Submission to:

The Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee of The Queensland Parliament

FOR ITS INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

Dying With Dignity Queensland
PO Box 432
Sherwood QLD 4075
The Honourable Aaron Harper  
Chair  
Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying  
Health Committee  
PARLIAMENT HOUSE, QUEENSLAND 4000

11 April 2019

Dear Mr Harper,

Dying With Dignity Queensland Inc. (DWDQ) is a Queensland-wide non-profit group formed in 1985. DWDQ aims to see legislation passed to allow Queensland residents, in select circumstances, to seek medical assistance to obtain a peaceful and dignified death.

Our members and supporters reflect the diversity of Queenslanders in variances of age, gender, race, morals, religion, education and employment. DWDQ has an eight-member committee. Five of these eight committee members are either currently practising, or retired doctors or nurses.

Since its inception, DWDQ has attempted to represent the passionate desire for law reform in the Queensland community based in a deep disquiet about unrelieved suffering at the end of life and the associated lack of autonomy and control. The passion is reflected in the tireless efforts of the members and the response to many polls showing that approximately 80% of people support law reform in this area. This was demonstrated again in a recent well conducted Queensland Poll commissioned by the Clem Jones group.

DWDQ believes that there must be a stand-alone Voluntary Assisted Dying (VAD) Bill introduced to Parliament to legalise the right of Queenslanders to have control over the timing and circumstance of their own death in the context of un-relievable and unacceptable suffering.

As the committee is aware, there are models around the world and in Victoria that provide templates for law reform in Queensland. These models refute the slippery slope and family coercion arguments and provide for carefully drafted eligibility criteria and safeguards to protect even the most vulnerable members of society.

DWDQ sees the provision and expansion of palliative care services as a crucial part of this process as occurred in Victoria, but we lack the expertise and data to mount a formal response to the Palliative Care section. We do believe, however, that VAD and Palliative Care are complementary in providing the best possible end of life care.

DWDQ welcomes this important far-reaching inquiry. DWDQ Committee members will be pleased to appear as witnesses at a public hearing if the committee so requests.

Yours faithfully,

Jos Hall  
Registered Nurse (retired)  
President  
Dying with Dignity Queensland Inc

Dr Jenny Brown,  
BSc, MBChB, MRCP(UK), FRACP  
Consultant Physician  
Vice-President  
Dying With Dignity Queensland Inc.
Introduction

The essence of DWDQ is that it is a grass roots organisation deeply in touch with the people that are its members and supporters. Around the state, meetings have taken place to support the implementation of this enquiry and consequent legislation. The passion in the rooms is palpable and the stories that are told are heart wrenching.

DWDQ does not have the resources or the information to address the Aged Care and End-of-Life and Palliative Care sections of this enquiry. This submission, therefore, will address only the Voluntary Assisted Dying component of the inquiry.

The format will be to look briefly at the ethical and legal foundations for such law reform and to address some of the main arguments for and against Voluntary Assisted Dying legislation. DWDQ will then respond to the questions that the Inquiry Committee has posed.

End of Life Decision Making: Practical and Ethical Issues for Health Professionals

Life-extending changes in medical technology and an ageing population pose practical and ethical problems relating to end-of-life decision making. Health professionals need to understand the fears and concerns of their patients, their preferred place to die, and to respect patient autonomy. Such wishes may be expressed verbally by a competent patient or through an advance directive (living will) or proxy by an incompetent patient. There is 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. In addition, physician-assisted suicide and euthanasia, two of the important moral issues of the 90s, will continue to require open community debate as we move into the new millennium. Australia, in company with most other countries, has many challenges ahead in relation to end-of-life decision making.

Ref 1

The Canadian panel chose to be guided by the Doctrine of Informed Choice that constitutes a central pillar of contemporary health ethics and of Canadian Law. Informed choice is grounded in autonomy; it seeks to apply the abstract value of autonomous decision making to the context of healthcare. It requires that competent patients must not be subjected to treatment unless they have consented to it. But consent is subject to three conditions:

First, it must be uncoerced;
Second, that it must result from the decision-making capacity of a cognitively competent individual;
Third, it must be informed. Ref 2

According to this definition, an autonomous decision would be made by a substantively cognitively competent and uncoerced individual who arrives at his or her decisions after having been offered relevant information about the decision at hand. It is beyond the capacity of this submission to address all the arguments that were put, but suffice it to say, the conclusions that the panel drew were as follows:

1. “That there is a moral right, grounded in autonomy, for competent and informed individuals who have decided after careful consideration of the relevant facts, that their continuing life is not worth living, to non-interference with requests for assistance with suicide or voluntary euthanasia.

2. That none of the grounds for denying individuals the enjoyment of their moral rights applies in the case of assisted suicide and voluntary euthanasia. There are no third-party interests, self-regarding duties, or duties toward objective goods that warrant denying people the right to assisted suicide and voluntary euthanasia. Prophesied undesirable social consequences are not sufficient to negate the right to choose assisted suicide and voluntary euthanasia, rather, they should be taken into account, in constructing the regulatory environment within which this right can be exercised. Ref 3
Arguments for Voluntary Assisted Dying Legislation

1. Relief of suffering and community support

DWDQ believes that suffering at the end of life and the consequent huge community support for legislative change to afford relief are the most important arguments for law reform.

Australia, like Canada is a liberal democracy in which the views of the community over time have changed greatly with regard to VAD. There is strong evidence now, across the Australian population that people desire to have control over the timing and place of their death. For very sick people, who have very little control over many aspects of their life, having this control is extremely important.

The level of this community support is underpinned by many Australia-wide polls (see Appendix A on page 14)

The 2018 ReachTEL poll in Queensland demonstrates approximately 80% support for Voluntary Assisted Dying legislation across a wide range of demographic groups including age, sex, and political affiliations (see Appendix B on page 15)

Polls conducted by Newspoll in 2007 and 2012 demonstrate overwhelming support from people of religious conviction (see Appendix C on page 16)

The main justification for this legislation then is to deal with unnecessary and unwanted suffering across the community, an intervention which has widespread support.

2. Clarification of the Legalities of Medical Interventions at the End of Life

The law, as it pertains to the decision-making processes at the end of life, is quite unclear.

There is a requirement for law reform which increases the clarity and certainty regarding the law in relation to severely sick individuals. There is general agreement that it is legal to withdraw treatment if it is felt to be futile and burdensome but even then, many doctors feel legally vulnerable and compelled to overtreat. This has huge implications for patients and relatives. The legal issues discussed below are;

a) “the Doctrine of Double Effect’
b) the legal status of terminal sedation
c) providing a legal structure to ensure lethal interventions are properly consented and documented with protection for patient, relatives and medical practitioner

a. The Doctrine of Double Effect

The "Doctrine of Double Effect" is widely practised in palliating patients according to both the Victorian and Western Australian Parliamentary Inquiry reports into End of Life Choices.

“Doctors told the Committee that this was uncontroversial standard practice where death is imminent, and pain is extreme.” Ref 5

“According to the doctrine, a doctor is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures taken may incidentally shorten life, provided the doctor’s intention is to treat the symptoms and not to cause death.” Ref 6

The Australian Medical Association’s Code of Ethics endorses the Doctrine of Double Effect by advising doctors to “Respect the right of a terminally ill patient to receive relief from pain and suffering, even where that may shorten their life.” Ref 7

However, some doctors have raised serious concerns regarding the Doctrine of Double Effect.
Doctors for Assisted Dying Choice implied that the current legal framework is subjective and grey in nature:

“The current law relies on the intent of the medical practitioner. An observer may not know this intent and may misinterpret the medication provided to relieve symptoms as an attempt to hasten death. Drugs used to sedate or relieve pain may also reduce respiration. Once this observer has this interpretation, they can report the death to the police, which would spark an investigation and charge. Only during a court proceeding, would the doctor be able to use the Doctrine of Double Effect as a defence.” Ref 8

We believe that doctors are fearful sometimes of interventions which will shorten life because the current legislation is very unclear, and they feel vulnerable to a court action. Without legislation, we cannot be certain that the life-shortening consequences of this medication have been adequately explained to the person, nor that they have consented to receive the medication. In contrast, VAD legislation can ensure that the process is transparent, and that the person has given informed consent and fully understands the implications of taking the medication.

b. Addressing the confusion with regard to the legalities of terminal sedation.

One of the most controversial Palliative Care interventions is terminal sedation. This is used when all other treatment options including Palliative Care cannot control severe, intolerable symptoms. This treatment is intended to render the patient unconscious using an infusion of narcotics and sedative drugs. It may potentially take days or weeks for the individual to die.

Fine lines are drawn between intending to relieve suffering as opposed to intending to end a person’s life. The differentiating point, as outlined above, is the doctor’s intent. It is hard to be certain of what lies in the heart of people when they undertake these procedures and there is no certainty in law, as this intervention has not been legally tested. This leaves practitioners vulnerable to litigation.

The Western Australian Parliament End of Life Choices report identified serious legal and ethical issues regarding the use of terminal sedation (see Appendix D on page 17)

1. Not recording the commencement of terminal sedation in patient medical records.
2. Varying effectiveness of terminal sedation across health services due to inadequate regulation.
3. Uncertainty regarding the legality of terminal sedation can lead to withholding of treatment.
4. Uncertainty as to whether the patient’s consent has been obtained prior to commencing terminal sedation.

c. Provision of a legal framework would give medical practitioners and family members legal certainty including framework and protection

Voluntary Assisted Dying legislation would eliminate this area of uncertainty. The absence of lawful Voluntary Assisted Dying has sometimes led to life ending medications being prescribed by doctors without explicit consent. Further, relatives may feel obliged out of compassion to assist in the dying request of their loved one, leaving the relatives vulnerable and open to prosecution. Providing legal certainty in this area would mean that doctors providing Voluntary Assisted Dying, currently without consent would have to fulfil all of the appropriate guidelines in a legal and transparent process. Further, family members would not have to contemplate desperate and illegal actions.

* http://drs4assisteddyingchoice.org/
3. Voluntary Assisted Dying as an alternative to suicide

Parliamentary inquiries in both Victoria and Western Australia concluded that a number of suicides in their respective states were by people with a terminal illness or severe progressive incurable disease.

DWDQ believe that statistics from Queensland are likely to show a similarly alarmingly high rate of suicides of Queenslanders with terminal or debilitating progressive illnesses.

The Report from the WA Joint Select Committee on End-of-Life Choices states:

“Prohibition of assisted dying is causing some people great pain and suffering. It is also leading some to end their lives prematurely and in distressing ways” \[Ref 9\]

The Parliament of Victoria End-of-Life Choices Final Report states:

“People are choosing suicide over dying with irremediable pain” \[Ref 10\]

These people are choosing suicide over living with their irreversible and unstoppable physical decline. DWDQ has received anecdotal evidence that some Queenslanders are choosing to end their lives while they are actively receiving palliative care.

Official suicide statistics provided by the Coroner's Offices of both Victoria and Western Australia show the high rate of suicide by people suffering with a terminal or debilitating progressive illness. These show that approximately 1 suicide per week, or 13.9% of the total state suicides are committed by people with a terminal or debilitating progressive illness.

“There were two-hundred and forty (240) deaths of relevance identified with the date of notification between 01/01/2012 and 05/11/2017 that were reported to a Western Australian Coroner where the deceased died as a result of an act of intentional self-harm and had been diagnosed with a terminal or debilitating physical condition prior to their death.

These two-hundred and forty (240) cases represented 13.9% of all intentional self-harm cases reported to a Western Australian Coroner between 01/01/2012 and 05/11/2017.” \[Ref 11\]

Table 2. Intentional Self-Harm Fatalities of Persons with Terminal or Debilitating Conditions by Age and Sex of the Deceased

<table>
<thead>
<tr>
<th>Age Range [Years]</th>
<th>Male</th>
<th>Male [%]</th>
<th>Female</th>
<th>Female [%]</th>
<th>Total</th>
<th>Total [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;21</td>
<td>4</td>
<td>2.2</td>
<td>3</td>
<td>5.2</td>
<td>7</td>
<td>2.9</td>
</tr>
<tr>
<td>21 - 30</td>
<td>9</td>
<td>4.9</td>
<td>3</td>
<td>5.2</td>
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<tr>
<td>31 - 40</td>
<td>17</td>
<td>9.3</td>
<td>2</td>
<td>3.4</td>
<td>19</td>
<td>7.9</td>
</tr>
<tr>
<td>41 - 50</td>
<td>27</td>
<td>14.8</td>
<td>6</td>
<td>10.3</td>
<td>33</td>
<td>13.8</td>
</tr>
<tr>
<td>51 - 60</td>
<td>32</td>
<td>17.6</td>
<td>12</td>
<td>20.7</td>
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<tr>
<td>61 - 70</td>
<td>26</td>
<td>14.3</td>
<td>13</td>
<td>22.4</td>
<td>39</td>
<td>16.3</td>
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<tr>
<td>71 - 80</td>
<td>33</td>
<td>18.1</td>
<td>10</td>
<td>17.2</td>
<td>43</td>
<td>17.9</td>
</tr>
<tr>
<td>81 - 90</td>
<td>30</td>
<td>16.5</td>
<td>8</td>
<td>13.8</td>
<td>38</td>
<td>15.8</td>
</tr>
<tr>
<td>91 and above</td>
<td>4</td>
<td>2.2</td>
<td>1</td>
<td>1.7</td>
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<td>2.1</td>
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<td>Total</td>
<td>182</td>
<td>100</td>
<td>58</td>
<td>100</td>
<td>240</td>
<td>100</td>
</tr>
</tbody>
</table>

“The Coroners Court of Victoria presented particularly disturbing evidence that around 50 Victorians a year are taking their lives after experiencing an irreversible deterioration in physical health” \[Ref 12\]

“Analysis of evidence from international jurisdictions reaches similar conclusions on the incidence of suicide amongst the terminally ill.”
“The way in which people die in these circumstances is often starkly contrasted with the way in which they lived their lives, Victorian Coroner John Olle observed:

People who have invariably lived a long, loving life surrounded by family die in circumstances of fear and isolation.” Ref 13

Knowing that medical assistance will not be available to end their life later in a manner that is acceptable to the person, unfortunately, lead people suffering debilitating terminal decline, to commit suicide prematurely, while they are still physically capable of doing so.

“It is not surprising that many of those who choose to take their lives as a result of a terminal or chronic illness are doing so earlier than they otherwise would want to on the basis that they fear some future loss of physical capacity.”

“Some individuals who suicide under these circumstances are driven to take their lives early. All deaths under these circumstances are tragic and very often traumatic and distressing to family, friends and first-responders.”

The evidence confirms that people suffering severe debilitating and incurable conditions with irremediable pain/symptoms are killing themselves using horrific and violent means. The thought of someone who has lived a gentle peaceful life surrounded by friends and family, resorting to end their life by hanging or blasting their brains out with a gun – which, by the way, is legal - is nothing short of horrific. Ref 14

Arguments against VAD Law Reform

1. Palliative Care can relieve all suffering.

Many studies show this not to be the case as reported in the Western Australian End of Life Choices report page 92. “The percentage of patients for whom Palliative Care is ineffective in relieving symptoms varied. However, a range of 2-5% is consistent with the evidence.”

Uncontrolled pain is not usually the main reason for accessing VAD. The Oregon Voluntary Assisted Dying report 2018 showed that, as in previous years, the three most frequently reported end of life concerns were loss of autonomy (91.7%), decreasing ability to participate in activities that made life enjoyable (90.5%), and loss of dignity (66.7%).

In fact, over 90% of the patients who accessed Voluntary Assisted Dying were already enrolled in hospice care so that uncontrolled pain may not have been their main motivation.

Further DWDQ does not see Voluntary Assisted Dying law reform as being contrary to Palliative Care, but, in fact, complementary. As Archbishop Desmond Tutu said “People who are terminally ill should have the option of dignified and compassionate assisted dying alongside the wonderful Palliative Care that already exists”. Ref 15

Dying With Dignity Queensland supports the expansion of Palliative Care Services and respectfully requests that the Inquiry Committee recommends increasing the funding to Palliative Care, as has happened in Victoria, specifically for regional, rural and remote areas

2. Slippery slope

Opponents to Voluntary Assisted Dying legislation put forward the view that the pressure to further liberalise such laws in overseas jurisdictions, has been irresistible. In fact, in most jurisdictions where assisted dying has been legalised, little has changed regarding what practices are allowed or who can access assisted dying. There have been some changes such as in Belgium where competent minors can now request euthanasia.

In the North American jurisdictions which allow assisted suicide, there has been no change, apart from the state of Quebec in Canada. Indeed, the regulatory framework has been
unchanged in Oregon, the state of Washington, Luxembourg, and Switzerland for many years.

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Allows</th>
<th>Year Legalised</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oregon</td>
<td>Assisted suicide</td>
<td>1997</td>
<td>No expansion</td>
</tr>
<tr>
<td>Washington (state)</td>
<td>Assisted suicide</td>
<td>2009</td>
<td>No expansion</td>
</tr>
<tr>
<td>Vermont</td>
<td>Assisted suicide</td>
<td>2013</td>
<td>No expansion</td>
</tr>
<tr>
<td>California</td>
<td>Assisted suicide</td>
<td>2015</td>
<td>No expansion</td>
</tr>
<tr>
<td>Colorado</td>
<td>Assisted suicide</td>
<td>2016</td>
<td>No expansion</td>
</tr>
<tr>
<td>Belgium</td>
<td>Euthanasia &amp; assisted suicide</td>
<td>2002</td>
<td>Expanded</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Euthanasia &amp; assisted suicide</td>
<td>2002</td>
<td>Expanded</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>Euthanasia &amp; assisted suicide</td>
<td>2009</td>
<td>No expansion</td>
</tr>
<tr>
<td>Canada</td>
<td>Euthanasia &amp; assisted suicide</td>
<td>2016</td>
<td>No expansion</td>
</tr>
<tr>
<td>Quebec</td>
<td>Euthanasia &amp; assisted suicide</td>
<td>2016</td>
<td>Expanded (by federal law, not the provincial government)</td>
</tr>
</tbody>
</table>


Ref 16

3. **People will request Voluntary Assisted Dying because of unacceptable pressure from relatives**

Whilst the concern is valid, we believe it can be addressed by the implementation of appropriate safeguards which we will outline in response to the enquiry’s questions on that matter, to ensure that the request for Voluntary Assisted Dying is made freely and without coercion. This is crucial and very much the responsibility of the practitioners concerned.
Response to Questions 25 to 38 in the Issues Paper

25. Should Voluntary Assisted Dying (VAD) be allowed in Queensland? Why/why not?

DWDQ strongly supports the legalisation of Voluntary Assisted Dying in Queensland. The reasons for this are:

- Respect for autonomy and self-determination;
- Relief of suffering;
- Legal clarification for practitioners, patients and relatives regarding the laws of Double Effect and issues around palliative sedation;
- Making any end of life interventions transparent with appropriate process;
- Reducing suicide rates and illegal interventions by friends or family;
- Overwhelming community support even across religious lines;
- No evidence of legislative ‘slippery slope’ in overseas legislation produced so far.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

Voluntary Assisted Dying is the process by which a competent person receives assistance to die at a time and in circumstances of their choosing through the provision and/or the administration of a substance by a doctor. The purpose and intention of the administration of a substance is the ending of the patient’s life, in order to relieve suffering that the patient deems to be intolerable.

- The patient must have been offered and had explained existing options for active medication treatment and have rejected these.
- The patient’s request must be voluntary, fully informed, enduring but able to be withdrawn and not made under any duress.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

Clearly the doctors and nurses who are members of our DWDQ committee are all supportive of Voluntary Assisted Dying legislation. Even the AMA’s national poll indicated that if VAD was legalised, most responding doctors said they would be prepared to be involved.

Further, a survey by ‘Australian Doctor’ showed that of 366 doctors and 26 nurses, 65% supported legal reforms allowing patients to end their own lives and 49% would be willing to assist patients to take their own lives.  Ref 17

28. If there is to be a VAD scheme, what features should it have?

The person:

- must usually be aged at least 18 years, but please see exceptions listed in questions 30 below;
- must have been a resident of Queensland for not less than 3 months;
- must have been assessed by two doctors but only requires referral to a specialist if there are questions about treatment or prognosis;
- must be deemed mentally competent by the two practitioners;
- must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal OR chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to the person;
- is encouraged to discuss their decision with their family members, but there is no obligation to do so;
• must have been informed of and have explored all other treatment options reasonably available;
• must make two requests, oral and written to their doctor or by other means if the person is unable to speak or write. At least one of the requests should be with no other person except the doctor present.
• must re-confirm their request once all conditions have been met;
• can withdraw their request at any time;
• a doctor is to prescribe a lethal oral medication/s, or in the event the person is unable to swallow, a doctor may administer a lethal injection.

29. Are there aspects of VAD schemes in other jurisdictions that should or should not form part of any potential VAD scheme for Queensland, and why?

Whilst we are in broad agreement with the Victorian VAD model, DWDQ believes that medical personnel and Palliative Care specialists should be able to initiate a discussion about Voluntary Assisted Dying with their patients, as an option. This is in keeping with trusted doctor-patient relationships ethically involving discussion of all available options and outcomes. Safeguard against coercion by a doctor would exist elsewhere in a Queensland VAD Act based on the Victorian Assisted Dying Act 2017 which clearly states that coercion is an offence with penalty of up to 5 years imprisonment.

DWDQ believes that medical personnel and Palliative Care specialists should be able to initiate a discussion about Voluntary Assisted Dying with their patients as an option.

30. Who should be eligible to access VAD and who should be excluded?

CRITERIA FOR ELIGIBILITY

1) Illness eligibility;

DWDQ recommends 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’.

Canadian law states that for a patient to have a grievous and irremediable medical condition eligible for assisted dying, they must meet all the following 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 or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable;
• 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. Ref 18

Eligibility criteria in Victoria are very tight recommending an expected progression to death within six months (twelve months for neurodegenerative diseases). Prognostications are notoriously incorrect and DWDQ believes such timelines in this legislation would be inappropriate and that the Canadian approach has more merit.

2) Age eligibility

Most VAD legislations around the world have an age limit of 18 and over. Our view would be that consideration should be given to competent adolescents who, with the consent of their parents, wish to end their pain and suffering. DWDQ does not have sufficient experience in the treatment and management of young people to make a firm recommendation about this
but certainly in the Netherlands adjustments have been made to the legislation to allow for young people to have input into this decision-making process. We would recommend the Inquiry give serious consideration to this so that the suffering of adolescents is addressed.

3) Residential eligibility

With regard to length of time required as a resident, DWDQ recommends a minimum of three months as a resident in Queensland. Longer periods may unfairly exclude those with rapidly progressive disease following diagnosis which was unknown at the time of taking up residency.

31. Should the scheme by limited to those aged 18 and over? If so, why? If not, why not?

Age limitations were discussed in our response to question 30 above. Young people are often very cognisant of their condition and articulate in presenting their views. Advice from paediatricians, parents and young people would be of great assistance in developing an appropriate policy.

32. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

Broad eligibility is addressed in question 30.

At public meetings held by DWDQ around Queensland, the prospect of people with impaired cognitive function being excluded from this legislation was passionately disputed. Whilst this is a difficult issue to deal with, it is of such community concern that we would believe the Inquiry should give it special consideration.

Only the Netherlands allows for Medical Assistance In Dying (MAID) in the absence of contemporaneous capacity. It is done under the circumstances of valid Advance Health Directives written at a time when the person has capacity and expresses the desire to be assisted to die under a particular set of future circumstances. This would involve the very particular advance directives with also the appointment of an Enduring Health Decision Maker who is given the authority to initiate the Voluntary Assisted Dying process at a time which fits with the wishes of the person.

Whilst this legislation may be difficult, the issue is of such importance and such magnitude that we believe it requires special attention. Robust procedures and processes would be required to safeguard patients who have initiated such an advance directive.

33. What features should be included in a process to allow a person to legally access VAD?

DWDQ supports the Voluntary Assisted Dying legislation in Victoria with regard to assessment and documentation relating to requests, protections from liability for those who participate, and appropriate review mechanisms as listed in the Victorian Act.

34. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

Safeguards as outlined above in 28.

35. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

Counselling should be offered but not compulsory.
36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones

- Minimise delays from the time of request for VAD
- The person requesting VAD should be able to choose where they die e.g. at home or in a nursing home rather than a hospital.
- The service must be decentralised to cater for people living in rural, regional and remote areas

37. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

Legislation to allow VAD must not compel health professionals with conscientious or religious objection to provide assistance to people seeking VAD. VAD is about personal choice and the choice to participate should extend to health professionals. DWDQ also supports health services, including Palliative Care Services, not being forced to provide VAD services.

Health professionals are entitled to their beliefs on VAD, but they must not force their beliefs on others, including their patients.

“Personal objections must not present an impediment to those lawfully seeking assistance to die.” Ref 19

38. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

DWDQ supports the creation of a register of medical practitioners so people can knowingly access a doctor who will assist them.

DWDQ believes that a VAD law must allow for personal conscientious objection by health professionals who do not support VAD, but further believes that those objecting to VAD should be obliged to refer requests for VAD to participating health professionals within 24 hours. The register would be of assistance here.

DWDQ is aware that some private hospitals may choose not to participate in providing VAD services. Those hospitals receiving requests for access to VAD from their patients should refer such requests to compliant institutions and arrange transfer within 24 hours.

DWDQ recommends the legal requirement for all institutions to disclose VAD position and protocol following VAD requests prior to inpatient admission.
Summary

DWDQ makes the following recommendations:

1. That the Parliamentary Inquiry recommends Voluntary Assisted Dying legislation for the people of Queensland.

2. That the Queensland VAD legislation would be broadly similar to that of Victoria.

3. Areas of difference from the Victorian legislation that we suggest are:

   Canadian law states that for a patient to have a *grievous and irremediable medical condition* eligible for assisted dying, they must meet all the following 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.  

   a. Residential eligibility period in Queensland be three months;
   b. Age eligibility - there is broad acceptance of the age of eighteen or over as eligible, but we recommend consideration for age exempt requests by competent minors.
   d. Assessment would be by two doctors. Referral to a specialist in the area of expertise is required only if the doctor assessing requires further advice or clarity.
   e. Doctors are able to initiate discussion of Voluntary Assisted Dying.
   f. A doctor is to prescribe a lethal oral medication/s, or in the event the person is unable to swallow, a doctor may administer a lethal injection.
   g. Training of clinicians who will provide services in this area will be required.
   h. There is a need for education of the community regarding the provision of this service and the use of advanced directives and enduring powers of attorney.
   i. An appropriate review process with annual reporting will be required.

We have found the management of end of life for patients with diminished cognitive ability to be an issue of major community concern, anxiety and focus.

The DWDQ committee asks that the Inquiry pays special consideration to the development of specific Advance Health Directives for patients with diminished cognitive ability, to be used in combination with the nomination of an Enduring Health Decision Maker to achieve non-contemporaneous Voluntary Assisted Dying.

Dying With Dignity Queensland supports the expansion of Palliative Care Services and respectfully requests that the Inquiry Committee recommends increasing the funding to Palliative Care, as has happened in Victoria, specifically for regional, rural and remote areas.
Thank you for your consideration of our submission. For many people wishing the right to Voluntary Assisted Dying, their time is running out. None of us know when this will be an issue for ourselves or our families. Please do all you can to expedite this reform. It is an issue for us all. Representatives of our committee would be happy to speak as witnesses to the Inquiry Committee at a public hearing.

DWDQ committee members
Jos Hall – Registered Nurse 48 years (retired)
Dr. Jenny Brown – Consultant Physician.
Phyllis Wagner – High School teacher (retired)
Anyse Horman – Small business owner
Dr. Sid Finnigan - Medical practitioner 37yrs
Jeanette Wiley – Registered Nurse 50 years, Palliative Care Nurse 20 years (retired)
Phil Browne – Registered Nurse 37 years, Palliative Care Nurse 7 years
Denise Sauer - Corrections Officer (retired)
References


2,3 The Report by the Royal Society of Canada Expert Panel on End-of-Life-Decision Making 2011 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/ (Conclusion to chapter 3)


8 http://drs4assisteddyingchoice.org/


13 Victorian Coroner’s report

14 Victorian Coroner’s report

15 Desmond Tutu — https://www.theguardian.com/society/2016/oct/07/desmond-tutu-assisted-dying-world-leaders-should-take-action


Appendix A - Historic rise in public support (from page 2)

Recent decades have shown a marked growth in support for Voluntary Assisted Dying, as demonstrated in these Roy Morgan Research polls commencing in 1962, which asked this identical question:

Polls by the Newspoll organisation during the last 12 years, suggest there is 80 – 85% support for Voluntary Assisted Dying.

This overwhelming public support shown in the Newspoll poll is consistent with the 85% support obtained in the 2017 Roy Morgan poll.

These are credible randomised polls by professional polling companies. The below polls were of 2,423, 1,201 and 2,521 respondents respectively.
Appendix B – results of Queensland-wide survey conducted by ReachTEL on the evening of 28 August 2018 showing public support (from page 2)

As far as DWDQ is aware, there has only been one credible randomised Queensland-specific poll on Voluntary Assisted Dying, by a professional polling organisation.

The ReachTEL poll of 834 respondents included responses from all 93 QLD electorates. It showed an overwhelming support for Voluntary Assisted Dying, in Queensland including:

- 79.1% support for law reform
- Overwhelming support across all ages and both genders

Below are some of the key findings of the ReachTEL Queensland-wide poll:

**Question:** Thinking about voluntary assisted dying, sometimes known as voluntary euthanasia, where terminally ill people with no hope of recovery are given the choice of legally terminating their life with the assistance of medical professionals. Do you support or oppose voluntary assisted dying for people in those circumstances?

<table>
<thead>
<tr>
<th>ReachTEL Poll</th>
<th>Total</th>
<th>Female</th>
<th>Male</th>
<th>18-34</th>
<th>35-50</th>
<th>51-65</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support</strong></td>
<td>79.1%</td>
<td>79.7%</td>
<td>78.6%</td>
<td>88.2%</td>
<td>80.7%</td>
<td>83.6%</td>
<td>75%</td>
</tr>
<tr>
<td><strong>Oppose</strong></td>
<td>16.6%</td>
<td>15.2%</td>
<td>18.3%</td>
<td>8.8%</td>
<td>8.3%</td>
<td>13.9%</td>
<td>20.2%</td>
</tr>
<tr>
<td><strong>Unsure / Don’t Know</strong></td>
<td>4.2%</td>
<td>5.1%</td>
<td>3.2%</td>
<td>2.9%</td>
<td>6.2%</td>
<td>2.5%</td>
<td>4.9%</td>
</tr>
</tbody>
</table>

**Question:** How urgently do you believe the state government should address the possibility of introducing voluntary assisted dying laws for terminally ill people?

<table>
<thead>
<tr>
<th>ReachTEL Poll</th>
<th>Total</th>
<th>Female</th>
<th>Male</th>
<th>18-34</th>
<th>35-50</th>
<th>51-65</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Urgently</strong></td>
<td>78.3%</td>
<td>79.2%</td>
<td>77.3%</td>
<td>85.3%</td>
<td>81.2%</td>
<td>81.2%</td>
<td>74.9%</td>
</tr>
<tr>
<td><strong>Not at all Urgent</strong></td>
<td>21.70%</td>
<td>20.80%</td>
<td>22.70%</td>
<td>14.70%</td>
<td>19.40%</td>
<td>18.80%</td>
<td>21.50%</td>
</tr>
</tbody>
</table>
Appendix C – Religion (from page 2)

- **A 2007 Newspoll survey** of 2,423 respondents found 74% of Catholic respondents and 81% of Anglican respondents surveyed thought doctors should be allowed to provide “a lethal dose to a patient experiencing unrelievable suffering and with no hope of recovery.” [REFERENCE](https://cdn.theconversation.com/static_files/files/4/76079-2017-04-24-polling-Dying_With_Dignity_Summary_Report_V2.pdf?1518043685)

![Graph showing 2007 and 2012 Newspoll results](image)

- **A 2012 Newspoll survey** of 2,521 respondents found that 77% of Catholic respondents and 88% of Anglican respondents said Yes to the following question - “Thinking now about voluntary euthanasia. If a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose, or not?”

![Graph showing doctor's role in providing lethal dose](image)

Source: Newspoll 2012, Dying With Dignity report

Appendix D – Terminal Sedation (from page 3)

Terminal Sedation

The Western Australia Parliament *End of Life Choices* report found that terminal sedation is a largely unregulated practice and this leads to inconsistency, varying effectiveness of treatment, and possible illegal practices. This leads to some major ethical and legal concerns that do not exist with VAD, due to its legislative framework.

Inadequate guidelines and legal documentation.

Terminal sedation was found to be an unregulated practice that was not always recorded as such in patient medical records.

"Given the evidence received by the committee that the practice is not regulated, nor specifically noted in patient medical records." WA Government report, page 129

"It is also concerning that there is a lack of recording and data collection regarding this form of medical treatment." WA Government report, page 129

In addition to potential legal implications, this will lead to varying effectiveness of terminal sedation – including NOT relieving symptoms - depending on who is administering it, and the medications/s and doses provided:

Uncertainty regarding the legality of terminal sedation could lead to withholding treatment.

Some health professionals believe that terminal sedation is illegal as there is no legislation, or apparent clear regulation to guide the use of this practice.

Health professionals understand that terminal sedation involves withholding food, fluid and rendering the person unconscious until their hastened death. Therefore, it’s reasonable that some health professionals (as well as family members of the patient) could fail to see a distinction between terminal sedation and Voluntary Assisted Dying.

Knowing that Voluntary Assisted Dying is not yet legal, health professionals could - due to either ethical considerations, or fear of prosecution - intentionally under-treat their patient’s intractable symptoms thereby leaving their patient in a state of intolerable suffering.

"The uncertainty among some health professionals regarding the legal status of terminal sedation at the end of life may lead to patients receiving less than optimal treatment and continuing to suffer pain and other symptoms." WA Government report, page 129

"There remains some confusion among health professionals as to the legal status and reasonableness of the clinical practice of terminal sedation and this confusion is likely to result in the denial of adequate symptom relief to some patients at end of life." WA Government report, page 130

Uncertainty regarding if legal consent has been obtained for Voluntary Assisted Dying.

It’s a legal requirement that consent must be obtained prior to any medical treatment being commenced.

There are serious concerns as to "whether the patient (or patient's family) are involved in the decision-making process, particularly where consent is obtained before this kind of sedation is provided” WA Government report, page 129

"It is of concern to the committee that many patients at the end of life, and their family members are unaware of this treatment." WA Government report, page 129

This consent must be fully "informed consent", whereby it is completely and unambiguously understood, by the patient and/or their family that the expected outcome of terminal sedation is unconsciousness and the death of the patient. 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.