



respect for the right to choose

# **Legislating for choice**

## **Dying With Dignity Victoria**

**Submission to the Victorian Government  
Legal and Social Issues Committee  
Inquiry into End of Life Choices**

**July 2015**

## Definitions and abbreviations

The following key terms and abbreviations are used throughout this document with the meanings shown.

<b>Assisted dying</b>	A general term encompassing a range of medical processes to bring about an early or hastened death at the request of a patient.
<b>Voluntary assisted dying (VAD)</b>	A patient is prescribed or otherwise supplied with a lethal substance by a doctor, which the patient self-administers in order to end their life. (Also known as 'assisted suicide'.) <b>Dying With Dignity Victoria advocates VAD.</b>
<b>Assisted suicide (AS)</b>	See above. Because other jurisdictions use this terminology, it appears in this document when appropriate.
<b>Voluntary euthanasia (VE)</b>	A patient's life is ended at their own request by a doctor administering a lethal substance, usually by injection.



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30 July 2015

The Hon Edward O'Donohue  
Chair, Legal and Social Issues Committee  
Parliament House, Spring Street  
East Melbourne Vic 3002

Dear Mr O'Donohue

We present to you the submission of our organisation Dying with Dignity Victoria, to be considered by the Committee of Inquiry into End of Life Choices.

We have indicated our interest in appearing before the Committee of Inquiry at a public hearing.

Yours sincerely

A black rectangular box redacting the signature of Lesley Vick.

Lesley Vick  
President

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Rodney Syme  
Vice President

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# 1:

## Executive summary

### 1.1 Statement of purpose

In submitting this document, Dying With Dignity Victoria (DWDV) provides the Committee with information relevant to the Inquiry's *Terms Of Reference*, with particular emphasis on the need for a law allowing Victorian citizens to make an informed decision to access a controlled process of medically assisted dying among end-of-life choices available to them. To this end, we start by stating our recommendations for law reform, then examine the current situation for terminally ill people, and follow with substantive evidence and argument for new legislation.

### 1.2 Type of legislative change required (Term of Reference 3)

In [Chapter 2](#) we set out DWDV's purpose, aims and legislative principles, clarifying what we do and do not support in regard to assisted dying. We examine the ill effects of current law, and recommend remedial changes, subject to particular exclusions and safeguards. We note the relevance of the existing *Medical Treatment Act 1988* and reinforce the need for upholding its provisions. Finally, we advocate that the legal validity of advance care planning and instructional directives be made clear and binding and uncompromised by any future legislative change.

### 1.3 Current practices for enabling end-of-life choices (Term of Reference 1)

In [Chapter 3](#) we discuss the realities of dying in our society and how the situation could be improved for many people if the law permitted them the choice of assisted dying. Surveys of doctors' attitudes to euthanasia, here and overseas, are also noted. [Chapter 4](#) is a conference address by DWDV Vice President Dr Rodney Syme in which he points out the failure of the Palliative Care movement to deal compassionately with a percentage of patients who die in extreme and unrelievable pain. He ends with recommendations for improving the scope and practices of palliative care. This is followed by two verbatim accounts of unhappy deaths in palliative care from relatives of the deceased.

### 1.4 Frameworks of legislation, here and overseas (Term of Reference 2)

[Chapter 5](#) is a thorough overview of legal developments and legislative models relating to assisted dying in Australia and overseas. It concludes: *'current laws are unclear, ambiguous, discriminatory, unenforceable and incompatible. Abuse is more likely to occur in systems that are not transparent and monitored. Current legislation in Victoria lags well behind both public opinion and legal developments overseas.'* Included is a tabulated list of overseas jurisdictions which have enabled assisted dying, including details of their systems and some statistics of usage. [Chapter 6](#) deals with recent Canadian court rulings and legal argument, after a comparison of Australian and Canadian frameworks.

### 1.5 Supporting evidence

The remainder of the document reinforces the case for law reform. [Chapter 7](#), with its [Appendix A](#), proves the overwhelming public support for instituting an assisted dying option. [Chapter 8](#) contains a meticulously written ethical argument by a Canadian judge, and two opinions from Australian ethicists. [Chapter 9](#) presents responses to a list of claims commonly heard from opponents of assisted dying, and [Chapter 10](#) looks briefly at religious doctrinal opposition and concludes that it does not flow through all religious adherents, and in any case should not influence laws in a secular society.

## 2:

# DWDV and what we advocate

### 2.1 Our purpose

Founded in 1974, Dying With Dignity Victoria (DWDV) is a law reform and education organisation pursuing public policies and laws in the state of Victoria to enhance self-determination and dignity at the end of life. Dying With Dignity Victoria is a member of the World Federation of Right to Die Societies.

### 2.2 DWDV aims are to:

- Promote legislation that gives effect to freedom of choice and individual human rights by acknowledging the right of competent adults with a terminal illness or intolerable, unrelievable suffering, to die with dignity.
- Carry out a continuing public education policy to achieve such legislation.
- Educate the public in the need for Advance Healthcare Directives.
- Provide counselling and other assistance to people on their end of life rights.

### 2.3 Our legislative principles

1. Competent adults with a terminal illness or intolerable, unrelievable suffering shall have the right to choose to die with dignity in a manner acceptable to themselves and shall not be compelled to suffer beyond their wishes.
2. In the case of a competent adult with a terminal illness or intolerable, unrelievable suffering, it shall not be an offence for a doctor to confidentially advise the sufferer and/or relatives/guardian regarding end-of-life choices; nor for a doctor to assist the sufferer in choosing to hasten death in a manner acceptable to themselves; nor for a relative or friend to be present at the time of death.
3. No individual, group or organisation shall be compelled against their will to either participate or not participate in an assisted death of a sufferer.
4. Sufficient safeguards shall be in place to prevent abuse of the process.

DWDV appreciates and respects that there is a diverse range of views on voluntary assisted dying.

However, we have drawn a line in the sand that we believe is fair, reasonable, responsible and, most importantly, safe.

### 2.4 DWDV does not support

- Assisted death for individuals who are not suffering a terminal or advanced incurable illness causing intolerable, unrelievable suffering, nor for people who are incapable of rationally and persistently requesting assistance.
- A publicly available 'peaceful pill'.
- A 'DIY' approach to dealing with end of life issues.

**Dying With Dignity Victoria has no connection with Dr Philip Nitschke or Exit International.**

## 2.5 Current law and its ill effects

Under existing law it is not an offence to commit suicide. However, it is an offence to assist a person to commit suicide. Heavy penalties apply for those doing so, including imprisonment. There is also potentially a legal risk for others in merely being present at the person's death. There is currently no lawful process that allows a sufferer with no reasonable chance of recovery to voluntarily end their life in a humane and dignified manner. The ill effects of the current law include:

- Terminally or incurably ill people may suffer physically, mentally, emotionally, or existentially in a needless way. Despite very high palliative care standards in Australia, palliative care cannot always alleviate agonising symptoms.
- Some terminally ill people attempt to end their life in violent and undignified ways, which may result in major physical and psychological damage to those people if unsuccessful, as well as to their family, friends and the community whether or not the attempt succeeds.
- Anyone who attends the planned suicide of a terminally ill person may be liable to prosecution under criminal charges. So the terminally ill person must end their life in isolation rather than with the loving support of family and friends.
- Any medical practitioner (or other person) who assists a terminally ill person to end their life in a humane way is liable to criminal prosecution.
- Individuals and groups frustrated with the current state of the law and legislative inaction are seeking alternative 'remedies', such as illegally importing lethal drugs and publishing information on means of suicide – which may fall into the hands of psychologically vulnerable people (children, teenagers or the clinically depressed) who could use it to end their life instead of seeking and receiving appropriate and effective medical help. Once the information is in the public domain, it cannot be recalled. This is a development that cannot be withdrawn or corrected by further legislation.

These are all matters that any future legislation should consider and redress.

## 2.6 DWDV's recommendations for end of life choices

### Definitions

**Sufferer:** A mentally competent adult who has a terminal or incurable illness that creates intolerable suffering which cannot be relieved or treated in a manner acceptable to that person.

**Medical Assistance:** Doctor-supplied medication that provides ongoing palliation and may be used by the Sufferer to hasten their death, in which event the medication must be voluntarily consumed by the Sufferer.

Our recommendations for future legislation are that:

- a. A Sufferer who is mentally competent, may document the circumstances under which they wish to voluntarily die in a peaceful and humane manner with Medical Assistance, and receive that assistance. The request must be unwavering.
- b. A Sufferer who is not currently mentally competent may via an advance healthcare directive made under prior mental competence, specify the refusal of any and all medical procedures (including artificial feeding and hydration) in order to die. Palliative care must still be offered during this process. Advance healthcare directives are to be protected by statute.
- c. Two medical practitioners must be involved in responding to a Sufferer's request for Medical Assistance to die voluntarily, and in the decision-making process of granting assistance.



- d. In the case of a Sufferer who has an incurable illness that creates intolerable, unrelievable suffering but is not in its terminal phase, a psychiatric assessment must be conducted in response to a request for Medical Assistance to die voluntarily, and any identified depression treated prior to any decision being made in regard to VAD.
- e. In the case of a Sufferer whose illness is in its terminal phase and is creating intolerable, unrelievable suffering, mandatory psychiatric assessment is unnecessary, with the need for psychiatric assessment to be judged by the medical practitioners involved.
- f. Regulations shall be developed regarding the prescription and administration of the medication required for VAD.
- g. The primary medical practitioner shall prescribe medication for self-administration at a time and place of the Sufferer's choosing. The Sufferer and immediate family and/or carers must be properly counselled in the administration of the medication in compliance with the Regulations (see point f.).
- h. If the Sufferer is unable to self-administer, then the doctor may assist in accordance with the procedures and safeguards specified in the Regulations.
- i. The doctor and any other persons present at the Sufferer's death, whether assisting or not, shall not be subject to legal or disciplinary prosecution.
- j. Any medically-assisted death shall be conducted in privacy, with uninvited or unauthorised parties prevented from entering.
- k. Should a Sufferer subsequently lose mental competence, their advance healthcare directive(s) cannot be challenged, cancelled or altered by relatives or health care professionals; but may be so by an individual or authority to whom or which the Sufferer has assigned Enduring Power of Attorney (Medical Treatment).
- l. Any doctor or other health care professional who does not wish to participate in a medically assisted death shall not be required or compelled to participate or be present.
- m. Training shall be offered to doctors regarding the prescription and administration of required medication, and the processes and responsibilities enshrined in the legislation and specified in the Regulations.
- n. Consideration shall be given to instituting a project similar to the Netherlands SCEN (Support and Consultation on Euthanasia) whereby general practitioners (GPs) '*receive training in formal consultation and in giving expert advice to colleagues who have questions about euthanasia and physician-assisted suicide*' – see <http://www.ncbi.nlm.nih.gov/pubmed/15276315>.

## 2.7 Specific exclusions

DWDV's legislative charter specifically does **not** include or support the following:

- Assisting the death of babies, infants or young children, or any adult who has lost mental competence.
- Assisting the death of a person who is psychologically disturbed and wants to die, in the absence of a terminal or advanced-stage incurable illness with intolerable and unrelievable suffering.
- Assisting the death of 'inconvenient' persons in any way or under any circumstances. An assisted death must always be the mentally competent and legally documented choice of the Sufferer alone.
- Requiring or forcing any health care professional to participate in, support or allow assisted deaths
- Promoting 'do-it-yourself' death formulae in the public domain.

## 2.8 Safeguards – some recommendations

Various safeguards are implicit in the preceding discussion. The following is a more explicit set of recommendations.

- Requests for voluntary assisted dying (VAD) only to be considered from competent adults with a terminal illness or intolerable and unrelievable suffering.
- The patient to make at least two separate requests.
- Two medical practitioners to be involved in assessment and approval, with referral to a psychiatrist if clinical depression is suspected.
- Both doctors to carefully assess the voluntary nature of the request and the capacity or competence of the person making the request, and ensure that the request is not made under duress.
- The request and all assessment and approval processes to be documented and signed by all parties.
- The prescription and administration of medications required for VAD to comply with Regulations (to be put in place).
- All deaths under VAD legislation to be recorded on the death certificate as due to the disease underlying the request, but with notation that assistance in dying was provided.
- A register of applications, approvals and resulting deaths to be maintained by the Victorian Department of Health.

## 2.9 The *Medical Treatment Act* – relationship to new legislation

DWDV is aware of the concurrent review of the *Medical Treatment Act 1988* (MTA) and wishes to ensure that key patient rights stated in that Act are enforced and that the MTA is referenced in any legislation recommended consequent to this Inquiry – specifically, the rights of an individual to:

- Refuse unwanted medical treatment generally or of a particular kind for a current condition.
- Receive maximum relief from pain and suffering.
- Signify their wishes in regards to medical care.
- Be protected against medical trespass.
- Be accorded each of these rights even if unable to communicate, through the advocacy of a legally appointed agent or guardian holding Enduring Power Of Attorney (Medical Treatment).

## 2.10 Legal status for Advance Healthcare Directives

DWDV has for many years provided a variety of Advance Healthcare Directive forms to members and to the public. These have been developed over time from shared experience and with close knowledge of key medical decision making points and the healthcare system. Workshops are conducted which encourage participants to consider their instructions carefully and to discuss them freely with family and carers. There is clear evidence that people do not undertake the completion of these documents lightly; they feel strongly about their right to make decisions about their future care and about the need for those decisions to be treated with respect by all involved parties.

DWDV strongly advocates that the recommendations made in Chapter 11 of the Victorian Law Reform Commission (VLRC) 2012 *Guardianship - Final Report 24* regarding advance care planning and instructional health care directives be acted upon. Primarily, the legal validity of advance care planning and instructional health care directives must be made clear and binding, and not compromised in any legislation consequent to this Inquiry, and in amendments made accordingly in other relevant legislation.

**For particular reference in VLRC 2012:**

- *Instructional directives*: **Recommendation 134.**
- *Scope of instructional health care directives*: **Recommendation 141.**
- *Enforceability of an instructional health care directive*: **Recommendations 150 and 151.**
- *Offence of medical trespass*: **Recommendation 152.**

## 3:

# The reality of modern dying

## 3.1 Changes in the manner of dying

Dying has always been associated with suffering and distress. Throughout history, doctors have been associated with efforts to relieve this suffering, and this has commonly involved hastening of death. In previous centuries, when there were few effective drugs, infection was common, death was often quick, and morphine was the commonly utilised drug. Sir William Osler, a famed Canadian physician who is frequently described as ‘the father of modern medicine’, said in 1904, that it was a ‘doctor’s duty to ease death’. Most people died at home and the family doctor was the agent.

The 20<sup>th</sup> century saw a revolution in public health and medical treatment, and a dramatic change in the manner of dying. We now die slowly of cancer, heart disease, and organ failure (heart, lungs, liver, kidney and nervous system). Although 80% wish to die at home, only 15% do so, because dying has become such a prolonged process. We live longer, often into old age with the accumulated burdens of blindness, deafness, immobility, incontinence, and cognitive failure. Up to 30% of us die in institutional aged care.

Medicine has endeavoured to keep us alive as long as possible, commonly without asking us what we want, although thankfully this is beginning to change. People can refuse treatment, if they are aware of the right, but their wishes are often ignored. Dying has become highly medicalised, and patient choice minimal.

## 3.2 How do people die today?

**First, in hospital**, commonly after a period in intensive care and withdrawal of failed treatment, followed by palliative drugs. Some experienced intensive-care physicians (Profs Hillman, Saul and Corke) have railed against the futility of much of this treatment. If a patient is deemed not likely to recover enough to go home, they will either be moved to palliative care if they have cancer, or to institutional care for a chronic illness. Care of such patients now at home is diminished by the rarity of medical visits to the home.

**Second, in palliative care**, the symptoms of cancer patients are relieved by analgesia and sedation where those patients can clearly be seen to be dying and suffering. But prolonged dying in hospice is difficult and often transfer to high-care in institutions occurs. The dying process in palliative care is strictly controlled by the physician.

**Third, in aged care institutions**, people die slowly, with intermittent acute trips to hospital because doctors will not visit for acute symptoms (pain, breathlessness, collapse). Medical visits are infrequent, nursing is minimal and care is variable. Unrelieved pain is notoriously common. Dr John Vanlint wrote: *‘I have worked in a residential aged-care facility for the past 9 years and the incidence of non-cancer chronic pain is high – possibly around 60% of our residents over 75 are affected’*. Palliative care visits are insufficient. Many find these tragic places to end their lives – they have no control over their environment or their dying.

**Fourth, at home**, where some GPs with a strong relationship with a patient may still provide care to allow this preferred option to occur. This has traditionally been by the use of morphine, but it is now realised that this is not an effective medication for the common ‘terminal restlessness’ of dying patients, and is the reason why palliative care adopted sedation in the late 1980s.

### 3.3 Where do people die, and where do they want to die?

A study of over 2000 patients showed that 70% wished to die at home, 19% in hospital, 10% in hospice and 0.8% in a nursing home.<sup>1</sup>

Where do people actually die? Only 14% die at home, and more than 30% die in nursing homes. They do not do this by choice, but by default. One in four cancer deaths in people over 50 were in nursing homes.

### 3.4 Symptoms associated with dying

The medical literature details the following physical symptoms as associated with dying from cancer, cardiac and respiratory failure, diabetes, stroke and arthritis<sup>2</sup>:

- Pain – 48-76%
- Shortness of breath – 50%
- Fatigue – 83%
- Nausea and vomiting – 25%
- Loss of appetite – 63%
- Constipation – 40%

The incidence of distressing symptoms is consistently rated higher by patients than by carers.

In addition there are the severe psychological symptoms of anxiety, depression, confusion, inability to concentrate, loss of cognition, and communication. Other profound symptoms such as loss of mobility, paralysis, loss of continence of bladder and bowel, ulceration, and odour, and severe abdominal swelling are disastrous. McPherson et al. found that *'self-perceived burden is reported as a significant problem by 19-65% of terminally ill patients. It is correlated with loss of dignity, suffering and a 'bad death'*.<sup>3</sup>

While treatment may have some valuable impact on pain, breathlessness and vomiting, most of the other symptoms can be little mitigated. It is not surprising that many patients request a hastened death.

Roger Hunt found 25% of his palliative patients wished for a quicker death<sup>4</sup>. McCarthy and Addington-Hall found 23% of patients dying from heart disease had expressed a wish to die sooner<sup>5</sup>. Seale and Addington-Hall found that 26% of patients in hospice had wanted an earlier death<sup>6</sup>. They did not find support for the view that requests for euthanasia are uncommon in hospice.

### 3.5 Suffering is not confined to the terminal stage of a terminal illness

It is very important to realise that intolerable and unrelievable suffering is not confined to the terminal phase of a terminal illness (defined as *'the phase of an illness reached when there is no real prospect of recovery or remission of symptoms, on either a temporary or permanent basis'* – from the *South Australian Consent to Medical Treatment and Palliative Care Act 1995*). Even greater suffering can occur (because it can exist for so much longer) in chronic advanced incurable illness (defined as *'a severe permanent illness, with no predictable timeframe to death, which causes significant unremitting symptoms, and no effective treatment is available to alter the course of the illness, or to relieve the intolerable suffering. Its course may be either remorseless and progressive, or static'*). Such conditions as multiple sclerosis, motor neurone disease, Parkinson's Disease, quadriplegia, profound stroke, slowly progressive cardiac, respiratory, kidney and liver failure, and chronic unrelenting arthritis and spinal disease, can all make life unbearable and lead to rational requests for assistance to die. These circumstances need very careful assessment, particularly of the mental state; depression should be recognised and treated if possible, but is not a barrier to rational and competent decisions.

### 3.6 Reasons for requesting a hastened death

Kohlwes stated that the primary reasons for requests for assisted dying were physical symptoms, psychological issues and existential suffering, the most common cause of durable requests being existential suffering<sup>7</sup>. This included a sense of being a burden. He describes a professional code of silence, of difficulty in discussing this with other physicians. Wilson wrote: *'It is not necessarily physical distress that motivates desire to hasten death'*<sup>8</sup>. *Rather the psychological and existential dimensions of suffering – which are perhaps no less central to determining quality of life - also emerge as important reasons behind patient requests for physician assisted death'*. Jean-Jacques Georges wrote: *'Loss of dignity is tightly related to a feeling of hopeless suffering. Preserving one's dignity appears to be very important for patients and largely contributes to requests for hastening death'*<sup>9</sup>. Loss of control was equally important.

While illness and its physical symptoms are the overt cause of suffering, the psychological and existential dimensions of suffering are clearly of enormous importance, and exceedingly difficult to change.

### 3.7 Facts about modern dying

- Dying may be associated with intolerable suffering which may rise to a crescendo as death approaches.
- Palliative care cannot relieve all the pain and suffering associated with dying.
- Some suffering will only be relieved by death.
- People do make rational and persistent requests for a hastened death.
- Doctors have a duty to relieve suffering.
- Doctors have a duty to respect their patient's autonomy.
- The provision of control over the end of life is one of the most profound palliatives available.

It is clear that doctors may be faced with the necessity to hasten death in order to relieve suffering, and that their patients may substantiate that necessity by genuine, rational requests for such assistance, which should be respected.

The Australian Medical Association *Code of Ethics* implicitly acknowledges these truths in its statement on (1.4) 'The dying patient' :

- (a) *Remember the obligation to preserve life, but, where death is deemed to be imminent and where curative and life-prolonging treatment appears to be futile, try to ensure that death occurs with dignity and comfort.*
- (b) *Respect the patient's autonomy regarding management of their medical condition, including refusal of treatment.*

### 3.8 The prime importance of control

There are numerous references in the medical/palliative literature of the importance of control by the patient (see above). Medical professor Peter Singer and colleagues<sup>10</sup> cited the following five critical aspects to quality end-of-life care:

- (i) *adequate pain and symptom management*
- (ii) *avoiding inappropriate prolongation of dying*
- (iii) *achieving a sense of control*
- (iv) *strengthening relationships with loved ones*
- (v) *relieving burden.*

Having autonomy respected, achieving control, and having choice are intimately related.

Australian palliative care doctor John Zalcberg has stated: *'it is important to remember that patients decide about quality of life – not relatives, not doctors, not nurses'*<sup>11</sup>. Douglas Martin asserted that *'the principle of autonomy is the dominant ethic of health care in North America and Western Europe [and Australia]'*<sup>12</sup>.

The recent Grattan Institute report *Dying Well* listed ten important principles, six of which related to control.

The ultimate control for patients dying with intolerable suffering is the provision of oral medication which they can take to end their lives and their suffering, or not, depending on their need and their own decision. In Oregon, the legal provision of such control led to the drug not being used to end life in 30% of instances.

### 3.9 The process of assisted dying by oral means

The doctor's role is confined to the assessment of the criteria for assistance under the law, the provision of medication and subsequent support.

The decision as to when, where, or if the medication will be taken lies with the patient. This is an essential safeguard against the possibility of abuse. The responsibility for this decision and action lies entirely within the control of the person wanting to die. Death will not occur unless the suffering person makes that determination.

Death usually occurs at home. The patient can gather around them those people they wish to be present to share their death and to say goodbye. It is typically a calm, warm, loving process. The doctor can be present if requested by the patient and/or family, but is not essential to the process, which has the advantage of facilitating a non-medicalised death.

The patient takes the liquid medication by mouth, and drifts into a deep sleep, usually after about three to four minutes. Breathing becomes gradually slower until death occurs after ten to twenty minutes. The process is very calm, peaceful and dignified. It is in marked contrast to the slow induction of coma and prolonged dying that commonly occurs in palliative care.

### 3.10 The current reality of dying in our community

- There is no data available in our community to understand how people die (unlike in the Netherlands, Belgium and Oregon, where regular audits are conducted).
- Doctors do help their patients to die but do it in covert ways. Doctors, patients, and families are loath to talk about such matters for fear of prosecution.
- The assistance provided by doctors is entirely arbitrary, depending on the patient's disease, the patient's circumstances (home or institution), the security in relation to other persons (family, carers), and the courage of the doctor who may be prepared to take a risk on behalf of his patient.
- Fear of prosecution inhibits many doctors from action which they feel may be perfectly justified. Although the risk of prosecution may be minimal (the doctor can always claim intention to relieve suffering), it only takes one person to make a complaint and the doctor's career is in jeopardy. This occurred in Britain to Dr Nigel Cox, who openly hastened the death of his patient in hospital, at the request of patient and family and with the acceptance of doctors and nurses present. One nurse, returning to duty, duly made a complaint and Cox was prosecuted and convicted for attempted murder. No wonder doctors are extremely cautious. As Senior Counsel Richard McGarvie said, *'as the law stands, only the good sense of prosecuting authorities and juries stands between compassionate and courageous medical practitioners and convictions for murder'*. There is also



lack of clarity as to the application of ‘aiding and abetting suicide’ in the medical context. The lack of clarity in our law is grossly unfair to patients and doctors alike – neither are protected.

- As a result of a lack of legal protection of doctors, many patients take matters into their own hands. Many failures using combinations of prescription drugs occur. Some are successful in lonely circumstances, because people are extremely fearful that their loved ones may be prosecuted if present. Other violent deaths occur due to lack of peaceful means. The incidence of suicide in the elderly is greater than in youth, and many of these suicides are by people with terminal or incurable illnesses.
- Many people are now importing Nembutal into Australia from overseas internet sites. This is extremely dangerous. These drugs may be taken under circumstances devoid of any medical supervision or advice, yet people suffering from treatable depression have acquired and taken such drugs. Drugs of this type are an uncontrolled menace in the community, but otherwise law-abiding people acquire them in order to gain a sense of control which the absence of law denies them.
- The office of the State Coroner is a source of information regarding ‘rational suicide’ (where a person with intolerable and unrelievable suffering takes action to end their own life). The South Australian Coroner (Mark Johns), in correspondence with Marshall Perron (a former Chief Minister of the Northern Territory, who introduced the *Rights of the Terminally Ill Act*), acknowledged the concept of rational suicide and its occurrence from his own experience. He stated *‘the fact of the matter is that this is a subject for politicians who are quite capable of ascertaining the facts and publishing them in the parliament if they wish to do so. ... Any politician who cared to enquire of any coroner could quickly become acquainted with at least an anecdotal idea of the extent of the issue. There are avenues available to politicians such as Parliamentary Select Committees at which this information could be obtained’*.
- The Office of Public Prosecutions also almost certainly has information regarding theoretical breaches of the Crimes Act in relation to medical end-of-life matters. Its processes as to dealing with such matters are closed, which leaves doctors and the community without any guidance. In the United Kingdom in 2011, the last act of the Law Lords was to direct the Director of Public Prosecutions (DPP) to issue guidelines as to the principles involved in bringing charges in relation to aiding and abetting suicide, which provided some security to the community in such matters.

**DWDV advocates that both the State Coroner and the DPP be called to the Inquiry to provide information.**

### 3.11 Serious defects in the practice of end-of-life medicine

- Doctors have a lack of knowledge of and familiarity with the Medical Treatment Act.
- Many hospitals do not record details of patients’ medical Enduring Power of Attorney
- Patients are not asked about Advance Healthcare Directives, and such documents are often not placed in patient’s records.
- The Victorian Law does not yet, despite the recommendations of the Victorian Law Reform Commission, legally recognise Advance Healthcare Directives.
- Relatives are under the mistaken belief that simply being present when a terminally ill person ends their life is a crime. This is clearly not so, and the Office of Public Prosecutions could readily clarify this matter. It is another example where lack of clarity in the law creates fear and has a serious impact on how people die.



- Similarly, fear, associated with the lack of clarity in the criminal law, inhibits many doctors from providing assistance, which they feel is eminently justified, to their patients. Institutions are also fearful of being sued.

Patients, doctors, nurses and institutions seem to be largely unaware that competent patients have a legal right to refuse food and fluid, and that the courts do not consider such requests as suicidal, and that doctors have the same responsibility to provide palliation in such circumstances as for any other dying person (Kourakis J, *H Ltd v J and Anor*, 2010, SASC 176). The Royal Dutch Medical Association has recently issued comprehensive guidelines for the ethical management of voluntary refusal of food and fluids. (Guidelines available on request.)

- Nevertheless it is tragic that patients should have to consider making such requests because they cannot receive assistance to die in any other way (White, Wilmot and Savulescu, 2014)<sup>13</sup>.

### 3.12 References

- <sup>1</sup> Linda Foreman et al., *Palliative Medicine*, 2006:20;447
- <sup>2</sup> M Klinkenberg et al., *Journal of Pain and Symptom Management*, (JPSM) 2004:27;5
- <sup>3</sup> C J McPherson et al., *Palliative Medicine*, 2007:21;115
- <sup>4</sup> Roger Hunt et al. *Palliative Medicine*, 1995:9;167
- <sup>5</sup> M McCarthy & J Addington-Hall, *Journal of Pain and Symptom Management*, 1997:90;128
- <sup>6</sup> C Seale & J Addington-Hall, *Social Science and Medicine*, 1995:40;587
- <sup>7</sup> R J Kohlwes et al., *Archives of Internal Medicine*, 2001:161;657
- <sup>8</sup> K G Wilson et al., *Archives of Internal Medicine*, 2000:160;2454
- <sup>9</sup> J-J Georges et al., *JPSM* 2006:31:100
- <sup>10</sup> P Singer et al., *Journal of the American Medical Association*, 1999:281;163
- <sup>11</sup> J Zalcborg, *Melbourne Observer*, 19/1/1996
- <sup>12</sup> D Martin et al., *Lancet* 2000:356;1672
- <sup>13</sup> B White, L.Wilmot & J Savulescu, *Journal of Law and Medicine*, 2014:22;376

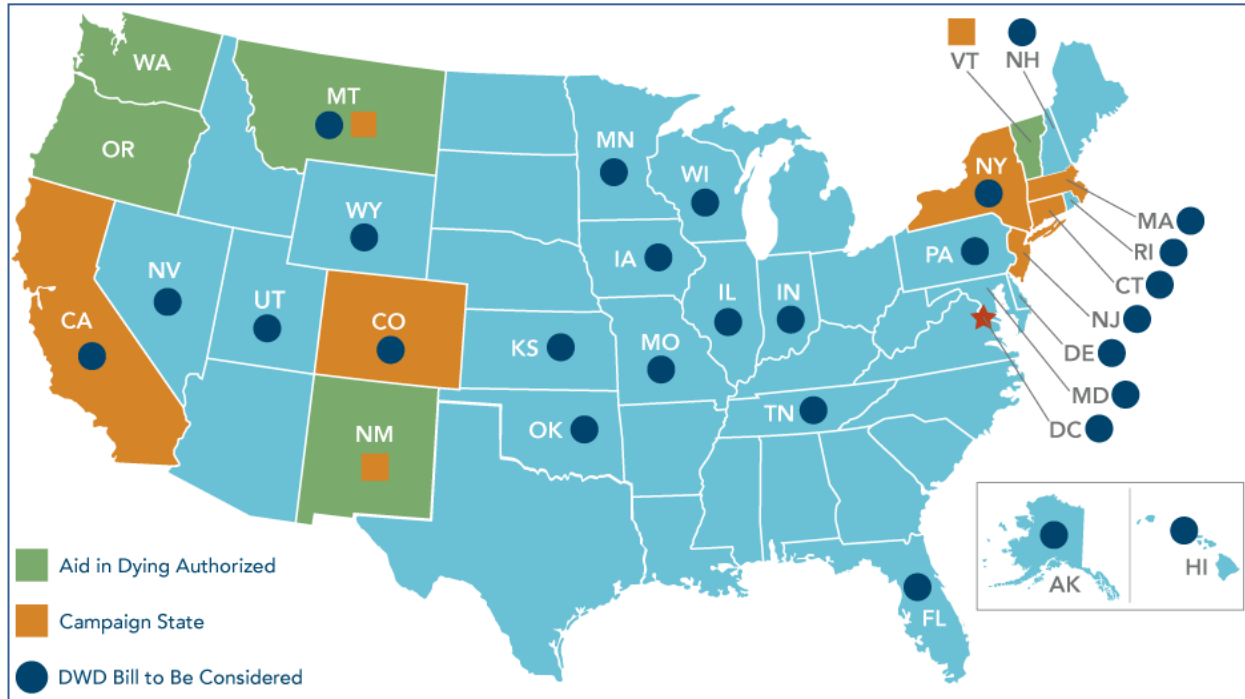
### 3.13 Surveys of doctors' attitudes to euthanasia

- In 1988, Kuhse and Singer reported the results of a survey of 869 Victorian doctors – 62% answered yes to the question 'Do you think it is sometimes right for a doctor to take active steps to bring about the death of a patient who has requested the doctor to do this?' (64% of Australian Medical Association (AMA) members polled said yes.) 93% thought such a request could be rational, 59% thought that practice similar to that in the Netherlands should be allowed, and 52% of AMA members thought that the AMA should change its stance on the issue. (*Medical Journal of Australia (MJA)*, 1988:148;623)
- In 1993, Weston surveyed 381 South Australian doctors and reported that 57% favoured the introduction of a law allowing practice similar to that in the Netherlands. (*MJA*, 1993:158;292)
- In 1994, Baume and O'Malley surveyed 1,268 New South Wales doctors – 59% thought actively hastening death on request was sometimes right; 96% thought such a request could be rational; 59% thought Netherlands practice should be allowed, and 52% thought their professional organization should approve medically assisted dying. (*MJA*, 1994:161;137)

- In 1994, Stevens and Hassan surveyed 298 South Australian doctors – 89% thought a request to hasten death could be rational, and 47% were in favour of legalization of voluntary euthanasia. (*Journal of Medical Ethics*, 1994:20;41)
- In 1997, the Royal Australian College of General Practitioners (RACGP) published its survey of 886 members. 45% personally wished to have the option of voluntary euthanasia. 56% would not be distressed if it were available to others, whilst 68% believed that euthanasia can be an act of caring. 45% did not believe that ‘present arrangements are adequate in delivering help to the dying’. (*Australian Family Physician*, 1997:26;399)
- In 1998, Cartwright et al. published their survey of 174 Northern Territory doctors and found that 53% approved of the *Rights of the Terminally Ill Act* that allowed active medical assistance in dying on request. (Report from Queensland and NT University)
- In 1997, Kuhse et al. published their survey of Australian end-of-life decisions (comparable to the Dutch Rummelink studies). From this survey of 1,918 Australian doctors, they estimated that 1.8% of deaths were by VE or physician assisted suicide, and 3.5% of deaths involved termination of the patient’s life without explicit request; in 24.7% treatment was withheld or withdrawn with the intention to hasten death, whilst in 6.5% of deaths opioids were administered with at least the partial intent to hasten death. They found that 36% thought a doctor should be allowed by law to assist a terminally ill person to die. (*MJA*, 1997:166;191)
- In 2001, Douglas et al. reported a survey of 683 Australian surgeons, revealing that 36% prescribed drugs for the relief of a patient suffering with the intention of hastening death, and more than half did so without explicit request from the patient. 54% believed that it was morally acceptable in some circumstances to hasten death to relieve suffering. (*MJA*, 2001: 175;508)
- In 2007, Neil et al. reported a survey of 854 Victorian doctors. 53% of these doctors supported the legalisation of voluntary euthanasia. Of doctors who had experienced requests from patients to hasten death, 35% had administered drugs with the intention of hastening death. (*Journal of Medical Ethics*, 2007:33;721).
- There have not been more recent studies of Australian doctors.
- Since the 2015 Canadian Supreme Court decision protecting patients’ rights to an assisted death, the Canadian Medical Association has announced a neutral position in the matter, stating that it is for the doctor and his conscience to determine in relation to the law. Its president, Luther Cobb stated: *‘as physicians we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we’ve made and the world-class hospice and palliative care we can provide, it isn’t always enough’*.
- Further, in response to legislative debate on a Bill before the Californian legislature, the Californian Medical Association has also moved to a neutral position on the same basis.
- In 2013, the National Council of the French College of Physicians supported a survey of French doctors of which 60% were in favour of ‘*assisted death*’ in cases where a patient is suffering prolonged and uncontrollable physical or psychological pain. Doctors described such action as a ‘*duty to humanity*’, and the appropriate response was ‘*suitable deep and continuous sedation*’. This may have been suitable for the doctors – what about their patients? The French government moved to legalise such practice in 2015.
- In 2014, a Medscape survey in USA surveyed 21,000 US doctors and found that 54% favoured ‘aid in dying’ (the phrase used for assisted dying in Oregon) – they supported the rights of patients with an *incurable* illness to seek a dignified death. The same question in 2010 had 46% support.

- Since the publication of this poll, and the death of young Californian woman Brittany Maynard (suffering from an inoperable brain tumour) after taking legal Nembutal in Oregon, **more than twenty American states are considering introducing Dying with Dignity legislation (see map).**

#### Current status of VAD legislation in USA



Source: <http://www.compassionandchoices.org/what-you-can-do/in-your-state/>

## 4:

# Current palliative care limitations

*A paper by Dr Rodney Syme, Vice President of Dying With Dignity Victoria*

### 4.1 Palliative care – a critique

From humble beginnings, due to the compassion and energy of Cicely Saunders, palliative care has grown from a single London hospice to a world-wide specialty with strong government support. It is one of the most important developments in modern medicine. It aims to provide compassionate and holistic care for the terminally ill.

However, examination of the at least 27 journals devoted to research into palliative care reveals an intuitively obvious conclusion – that ethical research in this area is obstructed by a constantly moving target, making accurate statistical analysis virtually impossible. Despite the impression that most patients benefit from their hospice care, it has been exceedingly difficult to demonstrate any objective benefits for such care. Yet this sheer volume of research gives an appearance of scientific validity to the specialty. We constantly hear of the tremendous advances in palliative care. Governments constantly say that there is no need to revise laws on assisted dying, because palliative care deals with all those problems very effectively.

What is the response from palliative care to this rhetoric? Only to confirm that it deals very effectively with pain in the terminal patient. There is no public discussion of how this terminal pain, or other suffering, is relieved. Any public discussion of other aspects of suffering is consistently evaded.

Careful examination of this literature reveals the extent of suffering in the terminally ill, and the difficulty in measuring and relieving it. The inordinate focus on the successful relief of pain is contested by Australia's most eminent pain specialist, Professor Michael Cousins, who said in 2010 that ten per cent of cancer pain was so difficult to treat at the end of life that some patients were given drugs to sedate them to unconsciousness, culminating in death over several days to a week. The Australian Government *Palliative Care Outcomes Collaboration Study* (October 2014) records that only just over 50% of patients with moderate to severe pain become pain-free.

But breathlessness, cachexia, (wasting, weakness, immobility, dependence), anorexia, nausea and vomiting, incontinence, ulceration, discharge and odour are common, far more difficult to palliate, and all impact on dignity. And this does not begin to address psychological, social and existential suffering, described by Francis Norwood<sup>1</sup> as 'social death'. For an erudite discussion of medical suffering, read Eric Cassell<sup>2</sup>.

It is not surprising that palliative care does not entirely succeed with the palliation of suffering. It is a monumental task, in light of these further facts: first, that intolerable and unrelievable suffering is common in terminally ill persons, and often escalates as death approaches; and second, that some suffering is only relieved by death.

Dr Nathan Cherny<sup>3</sup> wrote: *'The period leading to death is characterized by increasing prevalence and severity of a multitude of physical, psychological, existential and social problems. There is an ethical imperative to offer care and provide adequate relief of suffering. There is an overwhelming obligation to optimize comfort until death ensues'*.

It is an especially difficult task when it is maintained, as a matter of integral philosophy, that palliative care does not hasten death; and the battle is against a constantly accelerating target, using a relatively poor tool kit. As evidence of the latter, a recent paper by Rowett and Currow <sup>4</sup> states:

*'Patients receiving palliative care are at high risk of adverse effects from drugs. As these effects can be difficult to distinguish from the symptoms of the terminal illness, harm from medicines is often not recognised. Adverse effects contribute to the burden of symptoms at a time when good control of symptoms is paramount. Adding another drug to treat the adverse effects can compound the problem'.*

This paper effectively indicates that, even 50 years after the establishment of palliative care, a level of experimentation goes on in treating terminally ill patients.

A candid comment on palliative care was made in 1998 by palliative care physician Michael Barbato <sup>5</sup>:  
*'... he prepared for his death, he died in his own bed after saying goodbye to his wife and family. It was one of those deaths that we in palliative care hope to see but rarely do'.*

Larry Librach <sup>6</sup>, palliative care physician for 30 years at Toronto's Mount Sinai Hospital, has said: *'There's a group of people who are very rational and very reasoned and who are suffering immeasurably and still want that option, of assisted suicide, and it's becoming less clear to me that we can refuse these people that option. ... We used to say that palliative care would relieve all suffering, but that, of course, is nonsense. I've seen too much suffering to be glib about it any more'.*

## 4.2 Terminal sedation – 'slow euthanasia'

Palliative Care Australia acknowledged in 2008 <sup>7</sup> that it could not relieve all pain and suffering, even with optimal care, but it was being a little disingenuous because it did not disclose its trump card, terminal sedation. In the 1980s the Graseby pump was developed, and Midazolam became available, which was compatible with morphine in a common syringe. First reported in 1988 by De Sousa and Jepson <sup>8</sup> for 'terminal restlessness', terminal sedation was described by Burke et al. <sup>9</sup> as providing 'a readily available means of controlling symptoms and overcoming patient distress where no feasible alternative existed previously'. In 1990, Ventafridda <sup>10</sup> reported its use in 52% of palliative outpatients, to howls of anguish from others who stated they never, or very rarely, did so. Billings and Block <sup>11</sup> described it as 'slow euthanasia' to more howls of dissent. They famously defined 'slow euthanasia' as 'the clinical practice of treating a terminally ill patient in a fashion that will assuredly lead to a comfortable death, but not too quickly', and included terminal sedation in this definition. They were challenging the soft defence of intention, and focusing on outcome. They also asked 'Why should a patient who requests a quick death be subjected to a slow dying?'

Its use has subsequently expanded to refractory pain, breathlessness, and extreme fatigue, psychological and existential distress. It is very clear that palliative care has the tools to relieve any intolerable suffering, but I have never heard or seen this made evident to the public. It remains the 'Achilles heel' of palliative care because it is used in exactly those circumstances where other doctors might provide assisted dying if they were asked. And this very process is only associated with patient consent in up to 50 per cent of deaths, with no opportunity to say goodbye.

Far from acknowledging terminal sedation, the palliative care industry has been assiduously arguing that neither it nor morphine alone, if used in a proper palliative way, ever hastens death. Terminal sedation is justified for the treatment of 'refractory' or 'intractable' symptoms, as determined by the clinician, not the patient. Maltoni and colleagues <sup>12</sup> stated that *'Despite the huge progress made in palliative medicine in terms of symptom control, many are intractable symptoms, either because the treatment is ineffective or because the treatment itself is intolerable'.*

However, in order to demonstrate that hastening of death is not the intention, the treatment is slowly titrated to a level where consciousness is suppressed, and thus, in association with withdrawal of hydration, death inevitably follows. Surely one might suppose that if symptoms were intractable and death clearly imminent, there would be an imperative to provide maximal relief of any pain and suffering as soon as possible? But no, even though in law there is no problem with hastening death if the intent is to relieve suffering (Devlin in *R v Adams*, Victorian Medical Treatment Act), titration is obligatory under the ‘palliative model of care’ – so that suffering continues until unconsciousness ensues, which may take days. And this occurs despite senior consultant Robert Twycross<sup>13</sup> stating ‘*nothing short of deep unconsciousness could provide relief*’ and that ‘*inadequate sedation makes matters worse*’. For a profound analysis of terminal sedation, read Professor Erich Loewy<sup>14</sup> who wrote: ‘*Terminal sedation, we would claim, differs from some form of voluntary active euthanasia mainly in that it has not been and is unlikely to be legally challenged*’.

Despite the availability of terminal sedation, eminent British geriatrician and ethicist Professor Raymond Tallis reports the opinion of a palliative care physician that 15 per cent of deaths are ‘bad deaths’, and that is the opinion of the doctor, not the patient. In a *Lancet* editorial, Janet Hardy<sup>15</sup> wrote: ‘*The concept of sedation causes considerable unease in many palliative care workers, most of whom are ardently opposed to any form of euthanasia or patient-assisted suicide. There is concern that sedation as the best means of symptom control in the dying patient is under-used because of fear of employing ‘terminal sedation’.*

Jessica Corner<sup>16</sup> has written in the *British Medical Journal*: ‘*The easing of death, as an intentional double effect, is common in palliative care and general practice. ... Palliative care needs to take the lead by making clear the strategies it employs for managing difficult situations at the end of life, and, when the double effect is used with a view that death is a likely and welcome secondary consequence, to be open about this*’.

Palliative Care Australia acknowledges that patients do make rational and persistent requests for a hastened death – Roger Hunt<sup>17</sup> found 25 per cent of his palliative care patients did so. Sociologists Seale and Addington-Hall<sup>18</sup> found that ‘*respondents for hospice patients are significantly more likely to feel that an earlier death would have been better*’. Yet Ben Rich<sup>19</sup> states that ‘*a prominent segment of the palliative care professional community ... almost without exception maintains that patients who receive state-of-the-art palliative care, including psychosocial and spiritual interventions, almost invariably cease and desist from their desire for a hastened death*’. Surprising? No – for who has all the power in such discussions? Could this not be seen as duress?

### 4.3 How Palliative Care responds to requests for hastened death

The American Academy of Hospice and Palliative Medicine issued guidelines on how to address patients who requested a hastened death. These state: ‘*when a patient requests assistance in hastening death, determine the nature of the request, clarify the causes of intractable suffering, evaluate the patient’s decision-making capacity, and explore emotional factors.*’ All good practice. But it goes on to state:

*... (i) respond empathetically; (ii) intensify treatment of pain and other physical symptoms; (iii) identify and treat depression, anxiety and/or spiritual suffering when present; (iv) consult with experts in spiritual or psychological suffering or other specialty areas; (v) utilize a caring and understanding approach to encourage dialogue and trust and to ensure the best chance of relieving distress; (vi) commit to the patient to work towards a mutually acceptable solution to the suffering. When unacceptable suffering persists [and we might ask how long this process of response has taken], despite thorough evaluation, and provision of standard palliative care interventions, a search for common ground is essential. The following alternatives should be considered –*



*discontinuation of life-prolonging treatment, or voluntary cessation of eating or drinking, or palliative sedation, even to unconsciousness, if suffering is intractable and of sufficient severity.'*

Note how, even though the response should be 'empathetic' (Palliative Care Australia uses 'respect'), any consideration of assistance with a hastened death is dismissed. The patient is treated as a moral and intellectual pygmy who is intrinsically unable to make careful and considered decisions, such as assessing the severity of their own suffering as intolerable. This clearly is a decision for the physician, who has all the power in reaching this 'acceptable solution'. The concept of reaching a 'mutually acceptable solution' should be rephrased as 'a solution acceptable to the physician', since the patient's own solution is off the table.

Consider the alternatives so reluctantly offered. They are all options in which death will take a significant time to occur, and this for a person whose suffering is already intolerable and intractable. Cessation of food and fluids may take five to ten days, deep sedation two to five days, and withdrawal of life-prolonging treatment (if it is an option at all) an indefinite period of time. They all require medical assistance to make these processes reasonable. Refusal of life-prolonging treatment almost always will be accompanied by increased suffering, the relief of which lies in the hands of the physician, who may or may not be willing to address this vigorously. Cessation of eating and drinking leads to death by dehydration, and requires good nursing care and medical palliation of any distressing symptoms with sedatives and analgesics. Some in Palliative Care find this support morally challenging, and are very reluctant to assist. In terminal sedation, discussed above, the rate of production of deep sedation and the depth of sedation is in the hands of the physician, and commonly does not provide adequate relief of intolerable suffering until two to four days have elapsed. It is arguable that, for a person who judges her suffering to be intolerable, and seeks a quick dignified death after saying goodbye to her family, none of these options is acceptable. But these are the only 'choices' in palliative care.

#### 4.4 Other specialist opinions

Martin Klein<sup>20</sup> asked: *'Does it really show more respect for the vulnerability and dependence of the dying patient to coerce them to receive palliative care?'*

The inherent 'goodness' of the enterprise, and the essentially closed nature of hospice, has allowed the rhetoric of palliative care to escape examination. As palliative care specialist Derek Doyle<sup>21</sup> wrote, *'a metaphorical halo shines over specialist palliative care and its practitioners with the result that some of its claims and assumptions have gone unchallenged by all but a few'.*

Palliative care specialist Fiona Randall<sup>22</sup> is one of those few.

She describes *'the inflated and often contradictory claims made in the literature of palliative care – its rhetoric ... which cannot, in reality, be enacted in clinical practice'*. The language of palliative care offers an *'impeccable'* assessment and treatment of pain and other symptoms, and *'exquisite'* and *'meticulous'* nursing care. Randall says *'This is embarrassing rhetoric'* and:

*Palliative medicine claims to alleviate emotional, psychological, social and spiritual suffering, in addition to physical symptoms. There is no other speciality which claims to do all these.*

*Moreover, palliative medicine claims to be able to alleviate these forms of distress and improve quality of life, even in the context of dying. Dying is generally perceived to be associated with great distress, yet in palliative care it is held that we can apparently achieve relief of symptoms, including those of a psychosocial and spiritual nature.*

*The goal of impeccable relief of pain and other symptoms is unachievable, and the expectations generated by the philosophy statement are unrealistic. Setting unachievable goals for one set of people and promoting unrealistic expectations which will not be met in another group of people is unfair to both and likely to lead to harm for both.*

Ben Rich<sup>19</sup> stated in 2014 that: *'Others have raised concerns about an authoritarian streak, or a form of hard paternalism, in the philosophy and practice of hospice. Those concerns denote a perception that some in the hospice movement maintain a rigid and monolithic view of death: one size fits all; it's the hospice way or the highway.'*

Sociologist Julia Lawton<sup>23</sup>, who was embedded in British palliative care for ten months, wrote: *'The research highlights the difficulties of matching modern hospice movement's ideological goal of enabling patients to 'live until they die' with the realities of the ways in which many patients, cared for in hospices, bodily degenerate in practice'*.

#### 4.5 The 'models' of care and of dying

Palliative care has been described as a 'model of care', which has become more and more defined and specialised, into which the patient must fit. The Liverpool Care Pathway was an example of such a model, but failed because it did not treat people as individuals and ask what care they wanted. It led to abuse of autonomy. We are all individuals, shaped by our own experience and values. For government to suggest that we should all fit into a specific 'model of care' is extraordinary.

Of even more concern, is the development of a 'model of dying' – the pump, morphine and midazolam (known in palliative care as 'M and M'), withdrawal of fluids, coma and then death. This is not what everyone wants.

#### 4.6 Religion – the elephant in the room

Ian Maddocks, the first Australian Professor of Palliative Medicine, has stated on ABC Radio that *'the roots of modern palliative care are of course to be found in religious orders concerned with the care of the dying'*, and that *'palliative care usually has adopted a confrontational position against voluntary euthanasia, partly because of the historical association with Christian (Catholic) concern to preserve life'*.

How may this Catholic philosophy impact on the delivery of palliative care?

Ellen McGee<sup>24</sup> wrote: *'Since its inception, hospice has seen itself as a moral enterprise; it shares a vision of what constitutes "good dying". This moral vision is unique in the secular health care field'*. Derek

Doyle<sup>25</sup> wrote: *'suffering is potentially creative'*. Suffering may also be thought to be redemptive. A nurse in a Catholic hospital said to the sister of a dying patient, who was complaining of her appalling condition, that she should be grateful that her sister had been *'chosen to share in the agony of Christ'*. A woman, dying of motor neurone disease in a Catholic hospice, was described by her daughter, a nurse, as having a *'cruel and horrible death'*; she was told that her mother could not be given more relief as *'the law did not allow it'*.

Associate Professor Alex Broom<sup>26</sup> spent six months embedded in a Catholic hospice, interviewing doctors, nurses and patients. He found an atmosphere of tension, with death in the air, a place of unbounded and hopeless bodies. Patients had a sense of impotence; they were subdued within the hospice's ideological frame, with a sense of entrapment.

He found among the patients virtually unanimous support for assisted dying, but the hospice was totally opposed. A desire for a hastened death was seen as a call for help; the patient *'just needed more time'* to adjust; their request was met by spiritual and social support. The assessment was that it was *'not his time to go'*. Assisted death was not part of hospice care, which had an ideological model of dying based on religious contexts.

He also found an underlying Catholic influence in the hospice; although it was a site of medical care, it had Christian underpinnings, and an interplay of religiosity which was rarely explicitly acknowledged. The care was precariously placed between care of the body and care of the soul.



Cardinal George Pell proudly states that 57 per cent of Australian palliative care is provided by the Catholic Church. There is no other area of Australian medical practice which is so dominated by a specific moral framework. There can be no doubt that the religious origins of palliative care and this religious dominance in its provision has a profound effect on how people die.

Palliative Medicine Professor Sam Ahmedzai<sup>27</sup>, a critic of voluntary euthanasia but a supporter of assisted suicide, wrote:

*It is patronising to say that a few people should suffer unbearable distress and indignity because palliative care preaches that it values all lives – regardless of how meaningless they have become to their owners. It is inconsistent for palliative care to boast how it enables people to face the reality of dying and decide about place of care but then to deny choice for timing of death. Moreover, it is hypocritical to deny competent patients who are acknowledged to be dying, the right to die in a manner of their choosing, while allowing doctors and nurses to place them on a so called care pathway, which often entails increasing sedation and withdrawing fluids – unintentionally leading to a protracted form of assisted dying, but one that is medically determined.*

#### 4.7 Palliative care should encompass the VAD option

Consider the above in the light of some final self-evident truths. First, that a doctor has a duty to relieve suffering. Sir William Osler wrote over 100 years ago that a doctor's duty was to 'ease death'. Second, that a doctor has a duty to respect his patient's autonomy.

Given these fundamental ethical obligations, should a doctor, treating a patient with intolerable and unrelievable suffering who asks for assistance to die, simply offer refusal of treatment, or slowly progressive sedation, or the option of refusing food and fluids – as is suggested by the American Association of Hospice and Palliative Medicine?

Dying With Dignity Victoria is not opposed to palliative care. It supports the open and frank communication between dying patient and doctor, of supporting patients to go as far with their lives as possible, and encouraging the acceptance of the reality of dying. We applaud the maximal relief of pain and suffering, respect for patient autonomy, and encouraging dialogue between dying patient and family with the important object of allowing them to say goodbye – all good palliative principles. But we do not accept the rigid imposition of a particular model of care, and a limited choice at the end of life which condemns some people to die in a way that is anathema to them, in order to satisfy the moral view of their doctor.

American Supreme Court Justice Brennan wrote in his *Cruzan* judgement: '*dying is personal, and it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. A quiet proud death, bodily integrity intact, is a matter of extreme consequence*'.

It has been suggested that legislation for voluntary assisted dying would damage the development of palliative care. The 2011 *Report of the European Association of Palliative Care* stated:

*Palliative care is well developed in countries with legalised euthanasia/assisted suicide, or at least no less well developed than in other European countries. There is evidence of advancement of palliative care in countries with legalisation of euthanasia and/or assisted suicide. The idea that legalisation of euthanasia and/or assisted suicide might obstruct or halt palliative care development, thus seems unwarranted and is only expressed in commentaries rather than demonstrated by empirical evidence.*

## 4.8 Recommendations

DWDV recommends that:

- a. There be a more open and transparent acknowledgement of the limitations of palliative care.
- b. Doctors using more aggressive pain relief and sedation be protected by legislation to allow more effective palliation.
- c. Patients be routinely involved in consent to sedation.
- d. Hastening of death by sedation be reported so that its frequency can be evaluated.
- e. Home-based and aged care institutional palliative care be expanded.
- f. More choice of dying be available within palliative care.
- g. The predominant influence of religion-based palliative care be reversed.

## 4.9 References

- <sup>1</sup> F Norwood, *The maintenance of life (Preventing social death through euthanasia talk and end of life care)* Carolina Academic Press, 2009
- <sup>2</sup> E Cassell, 'Diagnosing suffering: a perspective', *Annals of Internal Medicine*, 1999;131;531
- <sup>3</sup> N Cherny, 'Guidelines to the care of the dying cancer patient', *Haematology-Oncology* 1996;10;261
- <sup>4</sup> D Rowett and D Currow, 'Pharmacovigilance in palliative care', *Australian Prescriber* 2014;37:204
- <sup>5</sup> M Barbato, *Medical Journal of Australia*, 1998;168;296
- <sup>6</sup> L Librach, a personal communication
- <sup>7</sup> Palliative Care Australia, *Position Statement on Voluntary Euthanasia*, 2008
- <sup>8</sup> E De Sousa & B Jepson, 'Midazolam in terminal care', *Lancet* (2/7/1988)
- <sup>9</sup> A Burke et al. 'Terminal restlessness – Its management and the role of midazolam.' *Medical Journal of Australia*, 1991;155;485
- <sup>10</sup> V Ventafridda et al., *Journal of Palliative Care* 1990;6 (3);7
- <sup>11</sup> J Billings & S Block, *Journal of Palliative Care*, 1996;12:21
- <sup>12</sup> M Maltoni et al., *Journal of Clinical Oncology*, 2012;30:1378
- <sup>13</sup> R Twycross, *Oxford Textbook of Palliative Medicine*, 3rd Edition, OUP 2004
- <sup>14</sup> E Loewy, 'Terminal sedation, self-starvation, and orchestrating the end of life', *Archives of Internal Medicine*, 2001;161:329
- <sup>15</sup> J Hardy, 'Sedation in terminally ill patients', *Lancet* 2000;356;1866
- <sup>16</sup> J Corner, *British Medical Journal*, 1997;315;1242
- <sup>17</sup> R Hunt et al. 'The incidence of requests for a quicker terminal course', *Palliative Medicine* 1995;9;167
- <sup>18</sup> Seale & Addington-Hall, 'Euthanasia; the role of good care', *Social Science and Medicine*, 1995;40;581
- <sup>19</sup> B Rich, 'Pathologizing suffering and the pursuit of a peaceful death', *Cambridge Quarterly of Healthcare Ethics*, 2014
- <sup>20</sup> M Klein, *Health Care Analysis* 2004;12;225
- <sup>21</sup> D Doyle, *Foreword to Palliative Care Ethics* OUP 2nd ED 1999
- <sup>22</sup> F Randall & R S Downie, *The Philosophy of Palliative Care: Critique and Reconstruction*, OUP 2006
- <sup>23</sup> J Lawton, *The dying patient's experience with palliative care*, Routledge, 2000
- <sup>24</sup> E McGee 'Can suicide intervention in hospice be ethical?', *Journal of Palliative Care*, 1997;134:27
- <sup>25</sup> D Doyle, 'Have we looked beyond the physical and psycho-social?', *Journal of pain and Symptom Management*, 1992;7;302
- <sup>26</sup> A Broom, 'On euthanasia, resistance and redemption', *Qualitative Health Research*, 2011;22;226
- <sup>27</sup> S Ahmedzai, 'My journey from anti to pro assisted dying', *British Medical Journal*, 2012;345;e4582

## 4.10 Personal stories of palliative care

(More on [www.dwdv.org.au/takeaction/read-personal-experiences](http://www.dwdv.org.au/takeaction/read-personal-experiences).)

### **Dad was on palliative care for three weeks with tears rolling down his face every day.**

I moved into his room at the nursing home and slept there in a bucket chair for the entire 3 weeks. He was not being cared for adequately, as the nursing staff were not experienced enough. He most certainly would have elected for assisted dying if it was offered to him. He had told the management 3 weeks before that he had had enough.

My mother's doctor placed her on palliative care and prescribed the appropriate medications. These medications were not followed up, and it wasn't until 4 days later I realised she was NOT being administered the medications ordered. She suffered on her own without any help. Assisted dying would have minimised that trauma for her in her last days.

Unfortunately, many people have stories like these that they are unable to tell because of the sheer stress they went through losing their loved one. Most people don't have enough energy left to take on the system with the view to improving it for others, so the system continues along ticking boxes to comply for accreditation. So many are locked into hopelessly ill conditions with nowhere to go but wait to die, with no quality of life.

Both my parents suffered needlessly at the end of their lives. Yet I constantly hear how things have changed and there are systems in place to solve many ongoing issues associated with aged care.

However, I recently went to a forum where there were 300 in attendance and it was quite clear that not much has changed over the years. There is a distinct lack of resources, training and experience, and staffing levels to deal with palliative care patients. One RN stated his patient to nurse ratio at times is 1:110 - how outrageous! It was interesting that there was over 60 nursing staff attending this forum with the view to getting it out there that something has to change.

Everyone has their own perception of the system, but from where I sit, we need an overhaul of age care. There were questions at the forum regarding how we solve this problem, but no one had the answer, other than to say it's a conversation we have to have.

### **My friend died an awful death, in a hospice.**

As a palliative care nurse, in a hospice for ten years, I witnessed many deaths – the majority were what is termed “good deaths” and the minority, about 5%, were deaths without dignity or comfort. The formal process of review seemed to produce no helpful results for these 5%. Throughout those ten years I remained disturbed and angry about those bad deaths; those feelings were intensified by the personal experience of seeing a personal friend die a “bad death”.

My friend “Fluff”, also a nurse, mostly in Intensive Care Units and Coronary Care Units, succumbed to cancer last year. She had been on the merry-go-round trying all avenues for cure, then just life extension until she got so uncomfortable that all she wanted was some relief. This discomfort, due to secondary cancer in the liver, manifested in many symptoms such as grossly distended abdomen, that only grew despite many ‘taps’ to reduce the size. As we were both midwives, the term that we applied about the size of her abdomen was that it looked like that of a woman at full term with quads. Normal activities of daily living were so difficult and often impossible.

“Fluff” was admitted to a Palliative Care Unit two days before her death. At this time she was breathless on exertion and at rest, had intermittent faecal vomiting, not eating, unable to be comfortable in any position and becoming increasingly restless exhausting any strength that was left. Her pain control was “OK”, as she put it. On the current morphine dose but she was so damned uncomfortable.

Sedatives gave short bursts of rest, but it wasn't enough. It seemed that use of this drug had to be justified for every dose given instead of complying with the patient's wish to sleep. “Fluff” was in and out of bed with this terrible restlessness trying to get comfortable and begging to sleep. At one stage she looked at me and said “I never knew palliative care was like this”. I felt rightfully accused.

My friend died an awful death, in a hospice. She was sitting on a chair trying to get her breath, trying to sit anyway that would make her comfortable, staring wide-eyed, clutching at her friends, and calling out as she took her last breaths. The Pastoral Care Worker (of some 15 years experience with the dying) who was there at the time of death said that her death was a shocker, and that no one deserved to die like that.

Patients in “Fluff's” position, who can't have their needs and choices met, are also at the mercy of those who deliver a bias of care instead of a standard or model of care. Why should it matter who is on duty as to the efficacy of the delivery of care; “if only so-and-so had been on duty, it would have been different” should never be considered or heard.

## 5:

# Current legislative frameworks in Australia and overseas

### 5.1 Australian legal framework

Sections 2.6 to 2.9 of this submission set out DWDV's recommendations in relation to voluntary assisted dying (VAD). Given our preferred legislative framework, this section is confined to requests for assistance to die, from competent adult patients who are terminally ill or suffering intolerable, unrelievable pain. It places our recommendations in the context of long-term legal trends in relation to medical decision-making, legal developments here and overseas relating specifically to end-of-life decision-making, other legal aspects and problems in current legal arrangements.

### 5.2 Long-term legal trends in relation to medical decision-making.

In 1987, in his submission to the Social Development Committee during its Inquiry into Options for Dying with Dignity, the late Professor Max Charlesworth, a leading Australian philosopher and ethicist, spoke about *'the right to control and determine one's life for oneself'*.

Legal recognition of individual autonomy and self-determination in relation to medical decision-making has a long history in Western jurisdictions. First famously stated by the American Judge Cardozo in 1914, the concept of the right of patients to make their own medical decisions has been regularly re-stated in the US itself, the UK, New Zealand and Australia. In the High Court in *Marion's Case*, 1992, the court referred to *'... the right in each person to bodily integrity ... to choose what occurs with respect to his or her own body'*. In the UK, *Bland's Case*, 1993, Lord Goff said that even the *'fundamental principle ... of the sanctity of human life'* must yield to that of self-determination.

### 5.3 Legal developments relating specifically to end-of-life decision-making

Commensurate with the above general legal trends there have been developments ensuring that patients are not subjected to treatment that they do not wish to have, even if this leads to their death and is contrary to medical advice.

In the UK case *Re T (Adult:Refusal of Medical Treatment)*, 1992, Lord Donaldson said

*The patient's interest consists of his right of self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount.*

Such decisions relate to patients having a right to refuse treatment they do not want, but they do not establish a right for patients to demand that they be treated in a particular way, such as receiving assistance to die. While voluntary assisted dying (VAD) and voluntary euthanasia (VE) are unlawful in Australia, and assisted suicide (AS) remains a criminal offence, the law does permit life-sustaining treatment to be withdrawn or withheld. Competent adults (or others on their behalf in certain circumstances) can refuse life-sustaining treatment or futile treatment and decline food and hydration (*Gardner; re BWV*, 2004). Put bluntly, patients have a right to decline antibiotics, for example, and to die from an infection or to starve and dehydrate to death.

The Victorian *Medical Treatment Act 1988* (MTA) reflects the existing common law principles in relation to refusal of medical treatment, and it also provides for substituted decision-making – enabling an appointed agent to make decisions about medical treatment on behalf of an incompetent person. The MTA does not alter the criminal law in relation to suicide pacts and the criminal liability of a survivor of a suicide pact.

Some would argue that there is a moral and legal difference between a positive act causing death – active euthanasia – and passively allowing someone to die – passive euthanasia – even though both these acts are being requested by a patient for the same reason, to have control over their own death, and the result will be the same. This distinction is shown to be rather contrived in the common law principle of the doctrine of double effect (DDE). Over-sedation or deep sedation, which often occur in the context of palliative care, are not unlawful if a doctor's intention is to relieve pain, even if the doctor knows that the drugs will cause or hasten death – i.e. a 'bad' act can be countenanced when it unintentionally produces a 'good' outcome. Quite apart from the impossibility of proving or even ascertaining the doctor's intentions, the lack of clarity in the concept of the DDE means there is considerable legal uncertainty and ambiguity about how this common law principle applies. The doctrine is easy to express but its practical application is not, a situation exacerbated by the absence of oversight and monitoring under current legal arrangements.

The issue of pain relief hastening death is further complicated by the *Medical Treatment Act 1988*, which in its preamble recognises that it is desirable 'to ensure that dying patients receive maximum relief from pain and suffering'. DWDV is aware of circumstances where patient wishes in relation to 'maximum relief' are not being respected. Furthermore, it is not clear how this statement in the preamble fits with the generally recognised current legal situation that patients have no 'right' to seek assistance in dying.

Within the current legal arrangements and despite the prohibition on AS and VE, there is clear evidence that these practices occur in Australia. In 1995, DWDV Vice-president, Dr Rodney Syme and several other doctors published a letter (the *Age*, 24 March 1995) admitting to having assisted patients to die. Magnusson's 2002 study (*Angels of Death: Exploring the Euthanasia Underground*) documents numerous examples. More recently, Dr Syme has publicly disclosed several situations where he has provided patients with the means to die. Significantly, Dr Syme has not been charged with any offences despite being interviewed by police on several occasions over the years. This situation represents yet another area of existing legal uncertainty surrounding AS and VE, and medical practitioners remain liable for criminal prosecution.

## 5.4 Legislative models and judicial rulings

There have been numerous attempts throughout Australian legislatures to reform the law relating to assisted dying, but with one exception, these have been unsuccessful. Voluntary euthanasia and assisted suicide were briefly lawful in the Northern Territory (*Rights of the Terminally Ill Act 1997*) but the Act was overturned in the federal parliament. Currently reform bills are being pursued in the South Australian and Tasmanian legislatures. At the federal level, Greens Senator Richard Di Natale has released the *Medical Services (Dying with Dignity) Exposure Draft Bill*, which has been examined by the Legal and Constitutional Affairs Legislation Committee which reported in November 2014.

However, a growing number of overseas jurisdictions have statutory regimes in place and the experience derived from these legislative regimes provides a vast body of evidence for this Victorian inquiry to consider. Section 5.8 of this chapter sets out details of the overseas frameworks, but some key points are noted here. While the frameworks vary in their approach, they all include review and oversight processes and the data collected show how the law is working.

## Oregon

For example, the Oregon legislation was passed in 1994 as a result of a citizen-initiated referendum and it came into full operation in 1998 (*Death with Dignity Act*, 1994). The legislation has been unsuccessfully challenged on several occasions and the model was copied in 2009 in Washington. The Oregon model permits AS (not VE), and to be eligible for assistance, a patient must be over 18 years of age, legally competent, suffering from a terminal disease and a resident of Oregon. Each year the Oregon Department of Human Services produces a report on the practice and demographics of PAD. These evidence-based reports show that accessing AS has not spiralled out of control as some had feared. The 2008 report, which summarised the findings of a decade of operation, found that approximately one-third of those who obtained a prescription for medication did not use it. As shown in many personal stories, giving people control over their dying circumstances is more likely to extend lives than to shorten them.

## Canada

In February this year, the Supreme Court of Canada, in a unanimous decision that reversed their 1993 decision (*Rodriguez*), confirmed that Canadians have the constitutional right to choose physician assistance in dying. (*Carter v Canada*, see Section 7.3). The Court strongly endorsed the factual findings of the original trial judge, Justice Lynn Smith, who conducted an extensive examination of legal developments in other jurisdictions. Based on her assessment Justice Smith concluded as follows in her 2012 judgement:

*In particular, I found that the preponderant ethical opinion is that there is no bright-line ethical distinction in an individual case, between physician-assisted dying and end-of-life practices such as withholding or withdrawing life-sustaining treatment or administering palliative sedation where the highly probable consequence is to hasten death.*

*... the evidence from other jurisdictions shows that the risks inherent in legally permitted assisted death have not materialized in the manner that may have been predicted. For example, in both the Netherlands and Belgium, the legalization of physician-assisted death emerged in a context in which medical practitioners were already performing life-ending acts, without the explicit request of their patients. After legalization the number of LAWER [life ending assistance without explicit request] deaths has significantly declined in both jurisdictions. This evidence serves to allay fears of a practical slippery slope.*

## 5.5 Adequacy of safeguards

Opponents of VE/AS law reform frequently claim that it is not possible to draft a law which protects vulnerable people from pressure to seek assisted dying. Commentators such as Magnusson suggest that it would not be possible to completely eliminate demand for unlawful euthanasia. Professor Sheila McLean, an international authority on this issue, points out this concern is inflated. It assumes that examples of unlawfulness would be a consequence of legalisation, rather than an existing fact of life. The proper question is: would law reform result in a worse situation than that which currently exists. Justice Smith in *Carter v Canada* outlined what she would consider acceptable safeguards, a position endorsed by the Canadian Supreme Court earlier this year. She concluded that stringently limited permission for physician-assisted death for ‘grievously ill and irremediably suffering people who are competent, fully informed, non-ambivalent, and free from coercion or duress’ would achieve the objective of protecting vulnerable people.

*In my view, the evidence supports the conclusions that the risks of harm in a regime that permits physician-assisted death can be greatly minimized. Canadian physicians are already experienced in the assessment of patients’ competence, voluntariness and non-ambivalence in the context of end-of-life decision-making.*

*Note:* s5f of the *Medical Treatment Act 1988* provides penalties for a person who is a beneficiary under a will of another person or has other interests in relation to that other person and who procures the



execution of a Refusal of Treatment certificate by that other person using deception, fraud, mis-statement or undue influence forfeits those interests. DWDV has made enquiries and been advised in writing by both police and health authorities that no action has been taken under that section since the MTA was passed in 1988.

## 5.6 Other legal approaches

Apart from the legislative models and judicial rulings outlined above there are other approaches that can be taken to regulate VE/AS. In brief they include the following.

**Sentencing options** – in AS cases that have come before the courts sentencing discretion has tended well towards the lower end of the range.

**Prosecutorial guidelines** – in England and Wales the DPP has a specific policy in relation to AS which sets out when it would not be in the public interest to prosecute a case. In Australia, prosecutors have a general discretion not to prosecute when it would not be in the public interest to do so.

**Defences for doctors** – Professor Paul Komesaroff and Stephen Charles QC proposed that legislation be enacted to amend the relevant Commonwealth and State Crimes Acts to provide a defence to a charge of homicide or manslaughter, if a doctor has prescribed or administered a drug that hastened or caused the death of a patient with a terminal disease, provided the doctor: (a) reasonably believed that it was necessary to prescribe or administer the drug to relieve the pain or suffering undergone by the patient; or (b) prescribed or administered the drug with the intention of relieving such pain or suffering. (The Age, 21 November 2014).

**The Victorian Charter of Rights and Responsibilities** – see Chapter 6 which examines this in light of the 2015 Canadian Supreme Court decision. While noting that the Canadian charter is part of the Canadian Constitution, there are similarities with the Victorian legislative charter.

## 5.7 Conclusions

**As set out above, current laws are unclear, ambiguous, discriminatory, unenforceable and incompatible. Abuse is more likely to occur in systems that are not transparent and monitored. Current legislation in Victoria lags well behind both public opinion and legal developments overseas.**

The considerable body of evidence available from overseas experience demonstrates that the law in Victoria can and should be amended in accordance with DWDV's legislative charter (see Chapter 2). DWDV urges that these legislative amendments be made to allow the terminally ill or those enduring intolerable, unrelievable suffering to end their life by choice, legally, and with dignity.

**A tabulated list summarising information on international jurisdictions with VAD/VE laws follows on next page. More detailed information is available on the DWDV website at <http://www.dwdv.org.au/resources/dwdv-overseas-legal-jurisdictions-research> .**

## 5.8 International jurisdictions with VAD/VE laws

### Oregon: Death with Dignity Act

How was VAD legalised?	Who can access it?	How is it administered?
A citizen led initiative that succeeded in placing the issue of Physician Assisted Suicide on a state-wide ballot. The law came into effect in November 1997.	An adult, 18-plus, and resident of Oregon; capable of making and communicating healthcare decisions; with terminal illness that will lead to death within 6 months.	Self-administered medication using a prescription from a physician – the Act prohibits euthanasia whereby a physician or other person would administer the medication
<b>Key safeguards:</b> The patient must make two verbal requests to the prescribing physician separated by no less than fifteen days. There must also be one written request. The attending physician must refer the patient to an independent physician for medical confirmation of the diagnosis and prognosis and a further determination as to whether the patient is capable and acting voluntarily. If either physician believes the patient's judgement is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination.		
<b>Key statistics:</b> Since the law passed in 1997, a total of 1,327 people have obtained DWDA written prescriptions and 859 patients have died from ingesting the medication. Of the 105 DWDA deaths during 2014, most (67.6%) were aged 65 years or older. The median age at death was 72 years. As in previous years, decedents were commonly white (95.2%) and well educated (47.6% had at least a baccalaureate degree).- During 2014, no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements.		

### Washington: Death with Dignity Act

How was VAD legalised?	Who can access it?	How is it administered?
The legislation was passed by voter initiative on 4 November 2008 and came into effect on 5 March, 2009.	An adult, 18-plus and resident of Washington State; competent to make informed decisions; suffering terminal illness with six months or less to live.	Terminally ill patients can obtain a prescription from their physician to self-administer the lethal medication.
<b>Key safeguards:</b> The patient must verbally request the medication from the prescribing physician twice, with each request separated by no less than 15 days, and must also make one written request. The patient is to be examined by an independent physician for medical confirmation of the diagnosis and a further determination that the patient is competent and acting voluntarily.		
<b>Key statistics:</b> In 2013, out of 173 participants: 159 are known to have died; 119 died after ingesting the medication; 26 died without ingesting the medication; for 14 people there is no indication that death has occurred. Of the 159 that are known to have died: 77% had cancer; 15% had neuro degenerative diseases; 8% had other illnesses; 97% were white, non-Hispanic; 76% had at least some form of college education; and the majority of participants were in 64-74 age group.		

### Switzerland: Article 115 of the Swiss Federal Criminal Code

How was VAD legalised?	Who can access it?	How is it administered?
Legal since 1942. Under Article 115, assisting a suicide is only a criminal offence if the motives are selfish, such as personal gains.	An adult, minimum age 18; of sound judgement, suffering from a terminal illness, and/or an unendurable incapacitating disability and/or unbearable and uncontrollable pain.	Active euthanasia, such as by administering lethal injection, remains prohibited in Switzerland. A physician may prescribe the lethal medication for the patient to self-administer.
<b>Key safeguards:</b> There are four Right to Die societies in Switzerland, two of which, Exit and DIGNITAS, provide services to assist eligible applicants (who must be members of the organisation) to end their life in a humane and dignified manner. DIGNITAS or Exit must have approved the individual's request after viewing medical reports containing patient history, diagnosis, and prognosis. Medical reports must not be more than three to four months old. The patient must possess a minimum level of physical mobility so that they are capable of self-administering the medication.		
<b>Key statistics:</b> According to Exit, the most common reasons for requesting physician-assisted suicide are terminal cancer, age-related diseases and chronic pain disorders. In 2014, requests for physician assisted suicide were more than 2,500, of which after thorough review, 880 were approved, resulting in 583 physician assisted suicides.		



## The Netherlands: *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*

How was VAD legalised?	Who can access it?	How is it administered?
The law was enacted on 1 April 2002.	A patient must be aged 12 or over and have suffering that is unbearable and lasting with no prospects for improvement. Patients between 12 and 16 years require parental or guardian consent.	VAD in the Netherlands may be by either doctor-administered lethal injection, or oral ingestion. In practice, the vast majority of assisted dying is by lethal injection.
<b>Key safeguards:</b> The request must be entirely voluntary, repeated and free from external pressure. The patient must be fully informed of his/her condition and prospects. The patient must have been examined by an independent physician who has confirmed the patient's medical condition.		
<b>Key statistics:</b> There has been stability of assisted dying from 1990 to 2010, ranging from 1.7% to 2.8% of all deaths. In 2013 the Euthanasia Regional Review Committee received 4829 notifications of life termination on request representing some 3% of 141,245 total deaths. This included 3588 cases with terminal cancer; 223 with cardiovascular disorder; and 294 neurological disorders. There is a growing take-up of assisted dying (by a variety of means including terminal sedation), with a 15% increase in requests from 2012.		

## Belgium: *Act on Euthanasia*

How was VAD legalised?	Who can access it?	How is it administered?
The Act was passed on 28 May 2002 and came into effect in September 2002.	An adult or emancipated minor, legally competent and conscious at the time of making the request. The patient must be in a medically futile state of constant and unbearable physical or psychological suffering which cannot be alleviated.	Lethal injection. In Belgium VAD and palliative care developed together and are fully integrated*.
<b>Key safeguards:</b> The patient must be informed about his/her situation and possible treatments and options available. It must be certain that the patient's request is voluntary and free from external pressure. The patient must consult with an independent physician to confirm that there is unbearable and constant physical and mental suffering that cannot be alleviated. Minors must be terminally ill rather than in a state of unbearable suffering and they must be capable of discernment. A psychologist must evaluate the minor to determine whether they understand euthanasia. They must also obtain parental or guardian consent.		
<b>Key statistics:</b> Out of 61,621 deaths in 2013, the percentage preceded by one or more possibly life-shortening end-of-life practices remained stable at 47.8%. Of these, the intensified alleviation of pain and other symptoms with the use of drugs, with possible shortening of life taken into account (24.2% of deaths), the withholding or withdrawing of life-prolonging treatment (17.2%), and terminal sedation (12%) remained the most prevalent end-of-life practices. VE accounted for 4.6% of cases.		
<b>*Palliative care services were involved in 73.7% of euthanasia and physician assisted suicide cases.</b>		

## Luxembourg: *Law on Euthanasia and Assisted Suicide*

How was VAD legalised?	Who can access it?	How is it administered?
The bill legalising euthanasia was passed on 20 February 2008 and came into effect on 19 March 2009.	An adult or emancipated minor, competent at the time of request and suffering constant and unsupportable physical or psychological pain resulting from serious accident or pathological condition, without prospects of recovery or improvement.	Lethal injection.
<b>Key safeguards:</b> The patient must be informed about his/her condition and possible treatment options. The attending physician ascertains the constant unbearable physical or mental suffering through several interviews over a reasonable time. The patient must be evaluated by an independent physician who will confirm his/her condition and provide a report of the consultation. The request must be well considered and made voluntarily without external pressure.		
<b>Key statistics:</b> Fifteen people were euthanased between 2013 and 2014. Eleven patients were suffering from terminal cancer, three from neurodegenerative disease, and one had suffered a stroke.		

**Montana: the *Baxter v Montana* ruling**

How was VAD legalised?	Who can access it?	How is it administered?
On December 31, 2009, Montana's Supreme Court ruled in <i>Baxter v Montana</i> that physicians are authorised under state law to provide aid in dying. Subsequent attempts at passing bills aimed at establishing a regulatory framework have been unsuccessful.	A terminally ill patient whose death, in the opinion of the attending physician or advanced practice nurse, will occur within a relatively short time without the administration of life-sustaining treatment.	The physician may provide the medication for the patient to self-administer.
<b>Key safeguards:</b> The Montana Supreme Court broadened the state's right under the <i>Terminally Ill Act</i> to include physician-assisted suicide. However, the statute does not include a regulatory framework for this. The purpose of this ruling is to protect doctors from being prosecuted as long as they have the terminally ill patient's request in writing.		
<b>Key statistics:</b> None available.		

**Vermont: *Patient Choice and Control at End of Life Act***

How was VAD legalised?	Who can access it?	How is it administered?
The <i>Patient Choice and Control at End of Life Act (Act 39)</i> was passed by Vermont General Assembly in 2013, and came into effect on 20 May 2013.	An adult, minimum age 18, suffering from a terminal illness with a life expectancy of six months or less. The patient must be competent and making an informed decision.	A physician may prescribe the medication for the terminally ill patient to self-administer.
<b>Key safeguards:</b> The patient must make three separate requests for life-ending medication: two verbal and one written. There must be no less than fifteen days between each request. The patient must be referred to a second independent physician to confirm the diagnosis and prognosis and determine that the patient is capable and acting voluntarily.		
<b>Key statistics:</b> In the first two years, only eight prescriptions have been written, in a population of 625,000. At least two of the recipients died of other causes.		

**Canada: *Supreme Court ruling***

How was VAD legalised?
<p>The Supreme Court of Canada in the case <i>Carter v Canada</i> came to a unanimous decision in February 2015 that Canadian citizens have the constitutional right to choose physician assisted dying. The court determined that s.241 and s.14 of the Criminal Code are void as they fundamentally violate the Canadian Charter of Rights and Freedoms. The Supreme Court found that the laws deprived the right to life, liberty and security of the person suffering from serious and incurable illnesses – a right that is guaranteed under Section 7 of the Charter.</p> <p>The Canadian Supreme Court has charged the Canadian federal and provincial parliaments with drafting facilitating legislation. In 2014, the Quebec Parliament passed legislation enabling VAD, which is not yet operative.</p> <p><b>No information about safeguards and no statistics are yet available.</b></p>

## 6:

## Considering rights and discrimination

### 6.1 Introduction and scope

This section examines issues pertaining to human rights and discrimination. It draws on recent landmark judicial developments in Canada concerning physician assisted suicide [VAD]. They are particularly relevant to Victoria, because of similarities in our laws and our *Charter of Human Rights and Responsibilities* and the Canadian *Charter of Rights and Freedoms*. We compare these two charters, to demonstrate how similar they are in relevant aspects, before reviewing recent court judgements in Canada, which critically rely on s.7 and s.17.(1) of the Canadian *Charter of Rights and Freedoms*.

The Canadian courts referenced here found that the Canadian criminal code breached the Canadian constitution, because of the code's incompatibility to the Canadian *Charter of Rights and Freedoms*, in respect of right to life, security of the person and freedom from discrimination. It therefore found the relevant sections of the criminal code to be invalid. Dying With Dignity Victoria argues that given the close similarities of the Charters and laws in Canada and Victoria, Victorian law is likewise in conflict with the Victorian *Charter of Human Rights and Responsibilities* in respect of voluntary assisted dying.

### 6.2 Comparison of Victorian and Canadian legal frameworks

#### Rights

Victoria	Canada
<p>The Victorian <i>Charter of Human Rights and Responsibilities</i> has the following two key provisions:</p> <p><u>9. Right to life</u>  <i>Every person has the right to life and has the right not to be arbitrarily deprived of life.</i></p> <p><u>21. Right to liberty and security of person</u>  <i>(1) Every person has the right to liberty and security.</i></p>	<p>The Canadian <i>Charter of Rights and Freedoms</i> embraces in one section the scope of the above two provisions of the Victorian charter:</p> <p><i>7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.</i></p>
<p><b>DWDV is of the view that the provisions in s.9 of the Canadian version cover exactly the same scope as the combined two sections of the Victorian Charter.</b></p>	

#### Discrimination on the basis of disability

Victoria	Canada
<p>S.6 of the Victorian Equal Opportunity Act 2010, states that discrimination due to impairment is prohibited (our emphasis):</p> <p><u>6. Attributes</u>  <i>The following are the attributes on the basis of which <b>discrimination is prohibited</b> in the areas of activity set out in Part 4—</i></p> <p>(a) age;  (b) breastfeeding;  (c) employment activity;  (d) gender identity;  (e) impairment ...</p>	<p>S.17. (1) of the Canadian <i>Charter of Rights and Freedoms</i> is very similar in this respect:</p> <p><u>Equality before and under law and equal protection and benefit of law</u>  <i>17. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (our emphasis)</i></p>
<p><b>DWDV concludes that with respect to the rights of the individual to life, liberty and security of the person, including the right to freedom from discrimination, the Victorian and Canadian provisions are very similar.</b></p>	

### 6.3 Ruling of the Supreme Court of British Columbia, June 2012

The following edited extract is from the judgement of Justice Lynn Smith from *Carter v Canada* (Attorney General), 2012 BCSC 886 15 June 2012. The emphasis below in [18] is ours.

<https://bccla.org/wp-content/uploads/2012/06/Carter-v-Canada-AG-2012-BCSC-886.pdf>

[15] The claim that the legislation infringes ... equality rights begins with the fact that the law does not prohibit suicide. However, persons who are physically disabled such that they cannot commit suicide without help are denied that option, because s. 241(b) prohibits assisted suicide. The provisions regarding assisted suicide have a more burdensome effect on persons with physical disabilities than on able-bodied persons, and thereby create, in effect, a distinction based on physical disability. The impact of the distinction is felt particularly acutely by persons ... who are grievously and irremediably ill, physically disabled or soon to become so, mentally competent, and who wish to have some control over their circumstances at the end of their lives. The distinction is discriminatory, under the test explained by the Supreme Court of Canada in Withler, because it perpetuates disadvantage.

[16] The legislation's infringement of s. 15 equality rights is not demonstrably justified under s. 1 of the Charter. The purpose of the absolute prohibition against physician-assisted suicide, as determined by Rodriguez, is to prevent vulnerable persons from being induced to commit suicide at times of weakness. That purpose is pressing and substantial and the absolute prohibition against assisted suicide is rationally connected to it. However, a less drastic means of achieving the legislative purpose would be to keep an almost-absolute prohibition in place with a stringently limited, carefully monitored system of exceptions allowing ... grievously and irremediably ill adult persons who are competent, fully-informed, non-ambivalent and free from coercion or duress – to access physician assisted death. ... the legislation has very severe adverse effects ... that are not outweighed by its benefits. For those reasons, and despite affording due deference to Parliament, I conclude that the legislation's absolute prohibition falls outside the bounds of constitutionality. ...

[17] The claimed infringement of s.7 rights differs as among the plaintiffs. With respect to Ms. Taylor [one of the co-plaintiffs with Carter], the legislation affects her rights to liberty and security of the person, as was found in Rodriguez. In addition, the legislation affects her right to life because it may shorten her life. Ms. Taylor's reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted. ...

[18] The legislation deprives the plaintiffs of their s.7 rights inconsistently with the principles of fundamental justice. First, **the legislation is overbroad**. Second, the legislative response – an absolute prohibition – is **grossly disproportionate to the objectives it is meant to accomplish**. As with the s.15 infringement, the s.7 infringement would not be justified under s. 1.

This judgement was subsequently overturned on appeal. The case then went before the Supreme Court of Canada.

### 6.4 Ruling of the Supreme Court of Canada - February 2015

<http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>

Many jurisdictions which allow voluntary assisted dying restrict it to cases of terminal illness, e.g. Oregon and Washington states. A distinguishing feature of the Canadian Supreme Court judgement, which will set Canada apart from such jurisdictions, is that the judgement makes no reference to its provisions applying only to cases of terminal illness. The judgement directs provincial governments to enact voluntary assisted dying legislation within a year, which will apply to people with **intolerable, irremediable** suffering. There is no further qualification or reference which can be construed as limiting it to cases of terminal illness. The penultimate paragraph of this section, quoted directly from the judgement, reflects this clearly.

The following article extract from the *Globe and Mail*, 6 February 2015, provides an overview of the ruling.

... The unanimous ruling, by establishing that the “sanctity of life” also includes the “passage into death,” extends constitutional rights into a new realm. ... The new ruling will change the way some Canadians are permitted to die.

In a brief, powerful opening paragraph, the court explained why it was creating a new constitutional right to autonomy over one’s death in some circumstances: Those who are severely and irremediably suffering, whether physically or psychologically, “may be condemned to a life of severe and intolerable suffering” by the government’s absolute ban on assisted dying. “A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.”

The decision was signed by The Court, which happens occasionally when the justices wish to lend their decisions extra weight. The nine judges, who range in age from mid-50s to 74, dismissed the notion that competent adults cannot consent to their death. “We do not agree that the existential formulation of the right to life requires an absolute prohibition on assistance in dying, or that individuals cannot ‘waive’ their right to life. This would create a ‘duty to live,’” ...

The court did not strike down the Criminal Code’s prohibitions on assisted suicide, but said they no longer apply “to the extent that they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.”

In the words of the Court (<https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>) :

Insofar as they prohibit physician-assisted dying for competent adults who seek such assistance as a result of a grievous and irremediable medical condition that causes enduring and intolerable suffering, ss. 241 (b) and 14 of the Criminal Code deprive these adults of their right to life, liberty and security of the person under s.7 of the Charter . The right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly. Here, the prohibition deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable. The rights to liberty and security of the person, which deal with concerns about autonomy and quality of life, are also engaged. An individual’s response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. And by leaving them to endure intolerable suffering, it impinges on their security of the person.

**Dying With Dignity Victoria is of the view that these Canadian court rulings are equally applicable to the Victorian Charter of Human Rights and Responsibilities and the Victorian criminal code, in that the two are clearly in conflict and incompatible at present.**

## 6.5 Discrimination in relation to suicides

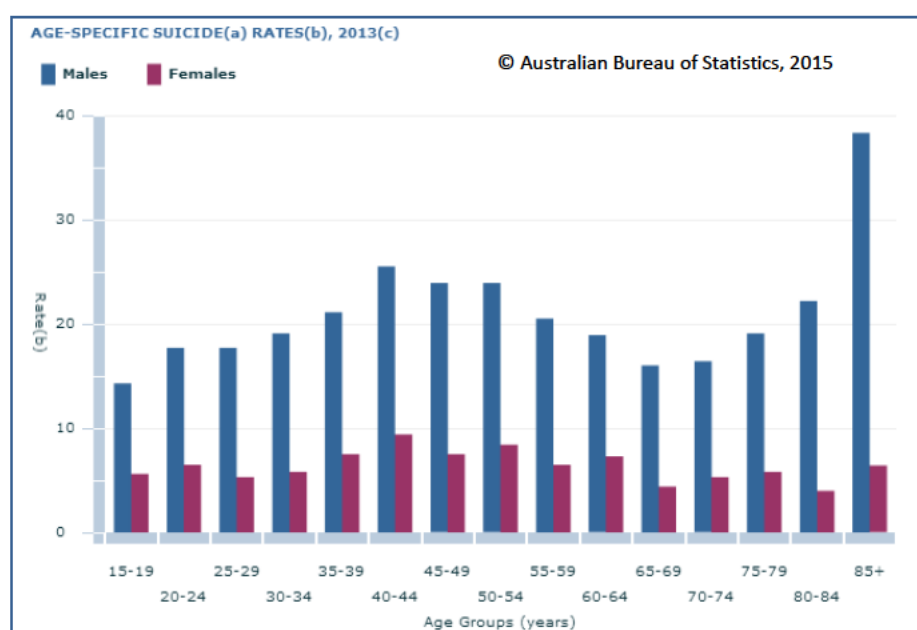
Although suicide is now decriminalised in Australia, the availability of suicide to the individual is restricted to those with the physical capacity to carry out suicide. To that extent, the current situation is discriminatory in favour of those with the resources – physical and/or financial – to carry out suicide. As ill-health and physical incapacity increases with age, this also presents as discrimination against the elderly.

<http://www.findlaw.com.au/articles/5556/what-is-the-law-on-suicide-in-australia.aspx>

Consideration of the extent to which this age effect is relevant may be aided by Chart 4, from the Australian Bureau of Statistics (ABS):

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2013~Main%20Features~Suicide%20by%20Age~10010>



**Chart 4. Age-specific suicide rates, 2013**

Age-specific death rates (ASDRs) are the number of deaths (occurred or registered) during the reference year at a specified age per 100,000 ...

The rising rate of male suicide with age after age 70 and the very high rate amongst males aged 85 and over, points to the hazards faced by an elderly group as they attempt to end their lives.

### Violent suicides

As few people have the medical training required to suicide in a safe and painless way, many suicides are then chaotic or violent. Table 6 shows ABS data for 2013 relating to 'Intentional self-harm'.

**Table 6. Selected external causes of death, Mechanism by intent, 2013, Intentional self-harm**

Mechanism of death	Number
Poisonings	552
Hanging	1,392
Drowning and submersion	53
Firearms	165
Contact with sharp object	68
Falls	116
Other	176
Total	2,522

The ABS also notes:

*'In 2013, the most frequent method of suicide was hanging, strangulation and suffocation (X70), a method used in more than half (55.2%) of all suicide deaths. Poisoning by drugs (X60-X64) was used in 13.8% of suicide deaths, followed by poisoning by other methods (X65-X69) including by alcohol and motor vehicle exhaust (8.0%). Methods using firearms (X72-X74) accounted for 6.5% of suicide deaths. The remaining suicide deaths included deaths from drowning, jumping from a high place, and other methods.'*

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2013~Main%20Features~Method%20of%20Suicide~10011>

## 7: Community support for change

### 7.1 The vast majority of people want VAD

Our analysis of data from the ABC Vote Compass survey conducted prior to the Victorian state election in November 2014 demonstrates that there is strong and widespread community agreement with the statement: ‘Terminally ill patients should be able to legally end their own lives with medical assistance’. This applies to all electoral Districts and Regions, and to all segments of the community, whether analysed by gender, religion, voting intention or any other of the eleven segmentation parameters used in the survey discussed. An explanation of the Vote Compass survey method and how we analysed the data appears in [Appendix A](#).

### 7.2 Level of agreement across electorates

A series of tables in Appendix A shows the level of agreement across all electoral Districts and Regions. The most notable observation that can be made is that respondents in *every single location and grouping* available for analysis have a high level of agreement with the survey statement that terminally ill patients should be able to legally end their own lives with medical assistance. Members of parliament should note that electors in *every* District and Region that they represent overwhelmingly agree with the statement to the level of 70% or more. This clearly indicates that the people who elected them want them to support voluntary assisted dying in parliament.

### 7.3 Level of agreement across demographic groupings

The following table summarises the data in Appendix A, providing a quick overview of where agreement with the survey statement is highest and lowest, analysed by the demographic parameters available.

**Table 1. Demographic analysis of range of agreement**

Category	Highest level of agreement	Level	Lowest level of agreement	Level
Electoral District	Northcote	98%	Mulgrave	70%
Electoral Region	Northern Metropolitan	82%	Eastern Metropolitan	73%
Age	35-54	78%	18-34	74%
Education	No university degree	77%	University degree	72%
Gender	Women	78%	Men	74%
Birthplace	Born in Australia	76%	Immigrant	74%
Income	More than \$2000	78%	Between \$800 and \$2000	75%
Political interest	Moderate political interest	76%	High political interest	75%
Religion	No religion	92%	Protestant	69%
Ideology	Left	87%	Right	65%
Region	Regional city	76%	Country	76%
Vote Certainty	Undecided	76%	Decided	76%
Vote Intention	Greens	87%	Other (i.e. not Greens, Labor or Lib/Nat)	68%

The following additional observations can be made about the data in Table 1:

**There is greater variation** in the level of agreement with the statement between electoral Districts, than there is between electoral Regions; i.e. the level of agreement in the Regions tends to even out the differences in the various Districts.

**There is relatively little difference** between the highest and lowest level of agreement when the data is examined in terms of:

- a. Age
- b. Education
- c. Gender
- d. Birthplace
- e. Income
- f. Political interest
- g. Region - Melbourne, Regional city, Country
- h. Vote certainty.

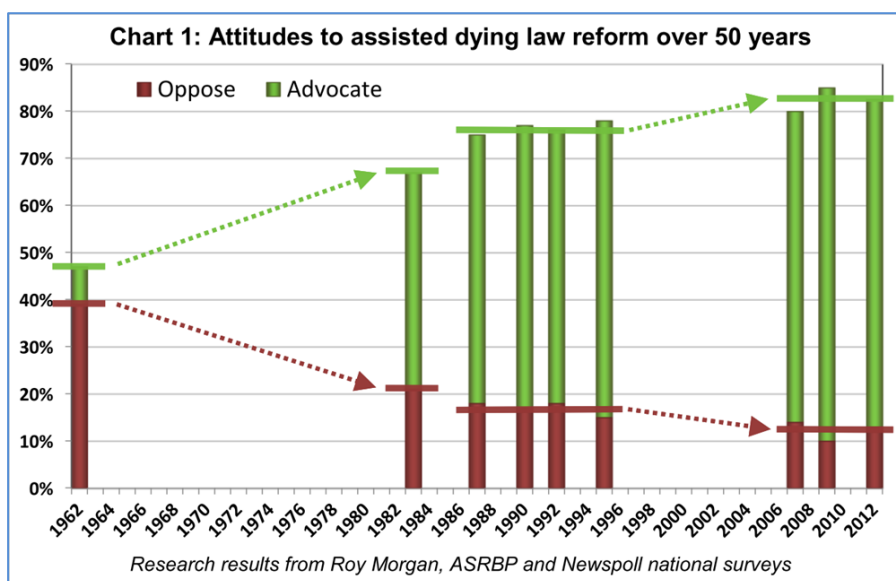
**There is significant difference** between the highest and lowest level of agreement when the data is examined in terms of:

- i. Religion – respondents identifying as having No Religion have the highest level of agreement of all groups (92%); interestingly more than 70% of Catholics also agree.
- j. Ideology – respondents identifying as having a Right ideology have the lowest level of agreement of all groups (65%)
- k. Vote intention.

## 7.4 Changing community attitudes to Voluntary Assisted Dying (VAD) in Australia

The *Medical Treatment Act 1988* (MTA) enabled patients to seek maximum pain relief and to refuse medical treatment. It is now some 27 years old and has not been substantially revised or reviewed since. During this time, there has been a change in community attitudes to voluntary assisted dying (VAD) for competent adults with a terminal or advanced incurable illness that creates unrelievable, profound suffering.

Support for assisted dying law reform reached a majority at least by the 1970s. In the 1980s it was a significant majority. By the 1990s, support had increased into the mid to high 70 per cents. Since 2000, support has been 80 per cent or higher.

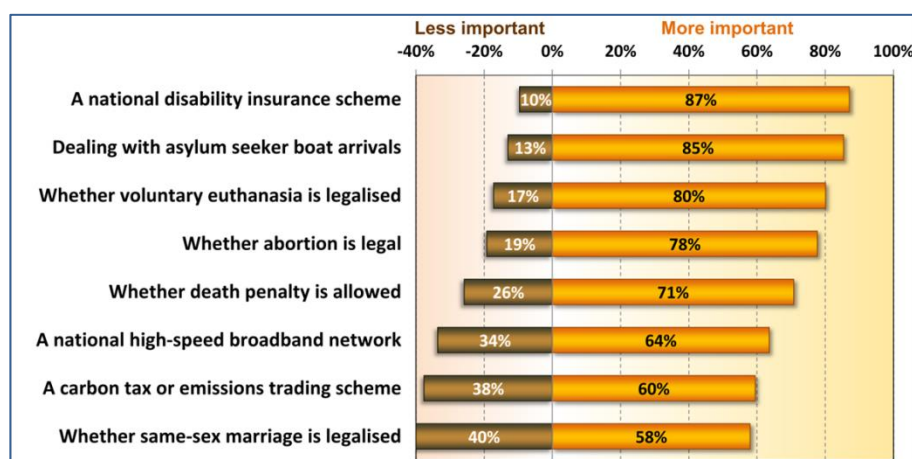




## 7.5 VAD is very important to voters

With 80 per cent support, voluntary euthanasia was the third most important issue for respondents to the 2012 Newspoll survey (see Chart 2) – considerably more important than other higher profile proposed reforms, such as marriage equality.

**Chart 2: The personal importance of "burning policy issues"**

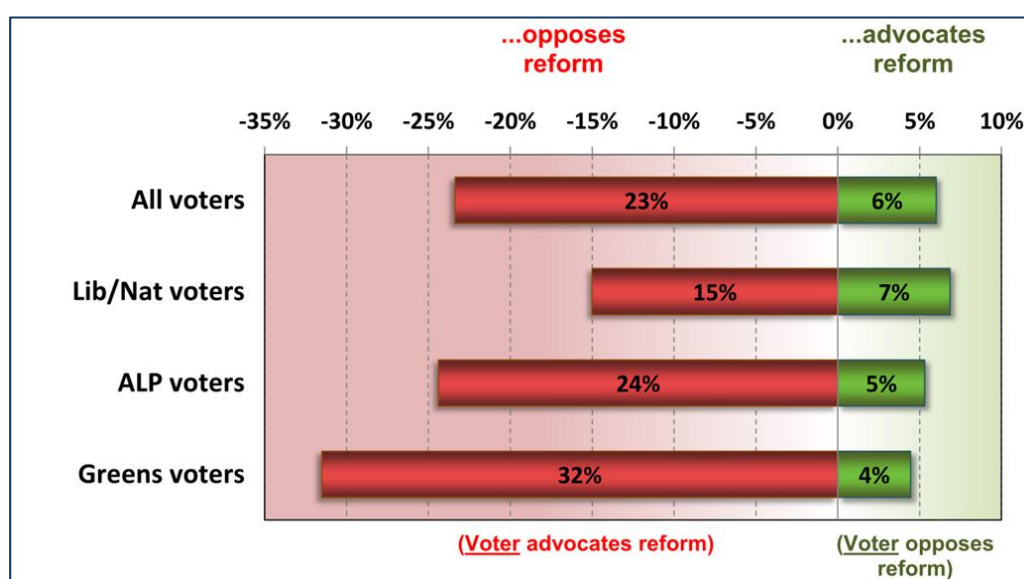


## 7.6 Voters will vote for MPs who support VAD

Some MPs may fear a backlash from powerful minorities, such as the religious hierarchies, if they were to act on introducing VAD. **Yet the 2012 Newspoll survey shows that for every vote an MP might lose for supporting VAD, she/he would gain four.** That is, election candidates have more to fear from *not* supporting VAD than they have from supporting it.

Chart 3 below, from the same poll, shows that by supporting VAD, nearly four times as many voters will change their vote against an election candidate who opposes assisted dying law reform, than will change their vote against one who advocates reform.

**Chart 3: Vote change if otherwise usual candidate opposes assisted dying reform**



## 8:

# Ethical argument

### 8.1 The ethics of VAD according to Justice Lynn Smith

The following is an edited extract from the judgement of *Carter v Canada* from 2012, with Justice Lynn Smith presiding. We present this edited extract here because it deals thoroughly and rigorously with the key ethical issues in voluntary assisted dying (VAD) in Australia as well as in Canada, since these ethical arguments transcend national boundaries.

Note that this judgement was overturned on appeal in British Columbia, and that decision was itself overturned on appeal to the Supreme Court of Canada in 2015.

(The boxed text emphases are ours.)

#### Summary of the ethical debate

[313] The plaintiffs do not argue that physician-assisted death should be imposed on patients who do not, themselves, request it. Therefore, the ethical debate relevant to this case focuses on a limited class of patients: those who are competent adults (decisionally capable); fully informed as to their diagnosis, prognosis and all options for treatment or palliative care; persistently and consistently requesting assistance with death (that is, non-ambivalent); and not subject to coercion or undue influence.

...

[315] ... my review of all the evidence shows that the ethical and practical arguments in favour of making physician-assisted death available to the limited category of patients described are:

- (a) The sanctity of life is a principle that is not absolute in our society (it is subject to exceptions such as self-defence) and, while it is central to the value system of a number of religions, that does not settle its place in a secular society.
- (b) The Hippocratic Oath derives from ancient Greece, but has been modified in modern times; a physician may not be harming a patient by assisting the patient to end a life of unbearable suffering.
- (c) The harm caused by death is to the individual who loses some time in life; but, for some individuals, death which brings an end to suffering is not a harm but a benefit.
- (d) No-one should be deprived of liberty, or forced to suffer, without adequate cause. Failing to respect an autonomous choice to die risks paternalism.
- (e) Individuals may experience such suffering (physical or existential), unrelievable by palliative care, that it is in their best interests to assist them in hastened death. Physicians are required to respect patient autonomy, to act in their patients' best interests and not to abandon them. Where those principles co-exist, assistance in hastened death may be ethically permitted.
- (f) If a patient's decision to hasten her own death by suicide is ethical, it may be ethical to provide assistance to that patient.
- (g) Medical ethics already permit practices that amount to assisting with hastened death (refraining from administering or discontinuing life-sustaining treatment, administering medication in doses which may hasten death and palliative sedation). The difference between those practices and physician-assisted suicide or voluntary euthanasia is ethically insignificant.

- (h) Some patients may find death while under palliative sedation repugnant or unacceptable, and may find other forms of palliative care unacceptable. Patients should not be required to submit to treatment against their wishes.
- (i) Decisions to give or withhold care are routinely made on the basis of medical prognoses and diagnoses, which have varying levels of accuracy. Physicians routinely assess whether their patients are competent and informed and whether their decisions to accept or reject treatment are influenced by depression, coercion or undue influence. The risks of error already accepted in end-of-life practice are low, and can be further reduced through stringent safeguards and monitoring.
- (j) The possibility of assisted death if continued life becomes unbearable may in itself alleviate suffering, even if a patient does not in the end take that course.
- (k) The availability of assisted death enables patients who believe that they will come to wish to end their lives, to prolong their lives because they will be able to postpone that choice to a time after they lose the physical ability to end their own lives.
- (l) It is unethical to refuse to relieve the suffering of a patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm.
- (m) Disabled people should not be deprived of the same degree of autonomy as others, and should not be presumed to be less likely to be competent and more likely to be susceptible to coercion or undue influence.
- (n) The physician-patient relationship is enhanced when a patient knows that her physician will not abandon her. It should not be assumed that physicians and other health-care providers will discard their focus on assisting patients and preserving life simply because assisted death becomes a legal option in limited circumstances.
- (o) Palliative care and physician-assisted death are not mutually exclusive; the former should be universally provided at a high level, and the latter should be available as a last resort option.
- (p) That there may be arguments for expansion of circumstances permitting physician-assisted death does not mean that those arguments will succeed.

## Conclusions about the ethical debate

...

[317] The overarching reason why the ethical debate is relevant is that both legal and constitutional principles are derived from and shaped by societal values.

[318] Additionally, the ethical debate bears on these questions:

- (1) Would Canadian physicians be willing to assist patients with hastening death if it were legal to do so?
- (2) Does current medical practice with respect to end-of-life care make distinctions that are ethically defensible, and is the distinction between suicide and assisted suicide ethically defensible?

...

### **a) Would Canadian physicians be willing to assist patients with hastening death if it were legal to do so?**

[319] The first question above can be answered concisely. The evidence reveals that there are experienced and reputable Canadian physicians who, in some circumstances, would find it consistent with their ethical principles to assist patients with hastening death if it were legal to do so.

- b) Does current medical practice with respect to end-of-life care make distinctions that are ethically defensible and is the distinction between suicide and assisted suicide ethically defensible?**

...

[321] The plaintiffs say that there is no relevant ethical distinction between physician-assisted dying on the one hand and end-of-life practices which are lawful, such as refraining from treatment, ceasing treatment or administering palliative sedation, on the other. ... In brief, the argument is that withdrawing a ventilator tube or maintaining a patient under sedation without hydration or nutrition are acts that will result in death, just as much as the act of providing a lethal prescription or administering lethal medications. To perform those acts, knowing of their inevitable consequences, is to hasten death. Similarly, refraining from life-saving treatment may result in the death of the patient, and is a passive form of hastening death. If those practices are ethical, then so is physician-assisted dying.

[322] The plaintiffs' position is that the accepted practices of respecting patients' wishes to withhold or withdraw life-sustaining treatment are both legal and ethical. Therefore, the plaintiffs say, physician-assisted death must also be ethical, and should be legal.

...

[334] The evidence shows that within the medical and bioethical community the question still remains open whether an ethical distinction is maintainable between withholding or withdrawing life-sustaining treatment and palliative sedation on the one hand, and physician-assisted death on the other.

[335] The preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death. I find the arguments put forward by those ethicists, such as Professor Battin, Dr. Angell and Professor Sumner, to be persuasive.

[336] In addition, the plaintiffs have provided evidence from a number of practitioners who doubt the existence of a valid ethical distinction.

[337] Some of the witnesses called by the defendants expressed similar doubts about an ethical distinction in individual cases, but opposed change in the law or in medical ethics because of the possible impact on other persons, on palliative care, on the physician-patient relationship or on society in general.

[338] In an individual case, whether based on a distinction between foreseeing and intending, on a distinction between acts and omissions, or on other grounds, a bright-line ethical distinction is elusive.

[339] I also find persuasive the arguments of Professor Sumner with respect to the absence of an ethical distinction between suicide and assisted suicide, if suicide is ethical. I agree that a distinction vanishes in the circumstances he specifies: the patient's decision for suicide is entirely rational and autonomous, it is in the patient's best interest, and the patient has made an informed request for assistance. The physician provides the means for the patient to do something which is itself ethically permissible. It is unclear, therefore, how it could be ethically impermissible for the physician to play this role.

**[End of extract.]**

## 8.2 Two additional ethical opinions

### Professor Max Charlesworth

... In a liberal society personal autonomy, the right to choose one's own way of life for oneself and correlative respect for the right of others to do the same is the supreme value. Certain consequences follow from the primacy given to personal autonomy in a liberal society. First, in such a society there is a sharp disjunction between the sphere of personal morality and the sphere of the law. Second, the liberal society is characterised by ethical pluralism, which allows a wide variety of ethical and religious (and non-religious) positions to be held by its members. Third, apart from the commitment to the primacy of personal autonomy and respect for the autonomy of others, there is no determinate social consensus about a set of "core values" or a "public morality" which it is the law's business to safeguard and promote. ...

M. Charlesworth, 'A Good Death' in *Willing to Listen – Wanting To Die*, ed H. Kuhse, Penguin, Melbourne, 1994, pp. 203ff.

### Professor Helga Kuhse

... Voluntary euthanasia offends against the sanctity-of-life view because it is an instance of the intentional termination of life. One person deliberately and purposefully terminates the life of an incurably ill person at that person's request. But are all cases of the intentional termination of life intrinsically or, as the sanctity-of-life view would hold, absolutely wrong? People who approach ethics from different moral, cultural or religious perspectives will often arrive at different answers. Because these different answers have their source in a particular value system, they cannot be shown to be true or false, in the ordinary sense of those terms.

This raises the question of an appropriate social response. Given that there is fundamental disagreement about the morality of a practice, how should modern pluralistic societies such as our own respond to it? Should they allow or prohibit the practice, and on what grounds?

It is now widely accepted that personal or autonomy or liberty is a very important value and that it is inappropriate for the state to either adopt a paternalistic stance towards its mature citizens, or to restrict their freedom through the enforcement of a particular moral point of view. Only if one person's actions cause harm to others is it appropriate for the state to step in, and to bring in laws that restrict individual liberty. As John Stuart Mill put it in his famous essay 'On Liberty': *'The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others ... over himself, over his own body and mind, the individual is sovereign'*.

The argument from liberty or autonomy suggests that people should, under the appropriate circumstances, be free to commit suicide, and that those who are terminally or incurably ill should be able to enlist the help of willing doctors to end their lives. ...

H Kuhse, 'Sanctity of Life, Voluntary Euthanasia and the Dutch Experience: Some Implications for Public Policy', in ed. Kurt Bayertz: *Sanctity of Life and Human Dignity*, Kluwer Academic Publishers, 1996, pp. 19ff.

## 9: Countering opponents claims

### 9.1 Objections raised in MTA debate – and what has transpired

The *Medical Treatment Act 1988* (MTA) was preceded by a parliamentary inquiry lasting some 18 months and debates in both houses of the Victorian Parliament. During the inquiry and subsequent debates, arguments were advanced about the dire consequences that would result if the bill were passed. DWDV expects these same arguments to be reused in the current inquiry. Here we review three of those key arguments, comparing the predicted outcomes with the actual outcomes. Since none of the predicted outcomes have eventuated, DWDV asserts that they were not valid predictions for MTA 1988, and therefore they are similarly unlikely to lead to actual outcomes for legalised voluntary assisted dying (VAD).

#### **Prediction: Destruction of trust between doctor and patient**

**Quotation:** *Such legislation should be opposed on the following grounds: ... (ii) it destroys the traditional relationship of trust between doctor and patient;* – Mr Hann MLA, Medical Treatment Bill, 6 May 1988, Assembly p.2249, quoting Rev Carter.

<i>Outcome to be expected if claim were correct</i>	<i>Actual outcome</i>
Patients would reduce their visits to doctors.	Per capita visits to doctors have increased, not decreased.*

\*In the 12 years to FY2014, there was a 37% increase in the number of Medicare funded services provided in Victoria, and an increase of almost 100% in the Medicare spending per capita over that period, from \$416.7 to \$830.9. [http://medicarestatistics.humanservices.gov.au/statistics/mbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/mbs_item.jsp)

#### **Prediction: Coercion by avaricious relatives to refuse treatment**

##### **Quotations:**

*There will be no waste of time in Committee. The government will consider argument. However, it is not assisted by public comment that says that if the Bill is passed old people will have forms refusing treatment shoved under their noses to sign so that they will prematurely die and their relatives will get their money.* The Hon D R White MLC, Medical Treatment Bill (No.2), 3 May 1988, Council p.1020.

*... It would be particularly obnoxious if powers of attorney were to be abused by persons expecting an inheritance and the death of a patient were to be hastened by neglect or even starvation. ...* Mr Williams MLA, Medical Treatment Bill, Assembly p.2257.

<i>Outcome to be expected if claim were correct</i>	<i>Actual outcome</i>
Prosecutions and complaints for investigation would be made to Victoria Police and to health officials and minister.	There is no record of any prosecutions or complaints of the nature described.*

\*DWDV holds letters from 2014 from the then Chief Commissioner of Police and Health Minister, advising no record of any prosecutions or complaints made against avaricious relatives inducing refusal of treatment under the MTA by an ill/elderly person.



**Prediction: Palliative care will be under-funded**

**Quotation:** *There is also a danger that there would be reduced investment in improving palliative care by research and reduced need seen to increase the availability and access to palliative care.* Mrs Terri Kelleher, President, Australian Family Association, Proof Committee Hansard, 15 October 2014, p.16.

<i>Outcome to be expected if claim were correct</i>	<i>Actual outcome</i>
Reduced per capita spending on palliative care.	Palliative care has received increased funding over the years since 1988.*

\*'The government has committed \$34.4 million new funding over four years for palliative care in the 2011–12 State Budget.' *Strengthening palliative care: Policy and strategic directions 2011–2015*

'In 2005 and 2011 additional growth funding was allocated... in 2013–14 DHHS' funding for palliative care provision was approximately \$111.1 million.' *Palliative Care*, Victoria Auditor-General's report, April 2015

'There was a 49% increase in palliative care-related separations between 2001–02 and 2010–11. ... Over the 5 years to 2011–12, the MBS benefits paid for all palliative medicine specialist services more than doubled ... This equates to an average annual rate increase of 21.1%.'

*Palliative care services in Australia 2013*, Australian Institute of Health and Welfare.

## 9.2 More opposing claims, with DWDV responses

Claim	DWDV response
<i>Medical training is designed to save life, not take it.</i>	Medicine has two aims – to preserve life and alleviate suffering. However, under certain circumstances, medicine may not be able to preserve life, therefore alleviating suffering becomes the legal and ethical priority.
<i>Some ageing people may be seen as a burden to their families who may seek to coerce them into 'choosing' VAD.</i>	Patients can already be coerced into refusing or withdrawing treatment. A formal, safe and secure process is needed, with effective safeguards that will protect the vulnerable ( <a href="#">see p. 10</a> ).
<i>Patients may change their minds after a request for VAD (see 9.2).</i>	A cooling-off period will be essential (except in the terminal phase of a terminal illness), and requests for VAD must be properly witnessed. Knowing VAD will be available removes the need to act hastily and make an immediate decision.
<i>VAD will be available to anyone, regardless of circumstances.</i>	We propose VAD should be available only to a mentally competent adult who is terminally ill or has intolerable, unrelievable suffering. It should not be available to people suffering clinical depression, as they may lack the capacity to decide. Choosing to die because of intolerable and unrelievable suffering near the end of life can be rational, but a psychological illness alone would not justify VAD.
<i>Some patients will have religious convictions about the sanctity of life.</i>	Religious convictions are to be respected, but it is not acceptable for the religious beliefs of some individuals to be imposed on others in a secular society. Patients have the right to make their own difficult end of life decisions.
<i>With life prolonged, a cure may be found for the patient's disease.</i>	Whilst this may be the case, the immediacy and intolerability of some suffering cannot wait for a possible future cure.
<i>VAD devalues life.</i>	Each person has the right to self-determination in choosing whether they preserve life or obtain medical assistance to end their life. Relieving intolerable suffering for someone who is dying respects life and quality of life.



Claim	DWDV response
<i>A slippery slope (1) - permitting VAD will lead to various abuses that are currently contained.</i>	With sufficient safeguards, abuse can be minimised. There is anecdotal evidence that abuse is occurring now. Putting in place a rigorous, formal, safe and secure process with VAD being available only to competent adults who provide informed consent will prevent abuse. The Oregon system has had a demonstrated absence of abuse.
<i>Slippery-slope (2) - assisted suicide legislation can be readily widened.</i>	Presumably any such widening could take place only under legislation from parliament.
<i>Alleviation of suffering by 'killing' the patient is sinful or unworthy.</i>	It is important to use the proper words to describe the process of VAD, which is justifiably ending suffering, not killing. Using such emotive words trivialises the suffering that people are forced to endure, and demonstrate a lack of compassion.
<i>The needs of the dying are covered by palliative care and the provisions of the Medical Treatment Act.</i>	Nearly all palliative care specialists agree that not all pain can be relieved by palliative care. The Medical Treatment Act allows for the withdrawal of treatment, but has no provision to assist those in great pain who are not in the final phase of a terminal illness.
<i>There is no way to guarantee the absence of coercion.</i>	People are now coerced into intolerable suffering. The greater good for the greater number is better served by the availability of a suitably regulated way to end suffering.
<i>A desire to harvest organs may become a reason for VE.</i>	Stringent legal safeguards will prevent this.
<i>'God will decide when I die.'</i>	Many in our society do not believe in God. There are also many who do, but who also see the regulated and compassionate ending of unendurable suffering as consistent with their belief.
<i>Few medical practitioners are trained or qualified to assess patients who ask for assisted suicide.</i>	We suggest that this matter be addressed with training, to be provided for in the relevant legislation.

## 10:

# Influence of religious belief

### 10.1 Religious hierarchies and their doctrines

A number of religious organisations have doctrines that dictate against any form of suicide and, unsurprisingly, also have adherents who are strongly opposed to VAD. But strength of feeling alone by a specific faith group is not sufficient as a basis for broad social policy in a secular society. At the same time, the official view of the religious hierarchies regarding assisted dying may not necessarily be held by all their followers. Indeed, this seems to be the case, as discussed in 10.3 below.

### 10.2 Doctrines against VAD\*

The Roman Catholic and Anglican churches are two examples of religious groups advocating against any form of assisted dying.

#### Roman Catholic

[http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19800505\\_euthanasia\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html)

The Roman Catholic *Declaration on Euthanasia* of May 1980 states ‘... it is ... an offense against the dignity of the human person, a crime against life, and an attack on humanity.’

and

2. *Everyone has the duty to lead his or her life in accordance with God's plan. That life is entrusted to the individual as a good that must bear fruit already here on earth, but that finds its full perfection only in eternal life.*

3. *Intentionally causing one's own death, or suicide, is therefore equally as wrong as murder; such an action on the part of a person is to be considered as a rejection of God's sovereignty and loving plan.*

(There is direct reference here to God, but a search of the Bible seems to provide no support for these statements.)

#### Anglican

<https://churchofengland.org/our-views/medical-ethics-health-social-care-policy/assisted-suicide/protecting-life-opposing-assisted-suicide.aspx>

Anglican doctrine provides: ‘*The Church of England is opposed to any change in the law, or medical practice, to make assisted suicide permissible or acceptable. Suffering, the Church maintains, must be met with compassion, commitment to high-quality services and effective medication.*’

**\*Statements in support of such doctrines are often expressed in the form of objections to VAD on general grounds, such as difficulties with interpretation of the law, and alleged pressures that legalisation of VAD would impose on patients and medical staff.**

### 10.3 Factors to be weighed against religious doctrines

#### Australia is a secular society

Section 116 of the Australian Constitution states:

*The Commonwealth shall not make any law for establishing any religion, or for imposing any religious observance, or for prohibiting the free exercise of any religion, and no religious test shall be required as a qualification for any office or public trust under the Commonwealth.*

There have been a number of High Court judgements in relation to the matter of religion. In particular, in 1943, Latham CJ in the *Jehovah's Witnesses Case* stated: "*The prohibition in s 116 operates not only to protect the freedom of religion, but also to protect the right of a man to have no religion ... Section 116 proclaims not only the principle of toleration of all religions, but also the principle of toleration of absence of religion.*" <http://www.uniset.ca/other/cs5/67CLR116.html>

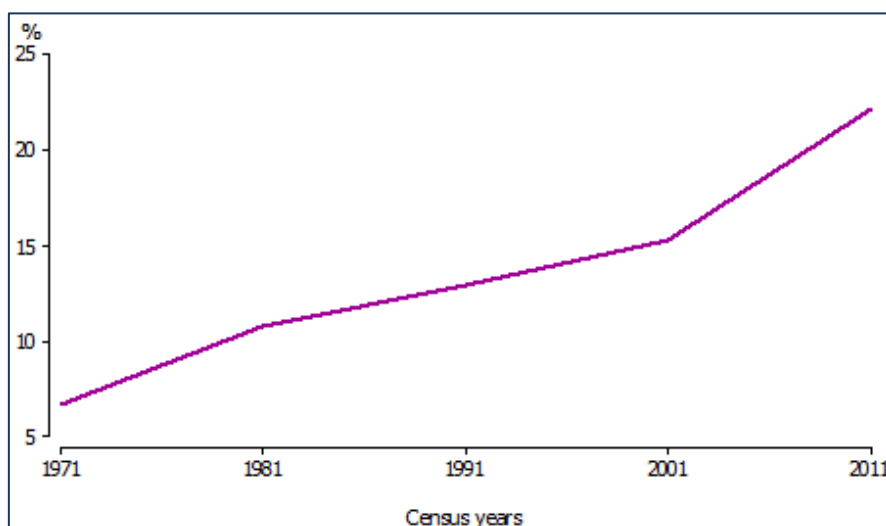
Accordingly, the dictates of any faith apply in Australia only to the adherents of that faith, and as a matter of faith only, not by direct reference to Australian law.

#### Religiosity is decreasing

As to the extent to which religious views hold sway in the community as a whole, a 2010 General Social Survey by the Australian Bureau of Statistics (ABS 4102.0, [Australian Social Trends](#), Nov 2013) found that:

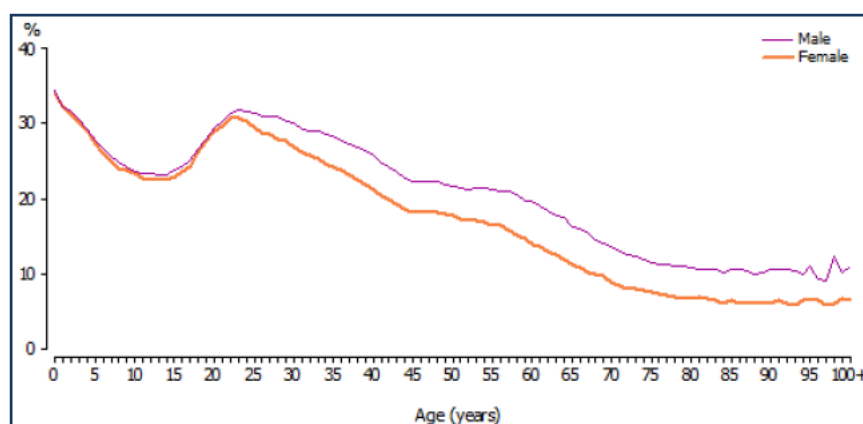
- [Only] 15% of men and 22% of women aged 18 years and over said they had actively participated in a religious or spiritual group.
- The number of people reporting no religion in Australia has increased substantially over the past hundred years, from one in 250 people to (now) one in five.
- Younger people make up a high proportion of those reporting no religion (around half who did so being less than 30 years old).
- As the rising trend of reporting no religion is driven by younger people, and the tendency is for religious affiliation to remain stable in cohorts, it is likely that we will see Australia become increasingly more secular in the future.

**Chart 5. Percentage of people reporting no religion, 1971 - 2011**



Source: ABS Censuses of Population and Housing, 1971- 2011

Chart 6. Percentage of people reporting no religion by age and sex, 2011



Source: ABS Census of Population and Housing, 2011

### Most people of faith support VAD

The table below, summarising results from the ABC Vote Compass survey preceding the 2014 Victorian state election, shows that the vast majority of adherents of all religions, as well as those with no religion, agree with the survey statement quoted in section 5.1:

***Terminally ill patients should be able to legally end their own lives with medical assistance.***

Table 7. Percentages of support for VAD, by religion

Religion	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree	Total agree	Total disagree
Catholic	39.4%	31.2%	10.6%	6.8%	10.9%	71%	18%
Protestant	42.6%	26.5%	10.5%	6.2%	12.9%	69%	19%
Other religion	51.9%	23.8%	10.3%	4.3%	8.0%	76%	12%
No religion	70.1%	21.8%	4.7%	1.6%	1.5%	92%	3%

The last two columns are rounded.

### There are religious groups which support VAD

The organisation Christians Supporting Choice for Voluntary Euthanasia (<http://christiansforve.org.au/>) provides the following:

*... the term 'sanctity of life' appears nowhere in the bible. Interpreting selected passages of the bible to mean so is a personal matter for the individual. It's a human construction. One could equally interpret other passages of the bible to authorise or justify selling daughters into slavery or putting whole peoples to the sword.*

*For a Christian, God is not honoured by a person (made in the 'image' of God) abdicating her autonomy and freedom of will and passively submitting to 'fate'.*

The Catholic theologian Hans Küng has taken a similar position. In his view, 'God, who has given men and women freedom and responsibility for their lives, has also left to dying people the responsibility for making a conscientious decision about the manner and time of their deaths. This is a responsibility which neither the state, nor the church, neither a theologian, nor a doctor can take away'.

## 10.4 Conclusion

We accept that religion has a substantial presence in Australia, and that there is significant opposition to VAD from several of the organisational bodies. However, in a secular society we do not consider that any opinion based on faith should determine legislation.

## Appendix A:

### Analysis of Vote Compass data on support for assisted dying law reform

Our analysis is based on the ABC Vote Compass survey conducted prior to the Victorian state election in November 2014. The Approach section below details the Vote Compass method and how we analysed the data, followed by a detailed tabulated analysis of the data.

#### Approach

The following edited extract is from the FAQ section about the survey results map at

<http://www.abc.net.au/news/2014-11-28/victorian-election-map-vote-compass/5922650>.

The ABC launched [Vote Compass Victoria](#) on Sunday November 2, in the lead-up to the state election. It is a tool that allows voters to see how their views compare to the parties' policies.

The data gathered about voters' views on the issues were weighted across a range of demographic factors using the latest population estimates to be a true representation of opinion at the time of the field.

The map [of survey results] is based on 61,691 respondents to the Vote Compass application between November 2 and November 21, 2014.

... Vote Compass is not a [random sample] poll. It is fundamentally an educational tool intended to promote electoral literacy and stimulate public engagement in the policy aspect of election campaigns.

That said, respondents' views as expressed through Vote Compass can add a meaningful dimension to our understanding of public attitudes and an innovative new medium for self-expression. Ensuring that the public has a decipherable voice in the affairs of government is a critical function of a robust democracy.

Online surveys are inherently prone to selection bias but statisticians have long been able to correct for this (given the availability of certain variables) by drawing on population estimates such as Census micro-data.

The ABC applies sophisticated weighting techniques to the data to control for the selection effects of the sample, enabling us to make statistical inferences about the Australian population with a high degree of confidence.

... There are multiple safeguards in place to ensure the authenticity of each record in the dataset.

Vote Compass does not make its protocols in this regard public so as not to aid those that might attempt to exploit the system, but among standard safeguards such as IP address logging and cookie tracking, it also uses time codes and a series of other measures to prevent users from gaming the system.

The more common alternative form of polling to this type of online survey is to use structured, random telephone calling. The latter technique suffers from two main problems:

- large samples of more than 10,000 respondents are very expensive (though omnibus surveys can be used to spread costs)
- the community is tiring of the extensive polling and market research being undertaken, so there are many refusals for interviews, thus affecting the actual 'randomness' of such polls. In other words, respondents to randomised telephone surveys are also to a degree self-selected, given the high level of refusals.

So while neither approach is perfect, they can provide a good indication of community sentiment on the various issues explored. A major advantage of the Vote Compass approach is that it has provided sufficient responses to be able to analyse responses by electoral District across the state, which would be difficult to achieve using random phone polling, due to high cost.

There were five possible responses to a Vote Compass question:

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree

We have grouped the first two response categories to derive the proportion who agree with the statement (at least to some extent), and likewise, we have grouped the last two response categories to derive the proportion who disagree with the statement (at least to some extent). This approach was used to analyse agreement levels in all categories except by District (and Region); data at that level of detail was not provided at the District level.

The Vote Compass map at <http://www.abc.net.au/news/2014-11-28/victorian-election-map-vote-compass/5922650>, with *Euthanasia* selected from the drop down list, shows the level of agreement in each District relative to the state average. To derive the actual level of agreement in a District requires a multiplicative combination of the two factors. For example:

Bayswater District agrees with the statement 3.8% less than the state average. We multiply the state average of 75.8% with  $(100\% - 3.8\% = 96.2\%)$  to derive the agreement level for Bayswater. ie,  $75.8\% \times 96.2\% = 72.9\%$ . We round this to 73% to reflect our perceived level of accuracy of this figure.

Agreement levels for Regions were calculated by averaging the District agreement levels within each Region.

#### Analysis by electoral Region and District

Vote Compass response	State average level of agreement	District compared to state average	Net level of agreement <sup>#</sup>
<b>Eastern Metropolitan Region</b>			
Bayswater District	75.8%	-3.8%	73%
Box Hill District	75.8%	-4.4%	72%
Bulleen District	75.8%	-6.0%	71%
Croydon District	75.8%	-1.8%	74%
Eltham District	75.8%	8.1%	82%
Ferntree Gully District	75.8%	-5.8%	71%
Forest Hill District	75.8%	-6.3%	71%
Ivanhoe District	75.8%	-3.5%	73%
Mount Waverley District	75.8%	-6.6%	71%
Ringwood District	75.8%	-5.3%	72%
Warrandyte District	75.8%	-3.1%	73%
Average for Region	75.8%	-3.5%	73%



Vote Compass response	State average level of agreement	District compared to state average	Net level of agreement <sup>#</sup>
<b>Eastern Victoria Region</b>			
Bass District	75.8%	0.3%	76%
Evelyn District	75.8%	-0.3%	76%
Gembrook District	75.8%	-1.4%	75%
Gippsland East District	75.8%	1.4%	77%
Gippsland South District	75.8%	2.6%	78%
Hastings District	75.8%	2.2%	77%
Monbulk District	75.8%	-1.8%	74%
Mornington District	75.8%	-1.0%	75%
Morwell District	75.8%	-2.9%	74%
Narracan District	75.8%	-2.5%	74%
Nepean District	75.8%	9.7%	83%
Average for Region	75.8%	0.6%	76%

<b>Northern Metropolitan Region</b>			
Broadmeadows District	75.8%	-6.9%	71%
Brunswick District	75.8%	19.4%	91%
Bundoora District	75.8%	-6.2%	71%
Melbourne District	75.8%	14.8%	87%
Mill Park District	75.8%	-7.2%	70%
Northcote District	75.8%	29.3%	98%
Pascoe Vale District	75.8%	3.4%	78%
Preston District	75.8%	1.6%	77%
Richmond District	75.8%	25.8%	95%
Thomastown District	75.8%	-2.9%	74%
Yuroke District	75.8%	-6.7%	71%
Average for Region	75.8%	5.9%	80%

<b>Northern Victoria Region</b>			
Benambra District	75.8%	-0.9%	75%
Bendigo East District	75.8%	-3.0%	74%
Bendigo West District	75.8%	-0.7%	75%
Eildon District	75.8%	18.0%	89%
Euroa District	75.8%	-0.1%	76%
Macedon District	75.8%	11.9%	85%
Mildura District	75.8%	-2.9%	74%
Murray Plains District	75.8%	-3.9%	73%
Ovens Valley District	75.8%	9.5%	83%
Shepparton District	75.8%	-2.1%	74%
Yan Yean District	75.8%	-2.8%	74%
Average for Region	75.8%	2.1%	77%



Vote Compass response	State average level of agreement	District compared to state average	Net level of agreement #
<b>South Eastern Metropolitan Region</b>			
Carrum District	75.8%	5.6%	80%
Clarinda District	75.8%	-0.7%	75%
Cranbourne District	75.8%	-4.9%	72%
Dandenong District	75.8%	-2.4%	74%
Frankston District	75.8%	1.4%	77%
Keysborough District	75.8%	-1.8%	74%
Mordialloc District	75.8%	-0.1%	76%
Mulgrave District	75.8%	-7.9%	70%
Narre Warren North District	75.8%	-6.3%	71%
Narre Warren South District	75.8%	-6.0%	71%
Rowville District	75.8%	-5.6%	72%
Average for Region	75.8%	-2.6%	74%

<b>Southern Metropolitan Region</b>			
Albert Park District	75.8%	11.9%	85%
Bentleigh District	75.8%	-0.3%	76%
Brighton District	75.8%	15.2%	87%
Burwood District	75.8%	-3.2%	73%
Caulfield District	75.8%	13.8%	86%
Hawthorn District	75.8%	1.1%	77%
Kew District	75.8%	-2.8%	74%
Malvern District	75.8%	-3.1%	73%
Oakleigh District	75.8%	-2.2%	74%
Prahran District	75.8%	9.5%	83%
Sandringham District	75.8%	7.4%	81%
Average for Region	75.8%	4.3%	79%

<b>Western Metropolitan Region</b>			
Altona District	75.8%	-3.4%	73%
Essendon District	75.8%	3.6%	79%
Footscray District	75.8%	4.9%	80%
Kororoit District	75.8%	-5.6%	72%
Niddrie District	75.8%	-3.6%	73%
St Albans District	75.8%	-2.0%	74%
Sunbury District	75.8%	-5.5%	72%
Sydenham District	75.8%	-5.4%	72%
Tarneit District	75.8%	-4.1%	73%
Werribee District	75.8%	-4.8%	72%
Williamstown District	75.8%	12.0%	85%
Average for Region	75.8%	-1.3%	75%

Vote Compass response	State average level of agreement	District compared to state average	Net level of agreement <sup>#</sup>
<b>Western Victoria Region</b>			
Bellarine District	75.8%	7.2%	81%
Buninyong District	75.8%	-1.9%	74%
Geelong District	75.8%	-2.5%	74%
Lara District	75.8%	0.6%	76%
Lowan District	75.8%	-6.6%	71%
Melton District	75.8%	-2.2%	74%
Polwarth District	75.8%	-1.3%	75%
Ripon District	75.8%	-1.4%	75%
South Barwon District	75.8%	-2.1%	74%
South-West Coast District	75.8%	-3.9%	73%
Wendouree District	75.8%	-3.3%	73%
Average for Region	75.8%	-1.6%	75%

<sup>#</sup> Net level of agreement is calculated by multiplying the state average by (100% + the district level compared to state average). The figures in this column have been rounded to reflect DWDV's perceived level of accuracy.

#### Analyses by demographics other than electoral District or Region

Vote Compass response	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree	Rounded <sup>#</sup>	
						Total agree	Total disagree
<b>Statewide average</b>	49.3%	26.5%	9.0%	5.1%	9.1%	76%	14%

<b>By Age</b>							
18-34	45.5%	28.8%	11.0%	5.1%	7.9%	74%	13%
35-54	50.1%	27.7%	8.1%	4.8%	8.5%	78%	13%
55+	51.7%	23.4%	8.4%	5.3%	10.5%	75%	16%

<b>By Education</b>							
University degree	43.2%	28.5%	9.6%	7.0%	10.7%	72%	18%
No university degree	51.2%	25.9%	8.8%	4.5%	8.5%	77%	13%

<b>By Gender</b>							
Men	46.9%	27.1%	10.0%	5.6%	9.5%	74%	15%
Women	51.5%	26.0%	8.2%	4.6%	8.6%	78%	13%

<b>By Birthplace</b>							
Born in Australia	49.3%	27.0%	8.9%	5.1%	8.8%	76%	14%
Immigrant	49.4%	24.4%	9.7%	4.8%	10.5%	74%	15%

Vote Compass response	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree	Rounded #	
						Total agree	Total disagree
<b>Income</b>							
Less than \$800	52.6%	22.8%	9.2%	4.4%	10.1%	75%	15%
Between \$800 and \$2000	49.8%	25.4%	9.1%	5.1%	9.7%	75%	15%
More than \$2000	48.2%	29.3%	8.8%	5.0%	7.9%	78%	13%

<b>By Political Interest</b>							
High political interest	52.3%	22.2%	8.7%	4.7%	11.3%	75%	16%
Moderate political interest	47.5%	28.9%	9.3%	5.1%	8.5%	76%	14%
Low political interest	49.3%	26.8%	10.0%	5.3%	7.6%	76%	13%

<b>By Religion</b>							
Catholic	39.4%	31.2%	10.6%	6.8%	10.9%	71%	18%
Protestant	42.6%	26.5%	10.5%	6.2%	12.9%	69%	19%
Other religion	51.9%	23.8%	10.3%	4.3%	8.0%	76%	12%
No religion	70.1%	21.8%	4.7%	1.6%	1.5%	92%	3%

<b>By Ideology</b>							
Left	64.0%	22.6%	6.2%	3.2%	3.1%	87%	6%
Centre-left	50.1%	29.8%	8.7%	5.5%	4.7%	80%	10%
Centre	49.7%	25.9%	10.1%	4.1%	9.4%	76%	14%
Centre-right	41.3%	26.6%	11.8%	7.2%	12.7%	68%	20%
Right	42.9%	22.4%	9.3%	4.8%	20.0%	65%	25%

<b>By Region</b>							
Melbourne	48.9%	26.9%	9.3%	5.0%	8.7%	76%	14%
Regional City	49.1%	26.8%	7.4%	5.6%	10.0%	76%	16%
Country	51.0%	24.8%	9.0%	4.8%	9.7%	76%	15%

<b>By Vote Certainty</b>							
Decided	49.6%	26.2%	8.8%	5.0%	9.3%	76%	14%
Undecided	46.5%	29.3%	11.0%	5.4%	6.5%	76%	12%

<b>By Vote Intention</b>							
Labor	51.2%	27.9%	9.3%	5.1%	5.4%	79%	11%
Liberal/National	42.1%	29.0%	10.1%	6.0%	12.0%	71%	18%
Greens	61.4%	25.7%	6.3%	2.8%	2.7%	87%	6%
Other	48.6%	18.9%	9.0%	5.0%	17.4%	68%	22%

# The totals have been rounded to reflect DWDV's perceived accuracy of these figures

## Appendix B:

### Glossary

**Advance healthcare directive:** A document by which a person makes provision for healthcare decisions to apply in the future in the event that he/she becomes unable to make or communicate decisions.

**Advanced incurable illness:** A severe permanent illness, with no predictable timeframe to death, which causes significant unremitting symptoms, and no effective treatment is available to alter the course of the illness, or to relieve the intolerable suffering. Its course may be either remorseless and progressive, or static.

**Assisted suicide (AS):** A patient is prescribed or otherwise supplied with a lethal substance by a doctor, which the patient self-administers in order to end their life. Also known as ‘voluntary assisted dying’.

**Euthanasia:** Translates from Greek as ‘a good death’. The act of painlessly, but deliberately causing the death of another creature suffering from an incurable, painful disease or condition.

**Graseby pump (‘syringe driver’):** An electrically driven pump providing continuous delivery of medication.

**Intolerable suffering:** Physical and/or mental suffering that is intolerable to a person, and confirmed to be reasonably so by at least two independent doctors.

**Medical Treatment Act 1988 (Victoria):** Establishes the right of a patient to receive maximum pain relief and to refuse medical treatment. The Act allows for the appointment of an agent with Enduring Power of Attorney (Medical Treatment) who is empowered to make decisions on behalf of an incompetent patient.

**Midazolam:** A sedative or hypnotic used for medical and surgical procedures and for sedating dying patients.

**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.’ [World Health Organization]

**Rational suicide:** The ending of one’s life for considered reasons as opposed to emotional or psychological reasons – suicide can be a rational choice by a terminally ill person.

**Slippery slope:** A term used in argument, claiming events or actions will readily progress from one state to another, less desirable state. The ‘slippery slope argument’ is often used by opponents of progressive reform in an attempt to maintain the status quo.

**Sufferer:** A mentally competent adult who has a terminal or incurable illness that creates intolerable suffering which cannot be relieved or treated in a manner acceptable to that person.

**Suicide:** The act of taking one’s own life intentionally and voluntarily.

**Terminal illness:** An irreversible condition that in the near future will result in death or a state of permanent unconsciousness.

**Terminal phase of a terminal illness:** The phase of an illness reached when there is no real prospect of recovery or remission of symptoms, on either a temporary or permanent basis.

**Terminal sedation:** The process of inducing a coma-like state through medication – generally practised during the final days or hours of a dying patient’s life, when symptoms such as pain, nausea, breathlessness or delirium cannot be controlled in the conscious patient. Death may occur from the sedation’s secondary effects of dehydration or other intervening complications, or because of the primary illness.

**Unrelievable suffering:** Physical and/or mental suffering that has persisted despite treatment and which the person and their doctor agree is unrelievable by any treatment available and acceptable to the person.

**Voluntary assisted dying (VAD):** A patient is prescribed or otherwise supplied with a lethal substance by a doctor, which the patient self-administers in order to end their life. Dying With Dignity Victoria advocates VAD. (Also known as ‘assisted suicide’.)

**Voluntary euthanasia:** A patient’s life is ended at their own request by a doctor administering a lethal substance, usually by injection.