

**ASSISTED DYING:  
SOME  
FREQUENTLY  
ASKED  
QUESTIONS?**



# TABLE OF CONTENTS

<b>INTRODUCTION.....</b>	<b>4</b>
<b>TERMINOLOGY. ....</b>	<b>6</b>
<b>PUBLIC SUPPORT. ....</b>	<b>7</b>
<b>DOCTORS' SUPPORT.....</b>	<b>9</b>
<b>THE LAWS OVERSEAS.....</b>	<b>10</b>
<b>PALLIATIVE CARE.....</b>	<b>12</b>
<b>CURRENT PRACTICES. ....</b>	<b>14</b>
<b>CHANGING THE LAW. ....</b>	<b>15</b>
<b>THE PROPOSED LAW. ....</b>	<b>16</b>
<b>THE ARGUMENTS.....</b>	<b>18</b>
<b>REFERENCES. ....</b>	<b>21</b>

# INTRODUCTION.

---

On Thursday 21 September, the Hon. Trevor Khan MLC, introduced the Voluntary Assisted Dying Bill 2017 in the Legislative Council on behalf of the NSW Parliamentary Working Group on Assisted Dying. The Voluntary Assisted Dying Bill has been prepared over the past two years by the cross-party working group, consisting of the Hon. Trevor Khan MLC (Nationals), Dr. Mehreen Faruqi MLC (Greens), the Hon. Lynda Voltz MLC (Labor), Lee Evans MP (Liberals) and Alex Greenwich MP (Independent).

The Working Group has consulted extensively since 2015 with key stakeholder organisations and NSW parliamentarians on the Bill. Since the release of the Exposure Draft in May 2017, the Working Group assessed more than 70 substantive submissions and made a number of key improvements to the Bill. The Working Group has also hosted community information sessions in collaboration with Dying with Dignity NSW and other organisations and parliamentarians across Sydney and key regional centres of NSW.

If passed, the Voluntary Assisted Dying Bill 2017 will allow terminally ill people, who meet strict eligibility criteria to request and receive assistance to die at the end of their life to avoid prolonged and unbearable suffering.

Dying with Dignity NSW has been the key advocacy group lobbying for this law reform for over 50 years. We believe that in the face of unrelievable suffering from a terminal illness, the ability to choose the manner and timing of one's death should be a basic human right. It is a right that is already available in many jurisdictions around the world, including Switzerland, the Netherlands, Belgium, Luxembourg, Germany, Canada, Colombia as well as six American States and the District of Columbia, which includes the nation's capital, Washington D.C.

In order to assist parliamentarians during their decision-making process in the lead up to the debate, we have put together two documents:

*'Assisted Dying: Setting the Record Straight'* dispels the common 'myths' being promoted by opponents of assisted dying.

*'Assisted Dying: Some Frequently Asked Questions'* aims to provide answers to many of the questions raised during this debate.

## AUSTRALIANS DESERVE A DIGNIFIED, RESPECTFUL AND EVIDENCE-BASED DEBATE ABOUT ASSISTED DYING.

We encourage all members of the NSW Parliament to examine the evidence and base their decisions on facts, not fear.

Terminally ill people deserve the compassion and protection of a robust law, with strict safeguards. They also deserve an informed, evidence-based debate when lawmakers are determining what end-of-life choices should be available to them.

If you would like any further information or references, contact Dying with Dignity NSW:

General Enquiries: (02) 9212 4782

Mobile: 0428 326 358 (Shayne Higson) or 0425 231 786 (Penny Hackett)

Email: [dwd@dwdnsw.org.au](mailto:dwd@dwdnsw.org.au)

Website: [www.dwdnsw.org.au](http://www.dwdnsw.org.au)

## Voluntary Assisted Dying Bill 2017 (NSW) – An Overview

The NSW Parliamentary Working Group on Assisted Dying prepared this overview.

### Eligibility under the Voluntary Assisted Dying Bill 2017 (NSW)

The Bill establishes a framework for certain terminally ill persons to request and receive assistance to end their lives voluntarily. To be eligible, a patient must be:

- *At least 25 years of age, an Australian citizen or a permanent resident, and ordinarily live in New South Wales,*
- *Suffering from a terminal illness with a 12-month prognosis, and*
- *Experiencing severe pain, suffering or physical incapacity.*

At any time and in any manner the patient will be able rescind a request for assistance.

### Framework under the Voluntary Assisted Dying Bill 2017 (NSW)

To receive assistance, eligible patients must be assessed by:

- *A primary medical practitioner,*
- *A secondary medical practitioner who is a specialist in the patient's terminal illness, and*
- *A psychiatrist or clinical psychologist to confirm the patient has decision-making capacity, and is making a free, voluntary and considered decision.*

The primary medical practitioner must provide the patient written information about: the nature of the illness and its likely course; medical treatment available, including palliative care, counselling and psychiatric support; measures for keeping the patient alive; and the patient's right to rescind a request.

The primary medical practitioner must offer to refer a patient who requests assistance to a palliative care specialist. The patient is not required to accept the offer of referral.

The patient, primary medical practitioner, secondary medical practitioner, and psychiatrist or psychologist will need to sign a certificate confirming that eligibility requirements have been met before assistance is provided. The patient cannot sign the certificate until seven days have passed since they made the initial request for assistance and a further 48 hours must pass after the certificate is completed before the primary medical practitioner can prescribe the lethal substance.

The patient must self-administer the lethal substance, however if the patient is physically unable to self-administer, the primary medical practitioner or a designated doctor or nurse can administer the substance. The lethal substance must be an authorised substance set out in the regulations. A patient is under no obligation to actually administer after having gone through the process.

### Additional protections under the Voluntary Assisted Dying Bill 2017 (NSW)

Medical practitioners, health facilities, and health care providers reserve the right to conscientiously object to being involved in providing someone assistance.

The Bill establishes a framework for judicial review by the Supreme Court. Close relatives of the patient may request the Supreme Court to make an order to make the request certificate not effective on the grounds that the patient does not satisfy the eligibility criteria or did not possess decision-making capacity, or that the patient's request was not made freely, voluntarily and after due consideration.

The Bill establishes a Voluntary Assisted Death Review Board that will review each assisted death under the Act. The Review Board will also monitor the scheme, refer breaches to authorities, conduct research, make recommendations, and report to Parliament and the public.

# TERMINOLOGY.

## QUESTION WHAT IS VOLUNTARY ASSISTED DYING?

Voluntary assisted dying (VAD) is a quick and peaceful death which results from a patient taking, or administering to themselves, a fatal dose of a medication. It involves a medical practitioner making the lethal substance available to an eligible patient (after having gone through a highly-safeguarded, medical assessment process), which the patient then uses to end their life at a time and place of their choosing. The patient is in control at all stages of the process.

## QUESTION WHAT IS THE DIFFERENCE BETWEEN VOLUNTARY ASSISTED DYING AND VOLUNTARY EUTHANASIA?

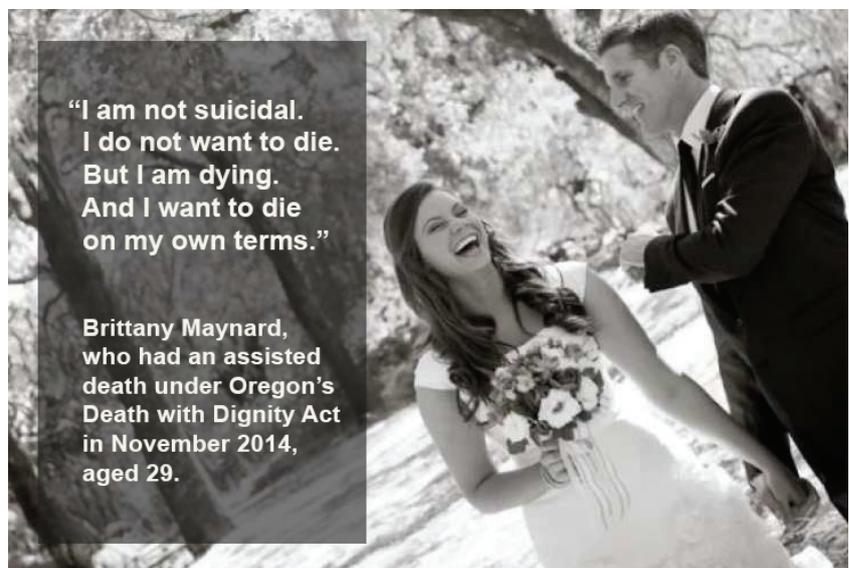
**Voluntary Assisted Dying (VAD)** and **Voluntary Euthanasia (VE)** are often used in common language to mean the same thing. However, they are actually defined differently. The difference is that in the case of VAD, the lethal medication is self-administered, whilst in the case of VE, the lethal medication is administered by someone else, usually a doctor giving a lethal injection.

Currently, both voluntary euthanasia and voluntary assisted dying are illegal in Australia.

NB: Both the NSW and the Victorian Voluntary Assisted Dying Bills are based on the conservative and narrow Oregon model, not voluntary euthanasia per the broader European models. Both the NSW and the Victorian Voluntary Assisted Dying Bills would allow assistance to die by self-administration only (i.e. voluntary assisted dying), with the only exception being administration of the lethal drug by the doctor (i.e. voluntary euthanasia) where the terminally-ill person is physically unable to self-administer the lethal drug.

## QUESTION WHY IS THE TERM 'ASSISTED SUICIDE' NOT APPROPRIATE?

Dying people who want to control the manner and timing of their death are not suicidal. Oregon's Death with Dignity Act itself states that a death under its provision is not a suicide — there being major differences between a rational and fully informed choice in the face of intolerable and unrelievable end-of-life symptoms, and irrational choices about transient problems.<sup>1.</sup>



# PUBLIC SUPPORT.

## QUESTION

### HOW MANY AUSTRALIANS SUPPORT VOLUNTARY ASSISTED DYING?

A recent poll commissioned by Dying with Dignity NSW and conducted by Essential Research<sup>2</sup>, confirmed the results of a 2015 Ipsos Mori poll.<sup>3</sup> Both polls showed that:

**73% OF AUSTRALIANS**

**SUPPORT THE CHOICE OF ASSISTED DYING FOR TERMINALLY ILL PEOPLE**

**AND ONLY 15% OPPOSE**<sup>2</sup>.

## QUESTION

### DO OLDER AUSTRALIANS SUPPORT VOLUNTARY ASSISTED DYING?

The Essential Research survey also showed that support for assisted dying rose to 81% for people aged 55 years or over, with only 10% in that age group being opposed.<sup>2</sup>

## QUESTION

### HOW MANY NSW VOTERS SUPPORT VOLUNTARY ASSISTED DYING?

A recent ReachTEL Poll commissioned by Fairfax Media in October 2017 has found 'an overwhelming majority of NSW residents support a law that would give the terminally ill the right to end their lives with a doctor's assistance'.

The poll revealed more than 87 per cent of Nationals voters supported the question, about 61 per cent of Liberals voters and 73 per cent of Labor voters.

About 18 percent of voters said they were undecided on the question and only 13 per cent said they were opposed or strongly opposed.<sup>4</sup>



Approximately

**70%**

**of NSW voters support voluntary assisted dying.**

## QUESTION

### HOW MANY DOCTORS AND NURSES SUPPORT VOLUNTARY ASSISTED DYING?

A recent survey showed that 60% of NSW doctors support the NSW Voluntary Assisted Dying Bill and 80% of NSW nurses.<sup>2</sup> This followed the AMA's survey that showed 68% of doctors agree that 'there are patients for whom palliative care or other end of life care services cannot adequately alleviate their suffering'.<sup>6</sup>

A key voice in the campaign for assisted dying is the nursing profession, with the NSW Branch of the Australian Nursing and Midwifery Federation leading the lobbying effort.

*"This is a very important issue for the nursing profession. Given our compassion for those who suffer and our concern for quality of life being afforded to every individual, this is an issue worth fighting for to ensure the right balance is achieved and all sides of the debate are well considered."*<sup>7</sup>

NSWANMF President, Coral Levett



# 60%

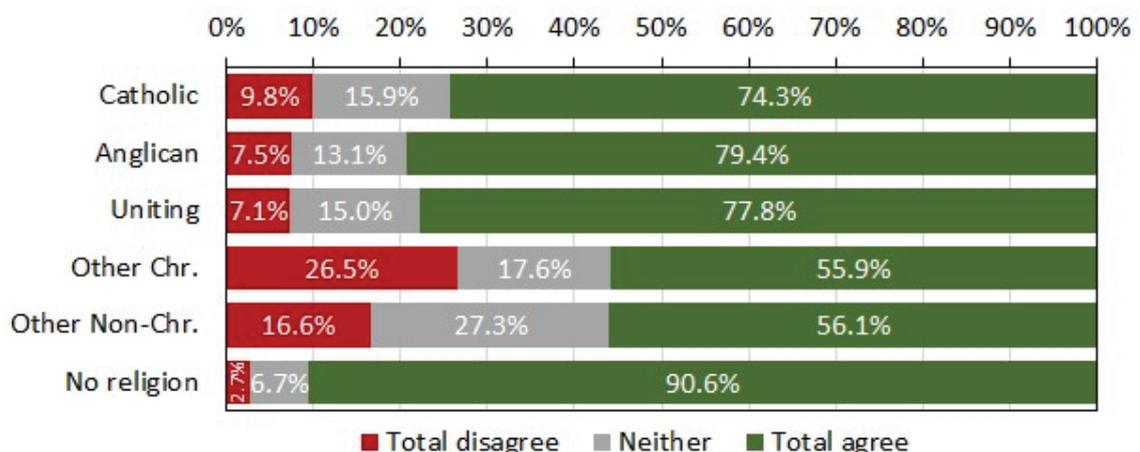
of NSW doctors support the Voluntary Assisted Dying Bill.

## QUESTION

### IS VOLUNTARY ASSISTED DYING SUPPORTED BY PRACTISING CHRISTIANS?

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

For example, the 2016 Australian Election Study (AES), conducted by scholars at Australian National University, found support for the statement that, "Terminally ill people should be able to legally end their own lives with medical assistance" for 74.3% of Catholics and 79.4% of Anglicans, 77.8% of Uniting Church and 90.6% for those with no religion.<sup>8</sup>



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 Euthanasia*, has an excellent website which sets out the arguments and closely examines Christian doctrine in relation to the question of voluntary assisted dying.

# DOCTORS' SUPPORT.

## QUESTION

### ARE THERE DOCTORS WHO SUPPORT VOLUNTARY ASSISTED DYING?

Although the current federal president of the Australian Medical Association, Dr Michael Gannon, is personally and publicly opposed to assisted dying law reform, the membership of the Australian Medical Association is split. <sup>6</sup>

Professor Brian Owler, neurosurgeon and the immediate past federal president of the Australian Medical Association, gave an address to the National Press Club on 12 October 2017, speaking in support of voluntary assisted dying.

Amongst other things, Professor Owler said:

*"Voluntary assisted dying is not about a choice between life and death. No. Rather, it is about respect for a dying person's choice, about the timing and manner of their death."*

*"The need for this legislation is plainly evident. Many of those most determined to see this law pass have personal anecdotes of loved ones whose death has been terrible. Not only was the person's suffering prolonged and unbearable but it left deep lingering wounds in the hearts of their family and friends. The impact and depth of those wounds should never be discounted."*

In closing, Professor Owler spoke directly to members of the Victorian Parliament, as they prepare to vote on their own assisted dying legislation, however, he could just as easily be addressing members of the NSW Parliament. He said:

*"I know that all of you went into Parliament to make a difference. As a doctor, I understand this desire. It's what motivates doctors as well. For some of you, this may be one of the hardest decisions you make in your political career. But to be able to make a decision, the result of which is to ease the suffering of a person who is dying, and those who love that person, to provide them with the comfort of a choice, not just for one day but for days into the future, that is a unique opportunity for our parliamentarians to exercise. This is an opportunity not to be wasted." <sup>9</sup>*

There are many other doctors who are speaking up in support of voluntary assisted dying, including those who are members of a national organisation called *Doctors for Assisted Dying Choice*.

The latest high profile doctor to support voluntary assisted dying laws is Professor Charlie Teo. In a recent Facebook post for Dying with Dignity, Prof Charlie Teo said:

*"I am proud of my reputation of never giving up on patients who still have the will to live despite what others believe to be an exercise in futility. I am equally as proud to support Dying with Dignity because the only situation that would be worse than not having control of your life is to not have control over your own death."*

Prof. Charlie Teo  
supports  
assisted dying  
laws

Dying with Dignity  
New South Wales



# THE LAWS OVERSEAS.

## QUESTION

### WHICH OTHER COUNTRIES HAVE LEGALISED VOLUNTARY ASSISTED DYING OR VOLUNTARY EUTHANASIA?

There are currently 14 international jurisdictions that provide access to either voluntary assisted dying or voluntary euthanasia, for those people who meet strict eligibility criteria within robust legal frameworks.

## Increasing access to legal assisted dying



**By end of 2016, close to 200 million people lived in places with some form of legal assisted dying. In the last two years, this figure has increased very dramatically.**

- 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)
- US  
Oregon (1997)  
Washington (2009)  
Montana (2010 - Court decision)  
Vermont (2013)  
California (2016)  
Colorado (2016)  
Washington DC (2016)



**Australia had the world's first assisted dying law in the Northern Territory (1995) but only 4 people were able to use it before it was overturned by the Federal Euthanasia Laws Act 1997. Now close to 200 million people live in places with access to legal assisted dying.**

## QUESTION

### HOW DO THE LAWS DIFFER AROUND THE WORLD?

There are differences between the various laws in regard to the eligibility criteria, the method of administration of the lethal medication and the legal framework, or 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 restrict access based on 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 require self-administration only, whereas under the European and Canadian models, both voluntary assisted dying and voluntary euthanasia are permitted.

Space in this booklet does not allow for a detailed comparison of the legal frameworks, safeguards and procedures involved in the various assisted dying models around the world. However, according to the Victorian Committee, which travelled to many of these

jurisdictions, although the models differ, 'what they all have in common is robust regulatory frameworks that focus on transparency, patient-centred care and choice.' The Committee found no evidence of institutional corrosion or the often cited 'slippery slope'<sup>10</sup>.

## QUESTION

### HAVE THE ASSISTED DYING LAWS OVERSEAS BEEN BROADENED OVER TIME?

As explained above, the eligibility criteria in the European and American laws has always been different. Out of the 14 jurisdictions that have legalised either voluntary assisted dying or voluntary euthanasia, only one jurisdiction has made an amendment to their law, all the others have remained unchanged. The only jurisdiction to have amended its law is Belgium, when in 2014, twelve years after legalising voluntary euthanasia, it amended the rules to permit doctor-assisted death for minors in a hopeless medical situation and with their explicit consent.<sup>11</sup>

NB. The Australian laws are based on the Oregon law that has remained unchanged for 20 years and only applies to competent, terminally ill adults.

## QUESTION

### CAN PEOPLE WITH MENTAL ILLNESS OR A DISABILITY QUALIFY UNDER THE OVERSEAS LAWS?

Under the American laws, (on which the NSW and Victorian 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 because for instance of a cancer, they would not be denied access to voluntary assisted dying so long as they satisfy 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 discriminated against because they had a mental illness but otherwise met all of the eligibility criteria unless the mental illness impairs decision-making capacity in relation to voluntary assisted dying.

As explained earlier, the eligibility criteria in the European model allows 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 their law, the numbers of people qualifying with a mental illness, or disability, are quite small. The vast majority of people accessing assisted dying in Europe are the same as those in America and Canada, that is, people dying of terminal, physical illnesses such as cancer, or MND.

## QUESTION

### 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.<sup>11</sup> 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.'<sup>11</sup>

NB. Under the NSW Bill the terminally ill patient must be at least 25 years of age.

# PALLIATIVE CARE.

## QUESTION

### CAN PALLIATIVE CARE RELIEVE THE PAIN AND SUFFERING OF DYING AUSTRALIANS?

Australia has one of the best palliative care systems in the world and it has improved significantly over the past 20 years. For the majority of dying Australians, palliative care can relieve the complex mixture of physical, emotional and psychological symptoms, however, it cannot relieve all pain and suffering.

## QUESTION

### 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 most recent Australian 'Palliative Care Outcomes Collaboration 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.<sup>12</sup> 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.<sup>12</sup> 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.

## Section 1 Benchmark summary

Table 1 Summary of outcome measures by setting

Description	Benchmark	Inpatient %	BM Met?	Community %	BM Met?	
<i>Outcome measure 1 – timely admission to service</i>						
Patients episode commences on the day of, or the day after date ready for care (BM1)	90%	97.2	Yes	87.4	No	
<i>Outcome measure 2 – responsiveness to urgent needs</i>						
Patients in the unstable phase for 3 days or less (BM2)	90%	89.0	No	80.5	No	
<i>Outcome measure 3 – change in symptoms and problems</i>						
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 (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
<i>Outcome measure 4 – case-mix adjusted outcomes (X-CAS)</i>						
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

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.<sup>12.</sup>

**Table 31 Profile of PCPSS at beginning of phase by phase type – inpatient setting (percentages)**

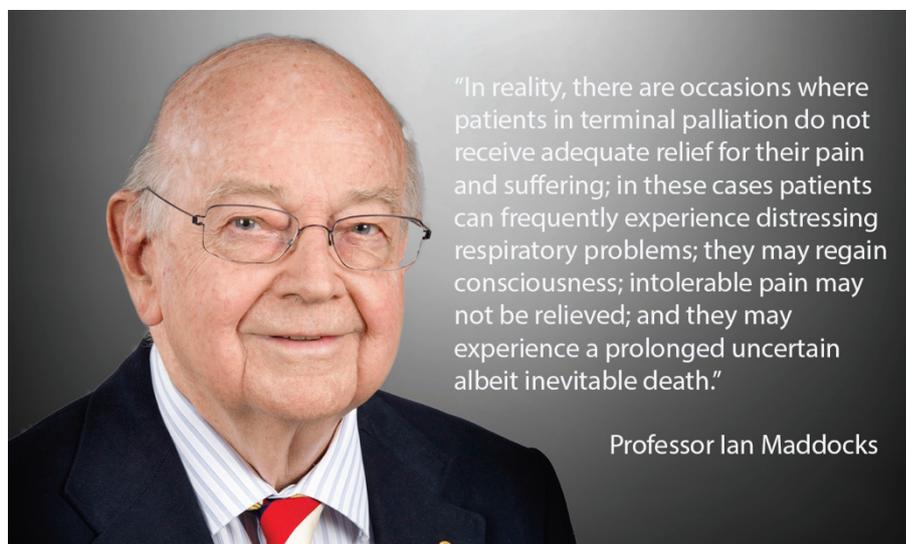
Phase type	Problem severity	Absent	Mild	Moderate	Severe
Stable	Pain	49.6	38.7	9.9	1.8
	Other symptoms	32.8	51.0	13.9	2.3
	Psychological / spiritual	43.9	45.9	8.6	1.6
	Family / carer	47.6	41.1	9.2	2.1
Unstable	Pain	30.9	33.7	25.1	10.3
	Other symptoms	17.8	39.4	31.6	11.1
	Psychological / spiritual	28.7	47.7	18.8	4.8
	Family / carer	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 / carer	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 / carer	28.2	39.6	23.5	8.7

## QUESTION

### ISN'T TERMINAL SEDATION AN OPTION WHEN PAIN OR SUFFERING CANNOT BE RELIEVED?

Terminal or palliative sedation is a last resort option, if a patient is experiencing intolerable and unrelievable suffering. However, as the Victorian Inquiry found 'doctors take differing approaches to continuous palliative sedation, including how deeply and quickly sedation should be administered.'<sup>10.</sup> As a result, not all patients will receive sedation to a level where their pain or suffering is alleviated.

Yet even terminal sedation doesn't guarantee a peaceful death. As Australia's most senior palliative care physician, Professor Ian Maddocks, explains:



# CURRENT PRACTICES.

---

## QUESTION

### ARE DOCTORS CURRENTLY ASSISTING THEIR PATIENTS TO DIE?

As the practice of assisted dying is currently illegal, there are significant impediments to accurately quantifying the extent to which these practices occur in Australia. However, research over many years has shown that some medical professionals are already assisting some of their patients to die but it is happening covertly, irregularly and usually at an advanced stage of illness (often hastening death by a week or two).<sup>13.</sup>

## QUESTION

### IF ASSISTED DYING IS ALREADY HAPPENING, WHY CAN'T WE LEAVE THINGS AS THEY ARE?

According to the findings of the Victorian Inquiry into End of Life Choices, 'existing end of life care legislation is confusing in many ways, and causes uncertainty, particularly for health practitioners.'<sup>10.</sup> This legal uncertainty can lead to under-medicating for fear of criminal liability for hastening a patient's death. This confusion and uncertainty can affect dying patients and their families and lead to unnecessary and prolonged suffering and that is why we shouldn't leave things as they are.

Although there are some doctors who have actually provided lethal medication to dying patients, very few are willing to admit to it publicly (Dr Rodney Syme is one exception). Because this practice has to be done covertly, a dying patient seeking the option of a peaceful death would find it very difficult to find doctors like Dr Syme.

Some people consider the practice of palliative sedation to be a form of 'assisted dying'. However, as the Victorian Inquiry found, because 'doctors take differing approaches to continuous palliative sedation, including how deeply and quickly sedation should be administered'<sup>10.</sup>, it means not all patients will have all their suffering alleviated.

Whether it is the provision of lethal medication or the provision of terminal sedation, because these practices are not regulated, there are no safeguards or monitoring and the ongoing unlawful practice of assisted dying brings the law into disrepute.

## QUESTION

### WILL AN ASSISTED DYING LAW CHANGE THE DOCTOR PATIENT RELATIONSHIP?

An assisted dying law may change the doctor patient relationship, however, evidence shows it is likely to be a positive change. Under an assisted dying framework, the paternalism encouraged by our existing laws is likely to be replaced by a partnership. Instead of doctors deciding unilaterally how much, or how little, or how quickly, a dying person should have their suffering relieved, it becomes a conversation between the doctor and that dying individual.

Assisted dying laws make it possible for honest conversations to start early after a terminal diagnosis. Patients can have these conversations with their doctors but also with family members and their dying can be managed in a rational and humane way. Providing this level of control has a significant palliative effect in itself.

According to a recent report from California, one year after their 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.'<sup>14.</sup>

# CHANGING THE LAW.

---

## QUESTION

### WHAT LEGAL OPTIONS DOES A DYING PATIENT HAVE UNDER THE CURRENT LAW?

Under the current law, if a dying individual is experiencing unbearable and unrelievable suffering, they have just three legal options:

- They can commit suicide, but this is a lonely, desperate and often violent option.
- They can end their own life by refusing all medical treatment, including food and water, and basically starve and dehydrate to death, but this is usually a long and psychologically painful process for the patient and their family.
- The third legal option can occur after a dying patient has been suffering for some time. If their suffering has become unbearable and unrelievable, their doctor can slowly put them into a coma – even without their consent – leaving them to die over days, or sometimes weeks. As discussed earlier, this is called ‘terminal or palliative sedation’, but there is a lot of suffering that has to be experienced before this last resort option is taken and it can be distressing for all involved.

## QUESTION

### WHY DO WE NEED TO INTRODUCE AN ASSISTED DYING LAW?

The Victorian Inquiry into End of Life Choices recommended introducing an assisted dying law because, after gathering evidence over a 10-month inquiry, they found:

- Existing Australian laws relating to end of life care are confusing and cause uncertainty, particularly for health practitioners.
- The current illegality of assisted dying can cause great pain and suffering for those who endure terminal illnesses.
- Repeated examples of inadequate pain relief being delivered to dying patients by doctors for fear of breaking the law.
- An inability of palliative care, despite its many benefits, to relieve all suffering.
- Although courts impose lenient penalties without jail time on people who do assist loved ones to end their lives, the potential burden of a court battle compounds carers’ distress and grief.
- Doctors being forced to break the law in order to help their patients die, but having to do so without support, regulation, or accountability.
- Trauma experienced by families watching seriously ill loved ones’ refuse food and water to expedite death and finally relieve their suffering.
- People experiencing an irreversible deterioration in health taking their own lives, often in horrific circumstances.

In its conclusion, the Committee rejected maintaining the status quo as ‘an inadequate, head-in-the-sand approach to policy making’ and the plight of the Australians discussed in their report. They recommended a law that would allow people to seek assistance to die. In their words, this would: ‘not only enable patients end of life wishes to be respected, but also to protect patients, particularly vulnerable people, from abuse and coercion’.

The Committee also found strongly in favour of increased resources and funding for palliative care. In so doing, they made it abundantly clear that assisted dying and palliative care were both important points on the spectrum of end of life care in general.

# THE PROPOSED LAW.

## QUESTION

### WHAT SORT OF PEOPLE WILL ACCESS THE VOLUNTARY ASSISTED DYING LAW?

Assisted dying laws are introduced to help a very particular, very small, group of people. They are individuals who are dying and who are experiencing unbearable and unrelievable suffering at the end stage of their terminal illness. Based on similar laws that have operated in America for 20 years, we can predict that they will be primarily dying from cancer (79%), progressive diseases such as Motor Neurone Disease (7%) and heart disease (7%).

## QUESTION

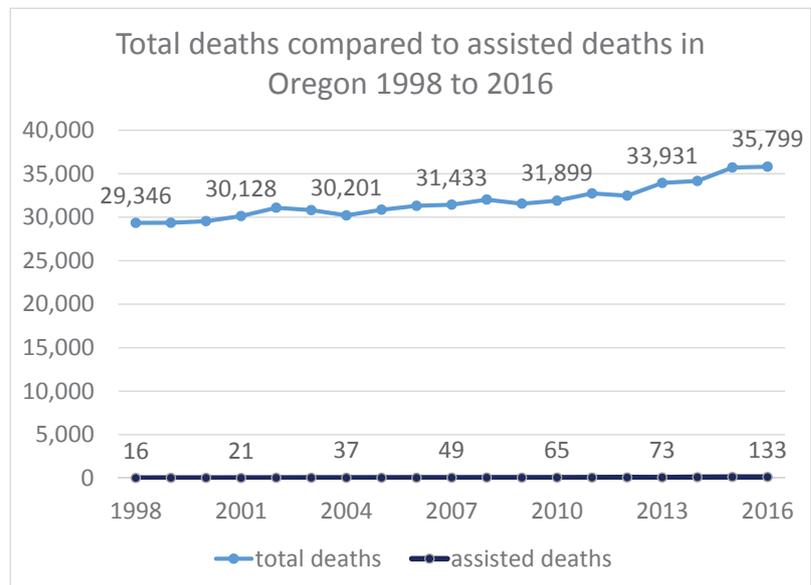
### WILL THE DISABLED BE ABLE TO ACCESS THE VOLUNTARY ASSISTED DYING LAW?

It is important to remember that the eligibility criteria are based on the diagnosis, not on a disability, therefore having a disability alone does not satisfy the eligibility criteria. However, if someone with a disability meets the eligibility criteria because for instance they have terminal cancer, they would not be denied access to voluntary assisted dying so long as they satisfy all of the eligibility criteria because of their cancer.

## QUESTION

### HOW MANY PEOPLE ARE LIKELY TO USE THE VOLUNTARY ASSISTED DYING LAW?

The number of people choosing to access voluntary assisted dying are likely to be small. Based on the evidence from Oregon, voluntary assisted dying deaths are likely to account for less than half of one percent of all deaths. Even in Europe where the eligibility criteria are much broader than the American model and the NSW VAD Bill, the total number is between 2-4% of all deaths.



## QUESTION

### WHY IS THE PROGNOSIS SPECIFIED AS BEING 12 MONTHS OR LESS TO LIVE?

In line with the recommendation of the Victoria Ministerial Advisory Panel, the NSW PWGAD found merit in the incorporation of a 12-month timeframe. 'This timeframe is consistent with existing end of life policy documents including the *National Consensus Statement on essential elements for safe and high-quality end-of-life care.*'<sup>15</sup>

Also as Professor Brian Owler explained in a recent address to the National Press Club, the 12-month outer-limit is there for two main reasons. 'First it provides clarity and certainty for those individuals who want to access voluntary assisted dying and their assessing doctors. Second, it provides allowance for diseases with longer time courses such as motor neurone disease who may otherwise find it difficult to access voluntary assisted dying. We felt that it was very important that this group not be excluded.'<sup>9</sup>

## QUESTION

### WHAT IF A PATIENT CHOOSES TO DIE EARLY, WON'T THAT MEAN THEY COULD MISS OUT ON QUALITY TIME WITH FAMILY AND FRIENDS?

Despite a terminal diagnosis, people fight to stay alive. Under the NSW Voluntary Assisted Dying Bill, in order to access assisted dying, the dying individual not only has to have a prognosis of 12 months or less, they also have to be experiencing 'severe pain, suffering or incapacity' before they would qualify for an assisted death. Based on the overseas evidence, most patients will make good use of palliative care right up until they can no longer tolerate their suffering. At that point, they may decide to take the medication and it is usually in the last days or weeks of their life.

## QUESTION

### WHAT ARE THE KEY SAFEGUARDS IN THE VOLUNTARY ASSISTED BILL?

- 1) To be eligible, the patient must be:
  - a. at least 25 years of age, an Australian citizen or a permanent resident, and ordinarily live in New South Wales;
  - b. suffering from a terminal illness that in reasonable medical judgement will result in death within 12 months; and
  - c. experiencing severe pain, suffering or physical incapacity.
- 2) The patient must be assessed by two medical practitioners (one of whom must be a specialist for the relevant terminal illness) to both conclude that the patient's illness is terminal and that they will likely die within 12 months, that the illness is causing severe pain, suffering or physical incapacity and that there is no cure.
- 3) The patient must be assessed by a psychiatrist or clinical psychologist who must conclude that the patient has decision-making capacity and has made their request for assistance freely, voluntarily and after due consideration.
- 4) The medical practitioners and the psychologist or psychiatrist cannot be related to the patient or a beneficiary of his or her will, and they cannot be from the same medical practice.
- 5) The patient and assessing doctors will need to sign a certificate before assistance can be provided. At least seven days must pass between when the patient first requests assistance and signs the certificate, and then another 48 hours must pass after the certificate is complete before assistance can be provided.
- 6) Doctors and health care providers are not required to participate in any way and can withdraw from any arrangement to provide assistance at any time.
- 7) Close relatives of the patient will be able to apply to the Supreme Court for an injunction on assistance on the grounds that the patient does not satisfy the eligibility criteria or, did not have decision-making capacity, or that their request was not made freely, voluntarily and after due consideration.
- 8) The patient must receive extensive written medical information about their illness and their request for assistance and must be offered a referral for a palliative care consultation.
- 9) A Voluntary Assisted Death Review Board will review each death under the Act, monitor the scheme, refer breaches to the authorities, make policy recommendations, conduct research and report to the government, Parliament and the public.
- 10) The State Coroner will review each death under the Act.

# THE ARGUMENTS.

---

## QUESTION

### WHAT ARE THE MAIN ARGUMENTS IN SUPPORT OF VOLUNTARY ASSISTED DYING?

Most advocacy organisations, both here and overseas, have websites that list the main arguments in support of voluntary assisted dying. However, because the Victorian Parliamentary Inquiry into End of Life Choices was the most comprehensive inquiry of its kind ever held in Australia, and its findings would apply to every state and territory, we have chosen to use the summary that was included in their Final Report. <sup>10</sup>

## AUTONOMY

This argument states that each person has the right to determine the course of their life in keeping with their values and beliefs, within the limits imposed by the rights and freedoms of others.

This autonomy, or self-determination, is fundamental to liberal democracy and the common law. Further, autonomy is a basic principle of medical ethics. It entitles patients to choose a preferred medical intervention or refuse treatment, and should also give a person the right to choose the time and manner of their own death.

This argument has also been framed by saying the state does not have the right to diminish the individual's autonomy in choosing assisted dying, as it does no harm to others.

The autonomy argument often includes reference to 'choice', or 'control'. A common argument relating to control is that simply having the option to choose assisted dying has a palliative effect in and of itself by enabling people at the end of life to reclaim control of their situation.

## RELIEF FROM SUFFERING – PATIENTS AND LOVED ONES

This argument holds that irremediable suffering is grounds for legalising assisted dying.

Even with more or better palliative care, there are some people whose suffering cannot be alleviated. Certain types of pain can be difficult to alleviate or cannot be controlled completely. Advances in medical practice have helped to prolong life, but for some this means an extended period of suffering. A recurring related argument is that it is cruel and contradictory to allow euthanasia of pets and other animals that are suffering, but not people.

Existing methods of pain relief, such as continuous palliative sedation, may not be viable for those who want to remain lucid or do not want to prolong their suffering.

Also, the existential suffering experienced by people at the end of their lives cannot be palliated in all cases.

People whose suffering cannot be relieved should have access to assisted dying.

Assisted dying enables people to ensure they are surrounded by loved ones at the time of death and have the chance to say goodbye to friends and family. Further, the death is more peaceful than it would otherwise be. This has benefits for the patient and the family, who can use the certainty around time of death to say final goodbyes, and are spared the trauma of suffering and seeing their loved one suffer.

## **PREVENTING SUICIDES AND ASSOCIATED SUFFERING**

With assisted dying unavailable, people with illness or injury that are suffering, or anticipate suffering, suicide alone, often in violent or disturbing ways. Having the option of assisted dying would allow these people to either end their lives in a more humane manner or let their illness run its course. It would provide them comfort in the knowledge that they could end their life with assistance if they decided to.

## **ASSISTED DYING OCCURS NOW BUT IS UNREGULATED**

Assisted dying occurs already in Australia, despite being unlawful. It occurs within and outside of medical settings. The instances that occur within medicine are nearly impossible to police. As these practices are not regulated, there are no safeguards, and the ongoing unlawful practice of assisted dying brings the law into disrepute.

## **ASSISTED DYING IS NO DIFFERENT TO REFUSING TREATMENT AND RECEIVING CONTINUOUS PALLIATIVE SEDATION**

There is no moral distinction between refusing or stopping treatment, combined with continuous palliative sedation, and providing assisted dying. This is particularly so when continuous palliative sedation is combined with removing nutrition and hydration. There is no logical basis for prohibiting assisted dying but permitting the refusal of treatment where the consequences are the same. If the distinction between continuous palliative sedation and assisted dying is 'intention', or intended and foreseen consequences, then it is too slight to identify precisely and routinely.

## **BENEFIT TO THE DOCTOR-PATIENT RELATIONSHIP**

Doctor-patient relationships will be enhanced by the openness and honesty that legalising assisted dying will foster. Discussing whether to stop treatment or administer continuous palliative sedation has not diminished trust between doctors and patients, by the same token an openness around assisted dying will not be harmful, but will be beneficial. Current restrictions on this discussion undermines the doctor-patient relationship, the ability to discuss all end of life options can only enhance it.

## **THE CURRENT LAW TREATS PEOPLE DIFFERENTLY**

The prohibition on assisted dying affects people differently and is therefore discriminatory. Some individuals have the physical ability to commit suicide, while the physical circumstances of others may prevent them from doing so. Further, some individuals may have the financial resources to travel overseas to jurisdictions such as Switzerland where assisted dying is lawful, while others may not.

## **THE OPTION OF ASSISTED DYING IS PALLIATIVE**

The option of assisted dying is in itself palliative and gives many peace of mind. Fear of death often stems from the fear of dying badly. Knowing that assisted dying can be accessed eases concern about the prospect of a 'bad death'.

## **ASSISTED DYING IS UNCOMMON**

Assisted dying will not cause the consequences its opponents fear because it is not something a large percentage of people desire for themselves.

## **OPPONENTS WOULD BE UNAFFECTED BY CHANGE**

Opponents to assisted dying will not be affected by a change in law, but those who want assisted dying are adversely affected by the current situation.

## GOD

God would want us to take a compassionate approach to those who are suffering. Providing assisted dying is a compassionate option.

## PUBLIC OPINION FAVOURS LEGALISING ASSISTED DYING

There is a long-standing history of strong public support for assisted dying in certain circumstances. In Australia, opinion polls have consistently shown public support for assisted dying.

Polling body	Date	Question	Yes	No
Newspoll	2007	Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose, or not?	80%	14%
Newspoll	2009	Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose, or not?	85%	10%
Australia Institute	2010	This question is about voluntary euthanasia. If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?	75%	13%
Newspoll	2012	Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose?	82.5%	12.7%
Australia Institute	2012	This question is about voluntary euthanasia. If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?	71%	12%
ABC Vote Compass	2013	Terminally ill patients should be able to legally end their own lives with medical assistance.	75.1%	15.5%
Essential Media Communications	2014	When a person has a disease that cannot be cured and is living in severe pain, do you think should or should not be allowed by law to assist the patient to commit suicide if the patient requests it? <b>NB:</b> this poll used the term "commit suicide", which is thought to be the reason for the lower than usual 'Yes' response	66%	14%
Ipsos Mori	2015	What do you think of doctor-assisted dying? Do you think 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), of sound mind, and expresses a clear desire to end their life?	73%	15%
Essential Media Communications	2015	When a person has a disease that cannot be cured and is living in severe pain, do you think should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?	72%	12%
ABC Vote Compass	2016	Terminally ill patients should be able to legally end their own lives with medical assistance.	75%	16%

# REFERENCES.

---

1. Francis, N. (2017), *Dying for Choice, Professor Somerville Should Retract Indefensible 'Suicide Contagion' Claim*, <<http://www.dyingforchoice.com/docs/SomervilleIndefensibleSCclaimApr2017.pdf>>
2. Essential Research Poll, August 2017.
3. The Economist/Ipsos MORI poll, June 2015.
4. Robertson, J. 2017, *Most voters in NSW support medical euthanasia: poll*, <<http://www.smh.com.au/nsw/most-voters-in-nsw-support-medical-euthanasia-poll-20171014-gz101t.html>>
5. Robertson, J. 2017, *Euthanasia survey hints at support from doctors, nurses and division*, <<http://www.smh.com.au/nsw/euthanasia-survey-draws-out-ethical-debate-among-doctors-and-nurses-20170624-gwxspn.html?csp=394107df0827d2678a8c771bd96b793a>>
6. Review of AMA Policy on Euthanasia and Physician Assisted Suicide – Member Consultation Report (2016)
7. Levett, C. 2017, NSWNMA Media Release, 21 July 2017.
8. Francis, N. (2017), *Dying for Choice, Opposition to Assisted Dying in Australia is Largely Religious*, <<http://www.dyingforchoice.com/docs/OppositionToADisLargelyReligious2017.pdf>>
9. Owler, B. 2017, National Press Club: Brian Owler, <<http://www.abc.net.au/news/programs/national-press-club/2017-10-13/national-press-club:-brian-owler/9047378>>
10. Parliament of Victoria, Legal and Social Committee (2016), *Inquiry into End of Life Choices – Final Report*.
11. Guarascio F. 2016, *17-year-old is first minor to be granted euthanasia in Belgium*, <<http://www.reuters.com/article/us-belgium-euthanasia-minor-idUSKCN11N09P>>
12. Palliative Care Outcomes Collaboration, *Patient Outcomes in Palliative Care, National Results for January – June 2016*.
13. White, L. & White, B. 2012, *Australia 21 Background Paper, How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide*, Health Law Research Centre, QUT
14. Karlamangla, S. 2017, *There's an unforeseen benefit to California's physician-assisted death law*, <<http://www.latimes.com/health/la-me-end-of-life-care-20170821-htmstory.html>>
15. State of Victoria, Department of Health and Community Services (July 2017), *Ministerial Advisory Panel on Voluntary Assisted Dying – Final Report*.

# CONTACT US.

**DWD NSW, PO Box 25, Broadway, NSW 2007**

**General Enquiries: (02) 9212 4782**

**Media Enquiries: 0428 326 358**

**MP's Enquiries: 0428 326 358 (Shayne Higson)**

**Or 0425 231 786 (Penny Hackett)**

**Email: [dwd@dwdnsw.org.au](mailto:dwd@dwdnsw.org.au)**

**Website: [www.dwdnsw.org.au](http://www.dwdnsw.org.au)**

**Facebook: [www.facebook.com/dignityindying](http://www.facebook.com/dignityindying)**

**Twitter: @DWDnsw**

**Dying with Dignity**   
New South Wales