Submission to
The Select Committee on End of Life Choices in the ACT
ACT Legislative Assembly
Inquiry on End of Life Choices in the ACT

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Preamble

Doctors for Assisted Dying Choice (http://drs4assisteddyingchoice.org) is a National Organisation of Australian medical practitioners, in current practice or retired, who are committed to attaining a legal choice for rational adults, who for reasons of intolerable suffering with no realistic chance of cure or relief, wish to gently end their lives, at a time of their choosing, in the company of those whom they choose.

To achieve our broad aim, we seek to strengthen societal and political recognition of the need for voluntary assisted dying, in Australia. We do so by providing evidence that the practice of voluntary assisted dying can be ethical, is actively sought by patients in Australia and is acceptable to Australians.

Term of Reference 1

Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care

The processes of life and death

While it is inevitable that all persons will die, in Australia the age at death has progressively increased in the past century. The median age at death is 78.5 years for males and 84.8 years for females; sixty-six per cent of deaths registered in Australia in 2014 occurred in people aged 75 or over.¹

There is now more time for chronic illnesses to occur.

The patterns of illness leading up to death vary. Typical patterns are illustrated in Figure 1.²

Typical patterns before death.

Trajectory A
Short period of evident decline
Mostly cancer

Trajectory B
Long-term limitation with intermittent serious episodes
Mostly heart & lung failure

Trajectory C
Prolonged decline
Mostly frailty and dementia

Figure 1. Patterns of illness leading to death.²

People with cancer typically experience the pattern shown in Trajectory A. A relatively short onset with a rapid decline towards death. In others, a slower progress of life is punctuated by intermittent illnesses preceding death. People who are frail or have dementia have a long period of poor health before death.

The end of life – general preferences

A few in the community may believe that there is value in suffering before death; the majority however, although they may not fear death, as it is inevitable, do fear pain and suffering; however, what most people eventually find intolerable is existential suffering. Evidence from Oregon, which has had voluntary assisted dying for almost twenty years, clearly shows that it is existential suffering, such as not being able to engage in activities that make life enjoyable, losing autonomy and loss of dignity, that are the predominant sufferings from which relief by assisted dying is requested. Inadequate pain control or concerns about it, is a fear for only 25 %.³

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A good death

A 2014 Report by the Grattan Institute,4 quoting Richard Smith, the then Editor of the British Medical Journal, defined the characteristics of a Good Death:5

To know when death is coming and to understand what can be expected
To be able to retain control of what happens
To be afforded dignity and privacy
To have control over pain relief and other symptom control
To have choice and control over where death occurs (at home or elsewhere)
To have access to information and expertise of whatever kind is necessary
To have access to any spiritual or emotional support required
To have access to hospice care in any location including home, not only in hospital
To have control over who is present and who shares the end
To be able to issue advance directives that ensure wishes are respected
To have time to say goodbye and control over other aspects of timing
To be able to leave when it is time to go and not to have life prolonged pointlessly

Do the practices utilised in the medical community assist a person to exercise their preferences in managing the end of their life and achieve a Good Death?

The above characteristics of a good death provide a basis to consider the current practices utilised in the medical community to assist a person to exercise their preferences in managing the end of their life.

The characterises of a good death

Although listed separately above it is convenient for discussion to consider some characteristics separately and to group others as they are interrelated and not mutually exclusive.

To know when death is coming and to understand what can be expected
To have access to information and expertise of whatever kind is necessary

Even though the expected time of death may be known, it is by no means certain that people may understand what to expect or to receive information and expertise to facilitate understanding. During the slow process downhill, as in Trajectory B, patients do not usually initiate discussion about end of life care. Indeed, there is a reticence in the community in general, to discuss death and dying. Euphemisms such as “passing away” and “shuffling off” are used. Similarly, it would be unusual in medical practice for discussion of end of life and care to be incorporated in management at this stage. Early initiation of such discussion by the medical community may be seen as threatening and as abandoning the patient. Management is directed towards dealing with the intermittent, acute illnesses and control of symptoms associated with progressive disorders related to age.

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Emphasis is on management of the conditions with assistance to achieve an independent existence and maintain living, within the limitations determined by the illness; death is not usually considered. An acute event (Trajectory A), such as a cancer diagnosis, may bring forward the necessity to discuss death but even then, both the patient and the medical practitioner may focus more on hopes for the next medical breakthrough, rather than on the limits of health care when death is near. The consequence of these attitudes is that most people get detailed information about end-of-life services only when they experience the process as a patient or a relative or friend of a dying patient. It is only then that thoughts about death come to the forefront. When, after extensive attempts to cure the illness or counter its effects have failed, discussion becomes inevitable. Management is then likely to involve palliative care. Often it would have been desirable to involve palliative care earlier in the progress of the illness but palliative care is usually seen as an end of life process; its involvement requires acceptance by patient, doctor and relatives that the end of life is near.

To be able to retain control of what happens
To be afforded dignity and privacy

Death is an increasingly institutionalised and medicalised experience. Admission to hospital usually means a loss of control of what happens. Hospital routines may take precedence over personal preferences. Attention to personal needs, even by compassionate hospital staff, may decrease personal dignity and privacy.

To have control over pain relief and other symptom control

These desired characteristics may not always be achieved. A multi-disciplinary approach of palliative care physicians, palliative care nurses, the medical community and carers, may be required but even then, control of the many symptoms that may occur near the end of life is not always achievable. The Final Report of End of Life Choices, Legal and Social Issues Committee, Parliament of Victoria highlighted many of the problems, in that State. Although not specific to the ACT, it is reasonable to assume that a similar situation exists in the ACT. The reader is referred to Chapters 2 and 3 in the Final Report for details.

Some quotes from the Report will highlight the situation:

“The evidence that the Committee heard on palliative care generally dealt with our ageing population which is resulting in an increased demand on palliative care…”

“...increased demand in recent times, caused by an ageing population and changing disease profiles, has put a strain on the system”

“Community palliative care services currently lack the capacity to sufficiently and effectively care for patients in their place of choice

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6 Swerissen, H and Duckett, S 2014, Grattan Institute, op. cit. page 11
7 Swerissen, H and Duckett, S 2014, Grattan Institute, op. cit. page 8
8 Inquiry into end of life choices, Parliament of Victoria, 2016.
“Palliative care provision is fragmented between services and at times poorly integrated with the rest of the health system”

Further compelling evidence is provided by two books, *The Damage Done*\(^9\), from Go Gentle Australia and *Dying Badly – New Zealand Stories*,\(^{10}\) from End-of-Life Choices Society of New Zealand. Each provides testimonies of relatives of people who died after prolonged periods of suffering and wretchedness, which could not be satisfactorily relieved.

**To have choice and control over where death occurs (at home or elsewhere)**

Death is an increasingly institutionalised and medicalised experience.\(^{11}\) Most people (70%) would prefer to die at home. Few favor a hospital death (19%), with lower preference rates for hospice (10%) and nursing home (<1%).\(^{12}\) In practice these preferences are not achieved. In Australia, only 30% of people 65 and over die at home and many are eventually hospitalised; in comparable countries including New Zealand, the United States, Ireland and France the numbers dying at home are about double the Australian rate.\(^{13}\) This occurs because people become progressively dependent; their carers, who are family and friends, cannot cope and there is no formal home care help available.

In Oregon, which has had assisted dying for nearly twenty years, most (90.1%) patients die at home.\(^{14}\) Despite widespread assumptions about the cost of end-of-life care, in Australia only about $5 billion a year is spent on the last year of life for older people in a health budget of $100 billion. But only about $100 million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well.\(^{15}\)

**To have control over who is present and who shares the end**

With the high percentage of deaths in Australia occurring in hospitals it is not always possible to have control over whom is present and who shares the end. The time of death may be preceded by a prolonged period of days or weeks, which may preclude the continued presence of those chosen or desired.

Assisted dying however, provides the opportunity to reliably decide on the time of death. It can be planned and accomplished quickly, in the presence of loved ones, after all goodbyes have been said.

At the present time, in the ACT this option of out-front, legal assisted dying cannot be undertaken. What can happen is that the covert process of the administration of heavy doses of drugs is undertaken on the stated intention of relieving suffering.

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\(^{11}\) Swerissen, H and Duckett, S 2014, Grattan Institute, op. cit. page 8.


\(^{13}\) Swerissen, H and Duckett, S 2014, Grattan Institute, op. cit. page 6.


\(^{15}\) Swerissen, H and Duckett, S 2014, Grattan Institute, op. cit. page 2
The numbers of times this is used in the ACT is unknown; it is not reported and not recorded. The availability to a patient is determined by the willingness of the doctor to provide it and the situation in which the patient is living.

**To be able to issue advance directives that ensure wishes are respected**

Legislation of advance care planning is well established in the ACT. Details are available on the ACT Health website. Three ways of recording decisions are provided, with access to the appropriate forms. Persons may choose (quote):

*An Enduring Power of Attorney.*
This is a legal document that gives trusted decision maker/s, the legal authority to act for a person, and to make legally binding decisions on their behalf.

*An Advance Care Statement*
This focuses on a person’s wishes and choices for healthcare into the future. It provides the chosen decision maker/s and doctors with information for treatment if a person is no longer able to make decisions.

*An Advance Care Plan (ACP) Statement of Choices*
This allows a person to legally record their future healthcare decisions, including refusal of medical treatment generally, or to withhold or withdraw treatment of a particular kind.

The problem with advance care planning in the ACT, as in all Australia, is not availability but the inaction of persons in discussing these options and the indolence in failing to complete one or more forms.

A greater effort by ACT Government is needed to publicise these options. Encouraging doctors to discuss these options is also required. In a busy medical practice, the process of filling out the Form is time consuming, with little financial incentive.

**To be able to leave when it is time to go and not to have life prolonged pointlessly**

There are many factors which contribute to an individual deciding when it is time to die. Although this should be a personal choice, other factors may impinge. Pressure can come from medical practitioners who cannot discuss that it is time to accept death. They may delay the inevitable by introducing possible new treatments and overemphasise the outcomes. Pressure can also come from family who are reluctant to accept death and wish everything possible to be done. This is especially if dying has not been discussed with them beforehand.

Usually it is the fact that total quality of life has gone and suffering cannot be controlled that result in the person’s decision that it is time. *Existential suffering*, such as not being able to engage in activities that make life enjoyable, losing autonomy and loss of dignity, are the predominant sufferings from which relief by assisted dying is requested.

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18 Oregon Death with Dignity Act, op. cit. 2016
THE END OF LIFE - RESTRICTIONS IN THE ACT

1. Palliative care

Palliative care restrictions

Palliative care can play a major role in care in life. Its place is not restricted to end of life care although this is a place where it is often a major part. Specialist palliative care in Australia ranks amongst the better, in the world. Palliative care physicians are skilled in the management of existential suffering and in relief of pain, however, even with the best palliative care available, in the ACT there remains a small number of patients whose suffering cannot be relieved (read infra)on.

The Position Statements of two leading medical organisations in Australia agree that palliative care fails to relieve all suffering in some individuals.

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) Position Statement on Euthanasia and Assisted Suicide, Statement 8, affirms that:

Despite the best that Palliative Care can offer to support patients in their suffering, appropriate specialist Palliative Care to remedy physical, psychological and spiritual difficulties may not relieve all suffering at all times.19

The Australian Medical Association (AMA) Position Statement on Euthanasia and Physician Assisted Suicide 2016, Statement 1.3 indicates that:

For most patients at the end of life, pain and other causes of suffering can be alleviated through the provision of good quality end of life care, including palliative care that focusses on symptom relief, the prevention of suffering and improvement of quality of life. There are some instances where it is difficult to achieve satisfactory relief of suffering.20

2. Effect of deficiency in specialist palliative care on managing end of life preferences

Two leading medical organisations agree that palliative care cannot relieve suffering in all individuals. It must therefore be concluded that the current practice of palliative care in the ACT fails to relieve suffering in some patients.

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19 ANZSPM-Position-Statement-Euthanasia-and-Assisted-Suicide, 2016, Statement 8, page4

20 AMA Position Statement Euthanasia and Physician Assisted Suicide 2016
3. Opposition to assisted dying by some medical organisations in inhibiting end of life preferences in the ACT

The ANZSPM states that:

The Palliative Medicine discipline does not include the practice of euthanasia or assisted suicide.21

It believes that:

Treatment that is appropriately titrated to relieve symptoms and has a secondary and unintended consequence of hastening death, is not euthanasia.22

and

Palliative sedation for the management of refractory symptoms is not euthanasia.23

The AMA Position Statement on Euthanasia and Physician Assisted Suicide 2016 indicates:

Statement 3.1
The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person’s life.24

and

Statement 1.4
All dying patients have the right to receive relief from pain and suffering, even where this may shorten their life.25

Neither of these organisations, after acknowledging that suffering cannot always be relieved for some persons, provides guidance on how the intractable suffering of those persons should be managed.

4. Support shown for assisted dying by other medical organisations indicates that more end of life preferences could be achieved in the ACT

Royal Australian College of General Practitioners (RACPG)
Although specialised palliative care is invaluable in providing end of life care, most every day care is provided by General Practitioners.
The RACGP recently issued a media release welcoming the passage of the Victorian assisted bill, in the Lower house.26

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The President said:

“The voluntary assisted dying bill is about meeting the needs of terminally ill patients with incurable medical conditions who do not find answers in palliative care.”

“They are dying and we should allow them to die with dignity and respect.”

“The RACGP is satisfied that appropriate safeguards for patients, relatives, and medical and health practitioners have been put in place in the legislation.”

“The RACGP is also satisfied that the principle of conscious objection has been upheld, which means that medical practitioners have a choice of not participating in the voluntary assisted dying process.”

**Australian Nursing and Midwifery Federation (ANMF)**

Nurses, above all health care professionals, are paramount in providing end of life care. They are at the bedside of people who are dying. Patients share their cares and concern with them; they in turn combine compassion with professional care; they are there at the time of death. The Australian Nursing and Midwifery Federation expressed its support for assisted dying in a recent media release, following the passage of Victorian assisted dying bill, in the Lower House (quote): 27

“The ANMF, in collaboration with the ANMF Victorian Branch, have long campaigned for laws which ensure that people suffering from terminal and incurable illnesses, are provided with the power and protection to have choices about the timing and manner of their death”.

“Today, we are heartened that Victorian politicians have listened.”

### 2. Effect of opposition of medical organisations on managing end of life preferences in ACT

Planners of health care delivery and politicians turn to medical organisations for advice in delivery of health care. Both the ANZSPM and AMA are not representative of the general medical community and their conservative views on assisted dying are not shared by all medical practitioners. 70% of doctors are not members of the AMA. Recent media releases (above) clearly confirm that opposition to assisted dying as a choice in end of life care is not supported by major sections of the medical community who are closely involved with delivery of end of life care. Despite these figures, there is no doubt that the Statements by some organisations and the seizing on them by opponents, is inhibiting the progression to legalisation of assisted dying in the ACT, resulting in unnecessary suffering by ACT citizens.

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3. **Methods of terminal care approved by medical organisations – effect on end of life preferences**

As indicated above, the ANZSPM believes that:

*Palliative sedation for the management of refractory symptoms is not euthanasia*

The AMA states:

*All dying patients have the right to receive relief from pain and suffering, even where this may shorten their life.*

Thus, both organisations agree that in the presence of unrelievable suffering sufficient medication should be given, even if this ultimately contributes to the patient’s death.

One treatment used is named palliative sedation or terminal sedation.

**Palliative Sedation/Terminal Sedation**

In this treatment a patient’s symptoms are controlled by administration of ever increasing doses of sedative and anxiety relieving drugs, till the death of the patient. This may take days, with the patient in a comatose or semi-comatose state, often watched by distressed relatives. Food and fluid are not given. In most cases additional intravenous hydration is not added.

The essence of this management is the **opinion** is that the drugs are given with the **intention** of controlling symptoms and not given to cause the death of the patient; nor is this the **intention** of the treating doctor. The patient’s death is an **unintended** side effect of the treatment. Administration of drugs to **deliberately** cause death, is a criminal offence. The criminality or not of palliative sedation rests with the **intention** of the doctor - an **intention** that cannot be known by the observer and perhaps sometimes by the doctor.

This procedure is labelled by some as **slow euthanasia**.

Some see hypocrisy in defining as legal the prolonged administration of drugs, till a slow death by sedation and dehydration occurs but as illegal the controlled administration of drugs, to consenting adults, to achieve a desired assisted death, at the time of the patient’s choosing, in the company of loved ones.

4. **Effect of legality and uncertainty of palliative sedation on managing end of life preferences by medical personnel**

1. Palliative sedation commits patients in the ACT, with unrelievable suffering in the terminal phase of illness, to a prolonged death process, in a coma, watched by loved ones; a process which could occur expeditiously at a time of the patient’s choice if assisted dying was available in ACT.

2. The frequency of the procedure in the ACT is undocumented. There is no accountability and no uniformity in availability in the ACT.

3. The uncertainty about the terms defining the legality and intent of the procedure causes many doctors to avoid it or to use minimal drug administration. Inevitably, in the absence of legalised protection for the medical practitioner undertaking the procedure, some patients in the ACT receive inadequate symptom relief.

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5. Place of death and end of life preferences

In Oregon between 1998 and 2016, 93.4% of people, who were assisted to die, died at their home or at the home of family or friend.\textsuperscript{29 30}

In Australia although 70% of people want to die at home, only 14% do.\textsuperscript{31}

Most ACT citizens die in institutions even though most would prefer to die at home. Lack of legal assisted dying prevents ACT citizens from achieving their preferred place of dying.

Term of Reference 2

ACT community views on the desirability of voluntary assisted dying being legislated the ACT

There is ample evidence from surveys in Australia for the past twenty years that Australians want the availability of the choice of legal assisted dying. The surveys have not been specifically for the ACT but there is no reason to doubt that the wishes of ACT citizens would differ from those of other Australians.

The Scanlon Survey

The Scanlon Foundation is based in the Faculty of Arts, Monash University, Victoria. The Scanlon Foundation Surveys, rely on probability-based methods for surveying the population and are more accurate than online panels. The Surveys use statistically based techniques which allow the surveyed population to be a statistically similarity structure to the total population. The Scanlon Foundation Survey 2016, Mapping Social Cohesion\textsuperscript{32}, asked the question:

“Do you support or oppose legislation for medically approved euthanasia for people suffering terminal illness?”

The following results were obtained:

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly support or support</td>
<td>79.9 %</td>
</tr>
<tr>
<td>Oppose or strongly oppose</td>
<td>12.9 %</td>
</tr>
<tr>
<td>Neither support or oppose</td>
<td>3.2 %</td>
</tr>
<tr>
<td>Refused or don’t know</td>
<td>3.9 %</td>
</tr>
</tbody>
</table>

\textsuperscript{29} Oregon Death with Dignity Act Data summary 2016  
\texttt{http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/pages/index.aspx}

\texttt{http://www.ohsu.edu/xd/education/schools/school-of-medicine/departments/clinical-departments/family-medicine/about/upload/17031616.pdf}

\textsuperscript{31} Sweerissen, H & Duckett, S 2014, ‘Dying well’, \textit{Grattan Institute}.  
\texttt{https://grattan.edu.au/report/dying-well}

\textsuperscript{32} Scanlon Foundation Survey 2016, Table 21, page 36.  
The conclusion is obvious:

**80 % of adult Australians support the establishment of legal voluntary euthanasia.**

**The Essential Poll – Australia – August 2017**

This nationwide poll was conducted by Essential Research from 10 to 14 August 2017. 1,000 respondents were asked:

“If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?”

![Essential Poll - Australia - August 2017 chart](chart.png)

The conclusion again is obvious:

**73 % of Australians support voluntary assisted dying.**

In the age group 55+, the support was 81 %

**Other Surveys**

There are many other surveys: they show a progressive increase in the support for legalised voluntary assisted dying. The trend is demonstrated in surveys by Roy Morgan surveys over the past 50 years, which asked the question:\(^{34}\)

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“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?”

Again, support for assisted dying was high.

Table 1. The support for assisted dying for a hopelessly ill person has been high from the late seventies to a level similar to that shown in the recent Scanlon Survey.

### Terms of Reference 3

**Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed**

Opponents to assisted fabricate scare tactics to bring doubt to considerations of the facts associated with properly formulated assisted dying legislation.

Some of the unsupported claims made by opponents:

- Palliative care relieves all suffering so assisted dying not required
- Legalising assisted dying undermines development of palliative care
- Legalising assisted dying will lead to a “slippery slope” of unrestricted killing
- Assisted dying degrades the doctor – patient relationship
- Assisted dying is killing and is unethical

There is ample. **research based** evidence that voluntary assisted dying can be practiced in a community without bringing risks to the community.
The Oregon Death with Dignity Act

The Act became law on October 27, 1997. It has remained, unchanged since then. The Act allows, under strictly prescribed circumstance, terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose. A requirement of the Act is that Oregon Health collects and publishes annual statistics relating to the application of the Law. Nineteen years of annual reports are available from Oregon Health.35 The 2016 Report provides a summary of the application of the Act from 1998 to 2016. Examination of the Report does not show that there are risks to individuals and the community associated with voluntary assisted dying and dispels the non-evidence-based claims of the risks associated with assisted dying, made by opponents.

Statements made by opponents of assisted dying

Experience in Oregon negates the following claims of opponents of assisted dying.

Slippery slope

There is none. In 2016, in Oregon, 133 people died as a result of ingesting the prescribed medication. This represents 0.372% of all deaths in that year. Not the catastrophic, inevitable slide into an increase in death rates, predicted by those opposing assisted dying.

Assisted dying will target the old and infirm

Not supported by evidence. From 1998 to 2016, 1127 people died under the conditions imposed by the Death with Dignity Act. 30.3% of these were in the age group 65 – 74; this is not an old aged group. If the groups below (55 – 64) and above (75 – 84) are added to this (65 – 74) group, 75.9% were clustered around the mean age of 71: only 15% were above the age of 85. There was no concentration of deaths in the elderly.

Assisted dying will disproportionately affect the disadvantaged

Not supported by evidence. The cumulative totals show that 96.5% of those who accessed assisted dying were white and 72.0% had some college, university or higher education. 90.2% were enrolled in hospice care, 98.6% had private or Government assisted medical insurance. These are not characteristics usually associated with disadvantage.

Criteria for assisted dying will progressively be relaxed
Not supported by evidence. The indication for assisted dying was malignant disease in 77.4% of deaths by assisted dying, in 1998 to 2016. Amyotrophic lateral sclerosis was present in 7.9%. The criteria of the Act have not changed since its inception.

Other evidence
1. Dr Roger Hunt, BM, BS, GDPH, FACHPM, MD is a palliative medicine specialist, working in the discipline for three decades. He is a life member of the Palliative Care Council of South Australia. He has an MD awarded by published work. Dr Hunt was a member of the Victorian Parliament Ministerial Advisory Panel on Voluntary Assisted Dying,37 whose recommendations were adopted in formulating the Victorian Voluntary Assisted Law 2017. Dr Hunt systematically refutes these claims made by opponents of assisted dying.38

2. A comprehensive, evidence-based report, by DWD NSW provides compelling factual proof of the fallacy of the claims, made by opponents,39 as does a report from Dying with Dignity.40

Other States and laws
The safety and functionality of the Oregon law has been accepted by other States in the USA. Laws based on the Oregon Act, have now been introduced into California, Colorado, Vermont, Washington and the District of Columbia. There are now 52.5 million (1 in 6) Americans with access to medically assisted dying and nine other States are considering similar legislation.41

The risks to the ACT community
The evidence clearly shows that legal assisted dying is being undertaken safely in other jurisdictions. It follows that an appropriately worded law, with accepted safeguards, could be instituted in the ACT without posing risks to individuals or the ACT community. Such a law could address the perceived risks, to ensure acceptance by the ACT community.

37 Parliament of Victoria. Ministerial Advisory Panel. Voluntary assisted dying
39 Assisted Dying: Setting the record straight. Dying with Dignity, NSW.
40 Death with Dignity: a report card on Medical Aid in Dying legislation in the United States.
https://www.deathwithdignity.org/news/2017/11/report%E2%80%8B-%E2%80%8Bcard%E2%80%8B-%E2%80%8Bon%E2%80%8B-%E2%80%8Bmedical%E2%80%8B-%E2%80%8Baid-in-dying%E2%80%8B-legislation/
41 Kliff, S 2015, 1 in 6 Americans now live in a state where physician-assisted suicide is legal.
https://www.vox.com/2015/10/7/9470537/assisted-suicide-where-legal
Term of Reference 4
The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme

Characteristics of the Oregon Death with Dignity Act which make it applicable to the ACT
Consideration of the nineteen years of the Oregon Health Report provides evidence for the applicability of a similar law in the ACT. Just as in Oregon, the numbers of people using the law would be very few; the old, infirm and disadvantaged would not be targeted and relaxation of the criteria could happen only by the passage of legislation in the ACT Parliament.

The Victorian Voluntary Assisted Dying Act 2017
The Victorian Voluntary Assisted Dying Act was Assented to on 5 December 2017. The Act is based on the Oregon Assisted Dying Act. In general, the Victorian Act regulations would be applicable as the basis for an Act in the ACT. It is very restrictive does however and imposes conditions which are not in the Oregon Act. Of particular interest to the medical community these are:

- Clause 8 states:
  Voluntary assisted dying must not be initiated by registered health practitioner.

Restricting medical practitioners from initiating discussion on assisted dying compromises the doctor-patient relationship of provision of information in the care of the patient. This restriction of information on all options available in care, in discussions between medical practitioner and patient, does not occur in any other area of medicine. There is no logical reason for this Clause.

- Death certificates
  The instructions issued by Oregon’s Public Health Division and Health Authority on how to fill out death certificates do not mention physician-assisted suicide at all. Testimony presented at trial in Carter v. Canada (Attorney General) indicated that it is “common, if not invariable” for physicians in Oregon “to record the underlying illness as the cause of death” for those who died under the Act. The Death Certificates for those assessing assisted dying in Vermont, Washington State, Quebec and Belgium contain no reference to assisted dying. Death Certificates under the Victorian Voluntary Assisted Dying Act will record the underlying illness as the cause of death but will also record the manner of death as voluntary assisted dying.

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Appendix 2. http://www.cmaj.ca/content/suppl/2015/12/14/cmaj.151130.DC1
45 Jocelyn Downie, J & Oliver, K. op. cit.
Statistics on number of deaths are recorded by other means. We see no reason for Victoria to record this on a death certificate, in inconsistency with all other situations where legalised assisted dying exists.

**Term of Reference 5**

**The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change**

Existing Federal legislation inhibits the ACT from determining its own voluntary assisted dying policy. The medical consequence of this situation is a continuation of unrelieved suffering by some residents of the ACT.

**Term of Reference 6**

**Any other relevant matter**

As the name of our group, *Doctors for Assisted Dying Choice* indicates, we believe that rational adults, who for reasons of intolerable suffering with no realistic chance of cure or relief, wish to gently end their lives, should have the right to access legal assisted dying, at a time and place of their choosing, in the company of friends and loved ones of their choice.

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Dr Nick Carr, MA MMed MB BChir DCH MRCGP FRACGP.
Dr Dennis Chambers, MB, ChB, LRCP, LRCS, LRFP&S, FRACGP.
Dr Chee Chang, MBBS.
Professor Rufus Clarke, MA MD PhD MPH FAFPHM.
Doctors for Assisted Dying Choice.

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Dr Ian Colclough, MBBS.
Dr David Cunningham, LRCP & S.
Dr Helen Cutts, MB ChB, D.Obst.RCOG.
Dr Frances Daily, BMBS, DTMH, DRANZCOG.
Dr William Davall, MBBS, D.Obst.RCOG.
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Dr David Fox-Smith, MB, BCh, FRACGP.
Dr Pam Fradkin, MBBS.
Mr John Freeman, MBBS, FRACS.
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Dr Robert Marr, MBBS MPH.
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