>134</sup>

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<sup>124</sup> *Voluntary Assisted Dying Act 2019* (WA) s 56 (2); B White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation*, 9 August 2019, <https://theconversation.com/was-take-on-assisted-dying-has-many-similarities-with-the-victorian-law-and-some-important-differences-121554>.

<sup>125</sup> *Voluntary Assisted Dying Act 2019* (WA) s 54(1)(a) ii, *Voluntary Assisted Dying Act 2017* (Vic), s 46.

<sup>126</sup> *Voluntary Assisted Dying Act 2019* (WA), s 43. *Voluntary Assisted Dying Act 2017* (Vic), s 35(3).

<sup>127</sup> *Voluntary Assisted Dying Act 2017* (Vic) s 10(1); including both GPs and specialist practitioners.

<sup>128</sup> *Voluntary Assisted Dying Act 2017* (Vic) s 10(3).

<sup>129</sup> *Voluntary Assisted Dying Act 2019* (WA) s 17(2).

<sup>130</sup> *Voluntary Assisted Dying Act 2019* (WA) s 17(2).

<sup>131</sup> *Voluntary Assisted Dying Act 2019* (WA) s 10.

<sup>132</sup> B White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation*, 9 August 2019.

<sup>133</sup> *Voluntary Assisted Dying Act 2019* (WA) s 20(5).

<sup>134</sup> B White et al, 'WA's take on assisted dying has many similarities with the Victorian law – and some important differences', *The Conversation*, 9 August 2019.

### 3.4 The *Rights of the Terminally Ill Act 1995* (NT)

In 1995, the Northern Territory Parliament became the first parliament in the world to legalise VAD when it passed the *Rights of the Terminally Ill Act (1995)* (NT) (the ROTI Act).

The ROTI Act included the following eligibility requirements and safeguards:

- the applicant has an illness that is causing severe pain or suffering
- there is no medical treatment available that would provide a cure
- the medical practitioner shall not assist the patient if there are palliative care options reasonably available to the patient to alleviate the patient's pain and suffering to the levels acceptable to the patient
- two other medical practitioners including a psychiatrist must examine the patient
- the psychiatrist must confirm the patient is not suffering from treatable clinical depression
- the patient is of sound mind, and
- the medical practitioner must not be influenced by extraneous considerations.<sup>135</sup>

The ROTI Act was overturned by the *Euthanasia Laws Act 1997* (Cth).<sup>136</sup> During the short time the *ROTI Act* was in force, four people took the option to lawfully end their lives.<sup>137</sup> These four people were assisted by Dr Philip Nitschke. Dr Nitschke made a submission to the committee's inquiry and gave evidence at the August 2019 Brisbane hearing.<sup>138</sup> Mr Marshall Perron who was the chief Minister of the Northern Territory Government at the time, and who introduced the Bill to establish the ROTI Act as a private member's Bill, also gave evidence to the committee's inquiry. Mr Perron provided the following reflection on the design of his Bill:

*If I made a mistake, it was probably not putting a residential requirement in the legislation. I did that for a good reason. I believed I was only legislating for my jurisdiction, which was the Northern Territory, but it seemed to me somehow wrong that if someone visited the Northern Territory and took ill in some way and was in a bed with the same condition as a Territorian, one entitled to voluntary euthanasia—it was full voluntary euthanasia, not just assisted suicide—and the person in the bed next to them was not, if the basis of this legislation is compassion then it should apply to anyone who was in the Northern Territory. For that reason we did not put in a residential requirement. I think that fact probably aggravated opponents in Canberra more than anything. It was stated that 'you've legislated for the whole of Australia'. I suppose you could have said we were legislating for the whole of the world, because we were not stopping a Japanese tourist from taking ill in the Northern Territory either. However, that may well have made the difference between the legislation surviving or not ...*<sup>139</sup>

Professors Jane Turner and David Kissane referred to the legislative gate-keeping mechanisms established by the Northern Territory Rights of the Terminally Ill (ROTI) legislation, which they stated:

*...failed to protect the vulnerable. Poor medical care was evident, with inadequate use of palliative medications, non-use of radiation therapy, inadequate treatment of depression and suicidal thinking in patients; in short, the abysmal use of palliative care. The experience of observing the poor quality of care delivered during this period of the ROTI legislation convinced*

<sup>135</sup> *Rights of the Terminally Ill Act 1995* (NT) ss 4-8.

<sup>136</sup> *Euthanasia Laws Act 1997* (Cth).

<sup>137</sup> Philip Nitschke, submission E1343, p 1.

<sup>138</sup> Submission E1343; Public hearing transcript, Brisbane, 23 August 2019, pp 70-72.

<sup>139</sup> Public hearing transcript, Brisbane, 5 July 2019, p 26.



*us of the legislative challenges of protecting the vulnerable while trying to meet the needs of those desiring voluntary euthanasia.*<sup>140</sup>

In evidence to the committee, Dr Nitschke disagreed with the views of Turner and Kissane:

*...I have watched also with some alarm a bit of the rewriting of the Northern Territory history. We have the likes now of Monash Professor David Kissane lobbying politicians such as yourselves redescribing the history of the Northern Territory law and describing the people who use [used] that law, such as Bob Dent, the world's first person to receive a legal lethal voluntary injection, in ways which really are so inaccurate as to distress to such a degree the widow of Bob Dent—that is Judy, who is now in Canada—that she is going to have to lodge a formal complaint with the Royal Australian and New Zealand College of Psychiatrists about the actions of Professor Kissane in his redescribing and repsychopathologising the people who use that law. I would point out that Bob Dent was actually examined by John Ellard, who was the head of the college of psychiatry, who travelled from Sydney to examine him. He is unfortunately deceased, but now we have another professor coming along and saying—in retrospect, a person who never saw Bob Dent—that he simply should not have been able to access such legislative initiatives and laws and should not have been helped to die.*<sup>141</sup>

### **3.5 The End of Life Choice Act 2019 (NZ)**

#### **3.5.1 The End of Life Choices Bill 2017**

In June 2015, former member of the New Zealand Parliament, the Hon Maryan Street lodged a petition requesting:

*That the House of Representatives investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable.*<sup>142</sup>

The House of Representatives' Health Committee of the 51<sup>st</sup> Parliament reported on this petition in August 2017, recommending the House of Representatives note its report. The report made no recommendation on whether VAD should be legalised.<sup>143</sup>

In October 2015, Mr David Seymour MP entered the End of Life Choice Bill into a ballot of Members' Bills.<sup>144</sup> In May 2016, he sought leave to introduce the Bill on the first Members' day after the Health Committee reported back to the House on its inquiry into the petition presented by Hon Maryan Street. Leave was not granted.

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<sup>140</sup> Submission 1209, p 15.

<sup>141</sup> Philip Nitschke, public hearing transcript, Brisbane, 23 August 2019, p 70.

<sup>142</sup> New Zealand Parliament, Petition 2014/18 of Hon Maryan Street and 8,974 others, Report of the Health Committee, p 5, [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24).

<sup>143</sup> New Zealand Parliament, Petition 2014/18 of Hon Maryan Street and 8,974 others, Report of the Health Committee, p 5, [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24).

<sup>144</sup> Members' Bills are introduced by Members of the New Zealand Parliament who are not Ministers. Every second Wednesday the House of Representatives gives precedence to local, private, and members' Bills. On these days members' Bills are debated. At least eight members' Bills awaiting first reading must be on the Order Paper on each members' day. When a space on the Order Paper becomes available, a ballot is held to decide which members' Bill(s) will be introduced. Members enter Bills in the ballot by lodging notices of proposal with the Table Office and providing a copy of the proposed Bill. <https://www.parliament.nz/en/pb/Bills-and-laws/proposed-members-Bills/?Criteria.PageNumber=2>.

The End of Life Choice Bill was drawn from the ballot, and introduced on 8 June 2017. The Bill was reinstated in the 52nd Parliament and passed its first reading following a personal vote (by 76 to 44 votes) on 13 December 2017. It was referred to the Justice Committee, which reported to the House of Representatives in April 2019. The Justice Committee was unable to agree that the Bill be passed.<sup>145</sup>

The Bill had its second reading on 26 June 2019 and was passed by the Committee of the Whole House on 23 October 2019 with an amendment requiring that the law be triggered only by referendum at the 2020 election.<sup>146</sup> The Bill was assented to on 16 November 2019.<sup>147</sup>

Table 5 outlines key elements of the *End of Life Choice Act 2019*.

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<sup>145</sup> New Zealand Parliament, End of Life Choice Bill, Member's Bill, as reported from the Justice Committee, p 1, [https://www.parliament.nz/resource/en-NZ/SCR\\_86640/c5b7adfc7598b85747ff94855bc46bfb40470db0](https://www.parliament.nz/resource/en-NZ/SCR_86640/c5b7adfc7598b85747ff94855bc46bfb40470db0).

<sup>146</sup> *End of Life Choice Act 2019* (NZ), s 2.  
<http://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html>.

<sup>147</sup> *End of Life Choice Act 2019* (NZ),  
<http://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html>.

### 3.5.2 Key features of New Zealand's *End of Life Choice Act 2019*

**Table 5 Key features of New Zealand's *End of Life Choice Act 2019***

Feature	Explanation
What the Act proposes	The administration by an attending medical practitioner or an attending nurse practitioner of medication to the person to relieve the person's suffering by hastening death, or the self-administration by the person of medication to relieve their suffering by hastening death. <sup>148</sup> The medical practitioner must either be available to the patient until they die, or arrange for another medical practitioner to be available to the patient until death occurs. <sup>149</sup>
Eligibility	Patient must be suffering from a terminal illness that is likely to end their life within six months and is in an advanced state of irreversible decline in physical capability. <sup>150</sup>
Level of suffering	The patient must be experiencing unbearable suffering that cannot be relieved in a manner the patient considers tolerable. <sup>151</sup>
Medical opinion needed	Yes – an additional independent medical practitioner must be satisfied that the person meets the criteria required. If either medical practitioner is uncertain that the patient is competent, both medical practitioners should refer the patient to a psychiatrist. <sup>152</sup>
Coercion prevention; ensuring informed decision	The Bill mandates the attending doctor follow steps which include: <ul style="list-style-type: none"> <li>• ensuring that the person knows that they are not obliged to discuss their wish with anyone</li> <li>• ensuring that the person has had the opportunity to discuss their wish with those whom they choose</li> <li>• doing their best to ensure that the person expresses their wish free from pressure from any other person</li> <li>• conferring with other health practitioners who are in regular contact with the person, and conferring with members of the person's family approved by the person.<sup>153</sup></li> </ul>
Information to be given to patient	A medical practitioner must provide the patient with the prognosis for the terminal illness and inform them of the irreversible nature and anticipated impacts of assisted dying. <sup>154</sup>
Residency requirement?	Yes – must be a New Zealand citizen or permanent resident. <sup>155</sup>
Access for under-18s?	No. <sup>156</sup>
Capacity needed when death occurs?	The patient must be able to decide at the time chosen for the administration of the medication, whether or not to receive the medication or to delay it. <sup>157</sup>

Source: This table presents information compiled from the *End of Life Choice Act 2019* (NZ).

<sup>148</sup> *End of Life Choice Act 2019* (NZ), s 16(5).

<sup>149</sup> *End of Life Choice Act 2019* (NZ), s 2.

<sup>150</sup> *End of Life Choice Act 2019* (NZ), s 4.

<sup>151</sup> *End of Life Choice Act 2019* (NZ), s 4.

<sup>152</sup> *End of Life Choice Act 2019* (NZ), ss 10-12.

<sup>153</sup> *End of Life Choice Act 2019* (NZ), s 8.

<sup>154</sup> *End of Life Choice Act 2019* (NZ), s 8(2).

<sup>155</sup> *End of Life Choice Act 2019* (NZ) s 4(1).

<sup>156</sup> New Zealand Parliament, Parliamentary Library Research Paper 2018/06, Assisted Dying: New Zealand, p 3. <https://www.parliament.nz/media/5372/assisted-dying-new-zealand-december-2018.pdf>.

<sup>157</sup> *End of Life Choice Act 2019* (NZ), s 16.

## 4 Voluntary assisted dying schemes in Europe and North America

Chapter 4 discusses the features of VAD schemes that operate in Europe and North America. Four European countries, the Netherlands, Belgium, Luxembourg and Switzerland provide access to VAD. Switzerland's scheme is distinctly different to the other schemes. The schemes in the Netherlands, Belgium and Luxembourg are discussed first.

### 4.1 VAD schemes in the Netherlands, Belgium and Luxembourg

Table 6 below compares the features of the VAD schemes available in Belgium, Luxembourg and the Netherlands. This is followed by a brief outline of the history and workings of these schemes. The VAD scheme in Switzerland which is distinctly different, is also outlined.

**Table 6 Overview of voluntary assisted dying schemes in Belgium, Luxembourg and the Netherlands**

Country; feature	The Netherlands <sup>158</sup>	Belgium <sup>159</sup>	Luxembourg <sup>160</sup>
Can a patient end their own life?	Yes	Yes	Yes
Can a physician end a patient's life?	Yes	Yes	Yes
Specific illnesses stipulated?	No	No	No
Unbearable and/or continuous suffering required?	Yes	Yes	Yes
Second opinion required?	Yes	Yes	Yes
Do doctors need assurances patient has not been coerced?	Yes	Yes	Yes
Residency requirement?	No	No <sup>161</sup>	No <sup>162</sup>
Available to under 18s?	Yes	Yes	No

*This table presents information compiled from: the Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Wet van 12 April 2001, Staatsblad 2001, 194; the Loi du 28 mai 2002 relative à l'euthanasie; and the Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide.*

<sup>158</sup> The official name of the Netherlands Act is *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, Wet van 12 April 2001, Staatsblad 2001, 194. (This translates into English as the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.) The officially published version of the Act in Dutch language is online at: <https://wetten.overheid.nl/BWBR0012410/2020-01-01>.

<sup>159</sup> The official name of the Belgian Act is *Loi du 28 mai 2002 relative à l'euthanasie*. (M.B. 22.06.2002). (This translates into English as *The Belgian Act on Euthanasia of May, 28th 2002. It is also referred to as the Act Concerning Euthanasia (Euthanasia Act) 2002*.) The officially published version of the Act in Dutch and French language is online at: [http://www.ejustice.just.fgov.be/mopdf/2002/06/22\\_1.pdf#Page16](http://www.ejustice.just.fgov.be/mopdf/2002/06/22_1.pdf#Page16) (See pp 28515-28520 of this document).

<sup>160</sup> The official name of the Luxembourg Act is *Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide*. (This translates into English as the *Law of 16 March 2009 on euthanasia and assisted suicide*.) The officially published version of the Act in French language is online at: <http://data.legilux.public.lu/file/eli-etat-leg-memorial-2009-46-fr-pdf.pdf>.

<sup>161</sup> Note, however, the doctor must be satisfied of the 'durable' nature of patient's request and must have several conversations over a reasonable period of time, which suggests some period of being in the country, or visiting it 'several' times are required.

<sup>162</sup> Note, however, that the doctor must have treated the patient for some time to ensure the 'persistence' of the patient's suffering and to hold several interviews with the patient, at reasonable intervals.

#### 4.1.1 Access for people under 18 years

A distinct feature of the schemes in Belgium and the Netherlands is that they provide access to under-18s.

For a person aged under 18 to be eligible for VAD in Belgium, they must have parental consent and:

- be in the final stages of a terminal illness
- be in constant and intolerable physical pain
- repeatedly and voluntarily request euthanasia, and
- be judged to possess 'capacity of discernment' (regardless of age).

In the Netherlands, patients aged 12-15 years can access the scheme if, in addition to the points listed above, their parents or guardians provide consent. Patients aged 16-18 years can access VAD if they have a reasonable understanding of their own interests, and their parents or guardians have been involved in the decision-making process.

#### 4.1.2 Common features

Other key features of the three schemes are:

- the two doctors that assess the patient must be satisfied that the request was well-considered, made voluntarily and not the result of external pressure, and
- patients are to be given information about their diagnosis and prognosis.

#### 4.1.3 Voluntary assisted dying in the Netherlands

An informal system of VAD evolved in the Netherlands from 1973 for patients who were experiencing unbearable suffering without the prospect of improvement. This followed a number of prominent court cases where doctors were prosecuted for assisting their terminally ill patients to die.<sup>163</sup> These cases led to a Supreme Court ruling in 1984 that a doctor would not be convicted for hastening the death of their patients if they had carefully balanced their conflicting responsibilities of the duty to alleviate hopeless suffering and their duty towards the law to preserve the patient's life. This became known in the Netherlands as a doctor acting in a situation of 'force majeure' (or necessity).<sup>164</sup>

After decades of public campaigning, the Netherlands became the first country to formally legalise VAD when the Dutch parliament passed the *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (the Dutch Act). Since 2002, this law has provided the codified criteria by which patients can access voluntary assisted dying in the Netherlands.<sup>165</sup>

The Dutch due care criteria are set out in section 2(1) of the Act which states that the doctor must:

- *be satisfied that the patient's request is voluntary and well considered;*
- *be satisfied that the patient's suffering is unbearable, with no prospect of improvement;*
- *have informed the patient about his situation and his prognosis;*
- *have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;*

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<sup>163</sup> Notable decisions include the Postma case in 1973 and the Alkmaar case in 1984.

<sup>164</sup> Sjef Gevers, 'Euthanasia: law and practice in The Netherlands', *British Medical Bulletin* 1996; 52 (No. 2): pp 326-333.

<sup>165</sup> Voluntary assisted dying is generally referred to as euthanasia and assisted suicide in the Netherlands.

- *have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;*
- *have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.*<sup>166</sup>

In its published information on the scheme, the Government of the Netherlands states:

*Requests for euthanasia often come from patients experiencing unbearable suffering with no prospect of improvement. Their request must be made earnestly and with full conviction. They see euthanasia as the only escape from the situation. However, patients have no absolute right to euthanasia and doctors no absolute duty to perform it.*<sup>167</sup>

Where the due care criteria have been met, voluntary assisted dying can then take either of two forms: a doctor can administer a fatal dose of a suitable drug to the patient, or the doctor supplies the lethal drug but the patient administers it.

The Dutch Act allows children to access voluntary assisted dying if certain additional conditions are met. Patients aged 16 to 18 years can access VAD if they have a reasonable understanding of their own interests and their parents or guardians have been involved in the decision-making process. Patients aged 12 to 15 years can access VAD if the preceding conditions apply and their parents or guardians provide consent.

Every instance of voluntary assisted dying in the Netherlands is required to be reported to a Regional Euthanasia Review Committee (RTE) which then determines whether the responsible doctor fulfilled the statutory due care criteria. The most recent annual report of the RTE states that in 2018, they received notifications of 6,126 deaths by voluntary assisted dying. This accounted for 4 per cent of the total deaths in the Netherlands in 2018.<sup>168</sup> From the RTE report, in the Netherlands during 2018:

- Just over 90 per cent of the deaths involved patients with incurable cancer, neurological disorders, cardiovascular disease, pulmonary disorders, or a combination of these conditions.
- There were three notifications involving the death of a minor (aged between 12 and 17 years).
- In over 80 per cent of cases, patients died in their homes.
- In six of the 6,126 notified cases, the RTE found that the responsible doctor did not comply with all of the due care criteria set out in section 2 (1) of the Act. (Doctors who fail to observe the statutory requirements may be criminally liable).<sup>169</sup>

At its Brisbane public hearings, the committee heard from two witnesses who shared experiences of relatives who accessed VAD in the Netherlands.<sup>170</sup>

## 4.2 Voluntary assisted dying in Belgium

In Belgium, VAD has been legal since 2002. This followed the passing of the *Loi du 28 mai 2002 relative à l'euthanasie* (the Belgian Act) by that country's Federal Parliament. Section 3 of the Act requires that the doctor assisting the patient must ensure that:

<sup>166</sup> Detailed definitions of each of the terms included in this criteria are published by the Regional Euthanasia Review Committees (RTE) in their document 'Euthanasia Code 2018. Review Procedures in Practice'.

<sup>167</sup> 'Euthanasia, assisted suicide and non-resuscitation on request', Government of the Netherlands, <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>.

<sup>168</sup> Regional Euthanasia Review Committees (RTE), Annual Report 2018, p 11.

<sup>169</sup> Regional Euthanasia Review Committees (RTE), Annual Report 2018, p 11.

<sup>170</sup> Kiki Paul, public hearing transcript, Brisbane, 23 August 2019, p 6; Peter Hamelink, public hearing transcript, Mackay, 29 October 2019, p 31.

- *the patient is legally competent and conscious at the moment of making the request;*
- *the request is voluntary, well-considered and repeated, and is not the result of any external pressure; and*
- *the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.*<sup>171</sup>

Before carrying out VAD, the doctor must:

- inform the patient about their health condition and life expectancy, and
- discuss with the patient their request for euthanasia and the possible therapeutic and palliative courses of action and their consequences.<sup>172</sup>

Together with the patient, the doctor must assess whether there is a reasonable alternative for the patient and whether their request is completely voluntary. The doctor must also be certain of the patient's constant physical or mental suffering and of the durable nature of their request. To determine this, the doctor should have several conversations with the patient over a reasonable period of time and take into account the progress of the patient's condition.<sup>173</sup> A second medical opinion is then required to confirm that these criteria have been met. The reviewing doctor must be independent of the patient and the first doctor, and must be competent to give an opinion about the disorder in question. The doctor must also be certain that the patient has had the opportunity to discuss their request with persons that they wanted to meet.<sup>174</sup>

Belgium's Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie (CFCEE) is required to review the documents relating to all deaths by voluntary assisted dying within two months of each death. The CFCEE report their statistics and findings to the Belgian Parliament every two years.<sup>175</sup>

In 2014, Belgium amended its law on euthanasia to authorise doctors to terminate the life of a minor in specific circumstances. These requirements are that doctors must first verify that the child is in a hopeless medical situation of constant and unbearable physical suffering that cannot be eased, and will cause death in the short term resulting from a serious and incurable, accidental or pathological condition. The minor must express their request in writing and psychiatrists must then conduct examinations and tests to determine the level of discernment and ensure that the minor was not influenced by a third party. Parents can prevent the request from being carried out.

Speaking at a public hearing for the inquiry, Professor Luc Deliens gave an outline of the changes and the background:

*... there was a huge debate about competency for children...*

*It is far more difficult to assess competency in a patient whose brain cancer has metastasised than it is for children. The whole issue was about competency for children. I think the lawmaker has found a very nice solution by putting it to a multidisciplinary team. Instead of one doctor who is assessing your competency, it is now a multidisciplinary team, with a psychologist and psychiatrist on board et cetera, to judge the competency of children. Another issue which we well know from research is that they age very quickly when they are undergoing two or three years*

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<sup>171</sup> European Journal of Health Law, 10: 329-335, 2003, contains an English translation of the Belgian Act.

<sup>172</sup> European Journal of Health Law, 10: 329-335, 2003, contains an English translation of the Belgian Act, s 2(1).

<sup>173</sup> European Journal of Health Law, 10: 329-335, 2003, contains an English translation of the Belgian Act, s 3.

<sup>174</sup> European Journal of Health Law, 10: 329-335, 2003, contains an English translation of the Belgian Act, s 2(3).

<sup>175</sup> French language copies of these reports are available online on the CFCEE website: <https://organesdeconcertation.sante.belgique.be/fr>.

*of treatment in the hospital. All of the doctors say, 'They are very adult to me—more adult than an average child of the same age'.*<sup>176</sup>

Speaking at the committee's July 2019 hearing in Brisbane, Professor Ben White indicated that, based on the latest data at the time, only three people under the age of 18 years had accessed the regime in Belgium since the laws were amended in 2014.<sup>177</sup>

### 4.3 Voluntary assisted dying in Luxembourg

In 2009, the Grand Duchy of Luxembourg adopted *The Law of 16 March 2009 on euthanasia and assisted suicide* (the Luxembourg Act), becoming the third European country to decriminalise voluntary assisted dying, after the Netherlands and Belgium. Chapter II, Article 2 of the Luxembourg Act states that a doctor will not be punished criminally for responding to a request for voluntary assisted dying if the following fundamental conditions are met:

- the patient is a capable and conscious adult at the time of their request;
- the request is made voluntarily, after reflection and, if necessary, repeated, and does not result from external pressure;
- the patient is in a terminal medical situation and shows constant and unbearable physical or mental suffering without prospects of improvement, resulting from an accidental or pathological disorder;
- the patient's request for euthanasia or assisted suicide is made in writing.<sup>178</sup>

The procedure a doctor in Luxembourg must follow after receiving a patient's request for VAD is similar to the procedures in Belgium under the Belgian Act. All deaths and related documentation must be registered by the responsible doctor with Luxembourg's La Commission Nationale de Contrôle et d'Evaluation (National Commission for Control and Assessment), which is responsible for the administration of the voluntary assisted dying laws.

### 4.4 Voluntary assisted dying in Switzerland

Swiss law permits 'assisted suicide' so long as the person commits the act themselves. Anyone who encourages a suicide or provides assistance must not have any 'selfish motives' in relation to their actions. This assisted suicide law has been in the Swiss *Criminal Code* since 1942. A translation of the relevant article is copied below.

*Art. 115 Inciting and assisting suicide*

*Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.*<sup>179</sup>

Article 115 does not link assisted suicide with any specific terminal illness or ill-health, or specify medical conditions under which assistance with suicide may be given. There is also no requirement for

<sup>176</sup> Public hearing transcript, Brisbane, 21 October 2019, p 10.

<sup>177</sup> Public hearing transcript, Brisbane, 5 July 2019, p 7.

<sup>178</sup> Government of Luxembourg, Ministry of Health and Ministry of Social Security, Euthanasia and assisted suicide Law of 16 March 2009 - 25 questions 25 answers, Appendix 1 contains an English language translation of the *Law of 16 March 2009 on euthanasia and assisted suicide*, <http://sante.public.lu/fr/publications/e/euthanasie-assistance-suicide-questions-reponses-fr-de-pt-en/euthanasie-assistance-suicide-questions-en.pdf>.

<sup>179</sup> The Federal Assembly the Swiss Confederation, Swiss Criminal Code (Status as of 1 July 2019) Article 115, pp 61-62, <https://www.admin.ch/opc/en/classified-compilation/19370083/201907010000/311.0.pdf>.



a doctor to be involved in the process, either as a consulting or administering practitioner. The Swiss Academy of Medical Sciences has described the role of physicians in assisted suicide as follows:

*The role of physicians in the management of dying and death involves relieving symptoms and supporting the patient. Their responsibilities do not include offering assisted suicide, nor are they obliged to perform it. Assisted suicide is not a medical action to which patients could claim to be entitled; it is, however, a legally permissible activity.*<sup>180</sup>

#### 4.4.1 Swiss right-to-die societies

A number of non-profit organisations in Switzerland, known as right-to-die societies, directly support their members who want to die at a time of their own choosing. The Swiss government closely monitors the actions of these groups, which must operate within the framework of Article 115 in order to be lawful. These groups, such as EXIT and DIGNITAS, have rules that restrict their end-of-life services to members of their organisation who demonstrate that they have the following conditions:

- a terminal illness and/or
- an unendurable incapacitating disability and/or
- unbearable and uncontrollable pain.<sup>181</sup>

Death is usually induced through a lethal dose of barbiturates prescribed by a doctor. Ingestion of the poison, whether by drinking it or through the use of intravenous drips or stomach tubes, must be carried out by the person wanting to die, without any outside influence.

The most recent statistics published by the Swiss Federal Statistical Office show that there were 928 deaths by ‘assisted suicide’ in Switzerland in 2016. For the period 2003 to 2016, a total of 6,137 persons died by this manner.<sup>182</sup>

#### 4.4.2 Australians travelling to Switzerland to die

A number of Australians have travelled to Switzerland to access the legal assisted suicide services there. Figures published by DIGNITAS show that 32 Australian citizens were assisted to die by that organisation in Switzerland between 2003 and 2018.<sup>183</sup> A recent high-profile case was that of 104 year-old Australian scientist, David Goodall, who travelled to Switzerland to die in 2018. In February 2019, 54 year-old Victorian man Troy Thornton also chose to end his life there. The committee received a written submission from Mr Thornton’s wife, Mrs Christine Thornton. In further evidence at a public hearing, Mrs Thornton shared her husband’s experience with the committee:

*Back in 2014 he [Troy] was diagnosed with degeneration of the back of the brain, the cerebellum, which was basically dissolving. There was no cure. Back in 2014 we were told that that was it. There was nothing we could do and we were told he would have around five years before the disease would eventually take him. It was a very slow process; it slowly attacked the body from being able to walk, talk, breathe, swallow—all the things that we all take for granted.*

*Last year in July the disease changed to the more aggressive form of the disease, which was multisystem atrophy. As soon as that was diagnosed in July they said, ‘It will take you very quickly,’ and that is when he said, ‘I’m going to choose my own way out.’ After being in the emergency services department for over 30 years and experiencing all forms of death from*

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<sup>180</sup> Swiss Academy of Medical Sciences, *Management of dying and death* (2018), p 22.

<sup>181</sup> DIGNITAS, Brochure of DIGNITAS, <http://www.dignitas.ch/images/stories/pdf/informations-broschuere-dignitas-e.pdf> and EXIT, FAQ Who Is Eligible for this Option, <https://exit.ch/en/faq/>.

<sup>182</sup> Federal Statistical Office (Switzerland), *Assistierter Suizid nach Geschlecht und Alter* (December 2018), <https://www.bfs.admin.ch/bfsstatic/dam/assets/7008105/master>.

<sup>183</sup> DIGNITAS, *Accompanied Suicides per Year and Residence*, <http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2018.pdf>.

*suicide to lots of things anyone can imagine when you are working in that industry, he said, 'I don't want that. I want to make my own choices'.*<sup>184</sup>

Mrs Thornton advised that her late husband's condition would likely not have met the eligibility criteria of Victoria's *Voluntary Assisted Dying Act 2017* which came into effect four months after his death in Switzerland. Mrs Thornton further stated:

*Not everyone is going to agree, and you do not have to. It should be a choice. If you do not want to ever make that choice, then you never have to. I do not understand why we cannot allow people to make that choice. Until you are in that situation - Troy would never have thought he would make the choice to end his life. However, when you are actually faced with something that is incurable, there is no coming back.*<sup>185</sup>

#### 4.5 Voluntary assisted dying in the United States of America

In the United States of America (US), VAD is commonly referred to as 'physician-assisted suicide' or 'aid-in-dying'. At the time of writing, VAD is legal in nine US states as well as in the District of Columbia, Washington D.C. In 1997, Oregon became the first US state to enact legislation enabling VAD. Oregon's scheme allows terminally-ill persons to end their lives through voluntary self-administration of lethal medications that have been expressly prescribed by a physician for that purpose.<sup>186</sup>

Eight other states followed Oregon with similar laws to legalise VAD: Washington (2008), Vermont (2013), California (2016), Colorado (2016), District of Columbia (2017), Hawaii (2019), New Jersey (2019), and Maine (2020).

In addition to the above states and the District of Columbia, Montana's Supreme Court ruled in 2009 that nothing in that state's law prohibited a doctor from honouring a terminally ill, mentally competent patient's request by prescribing medication to hasten the patient's death.<sup>187</sup> Since that ruling, several Bills have been introduced in Montana aiming to either codify or ban the practice; however, none have passed.

All US VAD schemes all have similar provisions based on the Oregon model. If their eligibility requirements are met, they allow mentally competent, terminally-ill adult residents to voluntarily request and receive a prescription medication to die at a time of their choosing. The state acts all require that the requestor meets the following rules: be a state resident with a minimum age of 18; have a life expectancy of six months or less; and have made two oral and one written request to a doctor to die. The timeframe for the oral requests to doctors varies between states from 15 to 20 days.<sup>188</sup>

<sup>184</sup> Public hearing transcript, Brisbane, 13 September 2019, p 50.

<sup>185</sup> Public hearing transcript, Brisbane, 13 September 2019, p 51.

<sup>186</sup> Oregon's *Death with Dignity Act* was enacted on 27 October 1997 after a ballot measure to allow for such a scheme was supported in 1994. A ballot to repeal the 1997 legislation was defeated soon after the law's enactment.

<sup>187</sup> Montana Supreme Court, DA 09-0051, 2009 MT 449, Robert Baxter, Stephen Speckart, M.D., C. Paul Loehnen, M.D., Lar Autio, M.D., George Risi Jr., M.D., and Compassion & Choices, Plaintiffs and Appellees, v. State of Montana and Steve Bullock, Defendants and Appellants, [https://appecm.mt.gov/PerceptiveJUDSupremeCourt/APP/connector/1/527/url/321Z18W\\_01YZNVY7P00473J.pdf](https://appecm.mt.gov/PerceptiveJUDSupremeCourt/APP/connector/1/527/url/321Z18W_01YZNVY7P00473J.pdf).

<sup>188</sup> The name of the relevant statute in each US state is: End of Life Option Act (California); End of Life Options Act (Colorado); D.C. Death with Dignity Act (District of Columbia); Our Care, Our Choice Act (Hawaii); Death with Dignity Act (Maine); Aid in Dying for the Terminally Ill Act (New Jersey); Death with Dignity Act (Oregon); Patient Choice and Control at the End of Life Act (Vermont); and the Death with Dignity Act (Washington).

## 4.6 Voluntary assisted dying schemes in Canada

Voluntary assisted dying is known in Canada as ‘medical assistance in dying’ or ‘MAID’. The first such scheme to become legal in Canada was in the province of Québec in 2014. This scheme allowed medical assistance in dying for mentally competent patients who met a strict set of criteria. A national MAID scheme was legislated by the Parliament of Canada in 2016 via amendments to their Criminal Code.<sup>189</sup> The Canadian Criminal Code now defines ‘medical assistance in dying’ as:

- (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or*
- (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.*<sup>190</sup>

A person requesting to access Canada’s MAID scheme must meet all of the following criteria:

- (a) they are eligible - or, but for any applicable minimum period of residence or waiting period, would be eligible - for health services funded by a government in Canada;*
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;*
- (c) they have a grievous and irremediable medical condition;*
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and*
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.*<sup>191</sup>

For criteria (c), the Canadian Criminal Code defines a person as having a ‘grievous and irremediable medical condition’ only if they meet all of the following criteria:

- (a) they have a serious and incurable illness, disease or disability;*
- (b) they are in an advanced state of irreversible decline in capability;*
- (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and*
- (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.*<sup>192</sup>

Informed consent must be given both at the time of the request for MAID and immediately before it is provided. Consent can be withdrawn at any time. Informed consent requires that the person has consented to medical assistance in dying after having received all of the information needed to make the decision. This information includes: a medical diagnosis; the available forms of treatment and the available options to relieve suffering, including palliative care. Before a medical practitioner or nurse practitioner can provide a person with medical assistance in dying, they must be of the opinion that the person has met all of the safeguards and criteria required under the Criminal Code.<sup>193</sup> These requirements include that: proper documentation has been submitted by the requester; two

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<sup>189</sup> This legislation was titled, ‘An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) (S.C. 2016, c. 3)’.

<sup>190</sup> Criminal Code (R.S.C., 1985, c. C-46) s 241.1.

<sup>191</sup> Criminal Code (R.S.C., 1985, c. C-46) s 241.2 (1).

<sup>192</sup> Criminal Code (R.S.C., 1985, c. C-46) s 241.2 (2).

<sup>193</sup> Criminal Code (R.S.C., 1985, cl C-46) s 241.2 (3)

independent witnesses have signed these documents; there has been independent medical confirmation of all requirements; the required amount of time has elapsed between the request and the requested provision of MAID; it has been ensured that the person has the opportunity to withdraw their request and that express consent is given immediately before providing the medical assistance in dying. The Canadian scheme allows eligible persons access to both physician-administered and self-administered methods. Each application to access MAID must include a physician or nurse practitioner who either:

- directly administers a substance that causes death, such as an injection of a drug (this is referred to as ‘clinician-administered medical assistance in dying’); or
- provides or prescribes a drug that the eligible person takes themselves, in order to bring about their own death (this is referred to as ‘self-administered medical assistance in dying’).

In the provinces where MAID is allowed, physicians and nurse practitioners are permitted to provide medical assistance in dying services. Those who can ‘help’ provide medical assistance in dying include: pharmacists; family members or other people who the recipient asks to help; and health care providers who help the physicians or nurse practitioners. Each of these people can assist in the process without being charged under criminal law. Physicians, nurse practitioners and other people who are directly involved must follow the rules set out in the Criminal Code and all applicable provincial and territorial health-related laws, rules and policies.

As part of this inquiry, the committee received a briefing from two Canadian doctors, Dr Sandy Buchman, President, and Dr Jeff Blackmer, Executive Vice President of International Health, at the Canadian Medical Association. Dr Buchman shared his experiences administering voluntary assisted dying for patients since the MAID scheme was legalised in Canada in 2016.<sup>194</sup> The committee heard that after two years of operation, approximately 1.5 per cent of deaths in Canada during that time were through assisted dying, and the vast majority of those were through the direct administration of a substance by the physician as opposed to the patient taking a substance that has been prescribed to them.<sup>195</sup>

Dr Sandy Buchman, told the committee:

*As passionate as I am about palliative care—you will not get a more passionate supporter—I recognise, like most of modern medicine, that palliative care cannot do it all and that there are situations or patient issues and problems and suffering that often cannot be addressed, even with all the best means that we have at our disposal.*<sup>196</sup>

In support of this, Dr Buchman advised the committee:

*I work hard as a palliative care physician to explore my patients’ suffering, and we know that palliative care can do a lot. Just listening to your patient as well as exploring their suffering, in any of the domains of physical, psychosocial, spiritual or existential suffering, is the key to this and often reduces the wish to hasten death by up to 80 per cent... I see it (MAID) as consistent with my efforts to alleviate suffering and, ultimately, to me it is an act of compassion and not abandonment. It has not damaged the doctor-patient relationship. As a matter of fact, I think it enhances trust when you are willing to explore this legal end-of-life option with patients. I have not seen that it has had a detrimental effect on the view of palliative care as a discipline.... It has not damaged our reputation. It has not hurt at all and may have in fact enhanced it in many ways.*<sup>197</sup>

<sup>194</sup> The transcript of the private briefing held on 10 April 2019 is available from the inquiry webpage.

<sup>195</sup> Dr Jeff Blackmer, private briefing transcript, Brisbane, 10 April 2019, pp 1-2.

<sup>196</sup> Private briefing transcript, Brisbane, 10 April 2019, p 3.

<sup>197</sup> Private briefing transcript, Brisbane, 10 April 2019, p 3.

## 5 Queensland community views

The terms of reference for the inquiry require the committee to inquire into and report on community views and relevant health practitioners' views on the desirability of supporting VAD including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.

### 5.1 Submissions received

The committee accepted 4,719 written submissions for the inquiry. Of the Australian submitters that identified their postcode, 93 percent were from Queensland. Ninety-eight percent (4,602) of submissions commented on VAD, with the majority of submissions indicating support for the introduction of VAD in Queensland.

Submitters expressed diverse views on the desirability of introducing VAD in Queensland. Some submitters expressed views shaped by their own lived experiences. Others shared views that appear to be based on philosophical beliefs or religious values, while others referred to research about VAD in their submissions.

### 5.2 The hearings and briefings

As noted above, the committee held 34 hearings and forums to hear from groups and individuals. At these meetings, witnesses expressed strong opinions both in favour of and in opposition to the introduction of VAD. The following sections present a snapshot of the evidence from witnesses appearing before the inquiry as well as the evidence gathered through submissions.

### 5.3 Reasons for supporting voluntary assisted dying

Of the submissions received from organisations individuals who supported 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 self-determination 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.

#### 5.3.1 Individual choice and the right to self-determination and control at the end of life

Allowing people autonomy and self-determination at the end of life was often a reason expressed by witnesses at public hearings in support of VAD. For example, the committee heard the following testimony from Ms Jeanette Wiley of Dying with Dignity Queensland:

*The lawmakers must take on board what the majority of Queenslanders want. The word that sums that up is choice—choice to receive the very best professional help in aged-care facilities, choice to receive the very best care from our palliative providers and choice when the time comes that we feel that our life has reached a stage where we have no quality, our suffering is intolerable and a peaceful death is our choice.*

*We respect those who disagree and respect the choices they have made throughout their lifetime. All we ask is that they pay us the respect we request and allow us our choice to die when our time comes with dignity and under the law.<sup>198</sup>*

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<sup>198</sup> Public hearing transcript, Brisbane, 23 August 2019, p 2.

At the Toowoomba hearing, Mr Alan Roughan expressed the view that personal freedom applies to most things in life but not the ability to die in a manner, or at a time, of one's choosing. He stated:

*I respectfully ask you all, regardless of your own personal beliefs, to give us the option of voluntary assisted dying. We live in a wonderful society with so many freedoms to do as we please, except when we wish to die for whatever reason. Nobody is allowed to be humane and assist us to die with dignity if we wish. Palliative care is fine, but it has its limitations in these circumstances.*<sup>199</sup>

Some submitters used the phrase 'My life, my choice' to express the view that they believed in a right to autonomy and did not want others making decisions for them.<sup>200</sup>

The Grattan Institute recognised the desire for autonomy at the end-of-life in its submission:

*A good death allows people to determine who is present, to have time to say goodbye, to control the timing of death, and not to have continued medical interventions when quality of life is low and there is little or no hope of improvement.*<sup>201</sup>

The committee also heard from seriously ill people who believed the choice should be theirs. A number of witnesses and submitters told the committee that they planned to end their lives in Switzerland so that they could choose VAD.<sup>202</sup>

At the Brisbane hearing on 13 September 2019, Mr Everaldo Compton AM, a former Presbyterian minister and founding director of National Seniors Australia, the nation's peak body representing older Australians, expressed the view that people wanted choice but that only a few would exercise that choice. He told the committee:

*...it is the right of all people to choose. What I believe is that only a small number will—maybe five per cent of the population—but they have the right to have that choice, the same as the rest of them have the right not to make that choice.*<sup>203</sup>

Others considered that having the choice to access VAD would relieve tension about pain and suffering (death anxiety) for patients in palliative care by knowing they had a legal option to end their life. In her submission, recently retired psychologist Ms Pamela Orreall stated:

*Death Anxiety is a well-researched phenomena (Yalom) if Voluntary Assisted Dying were available this would in many cases diminish the anxiety as people would experience a sense of control of the end of life process, thus decreasing despair and enabling integrity.*<sup>204</sup>

A witness at the Townsville hearing, who requested confidentiality, explained her situation in this way:

*Pancreatic cancer is acknowledged as being one of the cancers where pain cannot be controlled at the end. This means the patient is probably placed in an induced coma and left to die of starvation and thirst over a period of days or even up to two weeks or more. This is a terrible way to die. My brother and three of my friends died from pancreatic cancer. They lived in shocking pain for five to eight months before they finally succumbed to the peace of death. I have no*

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<sup>199</sup> Public hearing transcript, Toowoomba, 17 May 2019, p 16.

<sup>200</sup> See for example, submissions, E074, E308, E382, E954 and E1822.

<sup>201</sup> Submission 24, p 12.

<sup>202</sup> Ms Tanya Battel, public hearing transcript, Brisbane, 23 August 2019, p 52; Mrs Judith Echard, public hearing transcript, Cairns, 28 May 2019, p 18; Coral Mast, public hearing transcript, Mossman, 29 May 2019, p 10; Cecile Scherrer, public hearing transcript, Hervey Bay, 15 July 2019, p 28; Carole Tilling-Rekort, submission 160, p 1.

<sup>203</sup> Public hearing transcript, Brisbane, 13 September 2019, p 63.

<sup>204</sup> Submission E1831, p 1.

*intention of spending my last days like they did. I intend to end my own life. I know that it will be quick and peaceful.*

*I cannot find words to describe the peace of mind I have in knowing that I will not suffer at the end. Everyone should have access to this peace of mind. The worst part of ending my own life to escape the pain of death is that it has to be done alone. No-one can be with me in case they are accused of murder. Also, it has to be done while I am still capable of carrying out the necessary procedure and this means long before necessary. If we had a law, I would be able to have my family and perhaps doctors and nurses close by in case anything went wrong. I would not die alone. I would be able to wait until the last possible moment before choosing to die.*<sup>205</sup>

The Human Rights Commission argued that the right to personal autonomy should be balanced with state's obligation to protect life.<sup>206</sup>

#### **Committee comment**

The committee notes the strong desire expressed by submitters and witnesses for people to be able to exercise choice about the timing and manner of their death. 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.

#### **5.3.2 Voluntary assisted dying is necessary for the relief of pain and suffering that cannot be relieved by palliative care**

A recurring theme at the hearings and in submissions was that the introduction of VAD was necessary for the relief of pain and suffering at the end of life that palliative care may not alleviate. For patients whose symptoms are not relieved through palliative care, the pain and suffering can be unbearable.<sup>207</sup>

A submission from Dignity in Dying (DiD) cited information from the Australian Government funded Palliative Care Outcome Collaboration (PCOC), which stated:

*In the final stage of life, some people do experience problems with fatigue, pain, appetite, breathing, bowels, insomnia and nausea. PCOC's information tells us that around 5% of people experience severe distress from some, not all, of these problems.*<sup>208</sup>

Dying With Dignity Victoria (DWDV) noted in their submission:

*Palliative care has been reasonably successful in easing pain in the terminally ill, and is a valuable service to the community. However it cannot relieve all forms of suffering at end of life, and does not address the issue of intolerable suffering from ailments which are not terminal.*<sup>209</sup>

At public hearings, many witnesses provided personal accounts of the suffering of family members while they were receiving palliative care.<sup>210</sup> For example, Ms Sandie Wands submitted the following detailed account of the death of her mother:

*My beautiful mother lay in that bed, rotting in front of my eyes for an entire week beyond that day. Once they stopped taking her obs and said she was nil by mouth, it meant that medications*

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<sup>205</sup> Unidentified witness, public hearing transcript, Townsville, 29 May 2019, p 26.

<sup>206</sup> Neroli Holmes, Human Rights Commission, public hearing transcript, Brisbane, 5 Jul 2019, p 31.

<sup>207</sup> See, for example, Dying with Dignity, submission 1214, p 4; Sheila Nagel, public hearing transcript, Caloundra, 3 May 2019, p 33; Paul Smith, public hearing transcript, Hervey Bay, 15 July 2019, p 16; Moya Jackson, public hearing transcript, Bundaberg, 16 July 2019, p 16; Annabelle Vaughan, public hearing transcript, Gold Coast, 10 September 2019, p 29.

<sup>208</sup> Submission 1214, p 4.

<sup>209</sup> Submission 1216, p 3.

<sup>210</sup> See, for example, submissions 103, 124, 1573, 1577, 2471, and E1644.

*that she had so heavily dependent on (and was addicted to) were no longer being administered. In my opinion, that sent her into a violent withdrawal and she spent a lot of time, thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing. She was starving to death and by this stage was skeletal, and her dehydration was obvious. Her mouth was caked with thrush and because she had suffered very severe respiratory illnesses in her lifetime, the infected mucous was pooling on her chest, further preventing her from breathing. .... In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time. She continued to rot in that bed and I continued to sleep in the room with her and to sit beside her and listen to her every breath in ..... and every breath out .... praying that it would be her last one, whilst all the while being petrified of losing her. ... That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through. Her final days served absolutely no purpose to her or anyone else, and left me with a type of post-traumatic stress from having gone through it with her. What perplexes me about the whole situation is that if I had an animal that I allowed to suffer like that, I would most likely be charged, yet apparently it was ok for my mother to suffer that way.*

*I vowed and declared, as I sat sobbing in the car before I left the hospital, that I would do whatever I could to see assisted dying legalised.*<sup>211</sup>

Ms Annabelle Vaughan described the experiences of her grandparents as follows:

*My grandfather, a proud and independent man, begged for an end to days of sitting incontinent, immobile and helpless in a body that had crumbled around him. My grandmother told me every time I visited her nursing home that she was ready to die and asked why no-one would let her do so.*<sup>212</sup>

The committee also heard from witnesses and submitters that in some situations no amount of medication can relieve suffering. One example of this was provided by Ms Deborah Green who told the story of the death of her partner Dennis:

*From that time in January until he died in September, he had no time without pain. The lowest pain level we got him to was about a four. Some days he was screaming in agony and there was nothing that could be done. His head and neck specialist at the Royal Brisbane looked after him. He got some radiation which extended his life so he could attend his son's wedding. However, it really did not touch the sides of the pain. We had lots of access to drugs—so many drugs, so many different sorts of drugs—but nothing worked.*<sup>213</sup>

Others lamented that we treat our animals better than we treat our elderly.<sup>214</sup> In her testimony in which she supported the introduction of VAD, Ms Sherie Plotzki described to the committee the conditions her mother was enduring, and commented that animals are treated with more compassion:

*This is not my choice; this is her choice. Twelve months ago she did not have this cancer eating away at her arm. The aneurisms in the stomach were not this big. Once the cancers on her face explode they are one month behind the one on the other arm that exploded last week. That will take out her eye and nose. It will end up taking out half of her face. This is cruel and this should not be allowed. We treat our animals with more compassion than we treat our elderly.*<sup>215</sup>

<sup>211</sup> Submission 175, pp 1-2.

<sup>212</sup> Public hearing transcript, Southport, 10 September 2019, p 29.

<sup>213</sup> Public hearing transcript, Mackay, 29 October 2019, p 24.

<sup>214</sup> For example, see submissions 646, 650, 670, 1642, E1995 and E2035.

<sup>215</sup> Public hearing transcript, Ipswich, 9 September 2019, p 16.



By way of contrast, many contributors to the Inquiry argued that access to effective palliative care negated the need for VAD. Their arguments are outlined in section 4.3.4.

The committee also heard that there are beneficial sides to human suffering and death. The Most Reverend Mark Coleridge of the Roman Catholic Church told the committee:

*...there can be that sense that suffering and death are an unmitigated evil and that we should do all in our power to deny or escape from suffering and death. Human experience, to which we have to listen as well—and I have suggested this in my opening remarks—would suggest that suffering and death, though not good, can in fact in some mysterious and powerful way produce extraordinary human riches.*<sup>216</sup>

Dr Katrina Neal offered similar sentiments about suffering:

*We need to reframe how we feel about suffering. You might think it is easy for me to say this, but I know about suffering. Like all of you who have lost family members, I have lost a father to old age, a mother to cancer, three brothers to cancer and a 24-year-old son to a dreadful disability due to a chromosomal abnormality from birth. His life was one of suffering. I would have to say that, although I would never wish that upon anybody, as a result of his suffering and what he brought to our family, the other three children, because of what they saw, what they were required to do and how they were required to help, they are amazing human beings who appreciate and love every second of life. They know how precious life is and they know how he suffered because he could not do what they were doing. In some sense they grew a tremendous amount from understanding his suffering.*<sup>217</sup>

#### **Committee comment**

The committee notes that the final stages of life can involve a range of pain and other symptoms for people and, for around five percent of people, this suffering can be severely distressing.

The committee also notes that some Queenslanders experience profound suffering as they die, in part due to the challenges of accessing palliative care. The committee also notes that, even with access to the best quality palliative care, that sometimes not all suffering can be palliated.

#### **5.3.3 VAD would provide dignity for the patient and less distress for their loved ones**

Many people mentioned the importance of maintaining dignity at the end-of-life in their evidence to the inquiry. More often than not, they expressed the view that death should be dignified and that people should not have to die in circumstances where they lose independence, choice and control.

At the public hearing in Hervey Bay, Mr Scott Einam described the death of his wife through motor neurone disease:

*I lost my wife to motor neurone disease at the age of 47. For the last 12 months I had to listen to her every night asking me if she could die. I wish I could have helped her ... She died with no dignity, lots of shame, lots of embarrassment. That is not a way to die; not when you are 47 and your mind is 100 per cent.*<sup>218</sup>

Ms Susan Thwaites wrote the following submission about of the final days of her father's life:

*Where is the dignity of a grown man having to wear an adult nappy, not being able to urinate on his own, where is the dignity of a man not being able to brush his own teeth, where is the dignity of having a nasal tube in to feed his stomach nourishment to keep him alive, a drip in his*

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<sup>216</sup> Public hearing transcript, Brisbane, 23 August 2019, p 18.

<sup>217</sup> Public hearing transcript, Brisbane, 13 September 2019, p 65.

<sup>218</sup> Public hearing transcript, Hervey Bay, 15 July 2019, p 15.

*arm to keep up the fluids his body required to live, where is the dignity of not being able to shower, wash his body or even shave is own face.*

*I rarely left my father[']s side in those thirteen horrific, heartbreaking days, I relied on family to bring my food. Three days before my father passed away, they finely connected a morphine contraption to his frail body and continued to torture him with the removal of fluids from his red raw throat, pain racked and exhausted, the day he passed away at 8am they removed his feeding tube, at 11am the nurse came in and gave my father a so called top up morphine injection top up because she said she felt he was in pain, I asked her how would she know this? her reply was the wrinkles in his forehead indicated he was in pain. It was only fifteen minutes later that my father passed away, finely at peace, no more torture at the hands of a medical profession tied up by the law and protocol.<sup>219</sup>*

At the Bundaberg public hearing, Ms Cynthia Workman spoke in similar terms about the loss of dignity suffered by her late father-in-law:

*His pain was uncontrollable, even with the drugs administered by the palliative care he was receiving. His body was slowly shutting down, which was so distressing for him, with needing to use nappies and the indignity of having to be bathed and changed by another person. His breathing was laboured. His mouth was dry. Eating was getting harder and in the end all he could eat was soft foods. This once proud man had had enough. Unfortunately, he had to put up with all of this suffering until his last laboured breath.<sup>220</sup>*

In her submission, Ms Carol Cronk described the traumatic death of her parents stating:

*Both of my parents spent their last years enduring horrendous physical and emotional suffering in the "high care/needs dementia wards My father due to vascular type dementia. My mother due to 93yrs old with unfixable two broken shoulders and ribs which occurred in a normal ward in the nursing home, then her last 6mths being forced to live in this death ward in 24hr pain and intense shame, toilet issues all in her nappy, fed like a baby and machine hoisted naked by strangers into a shower. Her everyday screams were for God to take her. then at their end of this "nightmare existence , both died with my sister with them which she described as intensely [sic] traumatic for them and for herself. (and she had been a palliative care nurse.)<sup>221</sup>*

At the Rockhampton public hearing, Ms Linda Gardiner told the committee that she did not want to experience dying the way her mother had:

*...I do not want my children watching me drool, moan and soil myself. Towards the end, my mother was asking for assistance to go to the bathroom. She was told, 'We are too busy. Just sit there and soil your nappy.' That was the last time she basically spoke to any of us. She just refused. She had lost all dignity and she just wanted to die.<sup>222</sup>*

Professor Colleen Cartwright from Southern Cross University advised the committee that loss of dignity was a greater factor in requests for assistance to die than was pain:

*... in all of my research—is that it is not pain that causes people to request assistance to die; it is loss of control, loss of independence, being a burden on families, loss of dignity. One woman said to me, 'All my life I've been independent. If at the end of my life you force me to be dependent, you have negated my whole life'.<sup>223</sup>*

<sup>219</sup> Suzanne Thwaites, submission 244, p 1.

<sup>220</sup> Public hearing transcript, Bundaberg 16 July 2019, p 15.

<sup>221</sup> Submission E036, p 1.

<sup>222</sup> Public hearing transcript, Rockhampton 17 July 2019, p 19.

<sup>223</sup> Public hearing transcript, Southport, 10 September 2019, p 38.

Many people who contributed to the inquiry spoke of the loss of dignity at end of life and the distress this caused for families and loved ones. They believe that this distress would not occur if VAD were available. One example of this was provided by Mr Jon Adams:

*Words cannot begin to describe the agony she was in. I was there. It was simply grotesque. After her passing, one of the palliative care nurses told me that her death was one of the worst she had ever seen. She described it as unimaginably awful and that no-one deserved to die like that, but Gay did. Me and my brother, her husband and her friends have been haunted by her death for more than a decade and will continue to be for the rest of our lives.*<sup>224</sup>

In her submission Ms Sandra Baumann described the painful death of her mother from breast cancer and the damaging effect it had on her family:

*From the beginning of her operation in October to the 30th June when we lost her it was pain for her.*

*The effect on our family was consuming. My sister who had a 6 month old baby lost her milk, my father was overcome, and we were all so sad that there was no answer for the kind of pain mum was to suffer. There is a need to pass legislation in Queensland to allow people the right to end their suffering. I am sure if this letter can be used to support and help Dying with Dignity it will be a positive step.*<sup>225</sup>

Mr Ross Dignan's submission described the traumatic death of his grandmother, and the traumatic effect it had on her children:

*My grandmother suffered a stroke and spent the last four years of her life in a hospital bed unable to talk or move. Since it was possible, from her eyes, to see that her brain was still functioning in other ways, this experience must've been extremely traumatic for her. It was definitely extremely traumatic for her offspring. (But some sadists wish to ensure such trauma is experienced by most if at all possible).*<sup>226</sup>

Mr William Preedy outlined the distress he experienced watching the suffering of his father. In his submission, Mr Preedy suggested that expediting the process through VAD would prevent these consequences:

*What could be a more unnatural way of interfering with a natural death than withdrawing all nutrients and hydration! I realise that the Palliative Team could only act according to current law. My Father's slow, horrid yet inevitable death shall haunt me as long as I live. Once the decision is made to withdraw life support, surely the cessation of the patients and their families suffering must be accelerated. To allow an utterly inevitable but slow painful death to linger is absolutely inhumane.*<sup>227</sup>

Conversely, the Right Reverend Keith Joseph of the Anglican Church argued that there is dignity in caring for a terminally ill patient:

*Dignity comes from the love and from the care that is given. In contrast, I do not believe that dignity comes from the taking of a person's life, whatever the motives. For Anglicans, this crosses a boundary—the taking of life of course being very different from letting someone die.*<sup>228</sup>

A submitter whose name was withheld made the following comment:

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<sup>224</sup> Public hearing transcript, Brisbane, 23 August 2019, p 65.

<sup>225</sup> Submission 151, p 1.

<sup>226</sup> Submission 47, p 1.

<sup>227</sup> Submission E1971, p 1.

<sup>228</sup> Public hearing transcript, Brisbane 23 August 2019, p 21.

*VAD proposals are, in reality, legalized homicide. There is no dignity in killing a person and no dignity in being killed before the natural process of dying occurs.*<sup>229</sup>

In his submission to the inquiry, Mr Milon Chowdhury acknowledged the distress that comes with watching loved ones struggle but thought that the solution was better palliative care rather than VAD:

*I have read a number of the submissions to the Committee that are available on-line, and I understand the heartache and distress of watching a loved family member struggle with dreadful disease, having experienced it myself. One of the submissions referred to Huntington's Disease, a truly awful disease.*

*...greater support must be given to palliative care. I do not support assisted suicide, which is masked by euphemisms such as euthanasia, voluntary assisted dying, or dying with dignity.*<sup>230</sup>

#### **Committee Comment**

The committee notes concerns raised in submissions and other evidence about the loss of dignity during dying and the impact of seeing loved ones dying without dignity. For some people, preserving personal dignity may be as important as alleviating pain. The committee also heard of the inherent dignity in caring for terminally ill patients.

It was suggested to the committee that the ability to access voluntary assisted dying may help to ensure people do not have to die in circumstances where they lose independence, choice and control. The committee also heard of the importance of providing greater support for palliative care to help ensure dying with dignity is possible.

#### **5.3.4 The morals of others should not prohibit access to VAD for those who seek it**

Some who made contributions to the inquiry were opposed to VAD because of religious reasons and their view that VAD is morally wrong. This is discussed further in section 5.4.1. However, others shared the view that someone else's morals should not be forced upon the entire Queensland population.<sup>231</sup> For example, Ms Anne Awabdy told the committee:

*It cannot be just that minor groups are able to impose their particular creed on the community at large, in this case denying a very personal choice to those in the most distressing and painful predicaments imaginable. They just do not get it that we are not all alike and some of us simply do not want to be humiliated or suffer.*<sup>232</sup>

Reverend Sid Rogers, a retired minister, questioned a person's right to deny someone else's decision to end their life:

*Most importantly in this debate, prolonging death is not the same as extending life. Those who wish to prolong the extreme physical, psychological, cognitive and spiritual pain that I observed daily ... with many dying patients and families need to seriously question their motive. Who exactly benefits here? What gives you the right to deny somebody else's well thought through decision to end their life in dignity? VAD is not being legislated as compulsory for all. It is a choice people must make. If you do not wish to have VAD, then that is your choice and it will be honoured. However, you have no right to deny that choice to others who wish to have VAD.*<sup>233</sup>

In his statement to the committee Mr Graeme Reinbott expressed the view that churches should not impose their beliefs on others:

<sup>229</sup> Submission 2113, p 1.

<sup>230</sup> Submission 1724, p 2.

<sup>231</sup> See for example submission 184, 216, 232, 236, 265, E1675.

<sup>232</sup> Public hearing transcript, Southport, 10 September 2019, p 38.

<sup>233</sup> Public hearing transcript, Southport, 10 September 2019, p 34.

*The other group trying to exert its influence is, of course, the churches. In my submission I said the case in favour of voluntary assisted dying is all about two words: respect—allowing others to have their choice in end-of-life decisions; and compassion—allowing the individual to decide for themselves when enough is enough. Being brought up as a Christian and being a practising Christian for most of my life, respect, compassion, love and caring were synonymous with what I was taught. How is it possible for the church to turn its back on these things of which Jesus spoke? If church leaders want to preach to their people about the sanctity of life and other doctrinal matters, that is fine, but freedom of religion surely does not mean imposing these beliefs on others.*<sup>234</sup>

Mr Jeremy Ervine from South Australia made the following point in his submission:

*They believe that only God has the right to decide when a person dies and allowing assisted dying defies god. Dr Rodney Syme, the Vice President of Dying with Dignity Victoria said to me in an interview, ‘As a Doctor, I’ve been defying god my entire life, stopping people from dying prematurely’.*<sup>235</sup>

Mr Everald Compton who supported the introduction of VAD legislation, provided the committee with the following message:

*I do not believe in a god who decides who lives or dies, who gets sick or who gets better. In fact, I would cease to be a Christian if that was the case. If we say that, we are saying that God caused five million Jews to be killed by Adolf Hitler, because he is in charge of dying. We are saying that those people in Christchurch died because God wanted them to die. We are saying that the people in the Twin Towers 18 years ago in New York—3,000 of them—died by God’s will. I cannot accept that. God does not decide who lives or dies. God gives us the spiritual power to handle anything that life throws up at us, including death. I think we need to get away from the whole concept that we are somehow trespassing on God’s territory. ... I hope that we can get rid of dogma and doctrine, and that we can all live in an Australian society that is built on compassion and goodwill, and that is a great place to live and a great place to die.*<sup>236</sup>

Conversely, Archbishop Coleridge explained that the church was not imposing its religious views on others but that its position was based on an understanding of what it means to be human:

*My position and indeed my church’s position on these questions derives from a particular understanding—I think a very rich and comprehensive understanding—of what it actually means to be human and as part of that what suffering and death mean in the run of a human life, so it is not in any way forcing down people’s throats assumptions or positions that are narrowly religious and an imposition on people who do not share the assumptions that are prompted by my own Christian faith.*<sup>237</sup>

In their joint submission Daniel and Helen McGrath argued that individual autonomy must be balanced with obligations to the community:

*Voluntary assisted dying distorts the balance between our obligations to each other as members of the Queensland community and the principle of individual autonomy. We note, for example, that the features of a potential VAD scheme for Queensland could include:*

- *a person must want to end their life for a reason they consider to be valid*

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<sup>234</sup> Public hearing transcript, Southport, 10 September 2019, p 41.

<sup>235</sup> Submission 383, p 9.

<sup>236</sup> Public hearing transcript, Brisbane, 13 September 2019, pp 62, 63.

<sup>237</sup> Public hearing transcript, Brisbane, 23 August 2019, p 20.

*This feature enshrines the principle of individual autonomy at the expense of obligation to community.*<sup>238</sup>

Further discussion of the sanctity of life can be found at section 5.4.1.

#### **Committee Comment**

The committee notes that people of faith hold a range of views on death and suffering and the role that access to voluntary assisted dying might play in alleviating suffering, including strong support for voluntary assisted dying.

The committee also heard strong concerns that sections of the community should not be able to unduly impinge, based on their personal beliefs, on the rights of others who hold different views.

#### **5.3.5 The current legal framework is not working**

Some submitters who supported VAD argued that the current framework regarding the end of life is not working and argued that:

- some people commit suicide because they can't access VAD
- some refuse food and drink because they can't access VAD
- some access VAD overseas
- some doctors are performing VAD and it is unregulated
- palliative sedation is performed often without consent and needs to be regulated.<sup>239</sup>

The Clem Jones Group provided the following information in their submission:

- *information from state coroners to Victorian and West Australian parliamentary inquiries into voluntary assisted dying laws showing around one person a week with a debilitating and incurable physical condition is taking their own life,*
- *that the figure for Queensland is likely the same given comparative populations,*
- *that such deaths by suicide occur in often horrific and lonely circumstances which have devastating impacts on surviving family members, friends, and associates,*
- *that the horrific circumstances in which such deaths occur inflict a tremendous personal, psychological toll on first responders including police and ambulance officers or others, and*
- *that the lives of those taking such drastic action with such devastating repercussions would better end through a system of legislated and regulated voluntary assisted dying.*<sup>240</sup>

Several submitters said that they intended to suicide while they were still able to.<sup>241</sup> One submitter told the committee:

*My father's current plan is to commit suicide, alone, before he becomes a burden to our family. This is why voluntary assisted dying is neccisary [sic]. To give people who are in horiffic [sic], unpreventable conditions the option to go out on their own terms, without having to resort to illegal methods, or relying on their own family to do so.*<sup>242</sup>

Mr Alistair Scarr discussed the suicide of his uncle who suffered from motor neurone disease:

<sup>238</sup> Submission 1850, p 1.

<sup>239</sup> For example see submission numbers: 103, 160, 1202 and 1573.

<sup>240</sup> Submission 1202, p 6.

<sup>241</sup> For example, see submissions 12, 193 and 1573.

<sup>242</sup> Name withheld, submission 12, p 1.

*My very beloved uncle suffered with motor neurone disease. There exists no meaningful relief. Due to a lack of options he chose to suicide. This resulted in additional stress for family as a police and coronial investigation (appropriately) took place. I recall thinking that I hope, if I'm ever in his situation, I would have the courage to kill myself. I hope I'm never in such a position. I may not be able to prevent myself or others developing a terminal condition. But I hope my words might help change our law, so that I might have more peaceful alternatives than my uncle.*<sup>243</sup>

Ms Maria McGregor described the death of her mother who refused food and medication to hasten her death:

*Her cause of death was written down as Parkinson's Disease and malnutrition but in fact, she simply and awfully starved herself to death in full knowledge of what she was doing. She asked the nursing staff to give her something that would end her misery but their hands are tied so in the end she just stopped eating and refused medication to hasten her end. It is very hard to watch someone you love so dearly die this way.*

*Her death was traumatic for her, for us (her family) and for the nursing staff because nobody was legally allowed to agree to her simple, personal request to be 'helped along'.*<sup>244</sup>

The committee also spoke to Ms Christine Thornton who told of her late husband's decision to go to Switzerland to access assisted dying while he was still physically able.<sup>245</sup> Ms Thornton told the committee that the total cost was about \$30,000.<sup>246</sup> Other witnesses and submitters indicated they had already arranged or may arrange to go to Switzerland to access assisted dying,<sup>247</sup> although people commented they had to go earlier than they needed to and that this option was not affordable for some people.<sup>248</sup> For example, Mr David Bedford submitted:

*Being an incomplete quadriplegic means I fractured my neck at C2 just bruising my spinal cord which left me with limited movement below my neck and only slightly impairing my feeling. This leaves me laying in bed most of the day as I can only sit up in my wheelchair for short periods due to bedsores. Still having most of my feeling means I get lots of pain due to bed sore wounds I got in intensive care and pain from just laying in bed for long periods.*

*I have a friend who works in patient transport who will be taking me to Switzerland, this will come at significant cost to me, I would like to be able to do this in my own country ...*<sup>249</sup>

Submitters also argued that another reason that the current system is not working is that VAD is being performed anyway.<sup>250</sup> Mr Jeremy Irvine who made the documentary about assisted dying in Australia, *Fade to Black*, submitted the following about the current regulatory framework driving VAD underground:

*There is an underground practice in Australia where medical professionals provide assistance to people wanting to end their own lives, only it's illegal and not regulated which means we don't know how safe the practice is. Additionally, because more than 80% of people across all of society are in favour of assisted dying laws, police and prosecutors tend to turn a blind eye to the practice*

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<sup>243</sup> Submission E1665, p 1.

<sup>244</sup> Submission 103, p 1.

<sup>245</sup> Public hearing transcript, Brisbane, 13 September 2019, p 50.

<sup>246</sup> Public hearing transcript, Brisbane, 13 September 2019, p 51.

<sup>247</sup> See submission 160; Coral Mast, public hearing transcript, Mossman, 29 May 2019, p 10; Cecile Scherrer, public hearing transcript, Hervey Bay, 15 July 2019, p 28.

<sup>248</sup> Carole Tilling-Rekort, submission 160, p 1; Helen Parish, public hearing transcript, Rockhampton, 17 July 2019, p 19.

<sup>249</sup> Submission E147, p 1.

<sup>250</sup> Submission 1225, p 3. See for example R Magnusson, *Angels of Death: Exploring the Euthanasia Underground*, Melbourne University Press, 2002.

*when it does happen, even when doctors freely admit to committing the ‘crime’ of assisting a suicide.*

*Where there is an illegal practice driven underground and police will not enforcement the law, it increases the opportunity for abuse.*<sup>251</sup>

Concerns were also raised that palliative sedation is an unregulated practice that can have negative impacts on patients and their families. Mr David Muir from the Clem Jones Group made the point that:

*... voluntary assisted dying laws will empower those at the end of life, will offer them choice and will be an alternative to the current unregulated practice of terminal sedation, which is not guaranteed to be voluntary or without suffering.*<sup>252</sup>

In their submission, Dying With Dignity Queensland outlined their concern that the lack of regulation around palliative sedation could lead to a situation where informed consent is not obtained.

*Under the current unregulated framework, and without legislation, we have no guarantee that informed consent is being obtained in all circumstances prior to terminal sedation being used.*<sup>253</sup>

Palliative sedation is discussed further in Report No 33 from this inquiry.

In his submission to the inquiry Mr Richard Mill posed the questions:

*Why should doctors risk prosecution because they act to relieve suffering? Why should a compassionate act not be transparent and accountable?*<sup>254</sup>

Ms Kiki Paul from Go Gentle Australia summed up the situation in this way:

*Assisted dying in Queensland is currently an incoherent, largely unregulated and inequitable legal situation in which neither doctors and nurses nor patients and their families are protected. Under the current system patients can legally refuse all medical treatment, food and water, be put in a coma or commit suicide, often violently and alone. It is time Queenslanders were given a kinder, more compassionate choice. As a society we must do better by our often elderly terminally ill, who are among the most vulnerable in our society.*<sup>255</sup>

#### **Committee Comment**

A number of submitters argued the current legal options for ending life for terminally ill people are not meeting their needs. In their evidence, submitters noted the incidence of suicide involving the terminally ill, people refusing to take food and hydration to hasten their death, people travelling overseas to access voluntary assisted dying and the risks that doctors may already be providing voluntary assisted dying in an unregulated way, including by palliative sedation without the patient’s consent.

A number of submitters have advised of their intention to suicide rather than die naturally in pain and impose a burden on their loved ones. Based on these concerns, submitters have argued for voluntary assisted dying to be available in Queensland.

#### **5.4 Reasons for opposing VAD**

The following section discusses the views of witnesses and submitters who gave evidence to the committee opposing the introduction of VAD in Queensland. Evidence of witnesses and submitters

<sup>251</sup> Submission 383, p 8.

<sup>252</sup> Public hearing transcript, Brisbane, 23 August 2019, p 3.

<sup>253</sup> Submission 1215, p 17.

<sup>254</sup> Submission 1912, p 2.

<sup>255</sup> Public hearing transcript, Brisbane, 23 August 2019, p 6.



who provided counterpoints to these views are also included. Of the submissions received from individuals who opposed 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 non-voluntary 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.

The following sections outline the most common reasons given for opposing the introduction of VAD in Queensland.

#### **5.4.1 The sanctity of life should be respected and voluntary assisted dying contradicts religious beliefs**

Individual submitters as well as organisations stated they were opposed to VAD based on their faith's inherent religious beliefs. They mentioned sanctity of life and/or that only God should decide the timing of death. Faith groups and churches argued that euthanasia and suicide were morally wrong and against religious teachings. For example, the Presbyterian Church made the following point in its submission:

*Our life now and after death is in the hands of God. Trying to wrest control from God, including control over our own life and death, is an expression of defiance towards Him.*<sup>256</sup>

Similarly, the Anglican Church in its submission stated:

*In 2017, the Anglican Church General Synod addressed the issue of "Assisted Dying", passing a motion which "affirmed the sanctity of life; that life is God's gift ..." and opposed any legislation in favour of assisted dying. It urged all State and Territory governments to "better resource palliative care services, including in regional and remote communities, Aboriginal and Torres Strait Islander communities and nursing homes, and to provide better training in palliative care for all health professionals".*<sup>257</sup>

The Baptist Church commented that:

*Queensland Baptists believe that all people are made in the image of God, so human lives are precious and of intrinsic worth. The value of life is not diminished by age, lack of productivity or illness.*<sup>258</sup>

The submission by Roman Catholic Bishops mentioned the meaningfulness of life and the common good:

*Voluntary assisted dying, should not be legalised in the state of Queensland: ... because it undermines the meaningfulness of all life and with it the very idea of a society founded on respect for human dignity and protection of the common good...*<sup>259</sup>

Ms Janet O'Sullivan submitted her views on the sanctity of life:

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<sup>256</sup> Submission 1282, p 4.

<sup>257</sup> Submission 1229, p 2.

<sup>258</sup> Submission 1228, p 1.

<sup>259</sup> Submission 1279, pp 2-3.

*I have strong feelings about the sanctity of life and don't believe that any person has the right to dispose of another's life for any reason, even if they think it a compassionate one.*<sup>260</sup>

Mr Graeme Blines who gave evidence at the Mackay public hearing, explained his position with reference to his late wife's dying words:

*The way in which we treat the most vulnerable people speaks volumes about the kind of society we have become. Economic euthanasia becomes a real threat as people opt for euthanasia because they cannot afford, or the family is unwilling to pay for, the treatment of the patient. It may be easy for some to pretend that they have a divine right to destroy life in the womb or to send the sick or the elderly to the grave. I will finish with a few words that gave me great comfort from my wife as she was dying. Simply: 'It's okay. God's got me.'*<sup>261</sup>

In contrast, Mr Geoffrey Williams from Christians Supporting Voluntary Assisted Dying commented:

*Church leaders say, 'Choose life, not death,' as if the dying patient has a choice. Statements like this demonstrate how completely out of touch with reality they are.*<sup>262</sup>

The Queensland Law Society acknowledged the argument about sanctity of life but also sought to balance that view against individual choice:

*QLS acknowledges the view of some that consider and interpret sanctity of life to be paramount, and not malleable to changing public opinion. Whilst those who hold this view may perceive the introduction of VAD laws to impose the 'tyranny of the majority', we must remember that a VAD scheme is, by definition, voluntary in nature and will serve only to permit, not mandate, access to VAD. As such, the majority view is not imposing an obligation on those with personal beliefs against VAD to access the scheme. In contrast, the prohibition of VAD ensures that those who do not hold the same personal beliefs and concerns remain unable to exercise a choice to access VAD.*<sup>263</sup>

### **Committee Comment**

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

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 any attempt to interfere in that process is immoral and an expression of defiance toward God.

The Catholic Church argued that legalising voluntary assisted dying in Queensland should be opposed because it undermines the meaningfulness of all life and with it the very idea of a society founded on respect for human dignity and protection of the common good.

The committee also notes that the view expressed by some faith groups about the spiritual benefits from suffering at the end-of-life are not universally accepted, even within particular denominations.

While respectful of the views espoused by faith groups, the committee also noted the view proffered by the Queensland Law Society which highlighted in their submission that voluntary assisted dying is 'voluntary' and that legislating for it would 'permit' rather than 'mandate' access.

<sup>260</sup> Submission E1351.

<sup>261</sup> Public hearing transcript, Mackay, 29 October 2019, p 24.

<sup>262</sup> Public hearing transcript, Brisbane, 23 August 2019, p 5.

<sup>263</sup> Submission 1202, p 15.

The Queensland Law Society also noted that the prohibition of voluntary assisted dying ensures those with views that differ from religious groups would remain unable to exercise a choice to access voluntary assisted dying.

Submitters views about individual choice are outlined in section 5.3.1, Individual choice and the right to self-determination and control at the end of life.

#### **5.4.2 The risk of coercion of vulnerable people or that safeguards in the legislation would not be sufficient to ensure all assisted deaths were voluntary**

Some submitters and witnesses expressed concern that if VAD legislation were to be introduced, an individual may be coerced to give consent to VAD by family members, medical practitioners, the state or as a result of perceived pressure from society. For example, Ms Theresa Toomey told the committee:

*The word ‘voluntary’ presumes that every person requesting help to die is capable of making an informed decision and also that he or she is free from pressure. In a perfect world, the families of the terminally ill, the mentally ill, the elderly, the depressed and the disabled would value them, assuring them of their love, support and care and would recognise the inherent value of every life and that every person is infinitely precious. However, we do not live in a perfect world and vulnerable people would feel pressure, whether real or imagined, to do the so-called right thing by their families and request euthanasia.*<sup>264</sup>

Ms Fiona Forrest submitted:

*I respect the right of an individual to make their own decisions, however am very concerned in relation to the following:*

- *The danger of coercion and manipulation of people who are not in a strong position to withstand such pressure.*
- *People with disabilities or communication problems may not be able to effectively communicate their own wishes in relation to deciding to deliberately end their life. They are in an already vulnerable position and could easily [be] further disempowered in their ability to make their own decisions by other with their own agenda in relation to their person or assets.*
- *With the rising numbers of reported elder abuse, Euthanasia would be an ideal way for abusers to get what they want and at the same time remove any recourse of evidence.*<sup>265</sup>

At the public hearing in Hervey Bay, Mr Neil Folling stated:

*The compassionate answer to suffering is to recognise a person’s inherent dignity, regardless of their physical capacity or their mental abilities or health, and to strive to provide the best possible care for those with disabilities or who are at the end of their lives. I argue that crafting a euthanasia bill that provides adequate safeguards for the vulnerable or marginalised in society is impossible, because it is too complex. For this reason, for nearly two decades now euthanasia has been consistently voted down in Australian parliaments.*<sup>266</sup>

Ms Lynette Harrison of Bald Hills submitted:

*I ask you to focus your enquiry’s attention on improving palliative care availability in Queensland. Better palliative care options will really improve end-of-life choices, whilst legalised assisted dying will only result in more coercion of the elderly and less real choice.*<sup>267</sup>

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<sup>264</sup> Public hearing transcript, Townsville, 29 May 2019, p 22.

<sup>265</sup> Submission 1760, p 1.

<sup>266</sup> Public hearing transcript, Hervey Bay 15 July 2019, p 21.

<sup>267</sup> Submission E293A, p 1.

Some submitters raised concerns that legislation is not able to protect vulnerable people from harm. For example Catholic Health Australia wrote in their submission:

*VAD legislation is particularly dangerous for vulnerable members of the community including; the elderly and frail, marginalised groups such as non-English-speaking Australians, prisoners, homeless, mentally and physically disabled, those living alone without supportive families, and Aboriginal and Torres Strait Islander peoples. These groups face increased susceptibility to abuse, mixed messaging, misinformation, and pressure from others.*

*Legalising VAD advances the misguided belief that the elderly, sick and vulnerable constitute a burden to society. This type of thinking along with internal and external pressures including; financial concerns, inadequate access to alternative services, physical and psychological abuse, misinformation about treatment options, or a reduced sense of worth and autonomy, may impact on the individual's choice to make a request. These pressures may push an individual toward accessing VAD when it is a decision that they would not otherwise make.*<sup>268</sup>

Other submitters expressed the view that advance care planning should not extend to VAD for people who no longer have capacity.<sup>269</sup> This topic is discussed further in Section 9.1 Safeguards against coercion, elder abuse, fear of being a burden.

Many submitters argued that there are no effective safeguards from abuse.<sup>270</sup> The Baptist Church offered the following analogy:

*Just as with the best intentions, the legal system was incapable of preventing innocent people from suffering the death penalty, so with the best intentions legal systems will be unable to prevent some people being put to death who do not wish to die.*<sup>271</sup>

The Anglican Church submission also raised doubt about the effectiveness of safeguards: 'Given that there is currently no robust system that has effectively prevented elder abuse, there is no reason to believe that adequate safeguards can be put in place for euthanasia'.<sup>272</sup>

Ms Margaret Carlisle from Springwood submitted that safeguards are not effective when people believe they are a burden:

*Also there would be no safeguards to prevent people from feeling that their condition, be it a disease such as cancer or simply being very old, is becoming a burden to those around them, which would put them under pressure to choose euthanasia. There is also nothing to prevent families from pressuring relatives to take this path.*<sup>273</sup>

### **Committee Comment**

The committee notes the concerns raised by a number of submitters that vulnerable people at the end of their life cannot be adequately protected from coercion by legislated safeguards and that, as a result, some voluntary assisted dying deaths may not be voluntary.

Stakeholder groups raised particular concerns for the elderly and frail and marginalised groups such as non-English speaking Australians, prisoners, homeless people, people with mental and physical disabilities, those living alone without supportive families, and Aboriginal people and Torres Strait Islander people. The committee also heard of the inherent vulnerability of people who consider themselves to be a burden to those around them.

<sup>268</sup> Submission 1249, p 13.

<sup>269</sup> The Public Advocate, submission 1208, p 3, Palliative Care Australia, submission 1891, p 59.

<sup>270</sup> See for example, submissions 1357, 1367, 1623, 1628, and 1677.

<sup>271</sup> Submission 1228, p 3.

<sup>272</sup> Submission 1229, p 15.

<sup>273</sup> Submission 1495, p 1.

#### **5.4.3 Introducing voluntary assisted dying would lead to a slippery slope enabling expanded eligibility or non-voluntary euthanasia**

Some submitters raised concerns that once VAD laws were introduced, restrictions they believe would eventually ease and eligibility would be expanded.<sup>274</sup> It was also suggested to the committee by some submitters that once expansion happens the system would be more open to abuse and lead to non-voluntary euthanasia.<sup>275</sup> This is referred to as the 'slippery slope' argument.

Mr Dan McMahon told the committee at the Bundaberg hearing:

*The experience of countries that have already adopted VAD legislation is a sobering reminder of how easy it is, once the legislation is in place, to broaden the scope of practice. I am not a great supporter of the slippery-slope arguments in this area or others, but I am a student of history. It is an immutable law of history that if we do not learn the lessons of history we are doomed to repeat the mistakes of the past.*<sup>276</sup>

Similarly, Ms Hayley Lanzon submitted:

*Believing that one has the power to take life leads down a slippery slope where strict criteria around VAD becomes less strict as more and more cases are considered legitimate. VAD would be open to terrible manipulation and abuse.*<sup>277</sup>

In his submission, community member, Mr Dennis Stewart described the slippery slope hypothetically, by applying it to people with a disability:

*Finally, I turn to the nature of the "slippery slope" whereby there is already growing concern and alarm among people with a disability that this assisted suicide legislation could be altered and changed by future parliaments to include the same "benefit" to those initially with profound and severe disabilities. Once that occurred, what would eventually follow for the less disabled? The thought of people being "released" from their "misery" as perceived by perhaps well intentioned, but despotically inclined individuals, who would consider themselves to be "liberators" of any type of pain, misery or a life seen as less than perfect.*<sup>278</sup>

In their submission, the HOPE organisation made the following claim about a Bill that has been introduced to the Oregon state legislature:

*...legislation to expand the categories of those eligible for assisted suicide has been put before Oregon's House of Representatives. If passed, House Bill 2903 will no longer require death to be imminent or even foreseeable for a person to access lethal drugs. This would expand the remit of the assisted suicide regime to any disease from which a patient might die at some point in the future, including degenerative diseases.*<sup>279</sup>

At the time of writing this Oregon Bill had not been passed. Furthermore, Ms Ann Jackson, former CEO of the Oregon Hospice Association submitted to the committee:

*The law has remained unchanged over the past 20 years and is only available to dying people of sound mind —these criteria, and the safeguards associated with them, have not broadened since the law was enacted. Fears of a "slippery slope" have not come to fruition and there are no proven cases of coercion of individuals to have an assisted death. The risks of patients being*

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<sup>274</sup> See for example submissions 81, 113, 1749, 1928, 1941, E1537 and E1555.

<sup>275</sup> Submission 1210, p 4.

<sup>276</sup> Public hearing transcript, Bundaberg, 16 July 2019, p 23.

<sup>277</sup> Submission E1117 p 1.

<sup>278</sup> Submission 1896, p 2.

<sup>279</sup> Submission 2407, p 13.

*murdered or coerced into ingesting life-ending medication were far greater prior to the implementation of a transparent system with upfront safeguards and effective regulation.*<sup>280</sup>

The VAD schemes operating in Belgium and the Netherlands were often referred to in submissions as examples of schemes with safeguards that have not prevented the slippery slope. Submitters claimed that, in the Netherlands, doctors had euthanised patients without consent and that children in Belgium were being euthanised.<sup>281</sup> Ms Marie Harding-Smith from Cairns, mentioned the slippery slope in her submission to the inquiry:

*Euthanasia is a slippery slope, it always starts off with narrow parameters and over time broadens as difficult cases present. This has been seen overseas - for example in Belgium and The Netherlands they are now euthanasing children. There are no effective safeguards when it comes to euthanasia.*<sup>282</sup>

Professor Margaret Somerville in her submission to the committee also referred to the ineffectiveness of safeguards in these schemes:

*Slippery slopes: There is evidence that safeguards in the Netherlands and Belgium are ineffective and violated, including administering lethal drugs without patient consent, absence of terminal illness, untreated psychiatric diagnoses, and non-reporting.*<sup>283</sup>

However, there are also counter-arguments from those supporting the introduction of VAD laws that there is no evidence to support the slippery slope argument. Professor Luc Deliens who has been the Director of the End-of-Life Care Research Group, VUB and Ghent University, Belgium since 2000 made the following comments at a Brisbane public hearing:

*Show me the evidence. What is a slippery slope and show me the evidence for a slippery slope. We have done 20 years of studies now and we have never found any evidence for a slippery slope.*<sup>284</sup>

Professor Jan Bernheim also from the End-of-Life Care Research Group referred to the following quote in his submission:

*Two decades of research on euthanasia in the Netherlands have resulted into clear insights in the frequency and characteristics of euthanasia and other medical end-of-life decisions in the Netherlands. These empirical studies have contributed to the quality of the public debate, and to the regulating and public control of euthanasia and physician-assisted suicide. No slippery slope seems to have occurred. Physicians seem to adhere to the criteria for due care in the large majority of cases.*<sup>285</sup>

Queensland resident Mr Timothy Porter submitted:

*I don't give any credence to the "slippery slope" argument that says it will necessarily be extended to children or incompetent adults against their wills. It should not be beyond our politicians to write legislation to guard against that. Having said that, I don't see why it should not be extended to children dying of cancer for all the same reasons I have outlined.*<sup>286</sup>

<sup>280</sup> Submission 897, p 2.

<sup>281</sup> See for example, submissions 1749, 1777, 1867, E2043, E2057.

<sup>282</sup> Submission 2083, p 1.

<sup>283</sup> Submission 1210, p 2.

<sup>284</sup> Public hearing transcript, Brisbane, 21 October 2019, p 6.

<sup>285</sup> Rietjens J, van der Maas PJ, Onwuteaka-Philipsen B, et al. 'Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?' *J Bioeth Inq* 2009; 6:271–83. In Jan Bernheim, submission 278, p 3.

<sup>286</sup> Submission E1796, p 1.

Mr Michael Cope from the Queensland Council of Civil liberties also refuted the slippery slope argument:

*To those who are worried about the slippery slope, we give the answer that is always given to that which is they have no faith in people in the future to recognise the same problems that we recognise and that they recognise. They are ignoring the current situation of those who are in pain and cannot have that pain relieved. They ignore the fact that this is already happening except it is going on behind closed doors. They ignore the fact that people already have a right to refuse medical treatment. We would say that a legalised system will be a system of regulation which will control the system and thereby reduce abuses which may be occurring at the present time.*<sup>287</sup>

#### **Committee Comment**

A key argument presented by groups and individuals opposed to voluntary assisted dying is the slippery slope argument that if a voluntary assisted dying scheme were introduced, eligibility for accessing voluntary assisted dying would be expanded, and this would increase the risk of abuse and lead to involuntary deaths occurring.

The committee heard a range of views on the risks that this could occur based on experiences with voluntary assisted dying schemes in other jurisdictions.

The committee notes 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.

#### **5.4.4 Access to effective palliative care makes the need for VAD obsolete**

Some submitters to the inquiry and witnesses at the hearings were of the view that, when people have access to good palliative care, VAD is not needed.<sup>288</sup> At the Mackay public hearing, Ms Margaret Fenner stated: ‘... if a patient is so full of awful symptoms that they request assistance dying from their GP then they have been denied good palliative care’.<sup>289</sup>

Mrs Noelene Kidd in Ipswich emphasised the benefits of palliative care:

*I believe if people understood what palliative care really is they would be less likely to seek alternatives. Major hospitals and community teams offer excellent palliative care, allowing people to die respectfully in peace and dignity with up-to-date pain management. End-of-life care for patients and families may be holistic, with straightforward communication, appropriate counselling and the spiritual ministry of chaplains.*<sup>290</sup>

Similarly, Ms Vanessa Vanderbusch submitted:

*... we should be putting more effort into improving access to palliative care, and developing better end of life care. Many who are for assisted dying are unaware of the dignity and the almost complete elimination of pain that can be gained through palliative care.*<sup>291</sup>

Mr Paul Ruhl submitted that palliative care enables a painless death as well as dignity for the patient:

*The reason Euthanasia should never even be considered is that a solution is already available to assist the dying. Medicine has and is already excelling in the care of the dying in a painless manner through Palliative Care. This charitable process is rich in maintaining the dignity of the person and needs to be encouraged. The Governments at all levels via the respective Health*

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<sup>287</sup> Public hearing transcript, Brisbane, 5 July 2019, pp 5-6.

<sup>288</sup> See for example submissions 893, 1650, 1658, E598 and E1072 and Theresa Toomey, public hearing transcript, Townsville, 29 May 2019, p 22.

<sup>289</sup> Public hearing transcript, Mackay, 29 October 2019, p 21.

<sup>290</sup> Public hearing transcript, Ipswich, 9 September 2019, p 24.

<sup>291</sup> Submission E877, p 1.

*Departments need to increase funding and enhance the capabilities of Palliative Care Centres already available and expand on them. In addition an education program expounding the benefits of Palliative care needs to be implemented.*<sup>292</sup>

The committee also heard from Ms Tara Collyer who appeared at one of the Brisbane hearings. Tara explained to the committee that she had a progressive, degenerative and terminal condition: I have, at most, two to five years left to live now. I am losing my skills and senses at a rapid rate and I am now living in serious, chronic pain'.<sup>293</sup>

Ms Collyer also told the committee that she was concerned that end of life should be about better palliative care and not VAD:

*Life has not always been easy, but it is still precious. I have met so many people who wish that they could have just one more hour with their loved one to say something that would help them to feel that they have closure. I believe that true end-of-life care is not about terminating a person's life prematurely but rather providing a range of supportive and qualitative palliative care services in a range of settings where individuals are supported and comfortable in the last months and days of their lives. No matter how much I decline, I am still a person with value who is loved and cared for by others.*<sup>294</sup>

The Most Reverend Dr Phillip Aspinall of the Anglican Church argued that until palliative care was better resourced, a decision to request VAD would not be a free decision:

*When care for the dying is poor or when people are lonely and frightened, a decision to suicide is hardly uncoerced or free. I submit that this committee should recommend much better resourcing for palliative care, including in regional and remote communities, Aboriginal and Torres Strait Islander communities and nursing homes, and much better training in palliative care is provided for health professionals.*<sup>295</sup>

In contrast, former Premier Campbell Newman told the committee it should be up to the individual whether to try palliative care or to opt for VAD:

*I see it as an option that is up to the individual. For me, this is about a debate between society having a view on the sanctity of life and coming in over the top and telling people at a critical moment in their lives how they will end their life. I am for the individual at that stage if it is done appropriately and carefully. If I am in the situation of having a terminal illness like cancer or leukaemia or something, I would personally try palliative care. I would want to try palliative care because I love life. If I could have a quality of life, that is what I would go for first. I would give that a real go. But if it did not work—if I was bedridden, if I was in agony, if pain relief was not working—then I would want voluntary assisted dying. It is an option. I would have thought that most people, if offered palliative care, would give that a red-hot go first, and so they should.*<sup>296</sup>

Ms Jos Hall, President of Dying with Dignity Queensland, espoused the view that palliative care and VAD are complementary:

*DWDQ believes that VAD is compassionate, VAD is ethical, VAD protects the vulnerable and VAD allows choice for those who are suffering intolerably to die peacefully and in the company of family and friends. We believe that VAD and palliative care are complementary in providing the*

<sup>292</sup> Submission E1743, p 1.

<sup>293</sup> Public hearing transcript, Brisbane, 23 August 2019, p 50.

<sup>294</sup> Public hearing transcript, Brisbane, 23 August 2019, p 50.

<sup>295</sup> Public hearing transcript, Brisbane, 23 August 2019, p 15.

<sup>296</sup> Public hearing transcript, Brisbane, 23 August 2019, p 41.



*best possible end-of-life care. We see the provision and expansion of palliative care services as crucial, especially in regional and rural areas.*<sup>297</sup>

#### **Committee Comment**

A number of stakeholders have linked the issue of voluntary assisted dying directly to inadequacies in the palliative care services available in Queensland that need to be addressed. The committee acknowledges the concerns expressed by the Most Reverend Dr Phillip Aspinall of the Anglican Church and others about the importance of addressing shortcomings in the delivery and resourcing of palliative care, including in regional and remote communities, Aboriginal and Torres Strait Islander communities and nursing homes, and the need for much better training in palliative care for health professionals. The committee has recommended improvements to the delivery and accessibility of palliative care in Queensland in Report No 33 from this inquiry.

The committee also notes the views expressed in the inquiry on the relationship and linkages that should exist between palliative care and voluntary assisted dying.

#### **5.4.5 It would pose ethical problems for health professionals who may be required to administer VAD**

Some groups and individuals commented on the impacts VAD legislation would have on the relationship between doctors, nurses and their patients. They argued that legislating for VAD erodes the trust underpinning the doctor–patient relationship.<sup>298</sup>

The Women’s Forum submitted:

*The ability of physicians to end the lives of their patients fundamentally changes the nature of the physician patient relationship from one of healing and pledging to “do no harm” to one where physicians may take their patients’ lives. This may damage the relationship of trust and care between physicians and their patients and ultimately undermine the integrity of the medical profession.*<sup>299</sup>

Mr Neil Folling at the Hervey Bay public hearing argued along similar lines:

*The doctor-patient relationship is hampered because the ethical obligation of doctors is to preserve the life of their patients. You go to your own doctor to get better, not to be killed. Medicine’s longstanding Hippocratic ethic governs the care provided to all patients and residents—that is, to put into practice the ancient commitment of the medical profession to cure where possible, to care always and never intentionally to inflict death.*<sup>300</sup>

Mr Adam Louws submitted:

*Medical professionals are taught to do no harm, and to seek a patient’s best interests in all settings. Giving any medical professional the responsibility to authorise or provide life-ending medications or procedures would irreparably compromise the doctor-patient relationship. Many cultures are mistrustful of the medical profession, including Aboriginal and Torres Strait Islanders, due to their involvement in past atrocities such as the Stolen Generation. If doctors were to end the life of a family member, others from the family group or culture may avoid the medical system for fear of the same result, which would worsen health outcomes in these groups.*<sup>301</sup>

In her submission, Ms Lena Schrieder suggested:

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<sup>297</sup> Public hearing transcript, Brisbane, 23 August 2019, p 2.

<sup>298</sup> Informing the Euthanasia Debate: Perceptions of Australian Politicians, *UNSW Law Journal* 41(4) p 1396.

<sup>299</sup> Submission 1226, p 4.

<sup>300</sup> Public hearing transcript, Hervey Bay, 15 July 2019, p 22.

<sup>301</sup> Submission E1988, p 1.

*Perhaps improved public education about medical interventions would be valuable, to enable people to make more informed choices about their options and optimise quality of life, while not damaging the doctor-patient relationship by involving them in ending their patients' lives.*<sup>302</sup>

The Australian Family Association submitted:

*The motive of compassion can never justify extending the role of doctors beyond caring, curing, and healing to include the act of killing.*<sup>303</sup>

Other submitters suggested that medical practitioners may not act in the patient's best interest if VAD were introduced. For example the Catholic Women's League asserted:

*The doctor patient relationship is not necessarily one of equal power. To legalize doctors having ultimate power can jeopardize their role by removing the boundaries which are the foundations of the trust society places in them. The prohibitions and boundaries around doctors keep patients safe from aberration.*<sup>304</sup>

At the Gladstone hearing, Ms Janne Peterson commented that doctors should not be required to make decisions about administering VAD.

*I am not against the right to die. We all have a right to die and we all will die, but I am against somebody expecting or demanding another human being to end their life. This is something that I would never want on my conscience. I do not believe any doctor or any medical professional should have to make that decision.*<sup>305</sup>

By way of contrast, Ms Tanya Battel who has breast cancer, outlined the suffering she had experienced and asserted that a doctor cannot heal terminal cancer so the principle "do no harm" should be reconsidered:

*During the last three years I have dealt with welts appearing across my body, ongoing hot flushes rendering me dripping with sweat throughout the day, an abscess developed on my rectum that required surgery, excruciating shingles around my torso, oedema and swelling of my feet and legs where I could not walk, mouth ulcers, toenails that had died, severe constipation, raging diarrhoea where I cannot leave the house, ongoing fatigue, restless leg syndrome, impaired vision—they do not call it chemical therapy for nothing. Then there is the anxiety that comes with living your life from scan to scan, oncology appointment to oncology appointment. The Hippocratic oath says 'do no harm'. You might want to consider that one. The creed says, 'It is our job to heal,' but you cannot heal terminal cancer.*<sup>306</sup>

Ms Annette Deans submitted the following opinion: 'Doctors are there to bring us into the world, and to help us face a gamut of physical challenges. Surely we can trust them to help us through the most natural, final life event!'.<sup>307</sup>

The views of Health professionals on the administration of VAD is covered in detail in section 5.2.2.

#### **5.4.6 Introducing VAD sends the wrong message to people contemplating suicide**

Submitters and witnesses have also argued that introducing VAD legislation would validate suicide and therefore send the wrong message to people contemplating suicide.

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<sup>302</sup> Submission 2288, p 1.

<sup>303</sup> Submission 1310, p 12.

<sup>304</sup> Submission 1258, p 5.

<sup>305</sup> Public hearing transcript, Gladstone, 30 October 2019, p 19.

<sup>306</sup> Public hearing transcript, Brisbane, 23 August 2019, p 51.

<sup>307</sup> Submission 2002, p 2.

In its submission, the HOPE organisation argued:

*The issue is also challenging from the perspective of suicide contagion, given that once a jurisdiction legalises assisted suicide, the message conveyed by the law is necessarily a positive one about suicide in some circumstances. The implications of this for citizens with suicidal ideation must be taken into account as part of the discussion around the consequences of legalising euthanasia and assisted suicide.*<sup>308</sup>

The Australian Care Alliance submitted: 'Legalising assisted suicide for some Queenslanders undermines the commitment to suicide prevention for all Queenslanders'.<sup>309</sup>

At the Brisbane public hearing on 23 August 2019, Mr Richard Egan, a representative of the Australian Care Alliance, emphasised the point:

*I know your Queensland suicide prevention goal is to reduce suicides ideally of course down to zero. We have to work in that direction. We do not solve the problem of just changing the means of suicide, as I say, by giving the person a lethal drug to take home alone, because that is what is under the Victorian law. You get the lethal poison, you keep it at home and you take it at a time of your choosing.*<sup>310</sup>

Mr Kevin Hegarty made similar comments in his submission: 'Suicide devalues life and as a result it devalues our society. ... Ethics are valuable. Morals even more so. Legislation should support both. Good public policy upholds natural law'.<sup>311</sup>

A submitter who requested that her name be withheld stated:

*Why undermine the great work that Lifeline or Beyond Blue or undermine Mental Health services? These charities and counsellors are not looking for more work or clients or deaths or suicide contagion.*<sup>312</sup>

In her evidence presented to the committee, Ms Teeshan Johnson, Executive Director of Cherish Life took the argument further and suggested that it was highly likely legislating VAD would lead to an increase in the number of suicides:

*The legalisation of assisted suicide is utterly counterproductive to combating Queensland's very serious suicide problems. Legalisation of VAD would undermine all government and community suicide prevention programs. It is highly likely that it would lead to an increase in the number of suicides overall including non-assisted suicides.*<sup>313</sup>

These views were challenged by Mr Neil Francis, a medical researcher and founding member of Dying for Choice.com. In his submission Mr Francis explained:

*Opponents of assisted dying often claim that there is "suicide contagion" from assisted dying laws to the general suicide rate. The claim is contradicted by evidence from major jurisdictions where assisted dying is lawful.*<sup>314</sup>

Mr Francis's submission detailed evidence from Oregon, Switzerland, the Netherlands and Belgium which did not find a correlation between the introduction of VAD and suicide rates.<sup>315</sup>

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<sup>308</sup> Submission 2407, p 10.

<sup>309</sup> Submission 1023, p 20.

<sup>310</sup> Public hearing transcript, Brisbane, 23 August 2019, p 23.

<sup>311</sup> Submission E1847, p 1.

<sup>312</sup> Submission 1647, p 13.

<sup>313</sup> Public hearing transcript, Brisbane, 23 August 2019, p 24.

<sup>314</sup> Submission 1223, p 45

<sup>315</sup> Submission 1223, pp 45-52.

The Clem Jones group provided a similar view in its submission to the inquiry:

*There is no evidence of any wilful abuse of the system of voluntary assisted dying in each jurisdiction and no evidence of a wholesale widening of the scope of legislation, and no evidence of a “suicide contagion” allegedly sparked by the mere availability of voluntary assisted dying.*<sup>316</sup>

This topic of suicide is covered in Chapter 2.

### **Committee Comment**

The committee notes that temporary suicidal ideation is quite distinct from an enduring, considered and rational decision to end one’s life in the face of unbearable suffering. Given this distinction, the committee considers that a decision to legislate for the introduction of voluntary assisted dying is not inconsistent with suicide prevention campaigns and messaging.

## **5.5 Opinion Polls**

Some submitters and witnesses referred to opinion polls as indicators of public views on introducing VAD. Several recent polls suggest that the majority of Australians believe that people with a terminal illness should be able to access assisted dying.<sup>317</sup> For example, a poll of a representative cross section of 1,386 people across Australia aged 18 and over, conducted by Roy Morgan in 2017, found:

*A large majority of Australians, 87% (up a significant 18% from May 1996) are in favour of ‘letting patients die when they are hopelessly ill and experiencing unrelievable suffering with no chance of recovery’ compared to 10% (down 7%) who say doctors should ‘try to keep patients alive’ and 3% (down 11%) who are undecided.*

*In addition a large majority of Australians, 85% (up 11% from May 1996) are in favour of allowing a doctor to ‘give a lethal dose when a patient is hopelessly ill with no chance of recovery and asks for a lethal dose’ compared to 15% (down 3%) who say a doctor should ‘not be allowed to give a lethal dose’.*<sup>318</sup>

The specific results of that poll for Queensland showed that 86 percent of people surveyed supported allowing doctors to ‘give a lethal dose when a patient is hopelessly ill with no chance of recovery and asks for a lethal dose’.<sup>319</sup>

Some inquiry submitters questioned the wording of the survey questions and the responses. For example, the Endeavour Forum provided the following commentary:

*Unsubstantiated claims are made that “80 per cent of the population want access to euthanasia”. This has no foundation in reputable social research. Opinion polls may have some degree of reliability regarding simple issues, such as support for a political party. However, they*

<sup>316</sup> Submission 1202, p 19.

<sup>317</sup> See The Australia Institute, *Survey results - attitudes to voluntary euthanasia*, 6 January 2011, <https://www.tai.org.au/node/1316>, Roy Morgan Research, *It’s Official: Australians support assisted dying or euthanasia*, November 2017, Finding 7373, <http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349> and Catherine Hanrahan, ABC News, *Euthanasia support strengthens to nearly 90pc*, 9 May 2019, <https://www.abc.net.au/news/2019-05-08/vote-compass-social-issues-euthanasia-transgender-republic-drugs/11087008>.

<sup>318</sup> Roy Morgan Research, *It’s Official: Australians support assisted dying or euthanasia*, November 2017, Finding 7373, <http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349>.

<sup>319</sup> Roy Morgan Research, *It’s Official: Australians support assisted dying or euthanasia*, November 2017, Finding 7373.

*are useless for complex issues, such as euthanasia, in which there are so many variables. Moreover, an answer may be determined by the words in which a question is posed.*<sup>320</sup>

Some submitters who discussed opinion polls argued that the polls have consistently shown VAD was supported by a majority of Australians.<sup>321</sup>

For example, the Clem Jones Group stated:

*Opponents of voluntary assisted dying dismiss some polling methodologies and argue that the wording of questions unfairly shapes responses. Despite the criticisms of opponents there can be no doubt that voluntary assisted dying is supported by the overwhelming majority of Australians.*<sup>322</sup>

In 2018, ReachTel conducted a survey of 834 respondents across Queensland on behalf of the Clem Jones Group.<sup>323</sup> The results of the survey showed: ‘...around 80% support for voluntary assisted dying law reform, with high levels of support across age groups and by voters of all political persuasions’.<sup>324</sup>

The former HCDSDFVPC of the 55<sup>th</sup> Parliament sought expert advice on the reliability of opinion polls and community attitude surveys on previous work undertaken by the former committee. The advice provided by Professor Matthew Gray and colleagues from the Australian National University noted that a range of factors influence the results and reliability of polls, including: whether the preamble to a question has the potential to influence a person’s answer to that question; whether emotive questions were asked early on in the survey, potentially ‘priming’ the person’s answer to subsequent questions; whether questions include misleading statements; the survey design and methodology; the sample size of the survey; how people’s views were gathered; and the views of the organisation commissioning the poll.<sup>325</sup>

When asked by the committee about the credibility of polls, Professor Colleen Cartwright explained:

*In the research that my colleagues and I have done over these 25 years we set up a committee of people across the spectrum: those strongly in favour of assisted dying, those strongly against it and people in-between—doctors, lawyers, nurses, all sorts of people. Every question that went out in our questionnaires had to pass that whole committee so we would know we were not asking leading questions. That Clem Jones opinion poll did something similar. They did not talk about unrelieved pain and uncontrolled suffering.*<sup>326</sup>

#### **Committee comment**

The committee notes the suggestions from recent opinion polls that voluntary assisted dying is supported by a majority of Australians, and that voluntary assisted dying law reform has high level support in Queensland. The committee also notes the potential pitfalls associated with interpreting opinion polls on highly contentious social issues.

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<sup>320</sup> Endeavour Forum, submission 1241, pp 1-2.

<sup>321</sup> See Civil Liberties Australia, submission 1270, p1; Go Gentle Australia, submission 1291, pp 10- 11; Voluntary Euthanasia Party, submission 1307, p 13.

<sup>322</sup> Clem Jones Foundation, submission 1202, p 36.

<sup>323</sup> Clem Jones Foundation, submission 1202, p 35.

<sup>324</sup> Clem Jones Foundation, submission 1202, p 35.

<sup>325</sup> Health, Communities, Disability Services and Domestic and family Violence Prevention Committee of the 55<sup>th</sup> Parliament, *Report No 24, 55<sup>th</sup> Parliament, Abortion Law reform (Woman’s Right to Choose) Amendment Bill 2016 and Inquiry into laws governing termination of pregnancy in Queensland*, p 47, August 2016.

<sup>326</sup> Professor Colleen Cartwright, Southern Cross University, public hearing transcript, Southport, 10 September 2019, p14.

## 6 Relevant health practitioners' views

The terms of reference for this inquiry required the committee to inquire and report on relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for its being legislated in Queensland and any necessary safeguards to protect vulnerable persons.

For this part of the terms of reference, the committee has defined 'relevant health practitioners' views' to be the views of doctors, surgeons, medical specialists, psychiatrists, psychologists, therapists, pharmacists, nurses, counsellors and social workers, as well as the professional organisations that represent these medical practitioners; and health service providers who may:

- provide health and pastoral services to patients and their loved ones
- counsel or assess potential applicants for VAD
- prescribe or administer lethal substances for VAD to patients, or
- care for patients receiving lethal substances for VAD.

The views of health practitioners on VAD are as diverse as the views of other community members. This chapter of the report presents the views and arguments expressed by health practitioners both for and against VAD.

### 6.1 Health practitioners' views supportive of VAD

Practitioners who expressed support for VAD cited a range of arguments for its introduction, including stating there are limits to how much palliative care and palliative sedation can address pain and suffering, and the need for people to have choice, autonomy and a more humane option to pain and suffering at the end of their lives. Medical practitioners who are supportive of VAD also referred to the impact of pain and suffering experienced by the dying and terminally ill on their loved ones, not just the person dying.

#### 6.1.1 The limitations of palliative care

The limitations of palliative care for managing end-of-life pain and suffering was a key argument raised by health practitioners for supporting the introduction of VAD in Queensland. They argued that, despite the palliative care medications and other interventions available, not all symptoms can be relieved or well managed.<sup>327</sup>

At the committee's August public hearing in Brisbane, Dr Malcolm Parker from Doctors for Assisted Dying Choice (DFADC) told the committee that:

*...there is strong evidence, including from palliative care physicians and their organisations, that palliative care cannot relieve all suffering and distress at the end of life. Furthermore, some patients simply do not wish to utilise palliative care in the final stages of their lives.*<sup>328</sup>

Dr Finnigan, also from DFADC, added:

*Quite obviously, as the committee will have heard from palliative care people themselves and from their overwhelming evidence, sadly, palliative care does not cover all suffering and really probably will never cover all suffering. Therefore, to adopt the concept that we wait until palliative care becomes 100 per cent effective before we, as a community, push on to voluntary assisted dying legislation is somewhat of a shifting goal post that will never arrive.*<sup>329</sup>

<sup>327</sup> See for example, submissions E096, E127, E225, E366, E434, E661, E859, E1163, E1672, E1913, 169, 287, 429, 430, 646, 608, 977, 1646, 2160.

<sup>328</sup> Public hearing transcript, Brisbane, 23 August 2019, p 4.

<sup>329</sup> Public hearing transcript, Brisbane, 23 August 2019, p 7.

A senior clinician who gave evidence to the committee referred to reports from Oregon, that ‘... lots of the people who actually wanted voluntary assisted dying were already on hospice and palliative care programs. Clearly, they were not feeling that that was enough’.<sup>330</sup>

Mr Phil Browne, a registered nurse with 37 years’ experience told the committee:

*I have seen many good deaths - but tragically, I have witnessed many horrific deaths (even with the best palliative care).<sup>331</sup> Australia practices a very high standard of palliative care, yet palliative care repeatedly fails patient expectations to relieve intolerable suffering. I have on many occasions observed the failure of palliative care to relieve all symptoms in all of my patients.*

...

*I acknowledge that there is a place for both palliative care and also for VAD. From my observation as a health profession working in a hospice for 7 years, I believe some patients would choose to access VAD while an inpatient in a palliative care facility (especially once palliative care could no longer relieve their symptoms).<sup>332</sup>*

While opposed to voluntary assistance in dying, Dr Edward Mantle told the committee:

*...I completely support freedom of choice of individuals—completely. I think it is disingenuous, and it is probably closer to a bald-faced lie, when palliative physicians say that they can relieve all suffering for all patients. It is simply not true.<sup>333</sup>*

The inability of palliative care to treat all pain was a key theme in evidence provided to the committee. For example, Dr Chris Jackson submitted:

*... it remains the case that for some patients pain control is very difficult, and, if permitted to do so, some of those patients would want to end their life at a time of their choosing. Some doctors seem fond of trotting out the truism that all painful deaths can be avoided with good quality palliative care, but I have seen enough counter-examples to that belief to regard it as a convenient falsehood.<sup>334</sup>*

Ms Beverley Bailey, a former registered nurse with 47 years’ experience, including in aged care facilities, shared similar views:

*There are people, claiming experience in palliative care, who express the opinion that all pain can be relieved by the available drugs, so there is no suffering experienced by the patient...This is a long way from the truth. The legal dosage of the available drugs is insufficient in many cases to relieve extreme pain. It is a common belief that doctors kill patients by ordering lethal doses of analgesics, out of compassion, as they are unable to relieve their pain. The simple truth is that doctors order as much analgesia as allowed by the law, when a patient has extreme pain, in an attempt to relieve it. In many cases, the patient dies instead of having his pain relieved. Quite often relatives find this hard to accept, as they have been encouraged to believe that all pain can be relieved, safely. End of life scenarios like this could be a thing of the past, if voluntary assisted dying was legalised.<sup>335</sup>*

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<sup>330</sup> Private hearing transcript, Brisbane, 23 August 2019, p 3.

<sup>331</sup> Submission 977, p 1.

<sup>332</sup> Submission 977, pp 2-3.

<sup>333</sup> Public hearing transcript, Cairns, 27 May 2019, p 8.

<sup>334</sup> Submission E1322.

<sup>335</sup> Submission 429, p 1.

Dr Catherine Hellier referred to the impact of patient suffering on doctors, stating:

*...doctors often feel powerless or vulnerable and unable to provide the relief so desperately desired. It is a question of compassion and choice. Not to be feared.*<sup>336</sup>

Submitters also referred to the side effects of pain relieving medication. Dr Peter Stephenson submitted:

*With my 42 yrs of family GP [experience], I have seen people suffer unnecessarily from terminal diseases where the symptoms of dying cannot be controlled adequately by current management techniques. If only we had medications to control pain absolutely without side effects. A Holy Grail. Narcotics relieve pain, but have constipation as a major side-effect, as well as narcosis, a feeling of being doped up or zombie'd and unable to enjoy life while waiting for the inevitable relief by actually dying. Nausea can be controlled somewhat by today's therapies, but the best treatment (ondansetron) is not on the PBS as it is quite expensive at \$10.00 per tablet. There are conditions that just cannot be controlled like intestinal obstruction where the patient vomits their faeces.*<sup>337</sup>

Some submitters referred to symptoms other than pain that cannot always be treated or managed by palliative care. For example, Mr Phil Browne stated:

*Many people mistakenly believe that pain is the only symptom that can be difficult or impossible to relieve in patients receiving palliative care. This is not correct. There are many different symptoms that can be hard - and sometimes impossible - to relieve completely. This can include: pain, nausea, vomiting, breathlessness, excessive respiratory secretions, delirium [and] terminal agitation. It's common for people to experience several of these distressing symptoms at the same time. For example, patients could have severe pain, while also having nausea, and breathlessness, plus excessive respiratory secretions - all of which might not be able to be adequately controlled, leaving the patient in a severely distressed state which may persist for weeks or months.*<sup>338</sup>

A senior clinician referred to a patient with motor neurone disease who she described as not having pain, but who has terrible suffering:

*She is in a diabolical situation of constantly feeling like she is going to choke. She has no quality of life. She actually had palliative care and she was attending the motor neurone disease clinic. She could not breathe, she could not cough, she could not swallow, she could not speak and she could not roll over in bed.*<sup>339</sup>

Dr Carol Cox also referred to neurodegenerative disorders, stating:

*In my experience, those most interested in the option of voluntary assisted dying are those suffering from slowly progressive and incurable neurodegenerative disorders with total loss of independence and consequent loss of quality of life, as we have heard. Life then becomes a mere existence.*<sup>340</sup>

The inability of palliative care to address other types of suffering that are not symptom-related was also raised during the inquiry. For example, Ms Susie Byrne, a nurse, told the committee:

*As a nurse we are tasked to do no harm, but lately I have been thinking more deeply as to what that actually means. I truly feel that I am doing harm to the patients I care for by not being able*

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<sup>336</sup> Submission E1408.

<sup>337</sup> Submission E127.

<sup>338</sup> Submission 977, p 6.

<sup>339</sup> Private hearing transcript, Brisbane, 23 August 2019, p 2.

<sup>340</sup> Public hearing transcript, Toowoomba, 17 May 2019, p 17.



*to give them, should they make a request and all the criteria are met, a final choice if their suffering becomes unbearable. We must remember that despite having wonderful palliative care services, there will always be a small percentage of people for whom this is not enough. Suffering comes in many different guises and is different for each person. It is not always about pain. It is not always about loss of control. It is not always about fear...If we can make their dying in anyway easier, with less pain, less breathlessness, less fear, less loss of dignity and control, why wouldn't we do this?*<sup>341</sup>

Dr Will Cairns highlighted the reasons individual patients cite for wanting to end their lives, many of which of which are outside of the scope of palliative care:

*Obviously it was very important to explore the reasons individual patients might want to end their life because some of those were amenable to conversation, explanation, medical treatment, treatment of depression—all the reasons that people might want to do it that we could fix. It also recognised that some of the reasons that people wanted to end their life were related to things that we could not fix. The Oregon statistics, which are published every year, show that about 90 per cent of people reported that their reason was a decreasing ability to participate in activities that made life enjoyable. Some 90 per cent reported the reason being the loss of autonomy and 65 per cent reported loss of dignity. The symptom control issues were not a big part of it. Those are things we can deal with. The social issues and the sense of isolation and those kinds of things are not so easy to fix—the sense of loss of control.*<sup>342</sup>

Dr Sandy Buchman, President-Elect of the Canadian Medical Association, provided an example of when palliative care can reach its limitations:

*His conditions were marked immobility, uncontrolled shaking of his head and torso, difficulty feeding himself, difficulty swallowing and experiencing very early onset of hallucinations associated with Lewy body dementia. He had tried every known treatment for his Parkinson's for a number of years. He had sunk into a deep depression and was seeing a geriatric psychiatrist for that and was under medical treatment and support but really was not getting anywhere. He knew exactly what lay ahead of him. He could not turn over in his bed. He had a great fear of hooyer lifts—the canopies and lifts that you use to move a patient from their bed. The fear of hanging in the air and swinging over was unbearable for him.*

*He found that his life was intolerable the way it was. Aside from providing all the support to him and to his family and the nursing care that we were able to offer, dealing with some of his stiffness, we could not control his tremors, we do could not control his immobility and we could not control the onset of the Lewy body dementia any further. That is where I felt we had reached the limitations of palliative care and this man was making a very clear decision that he wanted to proceed with assisted dying.*<sup>343</sup>

Dr Rob Jonquière, the Executive Director of the World Federation of Right to Die Societies, addressed the argument that palliative care, and palliative sedation in particular, is an alternative to VAD, stating:

*In many countries now Palliative Care (PC) in general and Palliative (terminal) Sedation (PS) in particular is brought forward as alternative to euthanasia or medically assisted dying. But Euthanasia and PS are two different possibilities at the end of a process of dying guidance / palliative care trajectory; each has its own properties, the one never can be replaced by the other as if they are full alternatives.*

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<sup>341</sup> Submission E859.

<sup>342</sup> Public hearing transcript, Townsville, 29 May 2019, p 7.

<sup>343</sup> Private briefing transcript, Brisbane, 10 April 2019, pp 8-9.

*The suggestion that the availability of good PC would prevent having to provide Euthanasia can be falsified by the list below, where you can see that the main reasons to ask for Euthanasia are not or very [difficult] to be dealt with by PC.*

*Reasons to ask for euthanasia/assisted dying:*

- *Meaningless suffering 65%*
- *Deterioration 44%*
- *Total weakness 43%*
- *Dependence 33%*
- *Pain 29%*
- *Suffocation 23%*
- *Being a burden to others 27%.<sup>344</sup>*

Dr Jonquière also referred to instances when palliative care could not address a patient's suffering:

*Certainly when the (unbearable) suffering cannot be treated well, when even the best palliative care is not able to really make life comfortable, or when the prospect is hopeless, the meaning of life may dwindle so much, that some patients want to put an end to that suffering by having their life terminated, rather than going on leading a life with such a bad quality.*

*It is important to make a clear distinction between "ending a life" and "terminating (unbearable) suffering". I have never seen or heard terminal patients say they wanted to die; they do not want to continue this sort of life because of untreatable suffering. (Medically) Assisted Dying relates to suffering and not to ending lives.<sup>345</sup>*

For discussion on health practitioners' views on the benefits of palliative care see section 6.2.1.

### **6.1.2 VAD provides a humane option for end of life**

Some health practitioners described VAD as a more humane option to continuing palliative care when palliative care cannot relieve pain and suffering, or as an alternative to continued suffering.<sup>346</sup>

For example, Dr Bradley Butwell submitted:

*Many a patient and their families asked me to assist them to die to escape the misery of pain and distress, sometimes the most sensible and compassionate thing to do. Needless to say, I was unable to comply with their wishes even though I felt their request was the most humane thing to do...The law should be changed to protect well-meaning and humane doctors to practice Voluntary Assisted Dying when palliative care is not working or is inappropriate.<sup>347</sup>*

Ms Karen Terry, a nurse, stated:

*As a nurse, I see terminally ill patients go through needless suffering, and watch their loved ones suffer horrendous heartbreak. It is nothing short of cruelty, and arrogance, to deny someone the choice in how their life ends. To force someone to die slowly and painfully, with no compassion nor dignity, is inhuman.<sup>348</sup>*

<sup>344</sup> Submission 1222, p 9.

<sup>345</sup> Submission 1222, p 5.

<sup>346</sup> See, for example, submissions E052, E083, E084, E273, E763, E1187, 608, 977, 980, 1222, 1646, 2100, 2471.

<sup>347</sup> Submission E763.

<sup>348</sup> Submission E1447.

Dr Maurice Heiner provided a similar argument:

*[VAD] gives the dying control over their end of life and enables them to make suitable arrangements of when they die and to avoid a prolonged and sometimes painful end that affects both them and their loved ones...I have treated or known people who died in a way they never wished to die – in pain, in distress and certainly not in a dignified manner. Recently a desperate elderly patient drank a glass of weed killer in an attempt to die when other treatments had failed.*<sup>349</sup>

Some health practitioners suggested that VAD does not conflict with medical values as is argued by those who oppose VAD. For example, Ms Tiffany Rasmussen referred to Virginia Henderson's 'Need Theory' for nurses, arguing that it:

*...even highlights that nurses are to assist individuals, sick or well, in activities contributing to health or recovery and failing that, to peaceful death. I strongly believe that this means that voluntary assisted-dying should be legalised to reduce the inhumane suffering experienced by individuals with terminal prognosis and healthcare professionals given the ability to assist patients to voluntary peaceful, and dignified, death.*<sup>350</sup>

Likewise, Dr Timothy Porter told the committee:

*Much is made of how this conflicts with medical values, but I do not see that at all. We are accustomed to the approach of doing everything possible to save life and limb where it is appropriate to do so. There are many situations where it is not. Offering advice about, and indeed assistance to, access to life-ending intervention in these situations is simply an extension of that philosophy and is, in my view, simply humane. I would have a perfectly clear conscience with any intervention of this nature on the basis that it is intended to relieve suffering.*<sup>351</sup>

Dr Richard Osborne argued that in some situations the best thing a doctor can do for their patients to get the best out of a situation is to access assisted dying. He stated:

*Most doctors do not cure anybody, whether it is diabetes or heart disease. Similarly with cancer, it is commonly the case that people have incurable disease. As a doctor, your one job is to do your best for that person—that is, doing your best as an individual, doing your best with the technology that is available, whether you are a surgeon or in my case using chemotherapy drugs, doing your best informing them, advising them of things. What you want to do in these difficult, incurable circumstances is get the best out of the situation. My feeling, having thought about it in recent days since being invited to participate in this, is that for some patients you will get the best out of the situation if they do have access to assisted dying. I know that it is a deep and complicated area, but I do think if you imagine that what you are trying to do is for each individual person to get the best out of the situation with a limited life span, for some people that is going to be an appropriate way forward.*<sup>352</sup>

Dr Sandy Buchman gave the example of the first time he carried out a medically assistance in dying procedure in Canada:

*My first provision was about five or six minutes, when this cardiologist colleague-patient died in the arms of his daughter in bed in his own home. It was very touching. I have seen a lot of death. Death, even with the best palliative care, can be difficult, with terminal agitation and delirium. We are usually quite capable of getting that under control, but it can be a hard goal for quite*

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<sup>349</sup> Submission 1646, p 1.

<sup>350</sup> Submission E096.

<sup>351</sup> Public hearing transcript, Toowoomba, 17 May 2019, p 14.

<sup>352</sup> Public hearing transcript, Hervey Bay, 15 July 2019, p 6.

*some time. This was a gentle, planned thing. He kissed his loved ones goodbye and died in his daughter's arms. The whole thing took maybe seven to 10 minutes in total.*<sup>353</sup>

Some health practitioners argued that VAD is a more humane alternative to current end-of-life experiences such as suicide, refusing food or needing to travel overseas in order to access an assisted dying scheme. For example, Dr Christopher McMahon submitted:

*Legalisation of VAD would reduce the number of people with terminal illness or a diagnosis of progressive neurological conditions (including dementia) from taking their own lives by less humane means, such as the use of poisons, firearms or hanging. Due to the current legal situation, suicide in these circumstances is often committed in secrecy and isolation, robbing the person and their loved ones of the chance to say goodbye. Occasionally, the attempted suicide is unsuccessful, which can result in the surviving person living on in even more distressing circumstances.*<sup>354</sup>

Dr Kevin Barker referred to suicides he has seen during his time as a police medical doctor:

*I have seen many people who ended their own life or attempted same. I have seen some doctor assisted deaths. The self suicides are very traumatic to the person himself and also to the family and ambos and police and doctors. Medical assisted are usually clean and understood by the family the patient is lying in bed at home or in hospital in clean surroundings and loved ones nearby. The death occurs without trauma and helped by love. This is how people should end their life. Not with a gun shot or strangling on a rope or crashing into a tree or taking a bottle of valium and swimming toward New Zealand then washing up on a beach.*<sup>355</sup>

Similarly, Dr Will Cairns told the committee:

*Suicide is not illegal. What is illegal is making it into something peaceful and comfortable. I have seen patients who have suicided in very messy and unpleasant ways because they felt that the time had come for the end of their life.*<sup>356</sup>

Ms Salena Barrett submitted:

*As a cancer nurse I would like to submit my support of a change to the current voluntary assisted dying laws. I have looked after patients receiving cancer treatment for many years and for many the fear of suffering needlessly at the end of life is a huge concern. Cancer takes away the person's control and often they would like to at least take control of how of how they die. I wouldn't expect many patients to access voluntary assisted dying if it was available but the knowledge that option was available would be comforting to many patients. I believe with good palliative care that the need for voluntary assisted dying would be low and we should still continue to try and improve access to palliative care. I often see patients waiting too long to be seen by palliative care which increases the risk that they with [sic] end their life by suicide as their needs are not being met.*<sup>357</sup>

Ms Susie Byrne, a nurse, referred to the first responders who attend to suicides, stating:

*I am making this submission in honour and to thank the first responders who attend the scene where someone has taken their own life. The scene where there are no brake or skid marks on the road when a car has hit a tree or driven into a lake or river; the scene where they are found in a car with the engine running in a locked garage with carbon monoxide filling the air; the scene where pills are taken in the hope that they have taken enough to do the job and hope they won't*

<sup>353</sup> Private hearing transcript, Brisbane, 10 April 2019, p 5.

<sup>354</sup> Submission E1913.

<sup>355</sup> Submission E273.

<sup>356</sup> Public hearing transcript, Townsville, 29 May 2019, p 9.

<sup>357</sup> Submission E598.

*wake to find out it hasn't worked. Then, there are the violent suicides which involve a firearm and a forensic cleaning team has to be called in to remove all trace of the aftermath. To clarify, when someone takes their own life to avoid the inevitable suffering that they fear will befall them, these are rational suicides. These are far removed from a knee jerk reaction to a love affair gone wrong, not as a result of mental illness or depression. They are people who choose to suicide rather than "go the distance" with a terminal illness that, for some, will rob them of their ability to eat, drink, talk, move, and to do the things that most people in good health take for granted.*<sup>358</sup>

Ms Linda Whittington, a registered nurse for over 30 years, stated:

*How can it be right that we force people with incurable illnesses and terminal illnesses to leave the country, and leave behind their loved ones so they can end their lives in countries where it is legalized... We need to be given a legal right to be protected from unnecessary suffering, so there can be more compassionate choices available than starving ourselves to death, or violently taking our lives alone for fear of implicating others.*<sup>359</sup>

Dr Phillip Nitschke from Exit International referred to Professor David Goodall and Melbourne fireman Troy Thornton who travelled to Switzerland to access a VAD scheme:

*Neither man should have been forced to leave home in order to have a peaceful, elected, voluntary death. Troy's journey half way around the world was particularly traumatic, not only for his wife Chris but because he had to say goodbye to his kids Laura and Jack in Melbourne. What father would want to do that? This is a crazy situation and it must change.*<sup>360</sup>

Dr Jonquière concluded:

*I want to emphasize that medically assisted dying is to be considered as the final step in a longer process. An initial request seldom is made "out of the blue", patients are ill, diagnosed and in treatment and thus mostly already extensively "seen by doctors". After such a request there should be ample time to talk with patient and family; to try and make the suffering bearable, offering alternative treatments; so time enough "to grow" as doctor and patient "together" to the moment where the suffering is unbearable, because no longer treatable. And do not forget: patients do not easily put such a request to their doctor, and doctors generally are not eager to terminate a life – rather try and find other options to deal with the suffering of the patient.*<sup>361</sup>

Opposing arguments provided by health practitioners that VAD conflicts with the message of suicide prevention and may normalise suicide, are discussed in section 5.4.6

Some health practitioners advised that assisted dying is already being undertaken in Australia, and the lack of regulation means there may be harmful consequences. For example, Dr Malcolm Parker from Doctors for Assisted Dying Choice told the committee:

*...voluntary assisted dying occurs covertly and illegally, at times with harmful consequences, as a result of the absence of proper regulation. On this basis, we submit that it is now timely and appropriate for the state government to legislate for voluntary assisted dying with the appropriate safeguards.*<sup>362</sup>

Similarly, Ms Judith Nommensen, a former registered nurse with extensive experience in end-of-life care in the hospital system and in retirement as a volunteer with Cittamani, a home hospice

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<sup>358</sup> Submission E859.

<sup>359</sup> Submission 608, pp 2-3.

<sup>360</sup> Submission E1343.

<sup>361</sup> Submission 1222, p10-11.

<sup>362</sup> Public hearing transcript, Brisbane, 23 August 2019, p 4.

organisation on the Sunshine Coast, referred to the published surveys of Australian doctors' attitudes to practices of assisted dying, suggesting that:

*It is obvious from these statistics that Assisted Dying is surprisingly common in Australia despite the fact that it is illegal, and potentially subject to harsh penalties. On the hopeful and good side is the fact that over recent years a number of judgements in the courts make it clear that many Judges and public opinion do not consider it basically evil.*<sup>363</sup>

### 6.1.3 Patient choice and autonomy

Many health practitioners who supported VAD also supported the concept of patient choice and autonomy to choose how and when they died.<sup>364</sup>

For example, Ms Renee Sheil stated:

*As a nurse I have seen a lot of sick/terminally ill patients suffer an undignified death and at times painful death due to restraints imposed on them by our legal system. Not only should those patients be allowed to choose when they die, but they should be allowed to determine how.*<sup>365</sup>

Ms Carolyn May Bowser, a retired nurse with 50 years' experience, submitted:

*Voluntary assisted dying would enable the person to regain some control over their lives and the way life is lived. Many will not take up the option of voluntary assisted dying, but it will help them feel that they have some say in what happens. The worst part of the waiting, the hopelessness, the knowing that there is no way back to the life you had. VAD would give comfort in knowing that there is an alternative...It is quality of life which is important, not just the number of years lived.*<sup>366</sup>

Dr Rob Jonquière, who was involved in the public and parliamentary discussions on the implementation of the Dutch Euthanasia Bill and in later evaluations, stated that the most important outcome of the Dutch system was that 'the patient within this legal frame gets a real choice at the end of his/her life, to terminate unbearable, futile suffering'.<sup>367</sup>

One senior clinician told the committee:

*...for those of us who have been involved in the terrible suffering of some patients and had to be involved in palliative sedation, it is a truly awful situation for both the patient and their family, and the nursing staff and the doctors involved. The main reason I believe that voluntary assisted dying legislation is important is because I think an individual has the right to decide when their suffering is enough and that they would like to have the opportunity to terminate that.*<sup>368</sup>

Dr Vicki Willmot in her submission stated:

*People (and families) suffer and sometimes beg for assistance to die before things become too bad, knowing that the end is inevitable and that there is nothing left for them except more suffering. Unfortunately palliative care does not always do enough, soon enough. If this became law, then people still have the right to have their life end in the same way as they do now, but they would also have the right to put an end to their suffering in a peaceful dignified way at a time and place of their choice, which they don't have now. They would have the chance to be with loved ones (instead of sometimes dying alone) and say things they want to say and so would*

<sup>363</sup> Submission 980, p 2.

<sup>364</sup> See, for example, submissions E275, E434, E588, E661, E1322, 1740, 79, 162, 169, 287, 328, 454, 547, 558, 768, 1222, 1511, 1586.

<sup>365</sup> Submission 768, p 1.

<sup>366</sup> Submission 558, pp 1-2.

<sup>367</sup> Submission 1222, p 2.

<sup>368</sup> Private hearing transcript, Brisbane, 23 July 2019, p 1.

*their relatives. The population is aging, this is going to become an increasingly relevant issue and the choice needs to be available. I don't feel anyone has the right to deny people this option.*<sup>369</sup>

Ms Judith Nommensen, suggested that 'a culture that has developed the means to extend physical life, must then... to maintain its humanity, develop accepted and legal means for a person to terminate their lives when they and their family want this'.<sup>370</sup>

Dr Robert Grace referred to a patient's right to make their own decision, rather than expecting doctors to know best. He told the committee:

*Voluntary assisted dying will not be for everyone, but it will be for some. What right does any of us have to deny this option from another individual? This type of attitude represents a throwback to the paternalism of old where doctor knew best. Humans are endowed with reason and [conscience]. They are born free and equal in dignity and in rights. To withhold the option of voluntary assisted dying is to ignore these principles and, in some twisted logic, deny the fact that humans are able to and entitled to make decisions about their own life.*<sup>371</sup>

Dr Will Cairns referred to information from Oregon suggesting that, for many patients, having the choice to access VAD was far more important than actually exercising it. He advised the committee:

*Sometimes people find themselves in very difficult predicaments and they choose, or would like to be able to choose, to end their life sooner. In Oregon they found that for many people having the choice was the most important thing and whether they exercised it or not was almost secondary. Of the people in Oregon who are given prescriptions for life-ending medication, fewer than two-thirds actually use that medication. It is really about control of your own life.*<sup>372</sup>

#### **6.1.4 Assisted dying and palliative sedation**

The practice of palliative sedation, otherwise known as terminal sedation, was raised by a number of health practitioners. Dr Christopher McMahon raised the issue of prosecution: either by families who believe palliative sedation brought an early death to their family member, or doctors' fear of prosecution leading to under-treatment of patients. In relation to prosecution by families, Dr McMahon stated:

*Eventually, the patients' condition would deteriorate to such an extent that the palliative care team would prescribe a syringe driver to provide continuous pain relief, along with anti-emetic and anxiolytic medications (often referred to as "terminal sedation"). There is also the attempt to make the process more palatable to caring support, be that friends or family. Upon commencement of a syringe driver, the patients usually died within a number of hours to days....Patients' families may perceive the commencement of a syringe driver to be an underhand method of providing assisted dying (note the absence of "voluntary" in this use of the term, as by this stage many patients have deteriorated to such an extent that they lack the capacity to consent), leaving the treating doctor or palliative care team open to prosecution under current laws.*<sup>373</sup>

In relation to fear of prosecution, Dr McMahon stated:

*Fear of prosecution arising from the above scenario may lead to under-treatment of patients, resulting in sub-optimal symptom control and more protracted suffering for patients. It would be far safer for both medical professionals and their patients if practices involving end-of-life care were more transparent and regulated. This should include the option of VAD for those who want*

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<sup>369</sup> Submission E661.

<sup>370</sup> Submission 980, p 1.

<sup>371</sup> Public hearing transcript, Cairns, 27 May 2019, p 24.

<sup>372</sup> Public hearing transcript, Townsville, 29 May 2019, p 8.

<sup>373</sup> Submission E1913.

*it, with safe-guarding processes put in place to prevent mis-use in vulnerable populations. Long term data from other countries where VAD is legal supports the safety of the approach and there is evidence that palliative care services are improved by the people having the option of VAD.*<sup>374</sup>

Ms Linda Whittington made a similar statement, submitting:

*In my career I have seen the professional struggle of nurses and doctors, forced by law to keep patients alive and in pain, suffering because they could not and would not be the ones to take that pain away. Scared of the legal ramifications of such actions. Doctors afraid to order and administer morphine and other pain killing agents for fear it would be that patients last, and that the finger would be pointed at them.*<sup>375</sup>

Dr Neil Simmons also referred to the current alternatives to VAD, submitting that palliative sedation is a form of assisted dying:

*At the moment in Queensland, when somebody with a terminal condition is experiencing intolerable suffering and wants to die, they have limited options. They may refuse food and water and intravenous fluids and then spend their last few days debilitated, drugged and unconscious. Alternatively they or their loved ones may request higher doses of opiates to “keep them comfortable” and then they die as a result of respiratory depression from the medication. This latter situation is really a commonly practised form of assisted dying which is not formally recognised by the medical system.*<sup>376</sup>

Similarly, Jessica Aitken submitted:

*I am a Registered Nurse currently working in an oncology/medical and haematology ward. In the past 4 months, I have had 20 patients pass away. Some were peaceful through uses of continuous delivery devices of medications such as morphine and midazolam. Just this past week, I had a pt [patient], on a pump except, the pump was filled with phenobarbitone. What we are doing by delivering these medications/ the doctrine of double effect, it's legal and the same as assisted dying.*<sup>377</sup>

Mr Phil Browne stated that palliative sedation and voluntary assisted dying have much in common, that is, they both have the intention of relieving intolerable suffering and they both result in the death of the patient, however, a key difference is:

*...the amount of time it takes from the commencement of treatment until the patient dies. Typically a calm peaceful death occurs within around 30 minutes of VAD medication/s being administered - however, with terminal sedation, death often occurs some hours to days after commencing terminal sedation medication/s. Terminal sedation can be seen by health professionals - as well as by patient's relatives - as merely being a slow legal form of VAD.*<sup>378</sup>

In contrast, some health practitioners refuted the argument made by supporters of VAD that palliative or palliative sedation is a form of euthanasia. For example, Dr Ian Marshall argued:

*There is a debate as to whether palliative sedation is an euphemistic expression for what is really 'slow euthanasia'...However, the difference is clear. The intention once more is to relieve refractory symptoms and not to kill. With palliative sedation, terminally ill patients die as a result of their illness...There are no differences in survival between sedated and non-sedated groups of patients.' Furthermore, the point of palliative sedation is not to render the patient unconscious (let alone end the patient's life) but to find a way to address refractory symptoms, and hence the*

<sup>374</sup> Submission E1913.

<sup>375</sup> Submission 608, p 1.

<sup>376</sup> Submission 1586.

<sup>377</sup> Submission E180.

<sup>378</sup> Submission 977, p 2.



*level of sedation is adjusted ('titrated'), and the patient's consciousness affected, only as much as is needed to achieve this.*<sup>379</sup>

Similarly, Dr Anthony Herbert addressed palliative sedation for children, stating:

*In the control of pain, the dose of opioid required might be close to the level that depresses respiration, raising concerns that it may hasten the time of death. This is usually only in the terminal phase of the illness when the child often requires sedative medications in addition to opioids. This differs from euthanasia in that the intent is to control distressing symptoms of pain and agitation, and not to cause death. A study from Newcastle, Australia, found that there was no association between the dose of opioids and sedatives on the last day of life and survival (from hospice admission to death).*<sup>380</sup>

#### **6.1.5 Slippery slope argument and termination of life without a request**

Dr Rob Jonquière referred to the 'misuse' of data collected in the Netherlands by those who oppose VAD to support the slippery slope argument, and the view that doctors are terminating life without a request by the patient under the Dutch system. Dr Jonquière stated:

*These data include amongst others also figures on doctor's actions at the end of life of persons without a request, which thus are against our law as then as today (the number of cases of life-termination without request, of course happily misused by opponents); but, these figures have decreased by some 75% since our law was put into force.*<sup>381</sup>

Dr Jonquière also argued that the Dutch practice of VAD has not led to a slippery slope, and referred to an article which concluded that 'there seems to exist an idea that the boundaries of the Dutch euthanasia law are slowly being extended. The situations which are seen as new, however, always fall within the limits of the law...'<sup>382</sup> He stated:

*In no country in the world there is so much openness on medical decisions around the end of life as in the Netherlands. The scientifically well renowned reports of 1990, 1995, 2001, 2005, 2010 and 2015 (Rommelse, Van der Wal, Onwuteaka) are statistically sound and show no signs of a slope downwards, let alone a slippery slope:*

- *the absolute numbers of euthanasia and physician assisted suicide have shown to be rather stable, being some 2% of all death cases per year, slowly growing to 4%; the percentage of reported euthanasia cases has grown from 18% in 1990 to some 85% in 2015;*
- *the same reports even showed the decisions without requests (also in our eyes to be incorrect!) also to dramatically go down from 0.8% in 1990 to 0.3% in 2017 (some of them being termination of the life of severely multi-handicapped new-borns)*
- *since 2001 there was a significant rise in percentage of Palliative Sedation (PS), a development in the opposite direction of that of Euthanasia.*

*The lessons from the Netherlands can be that legalisation of Euthanasia turned into a better quality of all end-of-life care, a higher level of Palliative Care and a continued high level of trust between doctors and patients.*<sup>383</sup>

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<sup>379</sup> Submission 1758, p 6.

<sup>380</sup> Submission 1813, attachment, p 6.

<sup>381</sup> Submission 1222, p 7.

<sup>382</sup> Submission 1222, p 9.

<sup>383</sup> Submission 1222, p 12. Please note that in quoting the decimal figure statistics from Dr Jonquière's submission, the committee has changed the decimal separator symbol from a comma to a point.

Professor Luc Deliens explained to the committee the experience in Belgium, stating:

*What you see is that you have a very complex law that needs integration into your broad healthcare system. That takes time. It takes a long time to get a complex law integrated into your healthcare system.*

...

*A slippery slope means that you are applying a health law towards a group that might not need this kind of health law. I never found a group like that.*

*... having said that, of course you need to fulfil all due care criteria of your law. The assessment of all these due care criteria is sufficient to guarantee there is not the misuse of the implementation of such a law. If you assess competency within women, within children, within ethnic minorities, within people with disabilities and you do that properly in a professional way and you end up with a judgement by professionals that that person at that moment is competent, why should that person not get access to these healthcare services?<sup>384</sup>*

Ms Linda Whittington referred to the myth of the slippery slope, stating:

*The myths around assisted dying are just that – myths. It is not the beginning of a slippery slope as has been suggested by some of our mindless leaders. It does not pose a threat to the vulnerable if implemented with appropriate safe guards and strict criteria applied. We need to be given a legal right to be protected from unnecessary suffering, so there can be more compassionate choices available than starving ourselves to death, or violently taking our lives alone for fear of implicating others.<sup>385</sup>*

The opposing view of health practitioners on the slippery slope argument can be found in section 6.2.3.

#### **6.1.6 Impact of death on families and loved ones**

Some health practitioners who expressed support for the introduction of a VAD scheme referred to the impact that a persons' suffering has on family members and loved ones in addition to the suffering of the patient.<sup>386</sup>

For example, Ms Carolyn May Bowser, a retired nurse with 50 years' experience, stated:

*Too many times I have watched patients and their loved ones struggle to the end. Apart from the actual physical suffering, this causes immense distress to both the person and their family. They feel guilt because they cannot improve the situation.<sup>387</sup>*

Ms Marissa Pflasterer, a nurse for more than 26 years, similarly submitted:

*As a healthcare professional, a nurse of 26+ years, I have cared for numerous people during their final days. I have held their hands while they take their last breath and comforted the family after their loved one is gone. One thing I am unable to do is erase the haunting memories of families that have watched a loved one suffer through a terminal disease and become a shell, no longer the person they were.<sup>388</sup>*

Ms Susie Byrne referred to the difference between a good death and a bad death and the impact it has on families, stating:

*The way in which we grieve for those we love is often influenced by the way in which they die. When people are perceived to have had a "good" death, there is much comfort from knowing*

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<sup>384</sup> Public hearing transcript, Brisbane, 21 October 2019, pp 6-7.

<sup>385</sup> Submission 608, pp 2-3.

<sup>386</sup> See, for example, submissions E081, E242, E859, E1796, 558.

<sup>387</sup> Submission 558, p 1.

<sup>388</sup> Submission E242.

*that they died calmly, peacefully and without pain. When people are perceived to have had a "bad" death the opposite occurs. The feelings of helplessness, guilt and like they have never doing enough to help the person they loved, often stay with the bereaved forever.*<sup>389</sup>

Dr Heather McNamee commented on the difficulties for families when palliative sedation is used, stating:

*To avoid the risk of prosecution, the drugs must be administered to relieve pain. There can be no intention to hasten death, even though by the time someone is effectively unconscious there is nothing to be gained for the patient, the family or the doctor to prolong the process. For family travelling from far away or overseas the inability to accurately predict the time of death leads to added stress in situations where people arrive too late and miss the moment of passing or get there too early and have to leave to get back to their life commitments.*

*The patients themselves miss the opportunity to have a positive goodbye to their loved ones as their deterioration into coma is slow and their consciousness is erratic in the early stages.*<sup>390</sup>

## **6.2 Health practitioners views opposing VAD**

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

- the greater benefits of palliative care
- concerns that VAD will interfere with doctor-patient relationships and may discourage patients from seeking medical treatment for life-shortening 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
- risks of VAD schemes being abused
- impacts on families and loved ones, and
- conflicts with messages of suicide prevention; as well as fundamental legal, philosophical and moral concerns.

### **6.2.1 Role of palliative care**

#### **6.2.1.1 Purpose of palliative care**

Some doctors argued that VAD is unnecessary because of the role of palliative care to assist dying.<sup>391</sup>

For example, Dr Stephen Myers submitted:

*We already have legislation that allows assisted dying: palliative care is assisted dying. The practice of palliative care involves alleviating suffering, allowing people to find strength and value in their lives as they near their end...Good palliative care emphasises the value of human life, assisted suicide dismisses it.*<sup>392</sup>

Similarly, Dr David van Gend stated:

*...“Assisted Dying” is a domain that has already been taken. It describes what we, as doctors working in palliative care, already do for our patients: we assist them in every possible way*

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<sup>389</sup> Submission E859.

<sup>390</sup> Public hearing transcript, Brisbane, 23 August 2019, p 43.

<sup>391</sup> See for example submission 947, 1848, 2042, 2055.

<sup>392</sup> Submission 947, p 1.

*during the dying phase of life. It is offensive to take that description of the proper ethical work of palliative medicine and twist it to describe voluntary medical homicide or assisted suicide.*<sup>393</sup>

It was also argued that palliative care can sufficiently relieve suffering, making VAD unnecessary.<sup>394</sup> Dr Ashraf Saleh submitted:

*...all cases where euthanasia might be considered could still be adequately cared for to their natural death by means of the wide variety of analgesic agents and sedative/calmlative medications that promote comfort and dignity in the last days of a person's life. As such, ending the life of such a person on the basis of ending misery is thwart with complicated scenarios that would cloud judgement in the determination of when euthanasia could be appropriately performed. There are many foreseeable instances from a medical point of view where the life of a person would be prematurely terminated on account of perceived discomfort or distress. Suffering does not have to be a feature of palliative or end-of-life care when managed adequately. As such it is from a medical point of view a significantly dangerous piece of legislation superfluous to the needs of end-of-life care.*<sup>395</sup>

Dr Luke Garske similarly argued:

*I am yet to find a patient where the current approach has truly failed the patient and their family, provided there is an adequate team with adequate resourcing for palliative care. The response to the need to improve the experience of suffering before death must be to increase access to better resourced palliative care. Voluntary assisted dying (VAD) is a simplistic and fear-driven solution which will have unintended major consequences for many patients and their families as well as society.*<sup>396</sup>

Academics from the Faculty of Medicine and School of Psychology at the University of Queensland argued:

*There is no reason for any person to die with pain and uncontrolled symptoms in this country. There is a plethora [sic] analgesic and other options available and wide-spread expertise in pain and symptom management if sourced.*<sup>397</sup>

Melinda Jesudason, a registered nurse who has worked in palliative care, submitted:

*...I believe good palliative care is where the focus should be and often the general public does not understand it does not have to be a case of either dying in agony, slowly and without dignity or euthanasia as the only alternative. There is always the option for good palliative care, so even a slow, progressive, serious illness that leads to death can be managed well and treatments given for comfort and pain relief, such as morphine, that may hasten death but death is never the first intention.*<sup>398</sup>

Dr Ian Marshall submitted:

*Nearly all physical pain is treatable. True that nearly all is not all, and there is a small percentage of instances where patients may have physical 'refractory symptoms', defined as 'symptoms that cannot be adequately controlled despite aggressive efforts to identify and utilize a therapy that*

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<sup>393</sup> Submission 2055, p 6.

<sup>394</sup> See, for example, submissions E504, E925, E1739, E1803, E2006, 111, 761, 862, 1265, 1625, 1758, 2463, 2647.

<sup>395</sup> Submission 111, p 1.

<sup>396</sup> Submission E1739.

<sup>397</sup> Submission 1219, p 9.

<sup>398</sup> Submission 2647.

*does not compromise consciousness.' Yet, even here palliative sedation is, nonetheless, available as [a] last resort.*<sup>399</sup>

Some practitioners argued that VAD may not be the peaceful death people are seeking. For example, Dr Stephen Parnis submitted that assisted suicide and euthanasia regimes in other parts of the world have never been able to guarantee the painless exit that many claim.<sup>400</sup> Similarly, Health Professionals Say No! stated:

*Contrary to proponents' claims, legalizing assisted suicide does not guarantee patients a quick and peaceful death. Previous experience in jurisdictions where EPAS [euthanasia and physician - assisted suicide] is legal has suggested that complications occur regularly.*<sup>401</sup>

#### 6.2.1.2 Funding and resourcing of palliative care

A number of health practitioners argued that the state government should improve access to, and the delivery of, good palliative care before, or rather than, introducing VAD.<sup>402</sup>

For example, Dr Andrew Burke submitted that:

*...the provision of strong palliative care services removes many of the arguments put forward by those promoting death by lethal injection for the terminally ill. The reason people in our society still die in physical pain is primarily due to the failure to supply such services to the wider community.*<sup>403</sup>

At a public hearing in Brisbane, Dr Good argued:

*Our viewpoint is that, until you have an equitable, world-class palliative care system across the state, it seems premature to introduce a pathway that some people may choose to go down when they have not had adequate access to good symptom control. I think that is one of our big concerns.*<sup>404</sup>

Dr Michael Pearcy suggested:

*the consideration of VAD is a vote of no-confidence in our palliative care services, who do a wonderful job with the terminally ill relieving their pain. There are very few countries that can equal Australia's record in palliative care & we should be supporting them, not giving up on sick patients & letting them kill themselves.*<sup>405</sup>

Dr Peter Kraus succinctly stated 'most arguments of euthanasia are better addressed as arguments to improve palliative care'.<sup>406</sup>

Dr Stephen Parnis stated palliative care in Australia is widely unavailable, delayed in its implementation and argued for greater funding for palliative care:

*If high quality palliative care is well funded and readily available, then I would assert the demand for assisted suicide is dramatically reduced. I understand that in its Pre-Budget submission Palliative Care Queensland has stated there needs to an additional \$100m in funding for*

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<sup>399</sup> Submission 1758, pp 4-5.

<sup>400</sup> Submission 1811, attachment, p 1, 2.

<sup>401</sup> Submission 1265, p 6.

<sup>402</sup> See, for example, submissions E446, E993, E1185, E1396, E1543, E1702, E1834, 1733, 2042, 2054, 2072, 2186, 2266, 2612.

<sup>403</sup> Submission 2042, attachment, p 1.

<sup>404</sup> Public hearing transcript, Brisbane, 5 April 2019, p 8.

<sup>405</sup> Submission E1396.

<sup>406</sup> Submission 2266.

*specialist medical palliative care personnel. To proceed with an assisted suicide regime while palliative care is heavily underfunded is indefensible health policy.*<sup>407</sup>

Dr Robert Pollnitz also referred to the difficulties in accessing palliative care:

*My experience is that once patients have their pain and other distressing symptoms relieved, they no longer wish to die. However, Queensland does not yet have the recommended number of palliative care specialists. There can be delays in gaining access to pain management clinics, and remote and socially disadvantaged citizens can find blocks in accessing good palliative care.*<sup>408</sup>

Cara Whittred, a registered nurse and midwife who has worked with terminally ill and palliative care patients stated:

*What I wholeheartedly support, however, are palliative care choices - whether they include homebased care or in palliative care units, hospice care etc. There is such a scarcity of appropriate palliative and hospice care facilities in hospitals as well as in the community and this is where huge funding should be directed in my view. It seems to be a constant refrain around issues of intractable pain associated with life-limiting illnesses, but this has certainly not been my experience. And there are so many options and combinations available now. What needs to be addressed is specialist training and education for medical, nursing and allied staff working in these areas - and not only concerning physical pain but also issues around mental anguish and distress etc in patients/ clients and their loved ones...ie wholistic care. I remember reading a comment by an oncology consultant of many years experience, that even some palliative care medical staff can be remiss regarding effective, up-to-date pain relief combinations and options.*<sup>409</sup>

Concerns were raised that the introduction of VAD would see resources allocated to VAD rather than improving palliative care delivery. In her submission, Dr Zelle Hodge contended:

*It will mean financial resources for palliative care will be compromised. There are significant issues around increased longevity and death and dying and grief that we as a society need to address and VAD will result in those issues never being addressed adequately. With VAD as an option there are financial drivers to impede best palliative care options. Best practice palliative care must be funded and available to all dying patients.*<sup>410</sup>

*In reality it would seem that in most cases where individuals support VAD because of their personal experience with a dying relative, the major issue is inadequate palliative care. Palliative care must be appropriately funded and available for those in the terminal stages of life.*<sup>411</sup>

There were also concerns that VAD would be seen as a more financially attractive option compared to the cost of providing palliative care. For example, Dr Luke Garske stated:

*There is also no doubt that much greater resources are needed in both palliative care services and chronic pain management. If there is an option to end life earlier than through natural causes, society will inevitably face increasing financial pressure to make it easier to end life earlier. VAD will be more affordable for the rest of society than good quality palliative care and chronic pain management.*<sup>412</sup>

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<sup>407</sup> Submission 1811, attachment, p1, 2, 3.

<sup>408</sup> Submission 1660, p 3.

<sup>409</sup> Submission 2610.

<sup>410</sup> Submission 1812, p 3.

<sup>411</sup> Submission 1812, p 5.

<sup>412</sup> Submission E1739.

For discussion on health practitioners' views on the limits of palliative care see section 6.1.1.

### 6.2.2 Addressing fear as a type of suffering

Health practitioners questioned the reasons people seek access to VAD, and argued that people often seek VAD for reasons unrelated to pain such as a fear of dying and a fear of suffering. For example, Dr Phillip Good argued that 'People do not access VAD overseas for symptom control issues; they access VAD for societal issues, or what I think are societal issues. Those are things like fear of the future, loss of independence, loss of dignity, loss of autonomy—the idea of values'.<sup>413</sup>

Dr Andrew Burke supported the same view, stating:

*The inherently subjective nature of suffering is such that one cannot accurately establish the degree to which emotional and psychological distress is influencing the decision to end one's life. Indeed, physical pain is the primary reason for seeking euthanasia in only a minority of cases with loss of autonomy predominating in the majority of cases overseas.*<sup>414</sup>

Dr Anthony Herbert referred to his experience with paediatric palliative care, stating:

*Many children and their parents fear the loss of many domains of their childhood in such a situation. In addition to fear of suffering, these fears include the loss of dignity, control and autonomy. There is also a fear of unrelieved suffering and pain. Some children fear that they will become a burden, or alternatively, parents fear the burden of caring for their child will become too large to bear.*

*Such fears should not drive a push to legalise euthanasia. The paediatric sub-specialty of paediatric palliative care tries to provide a holistic approach to patients and their families to meet this huge need. Health care practitioners should try and address these fears for patients who have incurable or progressive disease. Although death is often a devastating experience, it does not preclude it becoming a time of strengthening and bonding for patients and families. In contrast to euthanasia, palliative care affirms life and regards dying as a normal process.*<sup>415</sup>

Further, Dr Allen Hibberd noted that 'emotional reasoning is neither a basis for a person to seek VAD nor for medical doctors to facilitate it'.<sup>416</sup>

Dr Ian Olver submitted that VAD cannot minimise the distress of a loved one dying:

*In fact, it may lead to later regret, when the emotional turmoil has lessened about whether a relative really needed to be killed prematurely. The distress of the relatives is caused by seeing their loved one suffer and that suffering may be alleviated in many cases without the need for death, so it is not the design of VAD that will determine the distress of the patient and their loved ones.*<sup>417</sup>

Some doctors argued that once fears around dying are addressed, people no longer seek VAD as an option. For example, Dr Donna Purcell stated:

*So many times, when one hears of stories to justify euthanasia, it is bound up with the actual fear of the dying process itself, either through a natural fear we can all understand, or because of a loved one's experience, a fear of losing control over one's circumstances or mode of dying, or other reasons...It is actually one of the vital roles of Palliative Care to explain or dispel the fears*

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<sup>413</sup> Public hearing transcript, Brisbane, 5 April 2019, p 6.

<sup>414</sup> Submission 2042, attachment, p 2.

<sup>415</sup> Submission 1813, attachment, p 4.

<sup>416</sup> Submission 2043, p 3.

<sup>417</sup> Submission E1435

*that people have around dying...Palliative Care specialists maintain that when patient's issues are addressed, almost no-one is still requesting suicide.*<sup>418</sup>

Dr Carol Douglas, representing the ANZSPM, questioned descriptions of unbearable suffering and pain, stating:

*Based on practice, we often hear the description of patients being in unbearable pain or having unbearable suffering. I would say that the experience of palliative medicine specialists is that the person who is expressing a wish to die earlier often is doing so due to a suffering that is in anticipation of what might occur—the loss of dignity, the reliance on others to provide them care eventually.*

*It would be a very unusual circumstance today...but in my experience of patients who have proceeded in various circumstances over the years to seek an early death it has not been about uncontrolled symptoms. I think that is a very important point to make. The will to live in progressive disease fluctuates constantly. The will to die or the wish to die fluctuates constantly. ...the ability to have the language and communication to have those conversations with your patients often in their despair and when they are suffering can change their ability to manage. We are not coercive. We are not persuasive, but it is very interesting when you see patients day to day, especially in an inpatient setting, how one day they can be despairing and the next day they are actually enjoying or feeling more comfortable with the position they are in.*<sup>419</sup>

*I think it is very important to see that humanity in general want to live longer—people want to live longer. It is a minority of people who, because of the perceived or anticipated suffering, are very clear that they want to shorten their lives when they have particular diagnoses.*<sup>420</sup>

Dr Andrew Burke submitted:

*I discuss death and dying on a daily basis with patients and their families. I discuss their fears and their hopes for the remaining days, weeks and months of their lives. These fears can be ameliorated with reassurance that they have a say in what level of intervention they wish to receive and a deeper understanding of the range of palliative and community service available.*<sup>421</sup>

Similarly, Dr Anthony Herbert submitted:

*Control of pain, and other physical symptoms, is paramount. A patient is unlikely to have hope for the future if they have unrelieved pain or other symptoms or are in a state of depression. There is a need for a comprehensive and holistic assessment of the child and their family. There is also a need to address physical, emotional (e.g. sadness or worry), social (e.g. financial burdens), practical and spiritual problems. A child and their family's outlook for the future often change if their pain is managed, depression treated and other supports put in place. Requests for euthanasia are often not sustained when such symptoms are treated.*<sup>422</sup>

Dr Luke Garske, a thoracic physician with experience caring for patients with a range of severe lung diseases, explained to the committee how he worked to address the fears of his patients:

*It is common for a patient diagnosed with an advanced lung disease, with expected survival of less than a few years and no curative options, to discuss euthanasia. Most often, this is the patient's way of saying that they fear that they will be a burden to family members or the community, or they fear severe distress before they die. With our current philosophical and legal*

<sup>418</sup> Submission 2054, attachment, p 3.

<sup>419</sup> Public hearing transcript, Brisbane, 13 September 2019, pp 39-40.

<sup>420</sup> Public hearing transcript, Brisbane, 13 September 2019, p 40.

<sup>421</sup> Submission 2042, attachment, p 1.

<sup>422</sup> Submission 1813, attachment, p 4.



*framework, this question can be addressed in a fairly straightforward and empathetic way. I explain that my goal is to relieve as much distress as possible, but that there may be some discomfort along their journey which I will work hard to relieve. I try to relieve their fears that they will be a burden on society, which for many patients is as simple as encouraging them to discuss this fear with their family, who may welcome an opportunity to provide care for their loved one. Where that is not possible or sufficient, patients are frequently not aware of services which can help. As they start to appreciate the possible solutions, their fears of being a burden or excessive suffering usually diminish.*<sup>423</sup>

### 6.2.3 Concerns regarding the ‘slippery slope’ effect

Some health practitioners opposed to VAD raised concerns about the potential for the ‘slippery slope’ effect to influence future VAD legislation.<sup>424</sup> For example, Dr Timothy Kleinig argued:

*There are only two logically consistent euthanasia positions; prohibition, or extension to all patients (or patient proxies) who request it. If our society accepts the basic principle, that suffering in some cases sanctions killing, then extension by degrees cannot be rationally opposed. It will not be logical to deny euthanasia to any ‘reasonable’ person who judges death more desirable than life, as suffering is unquantifiable and inherently subjective. Once euthanasia is permitted in principle, it is illogical - and ‘inhumane’ - to limit it to those whose suffering is of short duration. If euthanasia is a humane and reasonable way to reduce a short period of suffering, how much more humane is it to assist suicide when unrelieved suffering might persist for decades?*<sup>425</sup>

Similarly, Dr Donna Purcell submitted:

*It is all too easy for the boundaries to be relaxed so as to include euthanasia for other circumstances...if killing itself is not to be banned totally by the law, why should not other conditions be counted as equally burdensome? Some proponents of euthanasia are already complaining that the Victorian legislation is too restrictive before it even comes into effect, and it is predictable that pressure will be applied to make euthanasia more widely available there once it has been in effect for a time. Claims will be made that is “discriminatory” that it be restricted to people with less than six months to live, or only for those actually dying of a terminal-rather than a chronic-illness. This is only logical, because if killing itself is no longer wrong, it is an arbitrary judgement who should be included or excluded.*<sup>426</sup>

Dr Stephen Myers told the committee ‘there is no jurisdiction that has legalised assisted suicide, that has not seen the category of person this legislation is applied to broaden and continue to do so’.<sup>427</sup>

Particular reference was made to concerns that a VAD scheme could be extended to children, or people who are not terminally ill such as the mentally ill and the disabled.<sup>428</sup> For example, Dr David van Gend stated:

*There is no ethical principle or legal logic that can stop the so-called “right to die” being extended to ever wider categories of people, as we have seen overseas – from the terminally ill to the disabled and those with depression; to anorexics, autistics, and those merely “tired of life”. Advocates who say we can limit euthanasia to “the terminally ill in terrible pain” are defying the*

<sup>423</sup> Submission E1739.

<sup>424</sup> See, for example, submissions E1172, E1396, E1543, E1185, 914, 1758.

<sup>425</sup> Submission E1172.

<sup>426</sup> Submission 2054, attachment, p 2.

<sup>427</sup> Submission 947.

<sup>428</sup> See, for example, submissions E1396, 947, 2310.

*facts of history.*<sup>429</sup> *Because, if there is a “right to die”, who are you to limit that right? Who are you to question what is “valid” for someone else?*<sup>430</sup>

Health Professionals Say No! referred to overseas experience demonstrating that:

*...original changes to the law have been gradually extended or changed, that regulation and reporting is often inadequate, and that definitions of concepts including “suffering”, are so arbitrary, that there can be no significant evidence to demonstrate that safe-guards would work or be able to be used without bias. Specific concerns include the issues of extension of legal re-definition of what activity is decriminalised, consent, medical practice and process complexities. As such practices represent a seismic shift in how a society views individual lives, the potential harms and impacts to patients, carers/families and clinicians are also great.*<sup>431</sup>

A number of health practitioners referred to other jurisdictions to provide examples of the widening of eligibility for VAD. Belgium and the Netherlands were referenced in particular, both in relation to the widening of eligibility for VAD and the acceptance of involuntary VAD after initially having strict conditions on eligibility.<sup>432</sup>

#### 6.2.4 Impacts on vulnerable people

Some of the health practitioners who voiced opposition to VAD raised concerns about the impact the introduction of VAD would have on vulnerable people, particularly in relation to coercion by others.<sup>433</sup> Vulnerable groups mentioned included children, the elderly, the isolated, the poor, those with mental illness and those with intellectual impairment.

In relation to the potential for coercion, Dr Gerard Purcell stated:

*It is my experience the person who chooses freely and without external influences is a hard person to find. People, in my experience, approach death in as many varied ways as there are people. But despite this variation approaching death without feeling the pressure of external influences is rare. In fact I can think of only one person who would fit that description in the years that I have been involved in palliative care. It is clear in my mind that keeping euthanasia “voluntary” is not something that a legislative framework is capable off [sic].*<sup>434</sup>

Particular concerns were raised by doctors about the potential for elder abuse.<sup>435</sup> For example, Dr Timothy Kleinig stated:

*As much as we like to believe otherwise, we do not make our decisions as isolated autonomous individuals, but within a web of influences and relationships. If assisted suicide or euthanasia legislation is enacted, it is highly likely, over time, that elderly patients will feel an increasing obligation to take their own lives. Medical expenditure in the final year of life swallows a huge proportion of the health budget, and the final stages of life demand much time and energy from family supports. Not agreeing (or not ‘choosing’) euthanasia will be viewed as selfish.*<sup>436</sup>

Dr Ian Marshall submitted that ‘it would be naive not to believe that if VAD were legalised the elderly would not be the group most at risk of being pressured into making a ‘voluntary’ decision to have their lives ended’. He referred to Emeritus Professor David Richmond who he stated contends ‘Older people

<sup>429</sup> Submission 2055, p 5.

<sup>430</sup> Submission 2055, p 14.

<sup>431</sup> Submission 1265, attachment, p 16.

<sup>432</sup> See, for example, submissions E 1172, E1834, E1906, 914, 1209, 1625, 1848, 2040, 2055, 2293, 2610.

<sup>433</sup> See, for example, submissions E1185, E1435, E1906, 947, 1758, 1813, 1835, 2055.

<sup>434</sup> Submission 2040, p 1.

<sup>435</sup> See, for example, submissions E1172, E1185 and 1758.

<sup>436</sup> Submission E1172.

are, by and large very sensitive to being thought to be a burden, and more likely than a young person to accede to more or less subtle suggestions that they have 'had a good innings'.<sup>437</sup>

Concerns were also raised that it is difficult to identify coercion of the vulnerable.<sup>438</sup> For example, Dr Ian Olver stated 'In an economically rationalist society no safeguards will guarantee that vulnerable people will not be coerced. This can be a very subtle interaction between patient, family and health professionals'.<sup>439</sup>

Dr Andrew Burke submitted:

*Although coercion towards euthanasia is generally subject to criminal charges in the various euthanasia legislations this will not stop patients being heavily influenced towards this decision by others. A strategically placed comment such as, "It must be a great relief Mum to know that euthanasia is available should you request it?" will leave the dying person under no illusions as to what is expected of them by their family members. This will not show up on the legal radar but will nevertheless be an external pressure that will favour killing.*<sup>440</sup>

Health practitioners also referred to the pressure vulnerable people may feel to access VAD to reduce the burden on family and others.<sup>441</sup>

For example, Dr Michael Pearcy told the committee that 'vulnerable patients would be pressured into feeling it is their duty to accept euthanasia so as not to be a burden on their relatives, some of whom sadly are motivated by financial greed'.<sup>442</sup>

Similarly, Ms Melinda Ericksson, a registered nurse who works in palliative care, submitted:

*My concern is that it changes the moral framework of society very subtly and over time. As the numbers increase it starts to become more acceptable and a valid option. I know a lot of elderly people are concerned about being a burden on their family so over time does this become the right way to solve these feelings?*<sup>443</sup>

Dr Ian Marshall stated:

*The terminally ill and distressed will inevitably feel that VAD is 'the right thing to do'. They will not want to be a burden to their family and friends, nor to society as a whole. With the option of an efficient and painless exit route, the terminally ill will be put in the position of having to justify both to themselves and to others-why they should not avail themselves of this state-approved option.*<sup>444</sup>

Dr Marshall also referred to annual reports released by Oregon Public Health which contain data on the numbers of patients who reported that part of their motivation to request euthanasia was because they felt a 'burden on family, friends/caregiver'. Dr Marshall stated 'In the 17 years between 1998 to 2015 more than one in three patients (41.1per cent) perceived themselves as being a burden to their nearest and dearest'.<sup>445</sup>

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<sup>437</sup> Submission 1758, p 8.

<sup>438</sup> See, for example, submissions E1435, 2040, 2042.

<sup>439</sup> Submission E1435.

<sup>440</sup> Submission 2042, attachment, p 3.

<sup>441</sup> See, for example, submissions E1396, 1758, 1835, 2177.

<sup>442</sup> Submission E1396.

<sup>443</sup> Submission 2293, p 1.

<sup>444</sup> Submission 1758.

<sup>445</sup> Submission 1758, pp 8-9.

Some health practitioners raised concerns that the introduction of VAD would result in the devaluing of the lives of society's more vulnerable people.<sup>446</sup> For example, Dr Ciara Ross submitted:

*It is absolutely essential that VAD is not legalised in this country, as the culture toward life will become distorted into the view that there are certain people in our community who are less worthy of life - these are the most vulnerable in society. These people will then be required to prove why they should be 'allowed to live'.*<sup>447</sup>

In a similar vein, Dr Zelle Hodge stated:

*Such legislation would place some of the most vulnerable in our society at risk, in failure to provide adequate care when dying or in circumstances of physical or emotional ill health. We expect legislation to protect the most vulnerable in our communities and voluntary assisted dying legislation in essence does not do this. It changes society's view of the value of human life and in making the most vulnerable either through age or physical or mental ill health see their life as of decreased value they may be 'pushed' to agree to end it, or with the option of VAD we will fail to provide funding for adequate care both physical and emotional of our most vulnerable.*<sup>448</sup>

Health Professionals Say No! referred to concerns held by groups who may be considered to be vulnerable to VAD legislation:

*Importantly so, despite reported public support for this socio-political agenda, it is rarely discussed that this support is weak among groups who express concerns about being pressured to die (i.e. older adults, people with disabilities, people with less education, women, indigenous and racial and ethnic minorities).*<sup>449</sup>

The impact on people with a disability was specifically mentioned. Dr Gerard Purcell stated:

*This leads me on to my next point of the fear that people with disability have in regards to such legislation. While it is an uncomfortable truth, there is tendency that is strong in the minds of modern Australian's to value those with disabilities and illnesses less than those who are able bodied. I see this particularly at the extremes of ages (very young and elderly) but also those of any age. People with disabilities know this and that is why they are fearful of legislation legalising euthanasia.*<sup>450</sup>

Dr Robert Pollnitz submitted:

*...my disabled friends and patients tell me that they feel threatened by any law to permit assisted suicide. Already they feel that society often fails to respect them as having equal rights. To quote Tanni Corey-Thompson - "In their eyes, my life is not worth living." A law that promotes a societal view of the weak as "unproductive burdens" will be feared by every Queenslander living with a disability.*<sup>451</sup>

Some doctors argued that it is the role of government to protect vulnerable people, and the introduction of VAD by government would be a failure to do so.<sup>452</sup> For example, Dr Robert Pollnitz argued:

*Those most at risk from a law allowing lethal doses will be our vulnerable people – the aged and frail and those with a physical or intellectual disability. Our Parliaments and our society have an*

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<sup>446</sup> See, for example, submissions E1435, 1660, 1812, 1848.

<sup>447</sup> Submission 1848, attachment, p 2.

<sup>448</sup> Submission 1812, p 3.

<sup>449</sup> Submission 1265, attachment, p 3.

<sup>450</sup> Submission 2040, p 2.

<sup>451</sup> Submission 1660, p 2.

<sup>452</sup> See, for example, submissions 1660, 1811 and 1848.

*obligation to protect these people, and assisted suicide/ euthanasia does the opposite, it places them in danger. In legalising assisted suicide we will be accepting “therapeutic homicide”, and this will be a massive shift in the moral values of our society.*<sup>453</sup>

Dr Chrys Pulle provided an example of the difficulties in relation to assessing capacity with vulnerable people, telling the committee:

*A couple of weeks ago in my practice there was a disagreement between the patient, who was 94 years of age, who wanted the procedure to go ahead but the family member said, ‘No, this should not go ahead. He has dementia and he is delirious. The procedure should not go ahead.’ This man would die with a fractured hip. I believed that that patient had capacity. Eventually, the patient needed the procedure and went through without, thankfully, any significant complication. If the capacity of that older person is questioned, my concern is that their rights will be taken over by the enduring power of attorney for whatever reason. Granted, that is in an acute setting but these issues could also occur in a non-acute setting. The issue also arises if there is secondary gain. Oftentimes patients have underlying depression, or mental illness that is nonexacerbated and they wish to die using voluntary assisted dying potentially as a means to an end.*<sup>454</sup>

## **6.2.5 Role of health practitioners and their relationship with patients**

### **6.2.5.1 Role of doctor**

Some doctors who submitted to the inquiry argued that involvement in VAD and the deliberate ending of someone’s life is not the role of a doctor and is in opposition to medical ethics and the Hippocratic Oath to ‘first do no harm’.<sup>455</sup>

For example, Dr Stephen Parnis stated:

*Medical ethics are founded on doing good for the patient (beneficence), and not to harm them (non-maleficence). Killing a patient or providing the means for them to do so can never be sanctioned by these ethical principles.*<sup>456</sup>

Dr John Hayes referred to published research in the Internal Medicine Journal, which ‘revealed that 70% of Doctors want NOTHING to do with Euthanasia, which is regarded as a frank violation of the Hippocratic Oath. There is thus considerable opposition from the overwhelming majority of Doctors’.<sup>457</sup>

Similarly, Dr Julene Haack stated ‘a good doctor will do everything possible to preserve the life of their patient and, when this is no longer possible, they will do everything they can to keep the patient comfortable’.<sup>458</sup>

Ruth Curtis, a nurse, submitted that ‘euthanasia in fact oversteps the line of “do no wrong” and puts both medical and nursing staff in a very compromising situation where they are required to do the very opposite of the things they have been taught and trained to do’.<sup>459</sup>

To support this view, reference was also made to the opposition to VAD voiced by medical associations.<sup>460</sup> For example, Dr Zelle Hodge pointed out that VAD is ‘contrary to medical ethics as set

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<sup>453</sup> Submission 1660, p 3.

<sup>454</sup> Public hearing transcript, Brisbane, 4 July 2019, p 13.

<sup>455</sup> See, for example, submission E1396, E1185, 1660, 1848, 2054, 1811, 1813, 2055, 2615, 2043, 2280.

<sup>456</sup> Submission 1811, attachment, p 3.

<sup>457</sup> Submission 2186.

<sup>458</sup> Submission E1834.

<sup>459</sup> Submission 761, p1.

<sup>460</sup> See for example, submissions E1906, 1812, 2055, 947.

out in policies of the Australian Medical Association, the World Medical Association, the British Medical Association, the New Zealand Medical Association and the American Medical Association'.<sup>461</sup>

Similarly, Dr David van Gend stated:

*It turns society's bringers of life and health into society's bringers of death. It violates our Hippocratic Oath: "I will not give a lethal drug to anyone if I am asked." That is why the Australian Medical Association so strongly opposes euthanasia, stating in 2016, "Doctors should not be involved in interventions that have as their primary intention the ending of a person's life".*<sup>462</sup>

Doctors also raised concerns about the impact VAD would have on their profession. For example, Dr Clare Boothroyd expressed her fear that:

*...if we have VAD, palliative care will become dominated by those who are happy to perform VAD and who advocate for VAD. I would fear for a change of culture in a profession committed to caring for people, saving lives albeit for a finite time and valuing life.*<sup>463</sup>

Dr Timothy Kleinig referred to the perceived lack of support by health practitioners for VAD:

*Support for euthanasia is lowest amongst those doctors who personally treat dying patients - It is noteworthy that support for euthanasia declines in inverse proportion to the person's exposure to dying patients. This is of course the opposite of what would be expected if euthanasia were truly desirable or necessary. While community support seems to be strong, nurses' support is lower, doctors' lower again, and Palliative Care doctors' lowest of all. Both the Australia and New Zealand Society of Palliative Medicine (ANZSPM) and Palliative Care Australia (PCA) oppose it. The AMA also remains opposed, as does the World Medical Association.*<sup>464</sup>

Dr Ian Marshall argued that the role of the physician would be fundamentally altered by VAD.<sup>465</sup>

Professors Jane Turner and David Kissane expressed concern about the normalisation of medically assisted dying, submitting:

*It has also been suggested that the rate of medically assisted dying is stable in Oregon. Yet when one tracks the rate of utilisation over time, its recent growth has been at 13.2% annually. Such growth has been argued to represent the normalization of medically assisted dying in this society....The exponential rate of growth of euthanasia in Belgium is 19.6%. The process of normalization of medically assisted dying has been seen in every country, and ultimately changes forever the nature of medical practice. Legislators would be naïve to believe that they can introduce a tightly controlled process that won't increase in subsequent years once the door is opened.*<sup>466</sup>

#### 6.2.5.2 Impact on medical staff and their relationship with the patient

Concerns were also raised that the introduction of VAD would impact on the doctor-patient relationship.<sup>467</sup> For example, Dr Michael Pearcy argued 'Patients would be reluctant to seek health care for fear that they would be bumped off against their will, as has happened overseas where euthanasia is legal.'<sup>468</sup>

<sup>461</sup> Submission 1812, p 3.

<sup>462</sup> Submission 2055, p 5.

<sup>463</sup> Submission 1835, p 1.

<sup>464</sup> Submission E1172.

<sup>465</sup> Submission 1758, p 4.

<sup>466</sup> Submission 1209, pp 15-16.

<sup>467</sup> See, for example, submissions E1396, E1543, E1739, E1906, 947, 1848, 1758, 1812, 1813.

<sup>468</sup> Submission E1396.

Dr Ciara Ross submitted that people may become scared of their doctors:

*Doctors and nurses traditionally are seen in the community as protectors of life. Changing this to include killing as part of their role will change the dynamic and relationship that patients have with their medical providers. We will see a new wave of elderly people who will become scared of their doctors and refuse to seek medical help or go to hospital for fear of being euthanised. We have seen these patterns of behaviour in Belgium and the Netherlands.*<sup>469</sup>

Dr Luke Garske submitted:

*Having a legislated VAD option will change the relationship between the treating physician and the patient. This will have negative ramifications for society as a whole, and how patients view their place in society at a particularly difficult period. I do not believe there are any safeguards which can prevent negative impacts of VAD legislation on the physician-patient relationship, both for patients who will ask about VAD, as well as for the more numerous patients who will not. VAD legislation would change the dynamic of the patient journey and the physician-patient relationship.*<sup>470</sup>

Dr Terence Kent told the committee that he believed VAD undermines the trust in doctor-patient relationships, stating:

*I often see patients who are suicidal almost every second day and a lot of energy comes into helping them. Most of them eventually recover and are very glad that they no longer felt that way and never acted on it. Am I to change this treatment from prevention to assistance in their wishes to die? No. Voluntary assisted dying or physician assisted suicide undermines the trust in patient-doctor relationships. It changes the role of the doctor as healer to life taker.*<sup>471</sup>

Dr Zelle Hodge submitted that the introduction of VAD would complicate matters, stating that ‘with grieving relatives, legislative requirements, individual agendas etc it will result in complex difficulties for both patient and their treating doctor instead of the reassurance and best patient care that the patient should be given’.<sup>472</sup>

Health Professional Say No! commented on the impact on physicians:

*In jurisdictions where EPAS is legal, physicians who carry out assisted suicide have reported a negative impact from the act. In an American study, of 38 oncologists who reported participating in EPAS, nearly a quarter regretted their actions, and another 16% reported that the emotional burden of performing EPAS adversely affected their medical practice. Doctors were not trained for this task and have not asked for this role. If VAD is legalised, doctors should have nothing to do with it, so the role of healer is not confused. Shortly after legislative introduction in Ontario, over 200 doctors who initially had supported the enactment of legislation in Canada have removed themselves from the “Medical Assistance In Dying” Register, due to the effect of their experience into the reality of what their actions involved. There is a great and stark incongruence here in the role of the physician in the therapeutic relationship.*<sup>473</sup>

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<sup>469</sup> Submission 1848, attachment, pp 3-4.

<sup>470</sup> Submission E1739.

<sup>471</sup> Public hearing transcript, Toowoomba, 17 May 2019, p 12.

<sup>472</sup> Submission 1812, p 4.

<sup>473</sup> Submission 1265, attachment, pp 9-10.

Similarly, Dr Sue Colen told the committee:

*In fact, doctors in the Netherlands now have found that quite a percentage of them have post-traumatic stress disorder. They say that they are maybe willing to do one, but it is so traumatic for them to do it.*<sup>474</sup>

Concerns were also raised about the influence a doctor can have on a patient.

Dr Brendan Miller stated that ‘doctors have tremendous power to influence the decisions of patients’,<sup>475</sup> while Dr Andrew Burke submitted:

*Even in this modern age of openly available information a patient’s decision - and that of their family - is very much influenced by what they are told by their doctor. What information a doctor chooses to give and withhold about prognosis, therapeutic options and end of life care will heavily impact upon a person’s expectations. Before discussing options with a patient, we, as doctors, have usually made our decision about the appropriate course of action: whether to undergo chemotherapy, to commence dialysis or to undergo resuscitation and artificial ventilation. The manner in which we describe these options to the sick and their families is often intended to lead them to agreeing with our conclusion. We do this every day, usually subconsciously. As such it is often impossible for a patient to receive an unbiased opinion from their doctor. Thus, when a patient makes an “informed decision” it is in fact heavily influenced by the values and bias of their treating physician whichever way that may fall. It is naïve to suggest that the availability of euthanasia will in some way remove this fog of confusion and uncertainty which is the reality of medical practice. We can legislate to allow euthanasia but we cannot legislate for human nature and its imperfections.*<sup>476</sup>

Dr Albert Garth Thomas also referred to patients’ trust in doctors, submitting:

*Every time I administer a cocktail of drugs to render a patient unconscious I am aware of the immense trust that person places in me. Despite the overblown concept of individual autonomy, which is one of the principal motivators for this proposed legislation, the old trust based model of the doctor-patient relationship still has a lot to recommend it. I say this because no expression of autonomy, however great or profound, will ever completely bridge the knowledge gap and subsequent power gap that exists between clinicians and their patients. If voluntary assisted dying becomes an option that can be suggested by a patient’s doctor, that suggestion carries with it all of the authority and potential coerciveness that accompanies this power imbalance. Adding this therapeutic option to a clinician’s armamentarium places at risk the trust between doctors and patients.*<sup>477</sup>

#### 6.2.6 VAD schemes open to abuse or error

Related to concerns about the impact of VAD on vulnerable people, health practitioners raised concerns that VAD schemes could be open to abuse or error.

For example, Dr Ian Marshall stated that ‘one of the main concerns is the risk of abuse’ and that ‘the practical operation of any system of VE [voluntary euthanasia] or DAS [doctor assisted suicide] is susceptible to normal human error or even deliberate exploitation’.<sup>478</sup>

<sup>474</sup> Public hearing transcript, Brisbane, 4 July 2019, p 93.

<sup>475</sup> Submission E1543

<sup>476</sup> Submission 2042, attachment, p 2.

<sup>477</sup> Public hearing transcript, Brisbane, 23 August 2019, p 46.

<sup>478</sup> Submission 1758, p 11.



Dr Allen Hibberd submitted:

*Legislation most likely will guarantee loopholes be found by the unscrupulous to exploit the vulnerable to death and is therefore highly undesirable. To regard life as sacrosanct by its very nature is the only possible position to hold because it is not subject to manipulation.*<sup>479</sup>

Some doctors raised concerns that VAD legislation would be open to abuse or non-compliance by doctors, regardless of the safeguards in place.<sup>480</sup> For example, Dr David van Gend stated:

*Professors of psychiatry in Brisbane, Frank Varghese and Brian Kelly, warned years ago of the impossibility of protecting patients from doctors under laws for euthanasia:*

*Much of the debate about euthanasia and physician-assisted suicide has as its underlying assumption that doctors will always act in the interests of their patients. This assumption fails to take into account the doctor's unconscious and indeed sometimes conscious wishes for the patient to die and thereby to relieve everyone, including the doctor, of distress ... Legislation to enable assisted suicide has been designed to provide a safeguard, through psychiatric assessment, that protects patients from themselves. What these laws do not do and cannot do is protect the patient against unconscious factors in the doctor.*<sup>481</sup>

Dr van Gend also argued that 'there is nothing that can protect vulnerable patients from doctors who think they should be dead, as we have seen in Holland and Belgium'.<sup>482</sup>

Particular concerns were raised about doctors undertaking euthanasia on people without their consent.<sup>483</sup> For example, Dr Peter Kraus submitted:

*There is also the potential, which I believe is happening in places where assisted suicide has been legalised, for boundaries to be blurred and people in nursing homes to be euthanised, in practice even if not in theory, against their will. I believe there are documented cases. This borders on eugenics but is an inevitable consequence.*<sup>484</sup>

Dr Rory Donnellan, an anatomical pathologist, raised a concern about misdiagnosis, stating:

*I sometimes encounter cases where the clinical diagnosis is subsequently proven incorrect. I am concerned that, Queenslanders may be subjected to euthanasia when in fact they have easily treatable conditions which have been misdiagnosed or overlooked.*<sup>485</sup>

Dr Chrys Pulle raised the issue of the potential for inherent bias, stating:

*Because of the wide range of medical opinion, everyone has an inherent bias. I suppose it depends on who that doctor is. I know in Victoria they need two doctors to make a decision as to whether to proceed with voluntary assisted dying. It depends on which doctors you see. ... The doctor could have an inherent bias.*<sup>486</sup>

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<sup>479</sup> Submission 2043, p 2.

<sup>480</sup> See, for example, submissions E1172, 111, 2042, 2055.

<sup>481</sup> Submission 2055, p 10.

<sup>482</sup> Submission 2055, p 5.

<sup>483</sup> See, for example, submissions E1172, 2042, 2055.

<sup>484</sup> Submission 2266.

<sup>485</sup> Submission 2617, p 1.

<sup>486</sup> Public hearing transcript, Brisbane, 4 July 2019, p 13.

Dr Stephen Parnis similarly argued:

*The more complex the system, the greater the risks to those entering it. In Victoria, a regime which trumpets more than 60 specific legislative safeguards should be regarded as a system where there are more than 60 opportunities for error. Such errors include:*

- *Misdiagnosis and gross error in determining prognosis*
- *Undiagnosed mental illness*
- *Coercive pressure upon those who feel they are a burden.*<sup>487</sup>

Further discussion on possible safeguards to protect people from the potential for abuse, error or coercion can be found in Chapters 8 and 9 of the report.

### 6.2.7 Impact on families and other loved ones

Some health practitioners suggested that VAD is desirable for those who don't wish to watch a family member progress through the dying process, rather than the patient desiring VAD for themselves.

For example, Ms Melinda Ericksson submitted:

*I have only had one client ask for euthanasia and he had depression, most clients are trying to extend their life. In saying that I have seen family members struggle with watching the dying process (mostly the length of time) and hence bring up the topic of euthanasia. I have also noticed this in letters to the editor - supporters often cite it was terrible to watch their family member die, but this is about them not coping not the client. Dying has always been part of life and we need as a society to accept this.*<sup>488</sup>

Professors Jane Turner and David Kissane also expressed the view that 'It is conceivable that many who advocate for physician-assisted death have witnessed poor quality care to loved ones in their past'.<sup>489</sup>

Some health practitioners also referred to the importance of the palliative care process to assist patients and families to come to terms with the impending death. For example, Ms Christine Lenz, a Registered Nurse and Bereavement Counsellor for Metro South Palliative Care stated:

*Patients' time on the ward or in their homes is so precious, particularly as it often allows patients and their families to reunite and come to acceptance of their future loss. Complex or complicated grief is currently statistically 10-15% but if legislation was changed, I believe the statistics would increase rapidly, with attendant mental health issues.*<sup>490</sup>

Ms Teresa Parker, a retired nurse who worked in aged and palliative care, submitted:

*I experienced in every case, in this time of end of life, closure, peace and a letting go. With support around them (nurses, family friends doctors, councillors [sic]) pain and other symptoms controlled, families and friends, I found started dealing with issues, old squabbles ect [sic] and were able to die naturally and peacefully.*<sup>491</sup>

Dr Clare Boothroyd spoke of her own experiences with the passing of family members, stating:

*To have experienced such mercy, such care and love, such calm assurance was life changing and I am not sure that VAD would have allowed that time and relational journey. Had my family members elected to have VAD, VAD would have taken my family members from me before they*

<sup>487</sup> Submission 1811, attachment, p 2.

<sup>488</sup> Submission 2293, p 1.

<sup>489</sup> Submission 1209, p 13.

<sup>490</sup> Submission 2612, p 1.

<sup>491</sup> Submission E925.

*naturally left us and would have denied them and us those precious moments, shared experiences and exchanges.*<sup>492</sup>

Ms Shyla Mills, CEO of Palliative Care Queensland, commented on the impact that a VAD scheme might have on families:

*One of the biggest things about palliative care, that we have tried to get across today, is the whole of network that surrounds them. One of the biggest challenges within voluntary euthanasia is the fact that it is going to potentially disconnect families hugely because not everyone will agree. How is that considered within the conversation? I think that needs to be a big part of it.*

*Something that we have learned from the US and Canada is exactly that. There is no bereavement support following euthanasia that is really to that level appropriate. A lot of people did not agree and it has broken up families. There are a lot of additional things, other than just the procedure and agreement to do the procedure itself, that needs to be considered in the whole spectrum.*<sup>493</sup>

### 6.2.8 Conflict with the message of suicide prevention

A number of health practitioners questioned why someone ending their life via VAD would be considered acceptable but suicide in other circumstances is considered unacceptable.<sup>494</sup> For example, Dr Timothy Kleinig submitted:

*Our current mental health act (in a de facto fashion) defines suicidality as mental illness, because depression and 'rational' suicidality cannot easily be separated. However, once the underlying logic of euthanasia is accepted, suicide becomes just another reasonable choice. By what logic could suicide for physical suffering [be] facilitated, but suicide for mental suffering continue to be prevented by psychiatric incarceration?*<sup>495</sup>

Dr Ian Marshall referred to the 'inconsistency (and contradiction in terms) in affirming the autonomy of certain people to choose the time and manner of their death while denying the autonomy of others to do so by dissuading suicide'.<sup>496</sup> Dr Stephen Parnis stated that 'drawing an arbitrary distinction between suicide in this context and every other circumstance is dangerous and misguided'.<sup>497</sup>

Concerns were also expressed that introducing VAD would impact on efforts to address and reduce suicide, sending the wrong message to the community.<sup>498</sup>

For example, Dr Julene Haack submitted:

*... legalising euthanasia makes a mockery of all our suicide prevention efforts – if we can say it is perfectly alright for people who are in physical pain to kill themselves, it must, therefore, be alright for people who are in mental pain to kill themselves. Why bother to prevent suicides? Through allowing euthanasia, we lose sight of the fact that both physical and mental pain are eminently treatable.*<sup>499</sup>

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<sup>492</sup> Submission 1835, p 1.

<sup>493</sup> Public hearing transcript, Brisbane, 23 January 2019, p 31.

<sup>494</sup> See, for example, submissions E1172, E1834, E1906, 947, 2054, 1758, 1811, 1135.

<sup>495</sup> Submission E1172.

<sup>496</sup> Submission 1758, p 10.

<sup>497</sup> Submission 1811, attachment, p 1.

<sup>498</sup> See, for example, submissions E1834, 947, 1135 and 1265.

<sup>499</sup> Submission E1834.

Dr Donna Purcell, also questioned why aiding someone to commit suicide would be legal under VAD but not under any other circumstances. She submitted:

*The law of this land is opposed to the taking of human life, and whilst (attempted) suicide is not illegal, assisting another to commit suicide still is. The purpose of this law, and the function of government, is to protect the lives of its citizens. We have in this proposal a total reversal of this precept; people will be aided to kill themselves if they so wish, or have it done to them, with the sanction of the same government that would send others to prison for doing the same thing. In other words, legislating for euthanasia is establishing two parallel laws, one that says killing is acceptable and receives the sanction of government in such and such a situation, and in other situations, it is wrong.*<sup>500</sup>

Dr Katrina Ison referred to the normalisation of suicide:

*We can see the potential for suicide normalisation that occurred when the assisted dying laws were introduced in Oregon. One of the justifications given in Oregon for introducing assisted suicide is that it would reduce the number of people having to resort to committing suicide. The idea was that if voluntary assisted dying was introduced, less people would commit suicide in order to end their lives. However, the suicide rate in Oregon has INCREASED since they allowed euthanasia (from 14 per 100,000 in 2012 to 16 per 100,000 in 2016), and that is ON TOP OF all the physician-assisted suicides. The net result was to make suicide more acceptable and to devalue life in general. Not surprisingly, the suicide rate went up, not down.*<sup>501</sup>

Health Professionals Say No! referred to suicide data for jurisdictions that have a euthanasia and physician assisted suicide (EPAS) scheme, which is similar to VAD, stating:

*In the jurisdictions where EPAS is legal, non-assisted suicide rates have also increased, for example in Oregon USA, it was found that legalising EPAS was associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides. The authors concluded: 'This suggests either that PAS does not inhibit (nor acts as an alternative to) non-assisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals'.*<sup>502</sup>

Arguments by health practitioners that VAD is a more humane alternative to suicide can be found in section 6.1.2.

### 6.2.9 Legal, philosophical and moral concerns

A number of health practitioners raised concerns regarding the legal, philosophical and moral aspects of VAD. Some health practitioners referred to the importance of maintaining a stance on the prohibition of killing.<sup>503</sup>

For example, Dr David van Gend submitted 'In all civilisations, the prohibition of intentional killing is the foundation of law. Euthanasia is intentional killing, and that is a line that should never be crossed.'<sup>504</sup>

<sup>500</sup> Submission 2054, attachment, p 1.

<sup>501</sup> Submission E1906.

<sup>502</sup> Submission 1265, attachment, p 5

<sup>503</sup> See, for example, submissions E1172, 159, 2054, 2055.

<sup>504</sup> Submission 2055, p 5.

Dr Timothy Kleing also argued:

*The principle that no human is competent to direct his or her own death, or the death of another, underpins our society. The British House of Lords called the prohibition of intentional killing ‘the cornerstone of law and of social relationships’.*<sup>505</sup>

Dr Luke Garske raised philosophical concerns about the effects on society when patients expect to choose VAD to avoid any suffering or distress. He stated:

*Some individuals may pursue the VAD option out of fear and anxiety. It will be impossible to prevent some patients having VAD despite the probability that they will only experience mild or moderate distress. Measurement of parameters such as distress is impossibly complex. It is inevitable that defining severe distress will be subjective and inaccurate. Although we must make every effort to relieve distress and suffering wherever possible, we must also recognise that there are often unexpected positive consequences of suffering for both personal growth and relationships. A society that seeks to avoid all suffering will lose its positive, caring values.*<sup>506</sup>

Professor Ian Oliver stated:

*In bioethics choosing to die means placing the value of individual autonomy above the value of human life which is hard to defend since autonomy depends on life. Making balanced informed decisions usually requires equal knowledge of both choices. We can know life but we do not know death (we have faith what death is like, or may gamble that it will be better than a poor quality of life) but we cannot make a balanced decision to choose death. Moreover, what makes a rich life is one with many options and a poor life has fewer options. Death forecloses all options. This is not denying death but simply living life until death occurs. We must remember that the opposite of suffering is not death, it is a relief of suffering.*<sup>507</sup>

Doctors also referred to the importance of maintaining moral values in society. For example, Dr Eric Quan submitted that legislation ‘must take into account what we as the Queensland society are doing now and what legacy we will be leaving for our children and grandchildren’ and that ‘a good, moral society looks after all especially the most vulnerable from the unborn to the elderly in their golden years’.<sup>508</sup>

Dr Robert Pollnitz argued:

*Intentionally taking a human life, other than to save innocent human life, is inherently wrong and a breach of a universal moral code. Respect for individual freedom of choice must be balanced by other values, particularly respect for human life in general. I would submit that our dignity is inherent in our being human. Dignity is not dependent on the provision of a lethal dose.*<sup>509</sup>

Health practitioners also questioned the value placed on life by VAD schemes. Dr Stephen Myers submitted that assisted suicide sends a message that a person’s life is not worth living, and that consideration of legislation for VAD questions the value of human life, particularly towards the end of life.<sup>510</sup>

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<sup>505</sup> Submission E1172.

<sup>506</sup> Submission E1739.

<sup>507</sup> Submission E1435.

<sup>508</sup> Submission E1185.

<sup>509</sup> Submission 1660, p 2.

<sup>510</sup> Submission 947.

Dr Zelle Hodge stated:

*Many elderly or terminally ill patients at some time some will say 'Just give me a needle' 'I want to go'. This is often a poignant request to know that their life still is of value even though they cannot do what they have in the past. With some simple reassurance and, if necessary, modification of their medication, the next time they are seen they are more settled and have enjoyed some family or social event. If, as a society, we do not provide that reassurance for our most vulnerable, that their life is still worthwhile even though their capacity to 'function' is not as great as others in our community, we are at grave risk of moving to a society where one's contribution is weighed up and assessed and some considered less valuable than others.*<sup>511</sup>

Dr Ciara Ross argued that 'VAD does not respect human life, human rights or civil liberties because it creates a culture whereby some lives are considered inferior and less worthy of life than others'.<sup>512</sup>

Some doctors raised concerns that VAD will be considered a more economical alternative to providing aged or palliative care.<sup>513</sup> Dr Peter Kraus submitted 'Experience in places where assisted suicide is legal has shown that it becomes encouraged on financial grounds, it often being cheaper to aid in assisting suicide than provide expensive medical care to an aged person'.<sup>514</sup> Similarly, Dr Ciara Ross stated:

*...legal VAD sends the wrong message and will change the attitudes toward life in this country. There are people who want to see VAD used to rid society of people who are considered financial burdens. VAD cannot be considered a solution to managing the increasing cost of aged or disability care because it devalues human life at its core.*<sup>515</sup>

### 6.3 Hospices, hospitals and health care providers

Hospices providing palliative care differed in their views on VAD as an end of life option.

Ms Sue Manton, CEO of Little Haven Palliative Care, expressed support for people having control and being reassured they won't be left to suffer, telling the committee:

*I think very often in our admission interviews we have people expressing that they would like the right to voluntary assisted dying because they want control of their end of life and they do not feel that they have that control. I think universally where there is the right to voluntary assisted dying only a small percentage of people take it up. More often we see people wanting to pursue very futile medical interventions, because human nature is such that they want to live, not die. I think people should have control if that gives them a sense of reassurance that they are not going to be left suffering...Generally, you are dealing with a situation where people are fighting to live, but I am all about people having the right to choose, the right to feel in control of their end of life. Providing we are giving good care, I think very often that is not something that they will reach for.*<sup>516</sup>

<sup>511</sup> Submission 1812, p 4.

<sup>512</sup> Submission 1848, attachment, p 1.

<sup>513</sup> See, for example, submissions 1758, 1848, 2266.

<sup>514</sup> Submission 2266.

<sup>515</sup> Submission 1848, attachment, p 3.

<sup>516</sup> Public hearing transcript, Caloundra, 3 May 2019, p 12.

In contrast, the Toowoomba Hospice advised it does not support assisted suicide and euthanasia, stating:

*The Toowoomba Hospice is a purpose-built private health care facility, which provides specialised palliative care for adult individuals and families experiencing a terminal illness. Our values are based on the belief that every person is valuable and should be cared for as such.*

*We don't believe assisting someone to suicide, or ending their life directly and intentionally, can be an expression of care that upholds the values the Toowoomba Hospice was founded upon.*<sup>517</sup>

In her evidence while appearing in a private capacity, Ms Margaret Cassells of the Karuna Hospice explained to the committee:

*... the great majority of the time we can improve symptoms to the stage where they become tolerable. Occasionally in the terminal phase of their life people will have suffering that is very difficult to control, and we will use what we need to use to control that suffering without ever deliberately using an overdose as such, which is different. It really is different...the great majority of patients, certainly once they are comfortable and have access to good palliative care, are very happy for you to—many more people are asking us to prolong things than would be asking us to finish things if we could.*<sup>518</sup>

Ms Alex Moore, Director and Board Member of the Cittamani Hospice commented on the rarity of requests for VAD if good palliative care is provided, stating:

*...my experience is that it has been a very rare occurrence. I think it is happening more as the whole issue of voluntary euthanasia is more in the news. All I can say is that from my experience there is not a huge need. I guess the push is coming for it to happen and if it is going to happen then it needs to be done in a way where people have access to palliative care so that they are not being forced by circumstance into that position and where there are very, very clear guidelines around it. Personally, I think if people feel they are a burden to their family there might be pressure on them to do it. I see the value that people have from caring for a loved one at home. It is a very positive experience for most people if they are well supported and they feel good that they have done it. It gives them a chance to go through a process around dying. That helps them then to go on. That abrupt end and that lack of a process for people worries me, but that is just my personal opinion.*<sup>519</sup>

The committee heard from a number of health and aged care services that opposed VAD. These were mostly run by religious organisations, and their opposition to VAD was based on the belief that VAD does not value or respect human life, that no-one should purposefully end another person's life, and that it erodes trust in the medical profession who must care for individuals at all points in their journey.<sup>520</sup> Others called for greater investment in high-quality palliative care.<sup>521</sup>

Mater Misericordiae Ltd in their submission did not support the introduction of VAD into Queensland law arguing that VAD:

*...undermines these principles of respect for human dignity, and the common good on which a truly inclusive society is founded, by sending a message that life may be meaningless or less*

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<sup>517</sup> Submission 1218.

<sup>518</sup> Public hearing transcript, Brisbane, 18 October 2019, p 7.

<sup>519</sup> Public hearing transcript, Caloundra, 3 May 2019, pp 11-12.

<sup>520</sup> See, for example, submissions 1249, p 10; 1247, p 2; 1245, p 6; 1277, p19.

<sup>521</sup> Submission 1261, 13.

*meaningful for some, that some lives are less worthy or of less value than others; and ...promulgates a false binary choice – suggesting that vulnerable individuals have only two choices when contemplating and planning for end of life care: either a terrible death or intentional killing (by suicide).*<sup>522</sup>

Mater Misericordiae also explained their commitments as a Catholic health care provider:

*...Mater is committed to the ethic of healing, the ethic which is found in both the Hippocratic tradition of medical practice and the long Christian tradition of providing care, especially for poor and vulnerable people...The features of this ethic of healing include commitments: to heal and never to harm; to relieve pain and other physical and psycho-social symptoms of illness and frailty; to withdraw life-prolonging treatments when they are futile or overly burdensome or when a person wants them withdrawn and gives informed refusal of these treatments; and to never abandon patients...However, our clinicians do not and will not intentionally inflict death on patients (that is, to provide euthanasia), nor intentionally to assist patients to take their own lives, (that is, to provide physician assisted suicide).*<sup>523</sup>

Similarly, Southern Cross Care submitted that it is not in favour of allowing a VAD scheme in Queensland because:

*...assisting someone suicide, or ending their life directly and intentionally, can never be an expression of care for someone who has an intrinsic value and worth. Assisted suicide and euthanasia undermine centuries of clinical practice where the focus is on healing, not intentionally causing harm to patients, nor aiding them to harm themselves.*<sup>524</sup>

Catholic Health Australia (CHA) raised concerns that legislation would not be able to implement VAD in a way that guarantees public safety, submitting:

*The risks of VAD are wide-ranging and uncontrollable, threatening the health and safety of vulnerable groups, individuals, and communities, as well as fundamentally undermining the values and ethics that form the fabric of Australian society. It is CHA's belief that there is no way to adequately manage the risks of VAD.*<sup>525</sup>

Concerns raised by health and aged care services run by religious organisations included:

- governance and oversight of a VAD scheme<sup>526</sup>
- definitions of VAD<sup>527</sup>
- concerns regarding the adequacy of safeguards to protect the vulnerable, and the potential for the dilution of or removal of safeguards as seen in other jurisdictions<sup>528</sup>
- VAD undermining the value placed on human life<sup>529</sup>
- the risk that the most vulnerable will be more susceptible to VAD, through coercion or feeling a burden to society<sup>530</sup>

<sup>522</sup> Submission 1247, p 2.

<sup>523</sup> Submission 1247, p 3.

<sup>524</sup> Submission 1245, p 6.

<sup>525</sup> Catholic Health Australia, submission 1249, p 10.

<sup>526</sup> Southern Cross Care, submission 1245, p 7.

<sup>527</sup> Southern Cross Care, submission 1245, p 7.

<sup>528</sup> Southern Cross Care, submission 1245, p 7; HammondCare, submission 1261, pp 11-13.

<sup>529</sup> Southern Cross Care submission 1245, p 7; HammondCare, submission 1261, pp 11-13.

<sup>530</sup> Southern Cross Care, submission 1245, p 7; Catholic Health Australia, submission 1249, pp 10-16; HammondCare, submission 1261, pp 11-13.



- risk of inaccurate prognosis<sup>531</sup>
- failure of the procedure to be effective<sup>532</sup>
- impact on health practitioners, care recipients and their families<sup>533</sup>
- industry implications of implementing any PAS [physician assisted suicide] scheme, including withdrawal from the aged care industry<sup>534</sup>
- the risk of undermining mental health prevention and treatment, including the impact on suicide prevention strategies and programs<sup>535</sup>
- safety concerns of experts<sup>536</sup>
- risk of undermining community trust in the medical profession and impact on the relationship between doctors and patients<sup>537</sup>
- substantial government funding would be required to implement, administer and ensure compliance of a VAD scheme, which would have the potential to detract from adequate funding and resourcing being provided to palliative care services to ensure everyone had equal access to good palliative care across the state<sup>538</sup>
- risk of legalising lethal drugs<sup>539</sup>
- recognition of Queensland community opposition, including Indigenous community opposition, to voluntary assisted dying being legislated.<sup>540</sup>

Health care providers expressed differing views on whether they would allow VAD to be undertaken within their facilities. Reverend Dr Adam McIntosh, Associate Director of Mission for the Uniting Church, advised the committee that the Queensland synod made a decision to not support the legalisation of voluntary assisted dying in Queensland, and that if legalised, their health and community service agencies, UnitingCare Queensland and Wesley Mission Queensland, would not provide it as a service and that staff, in the course of their employment, would not participate in medical acts intended to end a life through VAD.<sup>541</sup> However, Dr McIntosh also advised they are:

*...leaving open the possibility of it happening in our facilities. It depends on the legislation and the legal complexities of that, but that is a possibility. We do not want to disrupt people; we want to minimise the physical pain of people as much as possible. However, at the same time our priority is really around bearing witness to the intrinsic dignity and value of all people at every stage of life in every circumstance of life. We want to uphold that, but at the same time we need to respect people's choice. We will honour that and we will do so in a compassionate way while maintaining opposition to it.*<sup>542</sup>

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<sup>531</sup> Catholic Health Australia, submission 1249, pp 10-16.

<sup>532</sup> Southern Cross Care, submission 1245, p 7.

<sup>533</sup> HammondCare, submission 1261, pp 11-13.

<sup>534</sup> Southern Cross Care, submission 1245, pp 7-8.

<sup>535</sup> Catholic Health Australia, submission 1249, pp 10-16; St Vincent's Health Australia, 1280, p 28.

<sup>536</sup> Catholic Health Australia, submission 1249, pp 10-16.

<sup>537</sup> Catholic Health Australia, submission 1249, pp 10-16; HammondCare, submission 1261, p 12; St Vincent's Health Australia, submission 1280, pp 28-29.

<sup>538</sup> See, for example, submissions 1245, 1249, 1261, 1280.

<sup>539</sup> Catholic Health Australia, submission 1249, pp 10-16.

<sup>540</sup> Catholic Health Australia, submission 1249, pp 10-16.

<sup>541</sup> Public hearing transcript, Brisbane, 4 July 2019, p 61.

<sup>542</sup> Public hearing transcript, Brisbane, 4 July 2019, p 63.

In contrast, Ms Suzanne Greenwood, CEO of Catholic Health Australia, told the committee that while they will not abandon a patient, they will also not allow any VAD-related services to occur within their facilities:

*...we will transfer a patient who is wanting to access a service. We will very strongly operate from a position of nonabandonment of our patients and nonjudgement of our patients, but we will not be providing the service within our facilities, we will not be allowing third parties to come into our facilities to undertake assessments of the individuals and we will not be referring them to a specific service in that we feel that we will not be in a position to know really where the appropriate place is for people to access these services or who the practitioners might be who have undertaken the training and that sort of thing, but we will certainly not resist any person who wants to access those services.*<sup>543</sup>

Southern Cross Care also advised that:

*If PAS [physician assisted dying] legislation becomes mandatory or there are inadequate provision for conscientious objection then, rather than compromise their ethical standards, many aged care providers, particularly those from a Judeo Christian religious tradition, may exit the industry.*<sup>544</sup>

On this matter, the Australian Medical Association Queensland (AMAQ) recommended that:

*...an institution should inform the public of their conscientious objection and what services they will not provide so that potential patients seeking those services can obtain care elsewhere (for example, this information could be highlighted on the institution's website, patient brochures and on posters clearly visible at the front of the facility).*<sup>545</sup>

## 6.4 Professional medical organisations

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 across their membership. For example, the Royal Australian College of General Practitioners submitted:

*The Royal Australian College of General Practitioners (RACGP) Queensland holds that while voluntary assisted dying impacts on medical practice it is fundamentally an issue of community values, best decided through the democratic and Parliamentary process.*<sup>546</sup>

Similarly, in its statement on VAD, the Royal Australasian College of Physicians (RACP) stated it:

*...respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to research, and to the views of medical and health practitioners...Our members are not unanimous in their support or opposition for legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying.*<sup>547</sup>

The RACP did express concerns about the introduction of VAD legislation:

*The RACP has concerns about the potential for legalised voluntary assisted dying to jeopardise vulnerable populations, be abused, expose health practitioners to professional risk, harm*

<sup>543</sup> Public hearing transcript, Brisbane, 4 July 2019, pp 68-69.

<sup>544</sup> Submission 1245, p 7.

<sup>545</sup> Submission 1233, p 40.

<sup>546</sup> Submission 1295, p 1.

<sup>547</sup> Submission 1203, p 4.

*patients and families and erode trust in the medical profession. If Parliaments in Australia decide that laws should be changed, the development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts, the RACP and other medical and health organisations.*<sup>548</sup>

Ms Catherine Smith, Treasurer of the Australian College of Nurse Practitioners, told the committee:

*As a college, we believe that our patients should always be the key and the centre of any care delivered. Therefore, their choices in who they choose to go ahead with their care should always be considered. Their choice as to what goes next should always be considered. As a college, we will support our members to decide on where they stand in this position. We are not enforcing that they decide to assist in voluntary dying...A number of our members obviously contributed evidence to be submitted for this inquiry. They are quite passionate about the fact that the patient chooses. Obviously it is about the patient choice...where they have to be educated and provided with the right information to make that choice.*<sup>549</sup>

The Queensland branch of the Royal Australian and New Zealand College of Psychiatrists (RANZCP QLD Branch) submitted:

*We recognise that VAD is a complicated ethical issue, and one that is best considered by the wider Queensland community. While the opinions of our members vary, a recent survey of RANZCP QLD Branch members indicates fairly strong support (73% of survey respondents) for the introduction of VAD under certain conditions – VAD being accessible to people over 18 years of age if they have a terminal illness, are experiencing intolerable suffering, and are in advanced state of decline, are close to death, and have decision-making capacity.*<sup>550</sup>

However, the RANZCP QLD Branch raised similar concerns to the RACP, which included:

- the potential for unintended consequences, including possible increased pressure on marginalised or disadvantaged groups to die rather than be a burden, including older people who have a high rate of suicide internationally, and may be more vulnerable to abuse under VAD legislation, and
- VAD being funded at the expense of making improvements to other end-of-life care options for Queenslanders, in particular palliative care not receiving adequate resourcing, thereby affecting the accessibility of palliative care and potentially presenting a perverse incentive for patients to choose to end their life.<sup>551</sup>

The Public Health Association of Australia did not take a position, but made the following points:

- *further research is required to support policy development in this area (Palliative Care Australia 2016)*
- *voluntary assisted dying needs to be considered in the context of overall improvement of access to palliative care and structured end of life communication such as advance care directives*
- *... any legislation in this area must include safeguards to protect patients and health professionals.*<sup>552</sup>

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<sup>548</sup> Submission 1203, p 4.

<sup>549</sup> Public hearing transcript, Brisbane, 4 July 2019, p 21.

<sup>550</sup> Submission 1207, p 8.

<sup>551</sup> Submission 1207, p 8.

<sup>552</sup> Submission 1239, p 6.

The Australian Psychological Society (APS) also stated it neither supports nor opposes VAD. Instead, the APS stated in its submission:

*...the APS endorses a best practice approach to end of life care, requiring that patients fully understand their alternatives and the main ramifications of their decision to access assisted dying services should they become legal outside Victoria. Ultimately, the APS emphasises the importance of a process that is characterised by care, compassion and considered decision-making over time (Maddocks, 2014). The APS envisages that such a process would include access to the full range of care options, from the highest quality palliative care and the most competent psychological assessment and psychosocial support.*<sup>553</sup>

The APS raised a concern about:

*...the potentially detrimental impact of legislative change on the health and wellbeing of people approaching the end of their life, their friends and family, their carers and the broader community, as well as the health professionals involved in implementing the legislative changes. Of most concern to the APS is the need to support and ensure that vulnerable people have an informed voice, particularly in legal decision-making around whether assisted dying should be permitted.*<sup>554</sup>

The APS made the following recommendations to address potential risks from a psychological perspective:

- *In the event VAD is legislated in Queensland, the APS strongly advocates for increased access to psychological services to assist in:*
  1. *Decision-making capacity assessment*
  2. *Therapeutic interventions for patients and their families*
  3. *Clinical supervision for the service/s delivering assisted dying services.*
- *Future legislation should include an equity impact assessment (a process designed to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people).*
- *Implementation of any VAD scheme needs to consider the existing and future capacity of an appropriately skilled workforce to meet the needs of people approaching the end of their life.*<sup>555</sup>

Some professional organisations took a stance against legislating for VAD, including the Australian and New Zealand Society for Geriatric Medicine (ANZSGM), the AMAQ and the Australian and New Zealand Society of Palliative Medicine (ANZSPM). However each of these organisations also recognised that there are differing views within their membership.

The ANZSGM informed the committee that, while it acknowledges the wide range of perspectives and ethical views amongst geriatricians in Australia and New Zealand on euthanasia and physician-assisted suicide:

*The Society maintains that euthanasia and physician-assisted suicide are not part of palliative care practice (in accordance with the Australia and New Zealand Society of Palliative Medicine's position statement). ANZSGM supports older patients' rights to refuse or discontinue burdensome or futile treatment.*

<sup>553</sup> Submission 1211, p 2.

<sup>554</sup> Submission 1211, p 8.

<sup>555</sup> Submission 1211, p 14.

Further the ANZGSM advised that their view:

*... is that policy makers and funders of health care can best help patients by ensuring adequate provision and funding of high-quality palliative care and geriatric medicine services, rather than by providing legislation allowing euthanasia.*<sup>556</sup>

The ANZGSM's key concerns reflected those outlined by health practitioners, including:

- portraying a conflicting public health message, i.e. that suicide is the preferred option in certain circumstances
- placing pressure on frail older people who may feel they are 'a burden' on others - such feelings are often due to underlying depression, financial concerns or family dynamics
- the risks of involuntary or non-voluntary euthanasia in patients with cognitive impairment, dementia or reduced capacity
- adverse effects on the funding for palliative care services and research
- changing the concept of doctors being 'treaters', 'life savers' and 'healers' to being providers of life-ending services, and the impact this may have on patient doctor relationships, and
- increasing justifications for euthanasia and potential for abuse, for example cost savings to health system.<sup>557</sup>

The AMAQ told the committee that, while acknowledging that laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government:

*The AMA Queensland council does not support the introduction of voluntary assisted dying in Queensland. In line with the federal AMA's position, we believe that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. The committee needs to be aware that the AMA Queensland's position is consistent with that of the World Medical Association, the British Medical Association, the American Medical Association and the New Zealand Medical Association. At the same time, we do understand and appreciate the diverse and strong views on this matter and respect the views of others, including our doctor members who support voluntary assisted dying.*<sup>558</sup>

The AMAQ expressed the view:

*If governments decide that laws should be changed to allow for the practice of euthanasia and/or physician assisted suicide, the medical profession must be involved in the development of relevant legislation, regulations and guidelines which protect:*

- *all doctors acting within the law;*
- *vulnerable patients – such as those who may be coerced or be susceptible to undue influence, or those who may consider themselves to be a burden to their families, carers or society;*
- *patients and doctors who do not want to participate; and*
- *the functioning of the health system as a whole.*<sup>559</sup>

Similarly, AMAQ contended that what the majority of Queenslanders are really seeking when pushing for physician assisted dying is reassurance that they will die in comfort and dignity alongside their loved

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<sup>556</sup> Submission 1720, pp 8-9.

<sup>557</sup> Submission 1720, p 9.

<sup>558</sup> Public hearing transcript, Brisbane, 4 July 2019, p 30.

<sup>559</sup> Submission 1233, p 39.

ones and with a level of self-determination and autonomy which they currently do not feel they have. AMAQ suggested that the way to do this is:

*...firstly, genuinely and adequately fund palliative care services; secondly, a strong focus on advance care planning, including education strategy for the public; thirdly, and importantly...legislative change so that doctors do not have to provide treatment of no medical benefit—that is, futile care—so that doctors can make end-of-life decisions for patients that are consistent with good medical practice.*<sup>560</sup>

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) also stated that it does not support the legalisation of euthanasia and physician assisted suicide, which reflects the majority view of its members, but recognises:

*...these are matters for government to decide having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners... ANZSPM acknowledges that, as with the diversity of opinion in the general and medical communities across Australia and New Zealand, there are divergent views on euthanasia and physician assisted suicide within its membership.*<sup>561</sup>

ANZSPM indicated that it believed ‘much of the community debate that is currently fuelling discussion about alternative end-of-life choices, including assisted dying, points to inadequacies in the current systems for end-of-life care across Australia and New Zealand, including in Queensland’.<sup>562</sup> The ANZSPM also contended that introducing legislation to facilitate assisted dying without first ensuring that people can receive end-of-life care in any clinical setting or location, and ensuring adequate and appropriate care including palliative care, does not provide genuine choice for end-of-life care, and therefore recommended that:

- a more responsive approach to the complex care needs in end-of-life care and dying, for patients and their carers be supported, and
- rapid response specialist palliative care models be made available to directly support urgent or complex issues, and other care needs in the location of the person’s preference, in particular when a person is imminently dying.<sup>563</sup>

The ANZSPM also raised concerns that legislation cannot provide sufficient safeguards for:

- persons who may change their minds with the right support and treatment, recognising that such wishes often wax and wane through the course of one’s illness, or
- wrongful death has taken place because of misdiagnosis, uncertainties around prognostications or determination of mental capacity, or guarantee that the request for assisted dying was free from coercion (direct or indirect).<sup>564</sup>

In contrast, the Queensland Nurses and Midwives Union (QNMU) expressed support for VAD as an end-of-life option:

*The QNMU supports legislative reform to enable persons who have an incurable, physical illness that creates unrelieved, unbearable and profound suffering to have the right to choose to die with dignity in a manner acceptable to them. They should not be compelled to suffer beyond their wishes.*

<sup>560</sup> Public hearing transcript, Brisbane, 4 July 2019, p 30.

<sup>561</sup> Submission 1252, pp 8-9; ANZSPM, Position Statement: The Practice of Euthanasia and Physician Assisted Suicide, <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1491523669&sid=>.

<sup>562</sup> Submission 1252, pp 10-11.

<sup>563</sup> Submission 1252, p 12.

<sup>564</sup> Submission 1252, p 11.

*We recognise the right of patients to high quality palliative care, but also acknowledge there are some circumstances in which palliative care cannot alleviate all pain and suffering. Irrespective of whether VAD is legalised, the QNMU will continue to seek adequate resourcing of palliative care (including suitably qualified and adequate numbers of nurses) for those requesting and/or requiring palliation.*

...

*As with other health matters, the overriding health principle is the individual determines their own destiny. This autonomy should extend to the time of death.*

*As a threshold issue, the QNMU recommends:*

- *the Committee recommend the drafting of a discrete legislative framework contained in a stand-alone Act making VAD legal in Queensland.*<sup>565</sup>

The QNMU suggested that VAD legislation should be informed by the moral and ethical dimensions of:

- *respect for self-determination;*
- *concern for quality of life; and*
- *compassion for those who suffer.*<sup>566</sup>

Potential eligibility criteria and safeguards which may apply to a VAD scheme in Queensland are discussed further in Chapters 8 and 9.

## **6.5 Health research, prevention and support organisations**

The Cancer Council, Dementia Australia, Leukaemia Foundation and Motor Neurone Disease Association of Queensland submitted to the inquiry but did not express views on whether VAD should be introduced in Queensland.<sup>567</sup> For example, the Cancer Council stated:

*Assisted dying is a complex topic and one which understandably evokes very strong feelings, of both support and opposition, among members of the Queensland community. We respect the rights of individuals to take a position on this very complex issue, however as an organisation which supports all people and all cancers, Cancer Council Queensland takes a neutral stance. While maintaining neutrality, we are cognisant that if assisted dying is legalised in Queensland this will impact on cancer patients and families. In jurisdictions where Governments have legislated for assisted dying in some form, cancer patients comprised the largest group of patients to access some form of assisted dying.*<sup>568</sup>

Dementia Australia, the Leukaemia Foundation and Motor Neurone Disease (MND) Association of Queensland also called for everyone to have equal access to treatment and care options.

The Leukaemia Foundation advised:

*The Leukaemia Foundation supports peoples' right to choose the treatment and care options that are right for them and their families. For some, this will include the option of accessing VAD.*<sup>569</sup>

*Alongside our position supporting peoples' right to choose the treatment and care options that are right for them and their families, we also strongly believe that people must have equal access to treatment and care options – no matter where they live.*

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<sup>565</sup> Submission 1213, p 36.

<sup>566</sup> Submission 1213, p 38.

<sup>567</sup> See submissions 1273, 1303, 1621; public hearing transcript, Brisbane, 13 September 2019, p 2.

<sup>568</sup> Submission 1303, p 12.

<sup>569</sup> Submission 1273, p 1.

*We therefore strongly urge that the Queensland Government works alongside its State and Territory counterparts and the Federal Government to ensure that these principles of equality and fairness are embedded throughout the health system in Australia.*<sup>570</sup>

Mr Ian Landreth, CEO of the Motor Neurone Disease Association of Queensland, told the committee:

*We have a really broad church in our membership, and that would include people who are desperate to find alternatives offered that are not currently available to them in the way of voluntary assisted dying. There are others who have a very staunch view that that is not even a choice that should be offered. For us as an organisation, to represent a position for our clients and those suffering MND is to disrespect that broad range. What we focus on is ensuring that they can access all the choices available to them within the legal framework and particularly focusing on the barriers to access. I know that where one of our board members was approached by somebody around the aspect of voluntary assisted dying, all we were able to do was refer them to what had happened in Victoria and what was available there.*<sup>571</sup>

### **Committee comment**

The committee thanks all groups and individuals who contributed to the inquiry. In particular the committee acknowledges the individuals who shared their deeply personal stories and opinions. The committee commends witnesses for their exceptional courage for doing so and for conducting themselves in a respectful manner, even when sharing a platform with others with contrary views.

The committee notes the strong and, at times, polarised views shared by members of the public, health practitioners and others who participated in the inquiry. The committee acknowledges the arguments raised against legislating for a voluntary assisted dying scheme, including arguments based on deeply held religious beliefs and values. The committee also notes that voluntary assisted dying by its nature must be voluntary. The committee accepts that some people are so fundamentally opposed to voluntary assisted dying that they will oppose any scheme regardless of its design.

The committee heard many emotional and deeply personal pleas, as well as expert evidence, research results and academic opinions, both for and against voluntary assisted dying.

After considering the evidence presented in submissions to the inquiry, the testimony of expert witnesses and others with opinions, and the expert advice provided by legal, medical and other stakeholder groups, and considering the experiences of governments and citizens with voluntary assisted dying schemes operating in other jurisdictions, the committee considers that, on balance, the Queensland community and health practitioners are supportive of voluntary assisted dying and for it to be legislated in Queensland.

The safeguards and features that a voluntary assisted dying scheme for Queensland are discussed in Chapters 8 and 9 of this report.

As a starting point for devising the legislation, the committee acknowledges the draft Bill submitted to the inquiry by Professors Ben White and Lindy Willmott of the Australian Centre for Health Law Research at the QUT. A copy of the Bill and explanatory notes is included at **Appendix A** to this report.

### **Recommendation 1**

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.

<sup>570</sup> Submission 1273, p 2.

<sup>571</sup> Public hearing transcript, Brisbane, 13 September 2019, p 2.



## 7 Palliative care and voluntary assisted dying

A key message from submitters and witnesses throughout the inquiry was the importance of palliative care services and that the delivery of palliative care needs to be improved and not devalued at the expense of VAD services, if a scheme were introduced in Queensland. Many have also suggested that improving palliative care should be a precondition to implementing VAD.

For example, Professor Kylie Ward, Chief Executive Officer of the Australian College of Nursing stated:

*The government should only offer options of voluntary assisted dying and/or palliative care or end-of-life care if there is support, infrastructure and investment in palliative care services, because both health professionals and the communities at large require this.*<sup>572</sup>

This stance was also taken by other professional medical organisations.<sup>573</sup> For example, the RACP submitted that palliative care must be given even greater priority and resourcing than it is now stating 'Every patient should have access to timely, equitable, good quality end-of-life care, with access to specialist palliative care where appropriate. These services must not be devalued'.<sup>574</sup>

The RACP also suggested:

*Governments and oversight bodies must dedicate resources to closely examine voluntary assisted dying requests that arise where the patient has poor options for good end-of-life care, for example in circumstances where symptom relief and a peaceful death cannot be provided to the patient because of limited access to palliative and supportive care.*

*Patients seeking voluntary assisted dying must be made aware of the benefits that palliative care can offer at the end of life and referral to specialist palliative care should be strongly recommended.*<sup>575</sup>

Dr Ian Marshall referred to the importance of providing a holistic approach to palliative care to ensure it provides the best value to patients:

*A desire to die may be motivated not just by unbearable pain, but by suffering in a wider sense, including the more protean physical reactions such as nausea, vomiting shortness of breath, nightmares, delirium and so on, as well as 'psycho-existential symptoms' (helplessness, futility, alienation, anxiety, isolation) which may be equally refractory. As Downie reminds 'the alleviation of physical pain is not necessarily congruent with the alleviation of suffering.' Interestingly, however, there is research on the actual experience of those nearing the end of life indicating that fears of dying tend to dissipate when terminally-ill patients receive good hospice or palliative care. A holistic approach is thus called for, animated by the philosophy that the care of patients with incurable illness could not be provided appropriately unless the therapeutic strategy included attention to the physical, psychological, social and spiritual domains of care.*<sup>576</sup>

The Cancer Council Queensland also took this view:

*Consideration of assisted dying should occur in the broader context of improving end-of-life care. High quality end-of-life care should be available for all Australians regardless of any choices a person may make about assisted dying. This includes equitable availability of palliative care and support for end-of-life decision-making....Assisted dying and palliative care are distinct, and if assisted dying is legalised, palliative care becomes even more important, and the community must have knowledge of, and access to, appropriate palliative care services. Any proposed*

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<sup>572</sup> Public hearing transcript, Brisbane, 4 July 2019, p 17.

<sup>573</sup> Submission 1203, p 4; 1233, p39; 1252, p 9.

<sup>574</sup> Submission 1203, p 4.

<sup>575</sup> Submission 1203, p 5.

<sup>576</sup> Submission 1758, pp 6-7.

*legislation should not result in a reduction in palliative care or in the efforts to improve palliative care; nor should it result in a reduction in the focus on, and funding for, the prevention and treatment of cancer.*<sup>577</sup>

The Clem Jones Group, in their submission, asked the committee to recognise that voluntary assisted dying would not replace current palliative care services in Queensland but would instead be another end-of-life option for people suffering a terminal illness or degenerative condition and experiencing unrelievable pain or suffering.<sup>578</sup> The Clem Jones Group also stated that it rejected the argument that improvements to palliative care reduce or replace the need for voluntary assisted dying law reform.<sup>579</sup>

Alongside recognising the role of palliative care, other submissions to the committee indicated that in other jurisdictions where VAD has been implemented, palliative care provision has been simultaneously strengthened.

Dignity in Dying (DiD) noted that in other countries with VAD schemes, the use of palliative care was high or had grown since implementation.<sup>580</sup>

A submission from DFADC cites research by the Apex Consulting Group on behalf of Palliative Care Australia, which determined that ‘the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation’. The research by Apex Consulting Group also noted that ‘in jurisdictions where assisted dying is available, the palliative care sector has further advanced’.<sup>581</sup>

In fact, VAD may complement existing palliative care options and provide further assistance to patients. In the Netherlands, a jurisdiction with access to VAD, the number of instances of euthanasia and physician assisted suicide have remained relatively stable.<sup>582</sup> At the same time, there has been a significant rise in the percentage of deaths occurring as a result of palliative sedation.<sup>583</sup> Funding for palliative care was increased at the time assisted dying was introduced in the Netherlands and Belgium.<sup>584</sup>

Dr Luc Deliens referred to the experience in Belgium, stating:

*It has had a very positive effect on palliative care systems. I have to remind you also that in 2002 we not only voted for a law on euthanasia but also voted for a law on palliative care and a law on patients’ rights. The three laws were coming together and they enforced each other. It is very important that it goes along together. There are two different issues. You have to have policies and the resources that have been put forward by the government, and you have the palliative care professionals.*<sup>585</sup>

Dr Jeff Blackmer told the committee ‘You will know from looking at other jurisdictions that, by and large, once someone introduces assisted dying access to palliative care in that jurisdiction it tends to improve over time’.<sup>586</sup> Both Dr Luc Deliens and Dr Sandy Buchman referred to legislation supporting palliative care being introduced at the same time as VAD legislation to ensure palliative care was well supported.

<sup>577</sup> Submission 1303, p 13.

<sup>578</sup> Submission 1202, p 10.

<sup>579</sup> Submission 1202, p 10.

<sup>580</sup> Submission 1214, pp 2-3.

<sup>581</sup> Apex Consulting Group, as cited in Doctors for Assisted Dying Choice, Submission 1225, p 6.

<sup>582</sup> R Jonquière, Submission 1222, p 4.

<sup>583</sup> R Jonquière, Submission 1222, p 12.

<sup>584</sup> N Francis, DyingForChoice.com, submission 1223, p 31.

<sup>585</sup> Public hearing transcript, Brisbane, 21 October 2019, p 3.

<sup>586</sup> Private briefing transcript, Brisbane, 10 April 2019, p 7.

Dr Buchman told the committee:

*It is also the case that in our province of Quebec they actually legislated access to palliative care and funded that access. They were the only jurisdiction to do that. We have seen this as a great opportunity to leverage the importance of palliative care and improve equitable access across the country. We have taken advantage of that opportunity so, ironically, assisted dying legislation has promoted palliative care and the importance of palliative care for our population.*<sup>587</sup>

Doctors for Assisted Dying Choice recommended the expansion of palliative care services to coincide with the introduction of VAD, identifying the two as ‘not only compatible but mutually reinforcing projects’.<sup>588</sup> The submission identified five factors related to current palliative care provision that support the need for VAD, in addition to the expansion of palliative care services:

- *lack of understanding and clarity concerning intentions about the relief of suffering;*
- *the unofficial practice of active assistance in dying and associated lack of uniformity, safeguards and oversight;*
- *the need for choice concerning different options such as terminal sedation and VAD, given that terminal sedation often involves a prolonged process of end-stage dying as against the speed and certainty of VAD, and that most people prefer to die at home, where terminal sedation is a less satisfactory and practical option;*
- *the vulnerability of patients to these deficiencies;*
- *the lack of legal certainty for patients, families and health professionals in relation to end-of-life practice.*<sup>589</sup>

Improvement of palliative care was also recommended by a number of other organisations and individuals who submitted to the inquiry.<sup>590</sup>

The implementation of VAD was also viewed as beneficial for encouraging more discussion of end-of-life matters between patients and doctors. In their submission, DiD suggested that requests to access assisted dying often facilitated discussion of important issues, and that medical practitioners felt that the availability of VAD better enabled them to discuss end-of-life issues with patients.<sup>591</sup>

In their submission to the committee, DWDQ identified an:

*...urgent need for increased and improved training of health professionals in pain management and palliative care, and for the development of practical, ethical policies and guidelines with respect to withdrawing/withholding life-sustaining treatment.*<sup>592</sup>

The RACP stated:

*Patients seeking voluntary assisted dying should be made aware of the benefits of palliative care. Referral to specialist palliative care should be strongly recommended but cannot be made mandatory. Voluntary assisted dying must not be seen as part of palliative care.*<sup>593</sup>

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<sup>587</sup> Private briefing transcript, Brisbane, 10 April 2019, p 7.

<sup>588</sup> Submission 1225, pp 6-7.

<sup>589</sup> Submission 1225, p 7.

<sup>590</sup> See, for example, submissions E918, E926, E977, E1377, E1652, E1801, 748, 1229, 1285, 2089.

<sup>591</sup> Submission 1214, p 3.

<sup>592</sup> Submission 1215, p 1.

<sup>593</sup> Submission 1203, p 4.

### **Committee comment**

The committee recognises that palliative care needs to be adequately resourced and supported irrespective of whether voluntary assisted dying legislation is introduced or not and, if it is introduced, it is imperative that people have the full range of options available to them so that they can make an informed choice.

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

## **7.1 Separation of palliative care and voluntary assisted dying**

The committee heard conflicting views on whether VAD should be considered part of palliative care if VAD were introduced into Queensland. For instance, Dr David van Gend submitted:

*I am aware, through long involvement in the euthanasia debate and many civil exchanges with its leading advocates, of the pro-euthanasia/VAD lobby's attempt to frame the intentional ending of a patient's life as merely another aspect of palliative care, or of aged care, or of end-of-life care. That framing is false: intentional killing has no place in ethical medical care. But that is the rhetorical tactic.*<sup>594</sup>

*There is no intention to kill when a doctor gives adequate morphine to relieve pain, and therefore that is not euthanasia. Sometimes morphine appears to hasten death, and sometimes morphine appears to delay death by relaxing a distressed patient. As palliative care doctors we have no interest in either hastening death or delaying death; we intend only to ease a patient's symptoms while they die of their underlying disease. Likewise, there is no intention to kill when a dying person is taken off futile life support; there is merely an acceptance of inevitable dying and the provision of all supportive care while the person dies of their underlying disease. Note that, if the patient continues living after life-support is removed they are simply cared for as any other patient: the intention was never to make them die. Third example: there is no intention to kill in those extreme cases when a doctor can only relieve suffering by inducing a form of light anaesthetic called 'terminal sedation' – a necessary but very rare form of pain control that ignorant people slur as 'slow euthanasia'. It is not, because there is no intention to make the patient die, only to do whatever it takes to ease suffering, while they die of their underlying disease.*<sup>595</sup>

Health Professionals Say No! argued that VAD does not belong in healthcare, submitting:

*We reject the notion that EPAS [euthanasia/physician assisted suicide] constitutes a form of medical care. Doctors are taught to care for the vulnerable and not to intentionally shorten life. By introducing EPAS as a procedure which is carried out by doctors in healthcare institutions, it is given a veneer of medical legitimacy which it does not deserve. If the Australian public insist on this practice being legalised, we suggest it be removed from the healthcare setting and not contaminate the environment of care and compassion which should be found there... Nor should it be implied that EPAS/VAD is part of palliative care or expected to be an extension of palliative care. There are many who already do not seek palliative care for their needs due to media and general misconceptions or misinformation around what constitutes palliative care and its implications. By even implying that EPAS/VAD is part of palliative care would create further misunderstanding and fear of those truly vulnerable and in need of care.*<sup>596</sup>

<sup>594</sup> Submission 2055, p 4.

<sup>595</sup> Submission 2055, p 7.

<sup>596</sup> Submission 1265, attachment, p 9.

Despite the differences in their stance on VAD, the ANZSPM and RACP submitted that voluntary assisted dying must not be seen as part of palliative care,<sup>597</sup> with the ANZSPM suggesting that a distinct service would be required to implement the scheme.<sup>598</sup>

However, Dr Albert Garth Thomas, who expressed his opposition to VAD, raised a concern about VAD services being separated from palliative care services, telling the committee:

*This poses a dilemma for our palliative care colleagues. As you have heard, any request to die in this sort of context must be met by a trained and sympathetic ear who can not only fully explore the strands of despair that have united to produce that request but also offer options to relieve that despair which go beyond voluntary assisted dying. While I understand and endorse the reluctance of my palliative care colleagues to be involved in voluntary assisted dying, I fear that the gap left will be filled by far less qualified practitioners who, lacking the expertise, will not be able to offer the necessary breadth of care and we will see unnecessarily premature deaths.*<sup>599</sup>

In other evidence the committee heard of the need to integrate VAD into end-of-life and palliative care. Dr Luc Deliens, Director of the End-of-Life Care Research Group and Professor of Palliative Care Research at Vrije Universiteit Brussel and Ghent University, Belgium told the committee:

*...voluntary assisted dying is just part of good end-of-life care. It is not outside good end-of-life care; it needs to be inside palliative care. It needs to be part of the end-of-life care. That is the only way we can be very sure, and that is why also the healthcare providers need to be responsible in that we do not have a separate system developed for euthanasia or, as you call it, voluntary assisted dying. You need to have it integrated into your healthcare system. You need to have it integrated into your palliative care systems. If they are not integrated, it will be very bad for any kind of euthanasia procedures, but it will also be very bad for any kind of palliative care procedures, because that means that there are a number of doctors and nurses who say, 'This is how far I go and from that point on I'm not listening anymore to my patients,' which for a normal doctor is unacceptable and it is hard to live with because you go all the way with your patients. You do not say, 'No, that's where my responsibility stops'.*<sup>600</sup>

Dr Deliens further stated:

*The integrated model is, in my opinion, the best model. Do not pull it apart. Patients will be disadvantaged if palliative care does not collaborate with euthanasia, and palliative care will not further develop and improve when euthanasia is not legalised. In Belgium more resources, as I said already, came into place for palliative care after the law was implemented and ever since, and they are not two systems; there is only one end-of-life care system.*<sup>601</sup>

Dr Sandy Buchman, President-Elect of the Canadian Medical Association and a physician who undertakes VAD procedures in that country advised the committee:

*When I saw how beautiful it was, how grateful and appreciative the family was, I knew I had done the right thing. It was not inconsistent with my objective of relieving suffering as a palliative care physician. It felt comfortable.*<sup>602</sup>

Dr Buchman also provided the following example of why health care practitioners should remain involved in VAD services:

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<sup>597</sup> Submissions 1252, p 9; 1203, p 4.

<sup>598</sup> Submissions 1252, p 9.

<sup>599</sup> Public hearing transcript, Brisbane, 23 August 2019, p 46.

<sup>600</sup> Public hearing transcript, Brisbane, 21 October 2019, p 2.

<sup>601</sup> Public hearing transcript, Brisbane, 21 October 2019, p 4.

<sup>602</sup> Private briefing transcript, Brisbane, 10 April 2019, p 5.

*People are concerned about their families and their family's wellbeing and the fact that they have become such a burden on their care and that if they do away with themselves earlier, so much the better for their loved ones. That is where I think the skills and competency of a physician who is trained in this and the competency to explore that suffering are key.*

*This is the kind of thing I was referring to earlier: when you explore suffering and you address that suffering and people feel heard. We make provisions—for example, improve personal support and care and give the main caregivers some time away on their own et cetera. We can all really improve on that and realise that this issue of feeling like a burden can be addressed. We bring families around together to discuss this.*

*This is why we cannot have a separate profession—for example, supplying the technical aspect of assisted dying—and why we need physicians to assess the suffering and assess capacity and competency. I am totally in favour of supporting the development of these kinds of competencies amongst all providers, not just physicians, who can express that.*<sup>603</sup>

Dr Will Cairns told the committee:

*It is a real challenge to know how it fits into health care. Obviously in places like Oregon, Washington, Belgium, Holland and Switzerland, people have learned how to do this in a way that leaves them unconflicted. I think it would be a real challenge to work out how to do it, but that does not mean that it should not be done.*<sup>604</sup>

Dr Malcolm Parker, Doctors for Assisted Dying Choice also advocated for integrating voluntary assisted dying with high-quality palliative care throughout Queensland.<sup>605</sup> He stated:

*As Doctors for Assisted Dying Choice we cannot emphasise strongly enough that, contrary to some views that the committee will have heard, voluntary assisted dying is entirely consistent with the ethos of medicine and the principles of medical and healthcare ethics. I make a number of points in support of that.*

*We have seen that 220 doctors have already registered for the training that is mandated under the Victorian legislation. Doctors are bound by the legal and professional duty to relieve suffering and to respect the self-determined goals of patients. Doctors must not abandon their patient and, in some cases, this will entail active assistance in dying as the best means of minimising suffering and supporting a gentle death. Assisted dying in such cases will fulfil the doctor's duty to his or her patient as the final compassionate component of continuous patient centred care. Finally, far from eroding community trust in doctors, their participation in properly regulated assisted dying will strengthen confidence in the profession as it participates in a regime that is a strongly endorsed by the community.*<sup>606</sup>

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<sup>603</sup> Private briefing transcript, Brisbane, 10 April 2019, p 7.

<sup>604</sup> Public hearing transcript, Townsville, 29 May 2019, p 10.

<sup>605</sup> Public hearing transcript, Brisbane, 23 August 2019, p 4.

<sup>606</sup> Public hearing transcript, Brisbane, 23 August 2019, p 4.

## 8 Provisions for VAD being legislated in Queensland

The terms of reference for this inquiry require the committee to inquire and report provisions for VAD being legislated in Queensland and any necessary safeguards to protect vulnerable persons.<sup>607</sup>

If VAD were legislated in Queensland, eligibility requirements and safeguards would be critically important to ensuring individuals were protected from external pressures and coercion and that risks of abuse of the system were minimised.

During the inquiry the committee heard a range of views from stakeholders on exact requirements that should be met to allow a person to access VAD. What was usually agreed upon, however, was that there should be requirements relating to age, citizenship and residency, the medical condition of the person, and the person's capacity. These features are discussed below. The chapter begins with a discussion of the principles that underpin the VAD schemes in Victoria and Western Australia.

Further safeguards to ensure a person is protected are covered in Chapter 9.

### 8.1 Principles

The VAD legislation in Victoria and Western Australia include a set of principles which apply to a person exercising a power, or performing a function, under the Acts.<sup>608</sup> The *Voluntary Assisted Dying Act 2017* (Vic) (the Victorian VAD Act) states:

*(1) A person exercising a power or performing a function or duty under this Act must have regard to the following principles—*

*(a) every human life has equal value;*

*(b) a person's autonomy should be respected;*

*(c) a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care;*

*(d) every person approaching the end of life should be provided with quality care to minimise the person's suffering and maximise the person's quality of life;*

*(e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained;*

*(f) individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted;*

*(g) individuals should be supported in conversations with the individual's health practitioners, family and carers and community about treatment and care preferences;*

*(h) individuals are entitled to genuine choices regarding their treatment and care;*

*(i) there is a need to protect individuals who may be subject to abuse;*

*(j) all persons, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics.*<sup>609</sup>

The *Voluntary Assisted Dying Act 2019* (WA) (the WA VAD Act) includes the principles listed above with additional provisions to offer 'genuine choices' about end-of-life care despite a person's culture and language or the region in WA where they reside.<sup>610</sup> The WA principles entitle a person who is a regional

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<sup>607</sup> See Inquiry referral and process pp 1-2.

<sup>608</sup> *Voluntary Assisted Dying Act 2017* (Vic) s 5, *Voluntary Assisted Dying Act 2019* (WA) s 4.

<sup>609</sup> *Voluntary Assisted Dying Act 2017* (Vic) s 5.

<sup>610</sup> *Voluntary Assisted Dying Act 2019* (WA) s 4(h).

resident to the 'same level of access to voluntary assisted dying as a person who lives in the metropolitan region'.<sup>611</sup>

Subsection (d) of the Victorian principles was also strengthened in the WA Act, so that a person approaching end-of-life should be provided with 'high quality care and treatment including palliative care' in order to minimise suffering.<sup>612</sup>

Health law academic, Professor Lindy Willmott, emphasised the worth of a values-based approach, and identified the values she and her colleague Professor Ben White thought should guide law reform in this area:

*Life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, reducing human suffering. ... [and] the concept of safe and high-quality care should underpin any legislation which is about health care.*<sup>613</sup>

These values are expressed in the principles section of the Bill presented to the committee for its consideration by Professors White and Willmott (White and Willmott VAD Bill).<sup>614</sup> According to Professors White and Willmott, 'these values are derived from existing Australian legal principle, as reflected in the common law, legislation or conventions or treaties that have been ratified by Australia'.<sup>615</sup>

### **Committee comment**

The committee notes the importance of including principles as a guideline for people working within voluntary assisted dying legislation.

The committee also notes the desirability of including provisions about equal access to voluntary assisted dying and end-of-life health care for all Queenslanders regardless of where they reside, with consideration of the specific cultural needs of Aboriginal and Torres Strait Islander Queenslanders.

## **8.2 Eligibility**

Eligibility criteria are used to determine who is able to access voluntary assisted dying. Access to voluntary assisted dying in other Australian and overseas jurisdictions is determined by a range of criteria which reflect the need to balance safeguards and accessibility.

In both Victoria and WA, eligibility to access VAD can be grouped into the following four main categories:

- age
- citizenship and residency
- condition(s), and
- capacity.

A number of organisations supported the introduction of a VAD scheme in Queensland with similar eligibility requirements to the current Victorian legislation.<sup>616</sup> For example, in its submission to the

<sup>611</sup> *Voluntary Assisted Dying Act 2019* (WA) s 4(i).

<sup>612</sup> *Voluntary Assisted Dying Act 2019* (WA) s 4(d).

<sup>613</sup> Private hearing transcript, Brisbane, 29 April 2019, p 7.

<sup>614</sup> Professors Ben White and Lindy Willmott, Australian Centre for Health Law Research, Model Voluntary Assisted Dying Bill, s 5, tabled paper no 0226, tabled by Professor Lindy Willmott.

<sup>615</sup> Willmott, Lindy and White, Ben, *Assisted Dying in Australia: A Values-Based Model for Reform* (January 4, 2018). Book chapter in Ian Freckelton and Kerry Petersen, *Tensions and Traumas in Health Law* (2017, Federation Press).

<sup>616</sup> See, for example, submissions 1225, E067, E173, E258, E436, E477, E478, E587, E705, E1689, E1745.



committee, DWDQ recommends that Queensland's VAD legislation should be broadly similar to the Victorian legislation.<sup>617</sup>

Doctors for Assisted Dying Choice also supported a number of the eligibility criteria in the Victorian legislation but had some reservations. In particular, the organisation did not support the restriction of VAD to people aged 18 years and over and limitations around the expected time to death related to prognosis.<sup>618</sup>

In its submission to the committee, the Queensland Branch of the RANZCP stated that the legal framework for VAD should be uncomplicated for participants, and include clear and easily accessible legislative and clinical guidelines and processes. The Royal Australian & New Zealand College of Psychiatrists (Queensland Branch) also noted that VAD processes need to be carefully regulated.<sup>619</sup>

A submission from Professor Colleen Cartwright, who has researched end-of-life decision-making for more than 25 years, provided an assessment about who should be able to access VAD in Queensland:

*All competent Queenslanders, regardless of age or disability, should be able to access the legislation if they meet the eligibility criteria. Adequate safeguards in the legislation, as for Victoria, should ensure that requests are voluntary and not being made because care and treatment is inadequate.*<sup>620</sup>

The RACGP noted that any eligibility criteria for access to VAD in Queensland should be clear to provide certainty and clarity to the community and health practitioners.<sup>621</sup>

The QNMU provided a list of eligibility requirements it recommended should be considered, which included that a person must:

- have made a voluntary, 'well considered' request
- be mentally competent to make decisions
- be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person.<sup>622</sup>

The White and Willmott Bill largely reflects Victoria's eligibility requirements, with key differences proposed including:

- that a person be 'ordinarily resident' in the relevant state, but does not include the Victorian requirement for a person to have lived in the relevant state for 12 months prior to the initial request for VAD
- no time limit until death, unlike Victoria which requires that a persons' prognosis includes that death is expected within six months (or 12 months for neurological conditions)
- a requirement that a person's suffering be 'intolerable and enduring', which is probably a higher threshold than it is in Victoria, which is 'suffering that cannot be relieved in a manner that is tolerable'.<sup>623</sup>

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<sup>617</sup> Submission 1215, p 11.

<sup>618</sup> Submission 1225, pp 11-12.

<sup>619</sup> Submission 1207, p 9.

<sup>620</sup> Submission 1224, p 9.

<sup>621</sup> Submission 1295, p 1.

<sup>622</sup> Submission 1213, p 9.

<sup>623</sup> Professor Ben White, private hearing transcript, Brisbane, 29 April 2019, p 9.

Some stakeholders believed the Victorian provisions, however, are too restrictive and Queensland should widen the eligibility criteria.<sup>624</sup>

### 8.2.1 Age

Age is used as a key determinant of who is able to access voluntary assisted dying in Australian jurisdictions and overseas. In Victoria, voluntary assisted dying is accessible only to persons aged 18 years and over. The proposed model in Western Australia has the same age restriction. In some overseas jurisdictions, including the Netherlands and Belgium, assisted dying can be accessed by children aged under 18 years.

During its inquiry, the committee heard differing views on whether a Queensland VAD scheme should be available to persons under 18 years of age. The Royal Australian & New Zealand College of Psychiatrists (Queensland Branch) supported restricting access to VAD to persons aged 18 years and over, and expressed concerns over the difficulty involved in assessing capacity in children, and the added complexity of the need for parental consent.<sup>625</sup>

Dr Anthony Herbert, Director of the Paediatric Palliative Care Service (PPCS) at the Queensland Children's Hospital (part of the Children's Health Queensland Hospital and Health Service) stated:

*For the current parliamentary enquiry, we would suggest voluntary assisted dying is out of scope for paediatrics due to the complex issues of children and young people aged less than 18 years in Queensland not having autonomous capacity to make such a decision - which has both serious and permanent ramifications.*

*Currently, there are only 3 jurisdictions in the world which allow euthanasia for children (Belgium, The Netherlands and Columbia).*

*In this context, we do not feel it appropriate to be considered for neonates or children in Queensland. The current focus should be on increasing palliative care and other supports for children who are requiring end-of-life care.*<sup>626</sup>

Health Professionals Say No! expressed similar concerns over having eligibility which extends to persons under 18 years of age, stating:

*In particular we do not believe that adolescents cannot have the experience to develop the breadth of intellectual, psychosocial and spiritual development required to deal with the existential questions from life to which suffering and dying belong. There is a large variability in the development between individuals. There are no standard routes to develop from child to adult and there is no fixed developmental speed, and there are also male and female differences in this. The minimal developmental levels reflecting full capacity to judge the situation and the full weight of the request for, and consequences of, euthanasia are rarely if ever reached during the teenage years. Further, we know from adolescent and young adult psychology studies action in this group may be driven by peer influence and impulse. The qualities provide great concerns in the face of legislation even for those up to the age of 25.*

*Furthermore, it is evident that the influence from those surrounding children and adolescents is strong and cannot be neglected. When faced with difficult medical decisions, minors will inevitably be dependent on the strong and evident authority of their parents, thereby diminishing their own autonomy in the decision-making process. Influence can exist through unspoken signals of pain and distress. Minors will try to take responsibility and look for methods to alleviate the suffering in his surroundings for which he is the cause. The opportunity to request euthanasia may be perceived by a minor in this situation as a chance, or even an obligation, to relieve this*

<sup>624</sup> See, for example, submissions E311, E413, E540, E834.

<sup>625</sup> Submission 1207, p 10.

<sup>626</sup> Submission 2558, attachment, p 10.

*suffering. It is impossible to assess these influences in an objective way and to weight them at the time when a minor requests euthanasia.*

*This group is also particularly vulnerable to suicide from mental illness, and particularly so in regional and indigenous populations...particularly...in men. Again psychological and mental health strategies, and earlier detection and management of illnesses and their psychosocial context are what need to be addressed here.*<sup>627</sup>

Dying with Dignity New South Wales also recommended a voluntary assisted dying scheme should only be available to persons 18 years or older, noting ‘this cut-off is of course arbitrary; there may be many 16 year-olds who have more decision-making capacity than some 21 year-olds but the bar needs to be set somewhere’.<sup>628</sup>

In contrast, the committee heard from a number of other stakeholders who recommended access to VAD for persons aged under 18 years.<sup>629</sup>

Dying with Dignity Queensland acknowledged that most VAD legislation limits access to persons aged 18 years or over but recommended that consideration should be given to extending access to VAD to competent adolescents with a life-limiting illness, who wish to end their suffering, subject to parental consent.<sup>630</sup> A similar view was held by QNMU, which recommended consideration of ‘circumstances in which a young person is aged under 18, may be living independently and capable of making their own decisions’.<sup>631</sup>

Dr Rob Jonquière, the Executive Director of the World Federation of Right to Die Societies, noted in his submission that Queensland could follow the Dutch model for VAD. This would extend access to VAD for youths aged 12 to 16 years with parental consent. Dr Jonquière also highlighted the Belgian model, which does not feature a specific age limit but restricts access to VAD for those demonstrating ‘competent understanding’. In practice, this ensures children aged below nine or 10 years are not able to access VAD.<sup>632</sup>

Professor Colleen Cartwright supported the extension of VAD for children and young people, noting:

*I find it incomprehensible that some people think VAD should be available to adults whose suffering is unbearable, but think that children and young people should just have to go on suffering. For very young children whose illness is causing them extreme suffering that is difficult to ameliorate, parents should have the right to request that they receive assistance to die. For children and young people under 18, who can demonstrate at least “Gillick Competence”, they should be able to request assistance to die themselves, preferably in consultation with their parents.*<sup>633</sup>

Similarly, the Queensland Council for Civil Liberties discussed Gillick competency and other case law in its views about whether a person under the age of 18 years should be able to access VAD.<sup>634</sup> The Queensland Council for Civil Liberties proposed, however, that the views of a mature minor should be respected in relation to VAD, with a ‘mature minor’ being ‘a child over 12 years of age who has a sufficient understanding and intelligence to enable him or her to understand fully what is proposed’.<sup>635</sup>

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<sup>627</sup> Submission 1265, attachment, p 15.

<sup>628</sup> Submission 1286, pp 11-12.

<sup>629</sup> See, for example, submissions 456, 642, 977, 1200, 1224, 1225, 1337, 1364, 2160, E1795.

<sup>630</sup> Submission 1215, pp 8-9.

<sup>631</sup> Submission 1213, p 40.

<sup>632</sup> Submission 1222, p 14.

<sup>633</sup> Submission 1224, p 9.

<sup>634</sup> Submission 1200, p 4-5.

<sup>635</sup> Submission 1200, p 5.

It was also recommended that a child wishing to access VAD should be assessed by an independent psychiatrist, and any request by a child should not be based solely on a psychiatric condition.<sup>636</sup>

Doctors for Assisted Dying Choice recognised ‘that young people under 18 can also be afflicted with incurable conditions that will lead to death, that they can have decision-making capacity, and that some other jurisdictions allow assisted dying for such people’. The submission recommended that people aged under 18 years could be permitted to access VAD if they have decision-making capacity and their guardian(s) or parent(s) consented to VAD.<sup>637</sup>

### **Committee comment**

The committee concludes that a voluntary assisted dying scheme for Queensland should restrict eligibility to adults aged over 18 years. This is consistent with schemes in Victoria and Western Australia.

### **Recommendation 2**

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

### **8.2.2 Citizenship and residency**

Citizenship and residency requirements are clearly outlined in the Victorian and Western Australian legislation, and are relatively consistent. The Victorian legislation requires that applicants to VAD are either:

- an Australian citizen or permanent resident
- ordinarily resident in Victoria; and
- at the time of making a first request [to access VAD], have been ordinarily resident in Victoria for at least 12 months.<sup>638</sup>

The WA Act has similar eligibility requirements stating that a person applying to access VAD:

- must be an Australian citizen or permanent resident; and
- at the time of making a first request [to access VAD] has been ordinarily resident in Western Australia for a period of at least 12 months.<sup>639</sup>

A number of submissions to the committee recommended shorter periods of minimum residency as a qualifying requirement to access VAD in Queensland. For example, DWDQ suggested that VAD should be accessible for people who have lived in Queensland for a minimum of three months. They cautioned against a longer minimum time period, noting that:

*Longer periods may unfairly exclude those with rapidly progressive disease following diagnosis which was unknown at the time of taking up residency.*<sup>640</sup>

The White and Willmott Bill also includes the requirement that a person must be an Australian citizen or permanent resident, and be ordinarily resident in the relevant state of the VAD scheme.<sup>641</sup>

<sup>636</sup> Submission 1200, p 5.

<sup>637</sup> Submission 1225, pp 11-12.

<sup>638</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(b).

<sup>639</sup> *Voluntary Assisted Dying Act 2019* (WA), s 16(b).

<sup>640</sup> Submission 1215, p 9.

<sup>641</sup> White and Willmott, Draft Bill, cl 9.

Including a requirement about being ‘ordinarily resident’ in a relevant state may ensure that people from outside the state will not move to the state purely to access VAD.

#### **Committee comment**

The committee believes that eligibility to access a voluntary assisted scheme for Queensland should be restricted to residents of the state, similar to the restrictions that apply in the Victorian and Western Australian schemes.

#### **Recommendation 3**

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

### **8.2.3 Condition of person wishing to access VAD**

In both Victoria and WA, VAD is not restricted by condition. Rather, an 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 to 12 months. For most conditions, the time limit is six months. This is extended to 12 months for some neurodegenerative conditions (such as motor neurone disease).

#### **8.2.3.1 Timeframe and prognosis of conditions**

During the inquiry, some stakeholders raised concerns about the practicality of obtaining a timeframe and prognosis for certain conditions.

The Australian Lawyers Alliance (ALA) highlighted the use of estimated timeframes for death in other jurisdictions as a determinant of eligibility and stated:

*...that the imposition of a condition requiring a person’s disease, illness or medical condition to result in their death within a specific period of time is problematic because it can be uncertain when a patient may die, there may be differing views within the medical profession as to when a patient’s death is likely to occur and it would prevent persons with incurable chronic diseases, illnesses or medical conditions from accessing VAD when their disease, illness or medical condition may cause immense pain and suffering without any hope of reprieve.<sup>642</sup>*

Associate Professor Sarah Winch, Head of Discipline and Medical Ethics at the University of Queensland, provided the following example of the difficulty of making an accurate prognosis:

*In the case I did last night I said to the palliative care physician, ‘I’m going to put you on the spot. Can you please give me a time when you think this woman is going to die?’ He said, ‘Yes, I actually do think it will be short weeks’—tick. He said ‘Short weeks’, but then a few weeks ago we thought it was a day or so. Prognostic ability in this area is not easy, yet you have to be able to say within six months or within 12 months of death.<sup>643</sup>*

Doctors for Assisted Dying Choice argued that including expected time to death as an eligibility criteria was restrictive due to uncertainty regarding prognosis. Rather, the submission recommended that the prognosis for death of otherwise eligible patients should be ‘reasonably foreseeable and predictable’.<sup>644</sup> Dr Malcolm Parker from DFADC told the committee:

*...we have not stipulated any six-month or 12-month period but we have used the phrase ‘reasonably foreseeable’. The reason is that, on the one hand, Victoria’s legislation does stipulate periods of time with an extension for neurological disease sufferers, but it circumscribes things for people. Disease conditions vary in their trajectory and so on. As we all know, particularly*

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<sup>642</sup> Submission 1204, pp 12-13.

<sup>643</sup> Public hearing transcript, Brisbane, 5 July 2019, p 48.

<sup>644</sup> Submission 1225, p 12.

*doctors, prognosticating in areas of terminal disease and all sorts of other diseases is a fraught exercise in many cases. It is mainly for that reason we use the term 'reasonably foreseeable'. On the one hand, people may say that 'reasonably foreseeable' sounds a very legalistic term. The question that arises is: what is reasonable? In the law and in medicine we depend on goodwill, the knowledge that we have on the basis of the evidence that we have, in order to make reasonable consensual agreed judgements about what is reasonable. I think those are the sorts of themes and principles that underlie that particular part of our submission.*<sup>645</sup>

A submission from Professor Colleen Cartwright also addressed timeframes for accessing VAD. Professor Cartwright noted the timeframes in the Victorian legislation and suggested that the requirement for a maximum 12 month prognosis to death for a neurological condition such as dementia may be too restrictive. Professor Cartwright highlighted the wide degree of accuracy in relation to prognosis, stating:

*...if the timeframe eligibility criteria is too tight (e.g., 6 months) some people will, erroneously, not be eligible for VAD while others will be assisted to die who could potentially live for several years.*<sup>646</sup>

Professor Cartwright stated that eligibility in the Canadian legislation is 'better, i.e. a terminal illness that has progressed to the point where natural death is "reasonably foreseeable"; (i.e. no specific time frame)'.<sup>647</sup>

Risks associated with inaccurate prognosis were also highlighted by Catholic Health Australia (CHA) in their submission to the committee that opposes the introduction of VAD. They stated:

*Clinicians have highlighted the risks associated with providing an accurate clinical prognosis regarding the longevity of a patient at the advanced stages of disease, and the difficulties of defining an individual as being 'at the end of life'.*<sup>648</sup>

Dying with Dignity Queensland noted that the 'eligibility criteria in Victoria are very tight' in terms of time limits for the expected progression to death of the patient and suggested that including 'such timelines in this legislation would be inappropriate' as prognostications can be incorrect.<sup>649</sup>

Similarly, the QNMU recommended that the Queensland legislation should not have explicit timelines, stating:

*It can be difficult to estimate how long someone will live. A criterion of advanced and progressive terminal or chronic or neurodegenerative illness, that is causing grievous and irremediable suffering for the person, would be sufficient without a prescribed timeline until death.*<sup>650</sup>

On numerous occasions, MND was raised as an example of where prognosis is difficult to ascertain, as is an estimated timeframe until death. Ms Stacey Thorpe, Director of Services at the Motor Neurone Disease Association of Queensland, talked about the ability to predict the progressiveness of the disease:

*...the predictability or the unpredictability of the disease means that, with 12 months, it is difficult to understand what somebody's condition will progress into in that time. It could appear to be a slowly progressing condition that changes rapidly. From today, you might think that 12 months*

<sup>645</sup> Public hearing transcript, Brisbane, 23 August 2019, p 8.

<sup>646</sup> Submission 1224, p 7.

<sup>647</sup> Submission 1224, p 7.

<sup>648</sup> Submission 1249, p 12.

<sup>649</sup> Submission 1215, p 8.

<sup>650</sup> Submission 1213, p 39.

*seems a reasonable survival period and then next week that might change quite considerably, so it is really difficult to put a time frame on that.*<sup>651</sup>

...

*It is also worth noting that it takes around two years sometimes to actually get a diagnosis. From the onset of symptoms, given the challenges to actually diagnose motor neurone disease, it can be quite some time that passes before that happens.*<sup>652</sup>

Mr Ian Landreth, CEO of the MND Association of Queensland, also referred to advice given by his Victorian colleagues that whilst the average survivability is two years, there are different types of MND, and that some varieties have a longer survival period than others.<sup>653</sup>

Kelli Downey shared her personal experience at the public hearing in Gladstone, telling the committee about her husband who passed away from motor neurone disease. Ms Downey commented on the process of prognosis and the timeframes of the disease, telling the committee:

*As you have mentioned, everyone progresses differently with MND. I can honestly say that within months of Matt's diagnosis he was in a wheelchair, unable to walk. He could not use his arm from the time of his diagnosis. Basically, I gave up my job instantly to care for him. I cared for him 24/7 by myself, with my kids' assistance. He progressed very quickly from being unable to walk or use his hands to within a year having a feeding tube, because every time he attempted to eat he would choke on food. He was unable to talk nine months before his death. It started with slurred speech to then being unable to talk. We developed our own sign language through blinking and mouthing.*

*The last six months of his life were torture. His whole body had started shutting down. He was bed bound for the last six months of his life. We were in and out of hospital. It is not kind. You do not know how it is going to progress, and a doctor cannot diagnose and say, 'In 12 months I think you'll probably pass away.' It just does not work like that. I do not think there should be the guideline that it has to be within 12 months because no-one can predict what is going to happen in those 12 months or how the disease is going to progress.*<sup>654</sup>

#### **Committee comment**

The committee notes the practical difficulties in obtaining a prognosis and timeframe of progression of some medical conditions, such as motor neurone disease (MND). Because of these difficulties, the committee believes the eligibility criteria must avoid specific timeframes for the eligibility period.

#### **Recommendation 4**

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.

#### **Recommendation 5**

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.

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<sup>651</sup> Public hearing transcript, Brisbane, 13 September 2019, p 3.

<sup>652</sup> Public hearing transcript, Brisbane, 13 September 2019, p 5.

<sup>653</sup> Public hearing transcript, Brisbane, 13 September 2019, p 3.

<sup>654</sup> Public hearing transcript, Gladstone, 30 October 2019, p 17.

### 8.2.3.2 *Conditions eligible for VAD*

A number of submissions discussed eligibility for people with mental illness and other conditions impacting on capacity (such as dementia) and whether these conditions should preclude a person from accessing VAD. Further information about mental illness in relation to access to VAD is provided in section 9.2.

In their submission, DWDQ suggested criteria for eligibility related to conditions. The submission recommended adopting the related eligibility criteria of the Canadian model, which requires patients to have a ‘grievous or irremediable medical condition, enduring intolerable physical or psychological suffering that is related to the condition’.<sup>655</sup>

Under the Canadian legislation, all patients must meet the following eligibility criteria:

- *they have a serious and incurable illness, disease or disability;*
- *they are in an advanced state of irreversible decline in capability;*
- *that illness, disease or disability or that state of decline causes them enduring physical suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and*
- *their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.*<sup>656</sup>

Dr Parker from DFADC suggested that those who have been diagnosed with a disease, illness or medical condition that is incurable, advanced, progressive, will cause natural death that is reasonably foreseeable and predictable, and is causing physical, psychological or existential suffering to the person that cannot be relieved in a manner that the person considers tolerable, should be eligible.<sup>657</sup>

Some stakeholders suggested that the conditions eligible for VAD should be widened beyond those with a terminal illness to cover suffering more broadly. For example, Ms Faye Tomlin, a nurse practitioner and experienced clinician in the delivery of end-of-life care within regional Queensland, proposed that legislation consider less restrictive options for individuals as more people are expressing a wish to make this choice regarding VAD outside terminal illness, and suggested that ‘[u]nderstanding of the experience of suffering for a person may need to be broadly defined in legislation to ensure access to VAD in QLD for those without terminal illness’.<sup>658</sup>

Ms Irene Harrison supported VAD for those with a terminal illness that cannot be cured, but also submitted that VAD should be allowed for those:

*...suffering intolerable pain which cannot be relieved. If a person is unable to care for themselves and finds the situation unbearable or if they acquire a permanent disability and they cannot live life as they wish they should be able to access VAD.*<sup>659</sup>

Some stakeholders raised concern that extending eligibility to conditions other than terminal illness may lead to a ‘slippery slope’. These arguments have been outlined in Chapters 5 and 6.

<sup>655</sup> Submission 1215, p 8.

<sup>656</sup> DWDQ, submission 1215, p 11.

<sup>657</sup> Public hearing transcript, Brisbane, 23 August 2019, p 8.

<sup>658</sup> Submission 287.

<sup>659</sup> Submission 1562, p 1.



### **Committee comment**

The committee also notes in most jurisdictions, eligibility to access voluntary assisted dying is restricted to persons suffering from a life-limiting illness (with exact definitions varying by jurisdiction).

#### **8.2.4 Capacity**

In the context of VAD, ‘capacity’ refers to the decision-making ability of the person accessing VAD. Having capacity is integral to accessing VAD in all jurisdictions that have VAD schemes. In some jurisdictions, capacity must be enduring, that is, those assessing the patient must be satisfied that the patient’s decision-making capacity is continuing.

This can be determined in a staged process where a medical practitioner asks—on a number of occasions—for confirmation from the patient that they wish to continue to participate in VAD.

The Netherlands is the only jurisdiction permitting access to the country’s VAD scheme in the absence of contemporaneous capacity. This is enacted through the use of valid Advance Health Directives (AHDs), prepared at a time when the person had capacity and expressed the desire to participate in assisted dying in the future.<sup>660</sup>

The Queensland branch of the Royal Australian and New Zealand College of Psychiatrists (the RANZCP) noted that capacity is central to the discussion on VAD:

*Any VAD scheme must include important safeguards to ensure patients have both the capacity to make the decision, and are making the decision freely and voluntarily. Therefore, both capacity assessment and undue influence screening should be required for every patient applying for VAD.*<sup>661</sup>

The RANZCP added that capacity assessments should:

- *be conducted by medical practitioners (doctors) with specialty training in this area.*
- *include the provision of information about VAD and the alternative care options, to ensure that patients are making an informed decision.*
- *include screening for psychiatric disorders, and if present, trigger further psychiatric assessment with a psychiatrist.*<sup>662</sup>

Generally VAD schemes require a person to have decision-making capacity, which can be determined by a person’s treating doctor. Psychiatrists have specialist skills to assess capacity but may not be available in certain areas, particularly regional and remote parts of Australia.

The RANZCP suggested that psychiatric assessment should be undertaken to determine capacity for any patient with a psychiatric illness. Psychiatric assessment might also be required for patients whose decision-making capacity is in question.<sup>663</sup> It noted that impaired capacity may be temporary due to reversible or modifiable causes, and recommended support and training be provided to medical practitioners to recognise diminished capacity, including for patients with dementia.<sup>664</sup>

Dying with Dignity Queensland (DWDQ) did not express an explicit preference on whether persons with dementia should be able to access VAD, but recommended that special consideration should be given to the issue of whether people with impaired cognitive function could have access. In their

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<sup>660</sup> DWDQ, Submission 1215, p 9.

<sup>661</sup> Submission 1207, p 9.

<sup>662</sup> Submission 1207, p 9.

<sup>663</sup> Submission 1207, p 9.

<sup>664</sup> Submission 1207, p 9.

submission, DWDQ states that public meetings around Queensland indicated that this was an issue of community concern.<sup>665</sup>

Doctors for Assisted Dying Choice acknowledged that capacity to consent to VAD would need to be assessed by a specialist health professional with experience of a particular disease. In some instances, a psychiatrist will need to assess the patient.<sup>666</sup> The organisation's submission notes that mental capacity will be assessed by the co-ordinating and consulting medical practitioners in the 'vast majority of cases'. Psychiatric consultation should be 'strictly limited to uncertainty concerning mental capacity, consistent with the longstanding recognition that, legally, capacity is a procedural matter, independent of the content of the patient's decision'.<sup>667</sup>

#### 8.2.4.1 *Dementia and use of Advance Health Directives*

The capacity of a person was an issue of importance to many stakeholders who provided evidence during the inquiry. In particular, views differed significantly on whether a person with dementia should be able to access VAD and if so, at what time their decision should be made.

Dr Kaele Stokes, Executive Director at Dementia Australia, explained to the committee:

*Certainly in the initial conversations when the Victorian parliament was looking at the formation of the legislation, there were concerns around the ability for somebody at the later stages of cognitive impairment making an informed decision around that desire to end their life. One of the other challenges of course is that it is very difficult to predict the process of cognitive decline, so it can occur quite quickly in some people and it is a much slower process for others. Dementia is a fatal disease. It does ultimately end up killing you, but it is very difficult to predict that kind of end-of-life period in a very specific way and that is obviously what the legislation was looking at.*

...

*We do have a number of people in Victoria that we have spoken to who are very disappointed that the legislation excludes them and their ability to put that in place. Of course, there are broader implications for anyone with a neurological disorder or a neurocognitive disease where their cognitive function may be impaired towards the latter stages of their disease process which rules them out from being eligible for that.*<sup>668</sup>

The committee heard many arguments that a person with dementia should be able to access VAD.<sup>669</sup> These included individuals who suggested a preference for accessing VAD if they developed dementia. Dr Jennifer McGill shared her personal experience as a general practitioner:

*Having cared for patients with dementia and seeing my father's descent into distress and confusion, his loss of dignity and his terrible end, I would like to be able to avoid a similar path if I too develop dementia. I know a large number of people of my age have similar views, especially those who have witnessed a parent dying of dementia... Any discussion of VAD always includes issues of consent and capacity. I would like the committee to consider a pathway for consent to be given potentially years earlier, only to be activated in the event of a diagnosis of dementia being made. The timing of [VAD] in dementia could be guided by certain criteria being met.*<sup>670</sup>

<sup>665</sup> Submission 1215, p 9.

<sup>666</sup> Submission 1225, p 9.

<sup>667</sup> Submission 1225, p 9.

<sup>668</sup> Public hearing transcript, Brisbane, 5 July 2019, p 17.

<sup>669</sup> See, for example, submissions 385, 411, 456, 1337, 1370, 1393, 1544, 1549, 1642, E1486, E1389, E1400, E1446, E1486, E1517, E1521, E1776, E1795, E1805, E1322.

<sup>670</sup> Submission 1815, p 1.

The Clem Jones Group expressed support for access to VAD by persons ‘facing the onset and progression of dementia’, suggesting a person be able to request VAD when ‘their condition progresses to a nominated point affecting their quality of life’.<sup>671</sup>

A number of stakeholders suggested that a person should be able to include in their advance health directive, that if they lose capacity from dementia or another reason, they should be able to access VAD.<sup>672</sup>

In his submission, Mr Kevin Heisner put it simply as ‘Yes, we have a right to decide to the very end, if we can speak, say it and if we can’t, write it in an advance care plan’.<sup>673</sup>

Mr Heisner’s views were echoed by Linda Whittington, nurse and daughter of a 90 year-old with dementia:

*It is time for Queensland to move forward. We have advanced health directives that allow us to clearly state our wishes. Why not take it a step further and allow us to nominate our choices for assisted dying. There are countries that have successfully enacted such laws and legislation. It is time to give people choices other than suicide or suffering if they are unfortunate enough to suffer an incurable life impacting disease, whether they are dying from it, or just suffering immensely from it.*<sup>674</sup>

Similarly, Ms Fiona Jacobs, a registered nurse, stated:

*Dementia and other terminal illness do not necessarily fit the criteria or time frame specified in Victorian Laws. ... To provide for those who suffer a condition that would eventually affect their mental capacity ... I would suggest that an Advance Health Directive include a clause that covers their wishes in regard to VAD. This document, made before loss of competency should be signed and witnessed, by a Doctor and Solicitor and describe the person’s wishes following a loss of capacity/competency.*

*Wills and testaments do not become invalid following loss of competency so why should the wishes set out in an Advance Health Directive?*<sup>675</sup>

Dr Kaele Stokes, Executive Director of Dementia Australia, noted that while the organisation had not taken a position for or against VAD, it supported the right for people to choose, and highlighted the need for consideration of advance care planning for persons with impaired capacity.<sup>676</sup> In its submission to the committee, Dementia Australia recommended ‘That people with degenerative disorders have the ability to make enduring requests for voluntary assisted dying in an advanced care plan’ and stated:

*Disallowing voluntary assisted dying instructions in advance care plans creates yet another barrier to people with dementia having genuine choice and control in end of life. People with incurable, degenerative diseases should, if they wish, be able to participate in voluntary assisted dying by working with their medical team, Medical Enduring Power of Attorney and other family members to identify a quality of life or level of pain which would be unacceptable to them and record this in their advance care plan (or other binding document). The person with dementia could then, if that is their choice, recommend that voluntary assisted dying be administered at a*

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<sup>671</sup> Submission 1202, p 24.

<sup>672</sup> See, for example, submissions 385, 411, 608, 1393, 1642, 2017, 2160, E1200, E2025.

<sup>673</sup> Submission 2017, p 2.

<sup>674</sup> Submission 608, p 3.

<sup>675</sup> Submission 162, p 1.

<sup>676</sup> Public hearing transcript, Brisbane, 5 July 2019, p 17.

*time when their medical team and family agree that their quality of life has declined in a way that meets their stated wishes.*<sup>677</sup>

In its submission to the committee, Doctors for Assisted Dying Choice (DFADC) supported the use of Advance Health Directives to facilitate access to VAD for patients with dementia. The organisation noted:

*Queensland was an early Australian leader in developing advance health directives of high quality, and they are an integral aspect of advance care planning. Although not taken up at a high rate in absolute terms, Queensland also leads in the relative uptake of advance health directives across Australia. Options the committee should consider are the recommendation that the matter of facilitating VAD for people with dementia could be given attention by the Queensland Law Reform Commission, or be the subject of a separate Queensland parliamentary inquiry, if they are not incorporated in the initial VAD legislation that we hope the parliament enacts.*<sup>678</sup>

The committee also heard arguments that VAD should not be available to persons suffering from dementia.<sup>679</sup>

Ms Amanda Lock explained in her submission:

*My own mother is 90 and suffering some dementia. I see how easy it would be to convince such a vulnerable person to sign paperwork agreeing to assisted dying without them fully knowing or understanding what they have agreed to. Not everyone is a person of care and goodwill, and the financial incentive to deceive and take life cannot be discounted. There are many instances of elder abuse now, without adding the possibility of taking their life for financial gain.*<sup>680</sup>

The Public Advocate, Ms Mary Burgess, did not support accessibility of VAD to persons with dementia and stated:

*The point I would like to make is that any future legislation enacted should specifically require that a person must have capacity to request to die voluntarily. Further, while I support the concept of advance care planning for people to express wishes about their care and treatment after they have lost capacity, at this point I think there should be no provision in any legislation that is enacted that would allow advance care planning documents to operate to allow people to request voluntary assisted dying after they have lost capacity.*<sup>681</sup>

Dr Sandy Buchman told the committee, 'If we get into advance consent, it is very important to me personally that each and every one of my patients has the exact capacity at the last moment to tell me very clearly that they wish to proceed'.<sup>682</sup> He then further explained:

*I have every sympathy for people who want to have advance consent. I may want it for myself, but as a provider I would feel very uncomfortable providing any assistance in dying to an individual who did not have capacity at that last moment. We see many patients with advanced dementia. My perception is that, if their physical and emotional needs are well looked after at any particular moment, they live in the moment. If you examine the literature on sufferings such as that written by Cassel, what is important is to have a sense of the past and a sense of the future. A lot of our patients with advanced dementia have neither. They are literally in the moment. If they tell me or their advance directive suggests, 'When I no longer recognise my*

<sup>677</sup> Submission 1621, p 12.

<sup>678</sup> Submission 1225, p 14.

<sup>679</sup> See, for example, submissions 1208, 1626, 1628, 1699, E1284, E1248, E1500, E1652.

<sup>680</sup> Submission E1284.

<sup>681</sup> Public hearing transcript, Brisbane, 5 July 2019, p 29. See also, The Public Advocate, submission 1208, p 2.

<sup>682</sup> Private hearing transcript, Brisbane, 10 April 2019, p 5.

*family members, that is when I want assisted dying,’ how do we know that? Who am I to know if they recognise their family members or even to take the family members’ judgement as to whether they recognise them—one day could be different than the next. I think I would not provide assisted dying in those situations where I did not know that my patient had that capacity to proceed at the very last minute. With all the sympathy towards the situation, that is currently my perspective.*<sup>683</sup>

Dr Jeff Blackmer referred to the clinical complexities of providing consent through an advance health directive, and provided the following example:

*I have spoken to colleagues in other jurisdictions, like the Netherlands, where the patient may eventually meet the criteria that they set out in the living will but when it comes time for the procedure to be done does not want it to be carried out. You are faced with a situation where you have a legally binding document saying that this patient has to undergo euthanasia and the patient is telling you that they want nothing to do with it.*<sup>684</sup>

However, both Dr Buchman and Dr Blackmer also referred to patients accessing VAD earlier than they might ordinarily do so for fear of losing capacity.<sup>685</sup>

Professor Colleen Cartwright noted that the Netherlands permitted requests for VAD through Advance Health Directives, in contrast with the Victorian and WA legislation. By using Advance Health Directives, people accessing VAD in the Netherlands do not need to be competent when VAD is carried out if they were competent at the time that they completed the Advance Health Directive.<sup>686</sup>

Professor Cartwright noted that the Victorian legislation may be ‘considered discriminatory by many people with dementia and their carers, and by people who fear dementia’ as they would not be permitted to access VAD through the use of an Advanced Health Directive. Professor Cartwright suggests that the committee should consider whether Advanced Health Directives could be used to request VAD to ‘accommodate the needs of people with dementia’.<sup>687</sup> Professor Cartwright did, however, question the reliance on Advanced Health Directives in the Netherlands, and told the committee:

*...in the Netherlands you can request assisted dying in your advance directive, but unfortunately it is not very often honoured. The reason for that is that when the doctors in the Netherlands first started assisting people they were hammered—absolutely hammered—by everyone all over the world and accused of doing all sorts of nefarious things, which in most cases they were not. Because the legislation there requires a current repeated request, they are afraid that they will be accused of not following due process if they follow a request in an advance directive because it is not necessarily current because the person made it before they lost capacity. The problem now, according to my colleagues in the Netherlands, is that because people over there are learning that their requests in their advance directive will not be honoured they are asking for assistance to die before they really are ready to die, which is sad.*<sup>688</sup>

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<sup>683</sup> Private hearing transcript, Brisbane, 10 April 2019, p 6.

<sup>684</sup> Private hearing transcript, Brisbane, 10 April 2019, p 6.

<sup>685</sup> Private hearing transcript, Brisbane, 10 April 2019, p 6.

<sup>686</sup> Submission 1224, p 7.

<sup>687</sup> Submission 1224, p 7.

<sup>688</sup> Public hearing transcript, Southport, 10 September 2019, pp 12-13.

Kiki Paul, Chief Executive Officer of Go Gentle Australia, summarised its position about persons with impaired decision-making capacity, and stated:

*We believe that decision-making capacity until the very end is a key component of a safe and workable law. We do not believe that outsourcing this to an advance care directive is a workable situation ... In a dementia situation it is very tricky in itself to keep determining capacity, and it is even trickier to determine what happens after that full capacity goes. ... It is very tricky to perceive how people with dementia will actually experience their situation once they get into that situation. We believe that decision-making capacity is crucial and it is part of the voluntary nature of this law. You have to be able to change your mind right up until the last second. It should not be handed to anyone else to make that decision for you.*<sup>689</sup>

**Committee comment**

The committee notes the contrasting views about whether a person should be able to stipulate their wishes to access voluntary assisted dying in an Advanced Health Directive, which can be acted upon if that person loses capacity.

The committee considers this issue needs to be further considered, and that any decision made balances people's wishes with the need to ensure robust protections for vulnerable individuals and medical practitioners who are providing voluntary assisted dying services.

**Recommendation 6**

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

**Recommendation 7**

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.

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<sup>689</sup> Public hearing transcript, Brisbane, 23 August 2019, p 7.

## 9 Further safeguards

Throughout the inquiry, stakeholders raised the importance of safeguards for any proposed model of VAD in Queensland.<sup>690</sup>

The VAD schemes in Victoria and Western Australia include multiple steps where safeguards and reporting requirements must be met before the process continues. The patient's access to voluntary assisted dying is assessed at several stages through the process. A staged approach ensures that the patient's decision-making capacity is enduring. The patient's choice to access VAD must be continuing for the process to progress.<sup>691</sup>

Some stakeholders agreed with the approach of the Victorian legislation which contains 68 safeguards. Those safeguards apply throughout the process of accessing the Victorian VAD scheme and include the establishment of the VAD Review Board as an independent oversight body for the scheme.<sup>692</sup>

Other stakeholders argued that the schemes in Victoria and Western Australia are too conservative and 'very difficult for people to access or use'.<sup>693</sup> Mr Simon Brown of the Health and Disability Law Committee, QLS, noted:

*It is essential that a VAD scheme safeguards against any assisted dying that is not entirely voluntary; however, safeguards must not be so restrictive as to render the scheme unavailable to many of those it is intended to benefit or to unnecessarily prolong suffering.*<sup>694</sup>

In addition to eligibility requirements, further safeguards which may apply to a Queensland model are discussed below.

### 9.1 Safeguards against coercion, elder abuse, fear of being a burden

Application of adequate safeguards for a VAD scheme is a paramount consideration in ensuring a VAD model addresses concerns by stakeholders such as coercion, elder abuse, and a person's accessing of the scheme due to fear of being a burden.

To address these concerns, a number of potential safeguards which should apply to a scheme in Queensland were proposed by stakeholders. They include:

- the application of eligibility criteria for accessing VAD
- the qualification requirements of participating medical practitioners
- training requirements for participating medical practitioners
- two independent medical assessments required prior to accessing VAD
- a rigorous procedure to access VAD
- rigorous governance for prescribing, dispensing and disposing of VAD substances
- transparent review mechanisms
- protections from liability for participants

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<sup>690</sup> See, for example, submissions E048, E067, E114, 086, 097, 135, 141, 219, E833, 876, 890, 897, 977, 1295, 1296, 2545, E1547, E1619.

<sup>691</sup> *Voluntary Assisted Dying Act 2017* (Vic); *Voluntary Assisted Dying Act 2019* (WA).

<sup>692</sup> *Voluntary Assisted Dying Act 2017* (Vic), Hon. Jill Hennessy MP, Minister for Health, Parliament of Victoria, Legislative Assembly, Parliamentary Debates, 21 September 2017, p 2949.

<sup>693</sup> Dr Philip Nitschke, Exit International, public hearing transcript, Brisbane, 23 August 2019, p 70. See also, E311, E413, E540, E834.

<sup>694</sup> Public hearing transcript, Brisbane, 5 July 2019, p 3.

- requirements for documentation and reporting at all stages of the process
- a comprehensive public education campaign.<sup>695</sup>

Many of the suggested safeguards were consistent with provisions contained in the Victorian and Western Australian legislation. In both jurisdictions a number of safeguards apply to persons involved in the VAD process. For example:

- an oversight body has advisory and monitoring functions (Voluntary Assisted Dying Review Board in Victoria; Voluntary Assisted Dying Board in WA)
- the Board receives notification of all stages of the process
- patients must make an initial request, a written declaration and a final request and can choose not to continue the VAD process at any stage
- a minimum time period from the initial request to final request exists
- patients must be acting voluntarily and without coercion throughout all stages of the process
- witnesses are required for particular stages of the VAD process
- the prescription, supply and administration of the voluntary assisted dying substance is carefully controlled.<sup>696</sup>

In its submission to the committee, medical defence organisation and medical indemnity insurance provider, Avant Mutual, stated that any VAD scheme ‘... must incorporate sufficient protections for those doctors who choose to participate, and those who choose not to participate.’<sup>697</sup> The submission noted that a potential VAD scheme must ‘... provide a clear framework within which patients and doctors can operate’.<sup>698</sup> As part of this framework, related legislation:

*...should balance the need for clear and unambiguous wording with the need to leave sufficient scope for the exercise of clinical judgment, consideration of the patient’s individual circumstances and changing standards of medical practice over time.*<sup>699</sup>

Avant Mutual’s submission cautions against legislation that is too prescriptive as it could make compliance difficult and restrict room for clinical judgment.<sup>700</sup>

Although opposed to VAD, Queensland Baptists included a number of suggestions for safeguards in their submission:

- certification of a terminal illness to cause death within three months
- compulsory counselling
- a minimum waiting period of two weeks following the initial written request
- a review of medical and counselling opinions by an independent person.<sup>701</sup>

<sup>695</sup> See, for example, submissions 24, 1225, 1233, 1309.

<sup>696</sup> *Voluntary Assisted Dying Act 2019* (WA); *Voluntary Assisted Dying Act 2017* (Vic).

<sup>697</sup> Submission 1238, p 5.

<sup>698</sup> Submission 1238, p 5.

<sup>699</sup> Submission 1238, p 5.

<sup>700</sup> Submission 1238, p 5.

<sup>701</sup> Submission 1228, p 3.



### 9.1.1 Preventing coercion

A concern of stakeholders, as further outlined in Chapter 5 was that a VAD scheme could allow a person to be coerced into accessing VAD.<sup>702</sup>

Stakeholders such as the Cancer Council and RACP, warned that any VAD scheme in Queensland would need to protect vulnerable people and ensure patients were protected from coercion.<sup>703</sup>

Dr Alex Deagon raised concerns regarding coercion in his submission to the inquiry, which stated:

*Physician assisted dying places people at risk of coercion that is both active and passive. As a consequence of assisted dying laws, society re-assesses the value of life; and the individual is taught to devalue their own life. Those with serious illness may perceive that they are a burden on society or their carers and come to feel that assisted dying is appropriate for them.*<sup>704</sup>

Palliative Care Queensland proposed that a VAD scheme should include eligibility requirements to ensure ‘there is no coercion by others to induce the person to request VAD’.<sup>705</sup> To assist in preventing coercion, it was recommended that there be no ‘advance prescribing’ and that medical practitioners involved in assessment of a person wishing to access VAD ‘must be taught skills to detect any coercion that might have been applied to the person requesting VAD’.<sup>706</sup>

Queenslanders with Disability Network (QDN) included a number of possible safeguards to ensure that vulnerable people were protected:

- *Only allowing VAD to be made available to terminally ill people for whom there is no hope of recovery (in line with Victoria’s Bill)*
- *Providing mediation or assisted decision-making processes for people who are vulnerable*
- *Providing targeted user friendly information to vulnerable people in a variety of formats that outlines options and treatment plans in relation to end of life treatment*
- *Providing counselling services delivered by professionals who are trained in the specific needs of vulnerable populations*
- *Providing peer support and safe places, and increased time for people to think through their options and come to informed decisions*
- *Seeking the views of family members, loved ones, informal and formal decision-makers, advocates and other professionals in the person’s life and encouraging them to form a circle of support around the person.*<sup>707</sup>

The Royal Australasian College of Physicians recommended:

- *Consideration must be given to enabling the exchange of information in formats accessible to the patient such as in the patient’s preferred language, via sign language, interpreters, or orally.*
- *Legislative and regulatory measures must reflect the legitimate concerns that exist around protection of vulnerable individuals or groups, especially where discussions may not be perceived to have been fully transparent.*

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<sup>702</sup> See, for example, submissions 040, E006, 135, E293A, 258, 284, E368, E805, E1005, E1049, E1127, 694, 796, 947, 959, 1023, 1043, 1061.

<sup>703</sup> Cancer Council, submission 1303, p 12; RACP, submission 1203, p 4; RACGP, submission 1295, p 1.

<sup>704</sup> Submission 135, p 5.

<sup>705</sup> Submission 1891, p 59.

<sup>706</sup> Submission 1891, p 59.

<sup>707</sup> Submission 1255, p 10.

- *Data must be collected, monitored and reported in a manner that can pinpoint abuse at an individual and population level.*
- *Avenues to report and investigate suspected coercion must be built into any scheme including via coronial review.*<sup>708</sup>

The RANZCP similarly suggested ‘... capacity assessments and undue influence screening must be mandatory for all applicants to ensure that the patient is independently making the decision to end their life’.<sup>709</sup>

The Cancer Council, in its submission, referred to the importance of public communication about assisted dying to reduce the risk of coercion, stating:

*Any decision to access assisted dying must be fully informed, freely made and respected. Public communication should not position assisted dying as the community’s expectation for people with a terminal illness, nor should people with a terminal illness feel pressured to enquire about assisted dying.*<sup>710</sup>

Ms Ros Knight of the Australian Psychological Society also raised the role of psychologists and social workers in a possible VAD scheme. Ms Knight told the committee:

*That comes to my first main point, which is that psychology’s involvement in ageing, aged care, palliative care and other areas has been very difficult to get established. We would see that the main psychological issues in very broad terms are around suffering, fear of suffering, experiencing suffering, control, the ability to make your own decisions and the ability to decide what will happen to you towards the end of your life. If I can speak to where psychology fits into those broad churches, we have a lot to contribute that just might help to tailor things to an individual, thereby saving money and improving their life quality for whatever time period remains for them.*<sup>711</sup>

...

*The family GP, obviously, is an important source of information and you would not want to lose that gold. It is part of the process of understanding whether coercion is occurring or depression has been present for a long time, et cetera. The fundamental is, yes, I think there needs to be somebody who has the expertise to assess both the mental illness components and cognitive impairments that might exist, but also somebody who can look at the level of family functioning and coercion—a range of things. Please do not hear me saying that families are coercive all the time.*

*Yes, I do think it needs to be people with expertise. Psychologists are definitely well placed for the mental illness and cognitive impairment side of things. Social workers would obviously have a role to play there too, in terms of more of the coercion side of things, assessment, recognition of rights and other things.*<sup>712</sup>

Ms Jane Smith suggested in her submission that legislation enable a person to be prosecuted if they are found to have coerced a person during the VAD process.<sup>713</sup>

<sup>708</sup> Submission 1203, pp 6-7.

<sup>709</sup> Submission 1207, p 11.

<sup>710</sup> Submission 1303, p 12.

<sup>711</sup> Public hearing transcript, Brisbane, 13 September 2019, p 24.

<sup>712</sup> Public hearing transcript, Brisbane, 13 September 2019, p 28.

<sup>713</sup> Submission E188. See also, submission 2016.

Other submitters recommended trusting medical professionals to assess whether a person is being coerced (and therefore finding the person does not meet the eligibility criteria to access VAD).<sup>714</sup>

#### **Committee comment**

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.

If voluntary assisted dying is legislated in Queensland, it should include: 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; a transparent review mechanism and protections for liability for scheme participants. The scheme must also require thorough documentation and reporting at all stages of the voluntary assisted dying process and a comprehensive education campaign for medical practitioners and the public.

#### **Recommendation 8**

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.

#### **Recommendation 9**

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.

## **9.2 Consideration of mental health conditions**

People with a sole diagnosis of psychiatric illness are not permitted to access VAD in Victoria and Western Australia. This contrasts with access to assisted dying in some European countries such as Belgium and the Netherlands where the legislation is silent on the impact of mental health conditions; although, in the Netherlands the request for assisted dying must be 'well considered'.<sup>715</sup> In Belgium, the patient must be competent to make a request.<sup>716</sup>

The issue of mental illness alone not satisfying the eligibility criteria was addressed in several submissions to the committee.

Although people with a sole diagnosis of mental illness (and who do not meet the other eligibility criteria) are not permitted to access VAD, the Victorian legislation allows for people who meet all the other eligibility criteria and also have a psychiatric illness to not be excluded from access to VAD.

The RANZCP supported the exclusion of persons with a sole diagnosis of psychiatric illness, suggesting that in such a case the persons' wish to die is not stable.<sup>717</sup> The RANZCP did, however, provide support

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<sup>714</sup> See, for example, submissions 176, 221, 232, 324, 327, 383, E1121, 1202.

<sup>715</sup> White, Ben & Willmott, Lindy. (2012). *How should Australia regulate voluntary euthanasia and assisted suicide?*, Journal of law and medicine, 20 p 438.

<sup>716</sup> White, Ben & Willmott, Lindy. (2012). *How should Australia regulate voluntary euthanasia and assisted suicide?*, Journal of law and medicine, 20 p 438.

<sup>717</sup> Submission 1207, p 10.

for a person who meets all other eligibility criteria and has a psychiatric illness to not be denied access to a VAD scheme.<sup>718</sup>

Other submissions argued that access to a potential VAD scheme in Queensland should be extended to those with mental illness. The DFADC stated:

*justice as fairness would require the inclusion in VAD eligibility of certain patients with “only” psychiatric conditions, given that while the nature of their suffering is different from a person with, say, terminal cancer, the continuing intolerability of their suffering is in no less doubt.*<sup>719</sup>

Further, DFADC noted that ‘it is well accepted that the existence of mental illness or disability does not imply that a patient lacks decision-making capacity’.<sup>720</sup>

The DFADC submission acknowledged the view that it is not possible to be certain that a patient with a mental illness will not get better over time. However, the organisation argued that ‘patients with recalcitrant depression who retain decision-making capacity can be discriminated against if excluded from access to VAD under cover of ostensible protection from vulnerability’<sup>721</sup> In this regard, DFADC recommended that:

*Queensland has the opportunity to extend the benefits of VAD to its citizens in an equitable way, as long as patients with mental illness or disability who conform to all eligibility criteria are treated similarly. The committee should recommend that mental illness and disability be included in the disease/condition eligibility criteria, but subject to specialist consultation regarding diagnosis, resistance to treatment, and the existence of unrelenting and unacceptable suffering until natural death. Should the committee not make this recommendation, it should recommend that the issue remain the subject of further exploration and consideration by relevant bodies.*<sup>722</sup>

The Queensland Council for Civil Liberties noted ‘... many psychiatric conditions distort the perceptions of those suffering from them, so that many patients with personality disorders or major depression feel as a result of their psychiatric condition that they can never get any better’, and recommended additional safeguards for persons whose underlying condition is psychiatric.<sup>723</sup>

#### **Committee comment**

The committee notes concerns raised regarding the additional vulnerability of persons with a mental health condition and how this may impact on their decision to access voluntary assisted dying.

The committee concludes that people should not be automatically excluded from voluntary assisted dying 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 voluntary assisted dying because of their illness. Their eligibility to access voluntary assisted dying needs to be considered on the same basis as anyone else seeking to access voluntary assisted dying.

#### **Recommendation 10**

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.

<sup>718</sup> Submission 1207, p 10.

<sup>719</sup> Submission 1225, pp 12-13.

<sup>720</sup> Submission 1225, p 13.

<sup>721</sup> Submission 1225, p 13.

<sup>722</sup> Submission 1225, p 13.

<sup>723</sup> Submission 1200, p 5.

### 9.3 Procedural timeframes

The Victorian and Western Australian legislation both provide for a minimum time period of nine days between when the first and final requests from a person to access VAD can be made. An exception to this timeframe may occur if the co-ordinating medical practitioner considers that the person's death is likely to occur within this nine-day period.<sup>724</sup> In addition, the WA Act allows for a shorter time period if the patient is likely to lose decision-making capacity before the end of the nine days.<sup>725</sup>

A number of submissions expressed the view that any period of time should be minimal. For example, DWDQ noted that timeframes should be minimised from the initial request to access VAD.<sup>726</sup>

Although opposed to VAD, Queensland Baptists, in their submission, recommended a minimum time period of at least two weeks from the first written request.<sup>727</sup>

### 9.4 Method of administration

The method of administration for a VAD substance is not specified in either the Victorian or Western Australian legislation. There appears to be limited public information about the use of particular methods of administration in Australian jurisdictions, though some submissions identified preferred methods from overseas schemes.

During the consideration in detail debate on the Voluntary Assisted Dying Bill in WA, the Minister for Health, Hon Roger Cook, identified some possible methods of administration for the voluntary assisted dying substance under the provisions of the WA VAD Bill:

*Obviously, the method depends on the patient's circumstances, as I mentioned in my response to the member for Churchlands. It will depend upon the patient's physical capacity to absorb or take the drugs. The member mentioned a number of ways that could happen and yes, they would be included. Kerry Robertson, the woman who accessed voluntary assisted dying in Victoria, took the substance orally, but other patients may need to have it administered by injection or IV drip. I am advised that the likely methods of death may include self-administration, which would be oral medication in liquid or tablet form administered by the patients themselves, or practitioner administration, which would be the administration of the substance by the administering practitioner—for example the coordinating practitioner, another medical practitioner or nurse practitioner—in the form of a liquid or tablet, or via injection, oral tube, nasal tube, intravenous line or stomach peg. I am not saying that is an exhaustive list, but it gives an idea.<sup>728</sup>*

The specific substance to be used is also not specified in either the Victorian or WA VAD schemes. However, the WA legislation allows for a Schedule 4 or Schedule 8 poison (as defined in the *Medicines and Poisons Act 2014* (WA)) to be prescribed for the purpose of causing a patient's death.<sup>729</sup>

The role of health practitioners in the administration of a voluntary assisted dying substance varies by jurisdiction. In Victoria, the default method of administration of the substance is self-administration. Practitioner administration is permitted but only if the patient is physically unable to self-administer.<sup>730</sup>

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<sup>724</sup> *Voluntary Assisted Dying Act 2019* (WA) s 48(3); *Voluntary Assisted Dying Act 2017* (Vic), s 38(2).

<sup>725</sup> *Voluntary Assisted Dying Act 2019* (WA) s 48(3).

<sup>726</sup> Submission 1215, p 10.

<sup>727</sup> Submission 1228, p 3.

<sup>728</sup> Parliament of Western Australia, Legislative Assembly, *Debates*, 17 September 2019, p 6797.

<sup>729</sup> *Voluntary Assisted Dying Act 2019* (WA) s 7.

<sup>730</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 53(1)(b).

A practitioner administration permit allows the coordinating practitioner to administer the substance.<sup>731</sup>

In WA, the circumstances permitting practitioner administration are extended to include patient concerns regarding self-administration and the administration method suitable for the patient, as determined by the coordinating medical practitioner. This allows additional circumstances where practitioner administration may occur, compared with the Victorian model.

#### Dispensing of medication

The Victorian Government established a Voluntary Assisted Dying Statewide Pharmacy Service to dispense voluntary assisted dying medication in Victoria. The role of the state-wide service is to:

- *liaise with the co-ordinating medical practitioner*
- *communicate with the patient*
- *dispense the prescription*
- *provide the medication to the patient.*<sup>732</sup>

To dispense the medication, the Statewide Pharmacy Service will visit the patient (anywhere in Victoria) to provide the medication and education regarding the voluntary assisted dying medication.

The Pharmacy Guild of Australia, while it did not express a view on VAD, noted that if legislation were introduced in Queensland ‘...pharmacists and community pharmacy should be considered an integral part of the successful implementation and delivery of any legislated pathways that provide consumers with access to medications for the purpose of assisting a person to voluntarily end their life’.<sup>733</sup>

The Pharmaceutical Society of Australia told the committee:

*While not taking a stance on VAD, the Pharmaceutical Society of Australia stated: As experts in medicines and their use, pharmacists provide a vital role in all instances that a medication is supplied. Pharmacists must be an integral part of the implementation and delivery of any legislated pathways that provide access to medications for the purpose of assisting a person to voluntarily end their life.*<sup>734</sup>

#### **Committee comment**

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 believes 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.

#### **Recommendation 11**

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.

<sup>731</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying Guidance for health practitioners, pp 52-53.

<sup>732</sup> Victoria State Government, Department of Health and Human Services, Health services information, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-services-information>.

<sup>733</sup> Submission 1294, p 3.

<sup>734</sup> Submission 1298, p 7.

## Recommendation 12

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.

### 9.5 Insurance implications of participating in VAD

When a person dies in Queensland, their death is ordinarily registered under the *Births, Deaths and Marriages Act 2003* (Qld).<sup>735</sup> A death certificate is then produced by the Registrar of Births, Deaths and Marriages which shows the details of the death (including the cause of death).

A number of submitters raised concerns about the potential impacts of accessing VAD on claims against life insurance policies and funeral insurance.<sup>736</sup> For example, Bruce and Patricia Patch in their submission proposed that ‘VAD not be legally seen as a suicide for the purposes of any insurance or end-of-life legal process that may exclude benefit to the estate of the person’.<sup>737</sup> One submission proposed that VAD should ‘invalidate life insurance’, but not funeral Insurance’.<sup>738</sup>

Dr Carol Portmann proposed in her submission, that ‘discussion needs to be made with insurance groups and private health insurers to allow voluntary assisted dying as a result of terminal illness to be considered as a form of death that allows life insurance to pay out to family and for medical costs to be covered and this will need to be retroactive’.<sup>739</sup>

Dying with Dignity Tasmania (Inc) in its submission included details of provisions from a proposed VAD Bill the organisation had prepared, based on the Voluntary Assisted Dying Bill 2016. The Bill proposed by Dying with Dignity Tasmania included provisions to protect any life, health or accident insurance or annuity or policy for the person accessing VAD and similarly protect any person assisting another person to access VAD:

#### 30. Insurance or annuity policy

*(1) The sale, procurement or issuing of any life, health or accident insurance, or annuity, policy or the rate charged for any policy is not to be conditional on, or affected by, the making or rescinding of, or the failure to make or rescind, an assisted dying request by a person.*

*(2) The act of a person self-administering prescribed medication to end his or her life in accordance with this Act is not to affect any life, health or accident insurance, or annuity or policy that may be held in respect of the person.*

*(3) The act of a person to end the life of another person in accordance with this Act is not to affect any life, health or accident insurance, or annuity or policy that may be held in respect of that other person.*<sup>740</sup>

In Victoria, VAD is not recorded on a person’s death certificate,<sup>741</sup> and a death from VAD is not considered to be a ‘reportable death’ under the *Coroners Act 2008* (Vic).<sup>742</sup> The second reading speech for the Victorian VAD Bill states:

<sup>735</sup> *Births, Deaths and Marriages Act 2003* (Qld), ss 26-27.

<sup>736</sup> Submission 605, p.2; submission 1836, p 3; submission 2076, p 2; submission 621, p 6.

<sup>737</sup> Submission 2076, p 2.

<sup>738</sup> Submission 1364, p 3.

<sup>739</sup> Submission 1836, p 3.

<sup>740</sup> Submission 1296, pp 55-56.

<sup>741</sup> Victoria State Government, Health and Human Services, Voluntary assisted dying Information for people considering voluntary assisted dying, p 38.

<sup>742</sup> *Coroners Act 2008* (Vic), s 4(3).

*The bill recognises that only people who are already dying may access voluntary assisted dying, and as such, their death should not be treated as unexpected or avoidable ... This will not preclude the coroner from investigating a death, but this will not be an automatic requirement.*

*As people may only access voluntary assisted dying if they are suffering from a disease, illness or medical condition that will cause death, this disease, illness or medical condition should be recorded as their cause of death.*<sup>743</sup>

The Victorian VAD Act does require the Victorian Registrar of Births, Deaths and Marriages, to record 'the cause of death as the disease, illness or medical condition that was the grounds for a person to access voluntary assisted dying' and that VAD was accessed by self-administration or administration by a medical practitioner.<sup>744</sup> The Registrar is then required to notify the Victorian VAD Review Board.<sup>745</sup>

#### **Committee comment**

The committee considers that it is important for protecting the financial interests of those accessing voluntary assisted dying that any scheme legislated in Queensland include safeguards to ensure that participation in voluntary assisted dying does not nullify life insurance, funeral or health insurance held in the name of the person participating in voluntary assisted dying.

#### **Recommendation 13**

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.

### **9.6 Access to counselling**

The importance of access to counselling was raised by a number of stakeholders during the inquiry.<sup>746</sup>

The RACP stated that 'support, counselling and conflict mediation services must be available for individuals, families and health professionals involved',<sup>747</sup> and should include:

- family/carer conferencing services to patients and health professionals (to acknowledge the impact on families and to enable family/carer participation and response)
- support systems for individuals, families and health professionals who may be involved and who may suffer emotional distress, personal trauma or other harm (regardless of whether the patient ultimately proceeds with a medically assisted death), and
- adequate funding for family support, counselling and conflict mediation services.<sup>748</sup>

A range of views was shared with the committee on whether counselling for a person wishing to access VAD should be optional or compulsory.

Dying with Dignity Queensland suggested counselling should be offered to people accessing voluntary assisted dying, but should not be compulsory.<sup>749</sup> The Australian Psychological Society, RANZCP and

<sup>743</sup> Vic VAD Bill, second reading speech, 21 September 2017, p 2949.

<sup>744</sup> *Births, Deaths and Marriages Registration Act 1996* (Vic), s 40(1A).

<sup>745</sup> *Births, Deaths and Marriages Registration Act 1996* (Vic), s 40A.

<sup>746</sup> See, for example, submissions 028, 052, 086, 141, E188, E227, 876, E1082, 1203, 1207, 1213, 1215, E1736, 2433, 2632.

<sup>747</sup> Submission 1203, p 4.

<sup>748</sup> Submission 1203, p 7.

<sup>749</sup> Submission 1215, p 9.



QNMU similarly recommended counselling be optional.<sup>750</sup> The QNMU noted counselling may involve costs that are unable to be met by an individual or family.<sup>751</sup>

Doctors for Assisted Dying Choice support counselling ‘within the therapeutic relationship with the patient’s regular doctor’. The organisation also supports the creation of specific VAD counselling services within Queensland Health and a system of liaison officers similar to those in Victoria’s system. The submission noted that counselling beyond the doctor-patient relationship should not be compulsory.<sup>752</sup>

Queensland Baptists, while expressing opposition to VAD, included recommendations about counselling if a scheme were introduced in Queensland. The organisation supported a minimum of two counselling sessions for persons wishing to access VAD, and stated that the counselling sessions should ‘... explore whether undiagnosed or untreated mental health conditions such as depression are present’.<sup>753</sup> Queensland Baptists also supported exploring ‘the question of guilt’ during counselling sessions, to ensure that persons accessing VAD are not compelled for feelings of guilt for loved ones who may be distressed by their suffering.<sup>754</sup>

The RANZCP noted that counselling should be ‘affordable and easily accessible, at every stage along the process. It should be unbiased and provided by an appropriately qualified person’.<sup>755</sup>

The committee also heard recommendations that family members of persons wishing to access VAD should have bereavement support which may include counselling or other services.<sup>756</sup>

#### **Committee comment**

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.

#### **Recommendation 14**

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.

### **9.7 Role of health practitioners**

The role of health practitioners in each stage of a VAD scheme for Queensland needs to be carefully articulated and regulated. This should include all practitioners involved in the VAD process such as consulting general practitioners, nurses or other professionals administering a VAD substance, and pharmacists who might dispense a VAD substance to a patient.

The QNMU noted ‘the role of nurses must be clearly prescribed and be within the boundaries of acceptable nursing practice, including ethical conduct and practice standards’.<sup>757</sup>

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<sup>750</sup> Ros Knight, Australian Psychological Society, Public hearing transcript, Brisbane, 13 September 2019, p 25; RANZCP, submission 1207, p 12; QNMU, submission 1213, p 43.

<sup>751</sup> Submission 1213, p 43.

<sup>752</sup> Submission 1225, p 24.

<sup>753</sup> Submission 1228, p 4.

<sup>754</sup> Submission 1228, p 4.

<sup>755</sup> Submission 1207, p 12.

<sup>756</sup> Cancer Council, submission 1303, p 12.

<sup>757</sup> Submission 1213, p 36.

The Australian Association of Social Workers suggested medical practitioners, nurses, psychologists and social workers who may be involved in an assessment of a person wishing to access VAD, would require ‘strong guidelines for group-decision making’ and should be subject to oversight and accountability.<sup>758</sup>

### 9.7.1 Two practitioners

In both the Victorian and WA schemes, two doctors (a coordinating practitioner and a consulting practitioner) are required to assess a person to determine their eligibility to access VAD.<sup>759</sup> The assessment of the consulting practitioner is independent to the coordinating practitioner’s assessment and is intended to act as a further safeguard for the patient. Both practitioners must inform the patient about the VAD process and other palliative care options in order to ensure that the person is making an informed decision and is acting voluntarily and without coercion.<sup>760</sup>

The required minimum levels of experience for medical practitioners varies by jurisdiction. As with other key differences between the Victorian and WA VAD schemes, these differences can be partially attributable to the difference in geography between the two states and the lower concentration of medical practitioners in regional and remote areas of WA.

No substantive opposition to requiring two doctors to determine eligibility was raised with the committee.

Dying with Dignity Tasmania (Inc) recommended retaining the Victorian position of requiring two doctors.<sup>761</sup> Similarly, Dying with Dignity WA supported a requirement of having ‘assessment by two doctors to satisfy themselves independently that the person has satisfied all the relevant criteria, with the ability in their discretion to refer the person for a specialist assessment’.<sup>762</sup> Dying with Dignity Queensland held the same view.<sup>763</sup>

The Western Australian Government’s independent expert panel recommended two medical practitioners be required to independently assess a person’s capacity and eligibility to access VAD; however, it recommended that ‘having regard to the scarcity of medical practitioners in many country districts and towns of Western Australia ... the second (consulting) practitioner may be a qualified nurse practitioner’.<sup>764</sup>

The difficulties for people in rural and remote areas seeking to access voluntary assisted dying are compounded by provisions in the *Criminal Code 1995* (Cth) s 474.29A and s 473.29B, inserted by the *Criminal Code Amendment (Suicide Related Material Offences) Act 2005* (Cth), that would limit communications between medical practitioners and their patients regarding voluntary assisted dying. Section 474.29A of the Criminal Code (Cth) provides that a person is guilty of an offence if they use a carriage service<sup>765</sup> to access, cause to be transmitted, transmit, make available, publish or otherwise distribute material that directly or indirectly counsels, or incites committing or attempting to commit suicide.

<sup>758</sup> Submission 1288, p 22.

<sup>759</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 6(b); *Voluntary Assisted Dying Act 2019* (WA) s 15(b).

<sup>760</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 19(c) and s 28(c); *Voluntary Assisted Dying Act 2019* (WA), s 27(1)(c) and s 40(4)(m).

<sup>761</sup> Submission 1296, p 17.

<sup>762</sup> Submission 1306, p 4.

<sup>763</sup> Submission 1215, pp 7, 10.

<sup>764</sup> Government of Western Australia Department of Health, Ministerial Expert Panel on Voluntary Assisted Dying Final Report, p vi.

<sup>765</sup> A carriage service is defined in the *Telecommunications Act 1997* (Cth) at s 7 as ‘a service for carrying communications by means of guided and/or unguided electromagnetic energy’.

### **Committee comment**

The committee considers it is appropriate and prudent to require two practitioners to determine a patient's eligibility for voluntary assisted dying. The committee is, however, mindful of the difficulties this requirement creates for applicants in rural and remote areas where face-to-face access to two independent doctors, or even one medical doctor, may be problematic.

Given these difficulties, the committee believes the 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.

### **Recommendation 15**

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.

### **9.7.2 Initiation of discussions about VAD**

The Victorian VAD legislation prevents a medical practitioner from initiating a discussion about VAD with a patient. Instead, the patient must be the one to instigate such a discussion.<sup>766</sup>

The *Voluntary Assisted Dying Act 2019* (WA) enables a registered health practitioner to begin a discussion about VAD with a patient where the health practitioner also informs the patient about their treatment options and their palliative care options and the likely outcome of taking either of these pathways.<sup>767</sup> During the second reading speech of the Legislative Council, the Hon Stephen Dawson, Minister for Environment, stated:

*A registered health practitioner will be able to begin a discussion about voluntary assisted dying with a patient to whom they are providing health or professional care services. There should not be an attempt to censor the conversations that health practitioners have with their patients and they should be able to raise and discuss voluntary assisted dying in the same way as other serious health or medical decisions at end of life.*<sup>768</sup>

The inability for a practitioner to instigate discussion about VAD with a patient was commented upon by a number of stakeholders during the committee's inquiry.

The QNMU provided support for the prohibition, and recommended legislation:

- *provide only the person seeking to access VAD can request it;*
- *make it an offence to coerce, threaten or intimidate another person into accessing VAD*
- *provide an individual's wishes and an AHD must prevail over the family's or any other person's wishes.*<sup>769</sup>

<sup>766</sup> *Voluntary Assisted Dying Act 2017* (Vic), s 8.

<sup>767</sup> *Voluntary Assisted Dying Act 2019* (WA), s 10.

<sup>768</sup> Western Australia Legislative Council, 26 September 2019, p 7430b-7437a, 4.

<sup>769</sup> Submission 1213, pp 41-42.

Dr Albert Garth Thomas told the committee, while he acknowledged the prohibition in Victoria of doctors from instigating a discussion about voluntary assisted dying with patients:

*... having had tens of thousands of conversations with patients over the last 30 years, knowing the avenues of suggestion open to practitioners, and also knowing that at least 60 per cent of communication is non-verbal, I have no doubt that this supposed safeguard will be completely ineffectual.*<sup>770</sup>

#### **Committee comment**

The committee believes that only the applicant should be able to initiate discussions with medical practitioners about accessing voluntary assisted dying.

#### **Recommendation 16**

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.

### **9.7.3 Regulation of health practitioners**

In his submission regarding a system of regulation that would apply to a VAD scheme, the Health Ombudsman stated:

*...should the Government resolve to undertake reforms to allow voluntary assisted dying, consideration would need to be given to the system of regulation that will apply to it. Registered health practitioners that may be engaged in this area are likely to come within the jurisdiction of the OHO and AHPRA. Therefore, practitioners' conduct and performance could be regulated to some extent within the existing framework. Whether the OHO would have broader jurisdiction over services in this space will depend on whether the practice constitutes a health service.*

*Other matters that would need to be addressed from a regulation perspective include: the necessary training and qualifications of practitioners who are likely to be involved, clear and transparent processes around the issue of consent and the recording of consent, and the need for robust clinical assessment standards.*<sup>771</sup>

The Australian Health Practitioner Regulation Agency (AHPRA) noted that in providing the ability for a medical practitioner to assist in a persons' death 'the power to lawfully provide this assistance often comes with requirements placed on the registered practitioner in order to ensure the legislative provisions are upheld'.<sup>772</sup> The agency also referred to the Medical Board of Australia's code of conduct for doctors in Australia, and stated:

*In conclusion, should Queensland elect to pursue legislation in support of voluntary assisted dying arrangements we would encourage members to continue to consult with the national scheme to ensure that appropriate regulatory mechanisms are in place to support both the implementation and then ongoing operation of such arrangements.*<sup>773</sup>

A decision by a registered practitioner to assist the ending of another person's life may raise questions about the practitioner's professional ethics and conduct. All professions regulated in the National Registration and Accreditation Scheme for the health professions (the National Scheme) have a Code of Conduct that sets out the expectations for professional conduct by registered practitioners within the profession which may be relevant to a VAD scheme. For example, the Medical Board of Australia's *Good Medical Practice: A Code of Conduct for Doctors in Australia* provides that good medical practice

<sup>770</sup> Public hearing transcript, 23 August 2019, p 46.

<sup>771</sup> Submission 1257, pp 4-5.

<sup>772</sup> Submission 1237, p 1.

<sup>773</sup> Public hearing transcript, Brisbane, 4 July 2019, p 40.

involves registered medical practitioners being aware of their right not to provide treatment for which they conscientiously object, but also not using this objection to impede access to treatments that are legal.

## 9.8 Conscientious objection

In both Victoria and WA, the participation of health practitioners in VAD is voluntary, and practitioners may choose to conscientiously object or object for other reasons. There are, however, clear points of difference in how this right to conscientious objection is communicated to the person wishing to access VAD. The WA legislation requires health practitioners to notify the person of their objection to VAD immediately.<sup>774</sup> In Victoria, health practitioners are required to respond to the first request to access VAD within seven days, including health practitioners who conscientiously object.<sup>775</sup> A practitioner who conscientiously objects to VAD in Victoria, is not required to refer a patient to someone who will assist them.<sup>776</sup>

The majority of organisations who commented on the right of practitioners to conscientiously object to VAD, also supported the right of medical practitioners to not participate in VAD.<sup>777</sup> In its submission to the committee, AMAQ stated:

*The AMA also recognises there are divergent views within the medical profession – and some of our members are supportive of voluntary assisted dying, and may choose to be involved in these processes. Should the Queensland Parliament approve legislation for voluntary assisted dying legislation in Queensland, then conscientious objections provisions must be included in the legislation to ensure that no doctor (or other health practitioner) will ever be forced to be involved in Voluntary Assisted Dying if they do not wish to be.*<sup>778</sup>

In their submission, AMAQ also supported the involvement of medical practitioners ‘in the development of any relevant legislation, regulations and guidelines’ should the law and community attitudes change in relation to VAD.<sup>779</sup>

Dying with Dignity Queensland stated that ‘Legislation to allow VAD must not compel health professionals with conscientious or religious objection to provide assistance to people seeking VAD’. However, the organisation suggested that health practitioners who object to VAD should be obliged to refer requests for VAD to participating health professionals within 24 hours of the request.<sup>780</sup> DWDQ also recommended a legal requirement for all institutions to disclose their positions on VAD following the receipt of a request for VAD and prior to patient admission.<sup>781</sup>

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<sup>774</sup> *Voluntary Assisted Dying Act 2019* (WA), s 20(5).

<sup>775</sup> B White et al, ‘WA’s take on assisted dying has many similarities with the Victorian law – and some important differences’, *The Conversation*, 9 August 2019; *Voluntary Assisted Dying Act 2017* (Vic), s 13(1).

<sup>776</sup> Victoria State Government, Department of Health and Human Services, Health practitioner information, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-practitioner-information>

<sup>777</sup> See, for example, submissions 1203, 1215, 1233, 1249, 1252, 1261; Dr Bruce Willet, Chair of the RACGP, public hearing transcript, Brisbane, 4 July 2019, p 3; Suzanne Greenwood, CEO, Catholic Health Australia, public hearing transcript, Brisbane, 4 July 2019, p 68; Reverend Dr Adam McIntosh, Uniting Church, representing the Queensland Synod of Uniting Church Queensland, public hearing transcript, Brisbane, 4 July 2019, p 62.

<sup>778</sup> Submission 1233, p 42.

<sup>779</sup> Submission 1233, p 7.

<sup>780</sup> Submission 1215, p 10.

<sup>781</sup> Submission 1215, p 10.

Both DWDQ and the RACP suggested a type of register of health practitioners who would be willing to participate in VAD to facilitate access to their services.<sup>782</sup> The RACP suggested '[a] central information source on the scheme should be available to assist patient access' and that any register of practitioners could include those who are willing to participate in restricted ways (such as only providing a second medical opinion rather than acting as the administering practitioner).<sup>783</sup>

In relation to allowing medical practitioners to hold conscientious objection against VAD, Doctors for Assisted Dying Choice expressed support for equal access for all eligible patients, stating that 'it is unprofessional to impede a patient's access to a lawful health service'. The submission further supported that a potential VAD scheme in Queensland 'include the requirement that objecting doctors and health care institutions refer requesting patients to others willing to participate'.<sup>784</sup>

Some stakeholders who supported a practitioners' ability to conscientious objection did not believe the practitioner should have to refer the patient to another practitioner.<sup>785</sup>

Mr Francis Price, Director of Southern Cross Care, expressed his view that should legislation be introduced for VAD in Queensland that requires referral even if a practitioner has a conscientious objection, that Southern Cross Care would 'exit the industry' and 'pull out of aged-care facilities'.<sup>786</sup> Mr Price stated: 'We are very clear that we are not going to allow assisted suicide in our facilities, but you are in an environment where a person has a right to stay in that facility. If push comes to shove, we will exit the industry'.<sup>787</sup>

Hammond Care submitted that practitioners who hold a conscientious objection should not be required to refer a patient, and stated:

*Forcing professionals and organisations to make such a referral would undermine their right to object and cause them to act in a way that goes against their own conscience. Again, this approach has been adopted in Victoria, where neither health practitioners nor health services are under any obligation to refer for voluntary assisted dying although they must not "inhibit a person's access to treatment".*<sup>788</sup>

The ANZSPM, while supporting conscientious objection for medical practitioners, raised concern about availability of services, particularly in rural and remote areas and noted that 'any assisted dying system needs to respect the ability of a single medical practitioner working in those areas to conscientiously object'.<sup>789</sup>

The QNMU supported extension of conscientious objection to nurses, midwives and assistants in nursing, who may be engaged as part of a VAD scheme.<sup>790</sup>

The Pharmacy Guild of Australia similarly recommended the right to conscientious objection should also be available to pharmacists who may be engaged in the dispensing of medicines that may be used in a VAD scheme, and that a pharmacist who holds a conscientious objection should not have an

<sup>782</sup> DWDQ, Submission 1215, p 10. RACP, submission 1203, p 6.

<sup>783</sup> Submission 1203, p 6.

<sup>784</sup> Submission 1225, p 25.

<sup>785</sup> See, for example, submissions 284, 1213, 1224, 1228, 1238, 1261, E1281, E1820, E2011, 2317, 2553, Suzanne Greenwood, Chief Executive Officer, Catholic Health Australia, public hearing transcript, Brisbane, 4 July 2019, p 74; Reverend Dr Adam McIntosh, Associate Director of Mission, representing the Queensland Synod of Uniting Church Queensland, public hearing transcript, Brisbane, 4 July 2019, p 74 .

<sup>786</sup> Public hearing transcript, Brisbane, 4 July 2019, p 75.

<sup>787</sup> Public hearing transcript, Brisbane, 4 July 2019, p 75.

<sup>788</sup> Submission 1261, p 13.

<sup>789</sup> Submission 1252, p 11.

<sup>790</sup> Submission 1213, pp 43-44.

obligation to ‘supply or to provide a referral to another practitioner’.<sup>791</sup> Mr Trent Twomey, President of the Pharmacy Guild of Australia, noted the difficulties that might be faced where there is only one pharmacy in a community and stated:

*I think pharmacists are highly professional; I know they are highly professional. If they do not feel they can play a role, I have no doubt that they will ensure, whether it is through the public community controlled health organisation or reaching out to another pharmacist, they can provide some form of remote care; they will ensure their professional duty of care is executed.*<sup>792</sup>

Mr Mark Lock, Queensland State Manager of the Pharmaceutical Society of Australia noted:

*... the obligation of pharmacists to refer on to other practitioners for the service is bound in the code of ethics that pharmacists are required to practise by, which they declare as part of their registration as a pharmacist. That is a requirement.*<sup>793</sup>

Other submitters proposed that protections should apply to any practitioners who conscientiously object to VAD.<sup>794</sup>

#### **Committee comment**

The committee notes the strong support for any voluntary assisted dying model in Queensland to provide that medical practitioners who may be involved in the voluntary assisted dying process are able to conscientiously object and therefore not be forced to participate.

The committee also notes that, in rural and remote areas where there may be only one local doctor, allowing practitioners to conscientiously object to participating in voluntary assisted dying may have profound implications for patients there wishing to access voluntary assisted dying.

If voluntary assisted dying is legislated in Queensland, it is imperative that the legislation ensures that voluntary assisted dying is genuinely accessible for all people with a life-limiting illness regardless of their location and whether their local doctor conscientiously objects to participating in voluntary assisted dying.

#### **Recommendation 17**

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.

#### **Recommendation 18**

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.

## **9.9 Oversight/review mechanisms**

A number of stakeholders recommended independent oversight and review mechanisms be included in a VAD scheme for Queensland. Professor Lindy White and other stakeholders recommended the establishment of a review body similar to the Victorian Voluntary Assisted Dying Review Board.<sup>795</sup>

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<sup>791</sup> Submission 1294, p 3.

<sup>792</sup> Public hearing transcript, Brisbane, 13 September 2019, p 35.

<sup>793</sup> Public hearing transcript, Brisbane, 13 September 2019, p 35.

<sup>794</sup> See, for example, submissions 1233, 1294, 1295.

<sup>795</sup> See, for example, submissions 1202, 1207, 1225, 1268, 1288; Professor Lindy White, private hearing, Brisbane, 29 April 2019, p 16.

The Clem Jones Group recommended ‘an effective and adequately resourced oversight body’.<sup>796</sup>

Doctors for Assisted Dying Choice proposed that:

*VAD legislation in Queensland should follow the model adopted in Victoria in relation to requests for voluntary assisted dying and associated assessment and documentation, protections from liability for participants, and review processes.*

*Review should be managed by an equivalent body to Victoria’s Voluntary Assisted Dying Review Board and by QCAT.*

*Doctors should be central participants in assessment, documentation and delivery of VAD, due to their comprehensive expertise.*<sup>797</sup>

Dr Stephen Parnis, an emergency physician, suggested that the Victorian Voluntary Assisted Dying Review Board does not go far enough and ‘it is really there to check that boxes have been ticked’.<sup>798</sup> Pro-Life Victoria similarly questioned the effectiveness of the Victorian review board.<sup>799</sup>

#### **Committee comment**

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

#### **Recommendation 19**

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.

### **9.10 Training and support**

In Victoria, medical practitioners must complete training before they are eligible to participate in the VAD process. The training can be undertaken online through the Department of Health and Human Service’s *Voluntary Assisted Dying Portal*.<sup>800</sup> The Victorian Government has also published a number of documents and videos to guide practitioners in their role, and noted that support is available to practitioners through the Australian Medical Association Victoria Peer Support Service and the Victorian Doctors Health Program.<sup>801</sup> The Western Australian legislation also requires that a person administering VAD undergo approved training.<sup>802</sup> Implementation of the WA VAD scheme is under development with the commencement of the program expected in mid-2021.<sup>803</sup>

The Cancer Council Queensland noted the importance of practitioners and services receiving education and training to support end-of-life care, including any VAD legislation that may be adopted. The council stated in its submission This education aims to ensure that people can access the support they need,

<sup>796</sup> Submission 1202, p 29.

<sup>797</sup> Submission 1225, p 23.

<sup>798</sup> Public hearing transcript, Brisbane, 23 August 2019, p 69.

<sup>799</sup> Submission 1266, p 12.

<sup>800</sup> Victoria State Government, Department of Health and Human Services, Health practitioner information, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-practitioner-information>.

<sup>801</sup> Victoria State Government, Department of Health and Human Services, Health practitioner information.

<sup>802</sup> *Voluntary Assisted Dying Act 2019* (WA) s 54(1)b.

<sup>803</sup> Government of Western Australia, Department of Health, *Voluntary assisted dying*. <https://www2.health.wa.gov.au/voluntaryassisteddying>.



including support to make assisted dying decisions, and should not depend of the views of the service or practitioner about assisted dying'.<sup>804</sup>

Dementia Australia recommended a collaborative approach to education and training of medical practitioners:

*...whereby medical professionals in addition to receiving dementia training, utilise the expertise of neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to the people with dementia.*<sup>805</sup>

The QNMU made the following recommendations in regards to professional development for health practitioners:

*The QNMU recommends health providers:*

- provide health practitioners with access to ongoing professional development about all aspects of VAD including the right of a patient to refuse medical treatment;*
- provide ongoing professional for all health professionals regarding the right of a competent patient to refuse food and water. Training should also include those working in aged care;*
- provide ongoing professional development for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments.*<sup>806</sup>

#### **Committee comment**

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.

#### **Recommendation 20**

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.

### **9.11 Monitoring and review of proposed legislation**

A number of stakeholders suggested a review period for any legislation introduced to provide VAD in Queensland to ensure the legislation was functioning as expected and continuing to meet the expectations of the community and medical practitioners.<sup>807</sup> The RACP also recommended the legislation be accompanied by 'rigorous documentation and data collection to enable review of any scheme and to assess changes in practice and the impacts on health professionals, patients and families'.<sup>808</sup>

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<sup>804</sup> Submission 1303, p 12.

<sup>805</sup> Submission 1621, pp 11-12.

<sup>806</sup> Submission 1213, pp 38-39.

<sup>807</sup> See, for example, submissions 1203, 1207, 1213, E597.

<sup>808</sup> Submission 1203, p 4.

Cancer Council Queensland stated:

*Assisted dying legislation must include clear reporting obligations and information collection requirements, which will be essential to track the operation of an assisted dying scheme, and to detect and address any negative, unintended effects.*

...

*An assisted dying scheme requires continuous and adequately resourced monitoring and evaluation.*<sup>809</sup>

The Victorian Act provides for a review by the Minister to be conducted during the fifth year of operation of the Act and that the review be tabled in parliament.<sup>810</sup>

The WA Act provides for a review of the Act by the Minister after two years initially, and at intervals of not more than five years after that.<sup>811</sup> The review must also be tabled in the parliament.<sup>812</sup>

#### **Committee comment**

The committee supports the inclusion of a review mechanism in any proposed voluntary assisted dying legislation to ensure the scheme is safe and workable.

#### **Recommendation 21**

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.

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<sup>809</sup> Submission 1303, pp 12-13.

<sup>810</sup> *Voluntary Assisted Dying Act 2017* (Vic) s 116.

<sup>811</sup> *Voluntary Assisted Dying Act 2019* (WA) s 164(1).

<sup>812</sup> *Voluntary Assisted Dying Act 2019* (WA) s 164(2).

## 10 Implementation

Chapter 10 discusses activities and timeframes for implementing VAD in Queensland.

### 10.1 Lessons from Victoria and Western Australia

Queensland is well placed to learn from Victorian and Western Australian experiences in devising and implementing VAD in those jurisdictions.

The Victorian VAD scheme included an 18-month implementation timeframe from the passing of the Voluntary Assisted Dying Bill 2017 until the date of commencement of the scheme. Implementation of the Victorian VAD scheme included an implementation taskforce and establishment of the Victorian Voluntary Assisted Dying Review Board. Adjunct Associate Professor Donna Markham, Chief Allied Health Officer of Safer Care Victoria, told the committee:

*The implementation task force was also responsible for establishing all of the guidance materials, so those for health services, consumers, medical practitioners—all of the models of care and service delivery options to help health services decide how they would want to participate in the scheme and all the education and training as well, including the mandatory training that all medical practitioners have to undertake to participate in the scheme. They also set up the two statewide services—that is, the statewide pharmacy service as well the care navigator service. The care navigator service is the staff that help connect the dots for people across the state when they are wanting to either gain more information or trying to coordinate and identify doctors who will help them participate.*

*The review board was established, as I said, in July 2018—12 months prior to the scheme coming into effect. The role of the review board is to retrospectively review every single case of voluntary assisted dying to ensure compliance with the law. They report on the operations of VAD.*<sup>813</sup>

The Victorian Government has developed training for practitioners, and a number of materials to inform and educate health practitioners, patients and families on the VAD scheme.<sup>814</sup>

The Victorian Government established the role of (VAD) ‘Care Navigators’ who provide support for anyone in Victoria who wishes to seek information or assistance with the VAD process. These navigators provide services as part of a statewide care navigator service.<sup>815</sup>

Federal law prohibits inciting suicide via the telephone, email or through the use of telehealth which restricts medical practitioners from discussing VAD with patients by these means.<sup>816</sup> To avoid potential breaches of this law, the Victorian Government has advised that ‘all discussions, consultations and assessments with patients, family and carers regarding voluntary assisted dying must occur face-to-face’.<sup>817</sup>

The QNMU referred to the Victorian VAD scheme’s implementation and stated ‘The Victorian legislation and implementation process will be a useful guide for such a scheme in Queensland.’<sup>818</sup>

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<sup>813</sup> Public hearing transcript, Brisbane, 18 October 2019, p 35.

<sup>814</sup> Victoria State Government, Department of Health and Human Services, Voluntary Assisted Dying, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>.

<sup>815</sup> Victoria State Government, Department of Health and Human Services, Getting support, <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/community-consumer-information/getting-support>.

<sup>816</sup> *Criminal Code Act 1995* (Cth), ss 474.29A-474.29B.

<sup>817</sup> Victoria State Government, Department of Health and Human Services, *Voluntary assisted dying Guidance for health practitioners*, p 74.

<sup>818</sup> Submission 1213, p 39.

Dying with Dignity New South Wales suggested that other states of Australia may be able to apply a shorter timeframe between passage of legislation and its implementation, as states ‘should be able to learn from Victoria’s experience and not have to reinvent the wheel’.<sup>819</sup>

The Western Australian Ministerial Expert Panel proposed ‘at least 18 months’ for its government and health services ‘to plan, consult on guidelines and protocols to ensure that the legislation is translated safely, effectively and appropriately for Western Australia’.<sup>820</sup>

The White and Willmott Bill also recommended an implementation period of 18 months for any legislation developed for VAD.<sup>821</sup>

In other published work, White, Willmott and Close concluded:

*The designated 18-month VAD implementation period provides scope to address these challenges and create the necessary clinical, legal and administrative infrastructure. This can be contrasted with Canada, where political delays led to their medical assistance in dying law coming into effect without an extended opportunity to prepare.*<sup>822</sup>

The RANZCP provided general commentary relating to access to information and scheme readiness:

*Patients considering VAD should be able to access clear information about the requirements, how to navigate the process, who can assist and the expected timeframes. For example, the Victorian government has provided a community and consumer information sheet on understanding VAD.*

*It is important that the necessary infrastructure and resources are in place prior to the commencement of VAD in Queensland, including an adequate number of trained medical practitioners to undertake capacity assessments and prescribe the medication, and other support services for the patient and their carers throughout the process. This will ensure patients can access VAD when they are ready, and not suffer with unnecessary delays.*<sup>823</sup>

#### **Committee comment**

If voluntary assisted dying is legislated in Queensland the implementation of the Victorian and Western Australian voluntary assisted dying schemes will provide a basis for the extent and types of material needed to guide both community members and medical practitioners for the Queensland voluntary assisted dying scheme.

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<sup>819</sup> Submission 1286, p 10.

<sup>820</sup> Government of Western Australia Department of Health, Ministerial Expert Panel on Voluntary Assisted Dying Final Report, p 102.

<sup>821</sup> White and Willmott Bill, cl 2(2); Professors Ben White and Lindy Willmott, submission 1199, p 7.

<sup>822</sup> Ben White, Lindy Willmott and Eliana Close, ‘Victoria’s voluntary assisted dying law: clinical implementation as the next challenge’ (2019) 210(5) *Medical Journal of Australia* 207-209.

<sup>823</sup> Submission 1207, p 12.

## Appendix A - The White and Willmott Voluntary Assisted Dying Bill 2019

### **Voluntary Assisted Dying Bill 2019**

This Bill was drafted by Professors Ben White and Lindy Willmott of the Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology in April 2019.

The purpose of drafting this Bill is to convey in practical terms our proposed policy framework for permitting and regulating voluntary assisted dying. The Bill is accompanied by a short Explanatory Notes document which provides some context for how the Bill was drafted and further background about some of the policy decisions made.

We gratefully acknowledge the critical review and feedback on earlier drafts of the Bill and/or the Explanatory Notes, including by Rebecca Meehan, Katrine del Villar, Dr Jayne Hewitt, Eliana Close, Dr Laura Ley Greaves, Emeritus Professor Malcolm Parker, Jodhi Rutherford, Dr Rachel Feeney, Dr Mark Thomas and interested members of the Queensland Law Society. The Bill represents our views and should not be taken to represent the views of those who provided feedback on it, the Australian Centre for Health Law Research or the Faculty of Law.

# Voluntary Assisted Dying Bill 2019

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# 2019

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## A Bill

for

**An Act to provide for voluntary assisted dying, in specific and restricted circumstances and subject to safeguards, for persons with an incurable, advanced and progressive medical condition that will cause death, to protect registered medical practitioners who wish to provide voluntary assisted dying and registered health practitioners who do not wish to participate in voluntary assisted dying, and for related purposes.**

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## **The Parliament of [State] enacts—**

# **Part 1 Preliminary**

## **1 Short title**

This Act may be cited as the *Voluntary Assisted Dying Act 2019*.

## **2 Commencement**

- (1) Subject to subsection (2), this Act comes into operation on a day or days to be proclaimed.
- (2) If a provision of this Act does not come into operation before [insert day 18 months after Parliament passing this Act], it comes into operation on that day.

## **3 Act binds all persons**

This Act binds all persons, including the State.

## **4 Main objects of the Act**

The main objects of this Act are to—

- (a) provide access to voluntary assisted dying for persons with an incurable, advanced and progressive medical condition that will cause death;
- (b) establish safeguards to ensure that voluntary assisted dying is accessed only by persons who meet this Act's eligibility criteria;
- (c) establish the Voluntary Assisted Dying Review Board to provide oversight of voluntary assisted dying under this Act;
- (d) provide protections from liability for registered health practitioners and other persons who facilitate voluntary assisted dying in accordance with this Act; and
- (e) enable registered health practitioners and entities who provide a health service, residential service or professional care service to refuse to participate in voluntary assisted dying without incurring liability.

## 5 Principles

A person exercising a power or performing a function or duty under this Act must have regard to the following principles—

- (a) human life is of fundamental importance and should be valued;
- (b) a person's autonomy should be respected;
- (c) freedom of conscience should be respected, including choosing to—
  - (i) participate in voluntary assisted dying; and
  - (ii) not participate in voluntary assisted dying;
- (d) a person's equality should be respected and they should be free from discriminatory treatment;
- (e) persons who are vulnerable should be protected from coercion and abuse;
- (f) human suffering should be reduced; and
- (g) the provision of voluntary assisted dying should reflect the established standards of safe and high-quality care.

## 6 Meaning of voluntary assisted dying

- (1) ***Voluntary assisted dying*** means the administration of voluntary assisted dying medication to a person and includes steps reasonably related to such administration.
- (2) To remove any doubt, ***voluntary assisted dying*** may occur through—
  - (a) a registered medical practitioner administering voluntary assisted dying medication to a person to bring about their death (***practitioner administration***); or
  - (b) a person taking voluntary assisted dying medication themselves to bring about their death under the supervision of a registered medical practitioner (***self-administration***).
- (3) For the purposes of subsection (2)(b), being under the supervision of a registered medical practitioner means that the registered medical practitioner is present while the person self-administers the voluntary assisted dying medication.

## 7 Meaning of decision-making capacity

- (1) A person has ***decision-making capacity*** in relation to voluntary assisted dying if the person is able to—
  - (a) understand the information relevant to the decision relating to access to voluntary assisted dying and the effect of the decision; and
  - (b) retain that information to the extent necessary to make the decision; and

- (c) use or weigh that information as part of the process of making the decision; and
  - (d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.
- (2) For the purposes of subsection (1), a person is presumed to have decision-making capacity unless there is evidence to the contrary.

## **8 Definitions**

The dictionary in Schedule 1 defines particular words used in this Act.

# **Part 2 Eligibility and requests for access to voluntary assisted dying**

## **Division 1 Eligibility for access to voluntary assisted dying**

## **9 Eligibility criteria**

For a person to be eligible for access to voluntary assisted dying—

- (a) the person must be aged 18 years or more; and
- (b) the person must—
  - (i) be an Australian citizen or permanent resident; and
  - (ii) be ordinarily resident in [State]; and
- (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
- (d) the person's decision to access voluntary assisted dying must be—
  - (i) enduring;
  - (ii) made voluntarily and without coercion; and
- (e) the person must be diagnosed with a medical condition that—
  - (i) is incurable; and
  - (ii) is advanced, progressive and will cause death; and
  - (iii) is causing intolerable and enduring suffering.

## **10 Clarification of eligibility criteria**

- (1) Whether a person's medical condition will cause the person's death is to be determined by reference to available medical treatment that is acceptable to the person.
- (2) For the purposes of subsection 9(e)(iii)—
  - (a) whether suffering is intolerable is to be determined by the person requesting access to voluntary assisted dying;
  - (b) suffering caused by a person's medical condition includes suffering caused by treatment provided for that medical condition; and
  - (c) suffering includes physical, psychological and existential suffering.

## **Division 2 Requests for access to voluntary assisted dying**

### **11 A person may make a first request**

- (1) A person may make a request to a registered medical practitioner for access to voluntary assisted dying (a *first request*).
- (2) A person's first request for access to voluntary assisted dying must be—
  - (a) clear and unambiguous; and
  - (b) made by the person personally.
- (3) The person may make the first request verbally or by gestures or other means of communication available to the person.

## **Part 3 Assessment of eligibility for access to voluntary assisted dying**

### **Division 1 Two registered medical practitioners to assess eligibility**

#### **12 Two registered medical practitioners to assess eligibility**

- (1) A person may access voluntary assisted dying only if two registered medical practitioners (a *first medical practitioner* and a *second medical practitioner*) assess the person as eligible for access to voluntary assisted dying.
- (2) The first medical practitioner and a second medical practitioner must be independent of each other.

- (3) For the purposes of subsection (2), the first medical practitioner and a second medical practitioner will not be independent of each other if—
  - (a) they are family members; or
  - (b) one medical practitioner is employed by or working under the supervision of the other medical practitioner.

### **13 Qualifications and experience of first and second medical practitioners**

- (1) Each of the first medical practitioner and second medical practitioner must—
  - (a) hold a fellowship with a specialist medical college; or
  - (b) be a vocationally registered general practitioner.
- (2) Either the first medical practitioner or each second medical practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).
- (3) Either the first medical practitioner or each second medical practitioner must have relevant experience in treating or managing the medical condition expected to cause the death of the person being assessed.

### **14 Approved training**

The first medical practitioner and a second medical practitioner must not commence their assessment for eligibility for access to voluntary assisted dying unless that practitioner has completed approved assessment training.

## **Division 2 Assessment by first medical practitioner**

### **15 First medical practitioner may undertake first assessment**

- (1) A registered medical practitioner (the *first medical practitioner*) who receives a first request from a person may undertake a *first assessment*.
- (2) The first assessment requires an examination of the person and a review of their relevant medical records.

**16 First assessment**

When undertaking a first assessment, the first medical practitioner must assess whether the person requesting access to voluntary assisted dying meets the eligibility criteria.

**17 Further expertise required for assessment**

- (1) If the first medical practitioner is unable to determine whether a person requesting access to voluntary assisted dying meets one or more of the eligibility criteria, they must refer the person to a registered health practitioner or health practitioners with appropriate skills and training.

*Example—*

A first medical practitioner who is unable to determine whether a person has capacity in relation to voluntary assisted dying must refer the person to a registered health practitioner with expertise to undertake that assessment. This could be, for example, a psychiatrist or geriatrician.

- (2) If the first medical practitioner refers the person to a registered health practitioner under subsection (1), the first medical practitioner may adopt the determination of the registered health practitioner in relation to the matter in respect of which the person was referred.

**18 Information to be provided if first medical practitioner assesses person as meeting eligibility criteria**

- (1) If the first medical practitioner is satisfied that the person requesting access to voluntary assisted dying meets all the eligibility criteria, the first medical practitioner must inform the person about the following matters—
  - (a) the person's diagnosis and prognosis;
  - (b) the treatment options available to the person and the likely outcomes of that treatment;
  - (c) palliative care options available to the person and the likely outcomes of that care;
  - (d) the potential risks of taking voluntary assisted dying medication or having it administered;
  - (e) that the expected outcome of taking voluntary assisted dying medication or having it administered referred to in paragraph (d) is death; and
  - (f) that the person may decide at any time not to continue with their request for access to voluntary assisted dying.

- (2) The first medical practitioner must also encourage the person to inform their family and other treating registered medical practitioners of the person's request for access to voluntary assisted dying.
- (3) Nothing in this section affects any duty a registered medical practitioner has at common law or under any other enactment.

## **19 Referral to second medical practitioner**

If the first medical practitioner is satisfied that the person—

- (a) meets the eligibility criteria; and
  - (b) understands the information required to be provided under section 18,
- the first medical practitioner must refer the person to a second medical practitioner for a second assessment.

## **Division 3 Assessment by second medical practitioner**

### **20 Second medical practitioner may undertake second assessment**

- (1) A registered medical practitioner (a *second medical practitioner*) who receives a referral from the first medical practitioner may undertake a *second assessment*.
- (2) A second assessment requires an examination of the person and a review of their relevant medical records.

### **21 Second assessment**

When undertaking a second assessment, a second medical practitioner must assess whether the person requesting access to voluntary assisted dying meets the eligibility criteria.

### **22 Further expertise required for assessment**

- (1) If a second medical practitioner is unable to determine whether a person requesting access to voluntary assisted dying meets one or more of the eligibility criteria, they must refer the person to a registered health practitioner or health practitioners with appropriate skills and training.

*Example—*

A second medical practitioner who is unable to determine whether a person has capacity in relation to voluntary assisted dying must refer the person to a registered health practitioner with expertise to undertake that assessment. This could be, for example, a psychiatrist or geriatrician.

- (2) If a second medical practitioner refers the person to a registered health practitioner under subsection (1), the second medical practitioner may adopt the determination of the registered health practitioner in relation to the matter in respect of which the person was referred.

## **23 Information to be provided if second medical practitioner assesses person as meeting eligibility criteria**

- (1) If a second medical practitioner is satisfied that the person requesting access to voluntary assisted dying meets all the eligibility criteria, the second medical practitioner must inform the person about the following matters—
- (a) the person's diagnosis and prognosis;
  - (b) the treatment options available to the person and the likely outcomes of that treatment;
  - (c) palliative care options available to the person and the likely outcomes of that care;
  - (d) the potential risks of taking voluntary assisted dying medication or having it administered;
  - (e) that the expected outcome of taking voluntary assisted dying medication or having it administered referred to in paragraph (d) is death; and
  - (f) that the person may decide at any time not to continue with their request for access to voluntary assisted dying.
- (2) Nothing in this section affects any duty a registered medical practitioner has at common law or under any other enactment.

## **24 Outcome of first and second assessments**

- (1) If the first medical practitioner and a second medical practitioner are satisfied that the person—
- (a) meets the eligibility criteria; and
  - (b) understands the information required to be provided under sections 18 and 23,
- the person is eligible for access to voluntary assisted dying.
- (2) If the first medical practitioner assesses a person as eligible for access to voluntary assisted dying but a second medical practitioner assesses that person



as not eligible for access to voluntary assisted dying, the first medical practitioner may refer the person to another registered medical practitioner for a further second assessment.

## **25 First medical practitioner report to Board about eligibility determination**

- (1) The first medical practitioner must, within 14 days of an *eligibility determination* being made in relation to a person, give the Board a report about a person's eligibility determination in the approved form.
- (2) The report must include a copy of the following—
  - (a) a record of the first request;
  - (b) the first assessment report;
  - (c) any second assessment report; and
  - (d) any other information required by regulation.
- (3) For the purposes of this section, an eligibility determination means a determination by the first medical practitioner that—
  - (a) a person is eligible for access to voluntary assisted dying in accordance with subsection 24(1); or
  - (b) a person is not eligible for access to voluntary assisted dying in accordance with subsection 24(1).

## **Division 4 Transfer of first medical practitioner's role**

### **26 Transfer of first medical practitioner's role**

- (1) The first medical practitioner for a person may transfer the role of first medical practitioner to another registered medical practitioner at—
  - (a) the request of the person; or
  - (b) the first medical practitioner's own initiative.
- (2) The first medical practitioner for a person may transfer the role of the first medical practitioner to a second medical practitioner for the person if the second medical practitioner has assessed the person as eligible for access to voluntary assisted dying

*Note—*

The first and second medical practitioners' assessments that the person is eligible for access to voluntary assisted dying remain valid despite this referral and so the person will have the two assessments as required under this Act. A second medical practitioner, who has already conducted their assessment, will become the first medical practitioner who will supervise the person's voluntary assisted dying.

- (3) The first medical practitioner for a person may also transfer the role of the first medical practitioner to a registered medical practitioner other than a second medical practitioner.
- (4) A transfer of the role of the first medical practitioner under subsection (3) can take effect only if the new first medical practitioner has assessed the person as eligible for access to voluntary assisted dying, having conducted their own assessment in accordance with sections 15 to 18.

*Note—*

The purpose of this subsection is to ensure that the first medical practitioner has always undertaken their own eligibility assessment given that practitioner is supervising the person's voluntary assisted dying.

- (5) The person requesting access to voluntary assisted dying must agree to the role of the first medical practitioner being transferred to the other registered medical practitioner before that transfer can take effect.

## **Part 4                      Access to voluntary assisted dying**

### **Division 1                Second request for access to voluntary assisted dying**

#### **27        Person assessed as eligible for access to voluntary assisted dying may make second request**

- (1) A person assessed as eligible for access to voluntary assisted dying in accordance with subsection 24(1) may make a written request (a *second request*) requesting access to voluntary assisted dying.
- (2) The second request must—
  - (a) specify that the person—
    - (i) makes the declaration voluntarily and without coercion; and
    - (ii) understands the nature and the effect of the request the person is making; and
  - (b) be in writing and in the approved form;
  - (c) be signed by the person making the request in the presence of two witnesses and the first medical practitioner.
- (3) Despite subsection (2)(c), a person may sign a second request at the direction of the person making the request if—
  - (a) the person making the request is unable to sign the declaration; and

- (b) the person signing—
    - (i) is aged 18 years or more; and
    - (ii) is not a witness to the signing of the request.
- (4) A person who signs a written request on behalf of the person making the request must do so in that person's presence.
- (5) If a person makes a second request with the assistance of an interpreter, the interpreter must certify on the request that the interpreter provided a true and correct translation of any material translated.

## **28 Witness to making of second request**

- (1) A person is eligible to witness the making of a second request if the person is—
  - (a) aged 18 years or more; and
  - (b) not an ineligible witness.
- (2) A person is an ineligible witness for the purposes of a second request if the person—
  - (a) knows or believes that the person—
    - (i) is a beneficiary under a will of the person making the second request; or
    - (ii) may otherwise benefit financially or in any other material way from the death of the person making the second request; or
  - (b) is an owner of, or is responsible for the day-to-day operation of, any facility at which the person making the second request is receiving a health service, residential service or professional care service; or
  - (c) is directly involved in providing a health service, residential service or professional care service to the person making the second request.
- (3) Not more than one witness may be a family member of the person making the second request.

## **29 Certification of witness to signing of second request**

- (1) A witness who witnesses a person signing a second request must—
  - (a) certify in writing in the second request that—
    - (i) in the presence of the witness, the person making the second request appeared to voluntarily and without coercion sign the second request; and
    - (ii) at the time the person signed the second request, the person appeared

- to have decision-making capacity in relation to voluntary assisted dying; and
  - (iii) at the time the person signed the second request, the person appeared to understand the nature and effect of making the second request; and
  - (b) state that the witness is not knowingly an ineligible witness.
- (2) A witness who witnesses another person signing a second request on behalf of the person making it must—
- (a) certify in writing in the second request that—
    - (i) in the presence of the witness, the person making the second request appeared to voluntarily and without coercion direct the other person to sign the second request; and
    - (ii) the other person signed the second request in the presence of the person making the second request and the witness; and
    - (iii) at the time the other person signed the second request, the person making it appeared to have decision-making capacity in relation to voluntary assisted dying; and
    - (iv) at the time the other person signed the second request, the person making it appeared to understand the nature and effect of making the second request; and
  - (b) state that the witness is not knowingly an ineligible witness.
- (3) A certification and statement under subsection (1) or (2) must be signed by the witness making it in the presence of the first medical practitioner.

## Division 2 Final request for access to voluntary assisted dying

### 30 Person may make final request for access to voluntary assisted dying

- (1) A person may make a *final request* to the first medical practitioner for the person that the first medical practitioner provide access to voluntary assisted dying to the person if—
- (a) the person has made a second request in accordance with section 27;
  - (b) the person has decision-making capacity in relation to voluntary assisted dying;
  - (c) the person's request for access to voluntary assisted dying is made voluntarily and without coercion;
  - (d) the person's request for access to voluntary assisted dying is enduring; and
  - (e) the person understands that access to voluntary assisted dying will be provided immediately after the making of the final request.

- (2) The person's final request for access to voluntary assisted dying must be—
  - (a) clear and unambiguous; and
  - (b) made by the person personally.
- (3) The person may make the request verbally or by gestures or other means of communication available to the person.
- (4) A final request must be made in the presence of a witness.
- (5) The first medical practitioner must refuse to accept the person's final request if the first medical practitioner is not satisfied of any matter under subsection (1).

### **31 Nature of voluntary assisted dying in final request**

The person's final request must specify the nature of the voluntary assisted dying requested from the first medical practitioner, namely—

- (a) practitioner administration of voluntary assisted dying medication to the person; or
- (b) supervised self-administration by the person of voluntary assisted dying medication.

### **32 Witness to making of final request**

- (1) A person is eligible to witness the making of a final request if the person is—
  - (a) aged 18 years or more;
  - (b) not employed by or working under the supervision of the first medical practitioner; and
  - (c) not a family member of the first medical practitioner.
- (2) The witness who witnesses a person making a final request must certify in writing in the approved form that—
  - (a) the person at the time of making the final request appeared to have decision-making capacity in relation to voluntary assisted dying;
  - (b) the person in requesting access to voluntary assisted dying appeared to be acting voluntarily and without coercion; and
  - (c) the person's request to access voluntary assisted dying appeared to be enduring.

### **33 Timing of final request**

- (1) A person's final request must be made—
  - (a) subject to subsection (2), at least nine days after the day on which the person made the first request; and
  - (b) in any case, at least one day after the day on which the second assessment that assessed the person as eligible for access to voluntary assisted dying was completed.
- (2) Subsection (1)(a) does not apply if the first medical practitioner for the person considers that the person's death is likely to occur before the expiry of the time period specified in that subsection, and this is consistent with the prognosis of a second medical practitioner who conducted a second assessment for the person.
- (3) A person's final request must also be made immediately before the first medical practitioner provides access to voluntary assisted dying.

## **Division 3 First medical practitioner may provide access to voluntary assisted dying**

### **34 First medical practitioner may provide access to voluntary assisted dying**

Upon receiving the final request from a person, the first medical practitioner for that person may provide access to voluntary assisted dying to that person in accordance with the final request.

## **Division 4 Management of voluntary assisted dying medication**

### **35 Collection, storage and disposal of voluntary assisted dying medication**

The collection, storage and disposal of the voluntary assisted dying medication by the first medical practitioner must occur in accordance with the requirements set out in the regulations.

## **Division 5            Person may decide at any time not to take any further step in relation to access to voluntary assisted dying**

### **36      Person may decide at any time not to take any further step in relation to access to voluntary assisted dying**

- (1) A person requesting access to voluntary assisted dying may decide at any time not to take any further step in relation to access to voluntary assisted dying.
- (2) The person may express their decision verbally or by gestures or other means of communication available to the person.

## **Division 6            Reporting of voluntary assisted dying**

### **37      First medical practitioner report to Board about voluntary assisted dying**

- (1) The first medical practitioner must, within 14 days of providing access to voluntary assisted dying to a person, give the Board a report about the voluntary assisted dying in the approved form.
- (2) The report must include a copy of the following—
  - (a) a record of the first request;
  - (b) the first assessment report;
  - (c) any second assessment report;
  - (d) the second request;
  - (e) a record of the final request;
  - (f) the witness's certification of the final request; and
  - (g) any other information required by regulation.

## **Part 5                Participation in voluntary assisted dying is voluntary**

### **38      Registered health practitioners with conscientious objection**

- (1) A registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following—

- (a) provide information about voluntary assisted dying;
  - (b) participate in any part of the request and assessment process for voluntary assisted dying;
  - (c) supply, prescribe or administer voluntary assisted dying medication;
  - (d) be present during voluntary assisted dying.
- (2) A registered medical practitioner exercising a conscientious objection in accordance with subsection (1) must disclose the practitioner's conscientious objection to the person and offer to refer the person to another practitioner or entity in accordance with subsection (3).
- (3) If requested, the registered medical practitioner must refer the person, or transfer their care, to—
- (a) another registered medical practitioner who, in the referring registered medical practitioner's belief, does not have a conscientious objection to voluntary assisted dying; or
  - (b) an entity at or through which, in the referring registered medical practitioner's belief, the person will have access to another registered medical practitioner who does not have a conscientious objection to voluntary assisted dying.

*Note—*

Subsection (3)(b) provides for referral of a person requesting access to voluntary assisted dying to be to an entity through which the person will have access to another registered medical practitioner who does not have a conscientious objection to voluntary assisted dying. This would permit a registered medical practitioner to provide the person requesting access to voluntary assisted dying with contact details of an entity which can provide information that will facilitate access to voluntary assisted dying.

### **39 Entity may refuse access to voluntary assisted dying within its facility**

- (1) This section applies to an entity, other than a natural person, who provides a health service, residential service or professional care service.
- (2) An entity may refuse access to voluntary assisted dying, including assessments in relation to voluntary assisted dying, within its facility.
- (3) Where a person who requests access to voluntary assisted dying is being cared for or resides in a facility of an entity that refuses access to voluntary assisted dying within the facility, the entity must—
  - (a) inform the person of the entity's decision to refuse access to voluntary assisted dying within its facility;
  - (b) offer to arrange a transfer of the care or residence of the person to an entity at which, in the entity's belief, access to voluntary assisted dying can be



- provided by a registered medical practitioner who does not have a conscientious objection to voluntary assisted dying; and
- (c) take reasonable steps to facilitate that transfer.

## Part 6 Voluntary Assisted Dying Review Board

*This Part of the Bill is not outlined in detail because legislative provisions for statutory boards vary by jurisdiction. However, the model outlined in the Voluntary Assisted Dying Act 2017 (Vic) is generally supported. Specific matters that the Bill should address include:*

- *establishing the Voluntary Assisted Dying Review Board and its functions, along with the powers needed to undertake those functions;*
- *determining the composition of the Board and its procedures and staffing; and*
- *the Board's monitoring role.*

*In relation to the Board's monitoring role, this would need to be both for individual cases and the system as a whole. In terms of individual cases, the Board should conduct a post-hoc review of each case of voluntary assisted dying to ensure that it complied with the requirements of the Act and this duty should be specified in the Act. The Board's powers should include the ability to request further information beyond that provided by the first medical practitioner if it considers this necessary. If there are concerns about compliance, the Board should be empowered to refer that case to entities such as the police, the Coroner and the Australian Health Practitioner Regulation Agency.*

*The Board's monitoring role also requires oversight of the system as a whole to ensure that it is functioning as intended and to make recommendations for improvement where needed. To support this, the Board would collect and analyse data provided to it by registered medical practitioners in their reporting. It may also need to collect further information to undertake this overall monitoring role. This data (in de-identified form) should also be made publicly available for community scrutiny in the form of annual reports tabled in Parliament. The Board should also have power to undertake educational initiatives for registered health practitioners and the wider community to promote understanding of, and compliance with, the requirements of the Act.*

## **Part 7                      Protections from liability for acting in accordance with Act**

### **40      Protection from criminal liability of person who assists or facilitates request for or access to voluntary assisted dying**

A person who in good faith does something or fails to do something—

- (a) that assists or facilitates any other person who the person believes on reasonable grounds is requesting access to or is accessing voluntary assisted dying in accordance with this Act; and
- (b) that apart from this section, would constitute an offence at common law or under any other enactment—

does not commit the offence.

### **41      No liability for registered health practitioner who acts in accordance with Act**

- (1) A registered health practitioner who, in good faith and without negligence, acts under this Act believing on reasonable grounds that the act is in accordance with this Act is not in respect of that act—
  - (a) guilty of an offence; or
  - (b) liable for unprofessional conduct or professional misconduct; or
  - (c) liable in any civil proceeding; or
  - (d) liable for contravention of any code of conduct.
- (2) To remove any doubt, subsection (1) includes when a registered health practitioner exercises a conscientious objection to voluntary assisted dying provided that occurs in accordance with this Act.

### **42      No liability for registered health practitioner present after voluntary assisted dying medication administered**

- (1) A registered health practitioner who, in good faith, does not administer life saving or life sustaining medical treatment to a person who has not requested it, and believes on reasonable grounds that the person is dying after being administered or self-administering voluntary assisted dying medication in accordance with this Act, is not, in respect of that omission to act—
  - (a) guilty of an offence; or
  - (b) liable for unprofessional conduct or professional misconduct; or

- (c) liable in any civil proceeding; or
  - (d) liable for contravention of any code of conduct.
- (2) This section does not prevent a registered health practitioner from providing medical treatment for the purpose of ensuring the person's comfort.

**43 Section [insert number] of the [insert relevant criminal law Act or Code] does not apply**

Section [insert number] of the [insert relevant criminal law Act or Code] does not apply to a person who knows or believes on reasonable grounds that a person is accessing voluntary assisted dying in accordance with this Act.

*This provision is based on section 82 of the Voluntary Assisted Dying Act 2017 (Vic) which states that section 463B of the Crimes Act 1958 (Vic) does not apply. Section 463B justifies the use of force to prevent a suicide. This means that the proposed provision in this Bill will only be needed in jurisdictions where a provision like section 463B exists authorising the prevention of a suicide.*

## **Part 8 Offences**

*The approach to and wording of offence provisions varies by jurisdiction so the below are illustrative of the standard type of offences included in Voluntary Assisted Dying Bills. Other offences may be added or the below proposed offences modified depending on how the criminal law is regulated by jurisdiction.*

**44 Inducing another person to request access to voluntary assisted dying**

A person who, by dishonesty or undue influence, induces another to make a request for access to voluntary assisted dying is guilty of a crime.

Maximum penalty— [insert]

**45 Inducing another person to access voluntary assisted dying**

A person who, by dishonesty or undue influence, induces another to self-administer voluntary assisted dying medication or induces another to request

that a registered medical practitioner administer that medication is guilty of a crime.

Maximum penalty— [insert]

#### **46 False or misleading statements**

A person who knowingly makes a false or misleading statement in, or in relation to, a request for access to voluntary assisted dying is guilty of a crime.

Maximum penalty— [insert]

#### **47 Failing to report to Board**

A registered medical practitioner who fails to report to the Board as required by this Act is guilty of a crime.

Maximum penalty— [insert]

## **Part 9 Miscellaneous**

*The approach to the Miscellaneous Part of the Bill will also vary by jurisdiction. Specific matters that the Bill could or should address include:*

- *a requirement to review the Act's operation after 5 years;*
- *provisions regulating the use of interpreters;*
- *approval of training for registered medical practitioners by the relevant government department;*
- *confidentiality duties for those with access to personal information in the course of administering the Act;*
- *the recording of the death on the Register of Births, Deaths and Marriages;*
- *that the death is not a 'reportable death' for coronial investigation;*
- *the effect that the Act has on wills, insurance policies, contracts and other statutes;*
- *forfeiture provisions in relation to a person's estate where another person is found guilty of an offence under this Act; and*
- *the making of regulations under the Act.*

*Consequential or transitional provisions will also vary by jurisdiction and so have not been included in the Bill*

## Schedule 1                      Dictionary

*Only a limited number of important terms used in this Bill are defined below as jurisdictions vary in their approaches to definitions sections. Variability also arises because jurisdictions have:*

- *different acts interpretation legislation which can define commonly used legislative terms in different ways; and*
- *different local health legislation from which definitions for Voluntary Assisted Dying Bills are sometimes taken.*

***approved assessment training*** means training approved by the [insert relevant government department official] under section 14.

***Board*** means the Voluntary Assisted Dying Review Board.

***decision-making capacity*** has the meaning set out in section 7.

***eligibility criteria*** means the criteria set out in section 9 and clarified in section 10.

***eligibility determination*** has the meaning set out in section 25(3).

***family member*** of a person means the person's spouse or domestic partner, parent, grandparent, sibling, child or grandchild.

***final request*** means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 30.

***first assessment*** means an assessment undertaken in accordance with Part 3 Division 2.

***first medical practitioner*** means the registered medical practitioner—

- (a) who receives a first request from a person and undertakes a first assessment;
- or
- (b) to whom the role is transferred in accordance with section 26.

***first request*** means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 11.

***ineligible witness*** has the meaning set out in section 28(2).

***medical condition*** means a medical condition whether caused by disease, illness or injury.

***practitioner administration*** has the meaning set out in section 6.

***professional care services*** means any of the following provided to another person under a contract of employment or a contract for services—

- (a) support or assistance;
- (b) special or personal care;
- (c) a disability service within the meaning of [the Disability Act].

***registered health practitioner*** means a person registered under the *Health Practitioner Regulation National Law* to practise a health profession other than as a student.

***registered medical practitioner*** means a person registered under the *Health Practitioner Regulation National Law* to practise in the medical profession other than as a student.

***request and assessment process*** means, in respect of a person, the making or the conducting of the following—

- (a) a first request;
- (b) a first assessment;
- (c) a second assessment;
- (d) a second request;
- (e) a final request.

***second assessment*** means an assessment undertaken in accordance with Part 3 Division 3.

***second medical practitioner*** means a registered medical practitioner who receives a referral from the first medical practitioner under section 19 and undertakes a second assessment.

***second request*** means a request from a person for access to voluntary assisted dying to a registered medical practitioner in accordance with section 27.

***self-administration*** has the meaning set out in section 6.

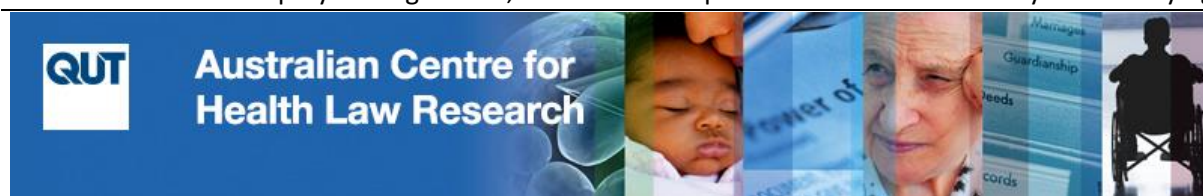
***special or personal care*** means—

- (a) assistance with one or more of the following—
  - (i) bathing, showering or personal hygiene;

- (ii) toileting;
- (iii) dressing or undressing;
- (iv) meals; or
- (b) assistance for persons with mobility problems; or
- (c) assistance for persons who are mobile but require some form supervision or assistance; or
- (d) assistance or supervision in administering medicine; or
- (e) the provision of substantial emotional support.

***voluntary assisted dying*** has the meaning set out in section 6.

***voluntary assisted dying medication*** means a poison or controlled substance or a drug of dependence prescribed by the first medical practitioner for the purpose of causing a person's death.



## Explanatory Notes for Voluntary Assisted Dying Bill 2019

These Explanatory Notes explain the approach taken to drafting the Voluntary Assisted Dying Bill 2019. This includes identifying the values and principles that underpin the Bill, the major policy positions taken, and the approach adopted in relation to drafting style. These Notes are different from the traditional Explanatory Notes which usually explain each provision sequentially. While some specific provisions are explained further below, this document is primarily aimed at explaining the Bill at a more global level. A diagram providing an overview of the process proposed by the Bill for accessing voluntary assisted dying is included in the Appendix.

### Values underpinning the Bill

The values underpinning the design of this Bill are those outlined and explained in the book chapter 'Assisted Dying in Australia: A Values-based Model for Reform' in the book *Tensions and Traumas in Health Law*.<sup>1</sup> Those values are:

- Life;
- Autonomy;
- Freedom of conscience;
- Equality;
- Rule of law;
- Protecting the vulnerable; and
- Reducing human suffering.

Added to this list which underpinned the design of the Bill is the concept of safe and high-quality care.<sup>2</sup> The proposed model situates voluntary assisted dying as part of health care and as being provided within the health system. Accordingly, voluntary assisted dying must be provided in a way that is safe and of high-quality like all other health care.

<sup>1</sup> Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

<sup>2</sup> For a discussion of the elements of safe and high-quality end of life care, see Australian Commission on Safety and Quality in Health Care, *National consensus statement: Essential elements for safe and high-quality end-of-life care*, available at: <https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf>.



## Position on key overarching policy issues

Many of the key policy decisions are explained in the book chapter ‘A Values-based Model for Reform’,<sup>3</sup> and so will not be repeated at length below. However, drafting a Bill necessarily requires more detailed decisions to be made about how a voluntary assisted dying system should operate and some of these other overarching positions will be briefly explained.

- Clause 6 outlines that voluntary assisted dying includes both of what has historically been called voluntary euthanasia (called practitioner administration in the Bill) and physician assisted suicide (called self-administration in the Bill). We do not endorse the Victorian approach of having self-administration as the default and primary method of voluntary assisted dying. Providing a choice of practitioner administration and self-administration for a person requesting access to voluntary assisted dying promotes the value of autonomy. Where both options are available internationally, people overwhelmingly choose practitioner administration.<sup>4</sup> Also, while the evidence base is limited, that which exists suggests that practitioner administration is safer than self-administration with fewer complications.<sup>5</sup>
- Clause 6 also explains that voluntary assisted dying must occur under medical supervision. This will clearly occur with practitioner administration when the registered medical practitioner administers the voluntary assisted dying medication. In relation to self-administration, being under the supervision of a registered medical practitioner means that the registered medical practitioner will be present while the person self-administers the voluntary assisted dying medication. We anticipate this could be done unobtrusively by the medical practitioner so as to respect the person’s wishes about how their death occurs.

We acknowledge that such an approach has disadvantages, including: access implications for persons living in rural and remote areas;<sup>6</sup> burdens on medical practitioners to supervise voluntary assisted dying; and some limits on a person’s autonomy in terms of timing of their death and who is present. In addition to there

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<sup>3</sup> Lindy Willmott and Ben White, ‘Assisted Dying in Australia: A Values-based Model for Reform’ in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

<sup>4</sup> For example, in the Netherlands in 2017, of 6585 cases reported to Euthanasia Review Committees, 6306 were of euthanasia, 250 were of assisted suicide, and 29 cases involved a combination of both: Regional Euthanasia Review Committees, *Annual Report 2017* (March 2018) 10. In Canada, drawing on the last two federal government reports covering the period from 1 January 2017 to 31 October 2018, of the 4575 medically assisted deaths reported, only 2 were self-administered: Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (April 2019) 5 (note: this does not include data from some provinces as outlined in the report).

<sup>5</sup> Ezekiel Emanuel, Bregje Onwuteaka-Philipsen, John Urwin and Joachim Cohen, ‘Attitudes and practices of euthanasia and physician assisted suicide in the United States, Canada and Europe’ (2016) 316(1) *Journal of American Medical Association* 79, 86.

<sup>6</sup> While we have not proposed this in the Bill, permitting nurse practitioners to provide voluntary assisted dying has been one response to address access issues in Canada.

being ways to address these concerns, our view is that the policy benefits of the proposed approach outweigh these disadvantages for three main reasons:

1. These disadvantages only arise in relation to self-administration as by definition practitioner administration is always medically supervised. Given that where choice is available, practitioner administration is overwhelmingly chosen, these disadvantages are only likely to arise in the small number of voluntary assisted dying cases where a person specifically wants to self-administer.
  2. The safety and quality of voluntary assisted dying for the person should be prioritised. This is enhanced by medical supervision.
  3. The voluntary assisted dying medication will be safely managed as it will always be in the possession or under the direct supervision of a registered medical practitioner. This also means that complex provisions relating to the medication's collection, storage and disposal, such as those in the *Voluntary Assisted Dying Act 2017* (Vic), are not required. Registered medical practitioners are subject to existing regulations in relation to the dangerous medications and the Bill provides scope for regulations to address this further if needed.
- The starting point for drafting the eligibility criteria in clause 9 was broadly the approach in the *Voluntary Assisted Dying Act 2017* (Vic). While there may be cases that many regard as appropriate to allow access to voluntary assisted dying which may fall outside that legislation, eligibility criteria necessarily involve a basis for determining access and the Victorian model is a defensible approach. We have, however, departed from this model in three important respects.

The first is that although the Bill requires a person to have a medical condition that will cause their death, it does not impose a time limit within which a person is expected to die. We adopt this approach because a time limit is arbitrary. While a secondary consideration, not imposing a time limit avoids a registered medical practitioner from having to engage in the difficult task of determining prognosis and timing of death. The Western Australian Joint Select Committee on End of Life Choices has also expressed reservations about requiring a specified time period until expected death.<sup>7</sup>

The second difference is that we have not required that a person be *both* (a) ordinarily resident in a State *and* (b) ordinarily resident in a State for a period of at least 12 months prior to a first request. The Bill only requires (a) as this is sufficient to achieve the policy goal of preventing non-residents having access to voluntary assisted dying in another State. The additional time-based requirement of (b) creates a further hurdle to access voluntary assisted dying for otherwise eligible persons and is unnecessary to prevent cross-border requests.

<sup>7</sup> Joint Select Committee on End of Life Choices, 40<sup>th</sup> Parliament of Western Australia, *My Life, My Choice* (Report 1, August 2018) 199, 213.

The third difference is in relation to the suffering requirement. To be eligible under the Bill, the medical condition must be causing the person ‘intolerable and enduring’ suffering. This is a higher threshold than under the Victorian Act but is consistent with some international approaches.

- Clauses 38 and 39 protect conscientious objection by registered health practitioners in relation to voluntary assisted dying and the ability of entities providing care and residential services to refuse access to voluntary assisted dying within their facilities. However, both provisions also create mechanisms that reflect the balance normally struck in medicine that respects conscience but values autonomy and equality in ensuring a person still has effective access to a lawful health service. As outlined in the Note at the end of Clause 38, subclause (3) is drafted sufficiently broadly to allow the person requesting access to voluntary assisted dying to be provided with contact details of an entity which can provide information that will facilitate that access to voluntary assisted dying. This provides an option that some registered medical practitioners might regard as morally preferable. This would, however, be dependent on the existence of an entity to provide such information enabling access to voluntary assisted dying.

## Approach to drafting

### Other legislation and Bills consulted

We adopted or adapted the drafting of the *Voluntary Assisted Dying Act 2017* (Vic) where our policy position was the same or similar, recognising that this Act had been passed already by an Australian Parliament. This includes retaining some wording that may otherwise be regarded as complex.

We also consulted a range of other sources in drafting this Bill. They include other recent Australian Bills<sup>8</sup> that were close to passing through the relevant Chamber in which they were introduced such as the Voluntary Assisted Dying Bill 2013 (Tas), the Death with Dignity Bill 2016 (SA) and the Voluntary Assisted Dying Bill 2017 (NSW) as well as the *Rights of the Terminally Ill Act 1995* (NT) which was in force for a 9 month period in the mid-1990s. Legislation regulating voluntary assisted dying overseas was also consulted but we note that drafting styles are quite different in some of these countries, especially in European civil law jurisdictions.

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<sup>8</sup> See also the account of Australian Bills in Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, ‘(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics’ (2016) 39(1) *University of New South Wales Law Journal* 1, and updated in Ben White and Lindy Willmott, ‘Future of assisted dying reform in Australia’ (2018) 42 *Australian Health Review* 616.

## **Acknowledging jurisdictional drafting styles and different laws**

We recognise that legislative drafting is a specific skill and that different jurisdictions have different drafting conventions. Accordingly, our approach in drafting this Bill was to make the policy position clear, being aware that it would be revised in line with local drafting guidelines. We also acknowledge that there are alternative drafting techniques to present the policy framework proposed in this Bill.

## **Preference for brevity**

Our view is that the Bill should be as short and simple as practicable. A decision was made therefore that the Bill should focus on establishing the wider legal framework for voluntary assisted dying, but not be the source of detailed procedural steps about how it is provided. In part, this is because unnecessary length and complexity can impede a clear explanation on the proposed policy position.

However, we favour this approach predominantly because of our view about the appropriate role of legislation within a regulatory framework. Voluntary assisted dying should be governed by a suite of regulatory tools including legislation, regulations, policies and guidelines. We consider the appropriate function for legislation is to establish the legal framework for these decisions, but that the detailed procedural guidance is better addressed in regulations, policies and guidelines.

This is one way in which we have departed from the *Voluntary Assisted Dying Act 2017* (Vic), which is very prescriptive in its approach. We also note this means that omitting a provision in the Victorian Act from our Bill does not mean we consider that the relevant issue should not be regulated. It may simply reflect that such a matter is more appropriately dealt with in regulations or policies and guidelines. It may also be that some matters are already adequately dealt with either by existing legislation or established protocols in the health system within which voluntary assisted dying will occur.

## **Specific policy issues explained**

Earlier in these Explanatory Notes, some key overarching policy issues were explained. Here we address a series of smaller and specific policy decisions that have been made in the course of drafting the Bill.

Some of the below discussion explains why certain safeguards in the *Voluntary Assisted Dying Act 2017* (Vic) have not been adopted. A global point to make here is that the Victorian Act is very unusual in its detail and complexity when compared with international models, the *Rights of the Terminally Ill Act 1997* (NT) and the other Australian Bills consulted. As mentioned above, some of this detailed procedural guidance in the Victorian Act is better placed in regulations, policies or guidelines.

Further, some of the Victorian Act's safeguards do not add substantive value to safeguarding vulnerable persons, may impose undue burden on persons requesting

access to voluntary assisted dying and the registered health practitioners assisting them, and are inconsistent with the overarching values that we consider should guide the law in this area. For these reasons, we concluded that their inclusion in the Bill was not justified. Instead, we have focused on safeguards that we consider are needed to ensure the voluntary assisted dying system operates as intended, and have drawn on approaches in other Australian Bills and international models.

- The Bill does not contain a prohibition on registered health practitioners initiating discussions about voluntary assisted dying with their patients as imposed by section 8 of the *Voluntary Assisted Dying Act 2017* (Vic). For reasons expanded on elsewhere,<sup>9</sup> this impedes the frank discussions needed for safe and high-quality end-of-life care. This also reflects the approach taken by the Western Australian Joint Select Committee on End of Life Choices.<sup>10</sup>
- The Bill does not contain a requirement to obtain a permit from the relevant government department prior to providing access to voluntary assisted dying as required by Part 4 of the *Voluntary Assisted Dying Act 2017* (Vic). This requirement is unnecessarily bureaucratic, delays access to voluntary assisted dying, and is of limited utility as a safeguard as it is only likely to be a review of the relevant documentation. The Western Australian Joint Select Committee on End of Life Choices has also recommended against requiring a permit.<sup>11</sup>
- The wording of clause 13(3) of the Bill prescribing the required qualifications and experience of one of the registered medical practitioners is intentionally different from section 10(3) of the *Voluntary Assisted Dying Act 2017* (Vic). Under the Victorian Act, one of the registered medical practitioners must be a *medical specialist in the person's disease, illness or medical condition* (emphasis added). The interpretation of this provision is that General Practitioners and Palliative Care Physicians would not qualify as having this 'expertise and experience'. The proposed wording in this Bill is instead that either of the registered medical practitioners 'must have relevant experience in treating or managing the medical condition expected to cause the death of the person being assessed'. While retaining the same policy goal that at least one of the registered medical practitioners has particular experience with the person's medical condition, this wider wording is intended to reflect that General Practitioners and Palliative Care Physicians may have such experience.

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<sup>9</sup> See for example, Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26 *Journal of Law and Medicine* 454.

<sup>10</sup> Joint Select Committee on End of Life Choices, 40<sup>th</sup> Parliament of Western Australia, *My Life, My Choice* (Report 1, August 2018) 199-200. Note also that the Ministerial Expert Panel on Voluntary Assisted Dying raises this as an issue for consideration in its discussion paper: Ministerial Expert Panel on Voluntary Assisted Dying, *Discussion Paper*, Government of Western Australia (2019) 23.

<sup>11</sup> Joint Select Committee on End of Life Choices, 40<sup>th</sup> Parliament of Western Australia, *My Life, My Choice* (Report 1, August 2018) 201. Note also that the Ministerial Expert Panel on Voluntary Assisted Dying raises this as an issue for consideration in its discussion paper: Ministerial Expert Panel on Voluntary Assisted Dying, *Discussion Paper*, Government of Western Australia (2019) 35.

- This Bill does not contain additional provisions in relation to notifications to the Australian Health Practitioner Regulation Agency as the existing law requiring mandatory notifications and permitting voluntary notifications is considered to be adequate.<sup>12</sup>
- This Bill does not include specific provisions about intervention in voluntary assisted dying decisions by the courts or tribunals. This is because these are primarily clinical matters for the first and second medical practitioner to assess. An exception is in relation to decision-making capacity. Depending on local legislation, guardianship or civil and administrative tribunals may have jurisdiction to adjudicate a person's decision-making capacity, and if not, it may be appropriate to specifically grant such jurisdiction to a tribunal in relation to capacity. Finally, should exceptional circumstances warrant wider judicial scrutiny, Supreme Courts have been willing to consider end-of-life issues in appropriate circumstances when approached for guidance.<sup>13</sup>
- Clause 2 of the Bill requires an 18-month delay before the Act comes into force to permit time for implementation as has occurred in Victoria.
- Clause 5 sets out the Bill's principles, which are based on the values outlined above. We note for completeness, however, that the value of respecting the rule of law does not appear in this list of principles. While it remains an appropriate value to inform the design and implementation of voluntary assisted dying laws, it is not as relevant in guiding a person or other entity who is exercising a power or performing a function or duty under the Act.
- Definitions of capacity or decision-making capacity (defined in clause 7 of the Bill) vary by jurisdiction and so the Bill's approach may need to be adjusted to reflect this. For example, Queensland includes the requirement for the person to have 'freely and voluntarily' made the decision as part of the capacity test in its guardianship legislation.<sup>14</sup> In the proposed model, this requirement is addressed as part of the eligibility criteria.
- Clause 33(3) contains the safeguard that a person's final request for voluntary assisted dying must occur immediately prior to access. This ensures it is a contemporaneous request by a person with capacity who is acting freely and voluntarily in requesting access to voluntary assisted dying.

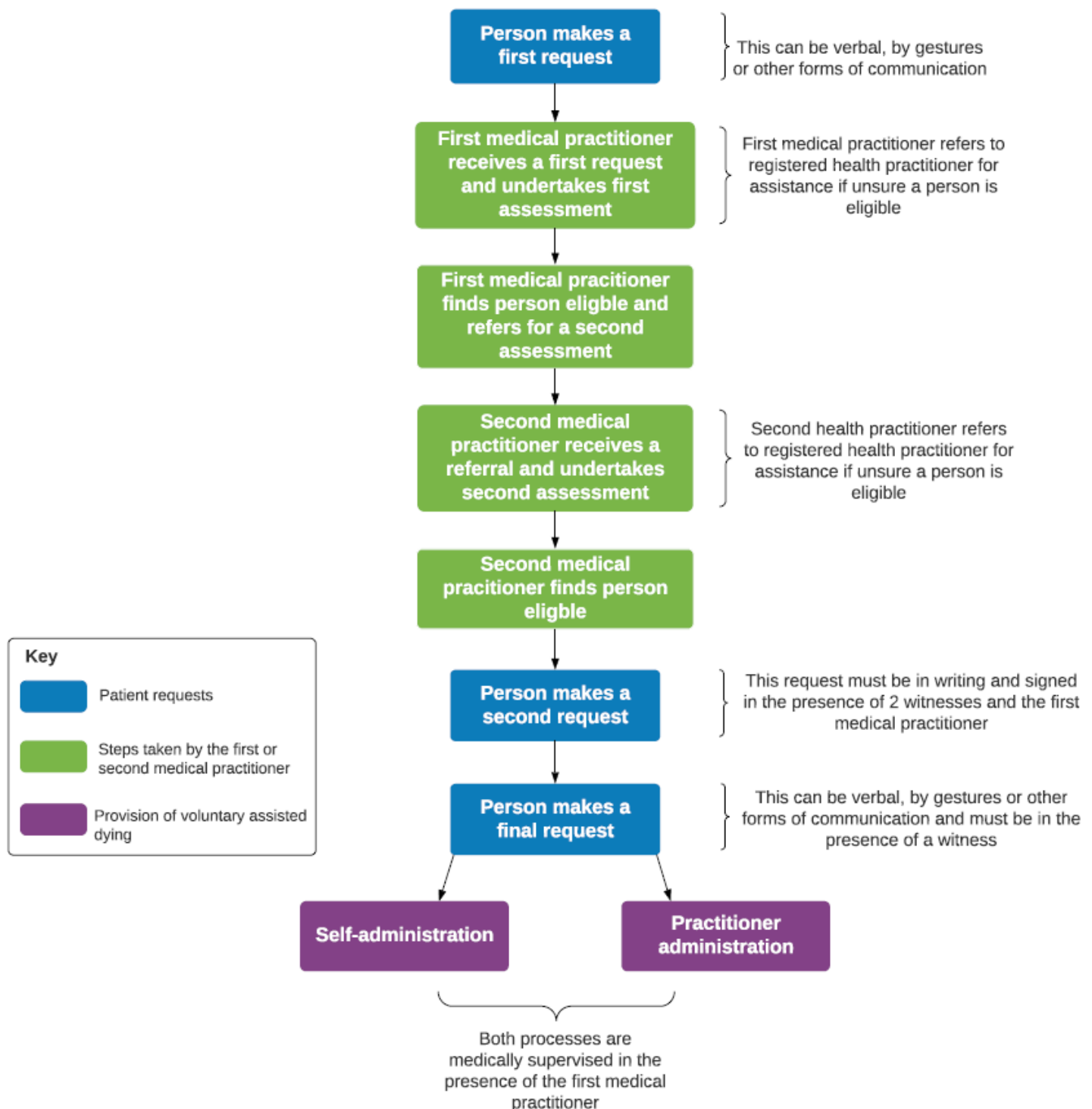
<sup>12</sup> See for example part 8, divisions 2 and 3 of the *Health Practitioner Regulation National Law* (Qld). Note that the provisions in part 7, division 1 of the *Voluntary Assisted Dying Act 2017* (Vic) closely resemble those in part 8, divisions 2 and 3 in the *Health Practitioner Regulation National Law (Victoria) Act 2009* (Vic).

<sup>13</sup> See for example, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *H Ltd v J* (2010) 107 SASR 352.

<sup>14</sup> See *Guardianship and Administration Act 2000* (Qld) sch 4 (definition of 'capacity') and *Powers of Attorney Act 1998* (Qld) sch 3 (definition of 'capacity').

- As noted in the Bill, the criminal law of each jurisdiction varies and accordingly, Parts 7 and 8 will need to be considered in light of local laws. This would include determining the appropriate reach of existing criminal law offences, such as those relating to assisting suicide, and how they would interact with the Bill including its proposed protections from criminal liability.

## Appendix: Short overview of the process to access voluntary assisted dying in the Voluntary Assisted Dying Bill 2019





## Dissenting Report

DISSENTING REPORT  
VOLUNTARY ASSISTED DYING  
BY LNP MEMBERS OF THE COMMITTEE

CONCLUSION

The LNP members of the Committee dissent from the Report of the majority on numerous grounds. Critical was the failure to discuss Palliative Care with Voluntary Assisted Dying. No decision should be made whilst the issue of Palliative Care is so poorly funded, understood, barely accessible and neglected.

Additionally, the logic relied on by the majority is flawed, or not supported by evidence.

The LNP Members accept this is a very emotional question and agree there are deeply held beliefs. The conclusion we have come to is not to be seen as belittling people's beliefs, rather a criticism of a flawed process.

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### REPORTING ON V.A.D. ALONE

1. The terms of the reference provided to the Committee consisted of a number of inquiries: aged care, end-of-life, palliative care, and voluntary assisted dying (V.A.D.).
2. Concerningly, the Committee determined to separate the Reports:
  - a) Into V.A.D, (Report)
  - b) The second dealing with aged care, end-of-life care and palliative care.
3. Nowhere in the Report, tabled in the House, is there an explanation given for this. Nowhere is there an analysis of why the Committee chose arbitrarily to separate the Reports.
4. One could argue the V.A.D. Report had a predetermined outcome. If the Report provided a combined assessment, as between palliative care and V.A.D., the basis on which people could assess whether or not V.A.D. should be legislated, would be a fully informed playing field.
5. It could be argued that this is a fundamental flaw in the report again indicating a predetermined outcome with a single focus on V.A.D. and taking the emphasis off an equally important question, i.e., the value of palliative care in today's modern society and its relationship to V.A.D.

### VOLUNTARY ASSISTED DYING VERSUS PALLIATIVE CARE

6. As we stated earlier it is regrettable, to say the least, that palliative care is not being debated in this document with V.A.D. We believe it is symptomatic of a process that is flawed, and it could be argued that the Committee had predetermined an outcome prior to the process being completed and all relevant evidence being properly assessed.
7. The report does not contain an analysis or "Committee comment" that looks at this question. It simply deals with V.A.D. in isolation.
8. The report could be read to advocate V.A.D. over palliative care, and that is a great travesty. The people of Queensland have the right to alternates properly debated in the one document. Only when both matters are adequately considered should a determination be made.
9. As was stated in the contribution made by Mr Robert Clark MP of the Legislative Assembly on 28 November 2017 on the Victorian Bill:

"On a conservative estimate more than 10 000 Victorians are dying in needless pain each year because they cannot get

palliative care. While those who urge this bill upon us argue passionately that voluntary assisted dying (VAD) is needed to end the suffering of 150 Victorians a year, they intend to leave more than 60 times that number to continue to die in pain...Whether you support VAD in principle or not, we should all be agreed that no Victorian should be forced to choose VAD because they cannot get access to palliative care that would ease their pain.” We accept that Palliative Care is the subject of an earlier report but its separation from V.A.D. should not have occurred.

10. In Queensland, Palliative Care Queensland state: “Each year more than 30,000 Queenslanders die. 75% of those could benefit from palliative care which is recognised internationally as a Human Right.” Further they state: “It is estimated that if Voluntary Assisted Dying became legal in Queensland, less than 2% of the population could be eligible, but 100% of the population could benefit from quality palliative care.” (“2020-21 Pre Budget-Submission Queensland” by Palliative Care Queensland).
11. The Report at pages 107 – 112 discusses palliative care and V.A.D. but no discussion occurs as to why palliative care is not part of this report.
12. Should Palliative Care and V.A.D. be discussed in the one document? One such comment occurred in the in the Hearing in Brisbane on 5 July where both Professors Willmott and White were asked: “Does that mean that when this committee goes to discuss the issues of Voluntary Assisted Dying and we consider a potential recommendation that a Bill be prepared, that discussion takes into account a discussion of palliative care needs as well.” Both answered “Yes.”

### ETHICAL QUESTIONS

13. One question that does need to be dealt with is how as a society we “value life” and whether or not we consider it to be “sacred”, not necessarily meant in the religious sense, and whether there should exist a right to end a life based upon a principle such as V.A.D..
14. It was often stated that an individual has autonomy to determine when they should die, i.e., “my life, my choice”. That statement is straightforward in nature but is it correct or should it be measured against society’s morés and other principles? Does society itself has a role in deciding society’s mores?

15. The House of Lords, in its “Assisted Dying for the Terminally Ill Bill—First Report” on autonomy, stated:  
“We are agreed that patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community to what a patient can require his or her doctor to do.”
16. The House then went on to say:  
“There is not consensus on where those limits should be.”
17. The evidence before the Committee was from both sides of the debate but again no Committee comment exists to explain why the autonomy of a person overrides the interests of the wider community.
18. Continued in Pages 38 to 63 is an overview of comments by numerous organisations, individuals and people covering both sides of the debate. Yet there is no Committee comment or discussion about their issue in line with the House of Lords’ comments.

#### NATIONAL CORONIAL INFORMATION SYSTEM

19. On page 11 of the Committee’s Report is a table drawn from the National Coronial Information System and comments on figures presented to the Committee which says that between 1 January 2016 to 31 December 2018, 168 Queenslanders took their own lives while suffering from “a terminal or debilitating physical condition”.
20. But it must be stressed the Report does not state that either the author of the document or a representative appeared before the Committee and be questioned about it. If this is correct the integrity of the document was never tested. It is a fundamental obligation of any committee to test evidence put before it. This did not occur based on the contents of the Report.
21. In Victoria, the Coroner dealing with the Victorian Bill provided a submission dated 26 August 2015 which stated that 240 Victorians had taken their own lives whilst experiencing “irreversible physical decline in physical health” due to “disease” or “injury”.
22. In its “Further Submission” dated 20 May 2016 to the Standing Committee on Legal and Social Issues the Coroner’s Court of Victoria, the Court made this comment in relation to that document:  
  
“—analysis of the individual deaths in the course of this study showed they were highly disparate in terms of the types of disease and injury that led to irreversible deterioration and physical health, the delay between onset of deterioration and

suicide, the nature of the symptoms associated with the deterioration and each individual's subject experience of and response to the deterioration.

The CPU therefore has noted the possibility that ultimately the deaths reported here will come to be understood as representing a range of different suicide phenomena and that grouping them together in this study was not ultimately a useful exercise."

23. The Coroner's Court in Victoria ultimately determined the "facts" and "figures" presented were not as black and white as first determined. Assessment of data presented in Queensland should have occurred.
24. As no assessment of the Queensland report was undertaken, it is important to consider a number of questions, including:
  - a) What proportion of patients had documented evidence of engagement with palliative care services;
  - b) Of the number who did take their own lives, how many had a pre-existing mental illness; and
  - c) Of those who took their own lives, how many had received psychiatric treatment prior to their cancer diagnosis.
25. In a letter to all members of the Legislative Council in Western Australia, dated 21 October 2019, by "Health Professionals Say No!", 770 health professionals stated:

"Reviewing the recently published detail of the Victorian coroner's data analysis based on 118 active cancer patients (1), it seems that 34% had had a history of mental illness, and only 42% of all cases having advanced cancer, meaning the remaining 58% had cancers at an early stage. Only 14% had had contact with a Palliative Care service, despite those being described as "illness probably related suicides" as having concerns about pain. Interestingly, 48% reported the heavy burden of cancer treatment as an issue, rather than the illness (a potentially avoidable burden). Those reported as "suicides likely being related to physical illness" made up only 10% of suicides in each state (one case per week)."
26. If questions could have been asked, it would have led to fulsome evidence being presented to the Committee, from which a much better understanding of the data would have been achieved.
27. Again, there is nothing in the report saying any assessment of the evidence was undertaken. There is in fact an inference in the Committee comment on page 11 that because a person was suffering from a

“terminal and debilitating illness” they took their own lives. There was no rigorous method undertaken to assess the evidence to come to that conclusion.

28. It is almost as though the Committee is saying that without voluntary assisted dying, suicides are going to continue to occur. There is no evidence presented to establish, based on this table, that that is in fact the case.

29. Further in the letter from the “Health Professionals Say No”, the 770 health professionals stated:

“In summary, there is no definite evidence in the analysis that most or many of these suicides would have either met the WA eligibility criteria, nor that VAD would prevent similar cases in future. *Finding 33* of the WA End of Life Inquiry Report therefore needs correction. One important implication, however, is that lack of access to high quality specialist palliative care and other supports may have resulted in many of these cancer patients being driven to suicide, but there is no evidence to suggest lack of access to VAD drove this group as a whole to suicide. As a recent survey of 2000 WA residents has shown, 75% would want the Government to address Palliative Care service provision and regional access issues ahead of VAD.”

#### PUBLIC OPINION AND THE ROLE IT HAS IN FORMING POLITICAL OPINION

30. Throughout the inquiry, Members were continually told that overwhelmingly Queenslanders endorsed V.A.D.

31. However, no analysis was undertaken into any of the opinion polls referred to. They were not analysed to establish whether the questions put were framed in an unbiased manner or provided full information to give a fully informed answer.

32. The question of opinion polls was considered by the previous Health Committee in the 55<sup>th</sup> Parliament which provided a detailed analysis at Appendix D to the report. (Report No 24 55<sup>th</sup> Parliament Abortion Law Reform -Woman’s Right to Choose- Amendment Bill 2016 and Inquiry into laws governing termination of pregnancy in Queensland.)

33. The Committee did not undertake such an analysis which raises concerns about the reliability of the outcomes.

34. We note that in terms of the Report, there is little by way of comment of a substantive nature delving into the opinion polls relied upon except the Committee comment at page 63, “The Committee notes the

suggestions from recent opinion polls that voluntary assisted dying is supported by a majority of Australians, and that voluntary assisted dying laws reform has high level support in Queensland. The committee also notes that potential pitfalls associated with interpreting opinion polls on highly contentious social issues." This is inadequate.

35. No one doubts this is a very emotional issue, no one doubts questions around how people die is also very emotional yet, at the end of the day, the Committee has to come to a conclusion based upon evidence.
36. The lack of vigour in assessing the opinion polls is a worrying point for ourselves and question has to be raised, was the Committee, in part, led to a conclusion based upon questions that did not provide a solid basis to assess the answers that were given?
37. This is a further flaw in the rationale of the Committee.

#### CURRENT LEGAL POSITION IN QUEENSLAND WITH RESPECT TO SUICIDE

38. The Committee deals with Queensland's current law on suicide on page 4 of the Report under the heading "Options for people with a life limiting illness".
39. The Chapter continues on and it deals with people pleading for help to end their lives in the absence of voluntary assisted dying, the impact of suicide on those that are left behind, and people planning to suicide in the absence of V.A.D.
40. We have no question that suicide is an incredibly distressing event for family and friends, nor can we imagine the agony a person goes through to bring them to the point of taking their own life.
41. Yet again, what is not debated, is the role of palliative care. We are aware that in Report No. 33, issues concerning palliative care are presented and Queenslanders will be horrified at the paucity of palliative care spent by the Queensland Government as a proportion of the Queensland Health budget.
42. But this is another section in the Report where the benefit of palliative care should have been discussed. It is another major failing of the Report. Palliative care is of equal importance in the debate and it is sad that the Committee determined not to combine the debate.



## OVERSEAS JURISDICTIONS THAT HAVE IMPLEMENTED VOLUNTARY ASSISTED DYING

43. The Report does discuss jurisdictions that have forms of V.A.D legislation including The Netherlands, Belgium, Luxembourg, Switzerland, the United States and Canada.
44. But the Report does not provide a detailed of the history of what occurred in those jurisdictions from commencement of the law to the present time. It does not present a critique as to whether or not the initial intent of the legislation has continued or whether the scope of V.A.D. has been enlarged either by legislation or independent action. Further, it does not discuss the issues that have arisen because of the legislation.

### OREGON DATA

45. Very concerning is the fact that though the United States is referred to, it does not discuss the data from Oregon that tracks why people decide to access V.A.D.
46. “The Oregon *Death with Dignity Act* (DWDA) requires the Oregon Health Authority to collect information about the patients and physicians who participate in the Act and to publish an annual statistical report. The most recent of these reports was published on 6 March 2020 and the Oregon Health Authority’s overview of this report is below-

*In 2019, 112 Oregon physicians wrote 290 prescriptions to dying Oregonians who qualified for the Act; 188 people died using the medications obtained under the law. Similar to previous years, most patients*

- *were 65 years or over (75 percent), with the median age of 74;*
- *had cancer (68 percent);*
- *were on hospice at the time of death (90 percent);*
- *died at home (90 percent);*
- *had some form of health insurance (99 percent).*

*Consistent with reports from previous years, the most frequently reported end-of-life concerns were loss of autonomy (87%), decreasing ability to participate in activities that made life enjoyable (90%), and loss of dignity (72%). (Highlighting added)*

47. This data is not even considered, nor are there any conclusions about the mental health of people who are diagnosed with a terminal illness or life terminating injury. That should have been part of the discussion in the Report, but it was not.

#### THE WHITE AND WILLMOTT “BILL”

48. We note the first recommendation of the Committee states:

“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.”

49. (The comments that we make are not a personal reflection upon Professors Willmott and White. We acknowledge their contribution but our comments deal with the actions of the Committee.) This recommendation is not supported with any written assessment of the document. As the Report does not show the Committee undertook a detailed analysis it is very difficult to conclude that the “draft legislation” is “well considered.”
50. There is also no evidence in the Report that the Bill was disseminated to stakeholders nor detailed evidence taken from them including professional bodies as to whether or not the Bill should be put forward as “draft legislation”.
51. This is a fundamental breach of any Committee’s obligation. If it is to recommend a Bill, then the Report should and must provide a rigorous assessment undertaken with all stakeholders.

Again, a poor analysis and understanding of the role of the Committee process.

#### VICTORIA AND WESTERN AUSTRALIA LEGAL POSITION

52. Two Australian jurisdiction have passed laws on V.A.D. The Victoria legislation has been operating for approximately 12 months, whereas Western Australia has not yet commenced formal implementation.
53. If Queensland was to fully consider taking the step of putting V.A.D. into law one step should be to assess how the law in other Australian jurisdictions are operating, its faults and pitfalls. This would be a prudent step.

**Signed by:**

Martin Hunt MP  
Committee Member  
State Member for Nicklin



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Mark McArdle MP  
Deputy Chair  
State Member for Caloundra



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## Statement of Reservation

**Michael Berkman MP, Member for Maiwar**

The Greens support the right of people with severe and incurable disease to choose to die with dignity, and strongly support the primary recommendation of the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (**Committee**) in report number 34 (**Report**) that the Queensland Government legislate a scheme for voluntary assisted dying (**VAD**).

Broadly speaking, I support almost all the Report's recommendations and the views presented as Committee comments, but there are some points where my views diverge or require more detailed commentary.

### **Urgent law reform is required**

The introduction of a scheme to allow VAD is not only supported by most Queenslanders today, but available opinion polling suggests that this support has been growing for some time now. Law reform to create such a scheme should be treated as a matter of urgency, and the Queensland Government should take all possible steps to make this happen before the dissolution of the 56th Parliament.

The Committee has already, in the course of this inquiry, given detailed consideration to both the broad social concerns and context surrounding VAD, and the specific elements that need to be addressed in any VAD scheme. With the benefit of other jurisdictions' experience and the draft legislative framework submitted to the inquiry by Professors Lindy Willmott and Ben White (**Willmott and White Bill**), the Parliament is well positioned to legislate for VAD in this term of Parliament.

Additionally, any proposed VAD scheme should endeavour to take effect as quickly as possible. Given that Queensland can draw on the experience of other jurisdictions that have adopted analogous legislation, we would ideally apply an implementation phase shorter than the 18 months that has been adopted in other Australian states.

### **Eligibility for VAD**

#### *Dementia and decision-making capacity*

Decision-making capacity is a vexed issue in debate around VAD, particularly in relation to dementia sufferers, and is dealt with quite differently in different jurisdictions. Section 8.2.4.1 of the Report, *Dementia and use of Advance Health Directives*, sets out a brief overview of some salient evidence on this issue. It demonstrates both the deep moral quandary and the immense practical difficulties in attempting to formulate a functional VAD scheme in which sufferers of dementia may be eligible. Dementia is a terminal condition and one that deprives the sufferer of the decision-making capacity as they near death, which precludes access to VAD in most existing schemes in other jurisdictions. Evidence from other jurisdictions and practitioners with many years' experience were most helpful in drawing out this complexity.

A sensible starting position for this discussion is around the potential to access VAD through an advance health directive (AHD). AHDs are a common document used to record a person's predetermined choices around medical care and treatment, which take effect if or when the person is unable to make their own healthcare decisions. The position taken by several witnesses, including Doctors for Assisted Dying Choice, is that dementia sufferers should be able to request VAD in an AHD (prepared while they retain decision-making capacity) and that this directive take effect at some point after the person has lost decision-making capacity.

This proposal is in many instances likely to be relatively uncontentious, and the Committee heard from witnesses whose personal circumstances suggest this is the compassionate and sensible course. There were accounts from people who continue to watch a family member suffer with dementia and complete loss of bodily control, with full knowledge, and in some cases having explicitly discussed, that their loved one did not want to continue to live in those circumstances.

Under schemes where eligibility is not explicitly precluded by the loss of decision-making capacity (i.e. Belgium and the Netherlands), complexity emerges from the vastly different and unpredictable experiences of dementia sufferers and, for example, circumstances where the patient's wishes, having lost decision-making capacity, change from those recorded in the AHD.

A further practical obstacle to making VAD available to people who have lost decision-making capacity is that a substantial number of health practitioners participating in VAD in these jurisdictions are unwilling or for ethical reasons feel unable to honour that request unless the patient has capacity at the time of final sign-off or administration of the VAD medication.

The scheme in Canada requires informed consent to be given both at the time of the initial request for VAD – or 'medical assistance in dying' (MAID), as it is referred to – and immediately before it is provided. However, the eligibility criteria in the Canadian scheme allow access to MAID where, among other criteria, "natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining". The Committee heard evidence that, in practice, this means dementia sufferers have been able to access MAID earlier in the onset of dementia, before they lose decision-making capacity and the ability to give informed consent.

The Committee heard that in each of these jurisdictions, a consequence of dementia sufferers being able to access VAD – whether or not the scheme required that they have capacity at the time – was that people were choosing to end their life while they retain decision-making capacity but earlier than they might otherwise have chosen to, so that they don't lose capacity and the right to access VAD.

I find it equally difficult to accept either this outcome or any VAD scheme that completely excludes dementia sufferers, particularly given the growing prevalence of this disease in our ageing society.

Acknowledging the complexity of this issue, I support recommendations 6 and 7 in the hope that we can continue to work through these practical and ethical complications as a community, while progressing towards the adoption of a (slightly more limited) VAD scheme without delay.

## Age

Age limits on eligibility for access to any VAD scheme are similarly contentious and there are a wide variety of views, as is set out in section 8.2.1 of the Report.

The observation of Dying with Dignity New South Wales warrants repeating (noting that they support an eligibility age limit of 18): “this cut-off is of course arbitrary; there may be many 16 year-olds who have more decision-making capacity than some 21 year-olds but the bar needs to be set somewhere”. I share this view and note that, while I agree with the Committee’s recommendation 2 that eligibility be limited to people over 18 years old, I consider it is arbitrary and warrants further consideration.

The Report makes only passing reference to the concept of ‘Gillick competence’, which is commonly relied on in medical practice to determine whether a minor can be considered to have decision-making capacity in relation to their own health care. Queensland Health’s 2017 *Guide to Informed Decision-making in Health Care*,<sup>1</sup> prepared by the Clinical Excellence Division, provides a useful overview of Gillick competence:

*To establish that a child or young person has capacity to consent to health care, the health practitioner can carry out an assessment to show the patient has sufficient understanding, intelligence and maturity to appreciate the nature, consequences and risks of the proposed health care, and the alternatives, including the consequences of not receiving the health care.*

*When assessing a child or young person’s capacity, the following issues should be considered:*

- *the age, attitude and maturity of the child or young person, including their physical and emotional development*
- *the child or young person’s level of intelligence and education*
- *the child or young person’s social circumstances and social history*
- *the nature of the child or young person’s condition*
- *the complexity of the proposed health care, including the need for follow up or supervision after the health care*
- *the seriousness of the risks associated with the health care*
- *the consequences if the child or young person does not have the health care*
- *where the consequences of receiving the health care include death or permanent disability, that the child or young person understands the permanence of death or disability and the profound nature of the decision he or she is making.*

*The more complex the health care or more serious the consequences, the stronger the evidence of the child or young person’s capacity to consent to the specific health care will need to be. In these situations, it is recommended that the assessment is carried out by a medical practitioner.*

*The health practitioner documents fully in the patient’s clinical record the assessment they have carried out, including the details which influenced their decision as to whether the child has capacity.*

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<sup>1</sup> Available online: [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0019/143074/ic-guide.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf).

*Maturity and intellectual development varies from one individual to another and an assessment of a child or young person's capacity is performed for each new health care decision. However, as a practical rule of thumb:*

- *a young person aged between 16 and 18 is most likely able to consent*
- *a young person aged between 14 and 16 is reasonably likely to be able consent*
- *a child under the age of 14 may not have the capacity to consent, except for health care that does not carry significant risk.<sup>2</sup>*

This framework already contemplates a younger person's ability to understand and make decisions that may result in grave consequences, including death, and it warrants detailed consideration in the context of whether people under the age of 18 should be arbitrarily excluded from a VAD scheme.

Similar to the complex and unresolved questions around dementia and decision-making capacity, I support recommendation 2 for the practical reasons – further consideration of this important but highly controversial issue should not delay urgent progress towards implementation of a functional VAD scheme in Qld.

However, I believe the Report should have included an additional recommendation (like recommendation 7) 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 terminally ill patients who have not yet reached majority, with a particular focus on existing criteria and guidelines for determining Gillick competence in relation to other health related decision-making.

#### **Recommendation 16 – restriction on Initiation of discussions about VAD**

I disagree with the Committee's recommendation 16, which states:

*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.*

This reflects section 8 of the Victoria's *Voluntary Assisted Dying Act 2017*, which explicitly prohibits registered health practitioners from initiating discussions about VAD with patients.

By contrast, the Western Australian scheme includes no such prohibition as long as the health practitioner also informs the patient about their treatment options and their palliative care options and the likely outcome of taking either of these pathways.

The Committee heard evidence from Professor Willmott that Victorian medical practitioners had described to her and Professor White the very real difficulty this prohibition creates for them in practice. Professor Willmott described their concerns as follows:

*In relation to the fact that voluntary assisted dying cannot be raised by health professionals, the concern is that it will inhibit the discussion a doctor can have with a patient and the need for the 'dance' between the doctor and the patient. The patient provides the magic words, 'Doctor, can you please tell me about voluntary assisted dying?' You do not need those precise*

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<sup>2</sup> Queensland Health (2017) *Guide to Informed Decision-making in Health Care*, pp 46-47 (references omitted).

*words, but you need something very direct. You want to know about whether the doctor can assist you to die.*

*Ben [White] and I are currently writing a paper in relation to this specific issue. One problem arises—for example, if a patient is approaching the end of life and says, ‘Doctor, can you please give me all of the options that are available to me now?’ We do not believe that the doctor is able to tell them about voluntary assisted dying. We do not believe that that is a specific enough request for information about voluntary assisted dying and we think that is problematic in terms of the therapeutic relationship between the doctor and the patient. The patient is seeking to know what can be done and the doctor cannot tell them about voluntary assisted dying.<sup>3</sup>*

Professor White gave the following evidence in relation to this prohibition:

*The departments have set out a series of scripts—‘These words will enable a discussion to occur about voluntary assisted dying. These words will not.’ It is very clear from that that the department envisages that you would have to be very clearly requesting actual assistance to die. You do not have to use the words ‘voluntary assisted dying’ but the words that Lindy [Willmott] mentioned of, ‘I’ve had enough,’ or, ‘Is there a way out?’—those sorts of things—would not be enough, hence the reference to those magic words and the dance around a doctor saying, ‘Can you tell me some more’ and it going back and forward, impeding that frank discussion that we ordinarily would hope to see at end of life.<sup>4</sup>*

Rather than providing any useful safeguard against coercion in respect of VAD, this prohibition risks simply stifling open and direct dialogue between a doctor and patient about all the available options, and limits the provision of honest, best practice healthcare to people with terminal illness. Such a prohibitions should not be included in any VAD scheme in Queensland.

### **Ensuring equitable access in rural and remote areas**

It is essential that a VAD scheme in Queensland adequately accounts for our decentralised population, and that any safeguards don’t inadvertently hamper access for rural and remote Queenslanders.

#### *The presence of a medical practitioner or registered nurse*

The Willmott and White Bill raises some concerns in this regard, in that it proposes a registered medical practitioner must be present, even in the case of physician assisted suicide (i.e. self-administration of VAD medication). As Willmott and White acknowledge in the Explanatory Notes for their Bill, this presents particular difficulties for Queenslanders living in rural and remote areas. Additionally, this requirement may limit any person’s decisions about the circumstances of their death, not only in terms of the people who will be present, but also potentially the person’s choice of the place and time of their death.

Recommendation 15 goes some way to addressing this concern for rural and remote communities by proposing the flexibility to permit a registered nurse who meets the training and other requirements

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<sup>3</sup> Private hearing transcript, Brisbane, 29 Apr 2019, pp 3-4.

<sup>4</sup> Private hearing transcript, Brisbane, 29 Apr 2019, p 5.



(rather than a registered medical practitioner) to participate in the scheme by assessing an applicant for voluntary assisted dying and administering the voluntary assisted dying medication.

Willmott and White did note that, while the requirement for a medical practitioner to be present for the administration of the VAD medication is one way to enhance the safety and quality of VAD, provisions in Victoria for collection, storage and disposal of the medication could be replicated to deal with certain of these issues. In addition to recommendation 15, given the additional challenges posed by remoteness in Queensland, the Minister should also consider whether it is necessary in Queensland to mandate that any medical practitioner or registered nurse be present for self-administration of VAD medication. This is not required under the Victorian scheme and it may not be appropriate in a state as large and decentralised as Queensland.

### *Conscientious objection*

The Committee agrees that any VAD scheme must include provision for conscientious objection, as proposed in recommendation 17, and this will clearly have a disproportionate impact on access to VAD in rural and remote communities.

Appropriately, sections 38 and 39 of the Willmott and White Bill deal with these barriers to access by requiring that:

1. a health practitioner with a conscientious objection to VAD must offer to refer a person to a medical practitioner who they believe does not have a conscientious objection; and
2. an entity (such as a health service, residential service or professional care service) that refuses access to VAD must offer and take reasonable steps to facilitate the transfer of that person's care to an entity at which VAD can be provided.

These provisions (or their equivalent in a proposed scheme) could better ensure access for people in rural and remote areas by putting clear time constraints on the required referral.

### *Counselling*

I agree with recommendation 14 that eligibility should not require mandatory counselling, and note that this would create a further unnecessary barrier for rural and remote Queenslanders. That said, high quality counselling and comprehensive palliative care should be available to all Queenslanders, regardless of their location.

## **Relationship between VAD and palliative care**

This inquiry has shown the relationship between palliative care and VAD to be a complex one. The necessary starting point to consider this relationship is to acknowledge the preponderance of evidence that palliative care in Qld is not adequately funded or as widely accessible as it should be, particularly given the unique difficulties faced in rural and remote communities and Queenslanders' broad preference for palliation and death in home.

That said, as the Report details, there is ample evidence that even the best palliative care will not alleviate all suffering for all patients, and will leave a significant number of terminally ill patients without the option to end their lives if they choose this as an alternative to ongoing pain and suffering.

The assertion that effective palliative care makes VAD obsolete is simply not supported by the evidence heard by the Committee.

It is, in my view, unconscionable to suggest that introduction of a VAD scheme cannot be justified unless and until we address all the recognised shortcomings in the funding and provision of palliative care in Queensland. It would be equally unacceptable, whenever we do ultimately legislate a VAD scheme in Queensland, for this decision to in any way forestall or deprioritise the urgent steps that are required to improve palliative care in Qld.

A handwritten signature in black ink, appearing to read 'MB', with a long horizontal flourish extending to the right.

Michael Berkman MP

Member for Maiwar