dying with dignity victoria

Submission to an Inquiry into end-of-life choices

by a Joint Committee of the South Australian Parliament established for the purpose

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1 August 2019

Ms Leslie Guy
Secretary to the Committee
C/- Parliament House
GPO Box 572, Adelaide 5001.

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

This submission seeks to address the terms of reference as provided:

a) The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;

(b) The current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian and Western Australian Parliamentary Inquiries into end-of-life choices, Victoria's Voluntary Assisted Dying Act (2017) and implementation of the associated reforms;

(c) What legislative changes may be required, including consideration of: The appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's Voluntary Assisted Dying Act (2017); and an examination of any federal laws that may impact such legislation.

(d) Any other related matter.

Yours sincerely

Hugh Sarjeant
President

John Hont
Board Member

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Contents

1 Executive summary

The world moves toward options for assisted death with the increasing acceptance that it is the individual who should, subject to some conditions, be in control of the end of life process.

The practices currently being utilised to manage end of life, as requested in Term of Reference **ToR (a)** are addressed in Sections 2 and 3.

The current legal framework in Australia and overseas, in response to **ToR (b),** is detailed in Appendix E and very briefly reviewed in Section 5.

In response to **ToR (c),** as to the appropriateness of Victoria's Voluntary Assisted Dying Act 2017 for South Australia, in Sections 8 and 9 we provide information on the effectiveness of the Victorian implementation with some recommendations. This includes a comment on a conflict that has arisen between that Act and a federal law.

We provide other related material that should be considered by South Australia when contemplating a new voluntary assisted dying regime. This is in response to **ToR (d)**. It includes a view of the strong community support for this view (Section 4). Opposition by some sectors of the medical profession appears to stem from their view that they should have more control over their clients' fate rather than the clients themselves. The arguments offered against assisted dying have been refuted many times (Section 7), but are offered again, nevertheless. Perhaps this is based on the premise that an incorrect assumption, if offered often enough, somehow becomes correct. We also provide a discussion of the safeguards used in various jurisdictions. Ethical arguments supporting voluntary assisted dying are provided in Appendix C.

This submission supports a position that, while recognising the valuable work done by palliative care, albeit with its limitations (Section 3), there also should be voluntary assisted dying ("VAD") available to the community. The criterion for the availability of VAD should be suffering which is both intolerable and unrelievable. This would include cases of advanced incurable illnesses, noting also that loss of dignity is a serious matter for many. Safeguards should be sufficient to protect the vulnerable (Section 6), but not so onerous as to defeat the aim of providing assisted dying.

The Victorian experiment has provided some optimism that the chance of experiencing a bad death has been reduced, but, despite lengthy preparation, there are difficulties with the implementation (Sections 8 and 9).

There is no contention to the view that there should be no compulsion to either participate or not participate in an assisted death of a sufferer.

2 The reality of modern dying – where VAD is not available

2.1 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 20th 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.

2.2 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.

2.3 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.[1]

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.

2.4 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 [2]:

- 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'*. [3].

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 [4]. McCarthy and Addington-Hall found 23% of patients dying from heart disease had expressed a wish to die sooner [5]. Seale and Addington-Hall found that 26% of patients in hospice had wanted an earlier death [6]. They did not find support for the view that requests for euthanasia are uncommon in hospice.

2.5 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.

2.6 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 [7]. 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* [8]*. 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'* [9]. 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.

2.7 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.

2.8 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 [10] 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'* [11]. Douglas Martin asserted that '*the principle of autonomy is the dominant ethic of health care in North America and Western Europe* [and Australia]'. [12].

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.

2.9 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.

2.10 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.

2.11 Serious defects in the practice of end-of-life medicine without voluntary assisted dying

- 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.
- 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) [13].

2.12 Attitudes of medical practitioners and their organisations

The Royal Australian College of General Practitioners (RACGP) made no submission to the 2015 Victorian Inquiry, but on the day after the passage on the Victorian bill in the lower house the then president Dr Seidel made statements resulting in the headline “RACGP welcomes moves to allow terminally ill Victorian patients to die with dignity and respect”.

An Australian Medical Association report into a survey of members notes

“ … *dying is ultimately a societal issue, and*
if governments decide that laws governing euthanasia and physician assisted suicide should be changed, medical practitioners must be involved in developing relevant legislation, protocols and guidelines which protect vulnerable groups, patients and doctors who do not want to participate and the functioning of the health system as a whole.

In terms of member support, “… it was clear that the results of the consultation process did not yield a mandate for change.”. However, whilst it was about 50/50 for the question “*medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life. …”* (50 for, 38 against ,12 neither)*, it* was notable that the values were 31, 52, and 17 respectively in the youngest age group.

2.13 References

[1] Linda Foreman et al., *Palliative Medicine,* 2006:20;447

[2] M Klinkenberg et al., *Journal of Pain and Symptom Management,* (JPSM) 2004:27;5

[3] C J McPherson et al., *Palliative Medicine,* 2007:21;115

[4] Roger Hunt et al. *Palliative Medicine,* 1995:9;167

[5] M MCarthy & J Addington-Hall, *Journal of Pain and Symptom Management*, 1997:90;128

[6] C Seale & J Addington-Hall, *Social Science and Medicine*, 1995:40;587

[7] R J Kohlwes et al., *Archives of Internal Medicine,* 2001:161;657

[8] K G Wilson et al., *Archives of Internal Medicine,* 2000:160;2454

[9] J-J Georges et al., JPSM2006:31:100

[10] P Singer et al., *Journal of the American Medical Association,* 1999:281;163

[11] J Zalcberg, *Melbourne Observer,* 19/1/1996

[12] D Martin et al., *Lancet* 2000:356;1672

[13] B White, L.Wilmot & J Savulescu, *Journal of Law and Medicine,* 2014:22;376

3 Current palliative care limitations

A paper by Dr Rodney Syme (retd), former President of Dying With Dignity Victoria

3.1 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 [1] as 'social death'. For an erudite discussion of medical suffering, read Eric Cassell [2].

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 [3] 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 [4] 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 [5]:

‘*… 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 [6], 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*’.

3.2 Terminal sedation – 'slow euthanasia'

Palliative Care Australia acknowledged in 2008 [7] 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 Midazolambecame available, which was compatible with morphine in a common syringe. First reported in 1988 by De Sousa and Jepson [8] for ‘terminal restlessness’, terminal sedation was described by Burke et al. [9] as providing ‘a readily available means of controlling symptoms and overcoming patient distress where no feasible alternative existed previously’. In 1990, Ventafridda [10] 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 [11] 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 [12] 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 [13] 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 [14] 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 [15] 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 [16] 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 [17] found 25 per cent of his palliative care patients did so. Sociologists Seale and Addington-Hall [18] found that '*respondents for hospice patients are significantly more likely to feel that an earlier death would have been better*'. Yet Ben Rich [19] 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?

3.3 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.

3.4 Other specialist opinions

Martin Klein [20] 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 [21] 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 [22] 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 [19] 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 [23], 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*'.

3.5 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.

3.6 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 [24] 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 [25] 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 [26] 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 [27], 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.*

3.7 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*.

3.8 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.

3.9 References

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4 Community support for voluntary assisted dying

Community support has been shown in many surveys, especially Roy Morgan 2017

> http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349

The Roy Morgan report contains “Historical Trends: Should a doctor be allowed to give a patient a lethal dose?”

In 1962 when Roy Morgan first asked this question the population was divided – more favouring allowing a doctor to give a lethal dose (47%) than not (39%) and 14% undecided. Support increased consistently over the years to 1996.

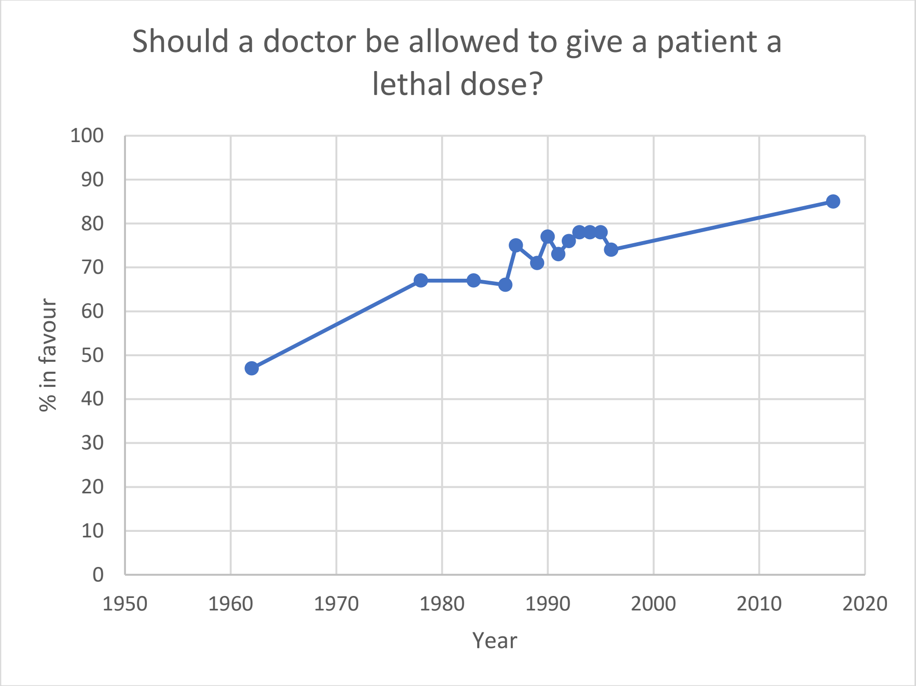
Since the 1996 survey there has also been a marked increase in support of allowing doctors ‘giving a lethal dose’. Now a large majority of 85% of respondents say a doctor should be allowed to ‘give a patient a lethal dose’ compared to 74% of respondents in 1996.

Questions:

> “A question on hopelessly ill people experiencing unrelievable suffering. If there’s absolutely no chance of a patient recovering, should the doctor let the patient die – or should the doctor try to keep the patient alive as long as possible?
>
> “Respondents who answered were then asked: “If a hopelessly ill patient with no chance of recovering asks for a lethal dose, should a doctor be allowed to give a lethal dose, or not?"

The results from the latter question were

Month	Year	Give lethal dose	Not give lethal dose	Undecided	Total
Oct	1962	47	39	14	100
Nov	1978	67	22	11	100
Sep	1983	67	21	12	100
Apr	1986	66	21	13	100
Apr	1987	75	18	7	100
Apr	1989	71	20	9	100
Jul	1990	77	17	6	100
Jul	1991	73	20	7	100
Mar	1992	76	18	6	100
May	1993	78	15	7	100
May	1994	78	13	9	100
Jun	1995	78	14	8	100
May	1996	74	18	8	100
Nov	2017	85	15	-	100



The results of other surveys are set out in Appendix A.

They show a consistent pattern of high, and growing, Australian community support for assisted dying.

There are religious groups which support voluntary assisted dying

While an overwhelming number of religious people support voluntary assisted dying, most, but not all, of the religious hierarchies are opposed.

A letter of 19 July 2019 from Rev Denise Liersch , Moderator of the Uniting Church in the Synod of Victoria and Tasmania, states … permission was given to the relevant UCA institutions and associated hospital group within Victoria, to make voluntary assisted dying allowable for their patients, clients and residents, under the specific conditions of the legislation. …

There is also the organisation Christians Supporting Choice for Voluntary Euthanasia (http://christiansforve.org.au/ which 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.*

5 Assisted dying overseas

Our comprehensive survey of voluntary assisted dying in the various world jurisdictions is detailed in Appendix B. In summary, for those places where assisted dying is available:

> Belgium: The Belgian parliament legalised euthanasia on 28 May 2002
>
> Canada: On 17 June 2016, a bill to legally allow assisted suicide within Canada became law.
>
> Colombia: On 15 December 2014, the Constitutional Court gave the Ministry of Health and Social Protection 30 days to publish guidelines for the healthcare sector to use in order to guarantee terminally ill patients, with the wish to undergo euthanasia, their right to a dignified death.
>
> Denmark: A study published in 2003 showed 41% of deaths under medical supervision involved doctors taking "end-of-life" decisions to help ease their patients' suffering before death (about 1% of which were via prescription drugs).
>
> Germany: On November 6, 2015, the German Parliament passed a bill legalising assisted suicide
>
> Luxembourg: From 19 March 2009, terminally ill patients have the option of euthanasia after receiving the approval of two doctors and a panel of experts.
>
> Netherlands: In 2001, the Netherlands passed a law legalizing euthanasia including physician-assisted suicide.
>
> Switzerland: Since 1942, deadly drugs may be prescribed to a Swiss person or to a foreigner, where the recipient takes an active role in the drug administration.
>
> United States: While active euthanasia is illegal throughout the US, assisted suicide is legal in Washington, D.C., Colorado, Oregon, Hawaii, Washington, Vermont, Maine (Starting January 1, 2020)], New Jersey (Starting August 1, 2019), California, one county in New Mexico, and is de facto legal in Montana.

It should be noted that since the implementation of this type of legislation in other countries, no country has overturned it.

6 Safeguards where VAD is available

The widely accepted position is that any voluntary assisted dying legislation should address topics such as the possibility of pressure from relatives, or the request for death when that request is prompted by a mental health problem that is amenable to treatment.

There are many summaries of potential problems, and their resolution. The Victorian bill provided for the most stringent set of tests, in that it covered all those in place elsewhere in the world, and then added some.
From https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/community-and-consumers

> "A person's choice to access voluntary assisted dying must be:
> - voluntary (the person's own choice) and
> - continuing (their choice stays the same) and
> - fully informed (the person is well-informed about their disease, and their treatment and palliative care options). …

For people to access voluntary assisted dying in Victoria, they must meet the following requirements:

1. They must have an advanced disease that will cause their death and is:
   - likely to cause their death within 6 months (or within 12 months for neurodegenerative diseases like motor neurone disease) and
   - causing the person suffering that is unacceptable to them.
2. They must have the ability to make a decision about voluntary assisted dying throughout the process.
3. They must also:
   - be an adult 18 years or over
   - have been living in Victoria for at least 12 months
   - be an Australian citizen or permanent resident. …"

Further requirements are that two doctors, one of whom is a specialist, need to be involved, and that a VAD Review Board which reports to parliament will oversee and regularly review the VAD process.

The safeguards applying in other jurisdictions are detailed in Appendix B.

7 Dealing with arguments against assisted dying

The Victorian *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. These same arguments were again rolled out in the 2015 inquiry into end-of-life choices in Victoria. 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.

Outcome to be expected if claim were correct	***Actual outcome***
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

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.

Outcome to be expected if claim were correct	***Actual outcome***
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.

Outcome to be expected if claim were correct	***Actual outcome***
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.

Below we deal the arguments that are usually advanced against voluntary assisted dying.

Claim	DWDV response
Medical training is designed to save life, not take it.	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.
Some ageing people may be seen as a burden to their families who may seek to coerce them into 'choosing' VAD.	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 (see p. 10).
Patients may change their minds after a request for VAD (see 9.2).	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.
VAD will be available to anyone, regardless of circumstances.	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.
Some patients will have religious convictions about the sanctity of life.	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.
With life prolonged, a cure may be found for the patient's disease.	Whilst this may be the case, the immediacy and intolerability of some suffering cannot wait for a possible future cure.
VAD devalues life.	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.
A slippery slope (1) - permitting VAD will lead to various abuses that are currently contained.	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.
Slippery-slope (2) - assisted suicide legislation can be readily widened.	Presumably any such widening could take place only under legislation from parliament.
Alleviation of suffering by 'killing' the patient is sinful or unworthy.	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.
The needs of the dying are covered by palliative care and the provisions of the Medical Treatment Act.	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.
There is no way to guarantee the absence of coercion.	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.
A desire to harvest organs may become a reason for VE.	Stringent legal safeguards will prevent this.
'God will decide when I die.'	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.
Few medical practitioners are trained or qualified to assess patients who ask for assisted suicide.	We suggest that this matter be addressed with training, to be provided for in the relevant legislation.

8. Commentary on the implementation of the VAD Act

8.1 A brief overview of the Act

Details of the eligibility requirements for access to voluntary assisted dying in Victoria can be found at:

https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/community-consumer-information

In short, they are:

(a) A progressive, incurable illness which is expected to cause death within 6 months (or 12 months for a neuro=degenerative disease). It must be a progressive terminal illness (usually in the terminal phase)
(b) Competency for the person making the request, and an absence of duress.
(c) Suffering which the person considers unacceptable
(d) The person is normally resident in Victoria.

The **most common conditions** which will lead to requests for assistance under the Act are:

(a) Terminal malignancy, which is characterised by a relatively rapid decline
(b) End-stage cardiac failure
(c) End-stage respiratory failure
(d) Progressive neuro-degenerative disease
(e) Frail aged (occasionally)

8.2 Analysis and commentary

8.2.1 Prognosis issues.

Prognosis is a major requirement for eligibility to VAD. It is a difficult exercise, most difficult when death is distant (say 6 months) but is more accurate when death is close (say 2 months).

Terminal disseminated malignancy follows a relatively common pathway, no matter the origin of the primary cause. Cardiac and respiratory failure have a slower trajectory, but with common symptoms of breathlessness, pain, and weakness, interspersed with acute life-threatening complications. Life may end with one of these acute episodes or just simply fade away.

Neuro-degenerative disease is more complex, with a wide variety of some very uncommon conditions, with commonly slow progression making prognosis difficult, and death is not uncommonly from a non-neurological complication, such as pneumonia, fall or bedsore. In this area, prognosis can indeed be difficult.

8.2.2 The treatment of these late terminal conditions

Thus there are some difficult areas of prognosis, but many late end-of-life situations do not require great prognostic or treatment skills. When symptoms are heading towards a refractory state (palliative care's term), what is required is good nursing care, and liberal use of palliative drugs (analgesics and sedatives) which are within the skills of experienced GPs. Many of these people can die peacefully at home (rather in hospital or hospice) with the appropriate use of this Act.

8.2.3 What the VAD Act states and its interpretation

Part 3 Division 1 Clause 10 (3) – "Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease ..."

This clause quite clearly does NOT require one of the two doctors to be a specialist. If one of the two medical practitioners (both of whom could be GPs) has 'relevant experience and expertise in the disease', then clause 10 (3) is satisfied.

A further matter is the application of the word 'relevant'. The experience and expertise required to consider the requirements apply particularly to the question of prognosis, and the experience and expertise required vary considerably dependent on the stage of the disease and the closeness to the end of life. The expertise and experience ('e and e') required diminish as the terminal phase of the terminal illness develops. Here is the importance of 'relevant'. Less 'e and e' is required to confirm the requirements if a person has a prognosis of 4 weeks as opposed to possibly 6 months. Specialist 'e and e' is less relevant in relation to the stage of the disease.

To many doctors, it is demeaning to many very experienced GPs to suggest that they lack the skills ('e and e') to certify the requirement in the late stage of many of the illnesses which will present.

Part 3 Division 2 Clause 18 (2) – "If the co-ordinating medical practitioner is unable to determine whether the person's disease, illness ... meets the requirements of the eligibility, the co-ordinating practitioner must refer the person to a specialist registered medical practitioner who has appropriate skills and training in that disease ..."

Clearly, this clause is contingent – if the co-ordinating doctor (let us presume a GP) is able to determine that the requirements are met, he/she does NOT have to refer to a specialist.

Examination of the *Interpretations and Guides to the Implementation of the Act* 2017 do not make any mention of the need for one supporting doctor to be a 'specialist'

The determination by the Victorian Department of Health & Human Services (DHHS) that two GPs cannot complete the certification process, and that one must be a 'specialist' is not supported by the Act – it is an unjustified interpretation. The word specialist is not defined in the Act, except in the sense that to engage with a request, doctors must be Fellow of a Specialist College, and this clearly includes GPs (Fellow of RACGP).

8.2.4 The consequences of this interpretation

Firstly, the field of medical graduates available for acting on requests is already narrowed by the requirement for Fellowship of Specialist College for at least 5 years. Secondly, there is the reasonable option to refuse a request on any ground (moral, ethical, personal, or not having done, or no interest in, the training, amongst other reasons). A number of hospitals/institutions have indicated their refusal to co-operate with requests.

If the field is further narrowed by insistence on a specialist with a narrow interpretation of this undefined term, one can foresee people who quite reasonably meet the requirements having extreme difficulty obtaining two supportive opinions (In some regional areas finding even one such opinion will be difficult).

8.2.4 How is a ‘specialist’ with relevant ‘experience and expertise’ to be identified?

Dr Rodney Syme (retd), a former president of Dying With Dignity Victoria, practised for over 40 years as a specialist urologist (FRACS). He treated many hundreds of people with urological cancers, but once his surgical skills no longer had a role, he usually referred his patients to others (their GP, oncologists, radiotherapists, or sometimes palliative care). Although a specialist in urological cancer, he could not claim to be a specialist in the end stage of such cancers. He believes this observation would apply to most of his FRACS colleagues. Many FRACP specialists (such as dermatologists, rheumatologists, rehabilitation specialists, psychiatrists and intensivists will have little if any relevance to this Act. Palliative care physicians should have a significant role in the implementation of this Act, but they have little if any ‘e and e’ in relation to people with 6 months to live. Their ‘e and e’ is relevant to the terminal phase of a terminal illness. Anaesthetists have great expertise in assessing frailty, prospects of survival from anaesthesia and surgery, but would have little role in this scheme, since they don’t consult except in hospital just prior to an operation.

8.2.5 Conflict with Commonwealth law

Early material distributed by DHHS shows the clear intent to deal with the likely difficulty of finding two qualified medical practitioners, particularly in the regions, was to use telehealth techniques. Thus only one medical practitioner would be required to conduct a face-to-face assessment of the person, while the second practitioner could do this by telehealth, typically videoconferencing.

However, it became evident that this would be in conflict with Section 474.29 of the Criminal Code Act *Using a carriage service for suicide related material.* Further, DHHS has now prohibited any person-specific information, assessment or discussion being conducted by telephone, Skype or email. This will significantly reduce a person’s ability to access VAD.

8.3 Summary

While the Victorian Voluntary Assisted Dying Act 2017 is a very welcome, compassionate and significant advancement of patients’ rights, its overly restrictive constraints militate to make the path of a person seeking VAD difficult and onerous, by:

- Insisting on a set of highly restrictive eligibility criteria, including prognosis which is necessarily difficult to determine
- The incorrect interpretation of the Act in guidelines that one of the assessing doctors be a specialist, whereas the Act does not require this; this has the consequence of reducing the field of suitable doctors available for VAD assessments
- Conflict with Commonwealth Criminal Code Act Section 474.29, prohibiting the use of telecommunications carriage services from transmitting patient-specific VAD information.

9 The Victorian experience to date – Some implementation issues

On 19 June 2019 the legislation passed in November 2017 was declared implemented. Seen as better than nothing, but also overly restrictive – removing too many reasonable claims for assistance in order to guard against undesirable but unlikely outcomes.

The Victorian progression (18 months) is seen as successful, in comparison with e.g. Canadian experience where the legislation was in force immediately it was passed; however

- Doctors are prevented from raising the topic of Assisted Dying with their clients. Some doctors consider this puts them in breach of their duty of care; it also has the potential deprive patients of fully informed consent for other treatments, if they are not offered all possible alternative options available to them.
- The requirements for doctors seem burdensome: needing two, but under the assumption that one must be a 'specialist' would appear as a doctrine of perfection but often hard to implement. To find a specialist, and one who is prepared to assist, seems to be difficult to deliver on;
- A 'Navigation' service has been developed, but appears to be insufficiently resourced. For example, there is at present no government-sponsored system to provide information to identify doctors who will assist someone whose own doctor will not assist;
- Section 474.29 of the Criminal Code (Using a Carriage service – see 8.2.5) has resulted in limitations to the provision of advice
- Some politicians seem insufficiently informed, on matters that their constituents might raise with them;
- Whilst there has been 18 months of well-regarded preparation, it would seem that many doctors are left anxious about involvement, being unsure of the requirements;
- The system relies on two doctors being able to agree that (in general) death will occur within 6 months. According to Dr Danielle Ko, Quality and Safety Lead, Austin Health, and Member of the Voluntary Assisted Dying Review Board, doctors' skills are insufficient to make reliable prognoses (address to a seminar at the Law Institute of Victoria, 18 June 2019). It might be better to express the requirement as being that death is reasonably foreseeable, or some such less precise term.

10. Contact Details

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Appendix A - Analysis of data on support for assisted dying law reform

Over many years surveys of Australian have shown a high, and generally growing support for assisted dying. The summary below is from number of such surveys, and compares with the results in 4.

Assisted Dying Opinion Poll Results - Australia

Polling body	Year	Yes%	Question
Newspoll	2007	80	Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiency unrelieavble suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose, or not?
Newspoll	2009	85	As in 2007
Australia Institute	2010	75	This question is about voluntary euthanasia. If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?
Newspoll	2012	83	Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiency unrelieavble suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose?
Australia Institute	2012	71	This question is about voluntary euthanasia. If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?
ABC Vote Compass	2013	75	Terminally ill patients should be able to legally end their own lives with medical assistance.
Essential Media Communications	2014	66	When a person has disease than cannot be cured and is living with severe pain do you think should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?
Ipsos Mori	2015	73	What do you think of doctor-assisted dying? Do you think it should be legal or not for a doctor to assist a patient aged 18 or over in ending their life, if that is the patient's wish, provide that the patient is terminally ill (where it is believed they have 6 months or less to live), of sound mind, and where they have expressed a clear desire to end their life?
Essential Media Communications	2015	72	As in 2014
ABC Vote Compass	2016	75	Terminally ill patients should be able to legally end their own lives with medical assistance.
OmniPoll	2017	75	If a terminally ill patient, asks a doctor for a lethal dose, should a doctor be allowed to provide a lethal dose, or not?
Essential Research	2017	73	If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?
Roy Morgan	2017	85	If a hopelessly ill patient with no chance of recovering asks for a lethal dose, should a doctor be allowed to give a lethal dose, or not?

See
https://theconversation.com/factcheck-qanda-do-80-of-australians-and-up-to-70-of-catholics-and-anglicans-support-euthanasia-laws-76079
https://www.dwdv.org.au/documents/item/210
https://www.theguardian.com/society/2017/sep/01/voluntary-assisted-dying-supported-by-73-of-australians-poll-finds
http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349

Appendix B - Overseas developments

International jurisdictions with VAD/VE laws

Oregon: Death with Dignity Act

<table>
<tr><th>How was VAD legalised?</th><th>Who can access it?</th><th>How is it administered?</th></tr>
<tr><td>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.</td><td>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.</td><td>Self-administered medication using a prescription from a physician – the Act prohibits euthanasia whereby a physician or other person would administer the medication</td></tr>
<tr><td colspan="3">Key safeguards: 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.</td></tr>
<tr><td colspan="3">Key statistics: 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.</td></tr>
</table>

Washington: *Death with Dignity Act*

<table>
<tr><th>How was VAD legalised?</th><th>Who can access it?</th><th>How is it administered?</th></tr>
<tr><td>The legislation was passed by voter initiative on 4 November 2008 and came into effect on 5 March, 2009.</td><td>An adult, 18-plus and resident of Washington State; competent to make informed decisions; suffering terminal illness with six months or less to live.</td><td>Terminally ill patients can obtain a prescription from their physician to self-administer the lethal medication.</td></tr>
<tr><td colspan="3">Key safeguards:
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.</td></tr>
<tr><td colspan="3">Key statistics: 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.</td></tr>
</table>

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

<table>
<tr><th>How was VAD legalised?</th><th>Who can access it?</th><th>How is it administered?</th></tr>
<tr><td>Legal since 1942. Under Article 115, assisting a suicide is only a criminal offence if the motives are selfish, such as personal gains.</td><td>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.</td><td>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.</td></tr>
<tr><td colspan="3">Key safeguards: 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.</td></tr>
<tr><td colspan="3">Key statistics: According to Exit, the most common reasons for requesting physician-assisted suicide are terminal</td></tr>
</table>

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.**

Key safeguards: 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.

Key statistics: 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*.

Key safeguards: 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.

Key statistics: 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. ***Palliative care services were involved in 73.7% of euthanasia and physician assisted suicide cases.**

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	Lethal injection.

	improvement.	

Key safeguards: 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.

Key statistics: 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 *Baxter v Montana* 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.

Key safeguards: The Montana Supreme Court broadened the state's right under the *Terminally Ill Act* 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.

Key statistics: 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 *Patient Choice and Control at End of Life Act (Act 39)* 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.

Key safeguards: 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.

Key statistics: 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.

Colombia: 1997, 2015 & 2018 Amendment to Act, Resolution 285

How was VAD legalised?	Who can access it?	How is it administered?
In 1997 Colombia's constitutional Court ruled in favour of euthanasia however no guidelines or regulations were made at the time. Then in 2015 the Health Ministry finally presented a new protocol that put the court ruling into practice. In 2018, the family of a desperately sick child appealed to the Constitutional Court and the court supported	The patient must suffer from a terminal illness. Patients can be conscious or unconscious. Children as young as 6 years old may seek euthanasia. And children over the age of 14 may receive euthanasia without the consent of their parents. Children from the ages of 6-14 must undergo a psychological or psychiatric evaluation to prove	A doctor must be the active subject who performs the act to end the patient's pain and this is usually by intravenous injection

their request. On March 9, 2018, the Department of Health and Social Protection expanded the regulation by passing a resolution that offered the procedure of euthanasia to children as young as 6.	that they understand the request they are making and ensure that it is a free, voluntary and informed request. In addition, they must have parental consent. Adolescents aged 14 and older may request for themselves without parental consent and even if the parents disagree.	

Key safeguards: A patient must make and then reiterate a specific request either a verbal or written one. Patients must be informed of all their treatment options. The request must be free from family coercion. If the patient further requests euthanasia the physician must receive authorization form a special panel that consists of a doctor who specializes in the patient's illness, a lawyer and either a psychiatrist or a psychologist. Such committees are meant to be associated with every public health institution. The regulation gives a doctor the right to refuse to perform the procedure but requires them to find one who will within 24 hours. In the case of unconscious patients, relatives are required to prove patients previously expressed their desire to end their lives, in writing or by a video or audio recording.

This is the only jurisdiction that requires the prior approval of euthanasia requests by an independent committee.

Key Statistics: None available.

Canada: 2016 Medical Assistance in Dying

How was VAD legalised?	Who can access it?	How is it administered?
In June 2016, the Parliament of Canada passed federal legislation that allows eligible Canadian adults to request medical assistance in dying.	Individuals must be eligible for health services funded by the federal government, or a province or territory. They must be at least 18 years old and mentally competent. They must be considered to have a grievous and irremediable medical condition and make a voluntary request free from coercion and provide informed consent.	It can be provided by physicians and in certain provinces by Nurse practitioners. A substance can be directly administered, either orally or through intravenous injection or the patient may self-administer the medication.

Key safeguards: A physician or nurse practitioner must make sure that the patient is eligible to receive medical assistance in dying according to all the access criteria. Then a second physician or nurse practitioner must also provide a written opinion confirming that the patient is eligible. They must also be informed that they have the right to withdraw their request at any stage of the process. The physician or nurse practitioner providing the initial assessment and second opinion must be independent. The patient must then wait at least 10 days after signing the request unless both the first and second physician/nurse practician consider death to be fast approaching or that the patient may soon lose the ability to provide informed consent.

Key Statistics: Based on available data, there were at least 2,614 medically assisted deaths in Canada between January 1 and October 31, 2018. Medically assisted deaths accounted for approximately 1.12% of all deaths in Canada during this period.

WASHINGTON DC: 2017 *The District of Columbia Death with Dignity Act of 2016*

How was VAD legalised?	Who can access it?	How is it administered?
The District of Columbia Death with Dignity Act of 2016, D.C. Law 21-182 became effective in July 2017 after being first introduced by a council member in 2015.	A terminally ill patient whose death has been medically confirmed as likely to occur within 6 months. The patient must be a resident of the District of Columbia.	Patients must self-administer the lethal medication without assistance and in a private place.

Key safeguards: The law requires that patients make two requests to a doctor to end their life, 15 days apart. If their requests are granted, they must obtain the drugs and take their own life in a private place. Two witnesses must attest that the requesting patient was of sound mind. Participation is voluntary for doctors and pharmacies; not all medical professionals in the district are willing to prescribe and dispense lethal medications.

Key Statistics: April 10, 2018 Nearly a year after the District enacted a law allowing terminally ill patients to end their lives not a single patient has used it. And just two of the approximately 11,000 physicians licensed to practice in the District have registered to help patients exercise their rights under the law. Only one hospital has cleared doctors to participate.

HAWAII: 2019 The Our Care Our Choice Act

How was VAD legalised?	Who can access it?	How is it administered?
The Our Care Our Choice Act went into effect on January 1, 2019. The bill was passed by the Hawaii legislature with overwhelming support in 2018. In the 2019 legislative session further safeguards were added to the original law.	An adult, over the age of 18 who is a resident of Hawaii. They must be diagnosed with a terminal disease that is likely to cause death within 6 months. They must be considered mentally competent and able to communicate their health request.	The patient must be able to self-administer and ingest the lethal medication.

Key safeguards: The law requires that patients make two verbal requests to a doctor to end their life, 15 days apart. The patient fills in a specific written request form addressed to their doctor and signed in front of 2 adult and qualified witnesses. At least one of the witnesses cannot be related to the patient or employed by the health care facility. There is then a 48 -hour waiting period between the written request and the writing of the prescription providing the follow requirements are met. The prescribing doctor and another doctor confirm the diagnosis and prognosis and determine that the patient is competent to make medical decisions. If either doctor is concerned about the patient's mental state, then patient has a psychological examination. The prescribing doctor ascertain that the patient is not being coerced or unduly

influenced by others into making the request and must ensure that the patient has been informed about all other various options in end-of-life care. The prescribing doctor may ask but not request the patient to inform next-of-kin. The patient must be provided with the opportunity to withdraw their request prior to the provision of the prescription.
Key Statistics: On July 2, 2019, the Department of Health released a report on the first five months of the implementation of the Legislation. The legislation is reported to have been used sparingly—eight terminally ill patients qualified under the law; two of them used medical aid in dying to peacefully end their lives—and with no issues

NEW JERSEY: 2019 *Aid in Dying for the Terminally Ill Act*

How was VAD legalised?	Who can access it?	How is it administered?
The Governor signed the ***Aid in Dying for the Terminally Ill Act*** on April 12, 2019 and will become effective on August 1, 2019.	A patient who is at least 18 years old and who is a resident of New Jersey. The patient must be diagnosed with a terminal disease that will result in death within 6 months. The patient must be deemed mentally competent and capable of making and communicating health care decisions.	The patient must be able to self-administer and ingest the lethal medication.
Key safeguards: The law requires that patients make two verbal requests to a doctor to end their life, 15 days apart. The patient fills in a specific written request form addressed to their doctor and signed in front of 2 adult and qualified witnesses. At least one of the witnesses cannot be related to the patient or employed by the health care facility. There is then a 48 -hour waiting period between the written request and the writing of the prescription providing the follow requirements are met. The prescribing doctor and another doctor confirm the diagnosis and prognosis and determine that the patient is competent to make medical decisions. If either doctor is concerned about the patient's mental state, then patient has a psychological examination. The prescribing doctor ascertain that the patient is not being coerced or unduly influenced by others into making the request and must ensure that the patient has been informed about all other various options in end-of-life care. The prescribing doctor may ask but not request the patient to inform next-of-kin. The patient must be provided with the opportunity to withdraw their request prior to the provision of the prescription.		
Key Statistics: None available.		

MAINE: 2019 *The Maine Death with Dignity Act*

How was VAD legalised?	Who can access it?	How is it administered?
The Maine Death with Dignity Act was passed by The Maine State House on May 29, 2019 and will become effective on September 15, 2019.	Those patients suffering from a 'terminal disease' and be at least 18 - years old. They must be a Maine resident. A 'terminal disease' is defined as an 'incurable and irreversible disease that has been medical confirmed	The patient must be able to self-administer and ingest the lethal medication.

<table>
<tr><td></td><td>and will, within reasonable judgement, produce death within 6 months”.</td><td></td></tr>
<tr><td colspan="3">Key safeguards: The law requires that patients make two verbal requests to a doctor to end their life, 15 days apart. The patient fills in a specific written request form addressed to their doctor and signed in front of 2 adult and qualified witnesses. At least one of the witnesses cannot be related to the patient or employed by the health care facility. The prescribing doctor and another doctor confirm the diagnosis and prognosis and determine that the patient is competent to make medical decisions. If either doctor is concerned about the patient’s mental state, then patient has a psychological examination. The prescribing doctor ascertain that the patient is not being coerced or unduly influenced by others into making the request and must ensure that the patient has been informed about all other various options in end-of-life care. The prescribing doctor may ask but not request the patient to inform next-of-kin. The patient must be provided with the opportunity to withdraw their request prior to the provision of the prescription.</td></tr>
<tr><td colspan="3">Key Statistics: None available.</td></tr>
</table>

News from other Countries:

OREGON: July 25, 2019. An amendment to the Orgon Death with Dignity Act was announced. The 1997 Act originally stated that the patient must make two verbal requests to the prescribing physician separated by no less than 15 days. This amendment allows those with 15 days left to live to bypass the 15-day waiting period. This will reduce bureaucracy and bring relief to gravely ill people.

New Zealand: The End of Life Choice Bill was drawn from the ballot and introduced by ACT MP David Seymour on June 8, 2017 as a Private Members Bill. The bill passed its first reading on 13 December 2017, with 76 votes in favour, 44 opposed. In June this year the bill passed a second reading by 70 to 50 votes. More than 38,000 submissions were made to Parliament's justice select committee in reference to the bill. More than 90 per cent of Kiwis who made submissions on the euthanasia bill were said to want the proposed law scrapped. Prime Minister Jacinda Ardern is backing the bill but is at odd with Deputy Prime Minister Peters' NZ First who has agreed, only upon the condition that the bill eventually goes to a plebiscite. See End of Life Choice Bill. https://www.parliament.nz/en/pb/library-research-papers/research-papers/assisted-dying-new-zealand/

England: March 4, 2019, *The Guardian*, Legalise assisted dying for terminally ill, say 90% of people in UK An overwhelming majority of UK citizens have expressed their March this year the Royal College of Physicians announced that it would drop its longstanding opposition to assisted dying and adopt a ‘neutral position’. https://www.dignityindying.org.uk/news/royal-college-physicians-drop-longstanding-opposition-assisted-dying-neutral/. Two recent legal challenges to the Supreme Court to change the law on Assisted Dying have been dismissed with the court ruling that it is up to Parliament to decide on the issue. In early July a debate on assisted dying commenced in the House of Commons.

Korea: July 11, 2019 – The Korea Herald, Kim Arin, “53,900 opt out of life-prolonging treatment since adoption of “Death with Dignity Act”. Interesting article out of Korea. The Ministry of Health and Welfare said Wednesday the number of individuals who either withheld or withdrew from receiving life-prolonging treatment totalled 53,900 as of June 30. The end-of-life care legislation allowing terminally ill patients to abandon life-prolonging medical care went into effect on Feb. 4, 2018.

Spain: July 11, 2019 – El Pais-Spain**,** Carmen Moran Brena, Spanish Congress receives a million signatures in favor of euthanasia. One million citizens have signed a petition to present to Congress requesting the decriminalization of euthanasia. This follows the arrest of a man who helped his wife to end her life.

France: In 2016 the French Parliament approved a bill that let doctors keep terminally ill patients sedated until death but did not allow for assisted suicide or euthanasia. Recently France has been sharply divided by the case of a man involved in a near-fatal car crash in 2008 that left him a quadriplegic with severe brain damage, which doctors had long said was irreversible. Left in a vegetative state, the question of whether to continue keeping him alive artificially divided his family and the nation. Doctors halted treatment but were ordered to reinstate life support measures before the patient was finally removed again from life support and died days later on July 11, 2019. https://www.theguardian.com/world/2019/jul/11/vincent-lambert-man-at-centre-of-french-familys-battle-over-life-support-dies

Israel: June 25, 2019 – Jewish Telegraphic Agency, Cnaan Liphshiz, A Jewish farmer who is an activist and promotes assisted suicide in Israel relates the story of his wife suffering from MND and how she had to travel to Switzerland to die. In Israel suicide is a grave violation of religious law.

Scotland: In 2015 Holyrood rejected an Assisted Suicide Bill – despite widespread public support. In June ,2019 A Scottish man, suffering from MND, wrote letters to the Scottish Parliament calling for assisted death to be legalised stating that having to go to Switzerland to end his life is 'cruel, outdated and discriminatory', https://www.heraldscotland.com/news/17756505.neil-mackay-right-die-last-great-human-rights-battle/ In February 2019 a group of Members of the Scottish Parliament formed a group to attempt to reform assisted dying legislation.

Germany: **July 3, 2019**- In a case presented before the Federal Court, a decision was made not to punish two doctors who looked on as their patients ingested lethal substances. This is a significant step in Germany where VAD is governed by case law not statute. German court strengthens patients' rights in assisted suicide ruling

South Africa: **June 23, 2019** –By helping suffering patients to die, Dr. Sean Davison was not sentenced to imprisonment as a result of a murder charge. He was tried for 'murder' as South Africa does not have a law against 'Assisted Suicide'. It is hope that this may mark a turning point in the development of such legislation.

The Channel Island of Jersey: February 2019, Jersey's Council of Ministers announced that a new commission will research end of life options, including the legalisation of assisted dying. This followed the presentation of a petition signed by more than 1800 people.

The Channel Island of Guernsey: A proposal to consider legalising assisted dying was voted against in May 2018.
It has been said that in the USA upcoming legislative targets will include **Massachusetts, Maryland** again, **New Mexico, New York** and ***Nevada.*** https://www.nytimes.com/2019/07/08/health/aid-in-dying-states.html

Appendix C Ethical argument

The ethics of Voluntary Assisted Dying (VAD) have been discussed by many.

Some examples are as set out below: -

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**. (emphasis added)

(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.

...

[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.

[End of extract.]

Ethical opinion from 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.

Ethical opinion from 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.

Appendix D - Our submission to the 2015 Victorian Inquiry into End-of-Life Choices

In July 2015 we made a submission to the inquiry by the parliament of Victoria into End of Life Choices. See: https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_625_-_Dying_with_Dignity_Victoria.pdf