

Voluntary Euthanasia and Assisted Dying

Volume | 460



Edited by Justin Healey

ISSUES
IN SOCIETY

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INTRODUCTION

Voluntary Euthanasia and Assisted Dying is Volume 460 in the 'Issues in Society' series of educational resource books. The aim of this series is to offer current, diverse information about important issues in our world, from an Australian perspective.

KEY ISSUES IN THIS TOPIC

The topic of voluntary euthanasia and assisted dying has a long history of impassioned political and community debate in Australia, often appearing to raise more questions than answers. Recently, however, Victoria and Western Australia have passed voluntary assisted dying legislation which grants eligible people with a terminally ill condition, who are experiencing intolerable suffering, legal access to assisted dying services. Each state has specified a wide range of safeguards for patients and health practitioners, but questions will continue to be asked about voluntary assisted dying, above and beyond people's personal approval or opposition to it. In the meantime, other jurisdictions in Australia are also exploring the legalisation of some form of assisted death.

This title looks at a controversial topic through the lens of the latest legal developments in Australia and overseas. A range of complex issues involved in end of life decisions are explored and debated. What, in fact, is the difference between assisted dying and voluntary euthanasia? What are the various ethical, religious, medical, legal and practical considerations? Can palliative care always provide adequate pain relief? In certain circumstances, should we ever have a legal right to die?

SOURCES OF INFORMATION

Titles in the 'Issues in Society' series are individual resource books which provide an overview on a specific subject comprised of facts and opinions.

The information in this resource book is not from any single author, publication or organisation. The unique value of the 'Issues in Society' series lies in its diversity of content and perspectives.

The content comes from a wide variety of sources and includes:

- Newspaper reports and opinion pieces
- Website fact sheets
- Magazine and journal articles
- Statistics and surveys
- Government reports
- Literature from special interest groups

CRITICAL EVALUATION

As the information reproduced in this book is from a number of different sources, readers should always be aware of the origin of the text and whether or not the source is likely to be expressing a particular bias or agenda.

It is hoped that, as you read about the many aspects of the issues explored in this book, you will critically evaluate the information presented. In some cases, it is important that you decide whether you are being presented with facts or opinions. Does the writer give a biased or an unbiased report? If an opinion is being expressed, do you agree with the writer?

EXPLORING ISSUES

The 'Exploring issues' section at the back of this book features a range of ready-to-use worksheets relating to the articles and issues raised in this book. The activities and exercises in these worksheets are suitable for use by students at middle secondary school level and beyond.

FURTHER RESEARCH

This title offers a useful starting point for those who need convenient access to information about the issues involved. However, it is only a starting point. The 'Web links' section at the back of this book contains a list of useful websites which you can access for more reading on the topic.

ASSISTED DYING: SOME FREQUENTLY ASKED QUESTIONS

FAQS ANSWERED BY **DYING WITH DIGNITY WESTERN AUSTRALIA**

TERMINOLOGY

What is voluntary assisted dying?

Voluntary assisted dying (VAD) is a quick and peaceful death which results either:

- From a patient taking, or administering to themselves, a fatal dose of a lethal medication. This is commonly known as *self-administration*; or
- From a fatal dose of lethal medication being administered to them by a doctor, usually by injection. This is commonly known as *medical aid in dying* or *voluntary euthanasia*.

In both cases VAD is only available to a person who satisfies the statutory requirements applicable in the jurisdiction in which the VAD takes place.

Currently, VAD laws have been passed in Australia only in the states of Victoria and Western Australia. The Victorian VAD law came into effect on 19 June 2019. The WA *Voluntary Assisted Dying Act 2019* (the WA Act) received the Royal Assent on 19 December 2019 and will come into effect in or about June 2021.

The Victorian *Voluntary Assisted Dying Act 2017* and the WA Act are both modelled on the Oregon *Death with Dignity Act 1997*, not on the broader European models.

Why is the term 'assisted suicide' not appropriate?

In Western Australia, VAD is available only to people who are already dying, and who are suffering from "at least 1 disease, illness or medical condition ... that is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable".¹

These people are not suicidal. They are making a rational and fully informed decision to die a peaceful death in the manner and at the time of their choosing. The WA Act provides that VAD is not suicide, and suicide is not recorded on the death certificate as the cause of death.

PUBLIC SUPPORT

How many Australians support assisted dying?

Successive polls have shown support for VAD of close to or over 80%:



- November 2017 – 88% in WA (*Roy Morgan*)²
- November 2018 – 86% (*The West Australian*)
- December 2018 – 84% of COTA members (*Newgate Research*)
- May 2019 – 89% (*ABC Vote Compass*)
- July 2019 – 74% overall including 68% of Liberal voters (*small poll conducted by MediaReach for DWDWA*)
- August 2019 – 88% (*The West Australian*).

SUPPORT FROM CHRISTIANS

Is voluntary assisted dying supported by practising Christians?

Many Christians believe that voluntary assisted dying is consistent with Christian values and with Jesus's message of love and compassion, especially for those who are suffering. Today the overwhelming majority of Australian Christians support choice for VAD. A number of studies have confirmed that whilst support for VAD is strongest amongst those who say they have no religion, the vast majority of religious Australians are also supporters.

INCREASING ACCESS TO VOLUNTARY ASSISTED DYING



As at June 2019, more than 200 million people live in places with some form of legal voluntary assisted dying.

- Switzerland (Criminal Code 1942)
- Netherlands (2002)
- Belgium (2002)
- Luxembourg (2009)
- Colombia (2015, court decision)
- Germany (2015)
- Canada (2016):
 - Quebec Province (2014, came into operation Dec 2015)
- United States (USA):
 - Oregon (1997)
 - Washington (2009)
 - Montana (2010, court decision)
 - Vermont (2013)
 - California (2016)
 - Colorado (2016)
 - Washington DC (2016)
 - Hawaii (2018)
 - New Jersey (2019)
 - Maine (2019)
- Australia:
 - Victoria (2019)



Australia had the world's first assisted dying law in the Northern Territory (1995) but only four people were able to use it before it was overturned by the federal *Euthanasia Laws Act 1997*. It took two decades for the next VAD law to pass in an Australian parliament. Victoria's law came into effect in June 2019.

For example, the 2016 Australian Election Study (AES), conducted by scholars at the Australian National University, found that the statement “Terminally ill people should be able to legally end their own lives with medical assistance” was supported by 74.3% of Catholics, 79.4% of Anglicans, 77.8% of members of the Uniting Church and 90.6% of those with no religion.³

It is evident that the Catholic Church and members of the clergy who publicly oppose voluntary assisted dying are not representing the view of their ‘flock’.

The Australian organisation, Christians Supporting Choice for Voluntary Assisted Dying, has an excellent website which sets out the arguments and closely examines Christian doctrine in relation to the question of voluntary assisted dying.⁴

SUPPORT FROM NURSES

How many nurses support voluntary assisted dying?

A key voice in the WA campaign for VAD was the nursing profession. Support from the WA chapter of the Australian Nurses Federation was close to 90%, as illustrated by two full-page advertisements in *The West Australian* newspaper.

SUPPORT FROM DOCTORS

Are there doctors who support voluntary assisted dying?

In WA there was support and opposition from doctors. A number of high profile doctors in WA were outspoken ambassadors for the introduction of voluntary assisted dying in the state, including Professor Fiona Stanley. In October 150 doctors from WA signed an open letter to members of parliament in support of VAD.

Although the current hierarchy of the WA Branch of the Australian Medical Association (AMA) strongly and publicly opposed assisted dying law reform, the membership of the AMA is split. Ultimately the AMA worked constructively with the Labor Government in discussing possible amendments, and finally reached an agreement to support the Bill.

The national organisation Doctors for Assisted Dying Choice has always strongly supported VAD and other medical organisations came out in support during the campaign in 2019, including the WA Primary Health Alliance and the Royal Australian College of GPs.

THE LAW OVERSEAS

Which other countries have legalised voluntary assisted dying or voluntary euthanasia?

There is an increasing number of international jurisdictions that provide access to voluntary assisted dying for those people who meet strict eligibility criteria within robust legal frameworks. The position as at June 2019 is shown above.

How do the laws differ around the world?

There are differences among the various laws relating to the legal framework, eligibility criteria, method of administration of the lethal medication and process.

The American laws (on which the Australian laws are based) are considered the most restrictive, because the individual has to be suffering from a terminal illness, with less than 6 months to live, whereas the European laws do not require the person to be suffering from a terminal illness. In Europe, the eligibility and safeguards are based on a model requiring ‘due

care' on the part of the doctor assisting a patient to die and the patient must be experiencing 'unbearable and irremediable suffering' to qualify.

The American laws permit self-administration only, whereas under the European and Canadian models,

both self-administration and voluntary euthanasia are permitted.

Space on this website does not allow for a detailed comparison of the legal frameworks, safeguards and procedures involved in the various assisted dying

TABLE 1: SUMMARY OF OUTCOME MEASURES BY SETTING

Description		Benchmark	Inpatient		Community	
			%	BM met?	%	BM met?
Outcome measure 1 – timely admission to service						
	Patients episode commences on the day of, or the day after date ready for care (BM1)	90%	97.2	Yes	87.4	No
Outcome measure 2 – responsiveness to urgent needs						
	Patients in the unstable phase for 3 days or less (BM2)	90%	89.0	No	80.5	No
Outcome measure 3 – change in symptoms and problems						
Pain (clinician rated)	Absent or mild pain, remaining absent or mild (PCPSS, BM3.1)	90%	91.5	Yes	85.7	No
	Moderate or severe pain, becoming absent or mild pain (PCPSS, BM3.2)	60%	59.9	No	54.9	No
Pain (patient rated)	Absent or mild distress from pain, remaining absent or mild (SAS, BM3.3)	90%	89.5	No	82.5	No
	Moderate or severe distress from pain, becoming absent or mild (SAS, BM3.4)	60%	55.4	No	49.3	No
Fatigue (patient rated)	Absent or mild distress from fatigue, remaining absent or mild (SAS, BM3.5)	90%	85.4	No	70.5	No
	Moderate or severe distress from fatigue, becoming absent or mild (SAS, BM3.6)	60%	47.0	No	26.5	No
Breathing problems (patient rated)	Absent or mild distress from breathing problems, remaining absent or mild (SAS, BM3.7)	90%	94.8	Yes	91.5	Yes
	Moderate or severe distress from breathing problems, becoming absent or mild (SAS, BM3.8)	60%	46.6	No	35.8	No
Family/carer problems (clinician rated)	Absent or mild family/carer problems, remaining absent or mild (PCPSS, BM3.9)	90%	90.7	Yes	81.8	No
	Moderate or severe family/carer problems, becoming absent or mild (PCPSS, BM3.10)	60%	46.4	No	42.6	No
Outcome measure 4 – case-mix adjusted outcomes (X-CAS)						
Clinician rated (PCPSS)	Pain (BM4.1)	0.0	0.10	Yes	-0.07	No
	Other symptoms (BM4.2)	0.0	0.21	Yes	-0.05	No
	Family/carer (BM4.3)	0.0	0.13	Yes	-0.03	No
	Psychological/spiritual (BM4.4)	0.0	0.16	Yes	-0.05	No
Patient rated (SAS)	Pain (BM4.5)	0.0	0.32	Yes	-0.23	No
	Nausea (BM4.6)	0.0	0.21	Yes	-0.11	No
	Breathing problems (BM4.7)	0.0	0.29	Yes	-0.07	No
	Bowel problems (BM4.8)	0.0	0.23	Yes	-0.01	No

National Report on Patient Outcomes in Palliative Care in Australia, January–June 2016, detailed report.

models around the world. However, although the models differ, they all provide regulatory frameworks with strict eligibility criteria, numerous safeguards and strong reporting requirements. There is no evidence internationally of institutional corrosion or the often cited 'slippery slope'.⁵

Can people with mental illness or a disability qualify under the overseas laws?

Under the American laws, (on which Australian Bills are based), eligibility criteria are based on the diagnosis of a terminal illness, not on a disability, so having a disability alone does not meet the eligibility criteria. However, if someone with a disability meets the eligibility criteria for instance because they have cancer, they would not be denied access to voluntary assisted dying so long as they satisfied all of the eligibility criteria on the basis of their cancer.

The same applies to mental illness. Although a person with mental illness alone would not meet the eligibility criteria for voluntary assisted dying, they would not be refused access if they met all of the eligibility criteria unless their decision-making capacity in relation to voluntary assisted dying was impaired.

The eligibility criteria in the European model allow someone with 'unbearable and irremediable suffering' to request an assisted death. This means it is possible for someone with a mental illness, or a severe disability, to qualify if they have decision-making capacity and all the safeguards are met, including that the physician is satisfied that the patient's suffering is unbearable, with

no prospect of improvement.

Although it is possible under the European laws, the number of people qualifying with a mental illness, or disability, is quite small. The vast majority of people who access assisted dying in Europe do so for the same reason as in America and Canada, namely that they are dying of terminal, physical illnesses such as cancer, or MND.

Can children request assisted dying in jurisdictions where it is legal?

Under the American and Canadian laws, only competent adults aged 18 years or over can qualify, if they meet all other eligibility criteria. In Europe, the laws do allow access for some minors, however, the safeguards are stricter and only a very small number of children have accessed their assisted dying laws.

In the Netherlands between 2002 and 2015 only 7 children have had an assisted death. In Belgium, it was two years after the law was amended in 2014, before the first minor accessed an assisted death. He was 17-year-old and he died in mid-2016.⁶ In Belgium, for a minor to undergo voluntary euthanasia, they must be in a 'terminal medical situation with constant and unbearable physical pain which cannot be assuaged and that will cause death in the short term'.⁶

PALLIATIVE CARE

Can palliative care relieve the pain and suffering of dying Australians?

Australia has one of the best palliative care systems in

TABLE 31: PROFILE OF PCPSS * AT BEGINNING OF PHASE TYPE – INPATIENT SETTING (%)

Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	49.6	38.7	9.9	1.8
	Other symptoms	32.8	51.0	13.9	2.3
	Psychological/spiritual	43.9	45.9	8.6	1.6
	Family/carers	47.6	41.1	9.2	2.1
Unstable	Pain	30.9	33.7	25.1	10.3
	Other symptoms	17.8	39.4	31.6	11.1
	Psychological/spiritual	28.7	47.7	18.8	4.8
	Family/carers	31.0	45.2	18.2	5.7
Deteriorating	Pain	39.1	39.1	17.1	4.7
	Other symptoms	22.8	44.8	26.5	5.9
	Psychological/spiritual	36.0	46.5	14.6	3.0
	Family/carers	33.3	43.7	17.9	5.1
Terminal	Pain	49.1	34.1	13.3	3.6
	Other symptoms	40.3	35.7	17.5	6.5
	Psychological/spiritual	57.0	31.3	8.7	3.0
	Family/carers	28.2	39.6	23.5	8.7

* Palliative Care Problem Severity Score (PCPSS) is a screening tool used to measure the severity of physical and psychological problems.

the world and it has improved significantly over the past 20 years. However palliative care is unable to relieve all pain and suffering, including the complex mixture of physical, emotional and psychological symptoms.

What percentage of dying patients can't have their suffering alleviated?

Based on data collected by approximately 100 palliative care services across Australia every year, we know that a small yet significant percentage of dying patients cannot have their symptoms controlled, even with the best efforts of palliative care.

The Australian *Palliative Care Outcomes Collaboration Annual Report 2016* includes numerous tables documenting relevant data. Table 1 – ‘Benchmark Summary’ shows that a realistic goal for ‘moderate to severe pain, becoming absent or mild’ was only 60% and yet this benchmark was not achieved.⁷ The benchmark for ‘moderate to severe breathing problems, becoming absent or mild’ was also 60%, yet this outcome was only achieved for 46.6% of patients in inpatient services and 35.8% of patients using community palliative care services.⁷ Even if palliative care services reached their current benchmarks, there would still be a large number of patients whose pain or suffering was unable to be alleviated.

Table 31 from the same report shows that the percentage of patients experiencing severe pain can be as high as 10.3% in the unstable phase. Even for patients in the terminal phase of their terminal illness (usually the last two days of life), 3.6% had severe pain, 3% had severe psychological distress and 6.5% had other severe physical symptoms.⁷

It is important to note that VAD and palliative care are not at odds with each other. In a study carried out in 2018 by Palliative Care Australia it is stated that “An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.”⁸

Pursuant to a recommendation of the Joint Select Committee Inquiry into end of life choices, the state government significantly increased the resourcing and funding of palliative care, especially for the regions.

For the vast majority of terminally ill patients, palliative care will be enough to enable them to have a peaceful death. But for those for whom this is not the case, VAD should be a lawful end of life option.

Isn't terminal sedation an option when pain or suffering cannot be relieved?

Terminal or continuous palliative sedation is a last resort option, if a patient is experiencing intolerable and unrelievable suffering in the process of dying. It is considered to be lawful because the sedation is administered for the primary purpose of alleviating the suffering, even though death will inevitably result



as a “side-effect”. This medical intervention is in fact euthanasia, although not acknowledged as such. It is not voluntary assisted dying because the doctor makes the decision, sometimes but not always in consultation with the patient’s family, and takes the action required without, in the vast majority of cases, the express consent of the patient at the time.

Doctors take differing approaches to continuous palliative sedation, including how deeply and quickly sedation should be administered. These approaches may be based on an individual doctor’s personal belief about the morality of assisted dying. This means that not all patients will receive sedation to a level where their pain or suffering is alleviated.

Moreover, terminal sedation doesn’t always guarantee a peaceful death. As Australia’s most senior palliative care physician, Professor Ian Maddocks, explains:

“In reality, there are occasions where patients in terminal palliation do not receive adequate relief for their pain and suffering; in these cases patients can frequently experience distressing respiratory problems; they may regain consciousness; intolerable pain may not be relieved; and they may experience a prolonged uncertain albeit inevitable death.”

Professor Ian Maddocks

CURRENT PRACTICES

Are doctors currently assisting their patients to die?

At the end of 2019, the actual practice of assisted dying was lawful only in the state of Victoria. Although VAD legislation in WA had been passed by Parliament, it is subject to an 18-month implementation phase before becoming operative.

It is difficult to quantify accurately the extent to which assisted dying is already taking place in Australia. Although it is unlawful in most parts of Australia, research over many years has shown that a number of medical professionals are assisting patients to die, but usually covertly, for fear of prosecution. Although there are some doctors who have openly provided lethal medication to dying patients, very few are willing to admit to it publicly.

If assisted dying is already happening, why can't we leave things as they are?

Without legislation that sets out clear eligibility criteria and numerous process and reporting safeguards, including against duress and coercion, the prevailing practice of end of life care is uncertain and inconsistent. It is a lottery for the person who is dying because the individual conscience of the doctor may determine when, if at all, terminal sedation should be administered to bring a person's suffering to an end, and uncertain for medical practitioners practising within a system with no clear guidelines.

Will an assisted dying law change the doctor patient relationship

An assisted dying law is likely to change the doctor/patient relationship for the better. According to a recent report from California, one year after its assisted dying law was introduced, 'physicians across the state say the conversations that health workers are having with patients are leading to patients' fears and needs around dying being addressed better than ever before. They say the law has improved medical care for sick patients, even those who don't take advantage of it.'⁹

In Australia existing laws foster the paternalistic "doctor knows best" culture in which doctors decide unilaterally how much, or how little, or how quickly, a dying person should have their suffering relieved. Assisted dying legislation would allow an open conversation between doctor and patient while leaving the ultimate decision for a person who qualifies for VAD under the law to choose the time and manner of their death. Having this control has been shown of itself to have a palliative effect for the patient.

CHANGING THE LAW

What legal options does a dying patient have under the current law?

Under the current law in Australia, a person dying who is experiencing unbearable and unrelievable suffering can lawfully end their lives, or have it ended for them, in one of these ways:

- They can commit suicide. In WA the State Coroner's report for the period from 1 January 2012 – 5 November 2017 found that 10% of suicides are carried out by people with a terminal or debilitating chronic illness.¹⁰ This is a lonely, desperate and often violent option that frequently leaves those who find the body (usually the police or a family member) and loved ones left behind with unresolved and

long-lasting trauma.

- They can end their own life by refusing all medical treatment, food and water, and basically starve and dehydrate to death. This is usually a long and psychologically painful process for patients and their families.
- The third option is terminal palliative sedation as discussed above, which is lawful provided the primary intention is not to cause death but to alleviate suffering.

Why do we need to introduce an assisted dying law?

As set out above, the well-established ethical legal principle of self-determination allows a person to commit suicide, refuse life-saving medical treatment or starve themselves slowly to death, but not to choose a peaceful death that would end their suffering. This is ironic, if not barbaric, in an otherwise civilised society.

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EUTHANASIA AND ASSISTED DYING

This article from End of Life Law in Australia – a website managed by **Australian Centre for Health Law Research** at QUT – discusses the laws relating to euthanasia and assisted dying both in Australia and overseas, and the intersection of these laws with palliative care and other treatments.

Euthanasia and assisted dying are topical issues around the world. In Australia, attempts to reform the law occur regularly, while in Europe and North America there is a trend towards the legalisation (or decriminalisation) of voluntary euthanasia and physician-assisted dying.

Discussion of these issues remains prevalent within the media, fuelled by the not infrequent prosecutions of family members, friends and medical practitioners who have been involved with the death of persons. This article discusses the laws relating to euthanasia and assisted dying both in Australia and overseas, and the intersection of these laws with palliative care and other treatments.

DEFINING EUTHANASIA AND ASSISTED DYING

What is euthanasia?

Euthanasia is a deliberate, intentional act of one person to end the life of another person in order to relieve that person's suffering. For example, a doctor injects a patient with a lethal substance to relieve that person from unbearable physical pain. The term euthanasia is often used in different ways.

Three of the most common are:

- **Voluntary euthanasia:** Euthanasia is performed at the request of the person whose life is ended, and that person is competent. For example, a doctor injects a competent patient, at their request, with a lethal substance to relieve that person from

unbearable physical pain.

- **Non-voluntary euthanasia:** Euthanasia is performed and the person is not competent. For example, a doctor injects a patient in a post-coma unresponsive state (sometimes referred to as a persistent vegetative state) with a lethal substance.
- **Involuntary euthanasia:** Euthanasia is performed and the person is competent but has not expressed the wish to die or has expressed a wish that he or she does not die. For example, a doctor injects a competent patient who is in the terminal stage of a terminal illness such as cancer with a lethal substance without that person's request.

Any reference to euthanasia in this article is a reference to voluntary euthanasia, unless it is stated otherwise.

Euthanasia and assisted dying are topical issues around the world. In Australia, attempts to reform the law occur regularly, while in Europe and North America there is a trend towards the legalisation (or decriminalisation) of voluntary euthanasia and physician-assisted dying.

What is assisted suicide?

Suicide is the intentional act of killing oneself. *Assisted suicide* occurs where a person intentionally kills themselves with the assistance of another (who provides the knowledge or means to do it). For example, where a friend or relative obtains a lethal drug and provides it to the person to use to commit suicide.

Physician-assisted suicide occurs where a person requests a doctor to assist them in committing suicide, for example, a doctor provides a person with a prescription to obtain a lethal dose of drugs.





WHAT IS THE DIFFERENCE BETWEEN EUTHANASIA AND ASSISTED SUICIDE?

Assisted suicide is different from euthanasia as the person who provides the assistance (e.g. the friend, relative or doctor) does not do the final act that causes the death. The death is caused by the person themselves, by their own action of committing suicide.

Euthanasia occurs because the action of the first person e.g. the doctor, causes the death of another person.

The following example illustrates the difference:

- If a doctor prescribes barbiturates (a drug that depresses the central nervous system and sedates a person) to a person with the intention of assisting that person to die, and the person uses the drug to kill him or herself, the doctor has helped the person to commit suicide. In this case physician-assisted suicide has occurred.
- If a doctor administers a lethal dose of barbiturates to a patient that ends the patient's life, euthanasia has occurred.

LEGALITY OF EUTHANASIA AND ASSISTED DYING *Is suicide legal in Australia?*

Yes. Suicide and attempted suicide were originally crimes, but are now legal in Australia.

Are euthanasia and assisted dying legal in Australia?

Euthanasia is illegal in all Australian States and Territories, and may result in a person being charged with murder, manslaughter or assisting suicide.

Assisted suicide is illegal in all Australian States and Territories except for Victoria, where Voluntary Assisted Dying (VAD) is lawful in limited circumstances under the *Voluntary Assisted Dying Act 2017* (Vic). The Victorian VAD laws are discussed further below.

On 10 December 2019 the Voluntary Assisted Dying Bill 2019 (WA) was passed by the Western Australian Parliament and will be enacted on receiving Royal Assent. The Western Australian Department of Health will lead an 18-month implementation period of the new laws, which will permit VAD in the State providing certain criteria are met. VAD is expected to commence in Western Australia in mid-2021.

Between March 1996 and March 1997, voluntary euthanasia and physician-assisted suicide were legal in the Northern Territory under the *Rights of the Terminally Ill Act* (NT). However, in 1997 the Australian Government intervened, using the Territories power in the Australian Constitution to pass legislation abolishing the Act. Physician-assisted suicide and euthanasia are now illegal in the Northern Territory.

There have been many attempts to legalise euthanasia in Australian States and Territories, with an increasing number of Bills on this topic being introduced into State and Territory Parliaments. However, apart from the Northern Territory, none of these bills have become law.

Euthanasia and/or assisted suicide are legal in some countries.

VICTORIA'S VOLUNTARY ASSISTED DYING LAW

Voluntary assisted dying (VAD) is legal in Victoria under the *Voluntary Assisted Dying Act 2017* (Vic) ('the Act'). The Act provides for and regulates access to VAD, defined as 'the administration of a voluntary assisted dying substance, and includes steps reasonably related to such administration' (i.e. physician-assisted dying, not voluntary euthanasia).

Eligibility criteria

In order to access VAD, a person must meet strict eligibility criteria, including that the person must:

- Be aged 18 or over;
- Be an Australian citizen or permanent resident, ordinarily resident in Victoria, and, at the time of making a first request for VAD, have been resident in Victoria for at least 12 months;
- Have decision-making capacity; and
- Be diagnosed with a disease, illness or medical condition that is:
 - Incurable;
 - Advanced, progressive and will cause death;
 - Is expected to cause death within six months; and
 - Is causing suffering to the person that cannot be relieved in a manner that the person finds tolerable.

The only exception is if the person is diagnosed with a neurodegenerative disease, illness or medical condition. In that case, a person may access VAD provided

that disease, illness or condition is expected to cause death within 12 months.

A person is not eligible to access VAD only because they have a disability, or are diagnosed with a mental illness.

A person who is considered ineligible to access VAD because they:

- Were not ordinarily resident in Victoria, or
- Resident for at least 12 months prior to making the request), or
- Has or does not have decision-making capacity to make a request

... may apply to the Victorian Civil and Administrative Tribunal for a review of the decision.

Requests and assessment

The Act requires the person to make three separate requests for VAD, undergo two independent medical assessments, and make a written, witnessed declaration requesting access to VAD (once s/he has been assessed as eligible for access).

Conscientious objection

A health practitioner with a conscientious objection to VAD has the right to refuse to provide information about VAD to a patient, and to participate in any part of the VAD process (including supplying, prescribing or administering a VAD substance, or being present when a VAD substance is administered).

Administration

In order to obtain, possess, store, use and self-administer the VAD substance, the person accessing VAD must be issued with a self-administration permit. If the person is physically incapable of self-administering or digesting the substance, a practitioner administration permit must be applied for, permitting the coordinating medical practitioner to administer the substance to the person. The person must then make an administration request to the practitioner in order to be administered the substance.

Safeguards

The legislation contains a range of safeguards, including:

- The person seeking VAD must be provided with information about: diagnosis and prognosis; available treatment options; palliative care options; and risks associated with injecting the lethal medication (i.e. death). The person must also be advised that s/he may decide at any time not to continue the VAD process.
- A Voluntary Assisted Dying Review Board will be established with monitoring, reporting, compliance, safety and research functions.
- Regulations governing the prescription, dispensing and disposal of VAD substances.
- Mandatory reporting requirements for health practitioners and employers where they believe another practitioners' conduct breaches the Act e.g. offering to provide access to VAD in a way that contravenes the Act.

- Protection from criminal liability for persons who assist or facilitate a request for, or access to VAD.
- Protection from criminal and civil liability for practitioners who act in accordance with the Act.
- A range of new offences relating to non-compliance with or contravention of the Act.
- Statistical information about the people who access VAD (i.e. their disease, illness or condition, and their age at the time of their death from VAD) will be recorded and publically released (in a de-identified form).

Review

The Act will be reviewed by the Minister in its fifth year of operation.

KEY ASPECTS OF AUSTRALIAN LAW ON EUTHANASIA AND ASSISTED DYING

Is euthanasia murder or manslaughter?

Yes, potentially both. Under the criminal law, the act of killing a person falls within the definitions of murder and/or manslaughter.

While the criminal law varies between Australian States and Territories, murder generally occurs where there is the intentional killing of another, or where the person knows that death or serious bodily harm would be a likely consequence of his or her actions. If a person euthanises another, and that person intends to kill the other, or knows death or serious bodily harm is likely to occur, then that is murder.

Manslaughter is the unlawful killing of another in circumstances where an intention to kill cannot be proven, or there are mitigating circumstances. Manslaughter can be either voluntary (i.e. the accused intended to and did cause the death but there are mitigating factors justifying a reduced charge) or involuntary (the accused did not intend to kill but caused an unlawful death).

People accused of committing euthanasia are often prosecuted for the offence of voluntary manslaughter.

What if the killing is done for merciful reasons or is a compassionate killing, or the person consents to their life being ended?

A person's motives for killing another, even if merciful or compassionate (such as to relieve pain) are not relevant to whether they have committed a crime. This is also the case even where the victim consents to being killed (for example, a person asks a doctor to end their life). In those situations, a person may still be charged with and found guilty of murder or manslaughter.

Have people been prosecuted for euthanasia and assisted dying?

Yes. There have been a number of criminal convictions involving euthanasia and assisted dying. However, prosecution is rare and usually results in lenient penalties (such as wholly suspended sentences where the offender does not serve any time in prison).

The prosecution can choose whether they prosec-

ute for assisted suicide or for murder or manslaughter, and will look at:

- The level of assistance provided by the person (did they actually cause the death, or were they only involved in the preparation for the suicide);
- Whether the offender pleaded guilty early and assisted authorities;
- The mental capacity of the deceased (if the deceased was not mentally competent, the appropriate charge is likely to be murder or manslaughter); and
- Whether there was a suicide pact between the person and the deceased and that person survived.

INTERSECTION OF THE LAW ON EUTHANASIA AND ASSISTED DYING WITH OTHER TREATMENT DECISIONS AND PALLIATIVE CARE

If a health professional fails to provide medical treatment to a patient, can the health professional be guilty of killing that patient?

Health professionals have a legal duty to provide a person in their care with the 'necessaries of life', including medical treatment. If the health professional breaches this duty, they may be criminally liable for any consequences to the patient's life, health or wellbeing.

However, this duty will not apply where the patient has capacity and refuses life-sustaining treatment either at the time the treatment is offered, or in an Advance Directive, or where the treatment is considered by the doctor to be inappropriate in the circumstances (e.g. futile). In these cases the health professional is under no duty to provide the treatment, even though the patient will die without the treatment.

Does a health professional perform euthanasia or assist dying when he or she withholds or withdraws life-sustaining treatment?

No. A health professional does not unlawfully kill a patient when he or she withholds or withdraws life-

sustaining treatment in one of the situations outlined in the previous question. In those situations the person is considered to have died naturally from their medical condition or disease.

Can a person refuse ordinary food and drink without being force-fed?

Yes. If a person has capacity, they are legally able to refuse both artificial nutrition and hydration (for example, given through a tube into the person's stomach) and also ordinary food and drink. This is not considered to be suicide, but rather the person exercising his or her right to refuse treatment.

Does a health professional or other person assist dying by allowing someone to refuse food or drink?

No. If the person has capacity to refuse food or drink then respecting their refusal and not force-feeding the person is not assisting them to die.

Does a health professional perform euthanasia or assist dying when he or she provides palliative care that hastens a patient's death?

No. Giving palliative care is legal so long as the health professional's intention is to reduce or relieve a patient's pain and suffering, not hasten death. This is the case even if the health professional knows death may be hastened by providing palliative care. This is known as the 'doctrine of double effect'.

Emerging issue: voluntary palliated starvation

Voluntary palliated starvation (VPS) occurs when a competent person refuses to eat or drink and receives palliative care to relieve any pain, suffering or symptoms she or he experiences from dying due to a lack of food and water. In some situations it has been used as an alternative to physician-assisted suicide. VPS and its legal status in Australia is discussed on our *Palliative Medication* webpage.

JURISDICTION	ALLOWS	YEAR LEGALISED	STATUS
Oregon	Assisted suicide	1997	No expansion
Washington (state)	Assisted suicide	2009	No expansion
Vermont	Assisted suicide	2013	No expansion
California	Assisted suicide	2015	No expansion
Colorado	Assisted suicide	2016	No expansion
Belgium	Euthanasia and assisted suicide	2002	Expanded
Netherlands	Euthanasia and assisted suicide	2002	Expanded
Luxembourg	Euthanasia and assisted suicide	2009	No expansion
Canada	Euthanasia and assisted suicide	2016	No expansion
Quebec	Euthanasia and assisted suicide	2016	Expanded (by federal law, not the provincial government)

Sources: Health departments and/or medical associations in Oregon, Washington, Vermont, Colorado, Canada and the Netherlands; legislatures and/or senators in Washington, Vermont, California and Colorado; experts in Belgium (Prof Robert Vander Stichele) and Quebec (Dr Mona Gupta). Luxembourg is based on advice from Professor Penney Lewis.

LEGALITY OF EUTHANASIA AND ASSISTED DYING OUTSIDE AUSTRALIA

Are euthanasia and assisted dying legal outside Australia?

Yes. Voluntary euthanasia and/or assisted dying (generally physician-assisted suicide) are legal in a number of countries throughout the world including:

- **United States:** Only physician-assisted suicide is legal, and only in these states:
 - Oregon, Washington, Vermont, California, Colorado, the District of Columbia and Hawaii: Lethal medication can be prescribed by a doctor to patients over 18 who are suffering from a terminal illness and will die from that condition within six months.
 - Montana: The Montana Supreme Court confirmed in the case of *Baxter v Montana* that:
 - Neither Montana law or public policy prohibit physician-assisted suicide; and
 - Doctors who assist a person to die (i.e. by prescribing lethal medication) are protected from prosecution for homicide offences, so long as the patient consented to the doctor aiding him or her to die.
- **The Netherlands:** Assisted suicide and voluntary euthanasia are legal where a person has lasting and unbearable suffering.
- **Belgium:** Voluntary euthanasia is legal for patients who suffer untreatable, constant and unbearable physical or mental suffering.
- **Luxembourg:** Voluntary euthanasia is legal for patients who suffer a terminal or incurable illness. Assisted suicide is also legal.
- **Canada:** In June 2016 the Canadian Parliament passed federal legislation which legalises medical assistance in dying (MAiD) if the eligibility criteria are met and safeguards are followed. More information about the eligibility criteria, and these reforms is available from *End-of-Life Law & Policy in Canada*, a presentation by international end of life law expert Professor Jocelyn Downie, and a recent development on MAiD authored by Professor Downie.
 - In Quebec, physician-assisted suicide is legal, but not suicide assisted by people other than physicians.
- **Colombia:** Voluntary euthanasia is legal for terminally ill patients.
- **Switzerland:** The legal situation in Switzerland is unusual as voluntary euthanasia and assisted suicide are illegal under Swiss criminal law, but assisted suicide routinely occurs. This is because assisted suicide will only be an offence if it is carried out for 'selfish motives'. Provided there are no selfish motives, assisted suicide is not prohibited.

Under Swiss law, it is irrelevant whether or not the person has a terminal illness. Also, friends and relatives



can provide assistance for people to die, not just doctors. As a result, in recent years Switzerland has become a destination for individuals from countries where voluntary euthanasia and assisted suicide are illegal.

Is it legal to travel overseas to seek euthanasia or assisted suicide?

The legalisation of voluntary euthanasia and/or assisted suicide in some countries has resulted in some patients travelling overseas, in particular to Switzerland, to receive assistance to die. Whether or not it is lawful for Australians to accompany a person to travel overseas for this purpose has not yet been addressed in Australia.

In the United Kingdom case of *Local Authority v Z* the court considered whether a patient suffering from cerebellar ataxia could travel from Britain to Switzerland to seek euthanasia. The local welfare authority sought an injunction to prevent the patient from leaving Britain. The court found that the local authority had no duty to prevent the patient travelling to Switzerland. The court also considered whether the patient's husband, who had agreed to help her travel to Switzerland, was assisting a suicide and should be prosecuted. The court decided it was a matter for the Director of Public Prosecutions (DPP) whether to prosecute the husband.

Following this case, the United Kingdom DPP created guidelines detailing when they will or will not prosecute a person who accompanies another overseas to commit suicide. The guidelines state that a person commits an offence under the United Kingdom's *Suicide Act 1961*, punishable by up to 14 years imprisonment, if he or she encourages or assists the suicide or attempted suicide of another person. However, the consent of the DPP is required before a person can be prosecuted.

Although there are no similar guidelines in Australia, the United Kingdom's guidelines may be considered if this law arises in Australia.

KEY CASES

Director of Public Prosecutions v Nestorowycz [2008] VSC 385

Nestorowycz's husband suffered from dementia and diabetes and was in a wheelchair. Although her husband pleaded to be taken home from care, there was no clear evidence of his intent to die. Nestorowycz stabbed her husband and then attempted suicide. She pleaded guilty to attempted murder and received a suspended sentence of 2 years 9 months.

R v Cox (1992) 12 BMLR 38

Mrs Boyes, an elderly lady, was in agonising pain from rheumatoid arthritis. She had known Dr Cox for 13 years and he said she would not suffer. After many unsuccessful attempts to control her pain Mrs Boyes begged Dr Cox to kill her. Dr Cox administered a large dose of potassium chloride and Boyes died shortly after. Cox was charged with attempted murder (the Crown was unsure if they could prove the drugs killed Boyes or she died from her other conditions. Boyes' body had been cremated and therefore there was no scientific evidence the potassium chloride killed her).

During the trial the jury was instructed on the doctrine of double effect: Cox could only be convicted if his primary intention was to cause her death. Significantly in this case, the potassium chloride did not have any curative or pain-relieving properties and was estimated to be twice the legal dose. The jury convicted Cox of attempted murder (Cox received a suspended sentence of one year imprisonment and was allowed to return to his medical duties under supervision).

R v Justins [2011] NSWSC 568

Justins was the long-term partner of Wylie. Jennings was their friend. Wylie suffered from Alzheimer's disease and six months prior to his death he had attempted suicide by cutting his wrists. He stated he wanted to go to Switzerland to have assistance in committing suicide through an organisation called Dignitas. However Dignitas rejected Wylie's application on the grounds Wylie may not have the capacity to make the decision to end his own life. Wylie then attempted suicide again.

Jennings then travelled to Mexico to source the drug Nembutal (which is illegal in Australia) for the purpose of ending Wylie's life. Wylie was provided with the Nembutal, drank it voluntarily and died. Justins and Jennings then concocted alibis and denied any connection with Wylie's death. Prior to Wylie's death, and with Justins' assistance, Wylie had changed his will to provide Justins with a much greater benefit, to the exclusion of Wylie's daughters.

The jury must have been satisfied that Wylie lacked capacity to make an informed decision to end his life and found Justins guilty of manslaughter. She received a sentence of 2.5 years imprisonment with a non-parole period of 22 months to be served by periodic detention. Justins' conviction was overturned on appeal and she pleaded guilty to the lesser offence of aiding and abett-

ing suicide. She received no further punishment as, by that time, she had served 22 months in prison. Jennings committed suicide prior to being sentenced.

Other cases

- *Director of Public Prosecutions v Karaca & Price* [2007] VSC 190
- *Director of Public Prosecutions v Nestorowycz* [2008] VSC 385
- *R v Mathers* [2011] NSWSC 339
- *R v Maxwell* [2003] VSC 278
- *R v Mott* [2012] NZHC 2366
- *R v Nicol* [2005] NSWSC 547

FURTHER RESOURCES

Publications

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Ben White, Lindy Willmott and Penny Neller, *Euthanasia and Assisted Dying*, End of Life Law in Australia (Queensland University of Technology). Retrieved from <http://end-of-life.qut.edu.au> on 10 February 2020.

Assisted dying in Australia: where to next?

GO GENTLE AUSTRALIA LOOKS AT THE CURRENT STATUS OF ASSISTED DYING LAW REFORM AROUND AUSTRALIA

With three more Australian states looking to follow the lead of Victoria and Western Australia and introduce assisted dying laws, 2020 is shaping up as a pivotal year for more compassionate end of life choices.

VICTORIA

Victoria is the only Australian jurisdiction where adults in the end stage of a terminal illness and suffering intolerably can legally seek medical assistance to end their lives.

Passed by the Victorian parliament in 2017, the *Voluntary Assisted Dying Act* came into effect in June 2019, giving eligible adults with less than six months to live – or one year if they have a neurodegenerative condition – the right to access lethal medication.

According to the Voluntary Assisted Dying Review Board's second report, by the end of 2019 the system had received more than 136 applications to use the new VAD law. Of these, 81 people were issued with a permit and 52 died using the approved medication. However, access remains a serious issue, with concerns that people are being held back by a lack of accredited specialists to approve applications.

WESTERN AUSTRALIA

Western Australia made history in 2019 by becoming the second Australian state to pass a VAD law. The WA Parliament passed the Voluntary Assisted Dying Bill on 10 December after more than 180 hours of debate.

There are several important differences between the WA and Victorian laws: there is no requirement for a specialist physician to assess patients in WA, and doctors and nurses can raise the option of VAD with patients during a medical consultation. This ensures people with terminal illnesses are aware of all their options.

There is now an 18-month implementation period before the law comes into force in mid-2021.

QUEENSLAND

With a wide-ranging parliamentary inquiry into end of life care due to wrap up in March, Queensland could be the next state to consider a VAD bill.

However, advocates are concerned that the government is running out of time to draft and introduce legislation before the next state election, due in October 2020. Tanya Battel, a Queenslanders with terminal breast cancer, has launched a petition urging the Premier to move quickly on the issue.

Unlike other states, Queensland has never considered a VAD law. Significant work is required to prepare the community and parliament for what will be a gruelling debate.

Highlighting the urgency in Queensland was data from the National Coronial Information System which



showed that, faced with the prospect of an agonising death and seeing no other alternative, more than 80 Queenslanders with terminal or debilitating physical conditions are taking their own lives each year.

David Muir, chair of the Clem Jones Trust, has said the situation “indicates the damage done by the policy vacuum on voluntary euthanasia law reform”.

SOUTH AUSTRALIA

South Australia's parliament is also in the midst of a joint select committee inquiry into end of life choices to investigate whether SA should introduce VAD legislation similar to laws passed in Victoria and WA. Launched in April 2019, the committee overseeing the inquiry is due to hand down its final report in early 2020.

Advocates are hopeful the report will be supportive and recommend the introduction of a VAD bill, but it is unclear whether any resulting legislation would be government-sponsored.

If a bill is proposed, it will come three years after a private members bill – the 15th debated in the state – was defeated in the SA Parliament by one vote in 2016.

TASMANIA

Independent MP Michael Gaffney plans to introduce a VAD bill to the Tasmanian parliament in 2020. The MP released a draft bill for public comment in late January

and was seeking community feedback on its content.

Advocates are unsure of the Tasmanian parliament's appetite for revisiting the VAD debate, especially given the decision by Will Hodgman, in January, to stand down as Premier and leader of the Liberals. It is unclear where new Premier Peter Gutwein stands on the bill; however, he has voted against assisted dying bills in the past.

Since 2009, there have been three attempts to introduce VAD laws in Tasmania, with the last, in 2017, defeated 16 votes to eight.

NSW

The prospect of a VAD law in Australia's most populous state remains extremely uncertain. The most recent bill, in 2017, failed to pass the upper house by a single vote. Advocates had expected another bill this year; however, acrimonious debate over abortion reform in 2019 led Premier Gladys Berejiklian to rule out further conscience votes or significant social reform in the life of this parliament.

Meanwhile, the Voluntary Euthanasia Party in NSW has rebranded as the Reason Party NSW. Its sister organisation in Victoria, led by Fiona Patten MLC, was instrumental in pushing for a parliamentary VAD inquiry in that state. If no new bill eventuates in the life of the current parliament, the party will ensure VAD is a central issue at the next election.

NT AND THE ACT

The Northern Territory passed Australia's first voluntary assisted dying laws in 1995, only to see them overturned less than two years later by the federal government. Legislation introduced at the time by the Commonwealth stripped the NT and the Australian Capital Territory of the right to legislate for themselves on the issue.

Despite the prohibition, in 2019 the ACT government responded to a Report of the Select Committee on End of Life, renewing calls for the restoration of the territories' rights to legislate on VAD. Health Minister Rachel Stephen-Smith said the ACT was committed to offering more choices for people in end of life care.

NEW ZEALAND

A successful VAD law in New Zealand is of great interest to Australia, adding pressure for further law reform here. After a long and brutal debate, New Zealand's parliament passed the End of Life Choices Bill by 69 votes to 51 in November. The Bill sets out what the country's assisted dying law would look like.

The proposed law will now go to a referendum for final approval as part of the general election scheduled for 19 September 2020.

Go Gentle Australia was established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, their families and carers.

Go Gentle Australia believes every terminally ill Australian, no matter where they live, should have the same fundamental right to access more compassionate end of life choices, including voluntary assisted dying. Join our campaign for VAD laws in every Australian state and territory.

* This article was updated on 31 January 2020 to reflect the release of the Tasmanian draft VAD Bill and the announcement of the date of the NZ general election.

** A further update on 24 February 2020 included statistics from the Victorian Voluntary Assisted Dying Review Board 2nd Report.

Go Gentle Australia (25 February 2020). *Assisted Dying in Australia: Where to next?* (Updated 24 February 2020). Retrieved from www.gogentleaustralia.org.au on 25 February 2020.



Now that VAD is legal in Victoria, what is the future of assisted dying reform in Australia?

ABC RELIGION & ETHICS OPINION PIECE
BY **BEN WHITE** AND **LINDY WILLMOTT**

In November 2017, the Victorian Parliament passed the *Voluntary Assisted Dying Act 2017* (Vic). Following a planned implementation period of 18 months, the regime came into force on 19 June 2019. This is the first time voluntary assisted dying (VAD) has been lawful in Australia since the Northern Territory's short-lived *Rights of the Terminally Ill Act 1995* (NT), which was overturned by the Commonwealth Government's *Euthanasia Laws Act 1997* (Cth).

The *Voluntary Assisted Dying Act 2017* (Vic) permits an adult with decision-making capacity who is resident in Victoria to seek assistance to die, provided that request is made voluntarily and without coercion. To be eligible under the Act, a person must have an incurable disease, illness or medical condition that is advanced, progressive and will cause death within 6 months (12 months for neurodegenerative conditions). That condition must also be causing suffering that cannot be relieved in a manner that the person considers tolerable.

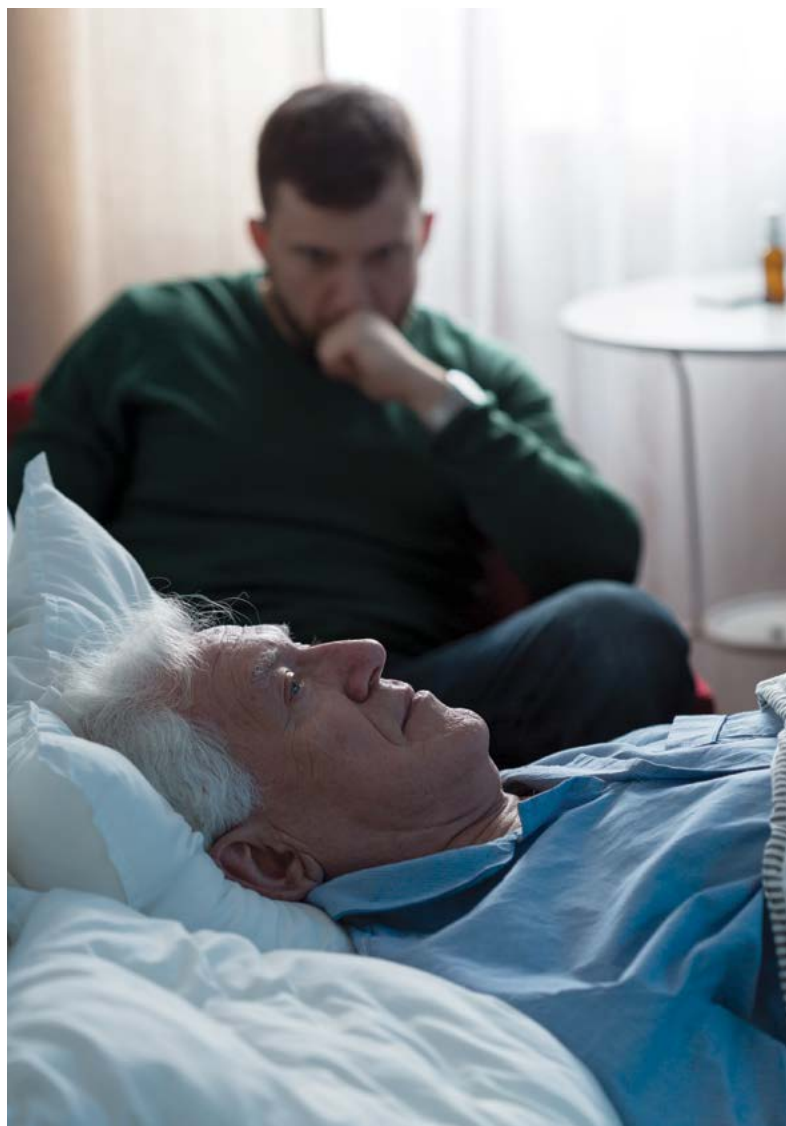
The nature of the assistance to die is intended to be primarily through prescribing lethal medication that the person then takes themselves (often called *physician-assisted dying*). However, there is an exception that operates when a person cannot physically take or digest that medication. In such a case, a doctor is permitted to administer the medication to the person (often called *voluntary euthanasia*).

Overall, the regime is very narrow in scope and has a large number of safeguards (68 in total). This enabled the Victorian Premier and others to describe it as the “most conservative scheme in the world”.

As Victoria implements its VAD laws, questions arise about whether other Australian states and territories will follow. There is considerable political activity and interest in many jurisdictions – such as the ACT, Western Australia, Queensland and South Australia – but whether this translates into law reform is a vexed issue. The Victorian experience, which saw an extended reform process and bitter parliamentary debate, demonstrates the major challenges of changing the law in this area. In this article, we want to consider the likelihood of future VAD reform in Australia having regard to both local and international developments.

A brief history of reform attempts

Commonwealth, state and territory governments have been attempting to reform laws relating to VAD for more than three decades. In 1995, the Northern Territory was the first jurisdiction in the world to have operative



legislation legalising VAD with the enactment of the *Rights of the Terminally Ill Act 1995* (NT). As we've already noted, this Act was overturned by the Commonwealth Government under its constitutional powers that relate to territory laws; that federal law still operates today to prohibit territories from passing laws about VAD.

The difficulty in effecting law reform on this topic is evidenced by the significant number of failed legislative attempts in Australia. A study of law reform efforts up to the end of 2015 documented 51 bills, introduced at the commonwealth, state and territory level, dealing with the issue of VAD. Although some bills dealt with matters such as referendums to consider the issue, 39 of these bills specifically aimed to legalise VAD. A high level of legislative activity has continued since that review, with a further seven bills being tabled from the beginning of 2016.

It is interesting to observe that the bills that have been tabled over more recent years have come close to passing the relevant parliamentary chamber (or

chambers) where they have been tabled. These bills include the Victorian bill that ultimately became law, the Death with Dignity Bill 2016 (SA), which was defeated by one vote in the House of Assembly, and the Voluntary Assisted Dying Bill 2017 (NSW), which was also defeated by a single vote in the Legislative Council.

At the commonwealth level, the Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015, a bill designed to allow territories to legislate on VAD, was defeated in the Senate by two votes in August 2018. Recent years have also witnessed a greater investment by sitting governments with the establishment of parliamentary reviews that have been funded to undertake careful consideration of the complex issues raised at the end of life.

In addition to the Victorian Parliamentary Committee that recommended the reform that preceded the VAD Act, another three Australian jurisdictions have or will engage a parliamentary committee process. The Western Australia Joint Select Committee on End of Life Choices recently delivered its major report proposing, among other things, that VAD be permitted and that a government-sponsored reform process be initiated to achieve that.

In the Australian Capital Territory, a Select Committee on End of Life Choices has been established to inquire into VAD and delivered its report. Most recently, in Queensland, the only State not to have considered a VAD bill in its parliament, a parliamentary committee is considering VAD reform and a South Australian parliamentary committee was also established in April to consider this issue.

Will other states follow?

We predict that other states will follow Victoria and permit VAD. Territories too may follow, although that will require the Commonwealth to overturn the *Euthanasia Laws Act 1997* (Cth), which prohibits territories from legalising VAD. Over the past three decades, there have been many complex factors that have combined to make reform difficult, despite ongoing public support to change the law.

However, there are three key factors that have become increasingly significant over time and now suggest further reform in Australia is likely:

- International trends to permit VAD;
- The growth of social science evidence about VAD; and
- Changing local political conditions.

A fourth significant factor that will affect the prospect of wider reform is how the new Victorian VAD regime operates in practice. But because data on its operation are not yet available, we leave it out of our consideration at this point.

International trends to permit VAD

There are two main parts of the world where VAD is legal: Europe and North America.

Europe has experienced decades of VAD with permissive legislation in the Netherlands (*Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*), Belgium (*Act on Euthanasia 2002*) and Luxembourg (*Legislation reglementant les soins palliatifs ainsi que l'euthanasie et l'assistance au 2009*).



The European model is broadly based on voluntary euthanasia or physician-assisted dying to relieve unbearable suffering. Switzerland has had a longer history of decriminalisation of assisted suicide.

In North America, VAD is permitted in the US by legislation in Oregon (*Death with Dignity Act 1994*), Washington (*Death with Dignity Act 2008*), Vermont (*Patient Choice and Control at End of Life Act 2013*), California (*End of Life Option Act 2015*), Colorado (*End-of-Life Options Act 2016*), District of Columbia (*Death with Dignity Act 2016*), Hawaii (*Our Care Our Choice Act 2018*), New Jersey (*Aid in Dying for the Terminally Ill Act 2019*) and Maine (*An Act to Enact the Maine Death with Dignity Act 2019*), as well as in Montana by court decision (*Baxter v Montana 2009*).

The US model permits physician-assisted dying for people with a terminal illness. VAD is also lawful in Canada with *An act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (SC 2016) passing in 2016. This legislation was in response to the Supreme Court decision the year before of *Carter v Canada (Attorney General)* (2015), which found that the blanket prohibition on assisting a person to die was overly broad and in breach of the *Canadian Charter of Rights and Freedoms*.

The Canadian law permits “medical aid in dying”, which allows both voluntary euthanasia and physician-assisted dying for a person with a grievous and irremediable condition, and for whom a natural death is foreseeable.

In an increasingly globalised world, the growing international trend to permit VAD is important as Australian states and territories consider their positions. Some may argue that the European countries that permit VAD are different from Australia in terms of the delivery of health services, health law, policy and culture, and there may be some merit in such assertions. However, the same cannot be said in relation to North America given our shared legal, political and cultural heritage. For example, law and policy in Canada is frequently used as a comparator by law reform bodies when considering future directions for reform in Australia.

The reach of VAD in terms of population for whom this is now an option is also significant for the Australian debate. It is no longer a ‘boutique’ activity available only in a small number of places: approximately 37 million Canadians now have VAD as an end of life option, and with California (population 40 million) passing its law, almost one in five Americans live in a state where VAD is lawful. It is difficult for politicians to avoid the reality of these international developments.

Growth of social science evidence about VAD

A key objection to reform is that VAD poses risks to the vulnerable in society. One concern raised is that of all who may be eligible under the relevant legislation, it is more likely to be the vulnerable within our society who

choose to access assistance to die.

Another concern is that there are some in our community, particularly the vulnerable, who will receive assistance to die even though they are not eligible under the legislative framework. This latter argument is sometimes referred to as a ‘slippery slope’.

However, modern debates can now draw on high-quality peer-reviewed research about how VAD regimes have been functioning over some decades, including whether vulnerable groups in society are disproportionately choosing VAD. Studies undertaken both in Europe and in the United States have consistently found that groups generally regarded as vulnerable are not more likely to access VAD. There is also evidence that illegal medical practices are not more likely to occur after the legalisation of VAD.

This social science evidence has been highly influential in recent law reform. In the Canadian *Carter v Canada* case, the trial judge found that it was possible to design VAD regimes that protect the vulnerable. This finding of fact was not overturned by the Supreme Court of Canada on appeal. Both the Victorian and Western Australian parliamentary committees also concluded that the vulnerable need not be at risk in a properly designed VAD regime. This social science research is likely to continue to shape VAD debates, making claims about risks to the vulnerable and slippery slopes more difficult to sustain. By removing or weakening a key argument against reform, there is now diminishing space or a ‘shrinking battlefield’ within which those opposing reform can operate.

Changing local political conditions

The sustained efforts over some decades to change the law in Australia to permit VAD are likely to continue. However, it seems that now there may be more favourable conditions for reform. Of the 39 bills aiming to legalise VAD that were introduced before 2016, only seven were described as “close to passing” – namely, as having support of at least 70 per cent of the number of members required to pass the bill in the parliamentary chamber.

However, since 2016, a higher percentage of bills has been “close to passing.” (It is worth noting that of the seven bills introduced since the beginning of 2016, two were Commonwealth bills that sought to restore territory powers to enact VAD legislation.) Of the five bills seeking to legalise VAD, three had either passed (Victoria) or been defeated in the relevant chamber by a single vote (South Australia and New South Wales). This may signal an increased willingness for politicians to contemplate reform. We anticipate that this mindset will grow now that Victoria has ‘broken through the wall’.

Effect of the Victorian VAD experience

A final key factor that will be relevant for the future of VAD reform in Australia is how Victoria’s law operates in practice. A particular challenge for the Victorian

regime will be its complexity, with its many safeguards and processes. Some evidence will emerge from data generated by the mandated reporting and other oversight mechanisms. There will also, no doubt, be independent empirical research undertaken into its functioning.

However, equally significant may be the wider public and political perceptions of the regime's success or failure. These may be based on less reliable sources, such as anecdotes or media reports, but may nevertheless be influential because political debates can sometimes be coloured by such evidence. Other Australian governments will closely watch the operation of the Victorian law, as well as community and other key stakeholder perceptions.

What VAD model will other states adopt?

In a federation such as Australia, reform at state level can occur in two ways. The first is the 'laboratory of a federation' approach where states each adopt their own model that can be adapted to reflect the particular circumstances of that state. This approach also facilitates comparative assessments of strengths and weaknesses – hence the 'laboratory' reference.

The second is for states to 'follow the leader' by adopting the original model. This latter approach has been the experience in the United States, with the Oregon model largely copied by the legislation in other states. It is too early to know which approach will be taken in Australia.

There may be political advantages for taking the second 'follow the leader' approach. As we have already noted, the Victorian VAD law is very conservative, with the focus on providing assistance to a person to die – rather than allowing doctors to administer medication

except in limited circumstances – and a large number of detailed safeguards and processes. Proposing such a conservative model was a deliberate strategy to secure the required support for the bill to pass through the Victorian Parliament.

Adopting this approach may also have political appeal for other state governments seeking to pass VAD laws. There may be less opposition in proposing a bill that another parliament has endorsed as an acceptable model. Displacing the default Victorian approach will require a plausible alternative.

However, there are also clear opportunities for states in adopting the 'laboratory of a federation' approach. Indeed, it would be logical to expect some departures from the Victorian model. On the one hand, it could be politically attractive to increase the safeguards and processes so that the new model is more conservative than the "most conservative model in the world." Commentators have argued this has happened with the addition of new safeguards in the VAD laws that were recently passed in Hawaii.

On the other hand, some of the processes of the Victorian regime may be regarded as unreasonably complex and so could be removed or changed while leaving the broad legal framework intact. There are indications this could happen in Western Australia, with its Parliamentary Committee report indicating a different view on some aspects of the Victorian law, such as the prohibition on doctors raising VAD as a possible option.

A further option would be to depart from the Victorian model by allowing doctors to provide assistance to die if so requested by the patient, rather than the role being limited to the prescription of medication.

Decisions about variations of the Victorian model



– and, indeed, whether to adopt it at all – will, of course, be informed by how the regime operates in practice. This is currently an unknown. But states engaging in reform further down the track will have access to more evidence from Victoria (and different VAD models internationally) to inform deliberations.

What's next for VAD?

In our view, VAD in Australia is “a train that has left the station.” International trends, growing Australian political support (coupled with strong and continued community expectation) and the weakening of key opposing arguments all point to other states following Victoria's lead by legalising VAD.

It will be interesting to observe whether the next states will adopt (or just tweak) the Victorian model, whether they will take an even more conservative path or whether they will throw off the shackles of conservatism and adopt the more liberal Canadian model. We consider it very unlikely that the European regimes of Belgium and the Netherlands will be serious contenders in Australia.

It is important to note that despite the suggestions that reform is travelling in the direction of legalising VAD, we should expect surprises in the politics of assisted dying. The heated debates in the Victorian Parliament about VAD laws in 2017 revealed a depth of raw emotion from many politicians. The late changes of position that saw support for reform recently disappearing in the parliaments of South Australia and the Commonwealth also show how illusory the task of securing and maintaining consensus on VAD reform is.

Although reform in other Australian states is likely, that train journey will be one that is slow, uphill and with plenty of twists and turns.

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This article draws on part of a presentation given by the authors for the 2018 Memorial John McPhee Seminar, Newcastle, 27 August 2018. An earlier version of this article appeared in the *Australian Health Review*.

White, B, and Willmott, L (24 June 2019). 'Opinion: Now that VAD is legal in Victoria, what is the future of assisted dying reform in Australia?' (Updated 25 June 2019), *ABC Religion & Ethics*. Retrieved from www.abc.net.au/religion on 10 February 2020.

CHAPTER 2

The assisted dying debate

ASSISTED DYING AND ETHICS: FIVE THINGS TO THINK ABOUT

The Ethics Centre sets out some of the ethical considerations a person might wish to take into account when forming a view on assisted dying

Making sense of our lives means thinking about death. Some philosophers, like Martin Heidegger and Albert Camus, thought death was a crucial, even defining aspect of our humanity. Camus went so far as to say considering whether to kill oneself was the only real philosophical question.

What these philosophers understood was that the philosophical dream of living a meaningful life includes the question of what a meaningful death looks like. More deeply, they encourage us to see that life and death aren't opposed to one another: dying is a part of life. After all, we're still alive when we're dying so how we die impacts how we live.

The Ethics Centre was invited to make a submission to the NSW Parliamentary Group on Assisted Dying regarding a draft bill the parliament will debate soon. The questions we raised were in the spirit of connecting the good life to a good death.

Simon Longstaff, director of the Centre and author of the submission, writes, "It is not the role of The Ethics Centre to prescribe how people ought to decide and act. Our task is a more modest one – to set out some of the

ethical considerations a person might wish to take into account when forming a view."

Here are some of the key issues we explored, which are relevant to any discussion of assisted dying, not just the NSW Bill.

DOES A GOOD LIFE INVOLVE SUFFERING?

The most common justification for assisted dying or euthanasia is to alleviate unbearable suffering. This is based in a fairly universal sentiment. Longstaff writes, "To our knowledge, there is no religion, philosophical tradition or culture that prizes suffering ... as an intrinsic good".

Good things can come as a result of suffering. For example, you might develop perseverance or be supported by family. But the suffering itself is still bad. This, Longstaff argues, means "suffering is generally an evil to be avoided".

There are two things to keep in mind here.

First, not all pain is suffering. Suffering is a product of the way we interpret ourselves and the world around us. Whether pain causes suffering depends on our response. It is a subjective experience. Nobody but the sufferer can really determine the extent of their suffering. Recognising this could suggest a patient's self-determination is crucial to decisions around assisted dying.

Second, just because suffering is generally seen as bad, it doesn't mean anything that aims to avoid suffering is good. We can agree that the goal of reducing suffering is probably good but still need to interrogate whether the method we've chosen to reduce suffering is itself ethical.

Whether pain causes suffering depends on our response. It is a subjective experience. Nobody but the sufferer can really determine the extent of their suffering.

THE CONNECTION BETWEEN A GOOD DEATH AND A GOOD LIFE

It's not always possible to treat someone's suffering – whether using medicine, psychology, religion or philosophy. When there is no avenue to alleviate someone's pain and anguish, Longstaff suggests "life can be



POLLS ON VOLUNTARY ASSISTED DYING

POLLING BODY	DATE	QUESTION	YES	UNDECIDED /OTHER	NO
Newspoll	2012	<i>Thinking now about voluntary euthanasia, if a hopelessly ill patient experiencing unbelievable suffering with absolutely no chance of recovering, asks for a lethal dose should a doctor be allowed to provide a lethal dose?</i>	82.5%	4.8%	12.7%
Australia Institute	2012	<i>This question is about voluntary euthanasia. If someone with a terminal illness who is experiencing unbelievable suffering asks to die, should a doctor be allowed to assist them to die?</i>	71%	17%	12%
ABC Vote Compass	2013	<i>Terminally ill patients should be able to legally end their own lives with medical assistance.</i>	75.1%	9.4%	15.5%
Ipos Mori	2015	<i>Do you think that it should be legal or not for a doctor to assist a patient aged 18 or over in ending their life if that is the patient's wish, provided that the patient is terminally ill (where it is believed that they have 6 months or less to live), are of sound mind, and express a clear desire to end their life?</i>	73%	12%	15%
ABC Vote Compass	May 2016	<i>Terminally ill patients should be able to legally end their own lives with medical assistance.</i>	75%	9%	16%
Essential Media Communications	Dec 2016	<i>When a person has a disease that cannot be cured, and is living in severe pain, do you think (doctors) should or should not be allowed by law to assist the patient to commit suicide, if the patient requests it?</i>	68%	13%	19%
Roy Morgan Research	Nov 2017	<i>If a hopelessly ill patient, with no chance of recovering asks for a lethal dose, should a doctor be allowed to give a lethal dose, or not?</i>	85%	None	15%
ABC Vote Compass	May 2019	<i>Terminally ill patients should be able to end their own lives with medical assistance.</i>	87%	6%	7%

Source: Dying with Dignity Queensland, www.dwdq.org.au/surveys

experienced ... as nothing more than an unrelenting and extraordinary burden”.

This is the context in which we should consider whether to help someone to end their lives or not. Although many faiths and beliefs affirm the importance and sacredness of life, if we're thinking about a good, meaningful or flourishing life, we need to pay some attention to whether life is actually of any value to the person living it.

As Longstaff writes, “To say that life has value regardless of the conditions of a person's existence may justify the continuation or glorification of lives that could be best described as a ‘living hell’”.

He continues, “To cause such a state would be indefensible. To allow it to persist without available relief is to act without mercy or compassion. To set aside those virtues is to deny what is best in our form of being.”

A RESPONSIBLE PERSON SHOULD HAVE AUTONOMY OVER THEIR DEATH

Most people think it's important for adults to be held responsible for their actions. Philosophers think this is a product of autonomy – the ability for people to determine the course of their own actions and lives. Some philosophers think autonomy has an intrinsic connection to dignity. What makes humans special is their ability to make free choices and decisions. What's more, we usually think it's wrong to do things that undermine the free, autonomous choices of another person.

If we see death as a part of life, not distinct from it, it seems like we should allow – even expect – people to be responsible for their deaths. As Longstaff writes, “since dying is a part of life, the choices people make about the manner of their dying are central considerations in taking full responsibility for their lives”.

VOLUNTARY EUTHANASIA: POSITIONS OF MEDICAL ORGANISATIONS

ORGANISATION	STANCE
Doctors Reform Society of Australia	Supportive
Palliative Care Australia (<i>confirmed 2019</i>)	Neutral
Australian and New Zealand Society of Palliative Medicine	Neutral
Royal Australian College of General Practitioners	Neutral
Royal Australasian College of Physicians	Neutral
Royal Australian and New Zealand College of Psychiatrists	Neutral
Royal Australian and New Zealand College of Obstetricians and Gynaecologists	Neutral
Royal Australasian College of Surgeons	Neutral
Australian Medical Association (<i>reaffirmed 2019</i>)	Opposed
World Medical Association (<i>reaffirmed 2019</i>)	Opposed

Source: Doctors for VE Choice, <http://drs4vechoice.org/societies/>

VOLUNTARY EUTHANASIA: STANCES OF MAJOR RELIGIONS

Buddhism

Buddhists are not unanimous in their view of physician-assisted dying, but many are critical of it. In Buddhism, the way life ends has a profound impact on the way the new, reincarnated life will begin. A person's state of mind at the time of death is important: their thoughts should be selfless and enlightened, free of anger, hate or fear – suggesting that suicide is only approved for people who have achieved enlightenment and that other people should avoid it.

Christianity

Numerous polls confirm that while support for VE/VAD is strongest amongst those with no religion, the vast majority of religious Australians are also supporters. Many Christians believe that voluntary assisted dying is consistent with Christian values and with Jesus's message of love and compassion towards people suffering.

Catholicism

Roman Catholic Church's position is strict: killing of a human being, even by an act of omission to eliminate suffering, violates divine law and offends the dignity of the person.

Protestantism

Protestant denominations vary widely on their approach to euthanasia and physician-assisted death, but are generally

more lenient than the Roman Catholic Church. As physician-assisted dying has obtained greater legal support, some liberal Protestant denominations have offered religious arguments and support for limited forms of euthanasia.

Orthodoxy

Eastern Orthodox Churches oppose euthanasia, stating that it must be condemned as murder, as it is *the deliberate cessation to end human life*.

Judaism

Jewish law is obligation-based, and the preservation of human life is a cardinal commandment. Both suicide and self-endangerment are forbidden. Life is sacred, a gift both given and taken by God. This teaching is called the *sanctity of life*.

Islam

Islam is against physician aid in dying. All human life is sacred because it is given by Allah, and Allah chooses how long each person will live. Human beings should not interfere in this. Aid in dying is, therefore, forbidden. Physicians must not take active measures to terminate a patient's life.

SOURCES:

- World Federation of Right to Die Societies, *Questions and Answers*, www.worldrtd.net/questions-and-answers
- Wikipedia, *Religious views on euthanasia*, https://en.wikipedia.org/wiki/Religious_views_on_euthanasia

THE ROLE OF THE TERMINAL DISEASE

Some proposed laws, like the draft NSW Bill, suggest a person can seek to end their own life when their terminal disease causes them unbearable suffering. So, if you're dying of lung cancer, you can only end your life if the cancer itself is causing you unbearable pain. It is necessary to consider if assisted dying be restricted in this way.

Imagine you've got a month to live and the only thing that gives you meaning is your ability to go outside and watch the sunrise. One day, you break your leg and are bedridden. Should you now be forced to live for a month in a state you find agonising and meaningless because your broken leg isn't what's killing you?

Longstaff argues, "If severe pain and suffering are essential criteria for being eligible for assistance, then on the basis that like cases should be treated in a like manner, assistance should be offered to a person who meets all the other specified criteria – even if their pain and suffering is not caused by their illness".

WHO IS ELIGIBLE FOR ASSISTED DYING?

Many laws try to carve out special categories of people who are and aren't eligible to request assisted dying. They might do so on the basis of life expectancy, whether the illness is terminal or the age of the patient. In determining who should be eligible, two principles are worth thinking about.

First, the principle of just access to medical care. Most bioethicists agree before we can figure out who receives medical treatment, we need to have a broader idea of what justice looks like. Some think justice means people get what they need. For these people, granting

medical care is based on how urgently it's required. Others think justice means getting the best outcome. These people think we should distribute medicine in a way that creates the most quality of life for patients.

Depending on how we view justice, we'll have different views on who is eligible for assisted dying. Is it those whose quality of life is lowest? If so, it might not be terminal cases in need of treatment. Is it those who are most in need of treatment? This might include young children who many people are reluctant to provide assisted dying to. Until we're clear on this principle, it'll be hard to decide who is eligible and who is not.

The second principle worth thinking about is to treat like cases alike. This idea comes from the legal philosopher HLA Hart. He thought it was essential for ethical and legal distinctions to be made on the basis of good reasons, not arbitrary measures. A good example is if two people committed the same crime, they should receive the same penalty. The only reason for not treating them the same is if there is relevant difference in the two cases.

This is important to think about in terms of strict eligibility criteria. Let's say we reserve assisted dying for people over 25 years old, which the NSW draft Bill does. Hart would encourage us to wonder, as Longstaff noted in The Ethics Centre's submission, "what ethically significant difference lies between a 24-year-old with six months to live and who wishes to receive assisted dying and a 25-year-old in the same condition?"

Dr Matt Beard, The Ethics Centre (24 August 2017). *Assisted dying: 5 things to think about*. Retrieved from <http://ethics.org.au> on 10 February 2020.

The facts about voluntary assisted dying

Surveys show that around 85% of Australians support the legalisation of voluntary assisted dying (VAD) to allow for better choice at the end of life but, despite this, only Victoria has passed an assisted dying law (with Victoria's in effect from 19 June 2019 and WA's law likely to come into effect mid-2021). Here's a guide from **Go Gentle Australia** to the top 10 facts that dispel the misinformation spread in the debate around voluntary assisted dying laws. This misinformation has encouraged politicians not to act in a way voters clearly want them to.

AUSTRALIA'S CURRENT LAWS DO NOT PROTECT US AGAINST UNNECESSARY SUFFERING.

In Australia today ...

- *It is legal*, if you are dying and suffering beyond medical help, to end your suffering by committing suicide, often violently and alone.
- *It is legal* to refuse all medical treatment, food and water, and to die slowly of starvation and dehydration while your disease takes its course.
- *It is legal* for a doctor to slowly drug you into a coma while your family waits for days, or weeks, for you to die. This can happen without your consent.

But ...

- *It is NOT legal*, if you are dying and suffering beyond medical help, to end your suffering painlessly and quickly with the help of a doctor.

As a patient, you do not have any legal right to insist that a doctor gives you more, or faster, pain relief. That decision is entirely up to the doctor whose personal beliefs you may not share.

This is why we need a law. So that we all have a legal right to be protected from unnecessary suffering at the end of life – so doctors have a legal right to help us – and so there can be more compassionate choices if we're dying and suffering than starving ourselves to death, being slowly drugged into a coma, or taking our own lives, violently and alone.

1. The voluntary assisted dying law in Victoria

Victoria's law came into effect on 19 June 2019, after an eighteen-month implementation period. It offers a choice to competent adults with a terminal illness and six months or less to live. For those dying of neuro-degenerative diseases, such as MND or MS, the time frame is extended to twelve months or less to live.

For detailed, up-to-date information please refer to the Voluntary Assisted Dying website of the Victorian Department of Health: www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying

2. The voluntary assisted dying law in Western Australia

On 10 December 2019, Western Australia became the second Australian state to pass a contemporary,

compassionate and safe voluntary assisted dying law.

Like the Victorian law before it, it offers a choice to competent adults with a terminal illness who have six months or less to live (12 months for neuro-degenerative illnesses). While modelled on the Victorian law, the WA law has several differences, namely giving doctors and nurses permission to raise the issue of VAD with their patients during clinical setting, and giving patients the choice of either self-administering the lethal medication or allowing doctors or nurse practitioners to administer it on their behalf.

More information can be found at the Western Australian Government's Department of Health website: www2.health.wa.gov.au/voluntaryassisteddying

3. A voluntary assisted dying law protects the vulnerable

Some organisations, like Right to Life and others, assert that Voluntary Assisted Dying laws are not safe. They warn of vulnerable people being coerced to end their lives for other people's gain. Numerous independent inquiries have found no evidence that this has occurred. These include:

Australian palliative care physician Dr Linda Sheahan whose 2012 Churchill Fellowship study of how these laws work overseas concluded ...

'the slippery slope in terms of risk to vulnerable groups has not been demonstrated by the data'

The cross-party parliamentary inquiries in Victoria and Western Australia, the most comprehensive and forensic reviews of the issue undertaken in Australia, found ...

'no evidence of institutional corrosion or the often cited slippery slope'

The Victorian committee said ...

'assisted dying is currently provided in robust, transparent, accountable frameworks. The academic literature shows that the risks are guarded against, and that robust frameworks help to prevent abuse.'

The WA Committee added ...

'there is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying.'

Perhaps most telling: representatives of peak elderly and disability groups in Belgium, the Netherlands and Oregon also report no abuse of their members under VAD laws.

The *Journal of the American Medical Association* in 2016, concluded ...

'in no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than those in the general population.'

The laws are designed for those at the end stage of a terminal illness whose suffering is beyond meaningful medical help. It is very hard to coerce a vulnerable person into a terminal illness they don't have. Even harder to coerce two doctors, whose work will be subject to review, to agree with them. That's why the safeguards work.

4. It shouldn't be a crime for a doctor to help a dying patient die peacefully

As the cross-party inquiries found, Australian doctors already practise unlawful assisted dying, but they do so ...

'without regulation, support, transparency or accountability.'

For those doctors currently faced with the agonising choice of helping a patient to die and breaking the law – or abiding by the law and leaving that patient to die with great suffering – a Voluntary Assisted Dying law provides protection. More than protection, it provides guidance and the opportunity to consult with colleagues and also the family of the person who is dying.

5. Assisting a dying person to die is not 'patient killing'

Those who oppose this law refer to Voluntary Assisted Dying as 'patient killing' or 'state sanctioned killing'. This dishonestly avoids the central fact that the law is to help those already being killed by an incurable disease. Being voluntary, it is entirely up to the patient whether or not they choose to end the suffering caused by that disease.

Nor are doctors being asked to 'kill' a patient. In reality, what they're being asked to do is what they already do – make a careful diagnosis that a patient's condition is terminal and their suffering intolerable and go through with them their treatment options.

If the patient meets the legal requirements for assistance to die, they write them a prescription for a life-ending medication. After that, it is up to the person whether or not they use it.

Only one person is being asked to make a life and death decision. The person who is dying.

6. Palliative care is great, but it can't help everyone

Australia has one of the best palliative care systems in the world. However, it is a fact that it can't help everyone. In Palliative Care Australia's own words: 'even with optimal care not all pain and suffering can be relieved'.

By their own estimates, the number of people truly beyond their help is about 4%. Their suffering, as recorded in evidence to the parliamentary inquiries, can be savage.

This is no criticism. It simply reflects the reality of modern medicine, which can keep us alive longer but which still has no cure for diseases like cancer and Motor Neurone Disease.

In the words of the 'father' of Australian palliative care, Professor Ian Maddocks ...

"If compassionate and loving care towards patients and families is what palliative care is all about then assisted dying is part of that. It is time the profession dealt with it."



The question is: why should those who palliative care can't help be left to suffer when we have the means to help them?

7. Voluntary assisted dying is also about better palliative care

The parliamentary inquiries' committees recognised the reality that for some Australians who are at the end of their lives even the best palliative care will not relieve suffering. But they also recognised that any voluntary assisted dying law has to work hand-in-hand with increased resources for good palliative care. We strongly support that.

Voluntary Assisted Dying is not intended to replace palliative care. It is adding one more end of life option alongside palliative care for doctors and their patients to explore. In Oregon, nine out of ten patients who choose a doctor's help to die are also enrolled in hospice care.

8. This is a law that respects a doctor's choice

According to the AMA's code of ethics ...

"Doctors are obliged to respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such treatment may shorten a patient's life."

Some doctors object to Voluntary Assisted Dying on the basis of the Hippocratic Oath which instructs "do no harm". Others see leaving a dying patient to suffer as the opposite of "do no harm".

A Voluntary Assisted Dying law is voluntary for everyone. It respects and protects the rights of those doctors who object. Just as it protects and respects the rights of those doctors with a different ethical view.

9. Faith-based arguments against voluntary assisted dying: are they made in good faith?

The extreme rhetoric being used by Right to Life and other faith-based objectors – such as "patient killing" and "murder" – is designed to inflame emotions. It does not acknowledge, or address, the clear evidence of suffering happening across the Australian community in the parliamentary committees' reports.

In a 2017 visit to Victoria, sponsored by MLC Inga Peulich and Right to Life, US doctor William Toffler suggested privately to MPs that, should Voluntary Assisted Dying become legal, that it be carried out by veterinarians who have 'training in giving overdoses to living things, living animals'. The rhetoric being used by Dr Toffler, Right to Life and others – and endorsed by some MPs – seeks to trivialise the genuine suffering and trauma being faced by Australian families.

That elderly Australians are killing themselves violently at the rate of more than one a week, according to the Victorian coroner, because there is no other way they can be legally helped to end their suffering, is a serious public health issue. It requires thoughtful and respectful debate. Opposing Voluntary Assisted Dying simply on religious grounds and with emotive language is not an answer to this suffering.



10. Voluntary assisted dying is just that ... voluntary

No one is forced to take part in voluntary assisted dying – neither the dying patient nor the medical professionals who care for them. Medical professionals can refuse to participate in VAD due to moral or ethical convictions without sanction or criticism.

Similarly, anyone with religious views that run counter to VAD can conscientiously object – in this way VAD laws respect religious freedom. At the same time a patient's right not to have those religious beliefs imposed upon them is also respected.

If you don't approve of VAD, don't take part in it. It's that simple.

If you would like to read more about voluntary assisted dying and why these laws are so desperately needed, please head over to Go Gentle's 'Publications' page, where you will find their collection of ebooks with references to research and further reading.

Go Gentle Australia. *The facts about voluntary assisted dying*. Retrieved from www.gogentleaustralia.org.au on 10 February 2020.

EUTHANASIA LAWS: THE FACTS

AN OVERVIEW OF ARGUMENTS OPPOSED TO THE LEGALISATION OF VOLUNTARY EUTHANASIA FROM THE AUSTRALIAN CARE ALLIANCE

KEY ISSUES

1. Advocates for assisted suicide or euthanasia laws frequently point to cases of poor palliative care, often decades old¹, and focus on fear of the dying process. However, current, best practice, palliative care can successfully manage pain² and other distressing symptoms at the end of life.
2. It is impossible to legislate safely to take life, without opening the door to rogue practitioners³, and putting vulnerable people at risk, including those with psychiatric disorders⁴, the disabled⁵ and the elderly.
3. No law can exclude a mistaken diagnosis⁶ or errors⁷ in prognosis⁸. Not all doctors are aware of all available, effective treatments⁹. Often the doctor providing assisted suicide has no long-term relationship with the patient and so may lack knowledge of the patient's full medical history, current management, mental state and family relationships. Doctor shopping for a doctor willing to "tick the boxes" and provide assisted suicide on request rather than engage in a genuine doctor-patient relationship becomes the norm.
4. Ill people often feel that they are a burden on others, making them vulnerable to overt or subtle manipulation¹⁰. This may be from family members exhausted with managing serious illness or from heirs impatient for an inheritance. Not all families are benign or caring. Pressure may be from medical professionals lacking clinical skills or with a zealous, ideological commitment to assisted suicide and euthanasia.
5. Laws permitting assisted suicide contradict public health messages which seek to encourage those with depression or suicidal thoughts to seek help by carving out an exception for whole categories of people from otherwise universal suicide prevention plans, and normalising suicide¹¹ as a rational, wise choice.
6. The evidence from all sixteen experiments in legalising assisted suicide or euthanasia tried since 1996 shows that these experiments are fatally flawed¹² and that assisted suicide or euthanasia laws cannot be made safe.

Legalising assisted suicide or euthanasia crosses a serious ethical 'line in the sand' with serious consequences for patients and the practice of medicine. It is not progressive, but a regression to a poorer standard of medicine, focused on quick solutions and convenience. Changing the laws to permit assisted suicide or euthanasia is unnecessary, unsafe, unfair, and ill-informed.

The wiser approach is to work towards a society where assisted suicide and euthanasia are *unthinkable* because:

- All have access to best practice palliative care, through wider dissemination of palliative care skills and knowledge among health practitioners and better integration of palliative care in all health services;
- Disabled persons have equitable access to health care and are supported to live their lives to the full as valued members of the community;
- Suicide prevention strategies and services offer hope to any person with suicidal ideation, including those with declining physical health; and
- The elderly are protected from all forms of elder abuse, including any pressure to see themselves as an unwanted burden.

ENDNOTES

1. www.smh.com.au/comment/i-believed-that-euthanasia-was-the-only-humane-solution-i-no-longer-believe-that-20161118-gss921.html
2. www.australiancarealliance.org.au/access_to_palliative_care
3. www.australiancarealliance.org.au/killed_without_request
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11. www.australiancarealliance.org.au/social_contagion_of_suicide
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© Australian Care Alliance. *The Facts: An Overview*. Retrieved from www.australiancarealliance.org.au on 6 March 2020.

EUTHANASIA



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VOLUNTARY ASSISTED DYING: QUESTIONS AND ANSWERS

DYING WITH DIGNITY QUEENSLAND ADDRESSES SOME QUESTIONS ON VOLUNTARY ASSISTED DYING FROM A PRO-EUTHANASIA PERSPECTIVE

Question: *Would legalising Voluntary Assisted Dying for the terminally ill provide a “slippery slope” to extend to the disabled, to persons in a vegetative state, to people who are intellectually disabled and so on?*

Answer: The legislation in Victoria, which we in Queensland expect to largely follow, is extremely conservative. Any future relaxation of eligibility criteria would only happen after very careful consideration by our government and law makers and in response to public demand.

Question: *How can we be sure that the person wants to die?*

Answer: Following repeated requests for voluntary assisted dying, the doctor would follow prescribed guidelines which would include being satisfied that the strength and persistence of the requests left no reasonable doubt as to the patient’s firm and rational intention, and that there is no duress from other parties.

Question: *Can we be sure that there is no possibility of cure or return to an acceptable quality of life?*

Answer: Cures take years to discover, test, and then become available. The doctor would discuss the person’s prognosis so that the person could make an informed decision as to whether a cure or remission was worth waiting for.

Question: *Doesn’t palliative care manage all pain?*

Answer: Palliative Care Australia acknowledges that not all pain can be controlled. Of greater concern for many people are the loss of faculties and the descent into total dependence on others over a lengthy period as a miserable prelude to death. In extreme cases “terminal sedation” may be used. This renders the patient unconscious until death from dehydration supervenes. This is simply “slow euthanasia” and for many, it is not a reasonable alternative to a quick and peaceful death.

Question: *Would efforts to find cures and to improve palliative care will be discouraged?*

Answer: The will to live is so strong that no one wishes to die while they still have a reasonable quality of life. There will always be pressure to find cures and improve treatment. Voluntary Assisted Dying would only be an option for those whom current medical knowledge cannot not help. The incentive to perfect cures would remain.

Question: *Would people want to know about other options?*

Answer: VAD would require that people are fully informed of all the other options that are available to them in terms of medical and palliative care.



Not all pain can be controlled. Of greater concern for many people are the loss of faculties and the descent into total dependence on others over a lengthy period as a miserable prelude to death. In extreme cases “terminal sedation” may be used.

Question: *Is it wrong to shorten life deliberately?*

Answer: Those who have this conviction would be free to abstain, either as doctor or patient, but they should not deny the option to those who do not share their belief. While most people hold that life should not be taken unlawfully, they accept that there are circumstances in which the taking of a human life may be justified and that the law should provide for these.

Question: *Most religious traditions regard life as a gift from God and the deliberate taking of one’s own life as a rejection of God’s will.*

Answer: We acknowledge and respect that this is some people’s beliefs. However, we believe that people who do not subscribe to this belief should not be required to live by it. We allow and encourage compassion and humane treatment of animals, why not for ourselves? VAD allows for choice, so that those who believe that God has set the term of each life will be unaffected

by the law, but there are many committed Christians and followers of other faiths who do not share that image of God. They believe that we have been given responsibility for our own lives and that a God of love and compassion would not wish any of us to end our days in needless, unwanted suffering.

Question: Will VAD make suicide acceptable?

Answer: Dying with Dignity comes from a place of empowerment, while suicide comes from a place of powerlessness. As the law now stands, some people are opting to suicide “while they still can”. If they knew they had a better option, they may choose to live longer and may not need assisted dying.

Question: Would legalised Voluntary Assisted Dying make it impossible to secure the criminal conviction of a health professional who causes the death of a patient by the administration of an overdose of a pain-relieving drug?

Answer: Under present law, a health professional who unintentionally causes the death of a patient by a drug overdose is free of criminal liability if he/she has acted with the intention of relieving pain or other symptoms and not to cause death. Under a voluntary assisted dying law, two independent doctors would have to follow detailed procedures and report comprehensively to the coroner. Overdosing with pain-relieving drugs would not be condoned by the new law.

Question: Would legalising VAD to cover a few heart-rending cases inevitably lead to wider use of physician-assisted suicide?

Answer: A survey in Holland in 1995-96 showed that 2.4% of total deaths each year resulted from (legally

sanctioned) voluntary euthanasia and 0.7% from (illegal) non-voluntary euthanasia. A similar study in 1995-96 in Australia showed 1.8% of total deaths to be due to (illegal) voluntary euthanasia and 3.5% to (illegal) non-voluntary euthanasia. Doctors in Australia are responding to a pressing need, but in the absence of an appropriate law they are doing so in an unregulated and arbitrary manner, with far less consultation with their patients, under the threat of criminal sanction.

Question: Would social acceptance of physician-assisted suicide tell the elderly, disabled and other dependent citizens that their lives are not valuable. Older, disabled or depressed family members could be pressured or coerced into ending their lives?

Answer: Voluntary Assisted Dying tells everyone that their lives are their own and are too valuable to be squandered at the end in irremediable suffering. The measure is not directed to “dependent people” but is an option for independently-minded, mentally competent adults. Doctors would be required to be satisfied that the patient is incurably ill and suffering intolerably, that there is no other relief acceptable to the patient, and that the requests are freely made. VAD legislation requires a person to expressly state that this is their own choice, not someone else’s.

Dying with Dignity Queensland. *Questions & Answers.*
Retrieved from <http://dwdq.org.au> on 10 February 2020.



EUTHANASIA: COMMONLY ASKED QUESTIONS

CHERISH LIFE QUEENSLAND ADDRESSES SOME COMMON QUESTIONS ON ASSISTED DYING FROM AN ANTI-EUTHANASIA PERSPECTIVE

WHAT IS EUTHANASIA?

Euthanasia is the deliberate and intentional killing of a human being by a direct action such as lethal injection, or by the failure to perform even the most basic medical care such as the provision of nutrition and hydration necessary to maintain life.

Euthanasia is not ...

1. The ceasing of medical treatment that is unwanted, imposes excessive burdens on the patient or is futile i.e. incapable of providing benefit.
2. The use of drugs in doses sufficient to relieve very severe pain. The use of pain-relieving drugs is limited only by the side effects produced by those drugs. Such drugs rarely endanger life unless used deliberately in extremely high doses to those unaccustomed to receiving those drugs. Medical actions intended to relieve suffering are ethical and lawful, as are the withdrawal of treatments that are only unnecessarily prolonging dying. Though the patient may later die of his or her terminal illness, and though such death was foreseen, death was not intended by what was done. To describe these practices as euthanasia is misleading. Good medical practice is *not* active killing.

Other euthanasia terms

Voluntary euthanasia – this refers to patients who are mentally competent and who ask to be killed in order to relieve either physical or emotional distress, which they declare unacceptable. In response, someone would intentionally kill them.

Medically assisted suicide – this refers to a situation where a person would be provided with the means of committing suicide and then would personally perform the act.

Involuntary euthanasia – this refers to people whose consent is not sought or given, or who cannot express their wishes due to immaturity (such as a newborn infant), mental disability, mental or physical illness, or coma. In these instances it is decided by others that the person should be killed.

WHO WOULD DO THE KILLING?

It is usually assumed that the medical profession would do the killing, despite the fact that every medical association in the world forbids euthanasia as being unethical. In the context of any illness, the doctor's role is to alleviate suffering, not to kill. If euthanasia were available, the motivation to improve patient care and to see advances in medical science would be lessened. The doctor/patient relationship, which is based on trust, would be severely damaged.



WHY EUTHANASIA HAS BEEN REJECTED?

In 1996, the Australian House of Representatives voted to overturn the Northern Territory euthanasia legislation. The Senate confirmed this action in 1997. As well, every major Government inquiry around the world has strongly recommended against legalising euthanasia (Canada 1982, Victoria 1987, Great Britain 1994, New York State 1994).

Most of the British House of Lord's select committee members initially supported euthanasia, including the Chairman, Lord Walton, who had been a medical consultant to the Voluntary Euthanasia Society. However, after thorough research and a trip to the Netherlands, the committee unanimously opposed the legalising of euthanasia, concluding:

"It would be next to impossible to ensure all the acts were truly voluntary. We are concerned that vulnerable people – the elderly, lonely, sick or distressed – would feel pressure, whether real or imagined, to request an early death."

"We believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life."



CAN EUTHANASIA BE CONTROLLED?

The Dutch experience

Euthanasia is allowable and widely practised in Holland. It is supposed to be subject to safe, established government guidelines but it has been proven that it has been widely abused. It is a disaster that we must not copy. The Dutch experience proves that euthanasia is not able to be controlled.

COMMONLY ASKED QUESTIONS

1. What about my 'right to die'?

Although a 'right to die' is claimed, what is meant instead is a right to be killed. There has never been a right to be killed in any code of ethics. It is a deceptive concept, and no argument is ever made to support it. Since there is no right to be killed, others are not required to kill or assist in killing, nor should they do so.

2. Why should I have to suffer?

Today, doctors can relieve pain and other problems associated with chronic or terminal illness. It is said by many experts in the field, that if pain is not under control then the patient is being mismanaged. The intention should be to eliminate distress in the patient, not to eliminate the patient in distress.

3. Shouldn't I be allowed to 'die with dignity'?

Certainly. However, it is a contradiction in terms to think that an act of killing can achieve a 'dignified' or 'natural' death. There is nothing dignified about being killed. Dying people should be treated with true dignity where their needs are met by providing effective medical care which values their worth.

4. But don't life support systems stop people dying a natural death?

The pro-life position is not to prolong life "at any cost".

The euthanasia movement has created the myth that there are many patients who should simply be allowed to die a natural death, being kept alive artificially on life support systems. The facts are quite different. Such systems are not used to keep people artificially alive in this manner. Patients receiving intensive care on life support systems either have a definite chance of recovery, or conditions that are not yet fully diagnosed or their prognosis is uncertain. Life support systems have their place in the care and recovery of many patients.

5. Do I have the right to refuse medical treatment?

Yes, common law has always held that you have a right not to be treated without your consent. For a doctor to ignore this, is a form of assault. You can make an informed decision to accept or refuse medical treatment if you are competent, but if you are not competent, someone else must make an informed choice on your behalf.

6. What about the severely disabled or deformed?

Who is to judge whether a person's life is 'meaningless' or not? All through history people have judged others' lives to be meaningless on arbitrary grounds including: disability, race, gender and religion. The answer is not to kill the person but to give them the most meaningful life possible. Most disabled people do *not* view themselves as objects of pity.

7. Why shouldn't I be able to die as and when I choose?

Those who believe that they ought to be able to choose euthanasia are saying that they ought to be able to involve others in their decision ... doctors, nurses, perhaps anyone who is able to give the lethal dose or assist the person to do so themselves.

This means the 'choice' of the person will move in to a wider arena – affecting many others in society,

particularly those in the health profession. For the good of all people, there are some “choices” we have no right to exercise.

PALLIATIVE CARE

Palliative care is ...

The care given to a terminally ill person facing the final stages of his or her life. This care is provided in the home, hospices and palliative care units attached to hospitals, and is tailored to meet the individual needs of the patient.

It is a service delivered by a team of healthcare professionals including doctors, nurses, pastoral care workers, physiotherapists, chaplains and volunteers.

Palliative care demonstrates a profound respect for the emotional, physical, social and spiritual needs of the dying patient and his/her family and may be relevant over months or even years.

HOW CAN I PREPARE FOR A COMFORTABLE DEATH FOR MYSELF AND LOVED ONES?

Talk to your loved ones and doctor about these issues. It is better to know how they feel about it now, rather than later. If you do not agree with your doctor's approach, you should change doctors now. Find out which hospitals have palliative care units. These are sometimes called hospices for the dying.

Palliative care is for people who have any medical condition for which there is no current cure and whose health is expected to deteriorate progressively. It does not seek to lengthen or shorten their last days but to

make them as comfortable and pain-free as possible. The emphasis is on comfort rather than cure. The patient has a say in all decisions about treatments.

Palliative care is a positive initiative that enriches the person, those around them, and society in general.

As the British House of Lords select committee in 1994 said:

“Belief in the special worth of human life is at the heart of civilised society. It is the fundamental value on which all others are based and is the foundation of both law and medical practice. The intentional taking of human life is therefore the offence which society condemns most strongly.

“Society's prohibition of intentional killing is the cornerstone of law and social relationships. It protects each of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend that there should be no change in the law to permit euthanasia.”

Cherish Life Queensland. *Euthanasia: commonly asked questions.*
Retrieved from www.cherishlife.org.au on 10 February 2020.



Viewpoints: should euthanasia be available for people with existential suffering?

*Some bioethicists argue it is inconsistent to allow euthanasia for terminal illness but not for existential suffering. **Xavier Symons** and **Udo Schüklenk** debate the topic*

Euthanasia debates often focus on people experiencing unbearable physiological or psychological suffering. But research suggests “loss of autonomy” is the primary reason for requesting euthanasia, even among patients with terminal cancer. There have also been suggestions existential suffering could be one of the main motivations behind such requests.

Existential suffering refers to an individual experiencing a lack of meaning or sense of purposelessness in life. Such sentiments bring feelings of weariness, numbness, futility, anxiety, hopelessness and loss of control, which may lead a dying patient to express a desire for death.

Some bioethicists argue it is inconsistent to allow euthanasia for terminal illness but not for existential suffering, as both are a source of profound pain and distress. While existential suffering usually tracks closely with catastrophic illness, it’s worth considering a situation in which there are no motivating medical reasons for a request for euthanasia or assisted suicide. Should a person be eligible purely on the basis they no longer wish to live?

A case in point: a largely healthy retired palliative care nurse in the UK who ended her life at an assisted suicide clinic in Switzerland. Should she have received medical aid in dying based on her carefully considered decision that she did not want to subject herself to the perceived awfulness of the ageing process?

THE CASE AGAINST

Xavier Symons, Research Associate, University of Notre Dame Australia

Some may think people who request euthanasia do so because of excruciating and unrelenting pain. The reality is almost always more complex. Literature on assisted dying suggests individuals who request euthanasia are typically suffering from a profound sense of purposelessness, loss of dignity, loss of control, and a shattered sense of self.

A 2011 study of Dutch patients who requested euthanasia indicated that “hopelessness” – the psychological and existential realisation one’s health situation will never improve – was the predominant motivation of patients who requested euthanasia.

And a recently published Canadian study of requests for medical assistance in dying stated “loss of autonomy was the primary reason” motivating patients to end their lives. Symptoms also included “the wish to avoid burdening others or losing dignity and the intolerability of not being able to enjoy one’s life”.

One option to address such requests is to establish a

state apparatus to assist patients in ending their lives. An alternative, and one I would advocate, is to address deficiencies in health care infrastructure, and attempt to alleviate the unique suffering that drives patients to request euthanasia in the first place.

New approaches to end of life care, such as spiritual or existential care, engage at a deep level with the complexity of the suffering of patients with terminal illness. And, as has been stressed by several commentators, there is a need to improve access to palliative care in poorer regions, and provide optimal symptom management for patients wishing to die at home.

Research suggests “loss of autonomy” is the primary reason for requesting euthanasia, even among patients with terminal cancer. There have also been suggestions existential suffering could be one of the main motivations behind such requests.

We could hypothesise about various situations where a person might request euthanasia without having a medical condition. Someone might wish to hasten their death because they are tired of life or afraid of ageing or death.

These cases are interesting insofar as they are not motivated by an underlying pathology. Yet there is much reason for concern.

Sanctioning euthanasia for the tired of life veers too close to a government endorsement of suicide. Where the state has a significant stake in suicide prevention, sanctioned euthanasia for existential suffering is not only counterproductive, it’s dangerous. Fundamentally, we would erode any meaningful difference between cases of suicide we regard as acceptable, and those we see as regrettable and befitting state intervention.

We might regard it as regrettable that an educated, wealthy 30-year-old takes their own life due to an existential crisis. Yet it is difficult to say how this is different in morally relevant respects from a 75-year-old who feels their life is complete and is undergoing an existential crisis.

THE CASE FOR

Udo Schüklenk, Professor and Ontario Research Chair in Bioethics, Queen’s University, Canada

This discussion is mostly hypothetical. There seem to be few, if any, real-world cases where a competent person’s request for an assisted death is not motivated by an irreversible clinical condition

that has rendered their lives not worth living in their considered judgement.

For instance, in the Netherlands, most people who ask for euthanasia and who are not suffering from a catastrophic illness, typically experience a terrible quality of life that is caused by an accumulation of usually age-related ailments. These involve anything from incontinence to deafness, blindness, lack of mobility and the like.

We do not give up on life for trivial reasons. Just think of the many refugees who – on a daily basis – are willing to risk their lives to escape an existence they do not consider worth living. Ending their lives is not typically on top of their to-do list.

The case of the anti-choice activists – who deny there is ever a justifiable reason for euthanasia – has been intellectually and politically defeated. None of the jurisdictions that have decriminalised assisted dying have reversed course, and more jurisdictions are bound to make this end of life choice available. Public support remains strong in each permissive jurisdiction, particularly so in Belgium and the Netherlands where the majority of citizens support the existing laws.

Inevitably the question of scope must be addressed: who ought to be eligible to ask for and receive assistance in dying?

If a competent person wishes to see their life ended for non-medical reasons, and asks for assistance to do so, I think a just society ought to oblige him or her if the following conditions are met:

1. The person has decisional capacity (is of “sound mind”)
2. The decision is reached voluntarily (without coercion)
3. No reasonable means are available, that are acceptable to the person, that would render their lives worth living again in their own best judgement
4. Based on everything we know, the condition that motivated their request is irreversible.

The view that medicine is a profession aimed only at maintaining life, regardless of a patient’s quality of life, is dying its own death. If a clinical, psychological or other professional intervention does not benefit a patient to such an extent that they consider their continuing existence worthwhile, by definition that is not a beneficial intervention.

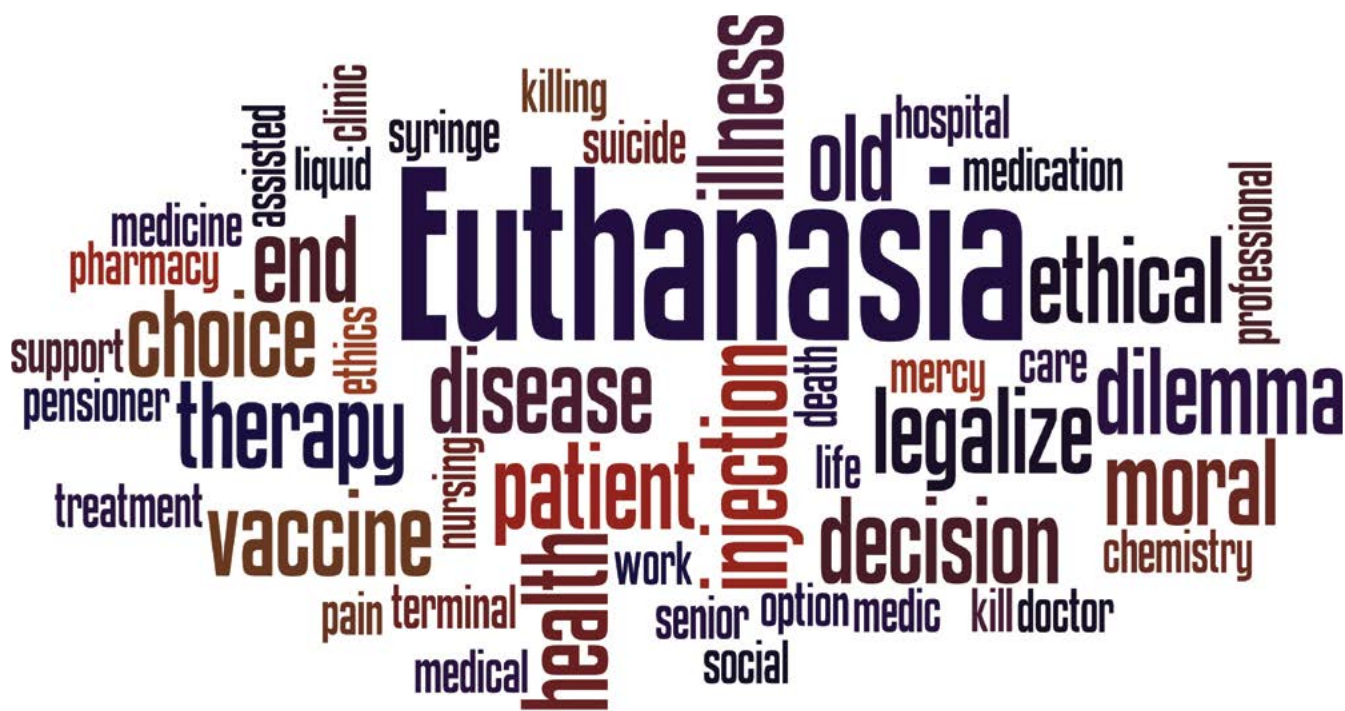
Equally, if an intervention, at a burden acceptable to the person, renders in their considered judgement their lives worth living again, they will not ask for an assisted death.

In most corners of the world people have fought hard to increase their individual freedoms to live their lives by their own values. A significant state interest is harmed if the state wishes to infringe on such autonomy rights.

Xavier Symons

It is true the health system, and indeed the state, should respect patient autonomy. Yet in practice we often put other considerations ahead of concerns like autonomy.





Patients may not receive the treatments they request for a variety of reasons, like they may be prohibitively expensive, have a negligible chance of success, or no medical justification.

I believe if it is harmful to the interests of the state to legalise euthanasia for patients without a terminal illness, then the state has a right to refuse.

Significantly more research needs to be conducted on the social impacts of euthanasia, and physician-assisted suicide, for patients without a medical condition. In this case, we have no “Oregon model” – an assisted suicide regime seen by many as an example of a safe and well-regulated system – to confirm or assuage our concerns. Jurisdictions such as Oregon only allow assisted suicide for patients with a terminal illness.

Udo Schüklenk

I echo Xavier's plea to improve health care in order to improve our quality of life, and, as a likely corollary of this, to reduce the number of requests for medical aid in dying.

However, even in the best of all possible health care worlds, unless unbearable suffering itself has been eliminated, some patients will ask for an assisted death. No amount of “dignity therapy” rhetoric and references to small-scale studies changes that fact of the matter.

Xavier correctly mentions some reasons for doctors justifiably not providing certain patient-requested medical care. They are all based in different ways on harm-to-others justifications such as resource allocation rationales, or are futility-related (arguably also a case of harm-to-others given the reality of limited health care resources). This reasoning is not applicable to the case under consideration given the self-regarding nature of the request.

Xavier is correct that the state would be under no obligation to legalise euthanasia for non-catastrophically ill patients if that was significantly harmful to

the interests of the state. However, there is no evidence that the availability of euthanasia is harmful to state interests.

If this article has raised issues for you or anyone you know, call or visit Lifeline 13 11 14 www.lifeline.org.au, or the Suicide Call Back Service 1300 659 467 www.suicidecallbackservice.org.au

DISCLOSURE STATEMENT

DISCLOSURE STATEMENT
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THE CONVERSATION

Symons, X, and Schüklenk, U (6 July 2017). *Viewpoints: should euthanasia be available for people with existential suffering?* Retrieved from <http://theconversation.com> on 10 February 2020.

Palliative care and voluntary assisted dying

A POSITION STATEMENT FROM **PALLIATIVE CARE AUSTRALIA**

Palliative Care Australia (PCA) recognises that the topic of voluntary assisted dying raises difficult and complex ethical issues, and that there is a broad spectrum of opinion and a level of support for reform within the Australian community which reflects diverse cultures, belief systems and populations. PCA recognises that this diversity of opinion is also reflected within the palliative care community.

A decision about whether or not to legalise voluntary assisted dying is one for governments. PCA neither advocates for, nor argues against the legalisation of voluntary assisted dying.

Voluntary assisted dying is not part of palliative care practice

It is important to recognise the difference between palliative care and voluntary assisted dying.

Palliative Care Australia (PCA) believes that:

- If palliative care health professionals or organisations choose to offer and provide voluntary assisted dying for their patients with life-limiting illness, this is a practice separate from palliative care.
- In Australia, an individual's choice to explore voluntary assisted dying should never be a choice based on a lack of access to palliative care.
- Palliative care is explicitly recognised under the human right to health.³ Every Australian living with a life-limiting illness should always have equitable access to quality needs-based palliative care at any point in their illness journey, with timely referral to specialist palliative care⁴ if required.
- Palliative care is person and family-centred care with the primary goal to ensure patient safety and to optimise the quality of life, as palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting illness.⁵
- When aligned with a person's preferences, withdrawing or refusing life-sustaining treatment (including withholding artificial hydration) or providing strong medication(s) to relieve suffering, do not constitute voluntary assisted dying.

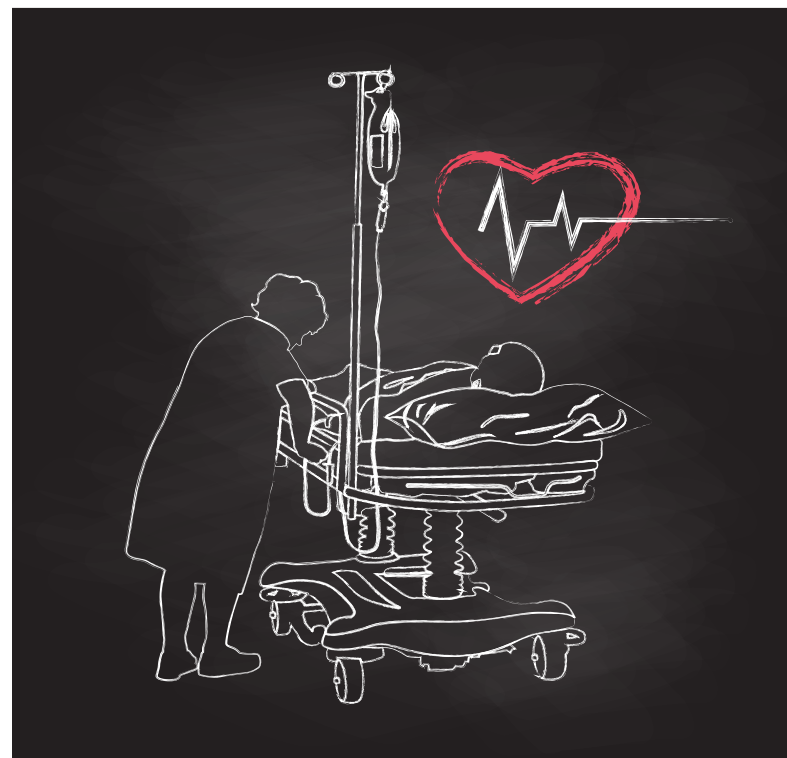
Definitions

Palliative care¹ affirms life, and regards dying as a normal process that intends neither to hasten nor postpone death. It improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Voluntary assisted dying² Medical practitioners may prescribe and potentially directly administer an approved substance for the purpose of causing death where the person meets the eligibility criteria outlined in the relevant legislation and has sought this outcome voluntarily.

Respecting the workforce which cares for people with life-limiting illness

PCA recognises that health professionals providing palliative care may be asked for information about voluntary assisted dying or receive direct requests from people with life-limiting illness to access voluntary assisted dying.





WHAT IS PALLIATIVE CARE?

World Health Organization (WHO):

Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

Australian Institute of Health and Welfare:

Palliative care is provided in almost all settings where health care is provided, including neonatal units, paediatric services, general practices, acute hospitals, residential and community aged care services, and generalist community services.

Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services. Specialist palliative care comprises of

multidisciplinary teams with specialised skills, competencies, experience and training to deliver care to people where the palliative needs are complex and persistent.

Department of Health explains further:

Palliative care differs from other types of care

It is not the same as end of life care. You can receive palliative care at any stage of your illness. You can also continue treatment for your illness while you are having palliative care.

End of life care

It is the care and services given to people and their families who are facing the end of their life. End of life care is an important part of palliative care. End of life care is for people of any age. It often involves bringing together a range of health professionals to help you to live out your life as comfortably as possible. Wherever possible you can have end of life care where you and your family want. This can be at home, in hospital, in a hospice or a residential aged care facility.

People who receive palliative care

It is for people of any age who have been diagnosed with a serious illness that cannot be cured. This includes children and young people, adults and the elderly. When you start palliative care depends on the stage of your illness. You may need to start palliative care not long after getting your diagnosis. This can often help you and your family deal with your diagnosis. Or you may not need it until your illness progresses. You can also have other treatments by different doctors even when you are having palliative care. Having palliative care doesn't necessarily mean that you're likely to die soon. You can receive palliative care for years if needed.

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- All people providing palliative care should be supported to ensure people with life-limiting illness in their care receive safe, compassionate, competent care regardless of whether they seek information about, or referral to, services that may provide voluntary assisted dying.
- It is the right of health professionals providing palliative care to make appropriate judgements about whether they will be involved in voluntary assisted dying based on their personal ethics and beliefs and those of the organisation/s by which they are employed.
- All people working in palliative care should be treated respectfully and demonstrate professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying and the decision to exercise their right to conscientiously object or conscientiously participate in any aspect of voluntary assisted dying.

PCA has developed *Voluntary Assisted Dying in Australia: Guiding principles* for those providing care to people living with a life-limiting illness to assist health professionals, care workers and volunteers who are providing care to people living with a life-limiting illness, or working in or engaging with organisations providing any level of palliative care. PCA recommends that the Guiding Principles be used alongside relevant legislation, organisation ethical frameworks and codes of conduct.

Considerations for end of life and voluntary assisted dying legislation

Should governments contemplate reform of the law to permit voluntary assisted dying in limited circumstances, governments should consider the following:

- People with a life-limiting illness should be able to make informed and autonomous decisions about their care, and be provided with the opportunity to discuss needs, hopes and care preferences consistent with their personal values, culture, beliefs and goals. Legislation should ensure patients are advised of the palliative care options available to them.
- Health professionals should be provided with legislative protection to ensure they are not required to undertake any acts which conflict with their personal or professional values.
- Any legislation should promote high-quality care and ensure patient safety. This includes ensuring patients will receive ongoing and safe continuity of care across settings and throughout the course of a person's illness.
- Governments should invest in research including data collection related to voluntary assisted dying to enable review of any scheme, the monitoring of safe practice and assess the impacts of voluntary assisted dying including the impact on patients,

their families, their carers and personal supporters. In addition, investment will also be necessary to research the impact (including the cultural impact) that the introduction of voluntary assisted dying has on the health workforce.

Further investment is required to meet Australia's palliative care needs

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed.⁶ There is significant unmet need for high quality palliative care in Australia and forecasts indicate significant increases in need in the years ahead.⁷

PCA calls for:

- Substantial coordinated investment by all jurisdictions to plan and prepare for the future where Australians will live longer, demand an improved quality of life, and access to high quality palliative care when living with a life-limiting illness.
- An investment in growing the specialist palliative care workforce, and increased support for the acute, primary care and the aged care sectors to provide quality palliative care as part of their core business.
- Further investment to ensure an adequately resourced and appropriately trained health workforce who are familiar with the broader aspects of palliative care provision including clinical, legal, and ethical aspects. Particularly important is developing advanced communication skills to actively listen and engage in respectful dialogue with people about their end of life preferences. The palliative care workforce supports people with life-limiting illness by enabling exploration of the complex social, spiritual, cultural, psychological, emotional and physical



aspects of their care preferences.

- Compulsory palliative care education for all medical, nursing, allied health and pharmacy students as part of undergraduate curriculum to ensure a consistent baseline competency in palliative care pain and symptom management together with the communication skills required for caring for people with life-limiting illness, their families and carers.
- Palliative care to be included as a component of all health and aged care quality standards.
- The difference between palliative care and voluntary assisted dying to be made clear at all times, supported by a fully resourced and sustained national public awareness campaign about palliative care, what it offers and how and when it can be accessed.

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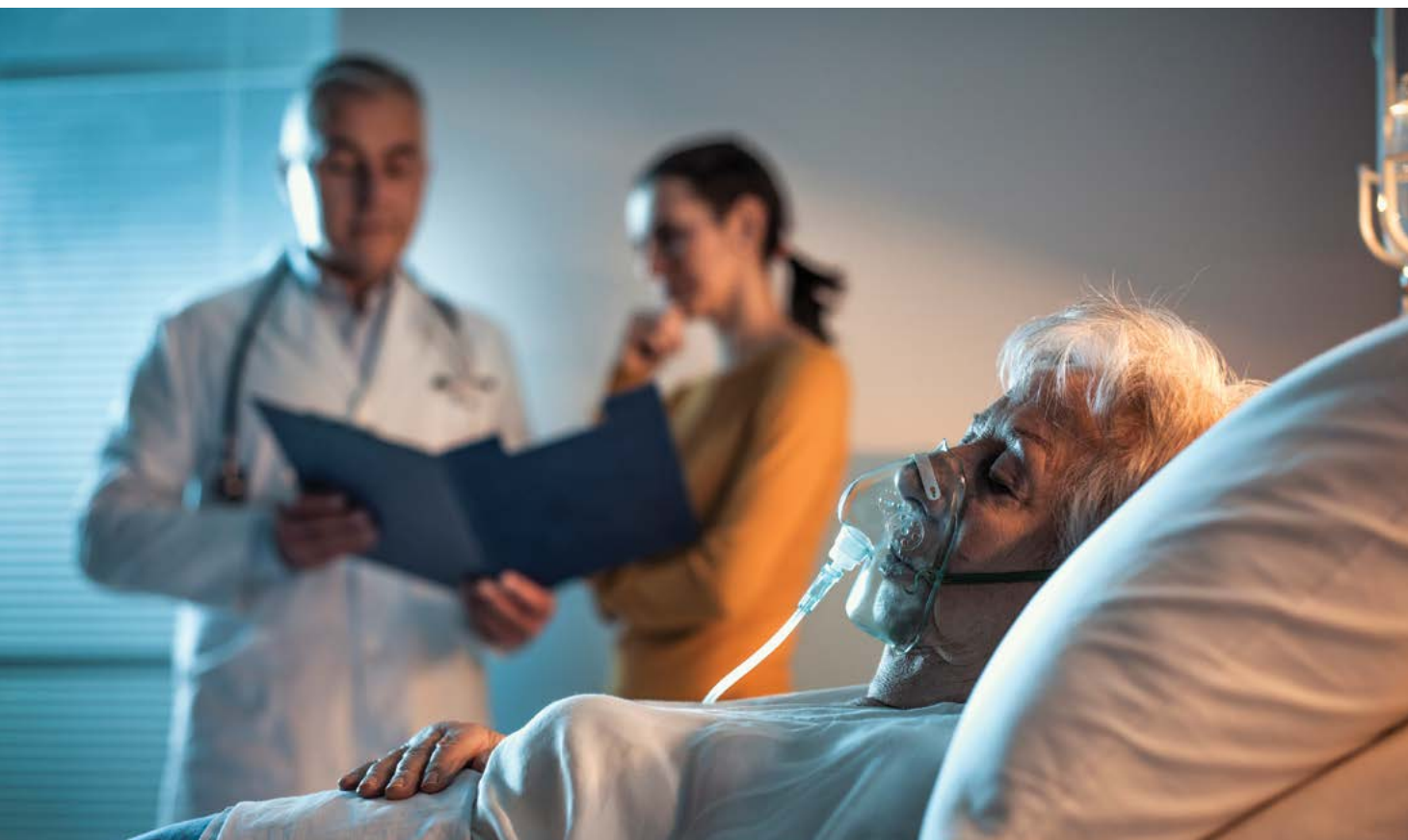
1. World Health Organisation and Worldwide Palliative Care Alliance (2014), *Global Atlas of Palliative Care at the End of Life* [accessed online].
2. Per the *Voluntary Assisted Dying Act 2017* (Victoria) which defines voluntary assisted dying as the administration of a voluntary assisted dying substance (a poison or controlled substance, or a drug of dependence for the purpose of causing death) and includes steps reasonably related to such administration. It is intended to incorporate other descriptions including medical assistance in dying, physician-assisted suicide, and voluntary euthanasia.
3. WHA, Resolution WHA67.19, *Strengthening of palliative care as a component of comprehensive care throughout the life course*, 24 May 2014.
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with specialised skills, competencies, experience and training in palliative care, and is one component of broader palliative care service delivery. Source: World Health Organisation (2018) *Fact sheet: Palliative Care* [accessed online], Palliative Care Australia 2018 *Palliative Care Service Development Guidelines*.

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Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its member organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

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Experience internationally of the legalisation of assisted dying on the palliative care sector

Executive summary from a report by Aspex Consulting for **Palliative Care Australia**

The review objective is to explore the international experience on the palliative care sector of the legalisation of voluntary assisted dying (VAD). This review used the term 'assisted dying' as a generic term to encompass voluntary assisted dying, physician-assisted dying, physician-assisted suicide, and euthanasia.

The following jurisdictions are included within the scope of the review: Oregon (USA); Washington State (USA); the Netherlands; Belgium; Canada; and Quebec Province, Canada.

LEGISLATIVE CONTEXT

There are several differences between the legislative contexts for each of the in-scope jurisdictions, largely relating to access criteria including age, required diagnosis and advance requests. It is noteworthy that there have been amendments to these criteria in some jurisdictions.

Prior to accessing assisted dying legislation, all jurisdictions require that patients be informed of alternative treatment options, including palliative care.

The legislation in Canada, Quebec and Belgium actively promote the use of palliative options:

- The enactment of the Canadian *Criminal Code* provides for a parliamentary review of its provisions and of the state of palliative care in Canada to commence at the start of the fifth year (2021);
- The Quebec *Act Respecting End-of-Life Care* states that every person whose condition requires it has the right to receive end of life care, inclusive of palliative care and medical aid in dying; and
- Although not specified within *The Belgian Act on Euthanasia*, the integrated nature of the Belgian model of end of life care includes the option of eligible patients accessing euthanasia as part of the palliative course.^{1,2,3}

DELIVERY OF PALLIATIVE CARE SERVICES FOLLOWING THE INTRODUCTION OF LEGISLATION

An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.

Where jurisdictional data is available, there are consistently high levels of patient involvement in palliative care services at the time of the death through assisted dying: 90.9% of Oregonians and 88.0% of patients in Washington State were enrolled in hospice care; and 70.9% of patients in Belgium (compared to 42.5% of



those patients who died non-suddenly and who had not sought assisted dying).

HEALTH CARE PRACTITIONER INVOLVEMENT

One of the distinctions between assisted dying in the USA relative to other jurisdictions is that there tends to be a relatively low proportion of patients for whom a health care practitioner is present at the time of death.

This is reflective of the legislative requirements of physician-assisted suicide. Key approaches are outlined below:

- **Oregon** – In 2017, a prescribing physician was present at the time of death for 16% of patients, another health care practitioner for 13% of patients, with 71% of patients having no health care practitioner present at the time of death;
- **Washington State** – In 2017, the majority (51%) of patients had a health care practitioner other than their prescribing physician present at the time they ingested medication, whilst prescribing physicians were present in 8% of instances, no health care practitioners were present for 15% of patients, and 26% of instances were unknown;
- **Canada** – In 2017, 95% of medically assisted deaths in Canada involved physicians with nurse practitioners involved in 5% of cases;
- **Quebec** – Only registered medical practitioners (those registered with the Collège des Médecins du Québec CMQ) are permitted under the Quebec legislation to proceed with medically assisted dying and administer the injection;
- **The Netherlands** – GPs were involved in assisted dying in 85% of cases, with aged care specialists (3.5%), other hospital specialists (3%), and other physicians (8%) also providing assistance; and



- **Belgium** – Palliative care professionals provided assistance in 59.8% of instances. This is a distinctive feature of the Belgium model.

PLACE OF DEATH

The predominant location of death for assisted dying patients was in their own homes in all jurisdictions except Canada where most patients died in hospital. There were substantial differences between jurisdictions in the proportion of patients who died at home:

- **Oregon** – 90% died at home (2017);
- **Washington State** – 88% died at home (2017);
- **Canada** – 40% died at home and 42% in hospital (2017);
- **Quebec** – no data was available on location of death;
- **The Netherlands** – 80% of patients died at home (2016); and
- **Belgium** – 50% of patients died at home (2007).

PEAK BODY PERSPECTIVES

Different cultural and policy drivers appear to influence the approaches of peak bodies. In some jurisdictions the role of health care peak bodies, particularly medical peak bodies, has been instrumental as a driver for the implementation of assisted dying, whilst in others there has been strong resistance that has subsequently eroded with acceptance and either explicit or tacit support for the legislation.

Key findings include:

- **Oregon** – In the years prior to the introduction of assisted dying in 1997, the issue was said to have divided the medical community. Most physicians were opposed to assisted dying. This level of opposition subsided and in the years that followed, opinion gradually shifted with a narrow majority (51%) of physicians in favour of the legislation in 2000. The Oregon Medical Association initially took a position against assisted dying. This has shifted over time and the organisation now has a position of ‘studied neutrality’, essentially neither advocating nor opposing assisted dying. A similar shift in position occurred for the Oregon Hospice and Palliative Care Association.
- **Washington State** – As with Oregon, in Washington State the medical community was sharply polarised. In the lead-up to the legislative change, more physicians were opposed to assisted dying than in favour. The Washington State Medical Association also reflected these views, with explicit opposition to the introduction of the legislation. Subsequently, the Association has attenuated its stance – it neither condones nor opposes. It does however advocate end of life care planning with a focus on palliative care options. The positions of health service organisation within Washington State are inconsistent, with some allowing participation of physicians according to the individual’s ethical stance, whereas other organisations explicitly preclude the cooperation of employed physicians. The inconsistency is remarkable in that it extends to inconsistencies between health service campuses from the same parent entity.
- **Canada/Quebec** – The position of the Canadian Medical Association substantially evolved from strong opposition in the lead-up to the 2016 implementation of legislation on assisted dying to subsequent endorsement of the direction of policy. Indeed, the Association was involved in the development of recommendations for the practitioner process required to support legislative change and it introduced a 2017 policy on Medical Assistance in Dying which confirmed the legitimacy of physicians choosing to participate, or not, guided by their own ethical stance. It reiterated the autonomy of patients to choose and to ensure that vulnerable patients were supported with adequate safeguards. It also strongly emphasised the principle of non-abandonment. The Canadian Hospice Palliative Care Association’s focus of lobbying in the pre-implementation phase was on adequacy of resourcing of palliative care as the first order issue. In 2017, the Association developed a guidance document for health care providers involved in hospice and palliative care to support them to address patient requests for assisted dying, acknowledging that choice to pursue assisted dying ought to be upheld and respected.
- **The Netherlands** – The Royal Dutch Medical Association played a pivotal role in the facilitation of the introduction of assisted dying legislation. The legislation was planned against a backdrop of existing legal precedents in which exemption from prosecution for physician involvement in assisted dying was in place in advance of the legislation. The association took a lead role in the development of guidelines for its members to be fully informed on the approaches that were necessary to meet legislative and patient care objectives.
- **Belgium** – A steady transition in mindset occurred for the medical practitioner community and the palliative care sector in Belgium in response to

moves to introduce assisted dying. Initial views were that such developments ran counter to principles of providing patients with highest quality health care, support and beneficence as the highest order priority. Over time, physicians who witnessed their palliative care patients seeking leave to access assisted dying elsewhere, began to question whether their opposition to assisted dying was compatible with serving their patients' strong preference for autonomy in end of life decision-making.

KEY LEARNINGS

Learnings from the implementation of assisted dying legislation in international jurisdictions reveal an increased focus on, and public policy attention towards, end of life care.

It is noted that *the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.* In Belgium, there was an intentional drafting of parallel sets of legislation covering assisted dying and palliative care system resourcing. In other jurisdictions, there were indirect system improvements in palliative care that occurred alongside the introduction of assisted dying.

Key considerations for the palliative care sector include:

- **The integration of assisted dying as a component of end of life care services.** Integration may provide an opportunity for the promotion of quality of end of life care. In some jurisdictions there is evidence that after the introduction of assisted dying legislation, physicians have sought to improve their knowledge and understanding end of life care support services;
- **Access to palliative care.** Tracking of assisted dying patients indicates that a very high majority of patients have had access to palliative care. Analysis of the resourcing of the palliative care sector in the permissive Benelux countries has identified higher per capita access to palliative care relative to non-permissive European countries. Further, reviews of patient use of palliative care in advance of assisted dying found that 74% of Belgian assisted dying patients had accessed a palliative care service before end of life. This runs counter to the argument that assisted dying may be used by patients in circumstances where palliative care is not available;
- **Potential erosion of safeguards.** A common concern across various jurisdictions has been that access to assisted dying pathways is a 'slippery slope' whereby vulnerable people may be at risk should safeguards fail. Whilst it is noted there have been amendments to legislated eligibility criteria over time, there is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards;

- **Routinisation.** An identified risk is the lowering of thresholds by physicians to accept patient requests for assisted dying without active review of the potential for this request to mask other concerns (e.g. symptom control, uncertainty about the future and financial concerns). Whilst the trend for requests for assisted dying has increased over time in both the Netherlands and Belgium, there is no evidence this is due to reduced thresholds. Primary reasons postulated include wider acceptance by the medical community and increased rates of requests by some patient groups including those with life-limiting conditions beyond cancer;
- **Access to assisted dying pathways.** Noting the ability of practitioners and organisations to ethically oppose assisted dying, the palliative care sector will have a role in facilitating access to information or referrals to an alternative provider who is prepared to meet the patient's request;
- **Workforce capability.** The case volume of patients seen by physicians who provide assisted dying is relatively low in most jurisdictions. There tends to be a skewed distribution with a large volume of assisted dying patients receiving services from a small number of physicians. The majority of physicians with any involvement in assisted dying have very low case volumes;
- **Workforce support.** In the absence of structured support for the health care workforce, the introduction of assisted dying may have harmful effects for both the practitioners and patients involved. For practitioners, uncertainties associated with the introduction of assisted dying can be very challenging professionally and personally; and
- **Safety and quality.** It is understood that medical complications may occur relating to patients who may not initially die from lethal medication. This may have a direct impact on the palliative care sector, depending upon the setting in which assisted dying takes place.

In an environment where assisted dying has been legalised in one jurisdiction and other governments at the state/territory level are considering reform, there is a necessity for Palliative Care Australia, and other key stakeholders, to consider each of the above opportunities and risks in the formulation of key strategic directions as it relates to policy, guidelines and service development initiatives.

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ASSISTED DYING IS ONE THING, BUT GOVERNMENTS MUST ENSURE PALLIATIVE CARE IS AVAILABLE TO ALL WHO NEED IT

While assisted dying is contentious, access to palliative care should not be, asserts **Stephen Duckett**

Assisted dying moved one step closer to reality in Victoria last week with the authorising bill passing the lower house with a comfortable 47-37 majority. Throughout the debate, many MPs spoke of terrible personal experiences of the deaths of family members. Such harrowing stories were also present in submissions to the parliamentary inquiry into end of life choices, that recommended an assisted dying regime leading to the bill.

These terrible deaths were most often used to argue in favour of the need for assisted dying. Yet they occurred in a state that prides itself on the quality of its end of life services. While assisted dying is contentious, access to palliative care should not be.

Palliative care in Australia

Palliative care's purpose is to enhance the quality of

life for patients and their carers. It also aims to fulfil choices about care style and location for those approaching death. Politicians regularly express their support for palliative care. Yet, there is often a chasm between such positive rhetoric and actual delivery.

The gap isn't new. A 2012 Senate review expressed concern at the "variance in the standard and quality of palliative care" across Australia. In April 2017, the New South Wales Auditor-General was scathing in her criticisms of the state's services, and in 2015 the Victorian Auditor-General highlighted "room for improvement" – this in a state recognised as having the gold standard in palliative care. A report by the Grattan Institute in 2014 also identified a need for better end of life services across Australia.

The 2010 National Palliative Care Strategy – that sets out areas to focus on in palliative care – is a worthy, well-received document, saying all the right things. But a review of the strategy conducted at the end of 2016 found little evidence states had used it in developing their frameworks for delivering services. It also found limited accountability or evaluation mechanisms and little detail about vulnerable populations.

Palliative care's purpose is to enhance the quality of life for patients and their carers. It also aims to fulfil choices about care style and location for those approaching death.





The most recent data on palliative care in Australia is incomplete. Although there is information on the provision of hospital-based palliative care, there is no information about services provided by community-based palliative care organisations.

What statistical information we have about the extent to which palliative care services meet patient and carer needs comes from voluntary reporting based on meeting certain benchmarks. These include targets such as having 60% of patients with moderate to severe pain at the beginning of the care period, reduced to absent or mild pain at the end of the period.

It is unlikely organisations that don't participate have outcomes as good as those that do, so this suggests what we see here may be at the upper end of outcomes. And even then, what we see is not so good.

Palliative care and assisted dying

The advisory panel set up by the Victorian government to set out the framework for the state's assisted dying regime did not make explicit recommendations about palliative care. But it did note:

A person has the right to be supported in making informed decisions about their medical treatment and should be given, in a manner that they understand, information about medical treatment options, including comfort and palliative care.

Provision of information is one thing, but access to services is another. Again the panel has nice words, stating:

Every person approaching the end of life should have access to quality care to minimise their suffering and maximise their quality of life.

Politicians regularly express their support for palliative care. Yet, there is often a chasm between such positive rhetoric and actual delivery.

But this rhetoric is not given any force in the panel's recommendations.

When Victoria's upper house, the Legislative Council, makes its decision about the assisted dying legislation, it should also ensure every terminally ill person in the state can get good quality palliative care if they want it.

The Victorian government's response to the report of the parliamentary inquiry, that recommended legalising assisted dying, has been strong on support for enhanced palliative care. This welcome rhetoric now needs to be translated into effective policies – and more money.

Funding for palliative care

Palliative care is an important part of end of life care. A 2010 study in the prestigious *New England Journal of Medicine* showed that people who received palliative care as they were nearing death actually lived longer than those who pursued aggressive treatment. A Grattan Institute report in 2014 showed increasing investment in palliative care would lead to better care and could save money.

One would think governments would do all they could to ensure palliative care is available to all who need it, and to put funding of palliative care on a sound footing. Sadly, that is not the case in Australia today.



Our politicians should commit to making palliative care available to all who are terminally ill.

In Victoria, funding for out-of-hospital palliative care is currently allocated according to a formula, based loosely on the notional population served by the relevant palliative care organisation. What that means is if a palliative care organisation provides more services, or looks after more people who are at the end of their life, it does not get extra money.

There is no incentive for these organisations to seek out and help people who might benefit from palliative care. It is possible Victorians are missing out on palliative care because of this poor funding design.

Although state budgets are limited, the lid on palliative care funding should be lifted. The risk of a budget blow-out is slim. After all, palliative care is for the dying, and the number of deaths is increasing very slowly – about 2% (1,000 deaths) each year.

Funding for palliative care should be put on the same basis as funding for most other parts of the health-care system; that is, palliative care organisations should get paid for the services they actually provide. Unlike other parts of the system, palliative care funding should be uncapped, with the aim that everyone who needs palliative care gets it, and no one is excluded because of budget limitations in a particular service.

Of course, removing the cap on funding should be accompanied by a push to ensure the money is not wasted on inefficient or poor quality services. A new funding regime should be based on the requirement services are provided at or below national efficiency

benchmarks. A broad suite of indicators should be used to assess the performance of palliative care organisations. The results should be published regularly, with bonuses paid to good performers.

The Victorian parliamentary debate about assisted dying has been emotional. But whatever the parliament ultimately decides, our politicians should commit to making palliative care available to all who are terminally ill.

DISCLOSURE STATEMENT

Grattan Institute began with contributions to its endowment of \$15 million from each of the Federal and Victorian Governments, and \$4 million from BHP Billiton. In order to safeguard its independence, Grattan Institute's board controls this endowment. The funds are invested and Grattan uses the income to pursue its activities.

Stephen Duckett is Director, Health Program, at the Grattan Institute.

THE CONVERSATION

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NO, MOST PEOPLE AREN'T IN SEVERE PAIN WHEN THEY DIE

Symptoms of an illness usually improve the closer a person gets to dying, according to research by **Kathy Eagar**, **Sabina Clapham** and **Samuel Allingham**

Many people fear death partly because of the perception they might suffer increasing pain and other awful symptoms the nearer it gets. There's often the belief palliative care may not alleviate such pain, leaving many people to die excruciating deaths.

But an excruciating death is extremely rare. The evidence about palliative care is that pain and other symptoms, such as fatigue, insomnia and breathing issues, actually improve as people move closer to death. More than 85% of palliative care patients have no severe symptoms by the time they die.

Evidence from the Australian Palliative Care Outcomes Collaboration (PCOC) shows that there has been a statistically significant improvement over the last decade in pain and other end of life symptoms. Several factors linked to more effective palliative care are responsible.

These include more thorough assessments of patient needs, better medications and improved multi-disciplinary care (not just doctors and nurses but also allied health workers such as therapists, counsellors and spiritual support).

But not everyone receives the same standard of clinical care at the end of life. Each year in Australia, about 160,000 people die and we estimate 100,000 of these deaths are predictable. Yet, the PCOC estimates only about 40,000 people receive specialist palliative care per year.

SYMPTOMS AT THE END OF LIFE

For the greater majority of those who do receive palliative care, the evidence shows it is highly effective. The most common symptom that causes people distress towards the end of life is fatigue. In 2016, 13.3% of patients reported feeling severe distress due to fatigue at the start of their palliative care. This was followed by pain (7.4%) and appetite (7.1%) problems.

Distress from fatigue and appetite is not surprising as a loss of energy and appetite is common as death approaches, while most pain can be effectively managed. Other problems such as breathing, insomnia, nausea and bowel issues are experienced less often and typically improve as death approaches.

Contrary to popular perceptions, people in their final days and hours experience less pain and other problems than earlier in their illness. In 2016, about a quarter of all palliative care patients (26%) reported having one or more severe symptoms when they started palliative care. This decreased to 13.9% as death approached.

The most common problem at the start was fatigue, which remained the most common problem at the end. Pain is much less common than fatigue. In total, 7.4% of patients reported severe pain at the beginning of their palliative care and only 2.5% reported severe pain in the last few days. Breathing difficulties cause more distress than pain in the final days of life.

An excruciating death is extremely rare ... More than 85% of palliative care patients have no severe symptoms by the time they die.

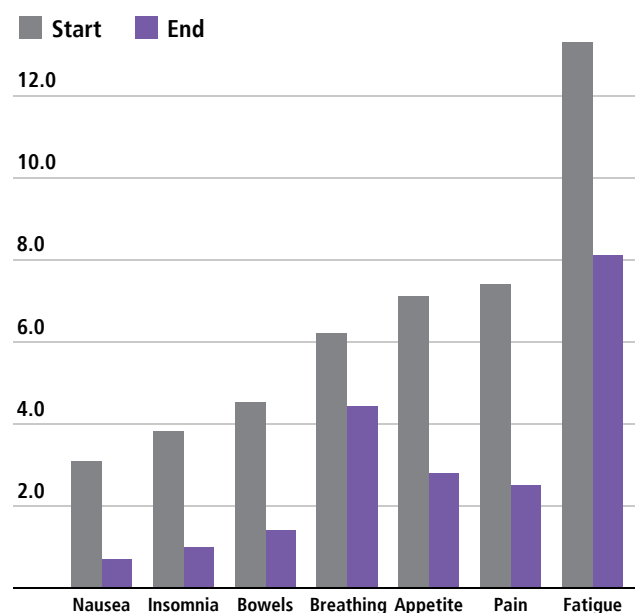
These figures must be considered in relation to a person's wishes. It's true for a small number of patients that existing medications and other interventions do not adequately relieve pain and other symptoms.

But some patients who report problematic pain and symptoms elect to have little or no pain relief. This might be because of family, personal or religious reasons. For some patients, this includes a fear opioids (the active ingredient in drugs like codeine) and sedating medications will shorten their life. For others, being as alert as possible at the point of death is essential for spiritual reasons.

NOT EVERYONE GETS THIS CARE

Patient outcomes vary depending on a range of factors such as the resources available and geographical location. People living in areas of high socioeconomic

Number of patients (%) reporting side-effects at start of palliative care, and at end of life



Source: University of Wollongong.

status have better access to palliative care than those who live in lower socioeconomic areas.

The PCOC data demonstrate those receiving care in a hospital with dedicated specialist palliative care services have better pain and symptom control (due to the availability of 24-hour care) compared to those receiving palliative care at home. There is now a national consensus statement to improve the provision of palliative care in hospitals. This needs to be extended to include death at home and death in residential care.

The evidence is Australian palliative care is effective for almost everyone who receives it. But the problem is that many thousands of people die each year without access to the specialist palliative care they need. As a country, we need to do better.

Although there are national palliative care standards and national safety and quality standards, each state, territory, health district and organisation is responsible for the individual delivery of palliative care. Subsequently, differing approaches to delivery and resources exist in the provision of palliative care.

Recent reports by the New South Wales and Victorian Auditor-General Offices highlight the demand for palliative care services and the need for appropriate resourcing to support patients, carers and families as well as for more integrated information and service delivery across care settings.

AUSTRALIA CAN DO BETTER

The Australian Palliative Care Outcomes Collaboration holds information on more than 250,000 people who

have received specialist palliative care over the last decade. Although participation in the data collection is voluntary, there has been steady uptake. The collaboration estimates that information on more than 80% of specialist palliative care patients is being reported each year.

Australia is in a unique position internationally as it has a national system to routinely measure the outcomes and experience of palliative care patients and their families. These data can help clinicians to measure the effectiveness of their care and help providers adopt best practice. This information is also critical evidence that can be used to inform public debate.

The evidence is Australian palliative care is effective for almost everyone who receives it. But the problem is that many thousands of people die each year without access to the specialist palliative care they need. As a country, we need to do better.

DISCLOSURE STATEMENT

The authors do not work for, consult, own shares in or receive funding from any company or organisation that would benefit from this article, and have disclosed no relevant affiliations beyond their academic appointment.

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EUTHANASIA AND PALLIATIVE SEDATION ARE DISTINCT CONCEPTS – INTENT MATTERS

Among doctors, there seems to be broad consensus about the relevance of double effect in end of life care, observes **Xavier Symons**

Debate over euthanasia in Australia has been renewed by the recently failed bill to legalise it in South Australia, and the Victorian government's announcement it will hold a conscience vote on assisted dying next year. As usual, parliamentary debates have spilt over into expert probing of current practices in end of life care.

From doctor and writer Karen Hitchcock to the Australian Medical Association, there seems to be broad consensus about the relevance of a doctrine called "double effect" in end of life care.

Double effect, in the most general sense of the term, is the view that a doctor acts ethically when she acts with the intention of bringing about a good effect, *even* if certain undesirable consequences may also result.

While doctors agree double effect is a useful principle, there is disagreement about how it applies in end of life situations. On one account, the doctrine can be applied to both palliative sedation and euthanasia. The former is the alleviation of symptoms in terminally ill patients using sedative drugs. The latter is the active killing of a patient by administering sedative barbiturates, such as Nembutal.

Some doctors suggest that, under the double effect doctrine, palliative sedation can be applied more liberally. The relief of pain can actually result in the death of a patient, which means palliative sedation can cover many of the cases of individuals seeking euthanasia.

The argument then is, because palliative sedation does the same work as the euthanasia law is intended to cover, we needn't create a law to legalise euthanasia; we need only clarify existing law on double effect and palliative sedation. I'll call this the "minimalist thesis".

But there is a strong argument to suggest the minimalist thesis is untenable. Euthanasia and palliative sedation are categorically distinct. This is because the *intent* – which is the operative word when it comes to moral philosophy and to legal principles – of doctors in each of the interventions is different.

In palliative sedation, doctors administer pain relief with the primary intent of relieving pain. In the case of active euthanasia, doctors administer barbiturates with the primary intent of ending the patient's life.

What is double effect?

The so-called doctrine, or principle, of double effect is a philosophical concept often employed when evaluating the morality of actions. It rests on the basic conviction that in morality *intentions matter*, and that a person's intentions are what make their actions moral or immoral.

There are various formulations of the doctrine,



In palliative sedation, doctors administer pain relief with the primary intent of relieving pain. In the case of active euthanasia, doctors administer barbiturates with the primary intent of ending the patient's life.

depending on which ethical, religious or legal tradition you are approaching it from. We can nevertheless posit a generic definition along the following lines:

The doctrine of double effect states, where certain criteria are met, a person acts ethically when acting to bring about a good or morally neutral outcome – even though her action may also have certain foreseen, though not intended, undesirable consequences.

In the end of life context, for example, the ethical act to bring about a morally neutral outcome would be administering pain medication. The potentially unintended consequence would be death.

An important phrase in the above definition is "where certain criteria are met". Depending on the tradition you work in, these criteria will vary.

There is, nevertheless, broad consensus about the following criteria:

1. We cannot intend the bad effect
2. The "bad" of the unintended consequences cannot outweigh, or be greater than, the intended "good" outcome
3. The good effect must not be produced by means of the bad effect.



It is generally said doctors should have, as their primary intent, the relief of suffering and not some goal that, while perhaps acceptable, is not within the purview of the role of doctor – such as ending a person's life. Doctors draw on double effect in serious cases where a treatment has certain foreseen, undesirable consequences. This may be minor or major injury to the patient, or even perhaps the hastening of death.

Palliative sedation v euthanasia

Doctors typically administer palliative sedation only in the last days or hours of a patient's life. This involves using sedative drugs to relieve acute symptoms of terminally ill patients where other means of care have proven ineffectual. These symptoms are known as refractory symptoms, and include vomiting, delirium, pain and so forth.

The sedative drugs that doctors administer – the most common of which are benzodiazepines such as Valium – render the patient unconscious or semi-conscious. Often these are administered in gradually increasing doses, depending on how long and to what extent doctors want to sedate the patient.

Sometimes the drugs administered may hasten death. Crucially, though, the primary intent of doctors is to relieve unbearable or otherwise untreatable suffering.

In the case of euthanasia, however, to state it tersely, a doctor or other health-care professional seeks to kill the patient. Medical euthanasia is administered in response to suffering, be it of a patient who is terminally ill, afflicted by intense and prolonged physiological suffering, or by psychological or existential suffering.

Muddying the waters

Monash bioethicist Paul Komesaroff and others have suggested that, instead of legalising euthanasia in Australia, we should clarify the law on double effect and palliative sedation.

The minimalist approach has the added benefit we needn't get involved in placing arbitrary restrictions on end of life care – as legislators are wont to do with euthanasia law.

Yet this argument equivocates on the nature of palliative sedation. In cases where patients still have six months to live, or where their suffering is broader than ordinary refractory symptoms, it is not permissible to provide palliative sedation – at least, not according to existing ethical guidelines.

If this were to be done, the primary intention would not be to relieve suffering but rather to hasten or actively bring about the patient's death. Even if one wished to suggest our ultimate intent were to relieve suffering, we would nevertheless be using the bad consequence as a means to that end. This violates one of the generally agreed upon criteria employed when invoking the doctrine of double effect.

We stand to lose rather than gain from muddying the waters around double effect and palliative sedation. The real question legislators need to consider is this: should the state sanction the active killing of terminally ill patients by their doctors? We do ourselves a disservice to pretend euthanasia is anything other than this.

DISCLOSURE STATEMENT

Xavier Symons does not work for, consult, own shares in or receive funding from any company or organisation that would benefit from this article, and has disclosed no relevant affiliations beyond his academic appointment.

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THE CONVERSATION

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EXPLORING ISSUES

WORKSHEETS AND ACTIVITIES

The Exploring Issues section comprises a range of ready-to-use worksheets featuring activities which relate to facts and views raised in this book.

The exercises presented in these worksheets are suitable for use by students at middle secondary school level and beyond. Some of the activities may be explored either individually or as a group.

As the information in this book is compiled from a number of different sources, readers are prompted to consider the origin of the text and to critically evaluate the questions presented.

Is the information cited from a primary or secondary source? Are you being presented with facts or opinions?

Is there any evidence of a particular bias or agenda? What are your own views after having explored the issues?

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Brainstorm, individually or as a group, to find out what you know about voluntary euthanasia and assisted dying.

1. What is 'euthanasia'? In your response, explain the three main forms of euthanasia: *voluntary*, *non-voluntary* and *involuntary* euthanasia.

2. What is 'voluntary assisted dying'?

3. What is 'palliative care'?

4. What is the principle or doctrine of 'double effect'?



Some doctors object to Voluntary Assisted Dying on the basis of the Hippocratic Oath which instructs “do no harm”. Others see leaving a dying patient to suffer as the opposite of “do no harm”.

From the list of key medical organisations below, choose three (3) and research the official position that each of those organisations takes in relation to voluntary euthanasia. Briefly explain the reasons why they take their particular position.

1. Australian Medical Association
2. Australian and New Zealand Society of Palliative Medicine
3. Doctors Reform Society of Australia
4. Palliative Care Australia
5. Royal Australasian College of Physicians
6. Royal Australasian College of Surgeons
7. Royal Australian College of General Practitioners
8. Royal Australian and New Zealand College of Obstetricians and Gynaecologists
9. Royal Australian and New Zealand College of Psychiatrists
10. World Medical Association

[illegible]



Voluntary assisted dying/voluntary euthanasia laws differ around the world. There are differences among the various laws relating to the legal framework, eligibility criteria, method of administration of the lethal medication and process.

Explain which US states and European countries currently have voluntary assisted dying laws. Choose one European country and one US state and compare and contrast their approaches to regulating assisted dying.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



Commonwealth, state and territory governments have been attempting to reform laws relating to voluntary assisted dying (VAD) for more than three decades.

Research all past voluntary assisted dying (VAD) legal reform proposals in relation to all of Australia's states and territories. Create a national timeline with a brief history of each state/territory's proposed VAD reforms. Indicate the outcome of each reform attempt – were they ultimately passed as legislation or not? Follow up with a brief update of all current state/territory attempts to introduce law reforms in relation to voluntary assisted dying.

[illegible]

Research and explain the conditions and restrictions which apply to Victoria's voluntary assisted dying legislation. Also review the latest information and detail how many people have to date been issued with a permit and how many have died using the approved medication.

[illegible]



DISCUSSION ACTIVITIES

Complete the following activity on a separate sheet of paper if more space is required.

Successive polls have shown support for voluntary assisted dying (VAD) of close to or over 80%.

Dying with Dignity Western Australia, Assisted dying: some frequently asked questions.

As a class, create a poll based on a key question to gauge the levels of support or opposition to voluntary assisted dying. Form into groups of two or more students and compile a brief list of the various ethical, religious, medical, legal and practical considerations involved. Discuss your ideas with other groups in the class. Once all groups have made their presentations, each student is to answer the poll question; compile all 'yes' and 'no' votes to determine the majority view on voluntary assisted dying in percentage terms.

Legalising assisted suicide or euthanasia crosses a serious ethical 'line in the sand' with serious consequences for patients and the practice of medicine. It is not progressive, but a regression to a poorer standard of medicine, focused on quick solutions and convenience. Changing the laws to permit assisted suicide or euthanasia is unnecessary, unsafe, unfair, and ill-informed.

Australian Care Alliance. The Facts: An Overview.

Split the class into two groups to debate the proposition above. One group is to argue in favour of the statement, and the other against it. Is there an ethical medical 'line in the sand', and if so, where is it? Take a straw poll after each group has presented their arguments in the debate to demonstrate the popular opinion of all students. If any students have changed their initial personal opinion on voluntary assisted suicide/euthanasia, discuss why they were persuaded to change their minds.



MULTIPLE CHOICE

Complete the following multiple choice questionnaire by circling or matching your preferred responses. The answers are at the end of the next page.

1. Which of the following countries have some form of legal voluntary assisted dying legislation in place, as at June 2020? (Note: may include states or territories within these countries)

- a. Australia
- b. Belgium
- c. Canada
- d. Colombia
- e. Germany
- f. Luxembourg
- g. Netherlands
- h. Switzerland
- i. United States

2. Which of the following Australian states/territories have ever passed legal voluntary assisted dying legislation, as at June 2020? (Note: may include places where laws are not currently operating)

- a. Australian Capital Territory
- b. New South Wales
- c. Northern Territory
- d. Queensland
- e. South Australia
- f. Tasmania
- g. Victoria
- h. Western Australia

3. In what year was Western Australia's *Voluntary Assisted Dying Act* passed?

- a. 2009
- b. 2011
- c. 2013
- d. 2015
- e. 2017
- f. 2019
- g. 2020

4. Match the following terms to their correct definition.

- | | |
|-----------------------------|--|
| a. Advance care directive | 1. Euthanasia that is performed when a person is competent but has not expressed the wish to die or has expressed a wish that he or she does not die. |
| b. Double effect | 2. Doctrine which recognises that medication may be given to a person to relieve pain (good effect), even if it hastens the person's death (bad effect). |
| c. Voluntary euthanasia | 3. Euthanasia that is performed when a person is not competent. |
| d. Non-voluntary euthanasia | 4. An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual. |
| e. Involuntary euthanasia | 5. Instruction that a person makes about their future medical treatment or health care in the event he or she loses capacity to make decisions. |
| f. Palliative care | 6. When a lethal medication is self-administered, which differs to voluntary euthanasia, which is when a lethal medication is administered by someone else (usually a doctor giving a lethal injection). |
| h. Voluntary assisted dying | 7. Euthanasia performed at the request of the person whose life is ended, and that person is competent. |



MULTIPLE CHOICE

5. Respond to the following statements by circling either 'True' or 'False':

- | | |
|--|--------------|
| a. The Northern Territory was the first jurisdiction in the world to legalise voluntary assisted dying. | True / False |
| b. Suicide is legal in Australia. | True / False |
| c. There have been no criminal convictions involving euthanasia and assisted dying in Australia. | True / False |
| d. A health professional is considered to have unlawfully killed a patient when he/she withholds or withdraws life-sustaining treatment when the patient has the capacity to refuse at the time or does so through an advance directive. | True / False |
| e. Successive polls held in Australia over the past decade have shown minority support for voluntary assisted dying. | True / False |
| f. Numerous polls confirm that while support for voluntary euthanasia and voluntary assisted dying is strongest among people with no religion, the majority of religious Australians are also supporters. | True / False |
| g. Voluntary assisted dying is part of palliative care practice in Australia. | True / False |
| h. For the greater majority of those who receive palliative care, the evidence shows it is highly effective at relieving pain. | True / False |

MULTIPLE CHOICE ANSWERS

1 = a, b, c, d, e, f, g, h, i; 2 = c, g, h; 3 = f; 4 = a = 5, b = 2, c = 7, d = 3, e = 1, f = 4, h = 6; 5 = a = true, b = true, c = false, d = true, e = false, f = true, g = false, h = true.

- Currently, voluntary assisted dying laws have been passed in Australia only in the states of Victoria and Western Australia. The Victorian VAD law came into effect on 19 June 2019. The WA *Voluntary Assisted Dying Act 2019* received the Royal Assent on 19 December 2019 and will come into effect in or about June 2021 (*Dying with Dignity Western Australia, Assisted dying: some frequently asked questions*). (p.1)
- The Victorian *Voluntary Assisted Dying Act 2017* and the WA *Voluntary Assisted Dying Act 2019* are both modelled on the Oregon *Death with Dignity Act 1997*, not on the broader European models (*ibid*). (p.1)
- As at June 2019, more than 200 million people live in places with some form of legal voluntary assisted dying (*ibid*). (p.2)
- Australia had the world's first assisted dying law in the Northern Territory (1995) but only four people were able to use it before it was overturned by the *Federal Euthanasia Laws Act 1997*. It took two decades for the next voluntary assisted dying law to pass in an Australian parliament. Victoria's law came into effect in June 2019 (*ibid*). (p.2)
- Voluntary assisted dying/voluntary euthanasia laws differ around the world. There are differences among the various laws relating to the legal framework, eligibility criteria, method of administration of the lethal medication and process (*ibid*). (p.2)
- Australia has one of the best palliative care systems in the world and it has improved significantly over the past 20 years. However palliative care is unable to relieve all pain and suffering, including the complex mixture of physical, emotional and psychological symptoms (*ibid*). (pp. 4-5)
- Euthanasia and assisted dying are topical issues around the world. In Australia, attempts to reform the law occur regularly, while in Europe and North America there is a trend towards the legalisation (or decriminalisation) of voluntary euthanasia and physician-assisted dying (Australian Centre for Health Law Research, *Euthanasia and assisted dying*). (p.7)
- Assisted suicide is different from euthanasia as the person who provides the assistance (e.g. the friend, relative or doctor) does not do the final act that causes the death. The death is caused by the person themselves, by their own action of committing suicide. Euthanasia occurs because the action of the first person e.g. the doctor, causes the death of another person (*ibid*). (p.8)
- Victoria is the only Australian jurisdiction where adults in the end stage of a terminal illness and suffering intolerably can legally seek medical assistance to end their lives. Passed by the Victorian parliament in 2017, the *Voluntary Assisted Dying Act* came into effect in June 2019, giving eligible adults with less than six months to live – or one year if they have a neurodegenerative condition – the right to access lethal medication ... by the end of 2019 the system had received more than 136 applications to use the new VAD law. Of these, 81 people were issued with a permit and 52 died using the approved medication (Go Gentle Australia, *Assisted dying in Australia: where to next?*). (p.13)
- There are two main parts of the world where voluntary assisted dying is legal: Europe and North America (White, B and Willmott, L, *Now that VAD is legal in Victoria, what is the future of assisted dying reform in Australia?*). (p.16)
- Europe has experienced decades of voluntary assisted dying with permissive legislation in the Netherlands, Belgium and Luxembourg. The European model is broadly based on voluntary euthanasia or physician-assisted dying to relieve unbearable suffering. Switzerland has had a longer history of decriminalisation of assisted suicide (*ibid*). (pp. 16-17)
- In North America, voluntary assisted dying is permitted in the US by legislation in Oregon, Washington, Vermont, California, Colorado, District of Columbia, Hawaii, New Jersey and Maine, as well as in Montana by court decision (*ibid*). (p.17)
- Advocates for assisted suicide or euthanasia laws frequently point to cases of poor palliative care, often decades old and focus on fear of the dying process. However, current, best practice, palliative care can successfully manage pain and other distressing symptoms at the end of life. It is impossible to legislate safely to take life, without opening the door to rogue practitioners, and putting vulnerable people at risk, including those with psychiatric disorders, the disabled and the elderly (Australian Care Alliance, *Euthanasia laws: the facts*). (p.26)
- Euthanasia debates often focus on people experiencing unbearable physiological or psychological suffering. But research suggests “loss of autonomy” is the primary reason for requesting euthanasia, even among patients with terminal cancer. There have also been suggestions existential suffering could be one of the main motivations behind such requests (Symons, X and Schüklenk, U, *Viewpoints: should euthanasia be available for people with existential suffering?*). (p.32)
- A decision about whether or not to legalise voluntary assisted dying is one for governments. Palliative Care Australia neither advocates for, nor argues against the legalisation of voluntary assisted dying (Palliative Care Australia, *Palliative care and voluntary assisted dying*). (p.35)
- An excruciating death is extremely rare. The evidence about palliative care is that pain and other symptoms, such as fatigue, insomnia and breathing issues, actually improve as people move closer to death. More than 85% of palliative care patients have no severe symptoms by the time they die (Eagar, K et al, *No, most people aren't in severe pain when they die*). (p.45)
- The evidence is Australian palliative care is effective for almost everyone who receives it. But the problem is that many thousands of people die each year without access to the specialist palliative care they need (*ibid*). (p.46)

Advance care directive

An instruction that a person makes about their future medical treatment or health care in the event he or she loses capacity to make decisions.

Assisted dying

Overarching term that includes both what has been called assisted suicide and euthanasia.

Assisted suicide

Act of intentionally killing oneself with the assistance of another who provides the knowledge or means to do it.

Autonomy

Ability of a person to make their own independent choices.

Capacity/competency

When people have sufficient understanding and memory to comprehend the nature and consequences of a decision, and to evaluate and weigh relevant information in making that decision.

Consent

For a person to provide valid consent to medical treatment, he/she must have: the capacity to make treatment decisions; the consent must be free and voluntary; and the consent must cover the act to be performed. A voluntary decision is one that is freely made by the person in response to an understanding of the treatment options. There must be no undue pressure, coercion or manipulation.

Death

Irreversible cessation of all function of the brain ('brain death') or irreversible cessation of circulation of blood ('circulatory death' or 'cardiac death').

Double effect

Doctrine based on moral philosophy, used in the context of palliative care, which recognises that medication may be given (usually by a health professional) to a person to relieve pain (the good effect), even if it hastens the person's death (the bad effect).

End of life

The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.

Euthanasia

Deliberate, intentional act of one person to end the life of another person in order to relieve that person's suffering. The term euthanasia is often used in different ways. Three of the most common are: *Voluntary euthanasia* – euthanasia performed at the request of the person whose life is ended, and that person is competent; *Non-voluntary euthanasia* – euthanasia is performed and the person is not competent; *Involuntary euthanasia* – euthanasia is performed and the person is competent but has not expressed the wish to die or has expressed a wish that he or she does not die.

Palliative care

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative sedation

Practice of relieving distress in a terminally ill person in the last hours or days of a dying patient's life, usually by means of a continuous intravenous or subcutaneous infusion of a sedative drug. It is an option of last resort for patients whose symptoms cannot be controlled by any other means – but it is not a form of euthanasia, as the goal of palliative sedation is to control symptoms, rather than to shorten the patient's life.

Physician assisted suicide

A physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request.

Right to die

A basic conviction that end of life decisions should be an individual choice.

Sanctity of life

Religious concept that holds that life is a gift from God and so can only be ended by God.

Slippery slope

Argument which asserts that voluntary euthanasia would eventually and inevitably lead to non-voluntary or even involuntary euthanasia.

Suicide

Intentional taking of one's own life.

Terminally ill

Terminally ill means suffering from a terminal illness, which is expected to end in death within a relatively short period of time, usually assumed to be 12 months.

Terminal sedation

The deliberate sedation of a patient to place them in a state of deep unconsciousness to relieve suffering. The drugs used in this process can often hasten death. During this process the patient is often not provided with food or fluid in anticipation of death.

Voluntary assisted dying

Voluntary assisted dying (VAD) and voluntary euthanasia (VE) are often used in common language to mean the same thing. However, they are actually defined differently: in the case of VAD, the lethal medication is self-administered, whilst in the case of VE, the lethal medication is administered by someone else, usually a doctor giving a lethal injection. Currently (at June 2020), both voluntary euthanasia and voluntary assisted dying are illegal in every state and territory in Australia except Victoria.

Websites with further information on the topic

Australian Care Alliance www.australiancarealliance.org.au
 Care for Life www.careforlife.net.au
 Cherish Life Queensland www.cherishlife.org.au
 Christians Supporting Choice for Voluntary Assisted Dying www.christiansforvad.org.au
 Dying with Dignity ACT www.dwdact.org.au
 Dying with Dignity NSW www.dwdnsw.org.au
 Dying with Dignity Queensland www.dwdq.org.au
 Dying with Dignity Tasmania www.dwdtas.org.au
 Dying with Dignity Victoria www.dwdv.org.au
 Dying with Dignity WA www.dwdwa.org.au
 Doctors for Voluntary Euthanasia Choice www.drs4vechoice.org
 Exit International www.exitinternational.net
 Go Gentle Australia www.gogentle.org.au
 Hope Australia www.no euthanasia.org.au
 Northern Territory Voluntary Euthanasia Society www.ntves.org.au
 Palliative Care Australia www.palliativecare.org.au
 Pro-Life Victoria (Australia) www.prolife.org.au
 Right to Life Australia Inc. www.righttolife.com.au
 Right to Life NSW www.righttolifensw.org.au
 South Australian Voluntary Euthanasia Society (SAVES) www.saves.asn.au
 The Conversation www.theconversation.edu.au
 World Federation of Right to Die Societies www.worldrtd.net

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