



The Uniting Church in Australia  
QUEENSLAND SYNOD

Consultation Paper

# **Voluntary Assisted Dying Queensland Synod 2019**



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*What are we witnessing to in relation to the experience of suffering and pain and our treatment of the vulnerable?*

*This is a complex question with no easy answers. However, a mission framing of this issue reminds us that our task is not academic or only about advocacy, but is a call to live as faithful disciples of Jesus Christ in pointing to and participating in God's mission in the world.*

# Contents

Introduction	4
Consultation Group	5
Submissions	5
Definitions	6
Summary of Consultation Paper	7
Theological Reflection	7
Voluntary Assisted Dying Around the World	7
Death and Dying in Australia	8
The Uniting Church and Other Churches Response to Voluntary Assisted Dying	8
Options for the Synod	8
1. Queensland Synod Current Position	10
2. Theological Reflection	11
3. Voluntary Assisted Dying Around the World	14
4. Voluntary Assisted Dying in Australia	22
5. Death and Dying in Australia	26
6. Australian Community Views	33
7. Uniting Church and Other Churches Responses to Voluntary Assisted Dying	36
8. Options for the Synod	40
9. Further Reading	41
10. References	42

# Introduction

The position that the Uniting Church Synod of Queensland currently holds regarding ‘Euthanasia’ was adopted over two decades ago. Since this time, community attitudes and the Australian legislative environment has significantly changed. In November 2017, the Victoria Parliament passed the *Voluntary Assisted Dying Act 2017*, which will come into effect in 2019. The Queensland Government has announced an inquiry into aged care, end-of-life and palliative care and will report to the Legislative Assembly by 30 November 2019. As a result of these changes, the Moderator has requested an update of the Synod’s current position.

This paper and consultation is focused on voluntary assisted dying as described in the definitions section. We acknowledge that there are a number of other related and complicated issues that people experience at the end of life, which often come up in conversation about voluntary assisted dying. While important, these issues are beyond the scope of this consultation process, which seeks to update the Synod’s position on voluntary assisted dying.

Voluntary assisted dying is a complex and highly sensitive issue. For Christians, this issue touches on complex theological areas such as the nature of suffering, death, freedom, what it means to be human, the nature of community, autonomy and free will, human dignity and worth, how we treat the vulnerable in society, and many other issues.

The position the Synod adopts on voluntary assisted dying will have significant implications for its agencies, which have services in hospitals, palliative care, end of life care, disability and aged care.

As the Synod considers this Consultation Paper, I encourage Uniting Church members to frame their response in terms of the nature of the church’s mission in being called to witness to and participate in the mission of God. A key mission question in relation to the Synod’s position on voluntary assisted dying is:

*What are we witnessing to in relation to the experience of suffering and pain and our treatment of the vulnerable?*

This is a complex question with no easy answers. However, a mission framing of this issue reminds us that our task is not academic or only about advocacy, but is a call to live as faithful disciples of Jesus Christ in pointing to and participating in God’s mission in the world.

I encourage you to prayerfully consider this paper and contribute to this consultation.

**Rev Dr. Adam McIntosh**

Chair of the Consultation Group

# Consultation Group

The consultation group members are Rev Dr Adam McIntosh (Associate Director of Mission, UnitingCare), Sue Hutchinson (Synod Research and Policy Officer), Rev. Chris Crause (Presbytery Minister, Mary Burnett Presbytery), Fran Larkey (Relationship and Innovation Manager, Wesley Mission Queensland), Victoria Lorrimar (Lecturer Systematic Theology, Trinity College Queensland), Sarah Lim (Director Office of the CEO, UnitingCare), Michael Krieg (General Manager, The Wesley Hospital) and Anne Curson (Policy Analyst, UnitingCare).

## Submissions

Submissions to this consultation are due before close of business on 9 March 2019.

Submissions should address the following four questions and be no longer than 400 words in total. Please include your contact details and your connection to the Uniting Church.

After carefully considering the Consultation Paper, please respond to the following questions:

1. Should the Synod adopt option 1?  
What comments do you have in support of this?
2. Should the Synod adopt option 2?  
What comments do you have in support of this?
3. Should the Synod adopt recommendations 1–5?  
What comments do you have in support of this?
4. Are there any other recommendations that the Synod should consider? Please clearly state the recommendation and rationale.

## Submissions to be made to:

Rev. Dr. Adam McIntosh  
UnitingCare  
GPO Box 45, Brisbane QLD 4001  
**Email:** adam.mcintosh@ucareqld.com.au  
**Phone:** 0448 572 953

# Definitions

There are many different definitions and ways of talking about voluntary assisted dying. In this paper, we have made a conscious decision not to use the word suicide when describing aspects of voluntary assisted dying, although we acknowledge it is often used in this context. While mental health impacts people at the end-of-life, this paper and conversation is focused on people's desire to die well and their fears and experiences of suffering when they face a terminal illness.

Term	Definition	Other Common Terms
Voluntary assisted dying	<p>A doctor or other person provides drugs, at a competent person's request, which they can take themselves to intentionally end their life.</p> <p>A doctor or other person intentionally hastens death by administering drugs, at the request of a person with decision making capacity.</p>	<ul style="list-style-type: none"> <li>• Physician assisted suicide</li> <li>• Voluntary assisted suicide</li> <li>• Euthanasia</li> <li>• Active voluntary euthanasia</li> <li>• Voluntary euthanasia</li> </ul>
Ending a life without explicit request	A doctor or another person administers a medication or performs another action to intentionally end life, either without a mentally competent person's request or the person is non-competent and unable to make a request.	<ul style="list-style-type: none"> <li>• Non-voluntary euthanasia</li> <li>• Involuntary euthanasia</li> </ul>
Withdrawal of treatments	<p>Withholding or withdrawing overly burdensome medical treatment from a person because of medical futility, non-beneficial care, or at the request of a competent person or a person without decision making capacity's surrogate decision maker.</p> <p>The intention of this is not to hasten death, but to provide comfort care.</p>	<ul style="list-style-type: none"> <li>• Refusal of treatment</li> <li>• Limiting of life-sustaining treatments</li> </ul>
Providing pain medication to relieve suffering	<p>Doctors provide pain medication to people with the intention to relieve their suffering.</p> <p>Depending on a person's condition, this may hasten death, but the primary purpose is to provide comfort and relieve suffering.</p>	
Advanced health directive	A written instruction, describing the medical care a person wants if they become unable to make or communicate their own health care decisions. The laws governing these vary between States and Territories and can be complex.	
Palliative care	<p>Palliative care is an approach that improves the quality of life of patients and their families facing a life threatening illness.</p> <p>Relief and prevention of suffering occurs through early identification and thorough assessment and treatment of pain and other physical, psychosocial and spiritual concerns.</p>	



# Summary of Consultation Paper

## Theological Reflection

- We reaffirm the desire to enter into and identify with the experience of those who are suffering and vulnerable, expressed in the Synod 1996 Report.
- The Christian faith upholds the sanctity of life, yet this must not extend to a fear of death and mortality. The hope of resurrection and eternal life places biological death in proper perspective.
- Life is both a gift of the Creator, and a task or responsibility. We wrestle with what it means to have freedom and responsibility in the decisions we make.
- Humans are made in the image of God, which means that we are made for community and this is also the source of our worth. We need to balance our individual needs and desires with those of the community in decision-making.
- Christians are called to take care of our sick, weak, poor and vulnerable. Though we may experience caring or being cared for as a 'burden', this is not ultimately true.
- Loving the other means reducing their pain and suffering as far as possible, recognising that a Christian vision of the good is more than just the absence of pain and suffering.

**“ I have to remind myself that the acronym ... can easily disguise or soften what we are talking about, which is how we live and how we die. This is about death, assisting someone to die, to hasten death. I stumble on what language to use, words like little stones in my mouth at times.**

*Roseanne Beuthin – Medical Assistance in Dying Coordinator, Canada<sup>1</sup>*

## Voluntary Assisted Dying Around the World

- The slippery slope argument continues, but has not been fully realised. The rates of voluntary assisted dying in Oregon and the Netherlands show no evidence of heightened risk for vulnerable groups such as racial or ethnic minorities. Debate continues around access to voluntary assisted dying for children and young people, people with dementia, and people with psychiatric illnesses.
- When available, voluntary assisted dying makes up a small proportion of all deaths. Between 0.3% and 4.6% of all deaths where it is legal.
- The most common disease people have when accessing voluntary assisted dying is cancer.
- Once legalised the number of voluntary assisted dying cases increases over time.
- Requests for voluntary assisted dying are complicated and they're not always about physical pain. The most common reasons for people to request voluntary assisted dying are loss of autonomy and dignity and the inability to enjoy life.
- People's requests and interest in voluntary assisted dying can change over time. Requests for voluntary assisted dying reflect a complex range of personal, psychological, spiritual, social, cultural, economic and demographic factors.
- Having access to voluntary assisted dying is important to people and can support a family's grief processes.
- People suffering dementia and psychiatric illnesses are starting to access voluntary assisted dying, but only in two countries. There has been a small but increasing number of cases in the Netherlands and Belgium where people suffering dementia or psychiatric illnesses have requested and been granted access to voluntary assisted dying. But this has not happened in all jurisdictions where people can access voluntary assisted dying.

## Death and Dying in Australia

- Australians are living longer.
- Life expectancies are: 84 years for women and 78 years for men.
- Death often follows a chronic illness.
- People often have more than one chronic illness at once and can experience symptoms for a long time.
- The terminal phase of a person's illness can last as long as one to two years.
- There is a mismatch between where people prefer to die and what support is available.
- Values and expectations around what happens at death are changing.
- Palliative care gives people positive death experiences, but is not consistently available to everyone.
- Advanced care planning and directives can provide greater choice and control, but only 14% of Australians have them.
- Palliative care should be seen as a core part of the Mission of the church to enable patients and their families to receive adequate support in the final months of life.

## The Uniting Church and Other Churches Response to Voluntary Assisted Dying

- There is currently no national position on voluntary assisted dying in the Uniting Church in Australia.
- The Synod of Vic/Tas is currently exploring their position on voluntary assisted dying.
- No other Synod, apart from Queensland, has developed a position on voluntary assisted dying.
- Although there are different ways of expressing it, the Salvation Army, Catholic Church and Anglican Church are opposed to voluntary assisted dying.
- No mainline Christian denomination within Australia currently supports voluntary assisted dying.
- There is a strong advocacy for well resourced and high quality palliative and end of life care across all churches.

## Options for the Synod

The following options present two different positions on voluntary assisted dying the Synod could take.

### Option 1

The Uniting Church in Australia – Queensland Synod affirms the God given dignity and worth of every human life. It recognises that the experiences of end of life in some situations can cause significant distress for the person dying, their families and care staff. While the church does not support the legalisation of voluntary assisted dying, it acknowledges that there are rare circumstances where people with a terminal illness can experience unbearable suffering. In these circumstances, if voluntary assisted dying is legalised, and a person chooses to access this, the church is called to offer a compassionate and pastoral response to people and families. Our facilities and staff will not participate in acts specifically designed to end a person's life.

### Option 2

The Uniting Church in Australia – Queensland Synod affirms the God given dignity and worth of every human life. It recognises that the experiences of end of life in some situations can cause significant distress for the person dying, their families and care staff. It acknowledges that there are rare circumstances where people with a terminal illness can experience unbearable suffering.

In these circumstances, if voluntary assisted dying is legalised, and a person chooses to access this, the church is called to offer a compassionate and pastoral response to people and families. Our agencies will ensure that the decision of the person is respected and can be carried out in our facilities.



## Other Recommendations

That the Synod -

1. Receives the report on Voluntary Assisted Dying.
2. Affirms the critical importance of high quality, well resourced and accessible palliative and end of life care that responds to the physical, psycho-social and spiritual needs of people at the end of life. The church undertakes the following actions:
  - I. Advocate for a well resourced and flexible system that consistently meets people's needs and preferences for care;
  - II. Continue to provide high quality and accessible palliative care, responsive to the pastoral and spiritual needs of the people we serve, as central to our mission as the church.
3. That in the case of the legalisation of voluntary assisted dying in Queensland, to request Wesley Mission Queensland and UnitingCare to develop a policy and practice approach in light of the Synod's position (Option 1 or Option 2) and any legislative requirements.
4. That in advocating to government regarding legalisation of voluntary assisted dying in Queensland, the church strongly recommends provisions for conscientious objection, for individuals and organisations, be included in any proposed legislation.
5. Thank the Consultation Group for their work.

**“ Requests for voluntary assisted dying reflect a complex range of personal, psychological, spiritual, social, cultural, economic and demographic factors.**

# 1. Queensland Synod Current Position

The current Queensland Synod position on 'Euthanasia' was approved at the 19th Synod in 1996. A report was received from the Synod Bio-Ethics Committee titled A Christian Ethical Response to Euthanasia.

The minutes from the 19th Synod resolved:

That the Synod - 96.100

1. Receives the report of the Synod Bio-Ethics Committee, (Volume 1, pp 47-53); and the Supplementary Report (Volume 2, p 51)

## (consensus)

2. Recommends the report, "A Christian Ethical Response to Euthanasia", as a contribution to the discussion on euthanasia within and beyond the Synod;

## (consensus)

Informs the Department for Community Service about its opposition to the legalisation of active voluntary euthanasia and encourages Divisions to use the Report as the basis for ongoing discussions and policy making with staff and volunteers; and

## (formal majority)

3. Requests the Moderator to -
  - I. inform the State Attorney General of the Synod's opposition to the legalisation of active voluntary euthanasia; and
  - II. request the State Health Minister to prepare and distribute appropriate guidelines which affirm the right of patients to refuse treatment and not to expect the active intervention by medical and associated staff to end their lives.

## (formal majority)

## Summary Statement from 1996

*At this stage, the Queensland Synod Bioethics Committee is agreed that active voluntary euthanasia and patient assisted suicide present substantial moral problems. It recognises the dilemmas and stresses facing many caring staff employed in Uniting Church agencies, as well as the distress often experienced by the sick, the infirm, the disabled and their loved ones.*

*While some members of the Committee acknowledge that there are individual cases in which active voluntary euthanasia may be appropriate, such cases do not readily form the basis for the legalisation of euthanasia in Queensland at this time.*

*The Committee is committed to monitoring any changes in legislation proposed by the Queensland Government or individual Members of the Legislative Assembly to ensure that the processes of consultation and the establishment of safeguards are both rigorous and compassionate.*

*There was a consensual position within the Committee in opposition to the practice of involuntary euthanasia.*

## 2. Theological Reflection

### Synod 1996 Report: A Christian Ethical Response to Euthanasia

The 1996 report considered insights from Christian theology and tradition to undergird policy principles that could be expressed in a commonly-understood manner in the broader society. This needs to be a reflection of the distinctive tradition and ethos of the Uniting Church, rather than merely providing another sampling of opinion from the general community.

The 1996 committee reaffirmed the initial principles for applying the New Testament ethic to the dilemma of voluntary assisted dying as accepted previously:

1. To define love as the will to act out of one's total concern for the total good of the other;
2. To make the best possible decision that one can in response to God's demand for integrity and faithfulness to one's duty;
3. To understand that when we decide that we ought to act in ways which fall short of the full demands of love, we do so on our own responsibility, not God's;
4. Having done what we must do, having done all we can do, we still know we fall short of God's perfect will for us, and that we must rely on His grace (undeserved loving kindness);
5. To act and live in the spirit of Micah 6: 8 - to do justly (to do what is right and fair), to love mercy (to share Christ-like compassion), and to walk humbly with God (to live in the presence of the all-pervading spirit of the Redeemer and Creator God).

These principles are permeated by a sense of solidarity and empathy - that is, a desire to enter into and identify with the experience of those who are suffering and vulnerable. The challenge in applying these principles involves hearing those who seek voluntary assisted dying, but also understanding how any legislation allowing it impacts the most vulnerable.

The 1996 report also noted that particular attention needs to be given to the relevant theological questions of:

- The Christian view of human life and the so-called 'sanctity of life.' This needs to include issues around human dignity;

- The meaning of freedom/autonomy especially in light of the heavy emphasis placed upon the 'voluntary' component of this action;
- From whose perspective should one enter into situations of extreme suffering? In other words, to what extent can the voices of those who are suffering in this situation be deemed authoritative in ethical deliberation?

These theological questions all align around several tensions within which ethical deliberation over voluntary assisted dying occurs.

### Sanctity of Life and Acceptance of Mortality

Our celebration of Easter reminds us that Christianity is a life-affirming faith. Upholding the sanctity of life recognises that life itself is a gift from the Creator. The sanctity of life must not extend to a fear of death, however, as the hope of resurrection and eternal life places biological death in proper perspective. Furthermore, an affirmation of life should also respect human finitude, which includes death. We can recognise and respond compassionately to the fear of death that many people experience, but a pastoral response will remind Christians of the assurance of eternal life and peace that is found in Christ.



*With advancements in medical knowledge and technology, we can now potentially exercise greater control over aspects of our life than in previous eras.*

## Life/Creation as Gift or Task

The affirmation of life as God's gift to creation prompts various responses. For the majority of human history we have considered the time and circumstances of our birth and death to be in God's hands alone. Indeed, before contraception was widely available even the timing of children was largely beyond our control. The theologian Küng points out that although we recognise life as a gift of the Creator, we may also understand it in terms of a task or a responsibility<sup>2</sup>. The extent to which humans participate in God's ongoing creation is a long-lasting debate in theology. With advancements in medical knowledge and technology, we can now potentially exercise greater control over aspects of our life than in previous eras. Suicide has always been an option, but careful medical management of illnesses and increasing social acceptance of voluntary assisted dying is a more recent development. These developments are therefore relevant for our understanding of the tension between life as a gift and the responsibility that accompanies it - if we acknowledge some degree of freedom and responsibility to make our own decisions, then might this extend to the time and manner of our own death?

## Individualism and Community

Humans are made in the image of God, and this is often understood to mean that we are fundamentally relational, i.e. we are made for community. As Christians, we need to consider what constitutes freedom, and whether autonomy is the primary goal. The desire for independence and to not be a burden to others owes more to the influence of Western individualistic culture than a Christian ethic. An unwillingness to be dependent or be cared for by others, or perhaps to be obligated to care for loved ones ourselves, sits in uneasy tension with a call to take care of our sick, weak, poor and vulnerable. This social context may be a constraint on the freedom of an individual to choose 'voluntary' assisted dying. People sometimes express fear about being a 'burden' in the end stages of life, and the challenges of being cared for or caring for the terminally ill must not be trivialised. However, by grace we do not view such responsibilities as ultimately a burden.

The freedom to choose and to pursue our own ends is the ultimate good according to a secular vision of human flourishing. The ultimate good from a Christian perspective is the future promised by God through the redemptive work of Christ, in fulfilment of God's purposes for creation. These understandings of the 'good' are not always in conflict, but neither are they always in harmony. Furthermore, for Christians, dignity is not reducible to autonomy, but stems from the fact that we are created by God in the divine image. In the debate surrounding voluntary assisted dying there are often appeals to the notion of 'dying with dignity'. To be able to choose the timing and means of death to avoid what may otherwise be experienced as a painful, difficult, messy or even humiliating death, recognising that these assessments are subjective ones. Locating human dignity in our createdness means our worth is intrinsic and our dignity is underwritten by a reality that is untouched by the circumstances of our lives or death. This is held in tension with the human impulse to associate lesser or greater dignity with particular circumstances i.e. an extrinsic sense of worth.

## Suffering and Compassion

Arguments against voluntary assisted dying must not appeal to notions of redemptive suffering, the idea that suffering in and of itself always produces character and leads to a greater good. Suffering may be redemptive if chosen, but coerced suffering under the guise of redemption is neither respectful nor compassionate toward those experiencing it. Suffering is part of the human condition as a result of fallenness, but this does not mean that Christians are resigned to suffering. Whatever understanding of sin is subscribed to, we are called to work against its consequences. Loving the other means reducing their suffering as far as is possible, while acknowledging that human existence in this period in salvation history cannot be entirely free of pain or suffering. The understanding of compassion as solely concerned with the relief of suffering is premised on the utilitarian pursuit of optimal happiness. Whereas a Christian account of the good is more comprehensive than the absence of pain and suffering in the present, anticipating a new creation in which these negative experiences are finally eradicated. In the present, compassion sometimes means coming alongside others in their suffering, though we seek to alleviate it as far as we can.

## Key Points

***We reaffirm the desire to enter into and identify with the experience of those who are suffering and vulnerable.***

***Humans are made in the image of God, which means that we are made for community and it is also the source of our worth.***

*We need to balance our individual needs and desires with those of the community in decision-making.*

***The Christian faith upholds the sanctity of life, yet this must not extend to a fear of death and mortality.***

*The hope of resurrection and eternal life places biological death in proper perspective.*

***Christians are called to take care of our sick, weak, poor and vulnerable.***

*Though we may experience caring or being cared for as a burden, this is not ultimately true.*

***Life is both a gift of the Creator, and a task or responsibility.***

*We wrestle with what it means to have freedom and responsibility in the decisions we make.*

***Loving the other means reducing their pain and suffering as far as is possible.***

*Recognising that a Christian vision of the good is more than just the absence of pain and suffering.*

# 3. Voluntary Assisted Dying Around the World

## *Voluntary assisted dying is currently legal in:*

- Canada (2016)
- The American states of:
  - California (2016)
  - Colorado (2016)
  - Hawaii (2018)
  - Oregon (1997)
  - Vermont (2013)
  - Washington (2008)
  - Washington DC (2017)
- The Netherlands (reporting from 1994, legalised in 2002)
- Belgium (2002)
- Luxembourg (2009)
- Switzerland (self-administered voluntary assisted dying is allowable under the 1942 Swiss penal code)

The following section examines key trends in countries where voluntary assisted dying has been legalised since the 1990s and 2000s. Understanding these trends is important, as they are often used in arguments both for and against voluntary assisted dying.\*

## **The slippery slope argument continues, but has not been fully realised.**

In debates around voluntary assisted dying there is often concern about what is called the “slippery slope”. The slippery slope refers to scenarios where legal voluntary assisted dying leads to an expansion of intentionally ending people’s lives without their request, often with a particular focus on risks to vulnerable groups.<sup>3</sup> Data from Belgium and the Netherlands show reported cases of life being ended without explicit request are decreasing over time.

This data is frequently used in arguments against voluntary assisted dying and must be examined carefully. In looking at these statistics, research has found:

*Although the absolute numbers are small, in half of these cases the decision has been discussed with the patient and in a quarter of cases the physician did not discuss the decision with either patient, relative, or other physicians.<sup>4</sup>*

In the United States, concern that vulnerable and marginalised groups would be pressured to take up voluntary assisted dying have not been borne out. People accessing voluntary assisted dying in the United States tend to be white, well-educated and well insured.<sup>5</sup>

*An evaluation of the rates of voluntary assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for vulnerable groups such as racial or ethnic minorities, compared with background populations. However, the first population-based study in Switzerland described that assisted suicide was associated with female gender and situations that may indicate greater vulnerability such as living alone or being divorced, although it was also associated with higher education and higher socio-economic position.<sup>3</sup>*

\* Note: Care must be taken when looking at assisted dying data and trends. Each number represented is a person's life, with their own story and cultural context. When governments produce statistical reports around assisted dying, it is not uncommon to see this information used in arguments both for and against the practice. Also, not all countries record information in the same way, so it can be difficult to compare across countries. To bring together information for this paper we have looked at original data sources and international comparisons from academic literature. In using academic literature we have looked for good quality analysis, which is open about its strengths and weaknesses. The data we are presenting provides a big picture view of assisted dying and has not been selected to justify a pre-determined position. If you see statistics that surprise you or you have more questions, we encourage you to review original sources and seek out discussions that include the personal, cultural and practice context surrounding the information presented.





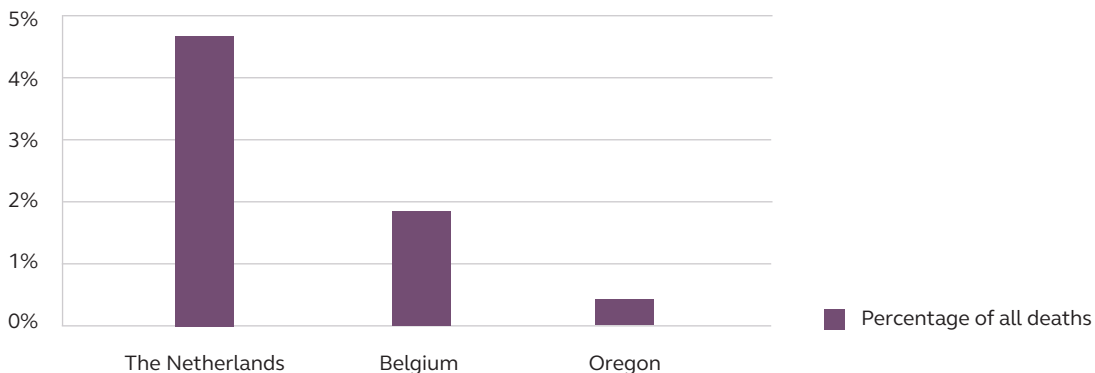
*In the countries where it is legal, voluntary assisted dying makes up between 0.3% and 4.6% of all deaths.<sup>5</sup>*

Debate continues around access to voluntary assisted dying for children and young people, people with dementia, and people with psychiatric illnesses. While voluntary assisted dying has been extended to some of these groups in the Netherlands and Belgium, they remain excluded in other countries whose laws have been operating for similar periods of time.

### **When available, voluntary assisted dying makes up a small proportion of all deaths.**

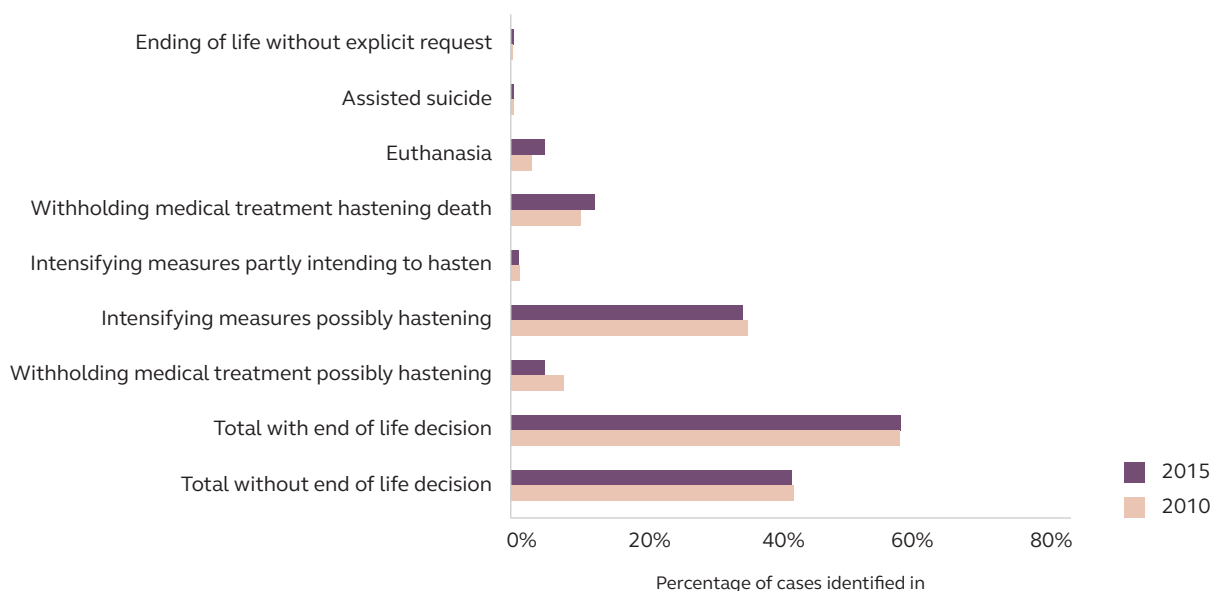
In the countries where it is legal, voluntary assisted dying makes up between 0.3% and 4.6% of all deaths.<sup>5</sup> This means that between 95% and 99% of people do not have medical assistance to explicitly hasten their deaths and rely on palliative care and other health support depending on their conditions.

#### **Voluntary Assisted Dying as a percentage of all deaths in three jurisdictions in 2015**



Source: Statistics Netherlands 2017<sup>6</sup>, European Institute of Bioethics 2016<sup>7</sup>, Oregon Health Authority 2018<sup>8</sup>

## Deaths and End of Life Decisions in the Netherlands 2010 and 2015



Source: Statistics Netherlands 2017<sup>6</sup>

### The most common disease people have when accessing voluntary assisted dying is cancer.

Cancer was the terminal illness for around 70% of voluntary assisted dying patients in the American states of Oregon and Washington, the Netherlands and Belgium. Other illnesses included neurodegenerative, respiratory, and cardiovascular diseases. In Belgium and the Netherlands, there are a small number of cases where people have dementia or psychiatric illnesses.<sup>5</sup>

### Once legalised the number of voluntary assisted dying cases increases over time.

Across all countries where the practice is legal, voluntary assisted dying deaths have increased over time, however they still only represent a small proportion of all deaths.<sup>5</sup> This may reflect cultural and generational shifts in people’s attitudes and values around choice at the end of life.

### Requests for voluntary assisted dying are complicated and they’re not always about physical pain.

The most common reasons for people to request voluntary assisted dying are loss of autonomy and dignity, the inability to enjoy life and other activities.<sup>5</sup> Research analysing people’s views of voluntary assisted dying found that:

*Unbearable suffering relating to psycho-emotional factors such as hopelessness, feeling a burden, loss of interest or pleasure and loneliness were at least as significant as pain and other physical symptoms in motivating people to consider voluntary assisted dying.<sup>9</sup>*

## Vignette 1: Motor Neurone Disease

Roger\* was in his early 40s and had motor neurone disease, which can affect a person's ability to walk, speak, swallow and breathe. When a person has this disease, their neurons stop working normally and their muscles gradually weaken and waste away.

Roger was referred to a hospital palliative care service for future care planning to manage his pain, difficulties breathing, loss of mobility, and distress surrounding his disease.

Roger was a real outdoors man and his suffering when thinking about his future with motor neurone disease was severe. He had two sons and did not want to leave memories of his decline embedded in their minds as they grew up. Roger knew he would completely lose his independence and felt life had lost all value. He could not imagine coping in this situation.

His preference was for voluntary assisted dying as soon as it could be arranged.

When Roger spoke to his doctor, his request was met with understanding and acknowledgment of the awfulness of his illness. He was asked to explain what it was about his illness that led him to want voluntary assisted dying. He said loss of manly independence, fear of suffocation and choking, the memories he would leave for his boys and the strain of care on his wife. When the doctor gently informed him it was not possible to carry out voluntary assisted dying, discussion around each of his fears took place.

It was important to try and give some control over management and treatment choices to Roger and his wife; to let him be 'the boss'. This meant they could choose not to have a range of available treatments if he was looking to allow life to end sooner rather than later.

He was reassured that if he make such choices his family would not be expected to endure alone in suffering and despair.

Roger decided he would not have any artificial feeding or breathing support. When he reached the point where these treatments could be used, he would instead use medication to reduce the associated suffering. He was reassured that the dose would match his distress and as his disease progressed his medication would be increased and life should end gently and in a dignified way. Roger completed an 'advanced care plan' and a 'do not resuscitate' form to reflect his wishes.

Roger had ongoing counseling, especially around the issues of masculinity, courage and dignity. Attempts were made to reframe these in the setting of his illness and how he could still set a manly example for his boys, despite suffering things like faecal incontinence. Roger received support in the community from nurses, a MND support group, the NDIS, and specialist palliative care nurses.

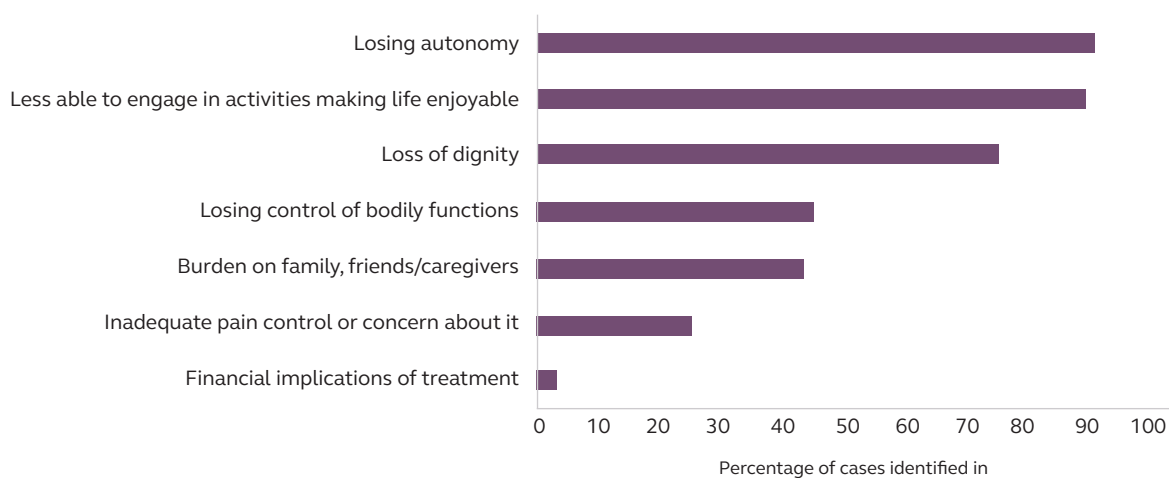
Roger experienced suffering on many occasions, but it was almost always attended to quickly and effectively. He never felt abandoned although his wife, while supported, did suffer a lot of disappointment and anger.

Roger ultimately chose to die at home, which was initially difficult for him but was managed with aplomb. No one in the family mentioned voluntary assisted dying again after the first meeting. His doctor felt this was not because he thought it would be a waste of time, but rather because he gained control and his fears and needs were recognised.

\*Names have been changed

The following diagram shows the end of life concerns reported by people accessing voluntary assisted dying in Oregon between 1998 and 2017.

### End of life concerns – Oregon, United States 1998 to 2017



Source: Oregon Health Authority 2018<sup>8</sup>

Of course, people’s motivations for seeking voluntary assisted dying can vary beyond what is available in a reporting form.

*In-depth evaluation found many meanings and uses of the expression of desire for hastened death, ranging from a manifestation of the will to live and a gesture of altruism to a despairing cry depicting the misery of the current situation and to a manifestation of the last control the dying can exert.*

*The expression seems to be an important tool of communication for the patients.*

*In a similar study, being a burden to others was a most important motivation for the desire for hastened death. Suffering was described as a reason as well, although most often it was anticipated suffering rather than suffering right now: patients were very afraid of disease-related deterioration in the future.<sup>3</sup>*

**“ The most common reasons for people to request voluntary assisted dying are loss of autonomy and dignity, the inability to enjoy life and other activities.<sup>5</sup>**

## People’s requests and interest in voluntary assisted dying can change over time.

On an individual level, people’s interest in and requests for voluntary assisted dying reflect a complex range of “personal, psychological, spiritual, social, cultural, economic and demographic factors.”<sup>3</sup>

*In a large survey of terminally ill patients, 10.6% reported seriously considering euthanasia or PAS [physician assisted suicide] for themselves, but the follow-up interview showed that 50.7% of these patients had changed their mind after 6 months, while a nearly equal number had started to consider it. Ultimately, in this survey, only 5.6% of the deceased patients had discussed asking the physician for euthanasia or PAS...*

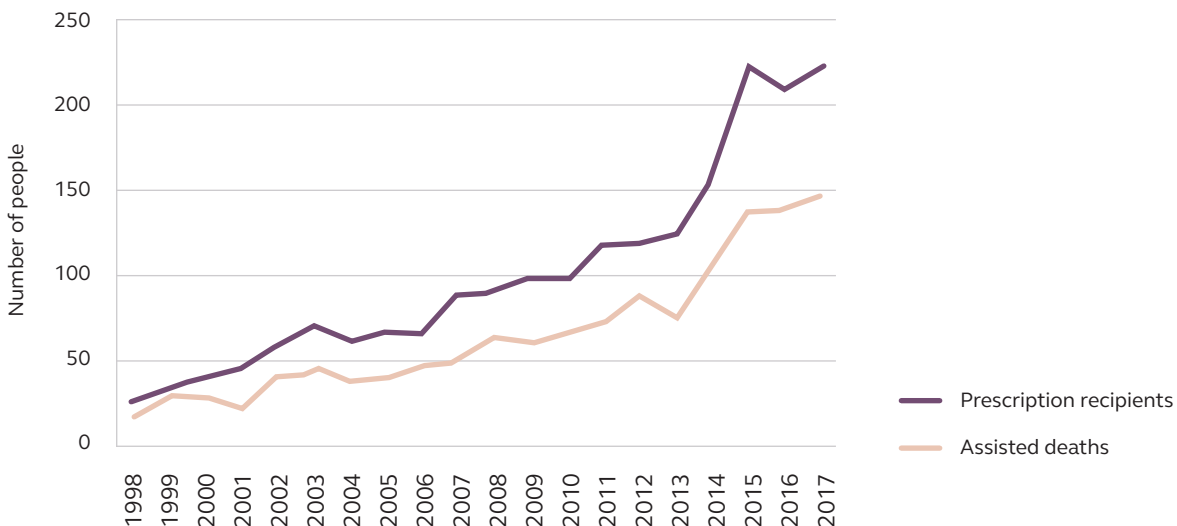
*In clinical practice, patients often show major ambivalence, with the wish for hastened death, on one hand, and the will to live, on the other, often in parallel or with short-term fluctuations. This coexistence of opposing wishes has been explained as part of authentic, multi-layered experiences and moral understandings at the end of life.<sup>3</sup>*

This changing nature of people’s wishes is also demonstrated in data from Oregon, where after an assessment process people can be given a script for a substance they can take to end their life. Ultimately, not everyone who receives a script from their doctor under their Dying With Dignity law ends up using it.

## Having access to voluntary assisted dying is important to people and can support a family’s grief processes.

As our values and attitudes have shifted towards autonomy and choice, access to the option of voluntary assisted dying is increasingly important for people. We see this need expressed through changes in public opinion and the increasing number of countries and states seeking to legalise voluntary assisted dying. Research also indicates that voluntary assisted dying gives family members the opportunity to say goodbye, plan and prepare, and feel comforted that death has happened in a way consistent with their loved ones values and choice.<sup>10</sup>

### Prescriptions given and number of deaths 1998 to 2017



Source: Oregon Health Authority 2018<sup>8</sup>

## People suffering dementia and psychiatric illnesses are starting to access voluntary assisted dying, but only in two countries.

There has been a small but increasing number of cases in the Netherlands and Belgium where people suffering dementia or psychiatric illnesses have requested and been granted access to voluntary assisted dying.<sup>5</sup> But this has not happened in all jurisdictions where people can access voluntary assisted dying. Every country has different laws, which reflect their cultural values and the history of the debates leading up to legalisation.

The idea that people with non-life threatening psychiatric conditions or people with impaired decision making can access voluntary assisted dying is ethically challenging, and based on community surveys is unlikely to be supported by most Australians.<sup>11</sup> This is reflected by the laws in Victoria, which restrict voluntary assisted dying to people with decision-making capacity who have terminal conditions and are in the last six months of their life, or 12 months if they have neurodegenerative disorders. However, given the second most common cause of death in Australia is Alzheimer's and dementia,<sup>12</sup> debate around the timeframes for people to access voluntary assisted dying may continue for a number of years.

## Unbearable Suffering

In Belgium and the Netherlands, the criteria for voluntary assisted dying includes that someone be experiencing "unbearable suffering". This can impact who accesses voluntary assisted dying as unbearable suffering is an open, subjective concept. It's the kind of thing you cannot take a blood test for or get a machine reading on. One person's experience of physical, psychological and spiritual suffering may be quite different from another's.<sup>13</sup> In the context of voluntary assisted dying, it can be difficult to know exactly where boundaries lie.

*Euthanasia is most often performed in cases of severe suffering due to physical disease and symptoms and severe function loss, for patients with a limited life expectancy. In such cases there is usually little discussion about whether or not the suffering was unbearable. However, it appears that in "boundary cases", such as suffering in the case of early dementia or existential suffering, there is more variance between physicians' and patients' perception of whether such suffering could be considered unbearable.<sup>13</sup>*

### Vignette 2: Dementia

*Kath\* was 78 years old and was living with frontal lobe dementia. This is a type of dementia where there is progressive damage to the front and temporal lobes of the brain. Damage in these areas can lead to reduced intellectual abilities and changes in personality, emotion and behaviour. Kath's dementia was assessed as moderate, leading to severe cognitive impairment.*

*Despite all medical, environmental and social interventions in care, Kath remained emotionally distraught, physically distressed, sobbing, continually crying out, and was ceaselessly wandering and looking for ways out. Her distress was visible in her behaviour as she alternated between clinging and clutching at staff and family, and hitting, biting, screaming and slapping those who tried to help her.*

*Kath had a major fall leading to a head injury, which resulted in a prolonged death.*

*Throughout her care Kath showed signs of great emotional pain, her family expressed feelings of helplessness, fear and anxiety for her future and their ability to keep seeing her in this state. Experiences such as these can last for many months and in this case, Kath's illness took several years.*

*Her family continually described their mother as someone who would never want to be like this, that they themselves prayed for it all to end and couldn't understand why she should be left to suffer.*

\*Names have been changed



## Key Points

**When available, voluntary assisted dying makes up a small proportion of all deaths.**

Between 0.3% and 4.6% of all deaths where it is legal.

**The most common disease people have when accessing voluntary assisted dying is cancer.**

**People suffering dementia and psychiatric illnesses are starting to access voluntary assisted dying, but only in two countries.**

There has been a small but increasing number of cases in the Netherlands and Belgium where people suffering dementia or psychiatric illnesses have requested and been granted access to voluntary assisted dying. But this has not happened in all jurisdictions where people can access voluntary assisted dying.

**The slippery slope argument continues, but has not been fully realised.**

The rates of voluntary assisted dying in Oregon and the Netherlands show no evidence of heightened risk for vulnerable groups such as racial or ethnic minorities. Debate continues around access to voluntary assisted dying for children and young people, people with dementia, and people with psychiatric illnesses.

**Once legalised the number of voluntary assisted dying cases increases over time.**

**Having access to voluntary assisted dying is important to people and can support a family's grief processes.**

**People's requests and interest in voluntary assisted dying can change over time.**

Requests for voluntary assisted dying reflect a complex range of personal, psychological, spiritual, social, cultural, economic and demographic factors.

**Requests for voluntary assisted dying are complicated and they're not always about physical pain.**

The most common reasons for people to request voluntary assisted dying are loss of autonomy and dignity, the inability to enjoy life and other activities.

# 4. Voluntary Assisted Dying in Australia

The Northern Territory was the first jurisdiction in the world to introduce legislation allowing a medical practitioner to end the life of a terminally ill patient at their request.

The *Rights of the Terminally Ill Act 1995* was both criticised and supported, and was ultimately repealed by the federal government who created the *Euthanasia Laws Act 1997 (Cth)* to prevent the practice. When voluntary assisted dying was legal in the Northern Territory, 7 patients accessed it. “All had cancer, 4 had depressive symptoms and none had uncontrolled pain.”<sup>5</sup>

In 2017, Victoria passed the *Voluntary Assisted Dying Act (Vic) 2017*, which will come into force on 19 June 2019. This legislation followed a substantial review of end-of-life care in Victoria and reflected the following findings:

- In Victoria and other parts of Australia, when family and friends are taken to court on criminal charges related to voluntary assisted dying they rarely receive custodial sentences. In the majority of cases, voluntary assisted dying is seen as an act of compassion and does not present a danger to the public. Any criminal sentences tend to be suspended and people are not sent to prison.

- There is evidence that unlawful assisted dying performed by doctors is occurring and is unregulated, unreported and may at times be involuntary. This raised serious concern about the protection of vulnerable people in the absence of any safeguards.
- There have been no prosecutions in Australia of doctors for assisting a patient to die, despite evidence that they do.
- While palliative care is effective in alleviating pain and suffering in the majority of cases, there is a small proportion of people who continue to experience irremediable pain despite receiving palliative care.
- Under the existing legal framework, Victorians with serious and incurable conditions and irremediable suffering are exposed to the possibility of a traumatic death. Some are driven to suicide.
- There is not compelling evidence that concerns raised in arguments against legalising voluntary assisted dying – such as the inability to implement and maintain effective safeguards – have eventuated in jurisdictions where it is legal.<sup>14</sup>

Work towards voluntary assisted dying laws continues in other parts of Australia. In November 2017, members of the New South Wales parliament attempted to pass legislation similar to Victoria’s, however it lost by one vote in their Upper House.

Following the passing of Victoria’s legislation, the Australian Greens and other cross benchers have been looking at national voluntary assisted dying legislation and removing limits on Territory governments to legislate on the matter.

“*While palliative care is effective in alleviating pain and suffering in the majority of cases, there is a small proportion of people who continue to experience irremediable pain despite receiving palliative care.*”

In Queensland, the Palaszczuk Government has announced a parliamentary inquiry into aged care, end-of-life and palliative care with the following terms of reference:

1. That the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee inquire into aged care, end-of-life and palliative care and report to the Legislative Assembly on:
  - I. the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems; and
  - II. 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:
  - I. 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;
  - II. outcomes of recent reviews and work including Queensland Health's Palliative Care Services Review; and
  - III. 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.



***Following the passing of Victoria's legislation, the Australian Greens and other cross benchers have been looking at national voluntary assisted dying legislation and removing limits on Territory governments to legislate on the matter.***

## Voluntary Assisted Dying Law in Victoria

The steps and regulatory mechanisms outlined in the *Voluntary Assisted Dying Act (Vic) 2017* create the following pathway for a person to access voluntary assisted dying:

1. A person makes a first request to their doctor.
2. They are assessed as eligible to access voluntary assisted dying by the coordinating medical practitioner and a consulting medical practitioner.
3. They make a written declaration, which is witnessed by two eligible people.
4. They make a final request to the coordinating medical practitioner.
5. They appoint a contact person, who cannot have witnessed their declaration.
6. The coordinating medical practitioner certifies the request and assessment process has been completed.
7. The person receives a voluntary assisted dying permit and can be prescribed the relevant substance. The permit can be a self-administered permit, or a practitioner administration permit. The latter authorises the coordinating medical practitioner to administer the death-causing substance.
8. The Registrar and Coroner are notified of a person's death if they are subject to a voluntary assisted dying permit.
9. The contact person must return any unused substances that have been prescribed under a voluntary assisted dying permit.

A person may choose to end the assessment process at any time, and even if a permit is issued, they may choose not to go ahead with voluntary assisted dying.

## Eligibility Criteria for Accessing Voluntary Assisted Dying in Victoria

To access voluntary assisted dying, a person must be:

- aged 18 years or more
- an Australian citizen or permanent resident
- ordinary resident in Victoria
- have been living in Victoria for at least 12 months at the time of making a first request
- have decision-making capacity in relation to voluntary assisted dying
- be diagnosed with a disease, illness or medical condition that is:
  - incurable
  - advanced, progressive and is expected to cause death within weeks or months, not exceeding 6 months
  - causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

If the person is diagnosed with a disease, illness or medical condition that is neurodegenerative, the illness must be expected to cause death within 12 months.

A person is not eligible for access to voluntary assisted dying only because they are diagnosed with a mental illness or a disability.

Registered health practitioners can conscientiously object to voluntary assisted dying and can refuse to provide information, participate in the request and assessment process, apply for a permit, supply or prescribe the substance, or be present when the substance is administered.

## Key Points

*Voluntary assisted dying is now legal in the Australian state of Victoria and the law will commence from 19 June 2019.*

*Other states and territories are examining options for voluntary assisted dying and parliamentarians are starting to advocate for it nationally.*

*The Victorian law limits voluntary assisted dying to people with decision-making capacity who have an incurable terminal illness and are experiencing unrelievable suffering.*

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*Death must be expected within 6 months or 12 months for people with neurodegenerative disorders.*

# 5. Death and Dying in Australia

To understand why parts of the community want to legalise voluntary assisted dying, we must understand people's experiences of dying in Australia.

## Australians are now living longer.

In 2016 the average age at death was 78 for men and 84 for women.<sup>12</sup> Trends also show that for most people, death happens between the ages of 70 and 85.<sup>16</sup> While longer life spans are a good thing, Australians are also living with more morbidity and disability as they age. This means people's health is likely to decline over a longer period and they will need more health care and support as they age.<sup>16</sup>

While a number of factors impact people's experience of these illnesses, rising rates of cancer and dementia are partly due to an ageing population. People are also more likely to have multiple illnesses at once.<sup>16</sup> This experience of chronic illness and disease means that the end of a person's life can now last up to one or two years.<sup>16</sup>

**“ Most people prefer to die comfortably at home or in a home-like environment with minimal pain and suffering. They hope to be surrounded by friends and family and the care services they need. A good death meets the individual physical, psychological, social and spiritual needs of the dying person.**

*Hal Swerissen and Stephen Duckett, the Grattan Institute<sup>15</sup>*

## People can experience symptoms from their illnesses for a long time.

Studies show that “pain, fatigue, impaired appetite, weight loss, bowel problems, nausea and shortness of breath are the most prevalent, intrusive or distressing” symptoms of various chronic and terminal diseases.<sup>16</sup> These symptoms can come and go, or last a long time. As death gets closer, there is a core cluster of symptoms people often experience. These include lack of energy, fatigue, shortness of breath, and pain. People can also experience cognitive impairment, which means their “capacity to carry out [their] will reduces and eventually disappears altogether in the last hours or days of life.”<sup>16</sup>

## There is a mismatch between where people prefer to die and what support is available.

In 2017, the Productivity Commission found:

*Most of the 160 000 people who die in Australia each year would benefit from end-of-life care but many do not receive care that fully reflects their choices or meets their needs. ...Where it is available, the quality of end-of-life care services in Australia is often excellent. But services are not available everywhere and to everyone who would benefit.<sup>17</sup>*

This reality is reflected in community surveys, which indicate around 70 percent of people would prefer to die at home, but are unable to.<sup>17</sup> However, the experience of UnitingCare and Wesley Mission Queensland, delivering hospital and community-based palliative care, is that people's preferences for place of care and death vary and change over time. While some may prefer to die at home, others will prefer a hospice or hospital setting. What's missing is a well-resourced and flexible system that can consistently meet people's preferences for care.



## Death often follows chronic illness.

In 2016, the 20 leading causes of death were:

Rank	Cause of death	Number	Percent
1	Coronary heart disease	19,077	12.0
2	Dementia and Alzheimer disease	13,126	8.3
3	Cerebrovascular disease	10,451	6.6
4	Lung cancer	8,410	5.3
5	Chronic obstructive pulmonary disease (COPD)	7,212	4.6
6	Diabetes	4,770	3.0
7	Colorectal cancer	4,413	2.8
8	Cancer of unknown or ill-defined primary site	3,882	2.4
9	Heart failure and complications and ill-defined heart disease	3,379	2.1
10	Influenza and pneumonia	3,334	2.1
11	Prostate cancer	3,248	2.0
12	Breast cancer	3,004	1.9
13	Pancreatic cancer	2,911	1.8
14	Suicide	2,862	1.8
15	Accidental falls	2,666	1.7
16	Cardiac arrhythmias	2,326	1.5
17	Hypertensive disease	2,228	1.4
18	Kidney failure	2,180	1.4
19	Other ill-defined causes	1,933	1.2
20	Liver cancer	1,864	1.2
	<i>Top 20 leading causes</i>	103,276	65.2
	<b>All causes</b>	<b>158,504</b>	<b>100.0</b>

Source: Australian Institute of Health and Welfare (2018): Supplementary tables<sup>12</sup>

### Vignette 3: High Quality Palliative Care

Costa\* is in his early 70s and has kidney cancer that had spread into his pelvis. This had destroyed his sacrum and nerves causing double incontinence and other damage. He was unable to sit, walk any distance or lie on his back. He was drowsy, confused and had short term memory loss from his medication.

Costa and his wife Nysa\* were very anxious, very afraid of death and would not even talk about it. They were reluctant to accept hospital admission due to fear that Costa would die in hospital. Eventually, they accepted a short hospital stay where they met with the palliative care team.

The team explained the nature and origins of the many pains he was experiencing. They offered him a fully explained medication plan, with back up plans to follow any failure. The team discussed what level of side effects from medication would be acceptable and every attempt was made to encourage Costa and Nysa to be active participants in decision making. Their case was taken to a multidisciplinary meeting and additional assistance was sought for radiotherapists and interventional radiology. Out of this came a plan for using multiple medications to manage Costa's steady background pain; a successful approach to deal with episodes of

sudden and unexpected pain; and the use of radiotherapy to diminish tumor volume and impingement. Following this plan, Costa's side effects reduced and his independence was partly re-established. The double incontinence could not be fixed, but was managed to the family's satisfaction.

Spiritual counseling was also offered to Costa and accepted with gratitude; social workers linked the family to community care and support; counseling was offered to both of them and Nysa benefitted greatly from more open discussions. She also bonded quite closely to the nursing staff. Home visits by occupational therapy and detailed discharge planning were a necessity. Targeted discussions with Costa about anxiety, poor sleep, fear of dying, loss of dignity and independence were also done slowly with a good outcome.

Trust evolved, control was handed back to Costa and a great reduction in pain and suffering were achieved.

Creating this outcome took a six week hospital admission and the work of the entire palliative care team. Costa's transition back home was successful and care continues with competent and close palliative care community support.

\*Names have been changed

UnitingCare and Wesley Mission Queensland deliver palliative care services in hospital and community settings. UnitingCare has a 17 bed palliative care unit at The Wesley Hospital and a smaller inpatient unit in St Andrew's War Memorial Hospital in Brisbane. We also provide services in people's homes through BlueCare, who provided 13,017 hours of palliative care to 1,024 people in 2017-18. Each of Wesley Mission Queensland's residential aged care communities offers palliative care with 24 hour registered nurses and clinical nurse specialists qualified in palliative care. All of these services struggle to meet demand for palliative care.

## Values and expectations around what happens at death are changing.

Longer life spans, increasing experience of chronic and complex illnesses and their symptoms, and patchy end-of-life care is fuelling the social movement for greater choice and voluntary assisted dying. But underlying this is a decades long value-shift towards self-expression and individual autonomy in decisions and personal well-being.

*From the self-expression perspective, the termination of life is considered morally justifiable when it is aimed at relieving suffering and when it is the result of a person's own independent and sane decision. In addition, the values of autonomy provide the basis for the idea of dying with dignity.<sup>18</sup>*

## Palliative care in Australia gives people positive death experiences, but it is not consistently available to everyone.

Palliative care is specialist care for people with life-threatening illnesses. People do not need to be at the very end of their lives to receive this care. In fact, good palliative care should begin early at the point of diagnosis and take a holistic approach. Palliative care works with individuals and their families, seeking to improve quality of life. Care focuses on prevention and relief of suffering through early identification, assessment and treatment of physical pain, as well as other issues such as physical, psychosocial and spiritual suffering.

### Vignette 4: Controlled Withdrawal of Treatments

*At 72, Dorothy\* was diagnosed with interstitial fibrosis, a disease of the lungs that is fatal over a 2 to 4 year period. Dorothy visited a palliative care specialist to talk about her future care and desire for euthanasia 'when time is right'.*

*While unable to offer voluntary assisted dying, Dorothy and her doctor discussed controlled withdrawal of active treatment at the time she chose. Her family was very grateful for the way that this was done and there was no need for voluntary assisted dying. In fact, once she felt trust and control was in her hands, Dorothy never mentioned her desire for 'euthanasia' again.*

*Dorothy died in the way she wished, with the people she wanted and in the place she wanted.*

\*Names have been changed



***It seems doubtful that any modern person would want to return to the unrelieved suffering of the past when people had no alternative to death at home without medical help, particularly given the protracted chronic disease journeys of most people today...However, it is important to question and, where necessary, move away from excessive 'medicalisation' of dying, especially where this over-emphasis of medical intervention occurs at the expense of other personal, social and spiritual aspects of life, and has negative and unsustainable consequences for the economy.***

*Professor Michael Ashby, Director of Palliative Care, Royal Hobart Hospital and Southern Tasmania Area Health Service<sup>16</sup>*

## **Advanced care planning and directives can provide greater choice and control, but many Australians do not have them.**

Advanced health planning and formal Advanced Health Directives provide greater understanding and control over what may happen when a person dies. They also improve communication between people, their families, doctors and other care staff.<sup>3</sup> Advanced care planning examines a person's goals, values, beliefs and preferences for treatment and care when they have been diagnosed with a life limiting condition. This planning can happen in hospital, aged care or community settings and involves the person, their family, their doctor and any nurses or support people involved in their care.

An Advanced Health Directive is a formal document that gives instructions about a person's health care if they become unable to make decisions. Advanced Health Directives outline what medical treatment a person would want and can include the withdrawal of treatments, such as resuscitation, ventilation, and artificial feeding and hydration.<sup>19</sup> An Advanced Health Directive can be developed during advanced care planning or when a person is well, as long as they can make decisions for themselves.

Unfortunately, very few people in Australia have advanced care plans or have talked about their end-of-life care wishes with their loved ones. In 2012, only 14 percent of Australians had an advanced care plan.<sup>17</sup> The reasons for this vary, but can include reluctance to talk about mortality and death, time taken to prepare plans in health settings, and lack of training for clinicians to begin these conversations with people and families.<sup>17</sup>

### ***Vignette 5: Advanced Care Planning in Place***

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*Marcus\* was admitted to a residential aged care service for palliative care. He was 67 years old with a life expectancy of 2 to 4 weeks. His wife, Roberta, had previously had a very poor experience with a death of a parent in aged care.*

*The service discussed advanced care planning with Marcus and Roberta on admission, which is a routine practice.*

*The most important focus for Roberta was after death care for Marcus so the tour of the aged care community included the processes and rituals following a person's death. Marcus passed away in his room with his family, chaplain and music therapist (Harpist) playing at his request.*

*\*Names have been changed*

### ***Vignette 6: No Advanced Care Plan in Place***

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*Sabrina\* lived in a residential aged care community and was no longer able to express her wishes. One of her family members was nominated as her Enduring Power of Attorney and was very stressed when she suddenly had to be admitted into care.*

*Sabrina's family members were not prepared to consider a non-interventionist approach to her care and wanted active life sustaining measures to be pursued at all costs.*

*Any initiative by the service to manage Sabrina's pain appropriately was met with fear and resistance as the family believed the service was seeking to actively end her life. This situation took significant time and patience by care staff to explain the palliative approach to end of life care.*

*Many family members have never discussed their wishes for end of life care or considered that this will ever be a possibility.*

*\*Names have been changed*

## Key Points

**Australians are living longer.**

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*But also have longer experiences of chronic illness and disability at the end of their lives.*

**The critical issue around 'death and dying in Australia' is the need for a well-resourced and flexible system that can consistently meet people's preferences for care.**

**Palliative care in Australia gives people positive death experiences, but it is not consistently available to everyone.**

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*High quality specialist palliative care, responding to physical, psychosocial and spiritual needs, should be available to people regardless of their location.*

**Well resourced Advanced Care Planning, combined with emotional, physical and spiritual supportive care of both the patient and their family, is also needed.**

**When considering the Church's response to voluntary assisted dying, it is critical to consider the place of improving people's access to, and the quality of, palliative care.**

**Palliative care should be seen as a core part of the Mission of the church.**

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*To enable patients and their families to receive adequate support in the final months of life.*



# 6. Australian Community Views

Community surveys in Australia have shown that more than half of Australians support voluntary assisted dying, although the proportion varies. In surveys taken between 2007 and 2016 support for voluntary assisted dying was between 66% and 85%.<sup>11</sup>

Responses to these kinds of surveys can vary due to “framing effects”. This describes how people’s responses to polls and surveys are influenced by how questions are worded, the examples given, and if endorsement of a particular view is embedded in how a survey is delivered.<sup>5</sup> Surveys on voluntary assisted dying are particularly influenced by the kinds of details given in examples, such as a person’s disease, their expected outcome, and their symptoms.<sup>5</sup>

Australian’s support for voluntary assisted dying tends to be higher when survey questions refer to unbearable and unrelievable suffering and people who have no chance of recovery. Their support falls when people do not have a terminal illness.<sup>11</sup>

To understand what influences people’s views of voluntary assisted dying, a group of researchers from the United Kingdom completed a systematic review of surveys and research on people’s attitudes from across the world. In doing this they found four consistent themes, regardless of people’s legal, cultural and organisational contexts. These were:

- **Concerns about poor quality of life.** These include concerns around unbearable suffering, dependence on others, burden, loss of self, physical pain and suffering, and fear of future suffering.
- **The desire for good “quality of death”.** This includes having choice, autonomy and control around the manner of death. People also sometimes see voluntary assisted dying as a way to choose to avoid suffering or placing extra burden on their families.
- **Concerns about abuse if voluntary assisted dying were legalised.** These include the need for safeguards to prevent abuse and coercion, concerns about financial pressure, impacts on vulnerable groups, and the role of others in decision-making.

- **The importance of individual stance related to voluntary assisted dying.** People’s views of voluntary assisted dying are influenced by their moral or religious views and personal experience of death or suffering. For people with a disability, voluntary assisted dying was regarded very negatively due to previous experiences with health care that had removed people’s decision-making ability.<sup>9</sup>

## Medical View

The act of intentionally hastening death can have a significant personal emotional impact on medical practitioners. In countries where it is legal, doctors who perform voluntary assisted dying have reported it as being a stressful and difficult act that can have a substantial emotional impact that must be managed<sup>20</sup>. This is reflected in research showing that people in the community are more likely to support voluntary assisted dying than medical professionals<sup>5</sup>.

The Australian Medical Association (AMA) holds the view that:

*Doctors should not be involved in interventions that have as their primary intention the ending of a person’s life. This does not include the discontinuation of treatments that are of no medical benefit to a dying patient.<sup>21</sup>*

“ In surveys taken between 2007 and 2016 support for voluntary assisted dying was between 66% and 85%.<sup>11</sup> ”

However, they also recognise and acknowledge that there is a broad range of views both within the medical profession and the community around voluntary assisted dying. The AMA also notes that:

*Any change to the laws in relation to euthanasia and/or physician assisted suicide must never compromise the provision and resourcing of end of life care and palliative care services.<sup>21</sup>*

The diversity of views held by medical professionals was also seen in a survey of Australian medical oncologists, leading their professional body to neither support or oppose voluntary assisted dying.<sup>22</sup>

Palliative Care Australia is currently reviewing its position on voluntary assisted dying. However, their 2016 position states:

*The practice of palliative care does not include euthanasia or physician assisted suicide. Palliative care does not intend to hasten or postpone death... Compassion, dignity, respect and participation in decision-making are important to all and integral to delivery of high quality palliative care and end-of-life care. A request for euthanasia or physician assisted suicide requires a respectful and compassionate response.<sup>23</sup>*

Professor Margaret O'Connor describes Palliative Care Australia's position as one of 'studied neutrality'.<sup>24</sup> The goal being not to exclude anyone based on the choices they make about the end of their lives. Professor O'Connor argues:

*It is possible for a clinician to work with a person as they work through their decisions, regardless of one's own position on assisted death; and to be a conscientious objector without abdicating one's duty of care for a person until the time they choose to die. Nursing care has always been provided to any person when they are in need, regardless of what we may think of them. We provide care to criminals, to people who have a lifestyle different to our own, to people who resist common-sense treatments. We cannot abdicate the care of people seeking access to voluntary assisted dying, because we disagree with it; it is not our decision, it is a decision for each individual.<sup>24</sup>*

Balancing an individual's wishes at the end of life against personal, professional and organisational views around voluntary assisted dying will be a key challenge as laws come into effect in Australia.

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***The community does not speak with one voice on these issues: there is a wide spectrum of opinion and behaviour from 'keep me alive at all costs, no matter what the circumstances' through to 'let me die' and 'help me to die'.***

*Professor Michael Ashby, Director of Palliative Care, Royal Hobart Hospital and Southern Tasmania Area Health Service<sup>16</sup>*

## Key Points

*Between 2007 and 2016, community surveys of Australians showed support for voluntary assisted dying was between 66% and 85%.*

*Generally, people in the community are more likely to support voluntary assisted dying than medical professionals.*

*People's attitudes towards voluntary assisted dying are influenced by their concerns about poor quality of life, the desire for good "quality of death", concerns about abuse if legalised, and their individual stance as influenced by their moral or religious views and personal experience of death and suffering.*

*Australian's support for voluntary assisted dying tends to be higher when survey questions refer to unbearable and unrelievable suffering and people who have no chance of recovery.*

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*Their support falls when people do not have a terminal illness.*

*The Australian Medical Association does not support voluntary assisted dying, but recognises a diversity of views within the medical profession.*

*Palliative Care Australia holds a view that while the practice of palliative care does not include voluntary assisted dying, a person requesting it requires a respectful and compassionate response.*

# 7. Uniting Church and Other Churches Responses to Voluntary Assisted Dying

## Synod of Victoria/Tasmania

Voluntary Assisted Dying/Suicide – Consultation Paper by Justice International Mission Unit (JIMU) of the Vic/Tas Synod. This Consultation Paper was received by the 2017 Synod. There is currently no position of the Synod. The JIMU has been asked to recommend whether a position be developed. They recognise that, given that legislation has been passed, to be implemented in 2019, the Synod must make decisions about how its own bodies will respond.

In 2017 the Synod resolved:

1. In the event of the Parliament of Victoria passing legislation to allow assisted dying/suicide, to request the Synod Standing Committee to initiate a process including, but not necessarily limited to, consultation with Uniting AgeWell, Uniting Victoria-Tasmania, the faculty of Pilgrim Theological College and the Assembly Standing Committee, and taking into account the feedback from the wider Church through the current consultation process in relation to this matter being conducted by the Justice and International Mission Unit, to present a report with proposal(s) to the 2019 Synod meeting regarding the Uniting Church in Victoria and Tasmania's response to the assisted dying/suicide legislation, including a position on how the Synod and relevant UCA institutions and staff should be asked to respond to such legislation; and
2. To support the recommendation of the Victorian Government Ministerial Advisory Panel on Voluntary Assisted Dying that any voluntary assisted dying legislation include a broad provision to allow all health professionals and facilities the right of conscientious objection to participation in such legislation.

In February 2018 the Victoria and Tasmania Synod Standing Committee authorised the Moderator and General Secretary to commence a process of consultation.

## WA Synod, Northern Synod, NSW/ACT Synod and SA Synod

No papers have been produced by these Synods to date.

## National Assembly

The Uniting Church in Australia does not currently have a national position on the issue.

## The Salvation Army

The International Positional Statement, Euthanasia and Assisted Suicide Statement of Position, states that:

*The Salvation Army believes strongly that all people deserve compassion and care in their suffering and dying. Euthanasia and assisted suicide should not, however, be considered acceptable responses. They undermine human dignity and are morally wrong. The Salvation Army believes therefore that euthanasia and assisted suicide should be illegal.*

*Death is a human reality. Even with the most advanced medical science and attentive care giving, cure is not always possible, and pain and suffering cannot always be overcome. We must never use anyone's suffering as a justification for causing their death, however, or judge a person's life as not worth living*

*The Salvation Army... prizes human autonomy highly, but believes human beings do not have the right to death by their own act or by the commissioning of another person to secure it. The Salvation Army considers each person to be of infinite value, possessing inherent dignity, and that each life is a gift from God to be cherished, nurtured and redeemed. Human life, made in the image of God, is sacred and has an eternal destiny (Genesis 1:27). Human beings were created for relationships and for those relationships to be expressed living in community, including in times of death (1 Corinthians 12: 26; 1 John 3:14).*

*The priority that governs Christian compassion in the process of dying is to maximise care. We all know the fear of suffering and the frustration of being unable to relieve it fully, however, our continuing focus is not to eliminate suffering people but to find better ways of dealing with their suffering.*

## Catholic Health Australia Ethical Standards

Catholic Health Australia has developed a Code of Ethical Standards to guide their health and age care services. In this document, their position on euthanasia is outlined as:

*It is never permissible to end a person's life (whether that decision is made to relieve a patient's suffering by euthanasia, to comply with the wishes of the family, to assist suicide, or to vacate a bed).*

*By euthanasia is meant any action or omission which of itself and by intention causes death with the purpose of eliminating all suffering. Examples of euthanasia include administering deliberate overdoses of otherwise appropriate medications, and the unjustified withholding or withdrawing life sustaining forms of care.*

*Euthanasia must be distinguished from other care decisions which sometimes risk or have the effect of shortening life but which are not intended to hasten death (e.g. the giving of appropriate pain relief, the withdrawal of burdensome treatments).<sup>25</sup>*

## Australian Catholic Bishops Conference

The Australian Catholic Bishops conference report titled Real Care, Love and Compassion states:

*Compassion for the sick and suffering is something which unites us all. Many of us have accompanied friends or family as they face the fear and uncertainty of a serious illness. Our heart goes out to them and we wish only the best for them. From time to time euthanasia or assisted suicide is proposed as the compassionate choice for people who are facing such illness.*

*Euthanasia may be defined as intentionally bringing about death by active intervention, or by neglect of reasonable care in order to end suffering. Physician Assisted Suicide is when a person is prescribed lethal drugs with which to kill themselves, with the purpose of eliminating suffering. We hear people saying that this would allow people to 'die with dignity' and that it is each individual's 'right' to choose the timing and manner of their death.*

*This view, although born of compassion, is misguided and even dangerous. Killing people is wrong, and this principle is fundamental to our law. In the very few jurisdictions overseas where euthanasia or assisted suicide have been introduced, there is already ample evidence that the system is being abused and the legislated safeguards are being ignored.*

**“ Euthanasia must be distinguished from other care decisions which sometimes risk or have the effect of shortening life but which are not intended to hasten death (e.g. the giving of appropriate pain relief, the withdrawal of burdensome treatments).**

Catholic Health Australia

## Catholic Bishops in Victoria

In a letter to Victorian Catholics in October 2017, Catholic Bishops in Victoria warned that:

*“No ‘safeguards’ can ever guarantee that all deaths provided for under the proposed laws will be completely voluntary. Whether because of carelessness, error, fraud, coercion or even self-perceived pressure, there will always be a risk. Victoria abolished the death penalty because we learnt that in spite of our best efforts, our justice system could never guarantee that an innocent person would not be killed by mistake or by false evidence. Our health system, like our justice system, is not perfect. Mistakes happen. To introduce this law presuming everyone will be safe is naïve. We need to consider the safety of those whose ability to speak for themselves is limited by fear, disability, illness or old age.”*

*“Endorsing suicide as a solution to pain or suffering sends the wrong message, especially to the young. Suicide is a tragedy for the person who takes their own life, but it also seriously affects their family and community. It would be plain wrong to legally endorse any form of suicide when governments and community groups are working so hard to persuade others that there are always better options available than taking their own life.”*

*“It will be a tragic injustice if people opt for state-endorsed suicide because access to adequate emotional, psychological, spiritual and physical care is not available. For many people this is the reality.”*

## Anglican Church

Anglican Church in Sydney 2016 – Resolution passed at the Synod of the Anglican Diocese of Sydney (Resolution 17/2016):

*Recognising that all life is precious in God’s sight and that deliberately ending a human life is wrong, Synod views with deep concern the possibility that the Voluntary Euthanasia Bill 2016 may pass the South Australian Parliament shortly.*

Further Synod –

- a. *rejects the false notion that euthanasia represents dying with dignity;*
- b. *recognises that euthanasia represents a deep and fundamental change to society’s commitment to caring for people at their most vulnerable, and that the elderly in particular will be exposed to possible medical error and abuse;*
- c. *believes that euthanasia will fundamentally change the doctor-patient relationship by undermining the trust inherent in that bond and the “do no harm” purpose of medical care;*
- d. *supports the maintenance and if possible extension of funding available to palliative care units of South Australian hospitals, and respectfully urges Members of the South Australian Parliament to oppose the Bill.*

## Resolution passed at the Synod of the Anglican Diocese of Melbourne (2010)

The following motion was passed as a resolution of the 2010 Synod of the Anglican Diocese of Melbourne:

*This Synod reaffirms the resolution of the General Synod of Australia (1995) concerning Euthanasia, namely:*

- *We affirm that life is a gift from God not to be taken, and is therefore not subject to matters such as freedom of individual choice.*
- *We cast doubt on whether a practice of voluntary euthanasia can be prevented from sliding into a practice of involuntary euthanasia.*
- *We affirm the right of patients to decline treatment but not to expect the active intervention by medical staff to end their lives.*

*And calls upon*

- a. *members of the Victorian State legislature to vote against legislation to legalise euthanasia when such matters come before our Parliament; and*
- b. *governments to further improve access to high quality palliative care to ensure that all people will be able to die with dignity.*

## Key Points

*There is currently no national position on voluntary assisted dying in the Uniting Church.*

*No other Synod, apart from Queensland, has developed a position on voluntary assisted dying.*

*The Synod of Vic/Tas is currently exploring their position on voluntary assisted dying.*

*No mainline Christian denomination within Australia currently supports voluntary assisted dying.*

*Although there are different ways of expressing it, the Salvation Army, Catholic Church and Anglican Church are opposed to voluntary assisted dying.*

*There is a strong advocacy for well resourced and high quality palliative and end of life care.*



# 8. Options for the Synod

## Option 1

The Uniting Church in Australia – Queensland Synod affirms the God given dignity and worth of every human life. It recognises that the experiences of end of life in some situations can cause significant distress for the person dying, their families and care staff. While the church does not support the legalisation of voluntary assisted dying, it acknowledges that there are rare circumstances where people with a terminal illness can experience unbearable suffering. In these circumstances, if voluntary assisted dying is legalised, and a person chooses to access this, the church is called to offer a compassionate and pastoral response to people and families. Our facilities and staff will not participate in acts specifically designed to end a person's life.

## Option 2

The Uniting Church in Australia – Queensland Synod affirms the God given dignity and worth of every human life. It recognises that the experiences of end of life in some situations can cause significant distress for the person dying, their families and care staff. It acknowledges that there are rare circumstances where people with a terminal illness can experience unbearable suffering. In these circumstances, if voluntary assisted dying is legalised, and a person chooses to access this, the church is called to offer a compassionate and pastoral response to people and families. Our agencies will ensure that the decision of the person is respected, and can be carried out in our facilities.

## Other Recommendations

That the Synod -

1. Receives the report on Voluntary Assisted Dying.
2. Affirms the critical importance of high quality, well resourced and accessible palliative and end of life care that responds to the physical, psycho-social and spiritual needs of people at the end of life. The church undertakes the following actions:
  - I. Advocate for a well resourced and flexible system that consistently meets people's needs and preferences for care;
  - II. Continue to provide high quality and accessible palliative care, responsive to the pastoral and spiritual needs of the people we serve, as central to our mission as the church.
3. That in the case of the legalisation of voluntary assisted dying in Queensland, to request Wesley Mission Queensland and UnitingCare to develop a policy and practice approach in light of the Synod's position (Option 1 or Option 2) on voluntary assisted dying and any legislative requirements.
4. That in advocating to government regarding legalisation of voluntary assisted dying in Queensland, the church strongly recommends provisions for conscientious objection, for both individuals and organisations, be included in any proposed legislation.
5. Thank the Consultation Group for their work.

# 9. Further Reading

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## Submissions to be made to:

Rev. Dr. Adam McIntosh  
UnitingCare  
GPO Box 45, Brisbane QLD 4001  
**Email:** [adam.mcintosh@ucareqld.com.au](mailto:adam.mcintosh@ucareqld.com.au)  
**Phone:** 0448 572 953

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