



Go Gentle
Australia

Submission to
**Inquiry into
Voluntary
Assisted Dying**

Select Committee | Queensland | April 2019

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“Palliative care services are not offering what a percentage of their patients desperately need. Palliative care has become a mantra chanted by ... politicians and religious organisations opposing euthanasia.”

– Clive Deverall, founder of Palliative Care WA

“While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.”

– Palliative Care Australia

“It is not the role of any health care team to suggest its ministrations can give meaning, purpose and dignity to a dying person’s remaining life if that person feels that these are irretrievably lost ... palliative care is a model of care, not a moral crusade.”

– Professor Michael Ashby, Director, Palliative Care,
Tasmanian Health Service

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Introduction

Since 2016, we have witnessed the two most comprehensive examinations of end-of-life care ever undertaken in Australia. Though conducted independently, these cross-party parliamentary inquiries, in Victoria and Western Australia came to the same conclusions:

- Even the best palliative care cannot relieve all suffering for terminally ill patients;
- Doctors and nurses are delivering inadequate pain relief to dying patients for fear of breaking the law;
- Family and friends are being traumatised as they watch loved ones die agonising deaths;
- Doctors are breaking the law to assist patients suffering untreatably to die – but having to do so in secret, without consultation, oversight, or regulation;
- Elderly and terminally ill people are taking their lives, often in horrific circumstances.

Both inquiries found Australia's existing end-of-life laws to be inadequate. Both recommended, by a clear majority, that Voluntary Assisted Dying (VAD) be legalised as part of a broader approach to better end-of-life care including more resources for palliative care.

These findings are supported by a raft of international, peer-reviewed evidence gathered from multiple jurisdictions with VAD laws in place. Jurisdictions where, after 10, 15 and even 20 years, there is still widespread public and political support for assisted dying; where fears about the abuse of the vulnerable have not been realised; and where there is no loss of faith in doctors or degradation in palliative care – in fact, their opposite.

More than anything else, this combined evidence shows that it is possible to write sensible and compassionate laws, with strong safeguards, to assist people to die good deaths.

The Victorian and Western Australian inquiries heard testimonies from people of all ages and from all walks of life, describing with great clarity the damage being done in the absence of VAD laws.

It is clear from submissions already made public by this committee that Queensland is no different. Australians have long accepted that they should be free to make their own decisions about how their lives will end. It is a principle already established in Australian law.

Every opinion poll conducted on the issue over the past two decades has recorded more than 70 per cent support for giving terminally ill Australians access to VAD.

In the most recent polls, that support has grown to near 90 per cent.

In 2017, Victoria became the first state in Australia to pass an assisted dying law. It will come into effect in June this year. But that law, as significant as it is, covers only one in four Australians. There is an urgent need for VAD laws for all terminally ill people in this country.

Hastening death is already legal in Queensland. However, the laws as they currently stand are unfair, incoherent, and the source of mistreatment and abuse.

- Under Queensland law it is legal, if you are dying, and wish to hasten an end to your

suffering, to do so slowly and painfully – by refusal of treatment, starvation and dehydration. This is not considered suicide.

- Under Queensland law, when your suffering can no longer be controlled, it is legal to be drugged into a coma, from which it is not intended you awake, by a doctor (though entirely at their discretion, depending on their beliefs).
- Under Queensland law, it is legal to end your suffering by taking your own life. We know now, as a result the parliamentary inquiries in Victoria and Western Australia, that suicides of the terminally and chronically ill are happening every week. Brutal, lonely deaths that leave ineradicable scars in the families and first responders left to pick up the pieces.

What is not legal under Queensland law, if you are dying, is to end your suffering quickly and painlessly, at a time of your choosing, with the support of your family and medical team.

Instead, we have a dangerously unregulated system where, as the Victorian Inquiry found:

Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.

This is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.

We know from the Western Australian Inquiry and other research and doctors' accounts over the last two decades that this same unregulated practice of assisted dying is happening across Australia.

In this unregulated system no questions are raised about threats to vulnerable people. No one is examining, or vouching for, doctors' actions. Yet we are told by opponents to VAD that this is safer than a system where doctors are guided by strict regulations and held accountable by law.

Opponents also argue – in fact, it is their main argument – that if palliative care were properly resourced, no one need suffer so there would be no need for VAD. This argument doesn't just defy logic. It defies facts.

Here are Palliative Care Australia's own words.

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.

“While Go Gentle strongly supports greater resourcing for palliative care, all the resources in the world will not ease the suffering of all dying patients. It is not medically possible and palliative care's own words and statistics say so.”

So, too, do the powerful testimonies from doctors and nurses who have stood helplessly by in the face of terrible deaths.

All the resources in the world will not help hasten a dying patient's death, or alleviate their suffering quickly, if it goes against the beliefs of the treating doctor or institution to do so. There are too many testimonies now, from too many families, about terrible, prolonged deaths within palliative care, that attest to this.

Only a change in the law, which protects a patient's rights at the end of life, will do so.



Andrew Denton

Director, Go Gentle Australia

Part A

What The Evidence Shows

The need for Voluntary Assisted Dying laws in Australia

WHAT THIS SECTION IS ABOUT

The debate about Voluntary Assisted Dying (VAD) in Australia has transformed dramatically in the last three years. In that time, two comprehensive State parliamentary inquiries into end-of-life care have each put forward undeniable evidence of the need for such laws.

Of particular impact has been the evidence from State Coroners detailing the horrific suicides happening every week among the terminally and chronically ill. The need for legal reform is reflected in consistent polling over the last decade which shows that our parliaments are lagging behind public demand in addressing this issue.

This delay is even harder to explain because the core principle of Voluntary Assisted Dying – that a competent adult should be able to decide what is done with their body – is already established in Australian law.

1. PARLIAMENTARY INQUIRIES

Since 2016, two comprehensive cross-party parliamentary inquiries into end-of-life care – the first of their kind in this country – have found Australia's existing laws are inadequate when dealing with the needs and wishes of terminally ill Australians.

1.1 The parliament of Victoria's inquiry into end of life choices, 2016

Running over 10 months in 2016, with more than 1000 submissions and public hearings involving 154 witnesses, the parliament of Victoria's 2016 inquiry into end of life choices¹ found:

- Repeated examples of inadequate pain relief being delivered to dying patients by doctors for fear of breaking the law.
- The inability of palliative care, despite its many benefits, to relieve all suffering.
- People being put on trial for helping those they love find a merciful end.
- Doctors breaking the law in order to help suffering patients die, but having to do so without support, regulation, or accountability.
- Trauma experienced by families watching seriously ill loved ones refuse food and water

¹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

to hasten an end to their suffering.

- People experiencing an irreversible deterioration in health taking their own lives, often in horrific circumstances. In Victoria, evidence from the Coroner showed that such suicides are happening at the rate of one a week.

1.2 The parliament of Western Australia inquiry into end of life choices, 2017/18

Running for 12 months, the 2017/2018 Western Australian inquiry into end-of-life choices received more than 700 submissions and held 81 public hearings². It found that:

- Too many Western Australians are experiencing profound suffering as they die. This is, in part, due to inequitable access to palliative care. However, it is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.
- According to national coronial data about suicide, around 10 per cent of suicides in Western Australia are by people with a terminal or debilitating illness. These people die lonely and often violent deaths; including through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds, and by hanging.
- There are limitations to palliative care. This reality became clearer as more witnesses gave evidence of their experience of the death of those close to them. Some gave confronting evidence about the suffering of their loved ones, despite receiving the best palliative care available.
- Witnesses told of the prolonged suffering associated with particular diseases: motor neurone disease, Huntington's disease, Parkinson's disease and dementia can involve suffering over many months, and sometimes years, prior to death.

Both the Victorian and Western Australian parliamentary inquiries, when confronted with evidence of the impact of our existing laws, recommended that each state introduce legislation for Voluntary Assisted Dying.

2. PUBLIC DEMAND FOR BETTER END-OF-LIFE CHOICES

The reality about the inadequacies in our end-of-life laws is reflected in public responses to questions about whether or not Australia should legalise Voluntary Assisted Dying.

Consistent, reliable opinion polling in Australia over two decades has revealed support for VAD to be in excess of 70 per cent. Since 2012, this support has steadily increased, irrespective of variations in the questions asked and terminology used.

² Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Parliament of Western Australia, 23 August, 2018 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\[EvidenceOnly\]/702507C2CB8742824825818700247E53?opendocument](http://www.parliament.wa.gov.au/Parliament/commit.nsf/[EvidenceOnly]/702507C2CB8742824825818700247E53?opendocument)

Figure 1: Polls on Voluntary Assisted Dying – 2012 to 2018

Polling Body	Date	Question	Yes	Undecided/ Other	No
Newspoll	2012	Thinking about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose should a doctor be allowed to provide a lethal dose?	82.5%	4.8%	12.7%
Australia Institute	2012	If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?	71%	17%	12%
ABC Vote Compass	2013	Terminally ill patients should be able to legally end their own lives with medical assistance.	75.1%	9.4%	15.5%
Essential Media Communications	2014	When a person has a disease that cannot be cured, and is living in severe pain, do you think (a doctor) should be allowed by law to assist the patient to commit suicide if the patient requests it?	66%	20%	14%
Ipsos Mori	2015	Do you think that it should be legal or not for a doctor to assist a patient ages 18 or over in ending their life if that is the patient's wish, provided that the patient is terminally ill (where it is believed that they have 6 months or less to live) are of sound mind, and express a clear desire to end their life?	73%	12%	15%
ABC Vote Compass	May 2016	Terminally ill patients should be able to legally end their own lives with medical assistance.	75%	9%	16%
Essential Media Communications	Nov 2017	When a person has a disease that cannot be cured, and is living in severe pain, do you think (a doctor) should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?	72%	16%	12%
Review Partners	July 2017	Victorians supported the right of adults to choose to end their lives if they are suffering from a terminal illness.	72%	15%	13%
Roy Morgan Research	Nov 2017	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?	85%	None	15%
ReachTEL	Aug 2018 QLD Only	Do you support or oppose terminally ill people with no hope of recovery being given the choice of legally ending their life with the assistance of medical professionals?	79%	4.2%	16.8%

Roy Morgan Research, which conducted the most recent national poll on the issue in 2017, found that 85 per cent of Australians said they supported allowing doctors 'to give a lethal dose'. This support was consistent across the country:

... with clear majorities in all six States in favour of allowing doctors to 'give a lethal dose' to patients. The State with the largest support is Western Australia in which 88% of respondents support allowing doctors to 'give a lethal dose'. All other states and city and country areas are over 80% in support of allowing doctors to 'give a lethal dose'.³

Queensland was just behind Western Australia at 86 per cent support. The result was confirmed by a subsequent ReachTEL poll in 2018 which recorded 79 per cent support in Queensland for the prospect of 'terminally ill people with no hope of recovery being given the choice of legally ending their life with assistance from a medical professional'.⁴

3. GLOBAL MOMENTUM

Public opinion in Australia reflects a growing acceptance of the need for VAD/VE (voluntary assisted dying/voluntary euthanasia) around the world. As of April 2019, VAD/VE was available in the Netherlands, Belgium, Colombia, Luxembourg, Canada, Switzerland, and in the US states of Washington, Oregon, Colorado, Hawaii, New Jersey, Vermont, Montana, Washington D.C. and California. In Australia, Victoria's Voluntary Assisted Dying Act will come into effect in June 2019.

Figure 2: Number of people globally with access to Voluntary Euthanasia/ Voluntary Assisted Dying laws



Australia passed the world's first Voluntary Assisted Dying law in the Northern Territory in 1996. However, only four people got to use it before it was rescinded by the federal government. Now 200 million people have access to VE/VAD worldwide. In Australia, once Victoria's law comes into effect on 19 June 2019, three quarters of Australians will still be denied access to a more compassionate end-of-life law.

³ Gary Morgan and Michelle Levine, "It's Official: Australians support assisted dying or euthanasia", Roy Morgan, 10 November, 2017 – <http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349>

⁴ Editorial, "Poll finds Queensland backs voluntary assisted dying and changes to euthanasia laws", The Courier-Mail, 31 August, 2018 – <https://www.couriermail.com.au/news/queensland/poll-finds-queensland-backs-voluntary-assisted-dying-and-changes-to-euthanasia-laws/news-story/c4ad4647516967dee4347b352c177464>

4. THE PRINCIPLES OF VOLUNTARY ASSISTED DYING ARE ALREADY ESTABLISHED IN AUSTRALIAN LAW

In arguing against Victoria's proposed Voluntary Assisted Dying legislation, former Prime Minister Paul Keating wrote:

No matter what justifications are offered for the bill, it constitutes an unacceptable departure in our approach to human existence and the irrevocable sanctity that should govern our understanding of what it means to be human.⁵

Keating's claim that assisted dying represents an 'unacceptable departure' in our approach to human existence is wrong in fact, and in law. So too his defence of the 'irrevocable sanctity' of human life.

Australian law has already decided that there are circumstances where it is permissible for the State to direct, or intervene, in order to allow a person who is suffering incurably to end their life.

4.1 Brightwater Care Group v Rossiter (2009)

The Australian Centre for Health Law Research provides the following summary of a key legal case in Western Australia, which involved Mr Rossiter, who was in a facility that cares for people with disabilities.

[Brightwater Care Group v Rossiter](#) [2009] WASC 229

Mr Rossiter was a quadriplegic who was kept alive by receiving artificial hydration and nutrition through a tube into his stomach. He had capacity and decided he no longer wanted to receive this treatment. He asked the facility that was caring for him to withdraw the tube. The Supreme Court was asked for declarations about the rights and obligations of the facility and the patient.

The Court decided that as Rossiter had capacity, he was entitled to decide the treatment he wished to receive or refuse. The Court noted that the principle of autonomy prevailed over the sanctity of life, and decided that the duty of the facility to provide Rossiter with the necessities of life did not apply given he was a competent person refusing treatment. A declaration was made that the facility caring for Rossiter could lawfully withdraw the treatment if Rossiter requested it.⁶

In his decision in *Brightwater Care Group v Rossiter*, the Chief Justice of Western Australia referred to "clear and unambiguous" common law principles, including the principle of autonomy or self-determination. He stated:

Another principle well established at common law is the principle which has been described in the cases as the right of autonomy or self-determination. Lord Hoffmann has described this right as being related to **respect for the individual human being and in particular for his or her right to choose how he or she should live his or her life**: *Airedale National Health Service Trust v Bland* [1992] UKHL 5; [1993] AC 789, 826. Included within the right of autonomy or self-determination is the right, described as long ago as 1914 in the United States by Justice Cardozo, as the right of 'every human being of adult years and sound mind

⁵ Paul Keating, "Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross", *The Sydney Morning Herald*, 19 October, 2017 – <https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html>

⁶ Supreme Court of Western Australia, "Brightwater Care Group (Inc) -v- Rossiter [2009] WASC 229", 20 August, 2009 – <http://www7.austlii.edu.au/cgi-bin/viewdoc/au/cases/wa/WASC/2009/229.html>

... to determine what shall be done with his own body': *Schloendorff v Society of New York Hospital* 211 NY 125 (1914), 129.

The principle is applied without regard to the reasons for the patient's choice, and irrespective of whether the reasons are rational, irrational, unknown or even non-existent: *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18; (1993) Fam 95, 113 (cited with approval in *Ms B v An NHS Hospital Trust* [18] and *Hunter and New England Health Service v A* [15]). [Our emphasis]

An account of Mr Rossiter's legal victory, giving him the right to end his "living hell", can be found in the article "Perth Quadriplegic Wins Landmark Right to Die".⁷

Australian law has already decided that there are circumstances in which the principle of the sanctity of human life is not paramount.

4.2 Hunter and New England Area Health Service v A (2009)

This case concerned the obligation of a health service to provide dialysis to a patient who had lost consciousness following septic shock and renal failure in circumstances where the patient had apparently prepared a document some time earlier indicating that he would refuse dialysis.

McDougall J identified two conflicting interests recognised by the common law:

- a competent adult's right of autonomy or self-determination – the right to control his or her own body; and
- the interest of the State in protecting and preserving the lives and health of its citizens.⁸

McDougall J stated:

It is in general clear that, **whenever there is a conflict between a capable adult's exercise of the right of self-determination and the State's interest in preserving life, the right of the individual must prevail** ... In *Airedale NHS Trust v Bland* [1992] UKHL 5; [1993] AC 789 at 859, Lord Keith of Kinkel said that the State's interest is not absolute, and does not compel treatment of a patient contrary to the patient's express wishes. In the same case, Lord Goff said (at 864) that:

[I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. ... [t]o this extent, **the principle of the sanctity of human life must yield to the principle of self-determination.**⁹ [Our emphasis]

⁷ Editorial, "Perth quadriplegic wins landmark right to die", ABC News, Australian Broadcasting Corporation, 14 August, 2009 – <https://www.abc.net.au/news/2009-08-14/perth-quadriplegic-wins-landmark-right-to-die/1391380>

⁸ *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 90 [5] – Case Report available here: <http://www.mondaq.com/australia/x/97538/Healthcare/Advance+Care+Directives+Hunter+and+New+England+Health+Service+v+A+2009+NSWSC+761>

⁹ *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 92 [17] – Case Report included as an appendix here, at p. 20 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/504182F47CA615AF48258218000F911B/\\$file/20170926+-+EOLC+-+Sub+22+-+Mr+Kevin+Rickson.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/504182F47CA615AF48258218000F911B/$file/20170926+-+EOLC+-+Sub+22+-+Mr+Kevin+Rickson.pdf)

Part B

Assisted Dying in Queensland Today

An incoherent, largely unregulated, and inequitable legal situation

WHAT THIS SECTION IS ABOUT

When it comes to Voluntary Assisted Dying, we are not starting with a blank page. Patients' deaths are hastened, or aided – legally and illegally – throughout Australia every week. Some deaths – because of the nature of our existing laws – are necessarily slow. As a result, they can be cruel, both for the person dying and their loved ones watching on. Others happen in secret. Many leave behind lasting trauma; for families, friends, doctors, nurses, and also first responders.

1. ASSISTED DYING TAKES PLACE IN QUEENSLAND TODAY, BUT WITH LITTLE, OR NO, REGULATION OR OVERSIGHT

1.1 Doctors illegally assisting people to die

Research and doctors' testimonies over the last 20 years show that this unregulated practice takes place around Australia. This was summarised by the Australia 21 Institute in their document "The right to choose an assisted death: Time for legislation?". Under the sub-title 'The law has failed' the study's authors write:

Research among Australian doctors caring for seriously ill patients has documented current practices in some detail. According to that research, **voluntary, involuntary and non-voluntary euthanasia all occur in Australia in defiance of the law.** Some doctors have admitted publicly that they have acted with intent to end the patient's life but, despite this admission, they have not been prosecuted. [Our emphasis]

Kuhse et al concluded that in 1995-1996, 1.8% of all deaths in Australia occurred as a result of voluntary euthanasia and 0.1% were due to physician-assisted suicide. Despite these actions being unlawful in Australia, the incidence was broadly comparable with that in permissive jurisdictions. Other research demonstrates that some doctors who treat terminally ill patients intend to shorten life (rather than only relieve pain) when they administer pain relieving medication, and so will be acting unlawfully.¹⁰

The Victorian Cross-Party Parliamentary Inquiry into End-of-Life Choices (2016) also found that:

Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.

¹⁰ Bob Douglas, Lindy Willmott and Ben White, "The right to choose an assisted death: Time for legislation?", Australia 21, Health Law Research Centre, Queensland University of Technology, January, 2013 – http://australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf

According to the report, this is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.¹¹

In their submission to the Western Australian Joint Select Committee Inquiry into End-Of-Life-Choices (2018), Doctors for Assisted Dying Choice told the committee about:

... an anonymous survey of Australian medical practitioners [that] indicated that 35% of doctors have, at the request of their patient, provided medical treatments with the aim to hasten and shorten the duration of suffering for their patients. Because under the current laws, these doctors could face criminal charges, these practices remain hidden and are unspoken.¹²

On 28 July 2018, AMA (WA) President Dr Omar Khorshid admitted that doctors routinely hasten death, telling 7 News (video used in a report in *The West Australian*):

We (doctors) shorten patients' lives regularly if that's the right thing to do at the very end of life.¹³

1.2 Terminal Sedation

Terminal sedation is the practice of alleviating refractory suffering in patients by sedating them into a coma from which it is expected they will never awake.

According to the findings of the Victorian Committee, although widely practised, terminal sedation is:

... not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it.¹⁴

This end-of-life practice remains equally opaque in Queensland, despite the State being one of four (along with South Australia, Western Australia and the ACT) to have introduced legislation dealing with the use of palliative medication.

In Queensland, a doctor must order the sedation, and the doctor must give written authorisation. Even so, according to the Australian Centre for Health Law Research:

Whether or not palliative sedation is legal in Australia has not been considered by the Courts. However, it is likely that legality will depend on the circumstances of each individual case. For example, it would be lawful to use palliative sedation so long as it is performed to manage refractory symptoms, with the intention of relieving pain and suffering, not hastening or causing death, and the patient continues to receive nutrition and hydration.¹⁵

¹¹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Chair's Foreword", June, 2017, p. xvi – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

¹² A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4:133 'Unlawful Practices'", 40th Parliament, Parliament of Western Australia, August, 2018, p.146 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

¹³ Cathy O'Leary, "Perth pro-euthanasia Dr Alida Lancée cleared of wrongdoing by Medical Board", *The West Australian*, 28 July, 2018 – <https://thewest.com.au/news/health/perth-pro-euthanasia-dr-alida-lancee-cleared-of-wrongdoing-by-medical-board-ng-b88908204z>

¹⁴ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 6.3: Unlawful Medical Practice", June, 2017, pp.181-186, – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

¹⁵ Ben White, Lindy Willmott and Penny Neller, "Palliative Medication: Palliative sedation - Is palliative sedation legal in Australia?", *End of Life Law in Australia*, Australian Centre for Health Law Research, Queensland University of Technology – <https://end-of-life.qut.edu.au/palliative-care>

1.3 Doctrine of Double Effect

Under the legally recognised principle of the Doctrine of Double Effect, doctors can give increasing doses of medication to a dying patient, which may have the unforeseen consequence of hastening their death as long as it is not their intention to do so.

Like terminal sedation, no guidelines exist, nor is any record kept, about the application of the Doctrine of Double Effect in Australia.

Because no one is examining, or vouching for, the doctors' intentions, there is no way of knowing if the Doctrine of Double Effect is shielding abuse, or collusion between doctors and family members.

1.4 How can an unregulated system be safer than a regulated one?

A common argument made against Voluntary Assisted Dying is that it can 'never be 100 per cent safe'. This is true of any law. The relevant question is: "Does Voluntary Assisted Dying make our end-of-life practices safer than they are now?"

Under Queensland's existing end-of-life laws, we are asked to take it on trust that doctors are assisting people to die in the right way, and for the right reasons, *even when they're doing so illegally*. No questions are raised about threats to vulnerable people. No further safeguards are suggested.

Compare this with Victoria's Voluntary Assisted Dying Act (2017), which contains multiple safeguards, requiring that doctors' actions when assisting a person to die be checked against strict, legally enforceable, criteria.

Any system which sends doctors the message "we think it's safer if you just keep breaking the law" is a system that does not properly protect either its doctors or their patients.

2. WHAT IS LEGAL IN QUEENSLAND TODAY FOR A DYING PERSON SEEKING TO HASTEN THEIR DEATH

In Queensland, your legal options if you are suffering beyond medical help as you die, and seeking to hasten your death, are a choice of three, hard roads:

- refusing all medical treatment, food, and water;
- committing suicide;
- terminal sedation – being slowly put into a coma by doctors.

2.1 The right to refuse treatment and/or sustenance

Recent parliamentary inquiries into end-of-life care and Voluntary Assisted Dying have confirmed that the law recognises a person's right to relieve suffering at the end of life by exercising:

- the right to refuse further medical treatment, and/or;
- the right to refuse food and water in order to hasten death.

The [Australian Centre for Health Law Research](#) provides extensive information on end-of-life law in Australia.¹⁶

The law is clear that every adult has the right to refuse medical treatment if the adult has 'capacity' or is 'competent'. Medical treatment given without consent is unlawful, unless it was provided in an emergency in order to save the person's life, and it was not possible to obtain consent from the person or their substitute decision-maker.

¹⁶ Ben White, Lindy Willmott and Penny Neller, "Legal Overview: Can an adult with capacity refuse life-sustaining treatment?, and; Must health professionals follow a decision to withhold or withdraw treatment made by a patient with capacity?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – <https://end-of-life.qut.edu.au/stopping-treatment/adults>

In relation to adults with capacity, the Centre states:

It is lawful for an adult with capacity to make their own decisions to refuse or accept medical treatment, even if the decision they make results in their death. Doctors must respect those decisions to refuse treatment and, if directed to do so, doctors can legally withhold (not start treatment) or withdraw (stop treatment already started) life-sustaining treatment from adults, even if this might result in the person's death. It can also be lawful for a substitute decision-maker to ask that life-sustaining treatment be withheld or withdrawn from someone who can no longer make treatment decisions for themselves. [Our emphasis]

According to the Centre:

An adult can refuse medical treatment on any grounds including for example, religious reasons **or personal beliefs about what is an acceptable quality of life.** [Our emphasis]

It is important to note that such refusal is not considered suicide. Death by this method is medically supported with mouth, and other comfort, care. It can, however, be long, slow, and psychologically painful for the person going through it, their family, and the medical team caring for them.

This was underlined by Associate Professor Richard Chye, Director of Supportive and Palliative Care at St Vincent's and Prince of Wales Hospitals in Sydney, speaking on the podcast "Better Off Dead". In answer to the question if dying this way was painful, he said:

I think not physically but psychologically ... it is a very painful way to go, and I remember a patient who committed suicide who decided to stop eating and drinking and then because she was told, 'If you do that, you will be dead in two or three days'. She committed suicide because it hadn't happened after two weeks.¹⁷

Dr Alida Lancée explained to the Western Australian Inquiry that it is not necessarily an option free of suffering:

Stopping eating and drinking is a way to bring forward death, but it can take weeks. The person would have to endure several days of hunger pains followed by the symptoms of metabolic effect of starvation, which is ketotic acidosis. This causes headaches, confusion, breathlessness, delirium, agitation, weakness, muscle cramps and eventual sedation. Medical support is required to ensure these symptoms are controlled. When this is available, the process can be similar to terminal sedation.¹⁸ [Our emphasis]

Professors Ben White and Lindy Willmott, from the Australian Centre for Health Law Research, describe 'voluntary palliated starvation' as an option being more commonly taken by people who are dying:

This practice is occurring more frequently given the lack of options that patients have as they approach the end of their lives.¹⁹

The Victorian Inquiry into End-of-Life Choices wrote of the trauma families faced:

... watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.²⁰

¹⁷ Richard Chye in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway>
Transcript at Go Gentle Australia website, July 2017 – <http://www.gogentleaustralia.org.au/transcripts2>

¹⁸ Dr Alida Lancée in "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices: Transcript of evidence", Session Six, Perth, 5 April, 2018, p.4 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/AF83496EA799BE924825828A000C2036/\\$file/end180405.6.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/AF83496EA799BE924825828A000C2036/$file/end180405.6.pdf)

¹⁹ Lindy Willmott, Ben White and Penny Neller, Letter to the Joint Select Committee on End of Life Choices, EOLC Sub 560, 23 October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/5C9E02EB53E446D94825821E000FC3FB/\\$file/20171023+-+EOLC+-+Sub+560+-+Pro+Lindy+Willmot,+Prof+Ben+White+&+Ms+Penny+Neller.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/5C9E02EB53E446D94825821E000FC3FB/$file/20171023+-+EOLC+-+Sub+560+-+Pro+Lindy+Willmot,+Prof+Ben+White+&+Ms+Penny+Neller.pdf)

²⁰ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7: How the existing legal framework shapes end of life experiences", June, 2017, p. 193 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

CASE STUDY: DULCIE'S STORY

DULCIE, 73, FROM MT. GRAVATT EAST, DIED OF NEUROENDOCRINE CANCER – HER STORY IS TOLD BY HER DAUGHTER, SANDIE.²¹

IT WAS LIKE A HORROR MOVIE

She had a neuroendocrine tumour in her abdomen and a life expectancy of two months if she elected not to have chemotherapy.

She had suffered a lifetime of major illnesses, but given her history and the prognosis even with treatment, she decided the fight would be too hard, and she chose to die.

She was transferred to hospital two weeks prior to her death where she was given a blood transfusion, which was in contradiction to her express wishes that nothing be done to prolong her life.

By this stage, the pain was becoming unbearable and she was drugged to the eyeballs all the time.

My beautiful mother lay in that bed, rotting in front of my eyes for an entire week. Once they stopped taking her obs and said she was nil by mouth, it meant that medications that she had been so heavily dependent on (and was addicted to) were no longer being administered.

In my opinion, that sent her into a violent withdrawal and she spent a lot of time thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing.

She was starving to death and by this stage was skeletal, and her dehydration was obvious.

Her mouth was caked with thrush and because she had suffered very severe respiratory illnesses in her lifetime, the infected mucus was pooling on her chest, further preventing her from breathing.

I spent that whole entire week (day and night) by my mother's side, speaking on her behalf to try and get her more pain relief or a sip of water (until nil by mouth).

In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time.

Finally, she sat bolt upright in bed and her eyes flashed wide open with a look of terror on her face, then she fell back on the pillow and took her last breath. The mucus that had been pooling on her chest began to ooze out of her mouth, putrid, green sludge that just kept coming and coming.

That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through.

Her final days served absolutely no purpose to her or anyone else, and left me with a type of post-traumatic stress from having gone through it with her.

²¹ Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016. Free download available here – <https://www.gogentleaustralia.org.au/shop>

CASE STUDY: DULCIE'S STORY

According to The Australian Centre for Health Law Research:

A fundamental principle of health law is **an adult's right to decide what is or is not done to their bodies.**²² [Our emphasis]

This raises serious questions about what happened to Dulcie after invoking her legal right to refuse treatment, food, and water:

- Why was Dulcie given a transfusion in contradiction of her wishes to refuse all medical treatment?
- Why did Sandie have to push to get adequate pain relief and sedation for her mother?
- Why was Dulcie forced to endure a slow, painful and terrifying death from starvation and dehydration (and subsequent chest infection), when it was obvious that death was unavoidable?
- Why did Sandie have to watch her mother die this way?

Dulcie's experience robbed her of her autonomy, control and dignity. Her ordeal borders on mistreatment and abuse.

In allowing someone the legal right to refuse life-sustaining treatment, food and water, Queensland has already accepted the principle that a dying person has a right to hasten their own death.

As Dulcie's story demonstrates, they are just being told they have to do it slowly and painfully.

2.2 Committing suicide

In giving evidence to the Victorian Inquiry, Coroners John Olle and Caitlin English brought to light a very particular group of people: older Victorians, with no history of mental illness and from loving family relationships who, in Coroner Olle's words, were taking their own lives in "desperate and violent ways".

According to the Coroner, what these people had in common was that each was suffering an "irreversible decline", either from a terminal disease, multiple chronic illnesses, or permanent physical pain. He stressed that these were people of rational mind and, in his view, beyond the help of palliative care.

They included a 90-year-old man with brain cancer who shot himself repeatedly in the head and chest with a nail gun.

According to statistics gathered by the Coroner's Office over five years, these suicides are happening in Victoria at the rate of one a week.

In Coroner Olle's words:

... what seems to be a common thread through the family is this absolute sense of respect for someone they love [and] this absolute sense of helplessness. They know this person is screaming for help, but no-one is going to answer the call, not in this society. So, they have to die alone.²³

²² Ben White, Lindy Willmott and Penny Neller, "Legal Overview: Can an adult with capacity refuse life-sustaining treatment?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – <https://end-of-life.qut.edu.au/stopping-treatment/adults>

²³ John Olle in Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 7 October, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

In Western Australia, the Committee drew on statistics provided by the Coroner's Office and the National Coronial Information System (NCIS) to estimate that 10 per cent of suicides in WA in any given year were carried out by people with terminal or debilitating chronic illnesses.²⁴

They found that:

These people die lonely and often violent deaths; including through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds and, by hanging.²⁵

This pattern was corroborated by the South Australian Coroner, Mark Johns, in the podcast series "Better Off Dead". You can hear his testimony or read the transcript at the hyperlinks below.²⁶

The Western Australian Inquiry found that evidence from international jurisdictions had reached similar conclusions:

In the UK it has been estimated that around one in ten suicides is in the context of a terminal or severe chronic illness [...] and one in ten suicides in the USA has been determined to occur without an identifiable mental disorder.²⁷

There is no reason to think that Queensland is immune from a similar pattern of suicides among the terminally and chronically ill.

In fact, Queensland's ageing population suggests the State may be even more susceptible. According to the latest Australian Institute of Health and Welfare statistics, there are 727,000 Queenslanders aged 65+ years. That is one in seven out of a population of five million.

The 2018 report from Queensland's chief health officer says that in 2016, **cancer accounted for almost one third (9227) of deaths in Queensland – 2499 of these deaths were people aged 65–84** (figure not provided for 85+).²⁸

According to the Queensland Government, the number of new cancer cases in Queensland is among the highest in the world.²⁹ In Australia, Queensland has the highest rates of all major cancers for men and women – bowel cancer, breast cancer, prostate cancer, and melanoma.³⁰

Even if only a small number of these older Queenslanders with cancer mirror the patterns in Victoria and Western Australia and take their lives, the impact upon the wider community – on family members, doctors, nurses, and also on first responders called to the scenes of such tragic deaths – will be far greater than any statistic can show.

²⁴ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

²⁵ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

²⁶ Mark Johns in Andrew Denton, "Better Off Dead: #14 Australia's Dark Little Secret", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 30 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/14-australia-s-dark-little-secret>
Transcript at Go Gentle Australia website, <https://www.gogentleaustralia.org.au/transcripts2>

²⁷ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4.117 'Do people deliberately end their lives because of terminal or debilitating illness?'", 40th Parliament, Parliament of Western Australia, August, 2018, p.140 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

²⁸ Young, Jeanette, "The health of Queenslanders 2018: Report of the Chief Health Officer Queensland", State of Queensland (Queensland Health), November, 2018, p.34 – https://www.health.qld.gov.au/_data/assets/pdf_file/0032/732794/cho-report-2018-full.pdf (Statistics calculated from data in Table 9)

²⁹ Queensland Government, "Information for Queenslanders: Health and Wellbeing - Men's Health - Cancer", updated 23 September 2015 – <https://www.qld.gov.au/health/staying-healthy/men-women/men/cancer>

³⁰ Liz Burke, "Australia's cancer hot spots revealed", news.com.au, 1 July, 2017 – <https://www.news.com.au/lifestyle/health/health-problems/australias-cancer-hot-spots-revealed/news-story/372182126ea7a6a1f189848a481f8c8d>

See also: Torrens University Australia, "Torrens University Pioneers Interactive Map Revealing Cancer Rates Across the Nation", 25 August, 2017 – <https://www.torrens.edu.au/blog/general/torrens-university-cancer-research-findings>

CASE STUDY: DIANA'S STORY

DIANA'S STORY TAKES PLACE IN MACKAY, QUEENSLAND.

HER FATHER, ROGER, SUFFERED FROM INOPERABLE PROSTATE CANCER.³¹

OUR FATHER SHOT HIMSELF IN THE HEART

On 14 June 1994, our father shot himself in the heart with a rifle.

He was in the bedroom; our mother was in the kitchen no more than five metres away, my 12-year-old nephew in the lounge.

Dad was diagnosed with inoperable prostate cancer at the age of 54 with a 10 to 15-year prognosis.

And so, began his long battle with an exploratory operation that ended in a careless removal of the catheter that left him 'leaking' constantly, but he didn't give up due to that little hurdle.

He devised his own special 'nappy' so that he could continue to play his beloved golf. I don't think they had Tenas then!

I can't remember the exact point when he started to decline but I do remember distinctly his last couple of months.

He had been admitted to the palliative care ward of our local private hospital and was cared for so wonderfully by the nursing staff.

At the beginning, he would entertain other patients, and us when we came to visit, by playing the piano (totally self-taught and unable to read music).

But he was being given painkilling drugs that had him hallucinating and we could sense his

frustration at his lack of control. He couldn't conduct a reasonable conversation when friends came to visit.

Even though he had the best of care at the hospital, he was desperate to come home and, in the end, refused to go back.

I learned after his death he had begged his doctor for enough medication to safely and gently end his life when he knew all hope was lost.

He had written a note which I still have; a small piece of paper roughly torn from a page, upper case letters, obviously written with a shaking hand:

I LOVE YOU ALL. ALWAYS DO YOUR BEST. DAD.

I can only wonder at the beautiful memory we could have had of Dad's last moments; whether he had chosen to have us present when he passed or not, at least he would have died with the dignity that was rightfully his.

³¹ Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016. Free download available here – <https://www.gogentleaustralia.org.au/shop>

CASE STUDY: DIANA'S STORY

In Queensland it has been legal for a dying person to bring an end to their suffering by suicide since 1979, yet the death of Di's father raises serious questions about the choices offered by our existing law:

- Why, when it was clear that there was no further treatment to help Roger, was he denied a peaceful and dignified death with his family by his bedside?
- Why was no effort made by his doctor to help him when he begged for assistance to die gently?
- Why was Roger denied the opportunity to farewell those he loved?
- Why did he come to believe that taking his own life in this way was his only option?
- Why did his family have to witness the aftermath of his violent suicide?

Roger's was a brutal and lonely death that left his family with ongoing trauma. It suggests a system that promotes mistreatment and abuse.

In allowing someone the legal right to commit suicide, Queensland has already accepted the principle that a dying person has a right to hasten their own death.

They are just being told they have to do it violently and alone.

2.3 Terminal Sedation: Being slowly put into a coma by doctors

Terminal – or palliative – sedation is the alternative held out by palliative care when pain can no longer be controlled: the promise of powerful drugs that will put the dying person into a coma from which they will not awake. Associate Professor, Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health, Melbourne, defined it this way to the Victorian Committee:

Continuous deep sedation is sometimes instituted in people where we feel that they have intractable pain that we just cannot manage.³²

Because there is no record kept of its use, there is no way of knowing how widely terminal sedation is used, how often it is needed, who decides if it is, and on what basis.

The Australian Centre for Health Law Research says the primary purpose of terminal sedation is to:

Sedate a patient near the end of their life in order to relieve their symptoms, not to cause or hasten their death.³³

However, writing in the *Journal of American Medicine*, Dr Erich Loewy explains there is no meaningful ethical distinction between the foreseeable outcome of terminal sedation and that of Voluntary Assisted Dying:

At least in law, and I would reasonably hold the same true for ethics, one is responsible not only for what one has clearly intended, but also for what one could reasonably foresee. In terminal sedation, not only is the patient's death clearly foreseen, it is in fact the end point of what is being done. **Clearly (and however it may be cloaked by the use of language), the intent here is more than just the clear goal of relieving pain and suffering.**

³² Natasha Michael in Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 16 September, 2015, p.10 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

³³ Ben White, Lindy Willmott and Penny Neller, "Palliative Medication: Palliative sedation - What is palliative sedation?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – <https://end-of-life.qut.edu.au/palliative-care>

Because the goal of relieving pain and suffering adequately can be attained only by obtunding the patient until death ensues, the patient's death becomes the end point and, therefore, one of the intended goals.

These goals do not differ from those of physician assisted suicide or, for that matter, voluntary euthanasia.

The difference is maintained for two reasons. The first reason is to escape legal difficulties; the second is a form of self-delusion aimed at giving comfort to the physician and the medical team.³⁴ [Our emphasis]

2.4 Terminal sedation does not save a person from suffering

It is important to keep in mind that terminal sedation doesn't save a patient from suffering – it is a response to suffering that has already been happening and which can no longer be controlled.

The suffering may have lasted days, or weeks, or months before sedation is employed – and that decision is entirely up to the doctor and their own personal beliefs.

According to Australia's foremost pain specialist, Professor Michael Cousins:

About 10 per cent of cancer patients had pain that was so difficult to treat at the end of their life that they would be given drugs to sedate them until they die.

It could be several days, or as much as a week before a person dies.³⁵

And terminal sedation is not always effectively applied, as Australia's most senior palliative care physician, Professor Ian Maddocks, explains:

In reality, there are occasions where patients in terminal palliation do not receive adequate relief for their pain and suffering; in these cases, patients can frequently experience distressing respiratory problems; they may regain consciousness; intolerable pain may not be relieved; and they may experience a prolonged, uncertain, albeit inevitable death.³⁶

This is clearly demonstrated in the death of young Melbourne woman, Cassie Godden.

³⁴ Erich H Loewy MD, "Terminal Sedation, Self-Starvation, and Orchestrating the End of Life", JAMA Internal Medicine, 161(3), 2001, pp.329-332 – <http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/647177>

³⁵ Michael Cousins, quoted in Julia Medew, "Pain follows many cancer patients to the end", *The Age*, 12 February, 2010 – <https://www.theage.com.au/national/pain-follows-many-cancer-patients-to-the-end-20100211-nv43.html>

³⁶ Ian Maddocks in "Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150", Victorian Civil and Administrative Tribunal Administrative Division, Review and Regulation List, VCAT Reference No. Z164/2016, 97(c), 21-23 November, 2016 (Hearing), 20 December, 2016 (Date of Order), p. 31, link to document file here (automatic download) - <https://tinyurl.com/y88ac64f>

CASE STUDY: CASSIE'S STORY

CASSIE GODDEN, 18, FROM GIPPSLAND VICTORIA, DIED OF METASTATIC CANCER. HER STORY IS TOLD BY HER PARENTS, BRETT AND DIANNE.³⁷

SHE WAS IN EXCRUCIATING PAIN AND DISTRESS

Further tests showed the melanoma had moved into her bone marrow. Doctors said there was nothing else they could do and Cassie bravely made the decision to refuse any further treatment.

She knew she was going to die.

She asked for a week to say her goodbyes; doctors gave her four days, saying they could now only make her "comfortable".

What rubbish.

Cassie was on huge doses of painkillers and was outwardly unresponsive – but could still feel pain. She regained consciousness long enough to acknowledge she was being given painkillers and occasionally speak to us.

Cassie asked the nurses for "the biggest dose they could give".

“On the third morning, she begged the nurse: ‘Please tell me this is going to kill me.’”

She was in excruciating pain and distress. She had said her goodbyes, and wanted to go. The distress extended not just to her family and boyfriend, but to the medical staff.

Cassandra passed four days after ceasing treatment. The question of how she wanted to end her life was never broached. It was illegal to help her to die, so the question was never asked.

But having watched her die, hearing her ask for the biggest painkilling dose, and beg "Please tell me this is going to kill me", we have no doubt Cassie would have welcomed the choice to make an end-of-life decision.

Whether she would have acted and ended her life earlier, we will never know. But if all palliative care can do is keep you in an induced coma until your body gives out, it is not enough.

Doctors could do nothing more for her. She had said her goodbyes, but could not ask to be allowed to die at the time of her choosing.

Cassie was intelligent, understood her illness, did all the doctors told her to, participated in medical trials, and submitted to radiation, CT scans, blood transfusions and excruciatingly painful biopsies.

She maintained full control of her mental faculties and was capable of making an informed decision that the time had come to die.

Cassie was an adult, allowed to drive, drink, vote and leave home. But despite excruciating pain, she was not allowed to decide the time of her death.

Why do so many think it is acceptable to force humans to linger in this way?

³⁷ Dianne and Brett Godden, "Brett and Dianne Godden: Our lovely Cassie had no choice but to die in agony", *Herald Sun*, 17 October, 2017 – <https://www.heraldsun.com.au/news/opinion/brett-and-dianne-godden-our-lovely-cassie-had-no-choice-but-to-die-in-agony/news-story/24fa5ce9c44f8f12694e6c17069a9481>

CASE STUDY: CASSIE'S STORY

Under Australian law, decisions about terminal sedation (when, or even if, it is employed) and the speed at which drugs are administered are entirely in the hands of the treating doctor. The patient has no right to insist.

The Western Australian Inquiry noted this lack of transparency:

It is of concern to the committee that many patients at the end of life, and their family members, are unaware of this treatment. In this context, it is also concerning that there is a lack of recording and data collection...³⁸

Cassie's painful death raises questions about how decisions are made to employ terminal sedation and, once they are, how effective it is:

- Why did doctors claim they could make Cassie "comfortable" when there was clear evidence that sedation wasn't working?
- Why was Cassie's clear request for enough painkillers to stop her suffering not acted on?
- Why, despite having been allowed to make decisions about all other medical treatments, was Cassie denied the right to decide about how much suffering she had to endure as she died?
- Why did Cassie's family, boyfriend, and carers have to witness her prolonged and excruciating death?

Cassie's experience is similar to those of other terminally ill people in Queensland.

In allowing a dying person to be drugged into a coma, Queensland has already accepted the reality that there is some suffering that can no longer be managed by palliative care.

Patients are just being told that only a doctor can decide for them when they have suffered enough.

3. QUEENSLAND'S END OF LIFE LAWS ARE INCOHERENT AND INEQUITABLE

In 2013, following a roundtable on assisted dying involving doctors, lawyers, politicians and ethicists, the Australia 21 Institute concluded that Australia's existing end-of-life laws are incoherent:

- Withdrawal or withholding of life-sustaining treatment that results in a person's death may be lawful, but the provision of a lethal dose intended to cause death is not;
- Terminal sedation may be lawful, but can also be unlawful depending on the doctor's intention when giving the medication;
- Suicide is legal, but assisting someone to commit suicide is illegal;
- There is a lack of clarity about what is meant by "assisting" someone to die;
- Even in a clear case where a person has "assisted" another to die, some individuals are prosecuted and jailed for providing that assistance, and others are not.

³⁸ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4:72 'Terminal Sedation in Western Australia'", 40th Parliament, Parliament of Western Australia, August, 2018, p.129 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

The Institute also found that existing laws have not only failed, but that they are unfair:

The Rule of Law requires that law must apply equally to all, but this is not the case in this field. Whereas some may be able to end their own life, another person's disability may prevent them from doing so. [Our emphasis]

Further, a person who is ill and relying on life-sustaining treatment to survive (such as a respirator) may lawfully ask for that equipment to be turned off. Another person who is equally ill, but suffering from a different condition which does not require such treatment, cannot be assisted to die.

At present, there are some who can access voluntary euthanasia and assisted suicide despite it being unlawful. Those people are generally able to do so because they possess some privilege. It may be privilege in terms of education or it may be in relation to contacts and connections one has within the medical or veterinary professions.

The operation of the law cannot be justified if a privileged few are able to receive assistance to die, but others are not.³⁹

Queensland's current end-of-life laws do not provide sufficient protection from intractable suffering to people at the end of life.

Neither do they provide sufficient protection, or clarity, to doctors faced with such suffering.

³⁹ Bob Douglas, Lindy Willmott and Ben White, "The right to choose an assisted death: Time for legislation?", Australia 21, Health Law Research Centre, Queensland University of Technology, January, 2013, p.19 – http://australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf

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Part C

Beyond Pain

Why more resources for palliative care alone
will not address the need for Voluntary Assisted Dying

WHAT THIS SECTION IS ABOUT

The number one argument the Queensland Inquiry will hear against Voluntary Assisted Dying is that ‘there would be no need for it if only palliative care were properly resourced’.

Australia has one of the best palliative care systems in the world. However, claims it can help everyone are untrue. The words and statistics from palliative care tell us so. The many testimonies from medical professionals and families of those who have died badly tell us so, too.

Even so, representatives of palliative care – speaking, not just from a medical, but also from an undeclared moral perspective – continue to argue that VAD is unnecessary because palliative care has the answers for all.

1. THE PERSUASIVE MYTH: PALLIATIVE CARE HAS ALL THE ANSWERS

1.1 The Argument

Parliamentary records around Australia show that two arguments dominate equally the thinking of politicians who vote against Voluntary Assisted Dying:

1. They are not convinced such laws can be safe.
2. They are persuaded that the solution to people dying badly is giving more resources to palliative care.

The image of palliative care being the answer to all suffering is vigorously promoted by many palliative care doctors around Australia and frequently by their peak representative bodies.

But **the political case that, if properly resourced, palliative care is the answer for all end-of-life suffering is a myth. It is a myth retailed to politicians by senior doctors, many of whom have appeared before parliamentary inquiries representing faith-based organisations** and who believe that assisting a person to die is immoral in the eyes of God.

The professional authority of these doctors, as experts on the care of the dying, has been accepted by many politicians without any exploration of their personal moral agendas.

Here are recent examples of this myth being spread:

South Australia, 2016

On Tuesday, 16 November 2016, representatives of Palliative Care South Australia briefed MPs ahead of the next day's debate to legalise Voluntary Assisted Dying in that state.

According to Cathi Tucker, Manager for the Office of Kelly Vincent MLC who attended the meeting and took notes, a question came from Labor MP Jennifer Rankine:

It has been put to me that some people can't be treated with palliative care. Families suffer enormously through the dying process.

The answer was:

What we can't deal with is the existential distress. **From the symptom perspective – with palliative sedation as the fall back – we can control everything.** [Our emphasis]

The debate in the lower house the next day led to a tied vote, with the legislation being voted down by Speaker of the House and committed Christian, Michael Atkinson. The MP who dramatically crossed the floor at the last minute to tie the vote was then Attorney-General, John Rau. Rau had been in attendance at the previous day's briefing by Palliative Care South Australia. Speaking to *InDaily* after the vote, he gave as his reason:

My concerns were basically about palliative care, and in the end **I'm not convinced that ... there's a substantial group – or even a small group – of people who are not able to be adequately comforted by palliative care.**⁴⁰ [Our emphasis]

Victoria, 2017

On 17 October 2017, a group of senior physicians addressed MPs in Victoria's Parliament House ahead of debate due to start that afternoon to legalise Voluntary Assisted Dying.

No contemporaneous notes of that meeting exist, however a record of what was said can be found in Hansard, firstly from Liberal MHR, Murray Thompson, on 17 October:

It was tweeted earlier today that there are some examples of pain and suffering that are not able to be properly addressed. I put that question to a number of speakers at lunchtime. There was a geriatrician, a palliative care expert, an emergency physician, a general physician, a couple of oncologists, a psychiatrist and a GP. I was directed to the answer that medication can meet the pain relief needs of some 96 per cent of patients and that for the four per cent where there are difficulties, there can be palliative sedation so that no-one ought suffer. No-one need suffer in confronting their final days of life.⁴¹

On 2 November, Liberal MLC, Bernie Finn, told the Legislative Council:

I was greatly comforted by a professor of palliative care who said in this house just a couple of weeks ago that **palliative care can control all the pain and deliver relief until death inevitably knocks.**⁴² [Our emphasis]

⁴⁰ Tom Richardson, "Why did these MPs change their vote on voluntary euthanasia?", *InDaily*, Adelaide, 17 November, 2016 – <https://indaily.com.au/news/local/2016/11/17/why-did-these-mps-change-their-vote-on-voluntary-euthanasia/>

⁴¹ Murray Thompson, "Voluntary Assisted Dying Bill 2017 - Opening Speech", Murray Thompson, State Member for Sandringham website, 17 October, 2017 – http://www.murraythompson.com.au/news/article/voluntary_assisted_dying_bill_2017_opening_speech

⁴² Bernie Finn, "Voluntary Assisted Dying Bill 2017", Council, second reading, Hansard, Parliament of Victoria, 2 November, 2017, p. 5602 – https://www.parliament.vic.gov.au/images/stories/daily-hansard/Council_2017/Council_Daily_Extract_Thursday_2_November_2017_from_Book_18.pdf

In The Media

On 18 October, Dr Stephen Parnis, formerly federal vice-president of the AMA, who was present at the briefing of MPs the previous day, stated the following to Sarah McVeigh on Triple J's "Hack Live":

Parnis: And, when palliative care is done properly – and I've seen it, I've delivered it – **the causes of suffering go away**, and ...

Sarah McVeigh: But, isn't it also true that, for some people, they don't?

Parnis: Ah – maybe a tiny proportion. I have to say that the proponents of this law absolutely exaggerate the numbers. And when palliative care is delivered properly, **those sorts of horror deaths that some of the groups try and paint out, need never occur.** ⁴³ [Our emphasis]

1.2 The Reality: Those Beyond the Help of Palliative Care

Australia's palliative care is well regarded by international standards, and we have heard many accounts of people receiving good palliative care that has eased pain and suffering.

However, we know that not all patients' suffering can be relieved by palliative care from five authoritative sources:

- Palliative Care Australia
- Doctors surveyed by the AMA
- Parliamentary inquiries conducted in Victoria and WA
- Multiple testimonies from families, carers, coroners, and first responders testifying to extreme suffering as people die despite the best efforts of palliative care
- Multiple testimonies from doctors and nurses, in particular palliative care doctors.

1.2.1 Palliative Care Australia

These are their words, published in the Policy Statement on Voluntary Euthanasia in 2006:

While pain and other symptoms can be helped, **complete relief of suffering is not always possible, even with optimal palliative care.** ⁴⁴ [Our emphasis]

The Palliative Care Outcomes Collaboration (PCOC) collates data from over 100 palliative care services throughout Australia to produce detailed analyses and benchmarking of patient outcomes.

PCOC's latest report, covering the period January to June 2018, analyses the palliative care experiences of 22,452 patients nationally.⁴⁵

Patients are assessed over various phases of their illness, including the terminal phase. Patients' levels of distress are measured in relation to various categories of suffering that include, but are not limited to, 'pain'.

The 2018 report tells us that about two per cent of patients in the terminal phase suffer severe distress from pain.

It's crucial to appreciate that this single symptom – pain – is only one part of suffering that dying patients may experience. In the six months to June 2018, for example, 2.5 per cent of patients, 579 nationally, suffered severe distress from breathing difficulties during their terminal phase.

⁴⁴ Stephen Parnis on "Hack Live" with Sarah McVeigh, Triple J, 5.30pm, 18 October, 2017 – recording provided to Go Gentle Australia by the Australian Broadcasting Commission and transcribed by us.

⁴⁵ Australian Institute of Health and Welfare, Australia's health 2016, Australia's health series no. 15, Cat. no. AUS 199, Canberra: AIHW, 2016, p. 3.

⁴⁶ Palliative Care Australia, "Policy statement on voluntary euthanasia", Canberra, 2006, p.2. Quoted by: Neil Francis, "AMA uncovered: How its own review exposed its assisted dying policy as indefensible", Dying for Choice, 27 March, 2017, p.20 – <http://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf>

1.2.2 Doctors Surveyed by the AMA

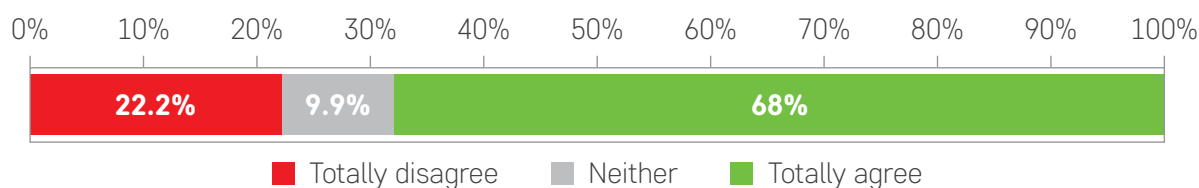
There is broad consensus within the medical community that palliative care, even when properly delivered, cannot always – as Dr Parnis claimed – make “the causes of suffering go away”.⁴⁷

In 2016, when the Australian Medical Association (AMA) asked its members:

To what extent do you agree with the following statement? ‘Palliative care and medical treatment cannot adequately alleviate the suffering of some patients’.

Nearly 70 per cent of respondents agreed that palliative care cannot adequately alleviate the suffering of some patients.⁴⁸

Figure 3: Australian Medical Association Member Consultation Report – Palliative Care



1.2.3 Parliamentary Inquiries

A key finding of the Victorian Parliamentary Inquiry in 2016 was that there are:

... many benefits of palliative care, an area of medicine which has advanced significantly over the last decade. However, palliative care does have limitations, as described by Palliative Care Victoria, who explained that palliative care can sometimes be ineffective at relieving all suffering.⁴⁹

The Western Australian Inquiry in 2017/18 came to a similar conclusion:

Too many Western Australians are experiencing profound suffering as they die. This is, in part, due to inequitable access to palliative care. However, **it is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.**⁵⁰ [Our emphasis]

Both inquiries accepted that some palliative care patients are beyond meaningful help from palliative care.

The Western Australian inquiry referred to “somewhere in the range of 2–5 per cent” of patients for whom palliative care was ineffective in relieving their symptoms as being consistent with the evidence, and also referred to “evidence from some health professionals that the figure may be even higher, perhaps as high as 30 per cent”.⁵¹

These are the people for whom we argue Voluntary Assisted Dying is most needed.

1.2.4 Multiple testimonies from families, carers, coroners, and first responders testifying to extreme suffering as people die despite the best efforts of palliative care

These are many, and their stories are harrowing. In APPENDIX – ‘When Palliative Care No Longer Works’ – more than 100 examples of the limitations of palliative care are gathered from around Australia. Here is just one:

⁴⁷ Stephen Parnis on “Hack Live” with Sarah McVeigh, Triple J, 5.30pm, 18 October, 2017 – recording provided to Go Gentle Australia by the Australian Broadcasting Commission and transcribed by us.

⁴⁸ Australian Medical Association, “Review of AMA Policy on Euthanasia and Physician Assisted Suicide – Member Consultation Report”, 2016.

⁴⁹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, “Inquiry into end of life choices: Final Report: ‘Chapter 3 – Towards a Community Based Approach to Palliative Care’”, June, 2017, p.51 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

⁵⁰ A Sanderson (MLA) and Hon. C J Holt (MLC), “Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: ‘Chair’s Forward’”, 40th Parliament, Parliament of Western Australia, August, 2018 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

⁵¹ A Sanderson (MLA) and Hon. C J Holt (MLC), “Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: ‘3.155: Limitations of Palliative Care’”, 40th Parliament, Parliament of Western Australia, August, 2018, p.92 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

CASE STUDY: BARRY'S STORY

BARRY JOHN LANGBECKER, 74, FROM GYMPIE, QUEENSLAND, DIED FROM PARKINSON'S AND OESOPHAGEAL CANCER. HIS STORY IS TOLD BY HIS DAUGHTER, DENISE KAPERNICK.⁵²

HE DID NOT PASS AWAY PEACEFULLY LIKE THE MOVIES PORTRAY

Due to the staph, he was not a suitable candidate for chemotherapy and the idea of operating was also eliminated as it was a major operation that would involve cracking his chest open and removing a considerable amount of the oesophagus and stomach, which would have been too much for his already unfit condition.

It was decided that he would instead undergo a course of radium to try to shrink the tumour enough so he could swallow (and keep) his food down, which he was now unable to do.

Unfortunately, this treatment did not reduce the tumour, so he continued to lose weight and strength until he eventually was unable to even swallow his own spit.

At this stage Dad knew his time was limited so, in an attempt to hasten his death, he stopped taking his staph medication in the hope the infection would return and end his time on earth quickly and painlessly.

... at 2am the next morning he suffered a catastrophic stroke, paralysing him completely down his left side, weakening his right side and leaving him totally bedridden.

He was unable to do anything for himself and was reliant on the nursing staff, my sister and me to feed him, wipe his face, clean him, roll him over, massage his legs and wipe away his tears.

As the weeks passed, his pain increased as the fluid built in his limbs and the morphine was not

enough. The Parkinson's was also a factor for his pain as his muscles seized and spasmed.

The doctors tried fentanyl patches, increased his morphine doses and eventually commenced a morphine driver but his pain was still unbearable.

He stopped asking the nurses to hoist him into a chair so he could be wheeled outside as the slightest movement would bring him to tears, even when we tried to trim his fingernails.

He put up an incredible fight against the staph, Parkinson's and the cancer, but the stroke robbed him of any quality of life and it was only at this time that he had no fight left and no desire to 'live' another day.

Dad lived seven weeks and three days after the stroke and this whole time he suffered, both mentally and physically. He did not pass away peacefully like the movies portray though. He drowned in his own phlegm and the noise of this is something I can never describe. His eyes were rolled back in their sockets and he was groaning and gurgling and his breaths were laboured, shallow and frantic.

My sister and I cried at his side, hoping that each breath was his last, but, as the hours passed, he continued his struggle for air until his body finally gave up and went silent.

⁵¹ Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, p.36 Free download available here – <https://www.gogentleaustralia.org.au/shop>

CASE STUDY: BARRY'S STORY

- Why was Barry forced to struggle on for more than seven weeks, with intolerable suffering and pain?
- Why were there no alternative end-of-life options available to Barry other than stopping his medication in the hope that a staph infection would take him?
- Even though the 'slightest movement would bring him to tears', why was he offered nothing further once fentanyl patches, increased morphine doses and a morphine driver failed to manage his pain?

Barry's terrifying ordeal – and the distress experienced by his family – border on mistreatment and abuse.

For an insight into the realities of how some people die within Australian palliative care, here are hyperlinks to three episodes from the podcast "Better Off Dead".⁵³

[Episode 10: Neither Hasten nor Prolong Death. Palliative Care in Australia Pt. 1](#)

[Episode 11: Whose Life is it Anyway? Palliative Care in Australia Pt. 2](#)

[Episode 12: Velvet Ray](#)

These episodes feature the voices of palliative care doctors and nurses, as well as of families recounting the deaths of loved ones. Transcripts can be read at Go Gentle Australia's website.

1.2.5 Multiple testimonies from doctors and nurses

Some of Australia's most senior palliative care physicians have publicly acknowledged the limitations of palliative care. These include:

Clive Deverall, former president of Palliative Care WA

In an interview with ABC TV months before his death, Clive revealed that palliative care was not the answer for between four and eight per cent of patients:

Certainly, I still embrace what palliative care stands for, but even with their clinical guidelines, they avoid the elephant in the room which is the very end-stage patients where symptoms cannot be controlled.

Patients in that distressed state, those patients should be offered voluntary euthanasia.

The take home message is that we have a cruel law at the moment that is prejudicial to the interests and wishes of patients, that needs to be changed.⁵⁴

In notes found after his death, he wrote:

I have attended so many palliative care meetings where problems have been discussed in context of the experience of individual terminally ill patients. The term 'palliative care nightmare' was used frequently when despite all the best efforts – clinically and despite access to all the drugs, the patient's developing symptoms of pain, nausea, panic and

⁵³ Andrew Denton, "Better Off Dead" podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre, 2015-2016 (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show_all=true

Transcripts available at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

⁵⁴ Claire Moodie, "'With his death he made a statement': Clive Deverall's widow speaks out on euthanasia", news report and video, ABC News, 20 September, 2017 (see quoted content in video at 4:00) – <https://www.abc.net.au/news/2017-09-19/clive-deveralls-widow-speaks-out-on-euthanasia/8882854>

breathlessness as well as emotional distress could not be controlled. So called 'nightmare scenarios' became an item for discussion at some professional meetings and conferences. (Palliative Care Australia has recently acknowledged these scenarios.)

Palliative care has been used as a mantra by politicians on all sides and health professionals to oppose euthanasia or to avoid having it debated.

“Even if good, modern palliative care was available for each and every terminally ill patient – we would still have the ‘nightmares’.”⁵⁵

Dr Roger Hunt, palliative medicine specialist and a life member of the Palliative Care Council of South Australia

Dr Hunt believes that, while palliative care is, without exception, helpful to dying patients:

it is fanciful and misleading to claim that all suffering can be eliminated.

Dr Hunt reiterates that physical pain is not the only concern for terminal patients:

... all surveys of patients receiving palliative care show they have multiple concurrent symptoms and other forms of suffering.

He also reminds us that treatments for pain often compound the patient's misery because of their adverse effects. Pain management is complex and highly subjective and Dr Hunt points to the difficulty of defining a “simplistic” cut-off point at which “palliative care cannot help”.

However, he notes that:

Refractory symptoms* that are severe enough to require continuous sedation occur frequently. Depending on the clinicians and patient populations, 5% to 50% of palliative care patients can have continuous sedation prior to death.

**Symptoms 'that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness'.⁵⁶*

He concludes:

The proportion of patients of palliative services who persistently request a hastened demise is 5% to 10% ... That is: 5% to 10% of patients who receive palliative care will experience suffering to the extent they will request VAD. The reasons are similar to those documented for people who access VAD in Oregon and the Netherlands (most of whom also receive palliative care).⁵⁷

⁵⁵ Noreen Fynn, “Submission to the Joint Select Committee on End of Life Choices (Western Australia)”, 17 October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\[Evidence+Lookup+by+Com+ID\]/30D73154F4D00AFF48258219000B3C84/\\$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/[Evidence+Lookup+by+Com+ID]/30D73154F4D00AFF48258219000B3C84/$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf)

Noreen Fynn is the widow of Clive Deverall

⁵⁶ NI Cherny and RK Portenoy, “Sedation in the management of refractory symptoms: guidelines for evaluation and treatment”, *Journal of Palliative Care*, 10(2), pp.31–8, 1994 – <https://www.ncbi.nlm.nih.gov/pubmed/8089815>

⁵⁷ Roger Hunt, “Re P.C. Figures”, Email to Andrew Denton, Go Gentle Australia, 23 July, 2017.

Professor Michael Ashby, formerly Professor of Palliative Medicine at Monash University, now Director of Palliative Care, Tasmanian Health Service

In his affidavit in support of Lecretia Seales⁵⁸, a New Zealand woman dying of brain cancer who took her Government to court in 2015 seeking the right to legally end her own life, Ashby wrote:

Palliative care is unable to relieve suffering in all circumstances for all people. Skilled palliative care can nearly always make a difference for the better but can be challenged by symptoms such as refractory cancer pain, fatigue, loss of function and independence, and by 'existential' suffering.

... Other physical symptoms that are addressed by palliative care with varying degrees of acceptable outcome for patients include mobility issues, agitation, breathlessness, incontinence and choking episodes.

... Many mentally competent end-of-life patients experience high levels of psychological and emotional suffering. As noted, palliative care takes a holistic approach. Palliative care teams tend to include social workers, psychologists, nurses and social care workers.
[Our emphasis]

“While they do an admirable job, in my experience it is with psychological and emotional suffering that palliative care teams have to acknowledge significant limitations.”⁵⁹

A number of testimonies from doctors attesting to the limitations of palliative care can also be found in APPENDIX: 'When Palliative Care No Longer Works'. Here is just one:

⁵⁸ John Weekes and Jared Savage, "She never planned to be poster girl for right-to-die: Lecretia Seales dies hours after family received judge's decision", *NZ Herald*, 5 June, 2015 – https://www.nzherald.co.nz/social-issues/news/article.cfm?c_id=87&objectid=11460184

⁵⁹ Michael Ashby, "Affidavit of Michael Ashby", *Lecretia Sales v Attorney-General*, High Court of New Zealand, Wellington Registry, 23 April, 2015, reference CIV-2015-485-235, points 13, 19 and 20 – http://lecretia.org/wp-content/uploads/2015/10/redacted_affidavit_of_michael_ashby.pdf

CASE STUDY: DR X'S STORY

DR X'S MOTHER DIED FROM STOMACH CANCER. THE DOCTOR ALSO RECOUNTS THE EXPERIENCE OF A WOMAN WITH VULVAL CANCER.⁶⁰

FIFTEEN YEARS ON, HER SUFFERING STILL MAKES ME SICK

I have witnessed the illness, suffering and deaths of many patients over the years.

Many deaths have been well managed with palliative care but there is a misconception that modern palliative care can alleviate most suffering and allow a dignified and reasonably comfortable death in nearly all cases.

This is simply not so.

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients.

Patients can suffer both physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids.

In my mother's case of linitis plastica (a form of stomach cancer), she had absolutely intractable and intolerable nausea and could not eat, and this was not adequately palliated despite maximum involvement of palliative care services.

It was dreadful to see her suffer without adequate relief. She asked me several times to be put out of her misery but she had to endure it to the end.

I can recall several other patients who were unable to be adequately palliated. In particular,

I vividly recall one unfortunate young woman. She was dying of advanced vulval cancer and had the most awful ulceration with severe pain at the slightest movement or touch and offensive discharge, bleeding and odour.

Fifteen years on her suffering still makes me feel sick.

“Nothing except death gave her release and death did not come peacefully despite morphine and palliative care.”

Patients dying of advanced motor neurone disease are also faced with unbearable suffering, witnessing in full alertness a body that is paralysed and fearing choking to death as they lose every last vestige of independence and dignity.

For some this is intolerable, yet our society demands that they endure the full course of their illness no matter what their wishes.

⁶¹ Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, p.126, Free download available here – <https://www.gogentleaustralia.org.au/shop>

CASE STUDY: DR X'S STORY

- Why was Dr X's mother's intolerable nausea not adequately palliated despite intensive palliative care?
- Why was Dr X put in a position where he could not act on his own mother's request to be 'put out of her misery'?
- Why was the woman with vulval cancer left to suffer in palliative care while enduring maximum indignity and excruciating pain?

The treatment enforced on these two women borders on mistreatment and abuse.

Please note the following stories from medical professionals in APPENDIX: 'When Palliative Care No Longer Works':

Dr Michael Cameron, p.136

Dr Geoff Wall, p.137

Dr Geoff Tresize, p.137

Nurse Coral Levett, p.138

Nurse Flora Metcalf, p.138

Dr X, p.138

Dr Alida Lancée, p.139

Dr Cheryl Wilson, p.139

Heather Bell (medical student), p.143

Nurse Kelly Somerville, p.145

Nurse Anne Korner, p.145

Nurse Carmel Hurst, p.146

Nurse Norma Kelly, p.149

2. THE ELEPHANT IN THE ROOM: WHEN RELIGION, ETHICS AND MEDICINE COLLIDE

Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.

- Catholic Health Australia's *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, 2008* ⁶¹

2.1 Doctor as God – Doctor for God

Under Australian law, decisions about terminal sedation – when and how quickly it is administered – are entirely in the hands of the treating doctor.

Professor Lindy Willmott from the Faculty of Law at QUT, explains:

... the use of terminal sedation falls within the discretion of the individual doctor based on what he or she regards as good medical practice ... there is no law in Australia that specifically defines or specifically regulates 'terminal sedation'.⁶²

Emeritus Professor Sheila McLean noted in the *QUT Law Review*.

⁶¹ Catholic Health and Aged Care Services, "Ethical Standards for Catholic Health and Aged Care", published by St Vincent's & Holy Spirit Health, 2008, point vii – <https://tinyurl.com/y4v45cbe> (cached version)
PDF download available here – <https://tinyurl.com/y2jy15t4>

⁶² Lindy Willmott, 'Question re Victorian Law on Palliative Sedation', Email to Andrew Denton, Go Gentle Australia, 24 July, 2017.

it is possible to conclude ... that **while terminal sedation decisions should be about the needs of the patient, all too often they depend to a large extent on the preferences of the patients' physicians.**⁶³

Equally, the Doctrine of Double Effect is based solely on the doctor's intention. A doctor can provide pain relief which *may* result in the patient's death as long as death is not their *intention*.

In other words, with the exception of a dying person's legal right to refuse treatment, food, and water (or to commit suicide), all their end-of-life treatment options are based on what a doctor thinks is right.

But what of the doctor's intention?

What if the doctor believes that it is not moral to hasten somebody's death? Or that suffering has redemptive value? Or that your cancer can be 'good for you'? All of these things have been expressed by some palliative care physicians working in Australia.

In that situation, a dying patient may be faced with little option but to endure a death they do not want – a slow death – regardless of how clear and persistent their request for a quick one may be. (Palliative Care Australia acknowledges there are patients who make rational and persistent requests for help to die.)⁶⁴

Our experiences in advocating for Voluntary Assisted Dying and improved palliative care have led us to believe that on too many occasions decisions are made within palliative care which are in accordance with the religious beliefs of the treating doctor or institution and not in accordance with the choices of the person who is dying or their family.

2.2 Care of the Dying: What the Vatican Instructs

Many of the accounts we have heard, including through the Victorian and Western Australian Inquiries, or which have come directly to us, relate to Catholic hospitals, hospices, doctors and nurses.

Catholic health and aged-care services form the largest non-government grouping of health and aged-care services.⁶⁵ However, the accounts are not limited to Catholic providers.

Palliative care has strongly Christian roots. The modern hospice movement was started in England by the Anglican nun Dame Cicely Saunders. Watching her husband dying of cancer, she observed that "as the body becomes weaker, so the spirit becomes stronger". Seeing no special place in the medical system for the dying – and realising that they needed care beyond the purely medical, including social, spiritual, and psychological care – she established the world's first purpose-built hospice, St Christopher's, in 1967.

In 1985, Pope John Paul II founded the Pontifical Council for Pastoral Assistance to Health Care Workers. Said to be inspired by faith and hope, he intended to offer a response to the challenges arising in the world of health care. In 1995, the first president of the dicastery, the late Fiorenzo Cardinal Angelini, published the *Charter for Health Care Workers*, translated into nineteen languages.⁶⁶

⁶³ Sheila A. M., McLean, "Terminal Sedation – Good Medicine?, Good Ethics? Good Law?", QUT Law Review, Volume 16, Issue 1, 2016, pp. 113-134 – <http://www.austlii.edu.au/au/journals/QUTLawRw/2016/7.html>

⁶⁴ Palliative Care Australia, "Position Statement on Euthanasia", March, 1999, states that PCA "Recognises and respects the fact that some people rationally and consistently request deliberate ending of life." Quote recorded by Dr Rodney Syme, South Australia Voluntary Euthanasia, "Euthanasia Fact Sheet", The VE Bulletin, Vol 16, No 3, November, 1999, South Australia, reproduced online by The World Federation of Right to Die Societies – <https://www.worldtrtd.net/euthanasia-fact-sheet-0>

⁶⁵ Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 28 February, 2018, p.1 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/1512F5C7DCBAD165482582440029A273/\\$file/180228+-+TS+-+Catholic+Health+Aust+St+John+of+God+Health+Care+-+Catholic+Homes+WA+-+FINAL.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/1512F5C7DCBAD165482582440029A273/$file/180228+-+TS+-+Catholic+Health+Aust+St+John+of+God+Health+Care+-+Catholic+Homes+WA+-+FINAL.pdf)

⁶⁶ The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

According to the *Charter for Health Care Workers*⁶⁷, released by the Vatican in English in 1995:

- The Church ... has always seen medicine as an important support for its own redeeming mission to humanity. [para 5]
- It follows that the work of health care workers is a sharing in the pastoral and evangelizing work of the Church. [para 5]
- **Borne 'in close union with the sufferings of Jesus', sickness and suffering assume 'an extraordinary spiritual fruitfulness'.** [para 54] [Our emphasis]
- For the Christian, pain has a lofty penitential and salvific meaning. [para 69]
- To help one to die means to help him to live intensely the final experience of his life. [para 116]
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love. [para 149]
- Death, then, must be evangelized: The Gospel must be announced to the dying person. [para 131]

In relation to pain relief for the dying, the Charter endorses medical assistance to alleviate pain, including palliative or symptomatic treatment but instructs that:

The most important assistance is 'loving presence' at the bedside of the dying person.

There is a proper medical-health presence which, though not deceiving him, makes him feel alive, a person among persons, because he is receiving, like every being in need, attention and care. This caring attention gives confidence and hope to the patient and makes him reconciled to death. **This is the unique contribution which doctors and nurses, by their being human and Christian – more than by their expertise – can and should make to the dying person,** so that rejection becomes acceptance and anguish gives way to hope. [para 117]
[Our emphasis]

The point for doctors and nurses is to make faith and hope present and to apply one's skills in order to "make going to God easy for the patient". [para 118]

The Charter includes more detailed instruction on the use of painkillers for the terminally ill. It allows for their use, reasoning that:

Human and Christian prudence suggests the use for most patients of medicines which alleviate or suppress pain, even if this causes torpor or reduced lucidity. With regard to those who are unable to express their wishes, one can reasonably suppose that they wish to take painkillers and these can be administered according to medical advice. [para 122]

However, it then refers to two problems with the use of painkillers for the dying. The first problem essentially describes the Doctrine of Double Effect, which is very well recognised in the Catholic moral tradition.⁶⁸ However, the Charter requires that there be "proportionate reasons" before it is permitted to use narcotics to alleviate suffering even though they hasten death [para 123].

⁶⁶ The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

⁶⁷ The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

⁶⁸ Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.2 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/0F66BD7CDFA1A0DB4825825600D0E6E/\\$file/180308+++TS++Archbishop+&+LJ+Goody+Centre++FINAL.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/0F66BD7CDFA1A0DB4825825600D0E6E/$file/180308+++TS++Archbishop+&+LJ+Goody+Centre++FINAL.pdf)

Specifically, the Archbishop says: "In the Catholic moral tradition ... taking whatever measures are available to us to relieve pain even if it means shortening a person's life – is both a justified and even a recommended action in the Catholic tradition."

The second problem the Charter⁷⁰ identifies is terminal sedation:

There is also the possibility that painkillers will cause unconsciousness in the dying person. This use must receive special consideration.

Without serious reasons, the dying person must not be deprived of consciousness. Sometimes the systematic use of narcotics which reduce the consciousness of the patient is a cloak for the frequently unconscious wish of the health care worker to discontinue relating to the dying person.

In this case it is not so much the alleviation of the patient's suffering that is sought as the convenience of those in attendance. The dying person is deprived of the possibility of "living his own life", by reducing him to a state of unconsciousness unworthy of a human being.

This is why the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is "a truly deplorable practice".

It is a different matter when there is a serious clinical case for the administration of analgesics which suppress consciousness, as **when there is violent and unbearable pain.**

In this case the anesthetic is said to be licit, provided certain conditions are fulfilled: that the dying person has fulfilled or could still fulfill his moral, family and religious obligations. [paragraph 124] [Our emphasis]

The Charter instructs that it is legitimate for health professionals to refuse futile treatment, but that the "right to die in total serenity, with human and Christian dignity ... cannot be interpreted as the power to kill oneself or to give this power to others" [para 119].

Voluntary starvation is addressed as follows:

The administration of food and liquids, even artificially, is part of the normal treatment always due to the patient **when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia.** [para 120] [Our emphasis]

An updated *New Charter for Health Care Workers*⁷⁰ was adopted in 2016 and published in English in 2018. The provisions in relation to dying are substantially the same as the original charter.

While the provisions outlined above suggest that the Charter does not prohibit sedation, including terminal sedation, or the acceptance of a person's decision to starve to death, it cautions against them in terms that empower the (Catholic) health care worker to make the decision, without any real regard for the wishes of the dying person or their family or carers.

Everything is assessed through the prism of the health care worker and their faith, and not through the wishes of the dying person. It applies without regard to whether the dying person is religious or not, and if they are, whether they are Catholic or of another faith.

⁶⁹ The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

⁷⁰ Pontifical Council for Pastoral Assistance for Health Care Workers, *New Charter for Health Care Workers*, The National Catholic Bioethics Center, August, 2018 – <http://www.fiamc.org/uncategorized/the-new-charter-for-health-care-workers-on-line/>

CASE STUDY: RUDI'S STORY

RUDI DOBRON, 67, DIED IN A CATHOLIC HOSPICE IN MELBOURNE FROM CANCER OF THE THROAT. HIS STORY IS RECOUNTED BY JULIA MEDEW, HEALTH EDITOR FOR *THE AGE*.⁷¹

THE BARBARIC RELIGIOUS RITUAL OF DYING WITHOUT DIGNITY

As death crept closer for Dobron and he was admitted to [the] hospice, he gave staff an advance directive that documented his desire to die as quickly as possible.

The directive said he did not want to be artificially fed, nor did he want to be resuscitated ... He felt his quality of life had already deteriorated beyond repair. All he wanted was to slip quietly away.

[Rudi's partner, Bev] McIntyre remembers the directive being noted by a doctor.

But within days, Dobron's struggle to swallow meant he was offered artificial feeding through his stomach. He declined.

"Rudi felt that if he took any sustenance, his life would be prolonged, so he said no.

"He didn't want anything that would do that, particularly if it involved another operation, so the only option was to starve and dehydrate himself to death," McIntyre says.

Dobron made it clear to staff that he did not want any food or fluids, but McIntyre says the offers kept coming.

"I don't know whether the doctor had a duty to keep asking every day or not, but it annoyed Rudi.

"The girl who came around with the menus would come in every day, too. She just kept coming, even though Rudi was saying no."

As Dobron started to lose control of his bowels

and was battling headaches in his second week, he told staff he wanted to be sedated.

His medical record states that on his 11th day in the hospice, he just wanted to be unaware.

The intervention was discussed but was not forthcoming. Soon after, Dobron's frustration with his situation peaked and he put pen to paper.

In a note handed to McIntyre, he wrote:

I am dying of cancer of the throat. I can no longer control my bowels, nor eat or drink.

If I was a pet, I would have had a peaceful injection days ago.

But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks.

"Incidentally, I am an organ donor. By the end of this type of death, my kidneys and other now healthy organs will be dead. Can't eat or drink anything. Been still losing fluid for five days now getting increased dosage of morphine and other stuff."

"Rudi had reached the stage of not being able to swallow his own saliva, so he had to keep spitting.

⁷¹ Julia Medew, "A wish before dying", *The Sydney Morning Herald*, 24 September, 2010 – <https://www.smh.com.au/national/a-wish-before-dying-20100924-15qo9.html>

He would rinse out his mouth with soda water to eliminate what must have been intense dryness," McIntyre says.

Around this time, a staff member wrote in Dobron's file that he felt as if he was choking and he had a scared look in his eyes that they had not seen before.

Dobron was slowly deteriorating.

Over the next two weeks, he became progressively more dehydrated, with headaches, nausea, shortness of breath and a pressure sore.

He was embarrassed to be wearing a nappy for incontinence and had terrifying hallucinations.

His doctors say they responded to these symptoms in a way that allowed Dobron to stay alert and interactive, which they believe he wanted at the time.

But McIntyre says his physical and psychological suffering was not relieved the way she thought it would be.

"All this time, the medics said he was not in pain and that he was comfortable, but I don't think that was the case. One day I was told he was peaceful, only to walk into his room and find him trying to get out of bed. He was very agitated at times, pulling off his bedclothes and writhing about his hallucinations. It was very hard to watch," she says.

On Dobron's 27th day in the hospice, his file says he was fed up and anguished. His doctors increased the sedation he was receiving, but it was a week before he was unresponsive and another week before he died

He had been in the hospice for 47 days.

CASE STUDY: RUDI'S STORY

Rudi's medical records, obtained through Freedom of Information, are detailed in the book *A Time to Die* (2017) by Dr Rodney Syme.⁷² They show that, despite exhibiting ongoing symptoms of physical, psychological and existential suffering, he did not receive 24-hour sedation until 32 days after he entered hospital. He eventually died a further 15 days later.

Speaking with Andrew Denton in 2019, Rudi's partner Bev McIntyre recounted what the experience was like for her:

They knew from the very beginning that he didn't ... want to have a prolonged death.

I can remember going home the last night before ... he died and ... I thought I just can't cope with going in here anymore you know. I felt I had reached the end of my tether. It was awful ... watching a person deteriorate and what they're going through ... the agitation and ... you know one time we went in there and he was taking off all his clothes. It wasn't a hot day. And he was just in a nappy you know and he'd lost control of bowel and bladder. That would be the height of indignity for Rudi. I spoke to Dr xxxx afterwards about that and he said 'religion didn't enter in to my decisions about Rudi's treatment'. They just say that they gave him the best treatment and they're still saying that.

Andrew Denton: And how do you react to that?

Bev McIntyre: Well it's bullshit. I mean ... the feeling is that I would never want to go in to a Catholic place if it was me ... I would never want anyone else to go in to a Catholic place.⁷³

- Why was Rudi's advanced care directive, which stated his desire to die as quickly as possible, not adhered to?
- Why, having also made clear that he did not want to be artificially fed, was Rudi offered a feeding tube?
- Why was Rudi, having invoked his legal right to refuse food and water, offered food daily?
- Why, despite persistent symptoms of Rudi's suffering observed by hospital staff – difficulty swallowing, dehydration, incontinence, headaches, nausea, shortness of breath, pressure sores, hallucinations, fear in his eyes – did his doctors say that he was not in pain and that he was comfortable?
- Why, despite weeks of observable suffering, did it take 32 days for Rudi to receive 24-hour sedation?
- Why does the hospital continue to respond to Bev McIntyre's complaints about Rudi's death by saying they gave him the 'best of treatment'?

The treatment enforced on Rudi Dobron borders on mistreatment and abuse.

⁷² Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 1 'Is this the best we can do?'.

⁷³ Bev McIntyre, Interview with Andrew Denton for Go Gentle Australia. Audio available on request.

2.3 Catholic Health Australia: 'The Mystery of Suffering and Death'

Catholic Health Australia's *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, in relation to 'Solidarity and the mystery of suffering and death', among other things, states:

Illness, disability and suffering are never good in themselves: health care properly seeks to relieve them. There are, however, limits to what health care can achieve. **Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.**⁷⁴ [Our emphasis]

The Code does not prohibit sedation, including terminal sedation, but states:

Advances in palliative care are now such that the control of pain should not normally lead to side effects such as loss of lucidity or consciousness or to the shortening of life.⁷⁵

Similarly, evidence to the Western Australian inquiry from the Reverend Dr Joseph Parkinson, Director of the LJ Goody Bioethics Centre, who appeared with the Catholic Archbishop of Perth, was to the effect that sedation will usually be provided on a temporary basis. In response to a question from the Chair in relation to how palliative care should treat people who are experiencing incredible pain at the end of their lives, the Rev Dr Parkinson said:

If a patient wishes to have freedom from pain and full consciousness, that is probably a stretch too far for any medical system, even in ideal circumstances.

... If you are able to provide consciousness, if you are able to preserve consciousness with pain relief, that is great. But you will also have heard, I am sure, reference to palliative sedation – so dealing with if not the pain, then the agitation that can accompany pain at the end, that can be managed; patients can be given relief from that. It is not, as we have discussed, about killing a patient, it is about controlling pain. **The beauty of palliative sedation is that it is temporary, so it is reversible. A patient can be given a break, get relief, have a couple of days good solid sleep and then be brought out of that and be able to continue making their autonomous health care choices.** I think there might be a bit of a myth floating around that somehow medicine ought to be able to provide everything that I want. The fact is, it never has been able and probably never will be able to provide both full consciousness and complete freedom from pain.⁷⁶ [Our emphasis]

The question of terminal sedation is ethically vexing for many in palliative care. In a *Lancet* (2000) editorial, Professor Janet Hardy from the Mater Research Institute at the University of Queensland's Faculty of Medicine 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'.⁷⁷ [Our emphasis]

⁷⁴ Catholic Health and Aged Care Services, "Ethical Standards for Catholic Health and Aged Care", published by St Vincent's & Holy Spirit Health, 2008, point vii – <https://tinyurl.com/y4v45cbe> (cached version)

PDF download available here – <https://tinyurl.com/y2jyl5t4>

⁷⁵ Catholic Health Australia, Code of Ethical Standards for Catholic health and Aged Care Services in Australia, Part II Decision Making in Health Care, Euthanasia 5.20, 2001, p 46 – Quoted here – https://myfuturecare.org.au/wp-content/uploads/2014/docs/St_Vincent%27s_Care_Services_education_material_2.pdf

⁷⁶ Rev. Dr Joseph Parkinson in Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.4 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\(Evidence+Lookup+by+Com+ID\)/0F66BD7CDFA1A0DB48258256000D0E6E/\\$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/0F66BD7CDFA1A0DB48258256000D0E6E/$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf)

⁷⁷ Janet Hardy quoted in Rodney Syme, *Time to Die*, Melbourne University Press, 2017

In evidence from representatives of Catholic Health Australia, Catholic Homes, Catholic Homes WA and St John of God Health Care, the Western Australian Inquiry⁷⁸ was told that:

Catholic aged care services would support the decision of a competent and 'mentally stable' person who requested palliated starvation, but they would look at why the person wished to end their life and they would address their distress or mental health issues and support them and their family to make informed decisions'.

- Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA (p.12).

Catholic Health facilities rarely see people who are so severely distressed at the end of life that sedation is the only option.

- Dr Alison Parr, Director Medical Services, St John of God Health Care; Palliative Medicine Consultant (p.13)

Sedation is considered at the last 24 or 48 hours of life to alleviate suffering.

- Ms Natalie Joseph, Manager, Clinical Services, Catholic Homes (p.13)

Patients or their substitute decision-makers sometimes request an increase in palliative medication, knowing the risk is to hasten death, but this is usually 'a reflection of levels of distress and a signal for us as a team to spend more time with patients and families and explore that distress, and often with intervention and time and the multidisciplinary approach, we are able to support people through that'.

- Dr Alison Parr (p. 17)

This is the case in aged care too, where a request for an increase in palliative medication is 'an opportunity for people to give families information around what is available as well. Often people are so distressed and they think medication is the only answer to that distress. There may be other interventions we can make to address psychological distress, spiritual distress, issues around meaning and family relationships that would be adding to that distress. It is a multidisciplinary conversation that needs to take place as well'.

- Ms Bernadette Brady (p.17)

In the accounts Go Gentle has heard, it is clear that, by the time desperate family members start pleading for something more to be done to better relieve the dying person's pain and suffering, pain and suffering is already extreme. To regard that as a suitable point to begin a discussion about their distress and family relationships is not what is required.

Clive Deverall, founding president of Palliative Care in WA, summed it up this way:

And every day, in different settings, terminally ill patients – most with advanced malignancies and uncontrolled symptoms – are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help. And there is little or no transparency and a legal risk to the doctor and/or nurse.⁷⁹

2.4 What Doctors Believe

In advocating for voluntary assisted dying, we have often been on the other side of the debate to some doctors who share a belief that there is spiritual growth to be found in suffering as you die. They argue for the sort of palliative care that the Vatican Charter promotes and their authority, as 'experts on the care of the dying', has been accepted without question by many politicians.

⁷⁸ Rev. Dr Joseph Parkinson in Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.4 – [http://www.parliament.wa.gov.au/Parliament/commit.nsf/\[Evidence+Lookup+by+Com+ID\]/0F66BD7CDFA1A0DB48258256000D0E6E/\\$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf](http://www.parliament.wa.gov.au/Parliament/commit.nsf/[Evidence+Lookup+by+Com+ID]/0F66BD7CDFA1A0DB48258256000D0E6E/$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf)

⁷⁹ Noreen Fynn, "Submission to the Joint Select Committee on End of Life Choices (Western Australia)", 17 October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\[Evidence+Lookup+by+Com+ID\]/30D73154F4D00AFF48258219000B3C84/\\$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/[Evidence+Lookup+by+Com+ID]/30D73154F4D00AFF48258219000B3C84/$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf)
Noreen Fynn is the widow of Clive Deverall

Their arguments are never presented as religious ones – only as medical – but they represent, nonetheless, a powerful belief system. The palliative care that they campaign to preserve enables them to practice in accordance with those beliefs without scrutiny or censure. What is more, they can do so regardless of whether or not those beliefs are shared by the dying person dependent on their care.

Here are some examples of those beliefs:

Within one's suffering is an opportunity for growth ... It's interesting that people facing death grow spiritually ... To the point where they say 'It's been such a good journey. I've learnt so much. The cancer has been so good to me'.

- Dr Douglas Bridge, formerly of St John of God Health Care – also formerly head of palliative care at Royal Perth Hospital.⁸⁰

... the individualistic, secular public isn't interested in the spiritual benefits of suffering, or in considering whether there might be a higher good than simply avoiding suffering at all costs.

- Dr Megan Best, palliative physician, Greenwich Hospital, NSW and board member of Spiritual Care Australia.⁸¹

The ultimate root of pain is the sin of all humanity in which they so deeply and wilfully participate, and for which they deserve judgement. In particular, I see how precious is the help of a doctor who can show me the Lord's mercy in my pain both physically and spiritually.

- Robyn Bain, emergency doctor, now gospel minister.⁸²

As Christians we have the privilege of entering into the pain of our patients and passing on the compassion and comfort of our God.

- Dr Murray Lean, pastor and medical doctor.⁸³

Yes, they will say this suffering is very hard for them and they would prefer to die, and I would say to them, 'Yes, I acknowledge that you are feeling that way but I will continue to try and make you feel better so you don't have to feel that way' ... It is not ... my morals to say, 'Because I can't look after you, you are better off dead...' [Instead] I walk with the patient. I say to them, 'Yes, the pain is still there, but I will help you live with that pain'.

- Professor Richard Chye, head of palliative care at St Vincent's Scared Heart Hospice, Sydney.⁸⁴

The Charter, the Code and evidence of practice in Catholic health and palliative care services suggest that, while the Charter and Code allow a competent person's decision to refuse treatment or food and water to be honoured and for sedation, including terminal sedation, to be given at the end of life, there is a real risk that time and effort – perhaps *considerable* time and effort – will first be spent trying to convince the person to make a different decision or to avoid providing sedation due to the religious beliefs of the operator of the health care service before the person's choices are finally acted on.

An example of this is provided by palliative care physician, Dr Douglas Bridge of Western Australia. Dr Bridge believes that “within suffering is an opportunity for growth”, and has spoken publicly of his “supreme Christian calling” in his work.⁸⁵

⁸⁰ Heather Dowling, "Healing at Journey's End", Crosslight, 3 March, 2013 – <https://crosslight.org.au/2013/03/03/healing-at-journey's-end/>

⁸¹ Megan Best, "Modern healthcare: are we playing God?", The Briefing, Matthias Media, 3 December, 2012 – <https://matthiasmedia.com/briefing/2012/12/modern-healthcare-are-we-playing-god/>

⁸² Robyn Bain, "Pain: What's the Point?", Luke's Journal, Christian Medical and Dental Fellowship of Australia Inc, Vol 23, No. 1, 2018, p.6 – https://issuu.com/lukejournal/docs/luke_journal_vol_23_issue_1

⁸³ Murray Lean, "Sharing Comfort through Christ", Luke's Journal, Christian Medical and Dental Fellowship of Australia Inc, Vol 23, No. 1, 2018, p.12 – https://issuu.com/lukejournal/docs/luke_journal_vol_23_issue_1

⁸⁴ Richard Chye in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, [audio] – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway>
Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

⁸⁵ Heather Dowling, "Healing at Journey's End", Crosslight, 3 March, 2013 – <https://crosslight.org.au/2013/03/03/healing-at-journey's-end/>

Discussing the onset of increasing weakness, drowsiness, and inability to control thoughts, that can afflict a dying person, Dr Bridge quotes Dr Robert Twycross, who was recruited by Dame Cicely Saunders as a Clinical Research Fellow at St Christopher's, which Dr Bridge describes as the first modern hospice. Dr Bridge describes Dr Twycross as "a committed Christian" who was "aware of the spiritual dimension of suffering, which no amount of morphine could relieve", and quotes his writing from 1993, including:

The possibility of such an outcome highlights the need to make every effort to deal with psychological 'skeletons in the cupboard' before the patient becomes too weak to address them. A few, however, resist every attempt to share what they have been hiding.⁸⁶

Dr Natasha Michael, from Cabrini Health in Victoria, reinforces the instruction in the Sacred Congregation for the Doctrine of the Faith's "Declaration on Euthanasia" that:

The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.⁸⁷

She writes:

For many, suffering entrenches the mind, soul and spirit. It overwhelms through the loss of meaning, hope and emotional strength in the face of illness.⁸⁸

Speaking to the Victorian Inquiry, Dr Michael explained that when a person says that their suffering is "so unbearable [that] I want to die", the solution is not to provide them with barbiturates, but to ask:

How can I help you with these factors that are making you feel that death has to be the better option?⁸⁹

If the dying person's wishes are honoured, it may only be after prolonged and determined advocacy from a family member or other substitute decision maker.

Pity the dying person who does not have access to such determined advocacy, and pity, too, the dying person who does have determined advocacy but who has to endure unnecessary pain and suffering waiting for their advocate's demands to have some effect.

⁸⁶ Douglas Bridge, "Making Health Care Whole", Submission to the WA Parliamentary Joint Select Committee on End of Life Choices, October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\[Evidence+Lookup+by+Com+ID\]/EEC848CF38BA51AF4825821E000FBEF4/\\$file/20171023+-+EOLC+-+Sub+530+-+Mr+Douglas+Bridge.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/[Evidence+Lookup+by+Com+ID]/EEC848CF38BA51AF4825821E000FBEF4/$file/20171023+-+EOLC+-+Sub+530+-+Mr+Douglas+Bridge.pdf)

⁸⁷ Sacred Congregation for the Doctrine of the Faith, "Declaration on Euthanasia", Vatican – http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html

⁸⁸ Natasha Michael, "Right to life: What treatment should doctors prescribe to end suffering?", The Age, 25 November, 2015 – <https://www.theage.com.au/opinion/right-to-life-what-treatment-should-doctors-prescribe-to-end-suffering-20151125-gl7q98.html>

⁸⁹ Natasha Michael in Standing Committee on Legal and Social Issues, "Inquiry into End-of-Life Choices" transcript, Parliament of Victoria, Melbourne, 16 September, 2015, p. 9 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

CASE STUDY: JAN'S STORY

JAN RYDER, 77, DIED FROM BRAIN CANCER IN A FAITH-BASED HOSPICE IN SYDNEY. HER STORY IS TOLD BY HER DAUGHTER, SHAYNE HIGSON.⁹⁰ (audio also available)

SHE KEPT ASKING, 'WHY ARE THEY TORTURING ME?'

Mum had an aggressive form of glioblastoma multiforme, and with multiple tumours they could not operate or do radiation therapy for fear of causing severe brain damage.

As the months passed Mum lost her ability to walk, she lost words and struggled to communicate, she was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort.

She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

Each day her condition worsened. The anti-nausea medication did little to ease her discomfort and as Mum's right side became more and more affected she could not even lie in bed peacefully. She was agitated and distressed.

Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. She had had enough. She kept asking, "Why are they doing this to me? Why are they torturing me?"

Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back

and forth inside your body but fortunately changes to her medication prevented this.

That is, until the end.

By the time she was admitted to hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night Mum suffered another seizure.

It took nearly an hour and a half to get the seizure under control because the nurses were only authorised to give small doses of medication, 15 minutes apart.

Mum didn't really like when the palliative care doctor came because Mum wasn't religious, and just the manner, the sort of questions that were being asked.

I know that he meant well, but coming in and saying, "Well Jan, how are you feeling?", and she'd say how she was feeling.

This was early on when she could talk. And when she started asking and saying "I just want to be knocked out" and he said "Why?", she said "Because I want to stop thinking. I want to stop – shut down what I'm thinking". And he said, "Well what are you thinking about?" I mean she just sort

⁹⁰ Shayne Higson, "We can do better", Open Drum, ABC, 1 September, 2015 – <https://open.abc.net.au/explore/102194>
Audio at: Shayne Higson in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway>
Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

of looked, you know. If she was the sort of person that would swear, I think she would sworn at him, because like what do you think she was thinking. I think she, that's what she said – "What do you think I'm thinking about?"

She knew that her life was coming to an end. She was about to lose the life that she was desperate to hang on to, and all the pleasure had gone out of it. She just wanted it to end.

I just know because I know my Mum, and that's the thing; they don't. They come in and they say things like that... I knew that Mum must be getting close to the end, and then to have someone not see that and to say that she might have depression – I was devastated.

She was very clear what she wanted and she'd said it right at the beginning as well. But they're not allowed to. That's the thing. You are not allowed to have a peaceful end, and once she went into hospital, that's when I really realised that it's just not allowed. It's not allowed. The terminal sedation which is the best option that we have now, does not guarantee a peaceful end ...

And she kept shaking. When she didn't stop shaking, we said "Can you give her more? It's not working".

He said, "I can only give her this amount and every 15 minutes. I'm not authorised to give her any more. If I give her more, it might end it".

And Rod and I just sort of said, "Well do you think – mum's dying", and he said, "I can't", and his face – he got a bit angry because I think he probably thought "What's this family doing. They're asking me to sort of up the dose", but it was, we just wanted her not to have to suffer.

So, every fifteen minutes we'd buzz the bell and he'd come in, and she was still shaking. It took five doses. I think it was Midazolam was the drug that they were using.

[We felt] completely powerless and angry ... that at such a terrible time that you are sort of battling this. It just shouldn't have to be like that. At one point my older sister ... she said to the GP, "What are we meant to do? Go down to Kings Cross on the street and try and score or something. What choice – what are you saying? What choice do we have?".

And the third night was probably the worst one. Then it definitely was pain. And I have to say that her face was just so contorted ... And then that's when they eventually put in that driver with the regulated amounts.

CASE STUDY: JAN'S STORY

- Why were Jan's clear requests for full sedation not adhered to?
- Why was Jan made to feel as though she was being tortured?
- Why was Jan, who was clearly dying and suffering, questioned as though she may have mental health issues?
- Why were Jan's seizures inadequately medicated, to the point where it took five different treatments with drugs to bring one attack under control?
- Why did it take repeated and emotional requests from the family before Jan was adequately sedated?
- Why did it take several days of suffering – until Jan's face was contorted in pain – before she was allowed a syringe driver with regulated analgesic?

The treatment of Jan Ryder borders on mistreatment and abuse.

2.5 What It's Like to Die in a Catholic Hospice: An Independent Six-Month Study

Alex Broom is Scientia Professor of Sociology and Co-Director of the Practical Justice Initiative, Centre for Social Research in Health, the University of New South Wales.⁹¹ He spent six months 'embedded' in a Catholic hospice to observe what the end-of-life experience was like for patients. While acknowledging the many benefits hospice care brought to patients and their families, when it came to assisted dying, **he observed that the experience for many was deeply unsatisfactory:**

A regular statement was, 'You wouldn't let a dog go through this'. Another comment was from an elderly man, who said, 'I came to palliative care because I thought they'd help, but you don't get help. They just keep you alive'.

There are quite a significant number who view the hospice model as inhumane because it doesn't allow them to, essentially, be the masters of their own demise.⁹²

Professor Broom described one dying patient who had tried to overdose on morphine at home and who ended up in the hospice:

The hospice staff said to me, 'He's just not in a good place. He is psychologically not well, and he'll get to the point where he accepts that this is just part of the process'. I think what that captured was how an organisation and how **a profession, if it's not careful, can instill particular values around what is dignity, what is a good death and can subtly disallow people's opportunity to make decisions for themselves.**⁹³ [Our emphasis]

Professor Broom observed a "one-size-fits-all" moral and ethical code:

What people don't realise is that on entering into the hospice you're entering into a contract, essentially, about how you can die. Hospices in Australia have a set of parameters around what is acceptable and what is ethical, and those are embedded in a particular series of

⁹¹ Alex Broom, Staff Profile, University of NSW – <https://research.unsw.edu.au/people/scientia-professor-alex-broom>

⁹² Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death>
Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

⁹³ Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death>
Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

moral structures which have religious underpinnings and certain ideas about what is okay or not okay and the nature of suffering.

The loss of a person occurs often way before the point of death. You get that period of time when there is such suffering that for a lot of people – carers – there isn't much left of the person.

I think we need to acknowledge the fact that if we overvalue this so-called natural course of dying and we normalise suffering – as Pope Benedict said, assisted suicide is this false solution to the drama of suffering. I would suggest that that suggests he has not seen much suffering, because it's not much of a drama if you ask me. It's something much more malevolent than that.

“If we overvalue suffering, which I think has very religious puritan roots around the virtue of stoicism, there's not much virtue in it when you see it happening.”

There's not much virtue in it when you are in that space. In fact, if anything, it's degrading of a person and all of those around the person.

So, I think we have a set of values, but they're highly compromising in terms of other really important values, which are choice, expressing one's preferences, agency, and the most important one, which is dignity. [Our emphasis]

CASE STUDY: ELIZABETH'S STORY

ELIZABETH RICHARDS, 77, DIED FROM MOTOR NEURONE DISEASE IN A CATHOLIC HOSPICE IN MELBOURNE. HER STORY IS TOLD BY HER DAUGHTER, JANE.⁹⁴
YOU CAN SEE JANE TALK ABOUT HER MUM'S DEATH [HERE](#).⁹⁵

NO-ONE LEFT HER BEDSIDE UNSCATHED

As my mother's MND progressed we placed our trust, and in fact our mother's life, in a system which only now I can say failed her dismally.

As it was, my dear beautiful mum went to palliative care to die. Her and our intention and understanding was that she would be cared for right up until the moment of death. And up until a few days before her death I cannot emphasise how exemplary her care was.

... not for a second did we envisage the horrific, inhumane and tortuous death to which she would succumb.

Mum was no longer under the care of her two neurologists but the palliative care specialist. Yet again we were assured that Mum would not suffer in the end and that terminal sedation would provide her with the least amount of pain and discomfort. She would supposedly be given adequate sedation to prevent any pain or associated anxiety. She would not, we were told, experience any thirst or hunger as a result of the withdrawal of fluids and nutritional supplements. "I promise you, you will not suffer at the end."

Mum did suffer. She had pain, breakthrough pain, because her prescribed dose was unable to adequately palliate her pain at all times. She managed to express to us her fear and, in one of her conscious moments, was able to convey to us that she wanted to be fed through her PEG tube. This was so very traumatic for all of us, many staff included.

We had been assured that Mum would be devoid of hunger and thirst, but no, the dying process is not a templated one and whilst her case may have been unusual it was nevertheless real and it was happening to my mother.

Mum suffered what I deem to be unnecessarily for days. Family members requested that her analgesia be increased. A request I made pleading for her analgesia to be substantially increased even if it meant hastening her obviously imminent death was directly replied to by the question,

***'Are you asking me to kill her?'
No, I was not trying to have my mother murdered, I simply wanted her tortuous pain and existential suffering to end.'***

We are told that death can be peaceful and that we should not fear it but no-one, even staff members, could leave her bedside unscathed. We chose not to allow young grandchildren and close friends to see Mum in her final hours.

This hideously prolonged death was visually ugly and this once beautiful, vibrant and radiant individual should not have been subjected to the haunting and unforgettable images that we were privy to.

My beautiful mum did not deserve to die the way she did.

⁹⁴ Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, pp. 44-47
Free download available here: <https://www.gogentleaustralia.org.au/shop>

⁹⁵ Go Gentle Australia, "Launch Video", 12 November, 2017 –
<https://www.youtube.com/watch?v=V-npGbBzgHU&feature=youtu.be&list=PLXQBeKmhJGYZCVQI394Wx7WKtGxI0q1Bk&t=40>

CASE STUDY: ELIZABETH'S STORY

- Why was Elizabeth's family wrongly assured that she would not suffer?
- Why were they told that terminal sedation would minimise her pain and discomfort when it did not?
- Why was Elizabeth left to suffer the discomfort of thirst and hunger when her family had been assured that she would not?
- Why was Elizabeth left to suffer fear and anxiety when her family had been assured that she would not?
- Why were the family's repeated requests for more analgesia rejected leaving Elizabeth to suffer breakthrough pain?
- Why was Elizabeth's family left with final memories of her that they could only describe as 'hideous' and 'ugly'?

The treatment of Elizabeth Richards borders on mistreatment and abuse.

2.6 Palliative Care: Real Value – and Real Limitations

Palliative Care Australia advertises their services as "person-centred", with their primary goal being to "optimise the quality of life" of a person who is dying.⁹⁶

In doing so, they cite the World Health Organisation's definition of palliative care as being the:

... impeccable assessment and treatment of pain and other problems.⁹⁷

Go Gentle acknowledges the important work done by palliative care – secular and religious – in Australia. For many, the services they offer at the end of life are of enormous value. **We continue to maintain that palliative care should be better funded at all levels of Government.**

However, Australia's palliative care system is already ranked second in the world, behind the UK. The case studies listed above, and many other testimonies of suffering at the end of life accepted by the Victorian and Western Australian inquiries, cannot be explained simply by a lack of funding.

In their majority report, the Victorian Committee commented on:

The trauma experienced by patients and their families when palliative care does not provide an adequate solution for their situation.⁹⁸

By arguing that the solution to this trauma is simply to give more resources to palliative care providers is to ignore the reality that – for a substantial portion of those providers – personal or institutional beliefs dictate how a person's suffering is to be treated, regardless of what the person may need, want, or request.

⁹⁶ Palliative Care Australia, "National Palliative Care Standards" – <https://palliativecare.org.au/standards>

⁹⁷ Palliative Care Australia, "Understanding Palliative Care" – <https://palliativecare.org.au/understanding-palliative-care-parent-menu>

⁹⁸ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7.1 'The legal framework and peoples' end of life experiences'", June, 2017, p.194 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

No amount of extra resourcing is going to change that.

Professor Michael Ashby, Director of Palliative Care at the Tasmanian Health Service, says that:

[While] religious groups still have a valuable role in reconnecting people to ancient traditions that can bring comfort and meaning to those facing death and loss ... It is not the role of any health care team to suggest that its ministrations can give meaning, purpose and dignity to a dying person's remaining life if that person feels that these are irretrievably lost ... **Palliative care is a model of care, not a moral crusade.**⁹⁹ [Our emphasis]

That doctors hold strong personal beliefs which may influence their treatment decisions is not at issue. We are not suggesting that they are wrong to do so, or that they should be required to act otherwise. Any proposed VAD law, rightly, protects and respects a doctor's right to act according to their conscience in providing end-of-life care.

What is at issue is an existing law which enables doctors to impose those beliefs on dying people dependent on their care. People who, in many cases, do not share those beliefs. People who are suffering as they die and who make persistent and rational requests to end their suffering quickly.

Until the religious elephant in the hospital room is addressed by a VAD law offering people the right to seek a better death, the trauma and suffering listed above (and also in the APPENDIX of this submission) will continue.

⁹⁹ Michael Ashby (Professor of Palliative Care, Monash Medical Centre), in PA Komesaroff, JN Lickiss, M Parker, and MA Ashby, "The euthanasia controversy: Decision-making in extreme cases", Letter to the Editor, *Medical Journal of Australia*, No. 162, 20 November, 1995, pp. 596-97, <https://www.ncbi.nlm.nih.gov/pubmed/7540716>
See full text here: <https://www.eurekastreet.com.au/article/denying-but-not-defying>

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Part D

Responding To Key Arguments Against VAD

WHAT THIS SECTION IS ABOUT

A key speaker at the HOPE international anti-euthanasia symposium in Adelaide in 2015 was former New Hampshire state representative, now organiser of Living with Dignity in that state, Nancy Elliott. **Elliott spoke about effective tactics that can be used to make Australian politicians hesitate to support VAD legislation:**

When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else ... Right now the disability argument is really kicking it ... It's very powerful. Now will it always be powerful? We don't know. Two, three, four years from now that may have holes kicked in it, just for different reasons, so we have to be flexible. You know, when one of our arguments dies, we need to be ready to pick up another one.

Elder abuse? Elder abuse is excellent ... Suicide contagion is another very good thing to point out to your committees, and it has worked very well in the States.

You don't have to win the legislators' hearts and minds. All you have to do is persuade them 'not this bill' and you have got your win'¹⁰⁰

In keeping with this strategy, you will hear many arguments against VAD. Often, they are based on misrepresentation, or selective use, of facts. In this section, we respond by putting them in context

'NOT THIS BILL': 9 COMMON MYTHS USED TO MAKE POLITICIANS HESITATE

- #1 VAD Laws Inevitably Lead to a Slippery Slope
- #2 Elder and Disability Abuse: Vulnerable People will be Coerced to Die
- #3 VAD Creates Suicide Contagion
- #4 VAD Will Damage the Doctor-Patient Relationship
- #5 People are Choosing to Die Because they Feel Like a 'Burden'
- #6 The Legalisation of VAD Means that Palliative Care will Suffer
- #7 VAD Leads to 'Doctor Shopping'
- #8 The Drugs Don't Work
- #9 VAD Breaks a Doctor's Oath to 'Do No Harm'

¹⁰⁰ Nancy Elliott in Andrew Denton, "Better Off Dead: #1 The invasion of death", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/1-the-invasion-of-death>
Transcript at Go Gentle Australia website – <https://www.gogentleaustralia.org.au/transcripts1>

MYTH #1. VAD LAWS INEVITABLY LEAD TO A 'SLIPPERY SLOPE'

1.1 The Argument

Opponents of voluntary assisted dying claim that VAD legislation inevitably results in the law being changed over time to allow more people and more conditions access. They point to the Netherlands and Belgium, claiming that laws which were originally only for the terminally ill, now extend to cover such vulnerable groups as people with mental illness and dementia – even children. This is the 'slippery slope'.

This 'slippery slope' argument is well summed up by former Prime Minister, Paul Keating:

The experience of overseas jurisdictions suggests the pressures for further liberalisation are irresistible.¹⁰¹

1.2 The Reality

In response to Mr Keating's claim, the ABC's Fact Check published the following:

In most jurisdictions where assisted dying has been legalised, little has changed regarding what practices are allowed or who can access assisted dying.

There have been some changes, such as in Belgium, where 'competent minors' can now request euthanasia.

In the Netherlands, doctors have published guidelines for providing euthanasia to severely disabled newborns. Though these guidelines may help doctors avoid jail, the practice itself remains illegal.

Canada's framework is still new and may yet evolve as it is challenged in the courts.

Despite pressure for change in the United States, there has been no further liberalisation in any of the five states involved. This includes Oregon, where the system has been operating since 1997.¹⁰²

In 2015, the Victorian Parliamentary Inquiry:

... found no evidence of institutional corrosion or the often cited 'slippery slope'. Indeed, the regulatory framework has been unchanged in Oregon, the Netherlands and Switzerland for many years.¹⁰³

Similarly, in 2018, Palliative Care Australia reported:

A common concern across various jurisdictions has been that access to assisted dying pathways is a 'slippery slope' whereby vulnerable people may be at risk should safeguards fail. Whilst it is noted there have been amendments to legislated eligibility criteria over time, there is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards.¹⁰⁴

¹⁰¹ Paul Keating, "Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross", The Sydney Morning Herald, 19 October, 2017 – <https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-qz412h.html>

¹⁰² RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – <https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640>

¹⁰³ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chair's Foreword'", June, 2017, p. xvii – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

¹⁰⁴ Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p. 8 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

1.3 Setting the Record Straight

1.3.1 Europe's Laws Were Never Written Only for the Terminally Ill

The legislation in Belgium and the Netherlands, written in 2002, has always been based on unbearable suffering, not whether a person has a terminal illness. In that time there has been one change to these laws.

Belgium

In 2014, Belgium extended its eligibility criteria to grant some children access to euthanasia.¹⁰⁵

Robert Vander Stichele, a medical professor with Belgium's University of Ghent and member of the European consortium End of Life Care, said that this was the only expansion of what Belgium allows.

When children are considered to be competent and autonomous, in exceptional circumstances they can be considered as being adults and given [euthanasia].¹⁰⁶

Changes to Belgian laws occurred through the considered deliberate processes of parliament. In December 2013, the Belgian Senate voted 50-17 in favour of amending the Act to remove the formal age limit and to permit minors to access the regime subject to an assessment of capacity. In February 2014, the Belgian Chamber of Representatives, by a majority of 86-44 with 12 abstentions, passed the amendments.

For euthanasia to proceed in Belgium, doctors must first verify that a child is "in a hopeless medical situation of constant and unbearable suffering that cannot be eased and which will cause death in the short term". Once a child has expressed a wish for euthanasia in writing, child psychiatrists conduct examinations, including intelligence tests, to determine the child's level of discernment and ensure they are "not influenced by a third party". Parents can, however, overrule the request.

To date, three minors – one with brain cancer, one with cystic fibrosis, and one with muscular dystrophy – have used the law.¹⁰⁷

The Netherlands

Professor Jocelyn Downie, an international health law expert who contributed to the Royal Society of Canada's End-of-Life Decision Making report¹⁰⁸, said that while some people claim the Netherlands originally excluded non-terminally ill patients from accessing euthanasia, this is not correct. "They never had that limit," she said.¹⁰⁹

The Royal Dutch Medical Association (KNMG) told Fact Check that there have been no changes to the law since it was introduced. They said that although there is debate in the Netherlands about whether assisted suicide should extend to elderly people who consider their life to be "completed", the change requires separate legislation and is not supported by the KNMG.

However, there has been some change *outside* the law.

In 2004, doctors from the University of Groningen developed a protocol describing the conditions under which severely disabled newborns could be euthanased. The so-called 'Groningen protocol' was later adopted as a national guideline by the Dutch association of paediatricians.¹¹⁰

¹⁰⁵ Rory Watson, "Belgium extends euthanasia law to children", British Medical Journal, 348 g1633, 2014 – <https://www.bmj.com/content/348/bmj.g1633>

¹⁰⁶ RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – <https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640>

¹⁰⁷ Henry Samuel, "Belgian children, aged nine and 11, youngest ever to be euthanised", The Sydney Morning Herald, 8 August, 2018 – <https://www.smh.com.au/world/europe/belgian-children-aged-nine-and-11-youngest-ever-to-be-euthanised-20180808-p4zw4l.html>

¹⁰⁸ Udo Schüklenk, Johannes J M Van Delden, Jocelyn Downie, Sheila A M Mclean, Ros Upshur and Daniel Weinstock, "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making", Bioethics, 25 (Suppl 1), November, 2011, pp. 1-4 – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/>

¹⁰⁹ Quoted in: RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – <https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640>

¹¹⁰ RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – <https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640>

1.3.2 Assisted Dying Legislation Elsewhere

North America

The legislation in Oregon has been in operation for 21 years and has never been changed. It has formed the basis for other legislation in California, Vermont, Colorado, Washington, Washington DC and, more recently, Hawaii and New Jersey.

Australia

Legislation passed in Victoria in 2017, and most recently proposed in South Australia, NSW, and Tasmania, did not provide access for patients with dementia. It did not allow access through advance care directives. It did not allow access on the basis of a disability or mental illness. It did not allow for minors.

Each society writes laws according to what that society will tolerate. Parliament itself is not a slippery slope – there is a rigorous process of review, expert advice, debate and decision making.

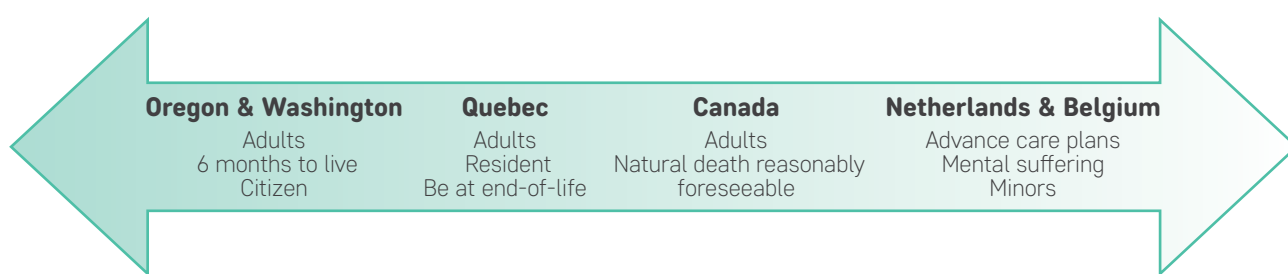
1.4 The Numbers of People Accessing VAD/VE Remain Extremely Low

The numbers of patients in each jurisdiction *has* increased over time – this is to be expected given ageing populations, disease profiles and community acceptance. However, as a percentage of all the people who die, the numbers have remained stable – and tiny: 2% of all those who die in Belgium; 4% in the Netherlands.

In Oregon, which has had a Death with Dignity Act (DWDA) in place for more than 20 years, it's less than 0.5% of people who die each year. In 2018, that number was 168 deaths in a population of 4.2 million people.

The key fact here, one often overlooked, is that all of these cases occur **within the scope of the existing legislation in those countries.**

Figure 4: Spectrum of Legislative Requirement¹¹¹



As the majority report of the Victorian Parliamentary Inquiry Committee found after visiting Europe and North America:

Instances of assisted dying are rare, even in jurisdictions where it is legal. Assistance in dying is, in the vast majority of cases, provided to people in what would otherwise be the final weeks of their lives.¹¹²

¹¹¹ Asper Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28: 'Figure 2-1 Spectrum of legislative requirement'", Palliative Care Australia, October, 2018, p.15 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

¹¹² Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Executive Summary", June, 2017, p.xix – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

MYTH #2. ELDER AND DISABILITY ABUSE – VULNERABLE PEOPLE WILL BE COERCED TO DIE

2.1 The Argument

Legalising VAD will create subtle 'hidden coercion' of vulnerable people. This can happen when a vulnerable person perceives – or is made to feel – that they are a burden on their family, or society in general, and that they have a 'duty to die'. It is also argued that vulnerable elderly people may be 'steered' towards VAD by greedy relatives.

2.2 The Reality

Go Gentle acknowledges that the abuse of vulnerable people in Australia is a genuine problem, as evidenced by testimonies to the *Royal Commission into Aged Care Quality and Safety* and the recent announcement of a *Royal Commission into the Abuse and Neglect of Australians with Disabilities*.

2.3 Vulnerable People Have Not Been Exposed to Abuse

Repeated, independent and exhaustive reviews have shown no evidence of abuse of the vulnerable overseas. These include:

Royal Society of Canada End of Life Report 2011:

What has emerged is evidence that the law is capable of managing the decriminalisation of assisted dying and that state policies on this issue can reassure their citizens of their safety and wellbeing.¹¹³

The Honourable Justice Lynn Smith, *Carter v. Canada* (Attorney General) 2012, after hearing exhaustive evidence for and against VE/VAD from numerous expert witnesses around the world:

This evidence serves to allay fears of a practical slippery slope ... I have found that the evidence supports the conclusion that a system with properly designed and administered safeguards could, with a very high degree of certainty, prevent vulnerable persons from being induced to commit suicide while permitting exceptions for competent, fully informed persons acting voluntarily to receive physician-assisted death.¹¹⁴

Dr Linda Sheahan, Australian Palliative Care Physician, Churchill Fellowship Report, 2012.:

It is highly reassuring to review the data and find no evidence of increased risk to vulnerable groups.¹¹⁵

Journal of the American Medical Association, 2016:

Euthanasia and physician assisted suicide are increasingly being legalised, remain relatively rare, and primarily involve patients with cancer. Existing data do not indicate widespread abuse of these practices.¹¹⁶

Victorian Parliamentary Inquiry, 2015:

Assisted dying is currently provided in robust, transparent, accountable frameworks. The academic literature shows that the risks are guarded against, and that robust frameworks help to prevent abuse.¹¹⁷

¹¹³ Udo Schüklenk, Johannes J M Van Delden, Jocelyn Downie, Sheila A M Mclean, Ros Upshur and Daniel Weinstock, "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making", *Bioethics*, 25 (Suppl 1), November, 2011, pp. 1–4 – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/>

¹¹⁴ *Carter v. Canada* (Attorney General), 2012 BCSC 886, paras. 1241 and 1367

¹¹⁵ Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p. 64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

¹¹⁶ J Emanuel Ezekial, Bregje D Onwuteaka-Philipsen, John W Urwin, and Joachim Cohen, "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe", *JAMA - Journal of the American Medical Association*, 316 (1), July 5, 2016, pp. 79–90 – <https://jamanetwork.com/journals/jama/article-abstract/2532018>

¹¹⁷ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chapter 8 – Victoria Should Legalise Assisted Dying'", June, 2017, p. 212 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

People with Disabilities WA and the Australian Federation of Disability Organisations, joint submission to the Western Australian Parliamentary Inquiry, 2018:

There is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying. Vulnerable groups generally including women, ethnic minorities, people from lower socio-economic circumstances, children, people with a psychiatric disability or dementia were not found to be at any heightened risk of assisted dying. People with psychiatric disability (mainly depression) constituted 20% of referrals to the Netherlands assisted dying process, but none progressed. Likewise, in Oregon, none of the 292 people who have accessed assisted dying did so due to mental illness.¹¹⁸

Representatives of peak elderly and disability groups in Belgium, the Netherlands and Oregon also report no abuse of their members under these laws. You can hear their voices in Episode 13 of Andrew Denton's "Better Off Dead" podcast.¹¹⁹

2.4 Why Using VAD Law to Coerce A Relative to Die is Harder to Pull Off Than *Oceans 11*

Under the Victorian law, if you were a greedy child wanting to get your hands on the inheritance by using the VAD process to coerce your elderly parent to death, you would have to engineer – and hope you would get away with – the following:

Inducing Doctors to Make a False Assessment

First, your parent would have to convince two doctors that they are dying of an incurable disease that is causing them intolerable suffering. 'Dying' means in the advanced stages of that disease – with six months or less to live. We're talking about diseases with long histories and clear symptoms such as cancer, MND, multiple sclerosis.

And these just aren't any doctors. Both must be trained at a level beyond that of a GP (a fellow of a College) and one must be a specialist in the particular disease. They must assess the person's symptoms, their medical history, the medications they are on to determine whether or not their claim that they are suffering intolerably matches with those symptoms.

Both doctors must act independently of each other. And, by law, they must also go through all other treatment options available to the person, in particular, palliative care.

More than that, they have to be specially trained in assessing a patient for eligibility for VAD as well as having specific training designed to assess a patient's mental capacity and to identify signs of abuse or coercion. Currently this training does not exist in any other area of medical practice.

Both doctors may make multiple assessments of the patient. They may refer to others involved in their treatment. They must, by law, receive three separate requests for VAD from the patient – two verbal and one written, separated by a minimum of 10 days.

If either doctor has any doubts about a person's mental capacity, they must refer them to a specialist such as a psychologist or geriatrician. If either doctor, for any reason, believes that the person applying is not eligible, they can deny the request.

¹¹⁸ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5:98 'What the evidence says'", 40th Parliament, Parliament of Western Australia, August, 2018, p.176 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

¹¹⁹ Andrew Denton, "Better Off Dead: #13 Now they're killing babies", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 24 March 2016, (audio) <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/13-now-they-re-killing-babies> Transcripts available at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2> Affirmation of 'no risk to vulnerable groups' comes from: Illya Soffer, director of *Lederin* (Everyone In) representing 250 organizations for disabled people in the Netherlands; Pierre Gyselinck, president of the Catholic Association of Persons with Disabilities, Flanders, and president of the Belgian Disability Forum; Bob Joondeph, executive director of Disability Rights Oregon; Joeri Veen, spokesperson for ANBO, representing about 180,000 senior citizens in the Netherlands; Mie Moerenhout, director of the Flemish Council of the Elderly; Cherrie Brounstein, vice president of the board for Elders in Action, Oregon.

So, the bar even to be considered eligible for VAD is extremely high. But it gets even higher.

Persuading Doctors to Risk Their Careers ... or Worse

It is almost impossible for someone to fake the symptoms of an advanced incurable illness. Which means that the only way for this elderly relative to be coerced to die through this law is for both doctors to make a wrongful assessment.

We know that most doctors act ethically; that they take seriously their oath of 'do no harm'. But let's assume that these doctors don't. The question is why would not one, but two, highly trained doctors allow somebody who clearly wasn't eligible, but was being coerced to apply by someone else, to access VAD?

Perhaps the greedy relative has offered them a cut of the inheritance? Possible, but highly unlikely as it is illegal for doctors to advertise in any way that they might participate in VAD. So, the relative would be taking a huge chance approaching any doctor hoping they might want to join in a conspiracy to convince someone to end their life. The chances of him finding two are even smaller.

Let's assume both doctors are tempted to join a conspiracy. They would be doing so at enormous risk.

The moment someone tries to go through this legislation they're under the spotlight, with every step of the process being reported in real time.

Both doctors have mandatory reporting requirements under the law. Within 7 days of assessing the patient, each must report their assessment to the voluntary assisted dying review board.

After the third, written request which, incidentally, has to be witnessed in the presence of the doctor by two independent witnesses (neither of whom is a beneficiary in the will or is directly responsible for their health care), the doctor has to complete a certificate for authorisation to prescribe the lethal drugs. This goes to the Department of Health and Human Services who won't sign off on it unless they are satisfied that all the legal requirements have been met.

By law, you also have to appoint a contact person – someone you trust – whose responsibility it is to return the lethal medication should it remain unused. Medication which, by the way, is formally tracked at every stage of the process. The pharmacist will not prescribe the medication until they've received this authorisation.

Everything both doctors do is checked – and checked against each other. If they act in a way that arouses suspicion they can be reported to the coroner, the police, or the Australian Health Practitioners Regulation Agency.

And there are serious penalties – which did not exist before this law – for those who break it: For inducing someone to request VAD, 5 years. For falsifying records, 5 years. For failing to report, 6 months.

A Conspiracy or Extreme Negligence

So, for someone to be coerced to die using this law it would require a conspiracy, or extreme negligence, of the medical profession and the State. It would assume that the witnesses are in on the act. And the contact person. And possibly the pharmacist. And the Department of Health and Human Services.

It assumes that others in the circle of care – nurses, perhaps other relatives, and friends – are completely oblivious to the fact that the patient is going through a stringent application process for VAD.

Of course, humans are capable of terrible things, but to carry off such a conspiracy involving so many people would be harder than *Oceans 11*.

Far easier, if you wanted to coerce an elderly relative to die, would be to do it outside of the Victorian law – away from the spotlight. Encourage them to stop taking their medication – or to take too much of it – take an overdose, or walk in front of a train.

Far easier to do it in Queensland today where none of these requirements exist and where we know that doctors do illegally assist people to die.

2.5 Queensland's Existing End-of-Life Laws Currently Enable Abuse of Vulnerable People

It is appropriate to raise concerns about elder abuse and disability abuse and coercion. But it is morally wrong in doing so to raise *hypothetical* concerns about the abuse of vulnerable people, as your reason not to address evidence of *actual* abuse happening right in front of us. Evidence accepted by the Victorian and West Australian Inquiries clearly shows that vulnerable people are being mistreated and abused within our medical system because of our existing laws. The case studies offered in Sections B, C & APPENDIX of this submission describe this abuse in disturbing detail.

To force a vulnerable person to suffer a painful and drawn out death against their wishes is abuse. To leave a dying person a choice only between further treatment which has become intolerable or suicide is coercion.

2.6 A VAD law will protect vulnerable Queenslanders

Elder and disability abuse is a serious problem. It is only made possible by abusers acting in what they believe to be secrecy. Under existing law, when Queensland doctors illegally assist a person to die, we do not know if that person has been subject to abuse or coercion.

We do not know – and do not ask – if a dying person's decision to refuse treatment, food and water has been made under pressure, subtle or otherwise.

A VAD law makes such abuse less likely, not more, by bringing practices that are currently happening in secrecy, into the light. It encourages better practice. It brings regulation and scrutiny to a space which is currently unregulated. It offers Queensland's vulnerable protections that they currently do not have.

It is not the prospect of VAD laws that heighten the risk of mistreatment and abuse, but rather their absence.

MYTH #3. VAD CREATES SUICIDE CONTAGION

3.1 The Argument

Opponents of VAD cite a phenomenon called 'suicide contagion', to suggest that voluntary assisted dying leads to an increase in suicides.

3.2 The Reality

There is no credible evidence of increased suicide rates as a result of assisted dying laws overseas. The Western Australian Parliamentary Inquiry 2017/18 found:

Suggestions of suicide contagion are not supported in the evidence.¹²⁰

¹²⁰ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Suggestion of suicide contagion are not supported in the evidence'", 40th Parliament, Parliament of Western Australia, August, 2018, p.179 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

Moreover, the data in European jurisdictions with assisted dying frameworks indicates that suicide rates either remained the same or fell. A 2014 Swiss government report shows that the suicide rate per 100,000 individuals has decreased steadily since 1942.¹²¹

In particular, claims have been made about 'suicide contagion' in Oregon, where Voluntary Assisted Dying has been legal for 21 years. Here is Father Anthony Kerin, episcopal vicar for life, marriage and family, representing the Catholic Archdiocese of Melbourne, testifying before the Victorian Inquiry into End-of-Life Choices:

We have noted, for example, since Oregon legislated, that the standard suicide rate has increased remarkably and alarmingly ... when Oregon had a very, very low suicide rate prior to that. It is not yet the largest rate in the US, but it's getting there.¹²²

Here is Oregon's State Health Officer, Katrina Hedburg, discussing allegations of a connection between Oregon's suicide rate and their Death with Dignity Law:

So, we do track suicide, just like we track death with dignity, and suicides in Oregon have been higher than the national rate but that's been going on for ... decades. **We have not seen any change in the statistics around rates of suicide in Oregon before or after the Death with Dignity Act took place.**

In Oregon ... the risk factors for suicide include a history of depression; of mental illness; previous suicide attempts. We know who is particularly at risk: older men who might be without their wife or their wife has died; veterans are at high risk of suicide. [We] have a number of groups and they're very different from the number who participate in Death with Dignity: equal parts men and women; the average age of 70; many of them are married and they have all been diagnosed with a terminal illness by definition otherwise they could not participate. **So I would say that there is nothing in our data to show that.**¹²³ [Our emphasis]

3.3 It is wrong to conflate Voluntary Assisted Dying with suicide

This is a deliberate, and false, conflation of two very different acts. This difference was underlined by the Western Australian Parliamentary Committee:

It is important not to conflate suicide with assisted dying. It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.¹²⁴

It is a difference that was clearly understood by the Chief New York Medical Examiner, Charles Hirsch, when investigating the deaths of office workers who jumped from the Twin Towers on 9/11.

Faced with a terrible choice – a slow, agonising death by fire, or a quick death by jumping – many chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.¹²⁵

¹²¹ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5.110 'Suggestion of suicide contagion are not supported in the evidence'", 40th Parliament, Parliament of Western Australia, August, 2018, p.180 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

¹²² Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Transcript, Parliament of Victoria, Melbourne, 18 November, 2015, p.20 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/18112015_CORRECTED_EoLC_-_Catholic_Archdiocese.pdf

¹²³ Katrina Hedburg in Andrew Denton, "Better Off Dead: #9 Death with dignity in Oregon", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/9-death-with-dignity-in-oregon>
Transcript at Go Gentle Australia website – <https://www.gogentleaustralia.org.au/transcripts1>

¹²⁴ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5.103 'Distinguishing between suicide and assisted dying'", 40th Parliament, Parliament of Western Australia, August, 2018, p.177 – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

¹²⁵ Vickers, Matt, *Lucretia's Choice: A Story of Love, Death and the Law*, Text Publishing, 29 August, 2016, p. 231 – <http://tinyurl.com/y36mt867>

3.4 VAD laws offer a compassionate alternative to suicides happening in Australia every week

While 'suicide contagion' as a result of VAD laws is made up, suicides in Australia for those beyond the help of palliative care are not.

Evidence to the Victorian Parliamentary Inquiry from the Coroner's Office showed that, faced with the fear of an agonising death or with unmanageable suffering, terminally ill Victorians are committing suicide at the rate of one a week.¹²⁶ In Western Australia, the Parliamentary Inquiry found 10 per cent of all suicides in that State were by people with terminal or debilitating chronic illnesses.¹²⁷

Former police officer Laurie Paul told the current Queensland Parliamentary Inquiry of attending countless suicides in his long career. But, he says, one in Townsville has stayed with him.

We were directed to the back yard shed. There lay an elderly gentleman who had suicided – his elderly wife and family grieved for him upstairs.

He had recently been advised that he had cancer and in his loving note to his wife of many years, outlined that he was of the view that he did not wish for her to suffer as he slowly died in front of her, and that she would have to nurse him in the last years of their lives.

This was wrong and a sad indictment on our society.¹²⁸

MYTH #4. VAD WILL DAMAGE THE DOCTOR-PATIENT RELATIONSHIP

4.1 The Argument

Those who oppose Voluntary Assisted Dying often refer to it as 'patient killing' and claim doctors' involvement in it violates the doctor-patient relationship.

4.2 The Reality

In countries where such laws have existed now for two decades, research shows that the opposite is true.

The latest (2017) OECD report on the Netherlands notes that satisfaction with health care in the Netherlands is high – 86% – compared to 70% across the OECD.¹²⁹

Of Belgium in 2017, the OECD reports:

Citizen satisfaction is among the highest ... at 90% of citizens satisfied ... significantly higher than the OECD [average], which amount[s] to 70% in the case of health care ...¹³⁰

In Oregon, former President of the Oregon Medical Association, Dr Leigh Dolin, states that the work of doctors in end-of-life care has been better since VAD was legalised:

I think we do a much better job because of this law ... Oregon's law has been a dramatic success. The dire fears that doctors would become less trusted, or worse, just hasn't happened.¹³¹

In her 2012 Churchill Fellowship Report, Australian palliative care physician Dr Linda Sheahan reported

¹²⁷ A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 – My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – <https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf>

¹²⁸ Tracey Ferrier, "Olders appeal for assisted dying laws", *Stawell Times*, 26 March, 2019 – <https://www.stawelltimes.com.au/story/5975032/olders-appeal-for-assisted-dying-laws/?cs=9397>

¹²⁹ OECD, "Government at a Glance 2017: Country Fact Sheet – Netherlands: 'Satisfaction and confidence across public services (2016)'", 2017 – <http://www.oecd.org/gov/gov-at-a-glance-2017-netherlands.pdf>

¹³⁰ OECD, "Government at a Glance 2017: Country Fact Sheet – Belgium", 2017 – <http://www.oecd.org/gov/gov-at-a-glance-2017-belgium.pdf>

¹³¹ Leigh Dolin in Andrew Denton, "Better Off Dead: #9 Death with dignity in Oregon", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/9-death-with-dignity-in-oregon>
Transcript at Go Gentle Australia website – <https://www.gogentleaustralia.org.au/transcripts1>

no erosion of trust in doctors where assisted dying/voluntary euthanasia are legal:

While I recognise and understand this fear, I do not believe it has been validated by the experiences of doctors and patients in jurisdictions where assisted death is legalised. There has been no erosion of trust, and not one clinician I spoke to felt that it had damaged the trust inherent in the doctor patient relationship.

Indeed, the individual cases of physician assisted death tended to arise out of that trust, helping doctors shift their thinking to encompass assisted death, where it may have traditionally conflicted with their sense of moral responsibility.

Many opponents to legalisation who feared this effect felt that this fear had eased since legalisation, and there were many stories of 'that one patient' with whom the trust and relationship were strong enough for the clinician to consider assisted death in that particular circumstance, despite their previous opposition. It was highly reassuring when PAS/VE arose out of this trust, rather than externally via a notion of pure patient 'right' to access assistance in dying.¹³²

Neither do many Australian doctors fear damage to the doctor-patient relationship, as a 2016 AMA survey of members found:

A majority (51.55 per cent) agreed that 'euthanasia can form a legitimate part of medical care'. And 45.43 per cent agreed that 'physician assisted suicide can form a legitimate part of medical care', while 13.32 per cent neither agreed nor disagreed.¹³³

This is perhaps best summed up by Professor Ian Maddocks, Australia's most eminent palliative care physician, who believes that assisting someone to die can be a loving act:

Voluntary assisted dying and palliative care go together. They have similar aims in relief of distress, and need to espouse similar approaches of compassion, lack of haste, involvement of family, transparency, clear consent, open reporting.

The existence of such a law would have made me a better palliative care physician.

It would have allowed me to travel through to the end with a patient under my care, who elected for Voluntary Assisted Dying.

It is against proper loving medical practice, to have rigid provisos that limit what can be done.¹³⁴

MYTH #5. PEOPLE ARE CHOOSING TO DIE BECAUSE THEY FEEL LIKE A 'BURDEN'

5.1 The Argument

Opponents of VAD argue that people in Oregon are using the Death with Dignity law to die, not because they are in pain, but because they fear becoming a burden to others.

Typically, they reference a 2006 review of the empirical literature on Oregon which states:

In the most recent report published by the Oregon Public Health Division, of the 132 deaths for which data was available, 48% listed being a burden on family, friends or caregivers as a concern.¹³⁵

¹³² Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p.64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

¹³³ Robyn Maggs, "Pain, Choice and the Art of Dying with Dignity", *The Mercury*, 1 March, 2018 – <https://www.themercury.com.au/news/opinion/pain-choice-and-the-art-of-dying-with-dignity/news-story/0304ece1d4e4e4d9c792c61ab0c5947e7fbclid=IwAR2WH1VXfwJX4774mF1J-BgE5bEQ7UaISJWMW3iVYy90bo58QJNc4EN-DqM>

¹³⁴ Ian Maddocks quoted in Andrew Denton, "The Damage Done", Transcript of an address to the Literary Festival of Phillip Island, Victoria, 9 June, 2017 – <http://www.dwdnsw.org.au/wp-content/uploads/2017/06/Denton-address-Phillip-Island-June-2017.pdf>

¹³⁵ Oregon Public Health Division, "Oregon Death with Dignity Act: 2015 Data Summary", Oregon Health Authority, 4 February, 2016, p.6 – <https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

5.2 The Reality

The information is correct. But, stripped of its context, the conclusion is misleading. On this question there are two other issues at play:

1. Where 'being a burden' sits on a patient's list of concerns.
2. What patients mean when they say they do not want to be a 'burden'.

'Being a burden' is not the only – or even the main – motivating factor in patients' decisions to avail themselves of Oregon's Death with Dignity option. The table below shows how low it rates on patients' overall list of concerns. 63.3 per cent of patients considered it a factor in contrast with the 95.1 per cent of patients, overall, for whom 'losing autonomy' was their important concern.

Figure 5: Characteristics – End of Life Concerns, Oregon Death with Dignity Act Data Summary 2018¹³⁶

Characteristics	2018		Total	
	(N=168)		(N=1,459)	
End of life concerns				
Losing autonomy (%)	154	(95.1)	1,322	(95.5)
Less able to engage in activities making life enjoyable (%)	152	(95.6)	1,300	(94.6)
Loss of dignity (%)	112	(79.4)	989	(87.4)
Losing control of bodily functions (%)	62	(46.3)	647	(56.5)
Burden on family, friends/caregivers (%)	91	(63.6)	654	(51.9)
Inadequate pain control, or concern about it (%)	43	(31.2)	375	(29.8)
Financial implications of treatment (%)	9	(7.3)	57	(4.7)

Read together, and *in context*, these two statistics support a different explanation of 'fear of being a burden' than opponents wish to convey.

George Eighmey was a member of the Oregon House of Representatives at the time their Dying with Dignity law was introduced in 1997. Mr Eighmey holds both bachelor of science and juris doctor degrees and is an attorney by profession.

He currently serves as president of America's Death with Dignity National Center. In both roles, he has been intimately involved in the end-of-life journeys of terminally ill patients and their families.

We asked Mr Eighmey to provide some clarity on the charge that Oregonians were choosing early deaths because they feared becoming a burden to their families. His response was that **this is an 'egregious' misrepresentation of the data.**

He reminded us that the list of reasons for using the law is a multi-choice *ranking*: 'Not wanting to be a burden' may be one of several answers supplied by patients. As we can see above, it is well down the list of reasons for seeking Physician Assisted Dying.

¹³⁶ Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2018", Oregon Public Health Authority, 25 February, 2019, p.12 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

Mr Eighmey rejects the implication that the 'burden' response means patients are acting against their own interests. Instead, he explains that concern about being a 'burden' relates to patients' grief at their loss of independence. It reflects a declaration by independent, self-reliant individuals, who do not *want* to be in the position of being 'waited on'.

Mr Eighmey further stated:

These people in no way are made to feel a burden, in fact it is the exact opposite. Family members and care givers repeatedly assure the patient that they wish to take care of them and that [it] is an honor and privilege to do so. It is the patient who, despite appreciating the offer, still wishes to be independent.¹³⁷

A balanced reading of the data suggests patients' concerns about being 'a burden' must be viewed within the context of their greater concerns about their loss of autonomy, dignity, control of bodily functions, and the many things which make life ... *life*. Altogether – including being a burden (remember, more than one category can be chosen) – these constitute *suffering*.

Most importantly, they must be viewed within the overriding context that the patient is dying.

Under Oregon law – and the Victorian VAD law due to come into effect in June 2019 – you can only access VAD if, according to the independent assessment of two doctors, you are terminally ill with six months or less to live (or 12 months in Victoria if you have a neurodegenerative illness).

In Oregon, all of the concerns on the list patients are asked to choose from – loss of autonomy, loss of dignity, burden on family, etc – sit within this all-embracing reality: a human being who is dying and who is suffering.

Nobody – not a single person – accessed voluntary assisted dying in Oregon because they felt like a burden.

They didn't choose to die because they felt like a burden.

They ticked 'being a burden' as just one of their end of life concerns because they were dying.

MYTH #6. THE LEGALISATION OF VAD MEANS THAT PALLIATIVE CARE WILL SUFFER

6.1 The Argument

Critics argue that the availability of Voluntary Assisted Dying will mean there is less funding, and less need, for palliative care.

6.2 The Reality

The existence of VAD laws in overseas jurisdictions does not result in a decline in palliative care. In fact, the exact opposite is true and Palliative Care Australia's own research says so.

Their October 2018 Report 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector', found:

no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. **If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.**¹³⁸ [Our emphasis]

¹³⁷ George Eighmey, email to Andrew Denton, Go Gentle Australia, 16 May, 2017.

¹³⁸ Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p. 5 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

According to the report, physicians in locations where VAD laws operate (Oregon, Washington State, the Netherlands, Belgium, Canada and the Canadian province of Quebec) have sought to improve their knowledge and understanding of end-of-life care support services, and access to palliative care has improved.

One of the 'key learnings' identified by the PCA report¹³⁹ (p.7) is:

... that the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.

The report notes (pp. 19-20) that in Oregon and in Washington State there has been an increase in the proportion of hospitals with a palliative care team since the introduction of VAD laws – 93% of all hospitals in Washington State and 89% of all hospitals in Oregon. This is high compared to the wider Pacific Coast region (77%) and the US as a whole (67%).

After Canada passed VAD legislation in 2016, the federal government committed \$6 billion over 10 years for home and palliative care.

In Belgium, a 2014 study found the government's expenditure on palliative care had increased by an annual rate of 10 per cent since its VAD law was passed in 2002 and assisted dying is now integrated into palliative care.

In the Netherlands, palliative care has grown remarkably beside assisted dying, so much so that it is now almost on a par with the United Kingdom in terms of standard of palliative care, and ahead of the other countries without VAD legislation including Spain, France and Germany.

In Oregon, hospice care, initially opposed to change, has come to endorse assisted dying as a patient right, and an additional string to their palliative bow.

In 2018, 90.9 per cent of Oregonians who accessed Voluntary Assisted Dying were also in hospice care (p.5).

Professor Ian Maddocks, Australia's most senior palliative care physician, believes Australian palliative care will see a similar improvement after the introduction of VAD laws:

Fears [by Palliative Care] of loss of reputation, trust and funding are quite unfounded. Palliative Care stands to gain in recognition and support through the introduction of VAD in Australia, just as has occurred overseas. Of the small number of dying persons who will consider the option of VAD (as many now do), only a tiny minority will satisfy its strict eligibility criteria. Most, if not all, will benefit from the continuing availability of Palliative Care.¹⁴⁰

For more about the positive impact of VAD on palliative care around the world, read Australian palliative care physician Dr Linda Sheahan's 2012 Churchill Fellowship report on the impact of VE and VAD laws on palliative care in Europe and North America.¹⁴¹

¹³⁹ Aspx Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, pp. 5, 7 and 19-20 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

¹⁴⁰ Ian Maddocks, Correspondence with Go Gentle Australia, 2017

¹⁴¹ Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p.64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

MYTH #7. VAD LEADS TO 'DOCTOR SHOPPING'

7.1 The Argument

Patients who may be refused access to voluntary assisted dying by their doctor continue to seek out other doctors until they find one keen to help.

7.2 The Reality

The law that passed in Victoria in 2017 specifically permits physicians to 'opt out' without sanctions or criticism. This may be on the grounds of religion. It may be because they are unwilling to participate in a process that is unfamiliar to them, because they have not been trained to the level the law requires, or because they view it as against their Hippocratic oath. Whatever their reason, a doctor has an absolute right not to participate.

When a doctor opts out, the patient must seek out another doctor who is not opposed to, or uncomfortable with, the decision to seek access to the law. This is called exercising one's right, not 'doctor shopping'.

The Australian Medical Association Code of Ethics states:

Respect your patient's right to choose their doctor freely, to accept or reject advice and to make their own decisions about treatment or procedures.

... When a personal moral judgement or religious belief alone prevents you from recommending some form of therapy, inform your patient so that they may seek care elsewhere.¹⁴²

Every patient has the right to pursue a legal medical intervention to relieve their suffering and to seek a second opinion. It is what a well-informed patient does when facing his/her options at the end of life.

Keep in mind:

- Regardless of how many doctors a person sees, the bar for access to Victoria's law remains the same: Two doctors, making independent assessments of the patient, must determine that they are terminally ill and with six months or less to live (or 12 months in the case of a neurodegenerative disease).
- People who successfully access these laws in Victoria are at the end stages of terminal illness. To be prescribed life ending medication they have to go through multiple medical assessments and find witnesses to support their application. It is extremely difficult for a dying person to go through the process multiple times.
- The work of doctors who assess patients to determine their eligibility for VAD is closely scrutinised. If they do not comply with the law, they risk losing their license or being sent to jail.

7.3 North America: The Facts

Figures from North America do not support allegations of doctor shopping. In Oregon, in 2018, 249 prescriptions for life-ending medication were written by 103 physicians.¹⁴³

¹⁴² Australian Medical Association, "AMA Code of Ethics", 2004 (editorially revised 2006) – https://ama.com.au/sites/default/files/documents/AMA_Code_of_Ethics_2004_Editorially_Revised_2006.pdf

¹⁴³ Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: 2018 Data Summary", Oregon Health Authority, 15 February, 2019, p.7 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

In Washington State in 2017, medication was dispensed to 212 individuals by 115 different physicians.¹⁴⁴

In California in 2017, 241 unique physicians prescribed 577 individuals aid-in-dying drugs.¹⁴⁵

In Colorado in 2018, prescriptions for aid-in-dying medication were provided by 66 unique Colorado physicians to 125 patients.¹⁴⁶

Palliative Care Australia's 2018 report 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector'¹⁴⁷ found that, in Oregon:

The distribution frequency shows that of the physicians involved in writing prescriptions, just under two thirds (62%) wrote only 1 prescription, where only a handful (3%) of physicians wrote more than 10 prescriptions.

The report also found that, rather than shopping around, patients established a clear relationship with their doctors:

The Oregon Health Authority also collects data on the median duration of the patient–physician relationship, which was just over three months (13 weeks) and ranged from 1 to 1,905 weeks.

It is important to keep in mind that, no matter how many doctors a patient sees, the bar never lowers. They can only access VAD if they are legally eligible.

In twenty years, there have been no successful prosecutions of doctors in North America for failing to comply with Death with Dignity laws.

MYTH #8. THE DRUGS DON'T WORK

8.1 The Argument

Opponents point to a handful of cases from North America in which patients regurgitated some of the lethal dose, and six regained consciousness after taking the drugs and died later. This, they say, is evidence of the failure of the life-ending drug.

These were summarised in the Palliative Care Australia, report, 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector' as:

In the US state of Oregon, over the period 1998 to 2015, there were complications reported for 2.4% of cases involving regurgitation of medication. A further 0.7% of patients regained consciousness after ingesting lethal medications.

A small number of patients are reported to have a lapse in time between ingestion and death with the median time between ingestion of lethal medication and death 25 minutes but the range extending to more than four days. In Washington State, 67% died within 90 minutes with a range extending to 30 hours.¹⁴⁸

¹⁴⁴ Center for Health Statistics, Washington State Death with Dignity Act Report", Washington State Department of Health, Disease Control and Health Statistics Division, March, 2018, p.1 – <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf>

¹⁴⁵ California Department of Public Health, "California End of Life Option Act 2017 Data Report", California Government, June, 2018, p. 3 – <https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADDataReport.pdf>

¹⁴⁶ Center for Health and Environmental Data, "Colorado End-of-Life Options Act, Year Two 2018 Data Summary, with Updates to 2017 Data", Colorado Department of Public Health and Environment, 2018, p.2 – <https://www.deathwithdignity.org/wp-content/uploads/2015/10/2018-CO-End-of-Life-Options-Act-Annual-Report.pdf>

¹⁴⁷ Aspek Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p.23 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

¹⁴⁸ Daniel Mulino, "Minority Report: Chapter 4.6.8 'Failure of drugs performing as designed'", in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

8.2 The Reality

- The life ending drugs have worked in 1127 cases out of 1133 cases in Oregon (1998-2016) and all cases in Washington.¹⁵⁰
- A success rate in Oregon of 0.997 is considered by any medical rating as almost perfect.
- The regurgitations mentioned are not failures, they are simply cases where the patient had a slight negative reaction to the bitter taste of the medication or had been nauseous prior to taking the medication or had some form of blockage, but nonetheless they died peacefully.
- In six cases in Oregon where patients awakened, they may have ingested only a portion of the medication before they fell asleep, or they may have mixed the medications too far in advance and let it sit on a shelf, which caused a decrease in potency or crystallisation. In one case, more than 15 years ago, an inadequate dose for the patient's weight was prescribed.
- No medical procedure is perfect. A 0.997 level of success is extraordinarily high. A failure rate of 0.003% is not a valid argument against VAD.

MYTH #9. VAD BREAKS A DOCTOR'S OATH TO 'DO NO HARM'

9.1 The Argument

Many doctors cite the Hippocratic Oath 'to do no harm' as their reason for not supporting VAD. They believe that their job is to heal people, not assist them to die. It is a passionately held view and they are entitled to it.

9.2 The Reality

There are also many doctors who cite 'do no harm' as their reason for supporting VAD. They see it as the definition of harm to leave a dying patient to suffer when they have the means to help ease that suffering.

These are two powerful, but different, ethical views. Neither are wrong, but the law, as it currently stands in Queensland, only supports one.

A VAD law – by exempting those against from ever having to participate, while protecting those in favour, should they help a patient to die – acknowledges that both views are legitimately held.

9.3 Where Does the Australian Medical Profession Stand on Voluntary Assisted Dying?

The Australian Medical Association

The AMA, which represents less than one-third of Australian doctors, has released a position paper on VAD that states:

Doctors should not be involved in interventions that have as their primary intention the ending of a person's life ... but that it is ultimately a matter for society and government.¹⁵¹

According to the AMA's Code of Ethics¹⁵², doctors are obliged to:

Respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such treatment may shorten a patient's life

¹⁵⁰ Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act Data Summary 2016", Oregon Health Authority, Public Health Division, 10 February, 2017, p.10 –

<https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>

¹⁵¹ Australian Medical Association, "AMA Releases Position on Euthanasia and Physician Assisted Suicide", AMA, 5 December, 2016 – <https://ama.com.au/edit-newsletter/ama-releases-position-euthanasia-and-physician-assisted-suicide>

¹⁵² Australian Medical Association, "AMA Code of Ethics", 2004 (editorially revised 2006) – https://ama.com.au/sites/default/files/documents/AMA_Code_of_Ethics_2004_Editorially_Revised_2006.pdf

The AMA Code of Ethics also recognises patient autonomy and states:

Doctors should respect the patient's right to make their own health care decisions. This includes the right to accept, or reject, advice regarding treatments and procedures including life-sustaining treatment.

A survey of AMA members in 2016 found that:

- 51% agreed that VAD can form a legitimate part of medical care.
- 52% disagreed that "allowing doctors to lawfully provide euthanasia will negatively affect the trust patients have in doctors"
- almost 70% agreed that "there are patients for whom palliative care or other end of life care services cannot adequately alleviate their suffering".¹⁵³

The Royal Australian College of GPs

The RACGP's submission to the Western Australian Joint Select Committee on end-of-life choices stated that:

The RACGP neither supports or opposes the introduction of laws to legalise voluntary assisted dying, we believe both patients and GPs must be appropriately supported if any legislation for voluntary assisted dying comes into the clinical setting.¹⁵⁴

The Royal Australian College of Physicians

The RACP released a November 2018 statement saying that:

Our members are not unanimous in their support or opposition for legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying ... On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of critical neutrality to encourage reflective dialogue.¹⁵⁵

The Australian Medical Students Association

AMSA, representing 17,000 medical students, issued a statement in support of VAD in 2017. It called for laws:

implementing [VAD] in a restrictive way with appropriate safeguards to protect vulnerable patients.¹⁵⁶

The Australian Nursing and Midwifery Federation

The ANMF's position statement on assisted dying says:

[We] support legislative reform so that persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.¹⁵⁷

¹⁵³ Australian Medical Association, "Review of AMA Policy on Euthanasia and Physician Assisted Suicide - Member Consultation Report", 2016.

¹⁵⁴ Timothy Koh and Sean Stevens, RACGP, letter re 'End of Life Choices – Public Submissions' to Ms Amber-Jade Sanderson MLA, Chair, Joint Select Committee on End of Life Choices, Legislative Assembly, Western Australia, 19 October, 2017 – [http://www.parliament.wa.gov.au/parliament/commit.nsf/\[Evidence+Lookup+by+Com+ID\]/C032ADE9BD8FAFF448258219000B496B/\\$file/20171019+-+EOLC+-+Sub+435+-+The+Royal+Australian+College+of+General+Practitioners.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/[Evidence+Lookup+by+Com+ID]/C032ADE9BD8FAFF448258219000B496B/$file/20171019+-+EOLC+-+Sub+435+-+The+Royal+Australian+College+of+General+Practitioners.pdf)

¹⁵⁵ Royal Australian College of Physicians, "Statement on Voluntary Assisted Dying", November, 2018 – https://www.racp.edu.au/docs/default-source/advocacy-library/racp-voluntary-assisted-dying-statement-november-2018.pdf?sfvrsn=761d121a_4

¹⁵⁶ Kate Aubusson, "Medical students declare support for euthanasia, opposing AMA stance", WA Today, 25 October, 2017 – <https://www.watoday.com.au/healthcare/australian-medical-students-association-throw-support-behind-voluntary-assisted-dying-putting-them-at-odds-with-amas-euthanasia-stance-20171025-gz7ngg.html>

¹⁵⁷ Australian Nursing & Midwifery Federation, "ANMF Position Statement: Assisted Dying", reviewed and re-endorsed November, 2016 – http://anmf.org.au/documents/policies/PS_Assisted_Dying.pdf

9.4 The Hippocratic Oath: Some Background

The Hippocratic Oath was written by the Greek physician Hippocrates. Historically it has been an oath taken by doctors around the world.

Originating 2400 years ago, it begins by swearing allegiance to ancient Greek Gods, forbids women from entering the profession, outlaws surgery and requires doctors to train the sons of their friends free of charge.

The central idea of 'do no harm' contained within it is not always possible for doctors in practice.

Many medical procedures, such as chemotherapy, have side effects, and doctors may need to evaluate harms and benefits before advising a course of action.

Although doctors are expert advisers, it is the patient who makes the ultimate decision on which treatment, or none, represents the greater benefit and lesser harm. For example, an incurably ill patient with unremitting suffering may decide, after consultation and advice, that refusing any further treatment is the lesser harm.

In 2017, the World Medical Association revised the Declaration of Geneva, the modern successor to the Hippocratic Oath, which is more commonly used today by physicians across the world.¹⁵⁸

The revised Declaration reflects changes over the decades in the relationship between physicians and their patients and between physicians themselves.

It makes specific reference for the first time to respecting the autonomy of the patient

9.5 Why VAD encourages better medical practice

We know from evidence accepted by both the Victorian and Western Australian Inquiries into end-of-life care that doctors illegally assist people to die throughout Australia. However, as the Victorian Inquiry found, they must do so:

... without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.¹⁵⁹

When the leadership of the AMA argues against a Voluntary Assisted Dying law, what they are actually arguing for is that it is OK for doctors to keep practising in a way that is illegal and which leaves both them and their patients vulnerable as a result.

And even when doctors abide by the law, their patients remain vulnerable.

The 2016 Victorian Parliamentary Inquiry heard many accounts of "irremediable pain despite receiving palliative care". It reported that:

... some health practitioners are uncertain about the law relating to administration of pain relief which may have the unintended effect of ending a patient's life.¹⁶⁰

¹⁵⁸ World Medical Association, "WMA Declaration of Geneva", 9 July, 2018 – <https://www.wma.net/policies-post/wma-declaration-of-geneva/>

¹⁵⁹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chapter 8 - Victoria Should Legalise Assisted Dying'", June, 2017, p. 207 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

¹⁶⁰ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7.2.1: Protecting Lawful Medical Practice of Doctors", June, 2017, pp.181-186, – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf
Based on submissions from: Australian Centre for Health Research, *Submission*, p. 6; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 37; Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 11.

It found that doctors may be inhibited from ordering adequate pain relief – it only takes one complaint for a doctor to be in serious trouble. Thus, under-treatment of pain and other suffering at the end of life is common in nursing homes, hospitals and even in palliative care.

The fundamental reason for this inadequate treatment is lack of communication between patients, families and doctors about end-of-life matters. Many doctors close down such conversations because of potential legal or Medical Board problems. Even if willing to have a dialogue, they are frustrated by the current 'dead end' to such discussion – the lack of a legal option, or the ability to provide 'a key to the fire escape'.

The fact is that no doctor has been prosecuted in Victoria for hastening death in the last 60 years, but the fear of such prosecution is real, and damaging for patients.

If doctors don't feel protected, their patients will suffer.

9.6 Doctors are Not Being Asked to 'Kill'

Doctors who object to VAD portray it as though they are being asked to 'kill' a patient. In reality, under Victorian law what they're being asked to do is what they already do – make a careful diagnosis that a patient's condition is terminal, at its end stages, that their suffering is intolerable, and inform them of their treatment options.

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

**Only one person is being asked to make a life and death decision.
Not the doctor. The person who is dying.**

Even in the rare cases where the doctor administers the dose, because the dying patient can no longer swallow or ingest, they do so at the voluntary request of that patient.

A doctor's mission statement doesn't suddenly change under this law. They still want to alleviate suffering. Determining whether a patient is eligible for Voluntary Assisted Dying is no more a life and death decision than those already taking place between patients and doctors every day around Australia, such as removing life sustaining measures and ceasing futile treatment.

In fact, in many ways, it is less. Whereas ceasing futile treatment or removing life sustaining measures will inevitably lead to the patient's death, the offer of assistance to die has no such certainty. We know this from Oregon where more than 30 per cent of those provided with the lethal prescription choose not to take it.¹⁶¹

Of course, those doctors who ethically object need never participate. The very core of this law is that it is voluntary – for doctors as much as everyone else.

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

VAD is not a choice between life and death. It is a choice about the manner and timing of death.

¹⁶¹ In Oregon in 2018, 249 prescriptions were provided to dying Oregonians who qualified for the Act but only 168 people died using the medications (including 11 who had received prescriptions the previous year), 81 people (32%) did not either fill or use their prescription. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2018 Data Summary", Oregon Health Authority, 15 February, 2019, p.3 – <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

Part E

Fear. Uncertainty. Doubt.

Tactics used to create an alarmist picture of assisted dying

WHAT THIS SECTION IS ABOUT

Queensland MPs will experience often-repeated anti-VAD tactics and misinformation campaigns during the parliamentary inquiry process and the subsequent parliamentary debate.

Many of the core anti-VAD arguments are presented as scare campaigns led by religious lobby groups such as Right to Life, HOPE, and the Australian Christian Lobby. These groups are well-organised and funded, and have strong links to sister organisations overseas.

For 20 years opponents to assisted dying have used misleading, cherry-picked, and distorted information – quoting in support ‘experts’ with a clear but undeclared anti-VAD bias – to persuade politicians not to support VAD legislation.

But in this debate – as in other matters of public policy – facts matter.

How do we know what we’re being told is real?

1. IS THE EVIDENCE RELIABLE?

Law professors Ben White and Lindy Willmott, from the Australian Centre for Health Research¹⁶² at QUT, are the leading researchers in Australia of end-of-life laws. They have commented on the need for politicians (and the public) to focus on facts, not rhetoric, in the debate on assisted dying legislation.

White and Willmott argue there is a need to identify whether opinion is based upon values (for example, the importance of autonomy or the sanctity of life) as opposed to facts (for example, as gleaned from the experience of assisted dying in other jurisdictions).

They argue differences of opinion based on individuals having different values is understandable in a complex issue such as this. However, if an opinion purports to be influenced by facts, it is critical that these facts are accurate and informed by empirical evidence:

A starting point is to distinguish between claims that something should or should not happen (a moral claim about right and wrong), and claims that something is or is not happening (a factual or empirical claim). This distinction matters, because what justifies each type of claim is different.

For example, a claim that the bill should not be enacted because it is wrong for doctors to be involved in deliberately bringing about the death of a patient is a moral claim. This moral

¹⁶² Australian Centre for Health Research – <https://www.qut.edu.au/law/research/achlr>

claim is based on values – that killing a person is always wrong, and/or it is wrong for doctors to be involved in such a practice.

Politicians should ask those making such claims what values they are relying on. This allows them to assess if those values are justifiable in contemporary Australia, recognising that our society respects a plurality of viewpoints.

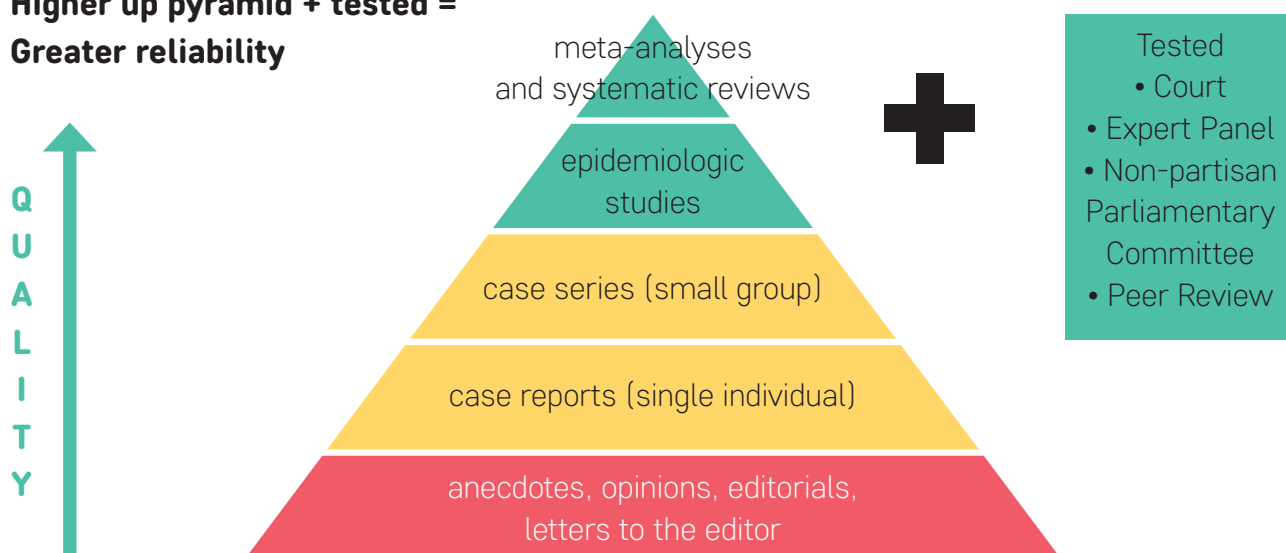
On the other hand, a factual (or empirical) claim depends on evidence. For example, a claim that vulnerable people will be at risk if the bill is enacted is a factual claim. This claim should be supported by evidence, and politicians should ask the claimant for that evidence.

If no evidence is provided for a factual or empirical claim, it should be ignored. If evidence is provided, the question then becomes: how reliable is it?¹⁶³ [Our emphasis]

White and Willmott argue that there are established ways to evaluate evidence, illustrated by the 'pyramid of quality' below.

Figure 6: The Pyramid of Evidence Quality (White and Willmott)

**Higher up pyramid + tested =
Greater reliability**



The researchers say key considerations include how high up the pyramid of quality the evidence is, and whether it has been robustly tested.

An example of low-quality evidence is anecdotal evidence, which hasn't been independently verified, about a small number of cases in an overseas assisted dying regime.

At the other end of the spectrum, high-quality evidence would be a peer-reviewed systematic review that analyses all existing research to determine what sorts of people are receiving assistance to die in a particular country.¹⁶⁴

We would add an additional consideration: how recent is the evidence? Opponents of VAD laws have been known to present outdated data (sometimes pre-dating VAD laws) to lend weight to their claims. Evidence needs to be tested, not only for its accuracy, but also for its relevance.

¹⁶³ Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", *The Conversation*, 20 September, 2017 –

<https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>

¹⁶⁴ Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", *The Conversation*, 20 September, 2017 –

<https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>

2. VICTORIA'S ASSISTED DYING LAW: EVIDENCE-BASED POLICY MAKING AT ITS BEST

In 2018, a first-time joint study by the 'right-wing' Institute of Public Affairs and 'left-wing' Per Capita Australia think tanks investigated 20 selected policy decisions in recent years by the federal Coalition government and the NSW Liberal and Queensland and Victorian Labor governments.

Seeking to assess the best examples of evidence-based policy making, they devised a set of ten criteria, including:

- Demonstrable, evidence-based need
- Public interest
- Consideration of alternatives, and
- Implementation choices

Despite differing outlooks, the IPA and Per Capita agreed overwhelmingly on what were good and bad policy processes.

Coming out at #1 – having passed nine of the ten criteria – was Victoria's Voluntary Assisted Dying legislation.¹⁶⁵

For an insight into the kind of evidence which supported this legislation, go to PART G, Evidence Considered by the Victorian Committee into End-Of-Life Choices.

3. 'FUD': 5 TACTICS COMMONLY EMPLOYED TO CREATE AN ALARMIST PICTURE OF VAD

1. Manipulation of Official Figures
2. Selective Quoting from Official Reports to Suggest They Came to a Different Conclusion
3. Avoiding the Central Issue of 'Suffering' by Defining It Only as 'Pain'
4. Minimising Patient Distress: Assertions That 'Very Few Ask to Die'
5. Undisclosed Bias of Expert Sources

3.1 Tactic #1: Manipulation of Official Figures

3.1.1 The Tactic

Partially quoting from official reports to create an alarming, yet false, impression that euthanasia and VAD rates are growing uncontrollably. Here are two examples.

Creating a false impression of Voluntary Euthanasia in Europe

In Chapter 3 of his dissenting report to the Victorian Inquiry into End-Of-Life Choices, Final Report, MP Daniel Mulino opens by claiming:

In all jurisdictions where euthanasia or assisted suicide is legal, there has been a sharp, sustained upward trend in the number of deaths – often over long periods of time.¹⁶⁶

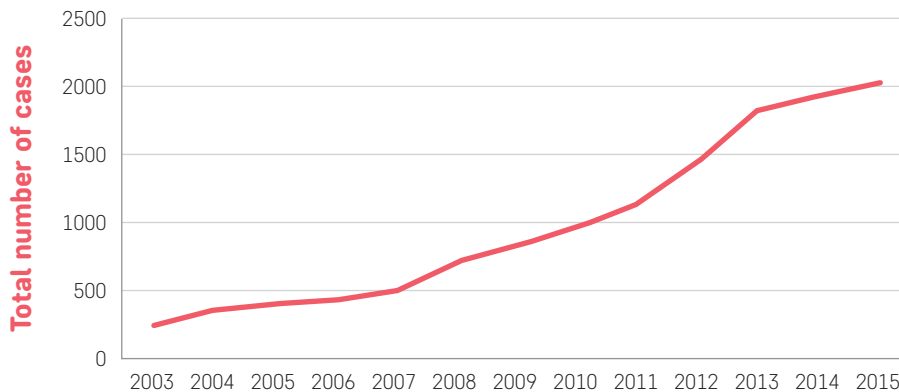
The following charts are used by Mulino to illustrate his claim of a sharp and sustained rise in Belgium and the Netherlands:

¹⁶⁵ Lesh, Matthew, "Evidenced Based Policy Research Project: 20 Case Studies", Institute of Public Affairs, October, 2018, p. 6 – <https://ipa.org.au/wp-content/uploads/2018/10/IPA-Report-Evidence-Based-Policy-20-case-studies.pdf>

¹⁶⁶ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 3.1 'The frequency of euthanasia and assisted dying is rising rapidly' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

**Figures 7 and 8 (Figures 1 and 2 in Mr Mulino's minority report):
Assisted deaths in Belgium and the Netherlands**

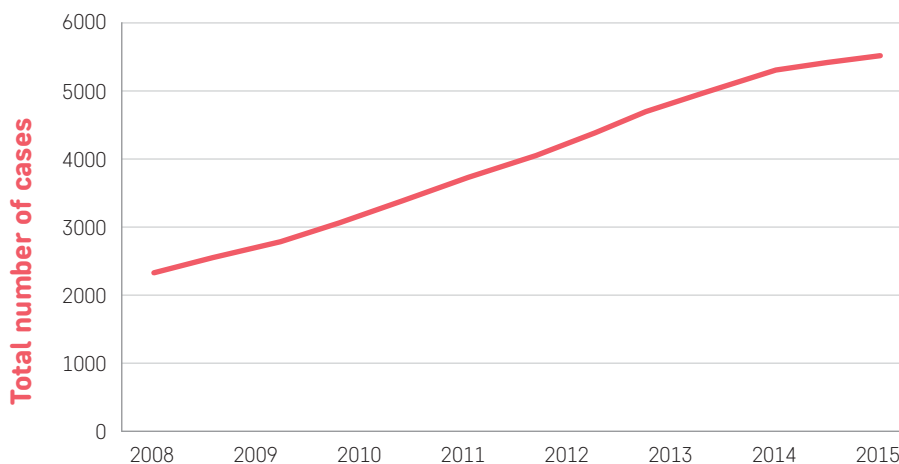
Figure 1: Belgium



Total Growth
2003-2015:
235 → 2012

Compound
Annual
Growth Rate:
19.6%

Figure 2: Netherlands



Total Growth
2008-2015:
2331 → 5516

Compound
Annual
Growth Rate:
13.1%

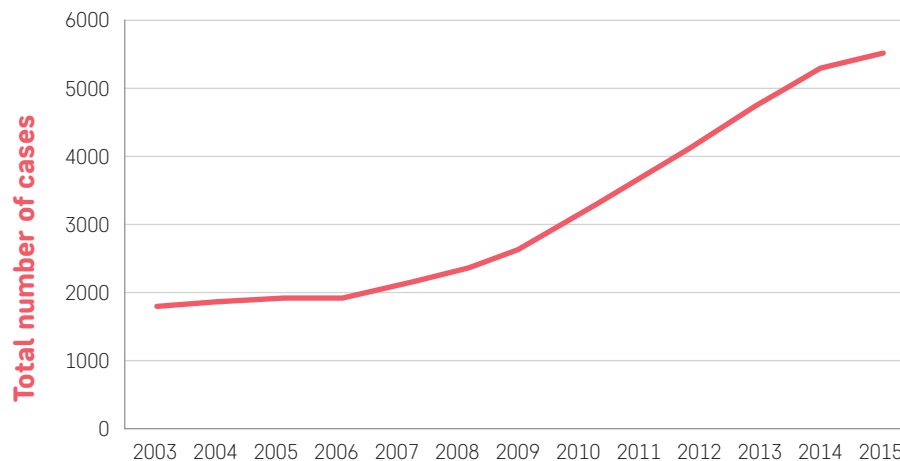
Taken at face value, they appear to confirm his claims. But closer inspection reveals crucial information that contradicts his analysis has been omitted.

Why does Mulino start Belgium's graph shortly after the introduction of their euthanasia Act, but only begins plotting the Netherlands data **five years after** their Act was introduced in April 2002? Why leave out the first five years? He offers no explanation.

But, when you factor in all the relevant data for the Netherlands (Figure 9, below), not just the years 2008–13, the reason becomes clear.

Figure 9: The full Netherlands assisted dying data, 2003-15
(Source - Official Euthanasia Commission reports) ¹⁶⁷

Figure 2: Netherlands



He has left out the first five years of Dutch euthanasia data, where the line is almost flat (and, indeed, shows a slight fall between 2005-06).

While it is true the graph still appears to show a relatively steep increase from around 2008, as an economist, Mr Mulino would know that, in statistics, context is everything. The raw data he presents is uncontextualised and offers no other explanation for an increase in numbers beyond assertions of a 'slippery slope'.

Euthanasia deaths do not occur within a statistical or societal vacuum. Mulino chooses not to include any of the following context:

- a predictably low initial take-up in the early years of the legislation
- a predictable increase in growth as patient and physician confidence in the process and safeguards increases
- population growth
- demographic changes (it is notable that the Global Financial Crisis occurred at about the same time as the upward trajectory begins, leading to greater stress-related disease and deaths)¹⁶⁸
- terminal illness frequency
- reporting improvements
- the corresponding decrease in LAWER (life-ending acts without explicit request) deaths

Of more significance is Mulino's decision to omit data that is crucial if one is to make a balanced reading of the evidence.

¹⁶⁷ Regional Euthanasia Review Committees (RTE), "Annual Reports, 2002-2015" –

<https://english.euthanasiacommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports>

¹⁶⁸ See, for example, Nicola Mucci, Gabriele Girogi, Mattia Roncaioli, Javier Fiz Perex and Giulio Arcangeli, "The correlation between stress and economic crisis: a systematic review", *Neuropsychiatric Disease and Treatment*, 12, published online 21 April, 2016, pp.983-993 – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/>

A Very Different Picture: Putting European Voluntary Euthanasia Figures in Full Context

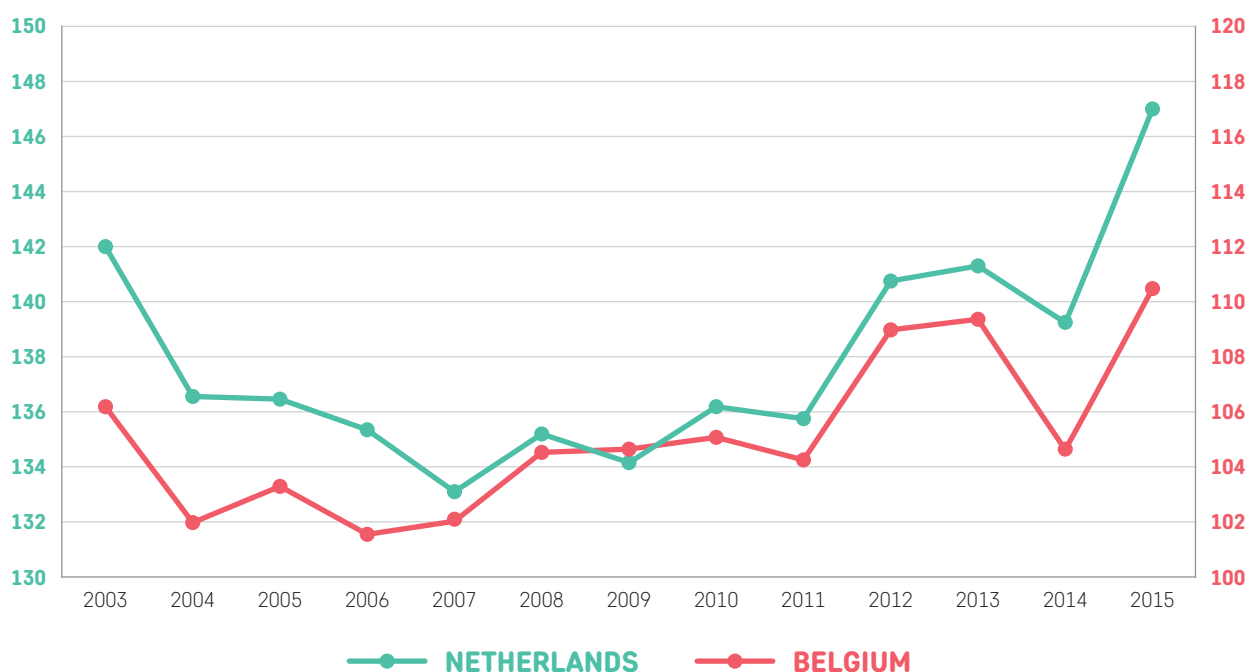
In focussing solely on euthanasia deaths in Belgium and the Netherlands year on year, Mulino has left out the essential piece of qualifying information – **the total number of deaths, year on year, in both countries.**

It is only within this context that the data can be properly understood. An increasing number of VE deaths may look alarming in isolation, but it's misleading to show it this way; VE numbers will inevitably rise as the population and total number of deaths increase. So, the fairest and most accurate expression of the data is as a proportion of overall deaths.

Here is the official data for deaths each year, 2003–15:

Figure 10: Total deaths by year in the Netherlands and Belgium ('000)
(Source - Official government mortality data)¹⁶⁹

Total deaths by year ('000)



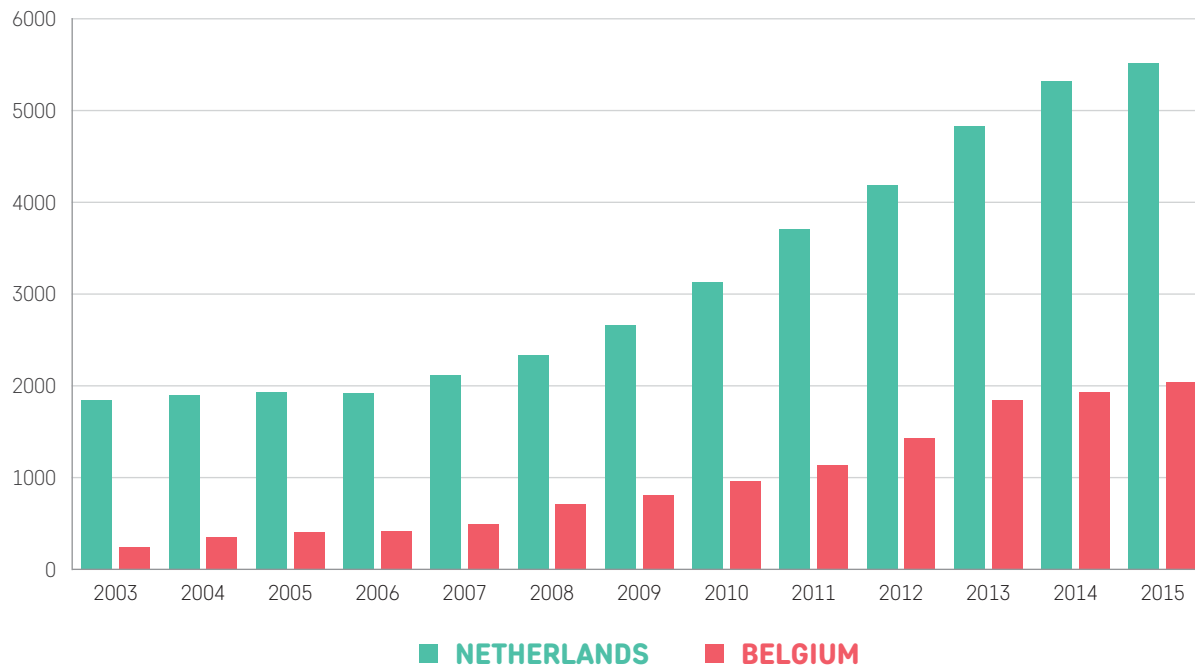
After an initial fall from 2003, since 2007 (and even with a spike down in 2014) there has been a rise in the annual total number of deaths in both countries, consistent with an increasing and ageing population. The rise in total deaths from 2007 to 2015 was approximately 11 per cent in the Netherlands and 8 per cent in Belgium. It is relative to these changes that assisted dying is properly assessed.

Now here is the official data for euthanasia deaths in the years, 2003–15 (not 2008–13 as shown in Mulino's chart of the Netherlands):

¹⁶⁹ The three graphs, Figures 10–12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – <http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>

Figure 11: Reported assisted deaths in the Netherlands and Belgium, raw counts
(Source - Official Euthanasia Commission reports)¹⁷⁰

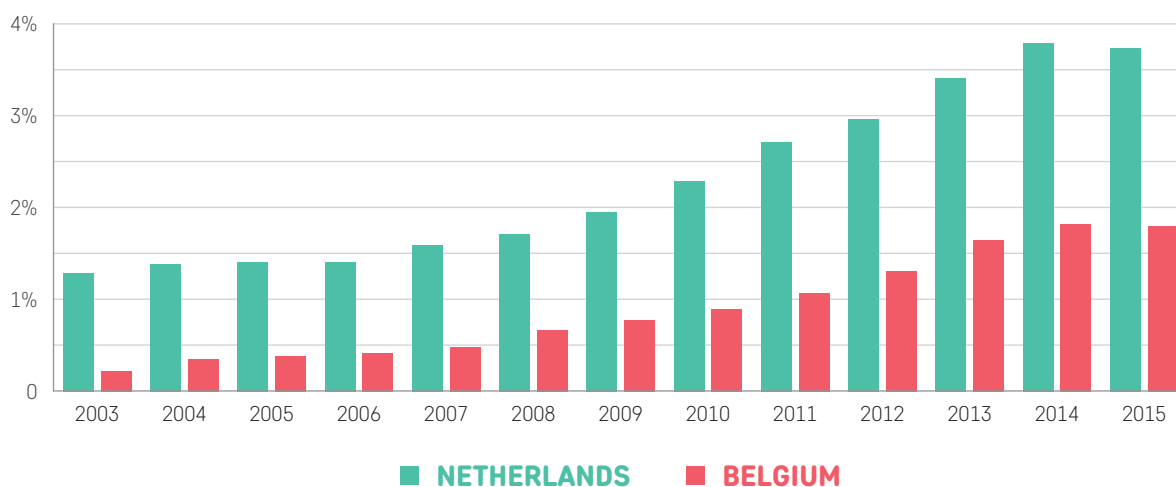
Reported assisted deaths – counts



And, finally, putting both together, euthanasia deaths as a percentage of all deaths:

Figure 12: Reported assisted death rates in the Netherlands and Belgium as a percentage of all deaths¹⁷¹

Reported assisted deaths as a percent of all deaths



¹⁷⁰ The three graphs, Figures 10-12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – <http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>

¹⁷¹ The three graphs, Figures 10-12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – <http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>

When all the data is tabled the following becomes clear:

- Euthanasia deaths in Belgium and the Netherlands remain, as they have been since the inception of laws, a tiny percentage of all deaths. In the Netherlands, always around 4 per cent. In Belgium, never above 2 per cent.
- Euthanasia deaths have remained statistically tiny despite an upward trend in total deaths in both countries.
- There was a drop in total euthanasia deaths in 2014–15, which Mr Mulino doesn't report.

Using incomplete data to create a distorted picture, Mulino argues that:

What appears to be manageable can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.¹⁷²

The facts – all on the public record – contradict him. As does the Victorian Committee which, in their majority report having referenced all the data, confirmed that:

In each jurisdiction, a relatively small number of total deaths each year are attributed to assisted dying.¹⁷³

Creating a False Impression of Voluntary Assisted Dying in Oregon

In 1997 Oregon became the first state in the United States to enact a physician aid in dying (PAD) law, known as the Death with Dignity Act (DWDA).

Suggesting that the number of DWDA deaths in Oregon are escalating out of control, Mr Mulino writes:

Annual growth rates in the order of 13–20 per cent are extremely high. It is worth noting that the impact of cumulative growth rates of this magnitude over the medium term can be deceptive. What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.

For example ... the number of cases in Oregon is 725% higher over the 17 years following legalisation.¹⁷⁴

The statistics sound alarming – and that is clearly Mr Mulino's intent. But, a fair and balanced reading of the evidence shows physician assisted deaths in Oregon in 2016 accounted for just 0.37 per cent of all deaths¹⁷⁵– 133 out of nearly 36,000 deaths¹⁷⁶ – or fewer than four in every 1000 people.¹⁷⁷

This is consistent with an unbroken trend since the law was enacted in 1997, as evidenced by the Oregon Public Health Division, Center for Health Statistics 2016 Report ¹⁷⁸:

- Since the law was passed in 1997, a total of 1749 people has had prescriptions written.

¹⁷² Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 3.3 'Challenges for the palliative care workforce in Victoria' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

¹⁷³ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June 2017, 'Introduction', p. 8 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

¹⁷⁴ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report" June, 2017, Chapter 3.3 'The sustained and long-term nature of growth' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

¹⁷⁵ Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 – <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>

¹⁷⁶ Oregon Government, "Deaths by Age Group and Country of Residence: Oregon Residents 2016, Final Data", 2016 – <http://www.oregon.gov/oha/PH/BIRTHDEATHCERTIFICATES/VITALSTATISTICS/DEATH/Documents/dage16.pdf>

¹⁷⁷ Death with Dignity National Center, "Debunking Myths and Falsehoods About Death with Dignity Legislation", Fact Sheet.

¹⁷⁸ Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February 2017, p.10 – <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>

- Of that number, 1127 patients have died from ingesting the medication – less than 0.5% of all the deaths in Oregon annually.
- More than one-third of all prescriptions issued were not used.
- During 2016, the rate of deaths was 37.2 per 10,000 total deaths. In that year, 204 people received prescriptions (compared to 218 in 2015), of whom 133 people had been reported as having died from ingesting the medication.
- Of those 133 people, the median age at death was 73 years.
- Almost 80% of them were dying of cancer. Just under 7% from Motor Neurone Disease, and just under 7% from heart disease.
- Close to 9 out of 10 patients who used DWDA (89%) were enrolled in hospice care.

According to Dr Charles Blanke, professor of medicine at the Knight Cancer Institute in Oregon, the people who avail themselves of this end-of-life option are predominantly elderly, white, and well educated and almost all are under hospice care. A majority are suffering from cancer.¹⁷⁹

Speaking from his long experience with the legislation, Doctor Blanke said:

... no evidence has emerged that the strict criteria are not being adhered to ... DWD deaths make up only a tiny fraction of Oregon resident mortality.

Dr Blanke's account provides the perspective of a leading specialist whose work immerses him in a system which provides VAD as a legal, medical option. The picture he paints – supported by publicly available statistics from the Oregon Public Health Division – is completely different from the account given by Mr Mulino (who, it must be remembered, did not travel to Oregon with the rest of the Victorian Inquiry Committee).

Alarmism: Raw Data About Oregon Presented out of Context

Oregon Public Health Division statistics show that, since 1997, the number of DWDA deaths in Oregon totals less than 0.5% of all deaths in the State annually.¹⁸⁰

In 2016, that equated to 37 out of 10,000 deaths.

Yet Mr Mulino writes:

What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.¹⁸¹

How does he reach this conclusion?

The graph below shows that after a slow, initial uptake, the rate of physician deaths in Oregon has risen, over the past 10 years, from just under 0.15 per cent in 2007 to 0.37 per cent of total deaths in 2016.

¹⁷⁹ Charles Blanke quoted in Roxanne Nelson, "Death With Dignity in Oregon: No Evidence of Abuse or Misuse", Coverage from the Palliative Care in Oncology Symposium (PCOS) 2016, Medscape, 20 September, 2016 – <http://www.medscape.com/viewarticle/869023>

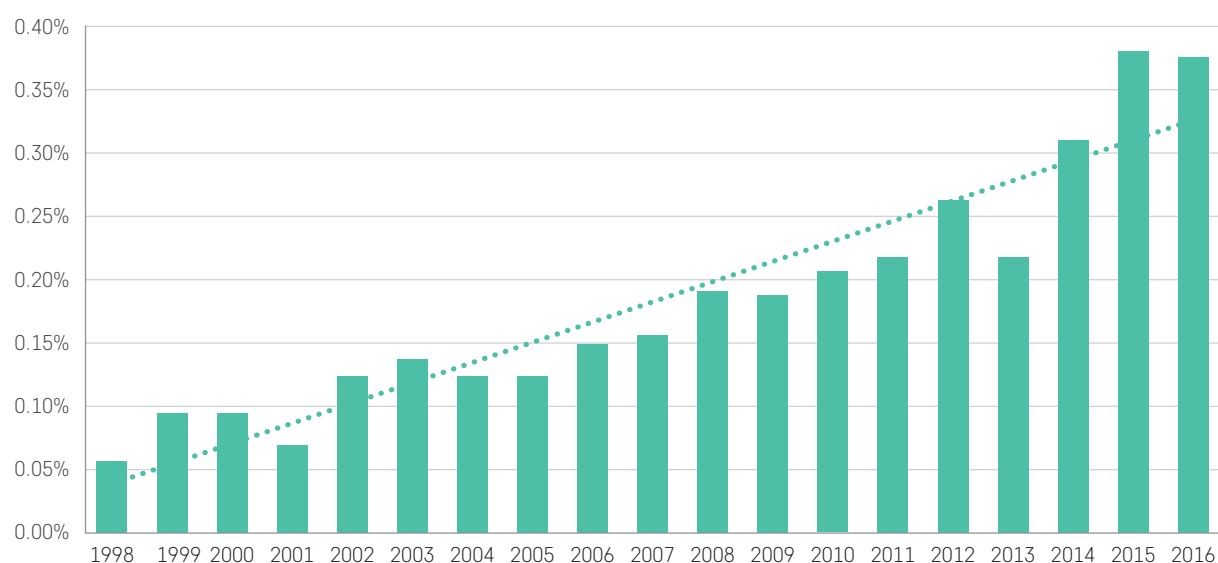
¹⁸⁰ Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 –

<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>

¹⁸¹ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 3.3 'The sustained and long-term nature of growth' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

Figure 13: Oregon DWDA deaths as a per cent of all deaths 1998–2016 ¹⁸²

Oregon DWDA deaths as a percent of all deaths



Mr Mulino's claim is distorted by his use of figures from the very early years of the Oregon legislation. The increase appears far more dramatic when it is compared with a very low initial number of just 16 deaths in 1998.

According to George Eighmey, who was a member of the House of Representatives in Oregon when the Dying with Dignity legislation was passed in late 1997, initial uptake was slow because it took time for patients to become aware of VAD as an option. Mr Eighmey says the dissemination of information was hindered, in the early years, by the concerted efforts of opponents to discourage physicians from participating. This, says Eighmey, made it difficult for terminally ill patients to find cooperating physicians.¹⁸³

Not only have the number of DWDA deaths, as a percentage of all deaths in Oregon, remained statistically tiny, once again Mr Mulino fails to consider other valid reasons why the raw numbers would have risen since 1997:

- As in Europe, the increase in numbers is consistent with an ageing population and with the growing confidence of patients and physicians in considering VAD among a suite of end-of-life options.
- It is relevant, too, that Oregon's population has increased by 33 per cent during the period 1998–2017.
- Other US factors influencing the data, include the socioeconomic stress of the GFC, (leading to an increase in stress-related disease),¹⁸⁴ and patients' lack of access to affordable health care in the early (treatable) stages of disease.

¹⁸² Graph plotted by Neil Francis, Dying for Choice, using data from Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 – <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>

¹⁸³ Information provided to Go Gentle Australia by George Eighmey, American politician, former member of the Oregon House of Representatives, and currently president of America's Dying with Dignity National Center.

¹⁸⁴ See, for example, Nicola Mucci, Gabriele Girogi, Mattia Roncaioli, Javier Fiz Perex and Giulio Arcangeli, "The correlation between stress and economic crisis: a systematic review", *Neuropsychiatric Disease and Treatment*, 12, published online 21 April, 2016, pp.983–993 – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/>

If Mr Mulino's figure of a **"725% rise in the number of cases"** in Oregon was truly as alarming as he's tried to make it sound, you would expect an uproar in the Oregon medical community, legislature, law enforcement agencies, and media.

There is no such uproar. Oregon's DWD law remains little used and widely supported. No effort has been made, in more than 20 years, to either repeal or amend it.

Finally, it should be noted that simply stating figures – no matter how much they rise – does not, in itself, prove any fault in the system.

No reasonable person would suggest there should be an arbitrary cap on the number of terminally ill people who can access such a law.

The question is not the numbers but whether or not these people were eligible under the law.

In 21 years, not one person has ever been sued, or charged with misusing the law, except by opponents of the law whose allegations have all been shown to be inaccurate or false. In that same time, there has not been a single demonstrated case of coercion.

20 years of peer-reviewed research has also found no evidence of heightened risk to, or in fact any instances of abuse of, particularly vulnerable groups.

3.2 Tactic #2: Selective Quoting from Official Reports to Suggest they Come to a Different Conclusion

3.2.2 The Tactic

Selectively quoting from official reports and academic research to make an uncommitted reader or listener think that they have reached the opposite conclusion.

In 2013, Canadian, Alex Schadenberg, founder of the activist Euthanasia Prevention Coalition, published a book *Exposing Vulnerable People to Euthanasia and Assisted Suicide*. In it he claimed to use official research from Belgium and the Netherlands to show how doctors were ending the lives of hundreds of elderly and vulnerable patients without their consent.

When asked if he was accusing doctors of murder he said: "murders, manslaughter ... yes they are".¹⁸⁵

Schadenberg's work was enthusiastically endorsed by a range of Australian politicians, with a foreword by Kevin Andrews MP. The book they endorsed turned out to be academically and morally fraudulent.

Here is Andrew Denton's account of meeting Schadenberg and uncovering his fraudulent claims, as submitted to the Victorian Inquiry into End of Life Choices:

The interesting conclusions of Alex Schadenberg – and why they matter in Australia

The most interesting person I met at the HOPE Symposium in Adelaide was Canadian Alex Schadenberg of the Euthanasia Prevention Coalition. Alex travels the world addressing like-minded groups and giving them serious amounts of information with which to fuel their arguments.

To meet Alex is to be bombarded with a multi-pronged attack direct from the Nancy Elliott playbook: elder abuse, disability abuse, invisible crimes, suicide contagion (He actually used the term 'suicide contagion' about Oregon. Said it's 'really happening' in that state now they

¹⁸⁵ Andrew Denton, "Better Off Dead: #7 The Killing Fields of Belgium, Part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 1 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/7-the-killing-fields-of-belgium-belgium-part-1>
Transcript at Go Gentle Australia website – <https://www.gogentleaustralia.org.au/transcripts1>

have Death With Dignity laws. You know, once the kids see grandpa do it legally, they'll think about doing it too. So, I checked with Katrina Hedberg, State Epidemiologist for the Oregon Department of Health. She said that, yes, Oregon does have a higher suicide rate than many other States in America and that they're not sure why. But that has been the case for the last 40 years and the introduction of Death with Dignity laws in 1997 hasn't caused those numbers to change one jot. So much for the contagion. Still, it sounds impressive when you say it quickly.

Alex's big thing is that he's about facts, not just conjecture. When I made the mistake of suggesting he was asserting something, he said:

'See, it's not even my assertion, 'This is what I think '. I'm just extrapolating the data. If this is the research, and it is, that's what they're saying. They published the information connected to it. You can look at the article. I'm not making anything up, which is the crazy thing about it.'

In his book *Exposing Vulnerable People to Euthanasia and Assisted Suicide*, Alex claims to have gone back to source documents and analysed major studies from the Netherlands and Belgium which prove that no assisted dying legislation can protect citizens from the possibility of abuse.

It's good methodology to go back to source documents rather than do what many others do, which is to work off other people's conclusions.

I was impressed, so I bought a copy of his book and then enlisted the help of Professor Margaret Otlowski, Dean of Law at the University of Tasmania, to help me determine if Alex's methodology was good, and his conclusions accurate.

As it turns out, neither hold. Because, when you follow Alex's trail and go back to the same source documents, an interesting thing happens.

Take a 2009 study published in the *New England Journal of Medicine* called 'Medical End-of-Life Practices under the Euthanasia Law in Belgium'. It focuses on "The unreported cases of euthanasia or those deaths occurring without explicit patient request".

Alex's conclusion, after analysing it, was:

Most people who die by euthanasia without explicit request are from a different demographic group to those who request euthanasia and that this group is more vulnerable ... that is, they're elderly, often incompetent patients with cardiovascular disease or cancer, often dying in hospitals.

On the face of it, very disturbing. This seems to be proof that the elderly are being euthanased without their consent in Belgium – an argument used by critics as evidence of the 'slippery slope'.

But it's what was omitted that is most telling. What Alex left out is the author's own conclusions which directly contradict what he claims they are saying:

We found that the enactment of the Belgian euthanasia law was followed by an increase in all types of medical end-of-life practices **with the exception of the use of lethal drugs without the patient's explicit request. No shift towards the use of life-ending drugs in vulnerable patient groups was observed.** [My emphasis]

That conclusion refutes absolutely the point Schadenberg makes. The studies show doctors were not using euthanasia drugs on vulnerable elderly patients.

It happens again with his analysis of the study 'Physician-Assisted Deaths under the Euthanasia Law in Belgium: A Population-Based Survey', appearing in the *Canadian Medical Association Journal* in 2010

After careful analysis, Schadenberg concludes that:

... the vulnerable die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime.

Once again, the original author's conclusions – peer-reviewed, unlike Schadenberg's – which directly contradict his, are omitted:

As was shown in other research, **no evidence was found to support the fear that, once euthanasia is legalised, the lives of elderly patients would be more likely to be ended with assistance of a physician.** According to our findings, patients of 80 or older were underrepresented among euthanasia cases compared with all deaths even after controlling for diagnosis and place of death. The number of reported euthanasia cases in this age group did not increase significantly over time. Older patients thus seem not to be at higher or increasing risk of euthanasia after legalisation.
[My emphasis]

There are other examples. For Professor Otolowski, author of a large body of recognised research in this field, Schadenberg's work is a cause for concern:

I'm really concerned that especially if he is travelling the world with this, on tour to make a strong case against legalisation of euthanasia, that these arguments will get traction and that there isn't enough exploring beyond the immediate surface message to understand what is he relying on – is it valid data – and identifying where the gaps are in the account. Because as soon as a close and systematic review of that work of his is undertaken you realise that it's highly problematic.

You could understand that some would, on a superficial read of his work, say 'Well this is just the evidence we've been wanting and needing to demonstrate that it would be dangerous to legalise euthanasia' and they would readily endorse it, but without recognising that there's so much more academic literature beyond his work and that in fact what he has done is to ignore a lot of the conclusions about practice in countries such as the Netherlands and Belgium. So, it's not an accurate portrayal of the current situation.

Why does this count in Australia? Because the foreword to Schadenberg's book is written by Kevin Andrews and it contains endorsements from half a dozen other Australian politicians, state and federal, as well. Their weight adds gloss to this counterfeit coin.

How easy, then, for this 'evidence' of a cold, heartless medical profession committing crimes in Belgium and the Netherlands, to slip onto the public record, uncontested? And once there to be repeated – perhaps even at this inquiry – until it is simply accepted as the 'truth' about what's happening under these laws?

You can learn more about Alex Schadenberg's misinformation techniques in SECTION F and hear him and Margaret Otlowski speaking on this subject on the podcast "[Better off Dead](#)" or [read the transcript \(Episode 7\)](#) at the Go Gentle Australia website.¹⁸⁶

¹⁸⁶ Andrew Denton, "Better Off Dead: #7 The Killing Fields of Belgium, Part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 1 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/7-the-killing-fields-of-belgium-belgium-part-1>

Misrepresenting Researcher Linda Ganzini to Create a False Picture About People with Depression Being Assisted to Die in Oregon

In Chapter 4 of his dissenting report to the Victorian Inquiry into End-Of-Life Choices, Final Report, MP Daniel Mulino turns to Linda Ganzini et al (2000) to support his argument that a significant proportion of people with depression are gaining access to assisted dying.¹⁸⁷

Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.

Mr Mulino's selection of words from Ganzini's report, leads the reader to conclude that, in the cohort of patients studied, 20 per cent who received assistance to die were suffering symptoms of depression.

But that's not true: it is, in fact, a clear misrepresentation of Ganzini's findings.

Mr Mulino's reference comes from page 559. The relevant section on this page reads:

Twenty percent of the patients had symptoms of depression, a finding that is similar to the reported prevalence of depression in patients with terminal illnesses.¹⁸⁸

Nowhere in the paragraph from which this sentence is extracted is there any suggestion that patients exhibiting symptoms of depression were given access to lethal drugs. A closer reading of the paper shows that 'the patients' referred to in the sentence are those who *requested* a prescription; not patients who received one.

Ganzini's paper tells us clearly and unequivocally how many of the 20 per cent of patients with symptoms of depression who requested assistance in dying were given a prescription for a lethal medication: None.¹⁸⁹

Further she sheds important light on a question raised earlier in the discussion by Mr Mulino, when he says:

Depression can impact on decision-making in a way that raises questions about the effectiveness of safeguards in relation to irreversible choices.¹⁹⁰

In the same paragraph from which he took Ganzini's sentence, she explains:

According to the physician's assessment, 20 percent of the patients had symptoms of depression, but 93 percent were competent to make medical decisions.¹⁹¹

Ganzini also contradicts Mulino's imputation that physicians in Oregon are providing lethal drugs to people with psychological disorders. Despite the fact most of these depressed patients were deemed competent, Ganzini's research shows that not one physician approved any one of them as a candidate for a lethal prescription.

Instead, patients with symptoms of depression were offered a suite of critical interventions, including, but not limited to, antidepressants and psychological and/or spiritual counselling.

¹⁸⁷ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.2 'Depression' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

¹⁸⁸ Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – <http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>

¹⁸⁹ Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – <https://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article> Ganzini states this specifically in the abstract of the article.

¹⁹⁰ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.2 'Depression' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

¹⁹¹ Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – <http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>

This was spelt out clearly in the abstract of Ganzini's study, published in the *New England Journal of Medicine*, which reads:

Twenty percent of the patients had symptoms of depression; **none of these patients received a prescription for a lethal medication.**¹⁹² [Our emphasis]

Contrast that with Mr Mulino's version:

Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.

In fact, in respect to the “instances of assisted dying” studied in Ganzini's paper, none of the patients had symptoms of depression. Her paper concludes:

... after two years of legalized assisted suicide in Oregon, we found little evidence that vulnerable groups have been given prescriptions for lethal medication in lieu of palliative care.

By selectively and misleadingly quoting published research, Mr Mulino fails his declared standard of a “balanced reading of the evidence”.

3.3 Tactic #3: Avoiding the Central Issue of Suffering by Defining it only as ‘Pain’

3.3.1 The Tactic

By minimising the suffering and trauma in Victoria and Western Australia as a result of current laws, opponents seek to raise a question in the public's mind: If there's not much of a problem, do we really need a VAD law to fix it?

A key method they use to do this is to narrow the problem by carefully defining it only in terms of ‘pain’. Pain, in most cases, can be ultimately dealt with by terminal sedation (though whether – and how well – that is applied, is another matter). ‘Suffering’, which is multi-faceted, cannot be easily treated by drugs, no matter how powerful.

3.3.2 Suffering versus Pain

In the second chapter of his dissenting Victorian report, ‘Almost All Cases of Pain Are Currently Manageable’, Daniel Mulino writes:

In almost all cases where a patient experiences a great deal of pain, including terminal cases, the symptoms of that pain can be managed by current best practice in pain relief and palliative care ... moreover, **the proportion of patients for whom pain is manageable is rising.**¹⁹³ [Our emphasis]

Beyond his admission that there are patients for whom pain is unmanageable, Mr Mulino's narrow focus on ‘pain’ sidesteps the reality that the symptoms of someone who is dying can cascade to the point of being unbearable. They will almost certainly include pain but, individually and collectively they make up something else – *suffering*.

Roger Hunt MD, “a specialist in Palliative Medicine over three decades” and “a Life Member of the Palliative Care Council”, explains how suffering is much more than just pain:

Dying people have varied and sometimes intense suffering, including physical, emotional, and existential suffering. All surveys of palliative patients, including those in most renowned

¹⁹² Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, ‘Physicians’ Experiences with the Oregon Death with Dignity Act’, *New England Journal of Medicine*, 342, 24 February 2000, pp. 557–563 – <http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>

¹⁹³ Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, June, 2017, Chapter 2.1 ‘Pain relief is effective in almost all cases’ – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

hospices, show they experience multiple concurrent symptoms. **Severe refractory symptoms, including suffocation, pain, nausea and confusion, requiring palliation with deep sedation, have been reported in up to 50% of palliative care patients.**¹⁹⁴ [Our emphasis]

This is supported by Australia's Palliative Care Outcomes Collaboration, which measures the following stressors faced by patients in the dying phase:¹⁹⁵

- Difficulty sleeping
- Appetite problems
- Nausea
- Bowel problems
- Breathing problems
- Fatigue
- Pain

In his book, *A Time to Die* (2017), urologist, Rodney Syme, a doctor who has assisted more than 100 patients seeking help to die, describes some of the ways in which dying people can suffer, none of which are directly related to physical pain:

Breathlessness: one of the commonest symptoms experienced by dying people but is virtually universal in chronic heart and respiratory disease and some neurological diseases such as MND. The essence of breathlessness is a sensation, a perception, bound up with fear. It quintessentially encompasses the concept of distress, as opposed to pain. He quotes Dr Martin Cohen describing breathlessness as 'an even more distressing symptom than severe pain'.¹⁹⁶

Cachexia ('wasting disease'): the slow disintegration of the body as the cancer cannibalises its metabolism.

Choking: Being unable to swallow your food due to an oesophageal blockage for fear that it will spill into your breathing tube and cause a bout of coughing and the fear of choking to death; Not even being able to swallow your own saliva, and having to repeatedly spit it out into a tissue.

Weight loss, asthenia (physical weakness) and anorexia (loss of appetite): Often associated with chronic nausea. Among the most common symptoms afflicting patients with advanced cancer ... this complex of ailments ranks at the top of physical causes of suffering and causes psych-social distress. The syndrome devastates family relations, and makes the patient dependent on the family and healthcare institutions.

Nausea and vomiting: Sometimes temporary and intermittent, as with chemotherapy, or persistent, as with many abdominal cancers.

Persistent diarrhoea: Perhaps alternating with constipation, or the persistent constipation and abdominal pain associated with palliative opioids.

Faecal and urinary incontinence. Untreatable ulcers: Puts the sufferer in an embarrassing and socially isolating state.¹⁹⁷

¹⁹⁴ Roger Hunt, "Submission 779: Inquiry into End of Life Choices", 11 August, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_779_-_Roger_Hunt.pdf

¹⁹⁵ Palliative Care Outcomes Collaboration, "Patient outcomes in palliative care: Results for Queensland January-June 2018", September 2018, Tables 32 and 33, pp.36-37 – <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow252860.pdf>

¹⁹⁶ Martin Cohen, et al, "Treatment of intractable dyspnoea - Clinical and ethical issues", *Cancer Investigation*, Vol. 10, 1992, p. 317.

¹⁹⁷ Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapters 5 and 6 'Suffering' and 'Palliative care'.

Dr Syme emphasises that, while many of these symptoms “may have no association with physical pain”, they are associated with “huge psychic pain” instead.¹⁹⁸

He explains how a combination of symptoms – to which he adds fatigue from both the disease and the burdensome nature of treatment; the many side-effects of multiple medications; loss of independence and control; depression; anxiety about what lies ahead; the sense of being a burden on those you love, and; the loss of enjoyment in life – may become increasingly intolerable over time, particularly if the only likelihood is that they will escalate.¹⁹⁹

American anthropologist Frances Norwood (*The Maintenance of Life*, 2009),²⁰⁰ describes the many losses experienced in suffering as “social death”:

There is something about a person that can die prior to the death of the body. Social death cannot be attributed to a single point in time nor to a strict set of behaviours. It is a series of losses – lost identity and lost ability to participate in social activities and relationships – that eventually culminates in a perceived disconnection from social life.²⁰¹

In his book, *The Nature of Suffering and the Goals of Medicine* (2004), Dr Eric Cassell, (Emeritus Professor of Public Health at the Weill Medical College of Cornell University, a member of the Institute of Medicine of the National Academy of Sciences, and a Master of the American College of Physicians) describes suffering as:

An affliction of the person, not the body²⁰²

Professor Cassel insists:

Not all suffering can be relieved, no matter how good the care ... and with even the very best treatment the suffering of some patients is terrible and unrelenting. Experienced clinicians know that even if you think you have seen the worst suffering possible, given time you will see someone suffering even more.²⁰³ [Our emphasis]

Syme sums it up this way:

These losses ... all relate to our fundamental existence as human beings, hence the term **existential suffering**. These existential losses are the very core of end-of-life suffering.²⁰⁴ [Our emphasis]

Pain can, in most cases, be dealt with by increased doses of sedatives. This is what opponents allude to when they say “almost all cases of pain are currently manageable”. But suffering, which is many-faceted, and at many levels, can go without effective relief for days, weeks, months, even years.

Suffering, not pain, is the heart of the matter. That’s why Palliative Care Australia, themselves, admit:

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.²⁰⁵

¹⁹⁸ Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapters 5 and 6 ‘Suffering’ and ‘Palliative care’.

¹⁹⁹ Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 4 ‘Advanced Incurable Illness’.

²⁰⁰ Frances Norwood, *The Maintenance of Life: Preventing Social Death Through Euthanasia Talk and End-of-Life Care - Lessons from the Netherlands*, Carolina Academic Press, 2009.

²⁰¹ Frances Norwood quoted in, Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 ‘Suffering’.

²⁰² Cassell, Eric, *The Nature of Suffering and the Goals of Medicine*, Oxford University Press, 2004, p.xii. Google Books edition, 19 July, 2017 – https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTq5uZZwC&redir_esc=y

²⁰³ Cassell, Eric, *The Nature of Suffering and the Goals of Medicine*, Oxford University Press, 2004, p.xii. Google Books edition, 19 July, 2017, p. 289 – https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTq5uZZwC&redir_esc=y

²⁰⁴ Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 ‘Suffering’.

²⁰⁵ Palliative Care Australia, “Policy statement on voluntary euthanasia”, Canberra, 2006, p.2.

3.3.3 Why Suffering, Not Pain, is the Worldwide Benchmark for VAD

While it suits opponents' purposes to focus only on pain (because pain can be largely dealt with by sedatives), it's relevant to note that no jurisdiction overseas uses this as a benchmark for eligibility to access their laws. In North America, it's terminal illness. In Europe, it's unbearable, hopeless and lasting suffering.

Pain is understood as too narrow a definition, and one which does not adequately address the complexities of dying.

There were many testimonies about suffering offered to the Victorian and Western Australian committees; people whom current laws fail to protect. These included testimony from Victorian Coroner, John Olle, of violent and lonely suicides as a result of such suffering, happening in Victoria at the rate of one a week.²⁰⁶

Yet opponents of VAD rarely mention them. It is relevant to ask why – for individuals and groups who claim to represent the needs of the vulnerable – these cases are unimportant?

3.3.4 What Suffering Looks Like

Lawrie Daniel had advanced multiple sclerosis. He took his life in 2016 because he could no longer live with his untreatable condition. This heartbreaking letter to his wife and children illustrates the deep suffering and distress that is beyond pain that Australians who have terminal and debilitating illnesses experience.

[Watch the video of Lawrie's last letter:](#)

Figure 14: Lawrie's Last Letter (Video) ²⁰⁷



²⁰⁶ John Olle (Coroner) evidence to Standing Committee on Legal and Social Issues, Transcript: "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 7 October 2015, p. 4, 9 July, 2017 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

Coroner Olle, for example, cites the case of an elderly man with advanced prostate cancer who killed himself with a nail gun.

²⁰⁷ Lawrie Daniel, "Lawrie's Last Letter", YouTube video, Go Gentle Australia, 3 August, 2017 – https://www.youtube.com/watch?v=BQifyG_LDmY&list=PLXQBekmhJGYy2PryxZ-wgxp_aso0PJYL-

3.4 Tactic #4: Minimising Patient Distress: Assertions that ‘Very Few Ask to Die’

3.4.1 The Tactic

Opponents of VAD seek to minimise the number of ‘problematic cases’ by pointing to doctors and palliative care physicians who say they have rarely been asked for help to die.

In his Victorian dissenting report, Mr Mulino, for example, quotes Professor Peter Hudson, Director of Palliative Care at St Vincent’s Hospital:

... less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia.²⁰⁸

He also cites Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health in Melbourne.²⁰⁹

Putting aside that it is often nurses who, as primary caregivers, receive requests to die,²¹⁰ research from palliative care physicians shows that requests to die are not uncommon.

Roger Hunt showed that up to 25 per cent of patients considered a hastened death,²¹¹ and, according to Dr Hunt, about 5 per cent asked for it ‘earnestly’.²¹²

In 2016 research by Australian palliative care physician Dr Linda Sheahan showed that:

- **97% of palliative care physicians had faced a request for assisted death**
- 80% of those requests came from a patient – almost half of those from a patient in concert with their family
- 15% of palliative care physicians had requests at least weekly for assisted dying, and another 27% at least monthly, and that;
- 30% of physicians were uncomfortable with such requests.²¹³

3.4.2 Patients in Faith-Based Palliative Care Are Discouraged from Seeking Help to Die

Professor Hudson and Dr Michael appear regularly in reports from opponents of VAD. Yet these rarely reveal that they represent Catholic healthcare providers whose central tenet – “neither prolong nor hasten death” – puts them in opposition, both as a matter of policy and philosophy, to assisted dying. As Professor Hudson explained in his evidence to the Victorian Committee:

Being a Catholic institution, St Vincent’s position is quite clear. It does not condone euthanasia.²¹⁴

²⁰⁸ Peter Hudson in Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, June, 2017, Chapter 2.3 ‘Very few people ask to be killed – especially if they are aware of care options’ - https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²⁰⁹ Natasha Michael quoted in Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, June, 2017, Section 2.3 ‘Very few people ask to be killed – especially if they are aware of care options’, viewed 19 July 2017 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²¹⁰ Coral Levett, former President of the Australian Nursing & Midwifery Federation explains that patients’ requests for euthanasia are often made to nurses, not doctors. If nurses know, from experience, that doctors will not accede to such requests, there is no point in passing them on. Ms Levett said: ‘I would go the pan room and cry for 10 minutes because I didn’t know what to do or say. I knew I couldn’t do it. There was nothing I could do about it. Saying that to a patient who is begging you to die doesn’t help. It doesn’t change their view to tell them that it’s against the law and that there is nothing you can do. They don’t see anything other than their own distress and their own suffering. Sometimes you just had to sit there and hold the hand of the person dying so that they could squeeze it and ease their own pain.’ Coral Levett, on Andrew Denton, ‘Better Off Dead: #4 It can never be perfect, so why try and improve it?’, podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 February, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/4-it-can-never-be-perfect-so-why-try-and-improve-it>.

²¹¹ Roger Hunt, Palliative Medicine, 1995, cited in Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 6 ‘Palliative Care’.

²¹² Roger Hunt, ‘Roger Hunt: Terminally ill South Australians deserve more than being left to die in agonising, debilitating pain’, The Advertiser, Adelaide, 15 November, 2016 – <http://www.adelaidenow.com.au/news/opinion/roger-hunt-terminally-ill-south-australians-deserve-more-than-being-left-to-die-in-agonising-debilitating-pain/news-story/d5990e80c333e355a99d70991c8e3ed0>

²¹³ Linda Sheahan, ‘Exploring the interface between ‘physician-assisted death’ and palliative care: cross-sectional data from Australasian palliative care specialists’, Internal Medicine Journal, 46(4), 2016, pp.443-51 – <https://www.ncbi.nlm.nih.gov/pubmed/26762669>

²¹⁴ Peter Hudson evidence given to Standing Committee on Legal and Social Issues, Transcript: ‘Inquiry into end-of-life choices’, Parliament of Victoria, Melbourne, 24 February, 2016, p.10 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI-Hudson-Boughey-Philip-End-of-life_choices_24_February_2016-FINAL.pdf

Speaking to the Victorian Inquiry, Dr Michael explained that when a person says that their suffering is “so unbearable [that] I want to die”, the solution is not to assist them, but to ask:

How can I help you with these factors that are making you feel that death has to be the better option?²¹⁵

This position has the practical effect of quashing any conversation patients in a religious healthcare institution, (or under the care of a physician with strong religious beliefs), may want to have about assistance to die.

Professor of Sociology at the University of NSW Alex Broom spent six months ‘embedded’ in a Catholic hospice to observe what the end-of-life experience was like for patients. While acknowledging the many benefits the hospice brought to patients and their families, he observed a “once-size-fits-all” moral and ethical code:

What people don’t realise is that on entering into the hospice you’re entering into a contract, essentially, about how you can die.

Hospices in Australia have a set of parameters around what is acceptable and what is ethical, and those are embedded in a particular series of moral structures which have religious underpinnings and certain ideas about what is okay or not okay and the nature of suffering.²¹⁶

The disempowered situation in which patients find themselves in religious healthcare institutions was confirmed by Dr Philip Redelman, a palliative care physician at St Vincent’s Sacred Heart Hospice in Sydney:

Look, you have to understand that it goes something like this in the hospice – you meet people and they say, ‘I wish it was over tomorrow’, and they say, ‘But you wouldn’t do that anyway’. I’ve already got my excuse before I even open my mouth ... once you come into hospital you lose control; you can’t do anything about it.²¹⁷

It is important to keep in mind that these are people who are dying and at their most vulnerable. Faced with an institution on which they are entirely dependent, and which fundamentally objects to any request for help to die, it is little wonder that they find it hard to ask.

3.5 Tactic #5: Undisclosed Bias of Expert Sources

3.5.1 The Tactic

Critics of VE/VAD fill official submissions to inquiries with ‘expert testimony’, without declaring the experts’ strong bias against Voluntary Assisted Dying, or towards the Catholic Church and its values, most particularly the sanctity of life. A reminder of what those values are:

According to the ‘[Charter for Health Care Workers](#)’, released by the Vatican in 1995:

²¹⁵ Natasha Michael in Standing Committee on Legal and Social Issues, “Inquiry into end-of-life choices”, Parliament of Victoria, Melbourne, 16 September, 2015, p.9 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

²¹⁶ Alex Broom in Andrew Denton, “Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1”, podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death> Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

²¹⁷ Philip Redelman in Andrew Denton, “Better Off Dead: #10 Neither hasten nor prolong death: Palliative care in Australia part 1”, podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March 2016, (audio) – <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death> Transcript at Go Gentle Australia website – <http://www.gogentleaustralia.org.au/transcripts2>

The Church ... has always seen medicine as an important support for its own redeeming mission to humanity.

- It follows that the work of health care workers is a sharing in the pastoral and evangelising work of the Church.
- Borne "in close union with the sufferings of Jesus", sickness and suffering assume "an extraordinary spiritual fruitfulness".
- For the Christian, pain has a lofty penitential and salvific meaning.
- To help one to die means to help him to live intensely the final experience of his life.
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.
- Death, then, must be evangelised: The Gospel must be announced to the dying person.

Example 1: Palliative Care Victoria's Submission to the Victorian Inquiry into End-of-Life Choices, 'Living, Dying & Grieving Well'

Described as an "in depth consideration of the issue", based on "consultations with our members, discussions with international colleagues, and reference to available evidence", this is, on one level, a fully-understandable 'sell' for the virtues of palliative care and the need for it to be better-resourced.

But on a deeper level, it is an entirely partisan anti-euthanasia document badged with all the authority of Palliative Care Victoria having given the issue "in-depth consideration".

The first tell is in the footnotes.

Look carefully and you'll see that many of the key sources while they may look neutral or 'scientific' are actually deeply committed anti-euthanasia campaigners from around the world. Alex Schadenberg isn't there, but many of his arguments and associates are, including:

- High-profile anti-euthanasia campaigner and academic Professor Margaret Somerville, is extensively quoted.
- Anti-euthanasia campaigner Emanuel Ezekiel, from the Anscombe Bioethics Centre, Oxford, UK – a Roman Catholic academic institute.
- The European Institute of Bioethics – the go-to people in Europe when media need an anti-euthanasia quote.
- Brian Pollard, a frequent contributor to the anti-euthanasia forum Adelaide Centre For Bioethics and Culture.
- Professor Theo Boer, a former Euthanasia Review Committee member in the Netherlands, now a critic.
- As well as individual, unnamed doctors in Belgium and the Netherlands who oppose the laws.

Of course, there's nothing wrong with any of these people being cited. But because absolutely **no-one** is quoted to address their criticisms, the picture that is painted about the systems in Belgium, the Netherlands, and Oregon, is deliberately distorted.

Example 2: Dissenting report to the Victorian ‘Inquiry into End-Of-Life Choices, Final Report’, by MP Daniel Mulino

Having found the majority report wanting on the grounds that, in his view, it did not demonstrate a “balanced reading of the evidence”, Mr Mulino populated his dissenting report with the following key sources:

Dr David Kissane

In his discussion on the Northern Territory and undiagnosed depression in terminally ill patients, Mr Mulino introduces us to Dr David Kissane.²¹⁸ Dr Kissane features five times in Mr Mulino’s footnotes. Yet, there is no disclosure that Dr Kissane is a ‘Knight of Obedience’ in the Australian Association of the Order of Malta.^{219 220}

According to the Annual Review of this Catholic religious order, in 2014, the ‘continuous pledge’ of each Knight and Dame is:

... to keep faithful to the traditions of our Order, to practice and defend our faith against the enemies of religion.²²¹

Professor Etienne Montero (aka Montero Redondo)

Professor Etienne Montero, is introduced in Mr Mulino’s Chapter 4.3.2, ‘Non-legislative and informal extensions within an existing frameworks’, to support Mr Mulino’s ‘slippery slope’ argument. Mr Montero is central to Mr Mulino’s arguments. He appears in 12 of Mr Mulino’s footnotes. Yet, not once does Mr Mulino disclose that Professor Montero also holds a position as an ordained priest in the order of Opus Dei.^{222 223}

At Professor Montero’s 2017 ordination, the ordaining cardinal:

... invited the new priests to be ‘priests’-priests, priests one hundred percent, as your holy Founder Saint Josemaria used to say. Exercise your priesthood with deep joy and ardent faith ... It doesn’t matter what sort of ministry is entrusted to you; always and everywhere you are called to build up Opus Dei, the Work of God, in humility, obedience and charity’.

Neither does Mr Mulino mention that Professor Montero’s evidence to the Court of British Columbia (in the *Carter vs Canada* case which paved the way for that country’s PAD law), was found by the judge to be largely irrelevant and unconvincing.

Dr Kathleen Foley

Dr Foley (and her co-writer Dr Hendin) are introduced to us through their selective telling of the story of Kate Cheney’s physician assisted death in Oregon. Mr Mulino relies heavily on evidence and opinions from Doctors Foley and Hendin, mentioning them 12 times in his footnotes. Yet, there is no disclosure of Dr Foley’s 2017 appointment by Pope Francis to the Pontifical Academy of Life, a bio-ethical advisory body composed of pro-life, mostly Catholic, anti-choice doctors, scientists, professors and ethicists.²²⁴

²¹⁸ Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, “Inquiry into end of life choices: Final Report”, June, 2017, Chapter 4.5.5 ‘Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: the Northern Territory’ – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²¹⁹ Dr Ian Marshall, ‘Message from the President’, “Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta”, 2014, p. 6 – https://issuu.com/australianhospitalier/docs/2014_20australian_20hospitalier_20-

²²⁰ The Hon. Sir James Gobbo, ‘Report of the Sub Priory’, in “Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta”, 2014, p. 8 – https://issuu.com/australianhospitalier/docs/2014_20australian_20hospitalier_20-

²²¹ “Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta”, ‘Welcome’, 2014, p.3 – https://issuu.com/australianhospitalier/docs/2014_20australian_20hospitalier_20-

²²² Opus Dei, “Cardinal Bertello ordains 31 priests from 16 countries”, 29 April, 2017 – <http://opusdei.org.au/en-au/article/ordinations-priestly-opus-dei-2017/>

²²³ Etienne Montero Redondo, Staff Directory Page, University of Namur, Belgium – https://directory.unamur.be/staff/emontero/publications?ordering=typeClassification&descending=True&_LOCALE_=en Included to verify that the Etienne Montero Redondo mentioned by Opus Dei is the same person referenced by Mulino.

²²⁴ Junno Arch Esteves, “Pope names members for renewed Pontifical Academy for Life”, Catholic News Service, 27 July, 2017 – <https://www.ncronline.org/news/vatican/pope-names-members-renewed-pontifical-academy-life>

Professor Alan Johnson

Mr Mulino presents evidence provided to the House of Lords Select Committee on Assisted Dying by the late Professor Alan Johnson.²²⁵ Professor Johnson's position as Chairman of the ICMDA (the Association of National Christian Medical and Dental Societies), or the fact that the members of this organisation practice 'Christian medicine', are not disclosed.

In 2001, Professor Johnson spoke at Christian Medical Fellowship's Juniors' National Conference where he "expounded", over three days, "on godly wisdom in three highly illuminating talks".²²⁶

European Institute of Bioethics

Mr Mulino's discussion on voluntary euthanasia in Belgium is informed by insights from the European Institute of Bioethics (EIB), specifically to support his assertion that euthanasia is becoming "normalised".²²⁷

Founded in Brussels in 2001, the EIB is self-described as:

... a private initiative of a group of citizens (physicians, jurists, and scientists) who are closely interested in significant advances in medicine and biology, which confer on humankind unprecedented control over the course of human life.²²⁸

The EIB's goals are to inform the general public and influence policy makers on bioethical issues. But, says a report commissioned by European member of parliament Heidi Hautala, this is done from a firmly anti-choice perspective.²²⁹

Members of the EIB's Honour Committee include MEPs Miroslav Mikolasik and Anna Zaborska, both members of the Christian Democrats.

It appears the EIB is a front for a pro-life, anti-choice, astro-turf, faith-based lobby group.

The report prepared for Ms Hautala also reveals links between the EIB and another anti-choice group, Alliance Vita. According to the report, Alliance Vita "gained notoriety due to its stance against same-sex marriage and misleading websites presenting anti-abortion propaganda as 'counselling' to pregnant teenagers". In 2016, Alliance Vita and the European Institute of Bioethics were operating out of the same premises in Brussels.

Vermont Alliance for Ethical Health Care

In his discussion on Depression in Chapter 4.8, under the heading Noteworthy Independent Cases, Mr Mulino refers the reader to the Vermont Alliance for Ethical Health Care for additional information on the story of the death of Michael Freeland in Oregon.

Like the EIB, above, the Vermont Alliance for Ethical Health Care is a faith-centred group of medical doctors. Its President Dr Robert D. Orr was honoured in 2010 with the 'Servant of Christ' Award from the Christian Medical and Dental Associations.^{230 231}

²²⁵ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.6 'Summary of evidence in relation to vulnerable people' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²²⁶ Liz Croton, "Beyond the Bleep 2001 - Wisdom Which Works", in Christian Medical Fellowship Newsletter, No. 161, October, 2001, p.3 – <http://admin.cmf.org.uk/pdf/cmfnews/cmf161.pdf>

²²⁷ Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.4.1 'Belgium' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²²⁸ European Institute of Bioethics, website – <http://www.ieb-eib.org/en/>

²²⁹ Elena Zacharenko, "Perspectives on anti-choice lobbying: Study for policy makers on opposition to sexual and reproductive health rights in Europe", report commission by Heidi Hautala, Member of the European Parliament, Brussels, 24 November, 2016 – http://www.heidihautala.fi/wp-content/uploads/2017/01/SRHR-Europe-Study_-Elena-Zacharenko.pdf

²³⁰ Vermont Alliance for Ethical Health Care, 'About Us', website – <http://www.vaeh.org/who-we-are/>

²³¹ Center for Bioethics and Human Dignity, "Who is Robert D Orr?", undated – <https://cbhd.org/orr-fellowship/robert-d-orr>

3.5.2 The Danger of Using Expert Sources with an Undeclared Bias

As Neil Francis argued on ABC's *Religion and Ethics*, while the majority of Australian Catholics and Protestant Christians *support* voluntary euthanasia, most of the opposition *still* comes from faith-based groups and individuals. Francis uses statistical evidence to show that:

... while a substantial majority of Australians support assisted dying, almost all the opposition to it is connected with religion – particularly among the most religious, who represent a small minority of the population' ²³²

There is no doubt many of Palliative Care Victoria's – and Mr Mulino's – sources are highly trained medical professionals and academics. It is appropriate that their perspective on this complex issue be heard.

But to pass off documents as a “balanced reading of the evidence” or an “in depth consideration of the issue” when, in fact, they are dominated by deeply partisan anti-VAD activists is dishonest.

More than that, it undermines genuine attempts by our parliaments to properly address end-of-life care in Australia.

²³² Neil Francis, "Opposition to Assisted Dying in Australia is Largely Religious, and Shrinking", ABC Religion and Ethics, 25 July, 2017 – <http://www.abc.net.au/religion/articles/2017/07/25/4707589.htm>

Part F

A Propaganda Case Study

Fatal Flaws

Fatal Flaws is a Canadian documentary film intended to cast a dark shadow over VAD. It is written, directed and fronted by Kevin Dunn – an apparently affable investigative reporter in the mould of *Bowling for Columbine*’s Michael Moore.

Excerpts of the documentary were aired on commercial TV in Western Australia in 2018 and shown to MPs in Canberra, where its arguments are believed to have persuaded at least one Senator to withdraw support for a private member’s bill to allow Territories to pass their own laws on VAD.



The Australian anti-euthanasia lobby group HOPE is now using the film as part of its messaging. It is also likely to be distributed in Queensland

During the course of the hour-and-20-minute-long film, Dunn embarks on a 50,000km journey, visiting Newfoundland, the Netherlands, Belgium and the United States, “in search of answers to questions about voluntary euthanasia and voluntary assisted dying”.

The film begins with Dunn's elderly father, who is in treatment for advanced colon cancer. Based on his dad's plight, Dunn poses several serious questions:

"What are [these laws] really saying to people with a terminal illness?"

"... how do these laws affect society, over time?"

"... is there a side to this story we *haven't* heard yet?"

"Where does it end? And have we gone too far?"

"Is it *really* about 'freedom'? About 'dignity'? Is everything we've heard about euthanasia dead wrong?"

Over the course of the film, Dunn seeks testimony from 'experts' – doctors, psychologists, journalists and politicians. He also interviews a number of 'ordinary' people who provide harrowing first-hand accounts of how voluntary assisted dying and euthanasia have affected them negatively.

These include a story of a young Nova Scotian woman with both physical and mental disabilities who was, allegedly, pressured to consider euthanasia in Canada in 2016; an alleged case of euthanasia without consent of a 94-year-old Dutch woman with pneumonia; a disability rights advocate, who recounts an incident in 2010 in which he felt pressured to forego life-saving antibiotics; and the reporter, himself, who meets a deeply depressed young woman in the Netherlands who tells of her wish to die after a long and unsuccessful treatment journey of serious mental health problems, yet wonders why "she seems so happy".

At face value, *Fatal Flaws* is persuasive. These seem to be compelling testimonies: hearing them encourages the viewer to question whether VE/VAD puts vulnerable groups at risk and is a recipe for elder abuse; the laws inevitably lead to a "tsunami of death" as they are broadened, weakened or ignored and; are even necessary given the existence of an 'alternative' of palliative care.

In this regard, the film achieves what it sets out to do – it sows fear, uncertainty and doubt about VAD in the minds of the viewer. A trailer for the film can be seen [here](#).

But *Fatal Flaws* is not what it seems. It is made by, and represents the views of, deeply conservative warriors of the Church.

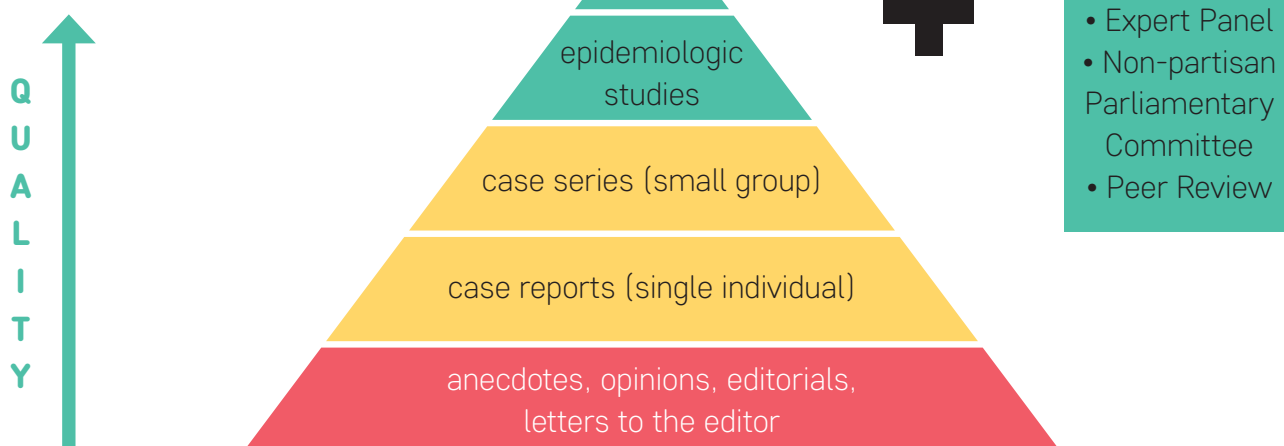
What it presents as 'evidence' is little more than anecdote and opinion, none peer-reviewed or independently tested.

1. HOW RELIABLE IS THE EVIDENCE IN *FATAL FLAWS*?

As outlined elsewhere in this submission, there are recognised methods for establishing and verifying types of evidence.

During the Victorian debate on VAD in 2017, QUT law professors Ben White and Lindy Willmott and law lecturer Andrew McGee advised politicians (and the public) to consider the comparative weight of evidence when forming their conclusions about VAD.²³³ They presented a 'scale' of reliability for evidence, as outlined below:

**Higher up pyramid + tested =
Greater reliability**



Assessed against this scale of reliability, the 'evidence' presented in *Fatal Flaws* rarely moves beyond the very bottom of the pyramid:

- it is not peer-reviewed
- it is not tested by a court, expert panel, or non-partisan parliamentary committee
- it does not show any systemic abuse
- it does not offer any further proof other than anecdotes or opinions.

Instead, *Fatal Flaws* focuses on other techniques. These include:

1.1 Arguing at the boundaries and 'the Straw Man'

Fatal Flaws locates its arguments at the farthest boundaries of VE/VAD law. Dunn never looks at how VE/VAD works for the vast majority of patients who utilise death with dignity laws in North America and Europe. Instead, he focuses on patients with dementia, disabilities and mental illnesses – people who (unless they are also terminally ill) do not have access to VE/VAD under Canadian, US or Australian law and represent only a tiny percentage of euthanasia deaths in Europe. In short, these are 'straw man' arguments.

For example, in 2017, 76.9 per cent of those who used the Death with Dignity (DWD) law in Oregon had terminal cancer (78.9 per cent the year before). Yet Dunn does not interview a single patient with terminal cancer in *Fatal Flaws*.²³⁴

In *Fatal Flaws*, Dunn is arguing against a law that doesn't exist, and is not even proposed, in Australia.

²³³ White, Ben, Lindy Willmott and Andrew McGee, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", *The Conversation*, 20 September, 2017 – <https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195>

²³⁴ Death with Dignity, "Annual Oregon Death with Dignity Reports", 2017–
<https://www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports/>

1.2 Red herrings

Information intended to mislead and distract appears routinely in *Fatal Flaws*. Dunn throws up a litany of discredited arguments against VE/VAD: the 'slippery slope'; that doctors will euthanase patients without their consent; that VAD will encourage more suicides and, that vulnerable people such as the elderly, disabled and mentally ill are at risk of abuse.

The truth is there is no reliable evidence that any of these threats exist. Not from meta analyses, systematic reviews or epidemiological studies, nor from any of the comprehensive and forensic parliamentary and judicial inquiries that have assessed them. All have concluded that elderly people, people with disabilities and people with mental illness have not been made more vulnerable by VE/VAD laws (See PART D, pages 61–62 of this Submission.) Under the guise of defending vulnerable people, it is *anti-VAD campaigners like Dunn* who are exploiting them by using fear-mongering campaigns to advance their agenda.

This appears to be a deliberate tactic. Mid-way through the film, Dunn interviews anti-euthanasia advocate Nancy Elliott, a US 'law-maker' who worries about assisted dying and its 'slippery slope'. In 2015, Ms Elliott was a keynote speaker at an anti-euthanasia symposium (HOPE) in Adelaide. There she gave advice on how best to make politicians hesitate:

When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else.

Right now, the disability argument is really kicking it. It's very powerful. Will it always be powerful? We don't know. Two, three, four years from now that may have holes kicked in it, just for different reasons, so we have to be flexible.

Elder abuse? Elder abuse is excellent. There is nobody in the world that denies that there is elder abuse, and some of the people that are on the left that are most concerned about elder abuse but might be against us can be turned to our side by explaining that this gives another avenue, a very final avenue, to abuse an elder.²³⁵

More about Nancy Elliott later.

1.3 Unsubstantiated accounts

As well as 'expert testimony', *Fatal Flaws* relies heavily on accounts from apparently 'ordinary' people. These help to personalise the issue and build a sense of fear, outrage and distrust of the medical profession.

As mentioned earlier, anecdote can be a useful tool for illustrating proven facts. But when used as stand-alone evidence, as it is in *Fatal Flaws*, it is notoriously unreliable and sits at the very bottom of the scale of reliable evidence. Dunn makes no effort to independently verify any of the stories recounted in his film, nor does he establish they are anything more than isolated cases or opinions.

1.4 What is missing from *Fatal Flaws*

Conspicuous by its absence throughout the film is any reference to the monitoring and oversight authorities, the auditing processes they apply, and the results they obtain. It is beyond belief that a careful researcher like Dunn did not seek out these bodies for interview.

Presumably he could gauge nothing out of them suitable for his purposes.

²³⁵ Nancy Elliott, quoted in Andrew Denton, "Voices from the Frontline: Submission to Victorian Parliament Legal and Social Issues Committee Inquiry into End of Life Choices", Submission 969, Victorian Parliament, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_969_-_Andrew_Denton.pdf

2. FATAL FLAWS: NOT WHAT IT SEEMS

Fatal Flaws is a slickly produced piece of filmmaking. But it is in no way a balanced or credible investigation despite its attempts to appear as one.

Perhaps most telling is Dunn's failure to inform his viewers of the source of his own opposition to VAD.

Throughout the entirety of his film he never once reveals that he is a staunch Catholic and son of Canadian Catholic 'pro-life' activists, and that he is head of his own pro-life media company.²³⁶

In an interview with a Catholic news network, Dunn explained how his company, Dunn Media, was founded:

... When I turned 50, I said to the Lord, I said, 'Lord, you know I'm doing all of this work and raising this family and I'm getting to mass and doing – but I want to do more.'

And a few people talked to me: 'Could you do more for pro-life?'

And I thought, 'You know what? I'll do this!'

That's where the impetus came. (Starts at 5:59) ²³⁷

In an interview with 'Jim and Joy' on the EWTN Catholic news network, Dunn reveals *Fatal Flaws* was funded by the Euthanasia Prevention Coalition (EPC), an organisation founded under the auspices of the Roman Catholic Diocese of London, Ontario and managed by its international chair, **Alex Schadenberg**.²³⁸

Schadenberg is Dunn's co-executive producer on *Fatal Flaws* and it was Schadenberg who offered to finance the film.

He is the author of the book *Exposing Vulnerable People to Euthanasia and Assisted Suicide* which selectively quotes from official reports to make fraudulent claims that doctors in Europe are using euthanasia laws to kill elderly people without their consent. (See PART E, pp.87–89).

Fatal Flaws seeks to make the same claims – claims that have been [debunked here](#).²³⁹

Like Dunn, Schadenberg is also the son of Canadian Catholic pro-life pioneers.²⁴⁰ In 2006 he was the recipient of the Archbishop Adam Exner Award for Catholic Excellence in Public Life.²⁴¹ It is no coincidence that Dunn and Schadenberg, like many of the 'experts' arguing against VAD in *Fatal Flaws*, are also committed opponents of abortion.

Both are using their time and money to defend the values of their Church, most particularly the sanctity of life. When it comes to end of life, it is worth reminding ourselves what those values are:

According to the 'Charter for Health Care Workers'²⁴², released by the Vatican in 1995:

- The Church ... has always seen medicine as an important support for its own redeeming mission to humanity.

²³⁶ Conlon, Mickey, "Dunn family lives pro-life message at home and work", Catholic Register, 3 December, 2016 –

<https://www.catholicregister.org/features/life-family/item/23754-dunn-family-lives-pro-life-message-at-home-and-work>

²³⁷ Dunn, Kevin, "Kevin Dunn, Part I", At Home with Jim and Joy, EWTN, 23 January, 2016 – <https://www.youtube.com/watch?v=VgNRa08oo6k>

²³⁸ Pete Vere, "Alex Schadenberg: Battling the Onset of Euthanasia", The Interim, 19 July, 2007 –

<http://www.theinterim.com/issues/euthanasia-suicide/alex-schadenberg-battling-the-onset-of-euthanasia/>

²³⁹ Kenneth Chamberle, "Separating fact from fiction about euthanasia in Belgium", The Conversation, 22 April, 2016 –

<https://theconversation.com/separating-fact-from-fiction-about-euthanasia-in-belgium-58203>

²⁴⁰ Pete Vere, "Alex Schadenberg: battling the onset of euthanasia", The Interim, 19 July, 2007 –

<http://www.theinterim.com/issues/euthanasia-suicide/alex-schadenberg-battling-the-onset-of-euthanasia/>

²⁴¹ Jean Ko Din, "Schadenberg honoured with Exner Award", Prairie Messenger: Catholic Journal, 8 June, 2016 –

http://www.prairiemessenger.ca/16_06_08/cnews_16_06_08_2.html

²⁴² The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 –

http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

- It follows that the work of health care workers is a sharing in the pastoral and evangelising work of the Church.
- Borne 'in close union with the sufferings of Jesus', sickness and suffering assume 'an extraordinary spiritual fruitfulness'.
- For the Christian, pain has a lofty penitential and salvific meaning.
- To help one to die means to help him to live intensely the final experience of his life.
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.
- Death, then, must be evangelised: The Gospel must be announced to the dying person.

3. UNDECLARED BIAS: WHO IS IN FATAL FLAWS?

The hidden agenda of the filmmakers extends to the majority of the 'experts' and 'ordinary' people Dunn interviews.

Though presented as neutral, like Dunn and Schadenberg many commentators are undeclared warriors for their faith.

Virtually all have close connections with religious institutions and pro-life groups. Some are on the public record propounding controversial views that are on the fringes of the political and scientific mainstream.

There is a clear pattern of their use throughout the film.

Dr William Toffler

Dr Toffler appears in *Fatal Flaws* as a professor emeritus at Oregon Health and Science University. He comments on the "euphemisms used to drive the pro VE/VAD debate" and what he describes as the conflict of interest inherent in doctors taking part in assisted dying.

What the film fails to disclose is that Toffler is a member of the Catholic Medical Association, and an ultraconservative, anti-euthanasia campaigner who has extreme views on a range of issues including abortion and contraception.

Dr Toffler believes contraception is "against God's plan" and abortion and suicide are sins.²⁴³

In 2017 he toured Australia, sponsored by Right to Life. During the visit, it was revealed that he was part of a small minority in the Oregon Medical Association who opposed a woman's right to choose abortion and did so because God told him so. He has opposed Oregon's Death with Dignity law since before its inception.

He has also publicly aligned himself with the widely discredited view that there is a link between abortion and breast cancer, a theory opposed by, among others, the Australian Medical Association²⁴⁴, the Cancer Council of Australia²⁴⁵ and the Breast Cancer Network, Australia.²⁴⁶

²⁴³ Emma Reynolds, "Anti-euthanasia campaigner touring Australia with some very extreme views", [news.com.au](https://www.news.com.au/lifestyle/health/health-problems/antieuthanasia-campaigner-touring-australia-with-some-very-extreme-views/news-story/feeb43fe98903ef73a21017c1dc7fc37), 28 June, 2017 – <https://www.news.com.au/lifestyle/health/health-problems/antieuthanasia-campaigner-touring-australia-with-some-very-extreme-views/news-story/feeb43fe98903ef73a21017c1dc7fc37>

²⁴⁴ Australian Medical Association, "Owler slams Minister for 'irresponsible' abortion remarks, AMA in Action, 19 August, 2014 – <https://ama.com.au/ausmed-features/ama-news?page=12>

²⁴⁵ Cancer Council, "Abortion does not cause breast cancer" – <https://www.cancercouncil.com.au/100629/cancer-information/general-information-cancer-information/cancer-questions-myths/medical-and-injuries/abortion-does-not-cause-breast-cancer/>

²⁴⁶ Breast Cancer Awareness Network (BCNA), "Myths about breast cancer" – <https://www.bcna.org.au/breast-health-awareness/myths-about-breast-cancer/>

Esmé Wiegman

Ms Wiegman is interviewed in *Fatal Flaws* as the CEO of the Dutch Patients Organisation. She expresses alarm about elderly people being coerced into ending their lives, and raises concerns about Dutch VE/VAD laws one day expanding to include people who are simply “tired of life”.

Dunn never tells the viewer that Wiegman is a former politician²⁴⁷ who was elected to parliament representing the Christian Union, an anti-LGBTQ, anti-abortion, bible-based party that formed after the merger of two right-wing political parties – the Reformatory Political Federation (RPF) and the Reformed Political League (GPV) – who believe in biblical-rule.

Catherine Glenn Foster

Ms Foster appears in *Fatal Flaws* as a lawyer and a “leading voice against assisted suicide in the USA”. Foster, the CEO of Americans United for Life, characterises her work as “about the value of life. It’s about caring, not killing”.

Dunn never mentions that Foster also has close professional links to both evangelical Christianity and Catholicism²⁴⁸ and is with the Charlotte Lozier Institute, an anti-abortion organisation.²⁴⁹

Interestingly, she previously worked for the Alliance Defense Fund (now the Alliance Defending Freedom) an organisation that has been described as “the 800-pound gorilla of the Christian right”²⁵⁰ and which the Southern Poverty Law Centre classifies as a hate group. The ADF has tried to recriminalise gay sex in the US.²⁵¹

Alexandra Snyder

Ms Snyder is interviewed by Dunn as “a lawyer fighting against the expansion of assisted dying laws” in the US. She is the CEO of Life Legal Defence Foundation, an organisation whose mission is “to give innocent and helpless human beings of any age, particularly unborn children, a trained and committed defense against the threat of death, and to support their advocates in the nation’s courtrooms”.²⁵²

She does not disclose that she is also an Evangelical Christian whose²⁵³ “passion for pro-life work was kindled while serving as a volunteer at a pregnancy resource center in southern California. She started out working one-on-one with clients and leading a post-abortion Bible study.”

Ms Snyder got her degree from Trinity, a private evangelical university which is part of the Evangelical Free Church of America, a group that vilifies LGBTQ people and believes homosexuality is a sin.

Annette Hanson

Dr Hanson, a forensic psychiatrist, is interviewed in *Fatal Flaws* to suggest that assisted dying is not about compassion or relieving suffering but “about changing the mindset of the medical profession” and making them “more comfortable about killing people”. She is the daughter of a Lutheran minister, a member of the Evangelical Lutheran Church in Minnesota, and her family are alumni of Augsburg University (associated with the Evangelical Lutheran Church).^{254 255}

²⁴⁷ Esmé Wiegman, Wikipedia – https://en.wikipedia.org/wiki/Esm%C3%A9_Wiegman

²⁴⁸ Evidence from numerous sources including Catherine Glenn Foster’s [LinkedIn page](#), comments made on her [public Facebook page](#), and her numerous educational and professional associations.

²⁴⁹ Catherine Glenn Foster, Lozier Institute – <https://lozierinstitute.org/team-member/catherine-glenn-foster/>

²⁵⁰ Alliance Defense Fund – Source Watch – https://www.sourcewatch.org/index.php/Alliance_Defense_Fund

²⁵¹ Equality Matters, “This Right-Wing Legal Powerhouse Wants to Make Gay Sex Illegal”, Huffpost, 19 November, 2015, updated 6 December, 2017 – https://www.huffingtonpost.com/entry/this-right-wing-legal-pow_b_6185878.html

²⁵² Alexandra Snyder, Executive Director, “Life Legal Defense Foundation” – <https://lifelegaldefensefoundation.org/about/key-staff/alexandra-snyder-executive-director/>

²⁵³ GodTube, “Alexandra Snyder and the Fight Against Abortion - Popular Christian Videos”, 2011 – <https://www.godtube.com/watch/?v=DLYDLPNX>

²⁵⁴ Chester E Hoversten, Obituary, Geni, 2015 – <https://www.geni.com/people/Chester-E-Hoversten-Rev/6000000039730984059>

²⁵⁵ Evidence from various links including Annette Hoversten-Hanson’s [LinkedIn profile](#) and [public Facebook page](#).

Dr Kenneth R Stevens

A radiation oncologist in Oregon, Dr Stevens tells Dunn of his concerns that an increasing number of people who are not terminally ill are choosing an assisted death, because they have “lost hope”.

Dunn fails to tell viewers that Dr Stevens belongs to the Church of the Latter-day Saints, also known as the Mormons.²⁵⁶ He is the son of missionary parents and is himself a two-time missionary. He got his degree from the University of Utah and identifies as a “Latter-day Saints Oncologist” [here](#).²⁵⁷

The Latter-day Saints are opposed to euthanasia as well as LGBTIQ people.

Dr Bud Pierce

Dr Pierce tells Dunn about his fears that doctors will be forced to participate in assisted dying despite their moral objections. He doesn't disclose that he is an active member of Salem First Christian Church and, in 2011, served as an elder of the church, chairing its stewardship committee.^{258 259}

Kees van der Staaij

While in the Netherlands, Dunn interviews Kees van der Staaij, a Dutch politician, about his fears that Dutch voluntary euthanasia laws are expanding, and leading to a “slippery slope”. Mr van der Staaij is the leader of a faith-based the Reformed Political Party ²⁶⁰, which believes in “organic suffrage” – i.e; restricted to the male heads of households. Women are not allowed to hold positions in the party, which strives towards a government totally based on the Bible.

Nancy Elliott

Ms Elliott is interviewed as a US politician who fears that if doctors are given the ability to participate in assisted dying “things will go the way they have in the Netherlands”. Elliot says she believes assisted dying is “state sanctioned killing”, and a development that gives “the government the right to decide who is deserving of death and who isn't”. Viewers are never told she is also chair of the American arm of the Euthanasia Prevention Coalition, which provided the film's funding. A staunch Christian, Elliot has said [elsewhere](#):

... this may be a political issue, but it is also a Christian issue. This is not just about politics. This issue, the church *owns* ...²⁶¹

Dr Benoit Beuselinck

Dr Beuselinck (Belgium) is quoted in *Fatal Flaws* as saying “we can manage all pain with palliative care, including palliative sedation”. He is a consultant oncologist of the Catholic University Hospitals of Leuven ²⁶² and works at Catholic University of Leuven.²⁶³

²⁵⁶ Holland, John and Frances J Storrs, “Interview with Kenneth R. Stevens, Jr., M.D., F.A.C.R.”, OHSU Digital Collections, 8 January, 2014 – <https://digitalcollections.ohsu.edu/concern/etds/02870w009>

²⁵⁷ Ken Stevens, “LDS Oregon Oncologist Speaks of the Tragedy of Physician Assisted Suicide”, originally published at Meridian Magazine, Church of Latter Day Saints, 4 November 2014 - (original link broken); the article is reproduced and referenced at the Mormon Lady blog – <http://en.mormonlady.se/2014/11/06/assisterat-sjalvmord-sparar-pengar-den-cyniska-sanningen-om-aktiv-dodshjalp/>

²⁵⁸ Bud Pierce - Wikipedia – https://en.wikipedia.org/wiki/Bud_Pierce

²⁵⁹ 76th Oregon Legislative Assembly 2011 Regular Session, “Senate Concurrent Resolution 4”, 2011 – <https://olis.leg.state.or.us/liz/2011R1/Downloads/MeasureDocument/SCR4>

²⁶⁰ Kees van der Staaij - Wikipedia – https://en.wikipedia.org/wiki/Kees_van_der_Staij

²⁶¹ Nancy Elliott, “Exposing the Lies Surrounding Euthanasia and Assisted Suicide and Why the Christian Should be in the Fight”, address to the Merrimack Valley Baptist Church (New Hampshire), 2 May, 2017, (audio - transcribed by us) – <https://mvbc.org/member-login>

²⁶² Simon Caldwell, “Palliative care nurses quit houses of euthanasia”, Catholic Herald, 18 January, 2018 – <http://catholicherald.co.uk/news/2018/01/18/palliative-care-nurses-quit-houses-of-euthanasia/>

²⁶³ Benoit Beuselinck - Wikipedia – https://en.wikipedia.org/wiki/KU_Leuven
Benoit Beuselinck, profile – https://www.researchgate.net/profile/Benoit_Beuselinck

Dr Charles Bentz

Dr Bentz (Oregon) does not disclose that he is employed by one of the biggest Catholic health care organisations in North America, the Providence St Vincent Medical Center²⁶⁴ which is run by Providence Health & Services, a not-for-profit Catholic health care system operating multiple hospitals across five states, with headquarters in Renton, Washington. Providence Health & Services was started by the Sisters of Providence (Montreal, Quebec) in 1859.

Here's [a video he did](#) for Illinois Right to Life.²⁶⁵

Alex Van Vuuren

Alex Van Vuuren is mentioned in the end credits of *Fatal Flaws* with a "special thanks". Van Vuuren is from Cry For Life, an organisation that asserts, among other things, that abortion rights mean "the trains to Auschwitz are still rolling".²⁶⁶

4. PUBLICLY DISCREDITED

The tactics used by Dunn and Schadenberg in *Fatal Flaws* are not only alarming, they are discredited.

During a study into the tactics of pro-life advocates, investigative reporters [Sofia Resnick & Sharona Coutts](#) discovered:

... the scientific and medical claims of these groups and individuals have been publicly discredited in episodes ranging from lying to the public, presenting false data in scientific journals, and being forced to retract articles that proved to be works of fiction presented as fact. Other doctors and professors ... [who] carry impressive credentials, appear to be apt in their fields ... However, fueled by their religious or political beliefs (or both), many of these professionals have testified in support of unproven or discredited theories.

... They create nonprofits, staffed with die-hard ideologues, and set about producing and promoting bogus science, to build the illusion of dissent or doubt over conclusions drawn by peer-reviewed scientific or medical research. They develop their own 'research findings' to suit their ideological views. Then they deploy scare tactics, all with the goal of passing laws that suit their agenda.

... It's a strategy that anti-choice activists have been working on for decades.²⁶⁷

This 'stealth strategy' is extensively employed by VE/VAD opponents worldwide. As Eli Stutsman, Portland attorney and primary author of Oregon's Death with Dignity Act, observes:

If our primary opponents were intellectually honest, they would admit that their opposition was faith based and would make a faith-based argument. But that doesn't resonate with the voters.²⁶⁸

²⁶⁴ Charles J Bentz, MD, Staff Profile, Providence Health & Services –

<https://www.providence.org/doctors/profile.aspx?name=charles+j+bentz&first=charles&middle=j&last=bentz&city=portland&id=198018>

²⁶⁵ Charles Bentz, "Dr. Charles Bentz: Physician Assisted Suicide", Illinois Right to Life, 10 April, 2018 –

https://www.youtube.com/watch?v=x_Kn3E5_q2k

²⁶⁶ Jor-El Godsey, "Cry for Life Conference", Heartbeat International – <https://www.heartbeatinternational.org/cry-for-life-update>

²⁶⁷ Sofia Resnick and Sharon Coutts, "Anti-Choice 'Science': The Big Tobacco of Our Time", *Rewire News*, 13 November, 2014 –

<https://rewire.news/article/2014/11/13/anti-choice-science-big-tobacco-time/>

²⁶⁸ Eli Stutsman, Eli, "It's not easy to kill yourself in Oregon. Certainly not as easy as opponents suggest", *Men's Health*, October, 2006 –

<https://tinyurl.com/y6pprrjg>

5. CONCLUSION

By any reasonable measure, *Fatal Flaws* fails the criteria by which information should be judged.

Virtually all Dunn's so-called 'evidence' of the threat posed by VE/VAD laws sits at the very bottom of the reliability scale.

This is in stark contrast to the numerous meta-analyses, systematic reviews, and peer-reviewed epidemiologic studies and case studies – tested by courts, expert panels and parliamentary inquiries – that have underlined the safety and effectiveness of assisted dying laws around the world.

The strategically hidden identities of the film's makers and participants; their undeclared, yet deeply conservative, pro-life views; and the failure to balance those views with other voices, makes the film intellectually dishonest and highly manipulative.

Part G

Evidence Considered By The Victorian Committee Into End-Of-Life Choices

In reaching its conclusion that:

... assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.²⁶⁹

what sources did the the Victorian Parliament's Legal and Social Issues Committee draw on?

1. PEER REVIEWED EVIDENCE

Firstly, there were the scores of publications and peer-reviewed academic papers listed in the Bibliography on pages 319–335 of the Report. These represented a range of views about VE and VAD. They included many papers providing long-term and wide-ranging research into the impact of these laws on vulnerable populations.

Evidence was drawn from papers from leading experts writing in a range of disciplines in a host of leading, peer reviewed journals. For example:

The Lancet

British Medical Journal

Journal of Pain and Symptom Management

Canadian Medical Association Journal

Journal of Medical Ethics

Journal of Clinical Ethics

Bioethics

Journal of Law, Medicine and Ethics

Social Science and Medicine

JAMA Internal Medicine

New England Journal of Medicine

²⁶⁹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.4 'The Committee's decision - An assisted dying framework', p. 212, – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

2. EVIDENCE FROM OTHER INDEPENDENT INQUIRIES

The committee also benefited from the work of other independent inquiries, both in Australia and internationally. Some were set up by governments. Some were judicial in nature. Others were established by independent think-tanks or academic institutions. Like the Victorian Inquiry, these inquiries were informed by peer-reviewed studies and evidence from primary sources.

They included:

- Udo Schüklenk's (2011) report on the Royal Society of Canada's Expert Panel on End-of-Life Decision-Making ²⁷⁰
- An expert legal analysis on the regulatory options in respect to VE and VAD legislation by QUT Law School academics Benjamin White and Linda Willmott (2012) ²⁷¹
- The report of the UK Commission on Assisted Dying (2011) ²⁷²
- The Québec Select Committee on Dying with Dignity report from the National Assembly of Quebec (2012) ²⁷³
- The final report from the External Panel on Options for a Legislative Response to Carter v. Canada, (2015) ²⁷⁴
- The final report from Canada's Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (2015) ²⁷⁵
- A bioethical report and recommendations on the Canadian hearing from the University of Toronto (2015) ²⁷⁶
- A report on a Patient-Centred Approach to Medical Assistance in Dying: A Patient-Centred Approach from Canada's Special Joint Committee on Physician-Assisted Dying (including a dissenting report) ²⁷⁷

Both the Victorian Committee and the Canadian Special Joint Committee (2016), also had the benefit of the most extensive independent inquiry ever held into VAD/VE laws and their safeguards. This was conducted by British Columbia Supreme Court Justice Lyn Smith in 2012.

Justice Smith cross examined, among others, academics, doctors, palliative care specialists, lawyers, activists and ethicists. She accepted into the court record the findings of the Royal Society of Canada's Expert Panel on End of Life Decision Making (2011) and the Quebec Select Committee on Dying with Dignity (2012). Both, having conducted lengthy public investigations into end-of-life choices and protection of the vulnerable, recommended a law for assisted dying.

²⁷⁰ Udo Schüklenk et al., "End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making", Bioethics, vol. 25, no. s1, 2011 – <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/>

²⁷¹ Lindy Willmott et al., "Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand", Journal of Law and Medicine, vol. 20, no. 4, 2013 – https://www.academia.edu/25506567/Withholding_and_withdrawal_of_futile_life-sustaining_treatment_Unilateral_medical_decision-making_in_Australia_and_New_Zealand

²⁷² The Commission on Assisted Dying, "The current legal status of assisted dying is inadequate and incoherent...", Demos, London, 2011 – https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_1_web_single-NEW_.pdf?1328113363

²⁷³ Select Committee on Dying with Dignity, "Dying with Dignity", National Assembly of Québec, Québec, 2012 – <http://www.assnat.qc.ca/en/travaux-parlementaires/commissions/CSMD/mandats/Mandat-12989/index.html>

²⁷⁴ Harvey Max Chochinov, et al., "Consultations on physician-assisted dying: Summary of results and key findings – Final report", External Panel on Options for a Legislative Response to Carter v. Canada, 2015 – <https://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/index.html>

²⁷⁵ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final report*, 30 November, 2015 – http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

²⁷⁶ University of Toronto Joint Centre for Bioethics Task Force on Physician Assisted Death, "After Carter v. Canada: Physician assisted death in Canada — Report and recommendations", University of Toronto, Toronto, Canada, 14 December, 2015 – <http://jcb.utoronto.ca/docs/JCB-PAD-TaskForce-Report-2015.pdf>

²⁷⁷ KK Ogilvie and R Oliphant, "Medical assistance in dying: A patient-centred approach – Report of the Special Joint Committee on Physician-Assisted Dying, Canadian Parliament, including a dissenting report", February, 2016 – <http://eol.law.dal.ca/wp-content/uploads/2016/05/Special-Joint-Committee-on-PAD-Final-Report.pdf>

After hearing all the evidence, for and against, Justice Smith concluded:

Empirical researchers and practitioners who have experience in those systems are of the view that they work well in protecting patients from abuse while allowing competent patients to choose the timing of their deaths.²⁷⁸

In their 2015 decision unanimously upholding Justice Smith's judgement on appeal, the Justices of the Canadian Supreme Court made note of the methodology that underpinned Justice Smith's conclusions:

The trial judge's findings were based on an exhaustive review of the extensive record before her. While the majority of the evidence was presented in affidavit form, a number of the expert witnesses were cross-examined, both prior to trial and before the trial judge. The record was voluminous: the trial judge canvassed evidence from Canada and from the permissive jurisdictions on medical ethics and current end-of-life practices, the risks associated with assisted suicide, and the feasibility of safeguards.

She reviewed the safeguards in place in each jurisdiction and considered the effectiveness of each regulatory regime. In each system, she found general compliance with regulations, though she noted some room for improvement. The evidence from Oregon and the Netherlands showed that a system can be designed to protect the socially vulnerable.

In conclusion, the Supreme Court found that the evidence established:

... [that the] predicted abuse and disproportionate impact on vulnerable populations has not materialized in Belgium, the Netherlands and Oregon.²⁷⁹

This deep archive of empirical research and literature, conducted and created by independent authorities laid a foundation for the Victorian Committee's conclusions.

3. EVIDENCE FROM PRIMARY SOURCES

Most powerful, however, was the knowledge gained by the committee from visiting Switzerland, the Netherlands, Oregon and Canada to learn firsthand how these laws operate. It is worth being reminded of just some of those the committee spoke with in these jurisdictions – this list is indicative, not exhaustive:

Legal

- Dr Frank Th. Petermann, President, Swiss Medical Lawyers Association
- Ms Maartje van der Linden, Legal Adviser, Directorate for Legal and Operational Affairs Ministry of Security and Justice
- Ms Jessica Prince, Senior Policy Adviser, Office of the Minister for Justice and Attorney General of Canada Parliament of Canada
- Ms Julia Nicol, Legal and Legislative Affairs Division, Parliamentary Information and Research Service, Library of Parliament, Parliament of Canada
- Mr Lane Shetterley, Chair, Oregon Law Commission

Medical

- Mr Eric van Wijlick, Senior Staff Member, Royal Dutch Medical Association (KNMG)

²⁷⁸ Carter v. Canada (Attorney General), 2012 BCSC 886, para. 685.

²⁷⁹ Carter v. Canada (Attorney General), 2012 BCSC 886, para. 684.

- Dr Karima Velji, President, Canadian Nurses Association; Member, Provincial-Territorial Expert Advisory Group on Physician Assisted Dying
- Mr Bryan Boehringer, Chief Executive Officer Oregon Medical Association

Psychiatry

- Dr Harvey Max Chochinov, MD, PhD, FRCPC, Distinguished Professor of Psychiatry, University of Manitoba, Director, Manitoba Palliative Care Research Unit; Chair, External Panel on Options for a Legislative Response to Carter v. Canada

Palliative Care

- Ms Barb Hansen, MA RN CWON, Chief Executive Officer, Oregon Hospice and Palliative Care Association

Ethical

- Mr Gert Van Dijk, Medical Ethicist, Royal Dutch Medical Association & Senior Ethics Adviser, Euthanasia Review Board

Government

- Dr Marianne Donker, Director, Public Health Department Ministry of Health, Welfare and Sports
- Ms Cynara Corbin, Committee Joint Clerk, Special Joint Committee on Physician-Assisted Dying Parliament of Canada
- Ms Barbara Kagedan, Senior Policy Adviser, Senate of Canada Parliament of Canada
- Senator Elizabeth Steiner Hayward MD, State Senator, District 17 Oregon State Legislature Family Physician and faculty member; Director OHSU Knight Cancer Institute; Breast Health Education Program Board member; Oregon Academy of Family Physicians
- Representative Mitch Greenlick, Chair, House Committee on Health Oregon State Legislature
- Ms Sandy Thiele-Cirka, Administrator, House Health Care Committee, Senate Health Care Committee Oregon State Legislature
- Dr Katrina Hedberg MD MPH, State Epidemiologist and State Health Officer, Oregon Public Health Division, Oregon Health Authority

Academic

- Professor Bregje Onwuteaka-Philipsen, End of Life Care, Research Institute for Health and Care Research, VU University Amsterdam

It should be noted that the Committee also spoke with opponents of these laws in overseas jurisdictions.²⁸⁰

The gathering of primary evidence emphasised to the committee the serious level of research and oversight which underpins the operation of existing VE and VAD laws. As the majority report noted of the Netherlands:

The Committee was impressed with the integration of research undertaken by universities and the provision of health services in the Netherlands. This research provides Dutch policy makers with detailed information about the treatment people receive at the end of life and how health services can be improved.

²⁸⁰ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.4 'The Committee's decision - an assisted dying framework', p. 213 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

Specifically, the Report says: "The Committee also met with opponents from overseas jurisdictions where assisted dying is legal, who expressed similar concerns [to those expressed by Australian opponents of the legislation]."

Repeated cross-sectional surveys of Dutch doctors undertaken every five years are particularly useful as they specify the number of deaths due to all end of life decision making. This includes assisted dying, as well as refusal of treatment, intensified alleviation of symptoms and ending of life without explicit request.²⁸¹

The combination of all these sources – independent committees of review, peer-reviewed academic literature, and primary evidence from those who work within VAD/VE regimes²⁸² – informed the Committee's majority conclusion that **there is *clear* evidence the robust safeguards in the proposed legislation²⁸³ will “protect patients from potential abuse”.**²⁸⁴

Finally, it is important to remember that, in all jurisdictions, the operation of these laws is subject to judicial and legislative review. It is deeply instructive then that in none of these societies has any attempt been made to wind back or repeal them.

²⁸¹ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.9.3 'Chair of end of life care', p.235. – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

²⁸² Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Appendix 4 'Legislation in jurisdictions that allow assisted dying', pp.283-287 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf
Specific safeguards are set out in Appendix 4.

²⁸³ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.5.3 'Criteria and safeguards' and 8.7.3 'Request must be properly considered', pp.217-227 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf
This section of the Report details the robust safeguards in the proposed legislation.

²⁸⁴ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June 2017, Section 1.2.3 'Overseas research', p.8 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf. Specifically, the Report says: *"The Committee heard about the robustness of the medical systems in place where assisted dying is legal. Each framework has rigorous safeguards to protect patients from potential abuse."*

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Appendix

In Their Own Words

When palliative care no longer works

WHAT THIS SECTION IS ABOUT

What follows is a collection of first-hand testimonies of suffering within our medical system.

In light of the 'Pyramid of Evidence Quality' (PART D, p.78) – which states that the second-least reliable source of evidence is 'case reports (individual)' – it is worth remembering that the suffering detailed in these pages has been shown to be systemic by the following:

- Statistical evidence gathered by Palliative Care Australia
- Multiple testimonies from doctors and nurses
- The Victorian Parliamentary Inquiry into End-Of-Life Choices (2016)
- The Western Australian Parliamentary Inquiry into End-Of-Life Choices (2018).

Further, many of the people whose testimonies you are about to read have either appeared before committees of inquiry, or would be prepared to do so in future if asked.

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Ailsa Rice – Husband.

One long and suffering week for him and his family. He begged me to find some way to help him go.

[He] accepted palliative care but [was] denied at the end the compassion we show to our beloved animals.

Elaine Buchan – Father.

His long suffering was painful to watch **as he withered away in palliative care for months.**

The effect on my mother, sisters and brothers was heart wrenching ... the pain of seeing him slowly deteriorate to a birdlike form crushed us all. It was a totally undignified ending for him and a lasting picture of our father which was seared into each of our memories.

Janice Stanley – Mother. 103. Starving herself. 70. Facing further cancer.

My late dear Mother, at 103 years was only in a full aged care facility for the last few months of her life but found a way to end her suffering by starving herself to death & refusing all medications. **Every day in her last 12 months she had begged to die.**

I am a 70-year-old mother & grandmother with a family breast cancer gene variant & as such have battled the cancer twice in 16 years. I know the cruel reality as it gets harder to treat each time & options will not be there in the future. I want to know there is a peaceful choice to end my life if all else fails & it gets to a point of unendurable pain & suffering.

I have witnessed many dear friends with terminal cancer suffer cruelly in terrible pain & discomfort during the remaining months of their lives.

Palliative care has not eased the pain in many cases.

Jenny Bosma – Mother-in-law. 96. Osteoarthritis in spine.

My darling mother-in-law passed away last year at the age of 96. She was a wonderful vibrant woman all her life raising five children and being a vital part of the Armadale community.

During the last five years she was in constant, terrible pain and would ask repeatedly for us to ring the doctor to help her die. We discussed the fact that we couldn't and it was against the law.

She had a catheter in place & suppositories for bowel movements as the pain meds she was given made her very constipated for many of the last years, could no longer walk and had lost everything that she held dear to herself and her dignity. This went on for years and was ghastly to watch and not be able to help her. She became completely dependent, like a little child and was so sad to become what she wasn't.

She was a powerful energetic woman and it broke my heart and hers to suffer so greatly for no purpose but to appease others idea of how her end should be.

She wanted to choose her time and was to die but was denied that choice. She wanted change but it will be too late to help her and **no doctor or palliative care was able to help.**

Karen and Brett Barnes – Grandmother and mother. Starvation and dehydration.

People often talk of Palliative Care as being the other option to Euthanasia but I do wonder if they have actually witnessed someone dying under Palliative Care! I have witnessed my Grandmother and Mother die while receiving Palliative Care and it was horrendous.

To drug a person to the point of unconsciousness and deny them food or water until they die, seems unbearably cruel – not just for the person slowly dying but for loved ones by their side. It is a myth to believe because they are unconscious, they are not suffering. The opiate-based drugs my Mother took to try and manage her pain gave her terrifying delusions and dreams.

Who really knows what is going on in a person's mind as they slowly starve and dehydrate to death over 7–14 days!

Where is the kindness and compassion? If I allowed my pet dog to die under similar circumstances, there would be a public outcry!

Marguerite Laurence – Friend. Steve. Lung cancer. 66. Submission to WA inquiry.

Two months ago, I watched my friend of thirty years die of lung cancer. He was 66 years old, and he lived for two years after his illness was

diagnosed. By six months before he died the cancer had spread to his bones and he was in well-nigh unendurable agony for all that time.

When the time came that his pain needed hour by hour management he agreed to go into the Hospice. **When he was admitted he said that he was entrusting himself to the care of strangers only on condition that when he asked to be allowed to die his wish would be granted.**

He had watched his mother die in slow agony from cancer, and he did not want such a death for himself. Nor did he want his wife and children to have to witness his dying in such a way.

He was told that management of his pain and palliative care would assure his comfort and peacefulness until the time of his natural death.

Nothing could have been further from what transpired. The staff of the hospice did their very best within the limit of what they are allowed under the law to do, and it was not even close to being enough to help Steve in the last weeks of his life.

No more brave and resolute man walked the earth than Steve, and if he had had control of his circumstances he would have died by his own hand at a time of his choosing, having said goodbye to his beloved family and friends.

As it was, he had no autonomy, no control, no choice, and the last two weeks of his life were spent in unbearable pain. He was so heavily drugged with so-called pain-killers that he was hallucinating, but constantly aware at the same time of the agony, the extreme discomfort, the nausea, the indignity, the loss of his sense of self.

One of the worst aspects of this aftermath is [his wife's] impotent rage at the betrayal of her and Steve's trust. Where they should have been looked after, in a first world civilised country, where he should have been helped to die by his own doctor, with his family by his side, instead he was effectively imprisoned by the law governing how an individual may die.

There was no peace in his last days, his last moments.

Mark Cox – Father. Mesothelioma.

In the final stages of his illness, my father was in dreadful pain and would voice this to me on the telephone and say that he wished he could end it now, because he was not living, he was just in excruciating pain.

Unfortunately, palliative care did not work for my dad because he was allergic to both Pethidine and Morphine and whatever else they tried to give him to ease his suffering did not work.

It is for people like my dad, where palliative care does not see them through to a peaceful end, that I support a change in the law to allow terminally ill patients a choice at the end of their life ...

Morag du Bois – Husband. Stomach Cancer. Asbestosis.

I lost my husband of 43 years to untreatable stomach cancer. He had a huge blockage in his stomach and could not eat, so he basically starved to death. It was the most heartbreaking experience for me, his kids and grandkids to go through. His main wish was to die at home. He also had asbestosis and for the last 2 months of his life he couldn't lay down as it was too much pressure on his lungs, so he sat up slumped over our pool table.

Silver Chain did all they could for him. The last two days of his life were horrific. He cursed at all of us demanding that we help him take his life. I cannot express enough what effect it has had on my family. He demanded that we give him a gun or a knife.

Peta Quinlivan – Husband. Rare neuroendocrine lung cancer.

Just twelve days before his passing ... At that stage of his illness (a rare type of neuroendocrine lung cancer, which ravaged his body to the point where it metastasised into his spine, ribs, shoulders and femur); my husband was barely able to move; and wasn't eating.

Despite the palliative care received in hospice by doctors, nurses and volunteers; my husband suffered terribly ... and as his enduring guardian, constantly beside him all day and all night, I suffered too.

My husband had no chance of any quality of life at all whilst in the final weeks of his life. Even the most-simple pleasures of being able to look out of the hospice window at the blue sky, see the beautiful waters of the bay or be comforted by me, his wife, were robbed from him.

Two years after his passing I am still traumatised by what he endured; especially the sounds of his suffering throughout the long, frightening nights when the effects of morphine began to wear off and my husband required 'breakthrough' painkillers. Although he couldn't speak, I knew when he was in pain.

Hospices are a wonderful asset in our society but without legalised medical assistance, to enable patients to die with dignity, there will continue to be unnecessary pain and suffering.

Sarah Chevin – Family Member.

I have personal experience of **how a family member died in a state of intense and unwanted suffering and at the hands of Palliation in WA.**

It was not their decision to die alone without us by their side. It was horrific and the suffering was completely unnecessary.

Along with the deceit and trickery to get them to this stage was in my view, totally unnecessary and was totally unacceptable for both family members and the person in question. It is not fair on staff members or on doctors alike.

Sarah Graythwaite – Father. Lung cancer. Starvation.

My father died of lung cancer in January 2001.

His last days were spent being slowly starved to death. We are told it would hasten his demise. To watch my father become a skeleton was the hardest thing ever. It traumatised me.

We stayed with him at the hospice in Murdoch literally willing him to die. That will haunt me until I die that I prayed to some unknown creature to hasten my father's suffering. I was with him when he died. I'll never forget how his hands went slowly colder. His breathing more laboured and then stopped.

It was disgusting that we allow a human being to suffer like that. And their family members. And the

poor staff who have to care for them and watch it all unfold.

William Phillip – Wife, Dorothy (Senior RN). Inoperable duodenal adenoma.

My late wife, Dorothy Maxine Philip died on January 7, 2017, after an illness of 3 years post diagnosis, at the age of 81.

By August 2016 Maxine was becoming very unwell, and had a period of most uncomfortable hospitalisation at the end of August. From then her condition steadily diminished, and we nursed her at home, with wonderful assistance from the Palliative Care service. From mid-November, she was completely bedfast, using an in-dwelling catheter, completely incontinent, and terrified.

She was fitted with a sub-cutaneous perfusion apparatus just after Christmas, which managed her pain levels better than oral meds. They did not reduce her terror, as she effectively drowned as her lungs gradually failed and became fluid-filled. Her death was horrible.

I believe that she should have been able to nominate while still totally aware, that her wishes to be assisted to die before the terrifying last stages were entered, to have been legally available.

Palliative care is a wonderful and humane service, but it does not, and cannot, help in extreme circumstances such as Maxine's.

Sian Briggs – Father (Gerald). Cancer of pleural lining.

When the end came, my dad's death was far more terrible than anything I ever could have imagined. **Palliative drugs were not coming close to controlling his pain.** For four days we sat in an airless room with him, as he screamed and bellowed and writhed and cried. The previous night he was so panicked from the rising pain level he had tried to get up and run from it. He crashed down, smashing his head and cutting it open. When the nurses found him on the ground, he was covered in blood and sobbing and begging to be "put down".

I'll never forget sitting next to my darling dad, as he lay there in a nappy, two twig-like bones for legs poking out, covered in purple bruises, drinking from

a child's sippy cup with a black eye and stitches across his forehead. He looked heartbroken. His urine bag was filled with what resembled dark brown syrup. His left eye was hanging down. And he was in absolute agony. All we could do was hold his hand and play his favourite music and pray for it to end. **He endured an agonising 96 hours of torture before he finally passed. There was nothing remotely peaceful about it and his body never stopped writhing or shouting out.**

Jacqui – Mother (Eulalie). Liver cancer.

My mum had to go into palliative care to get her pain under control. In palliative care there would always be someone screaming out in pain, begging for a nurse to come. In the end they gave my mum so much morphine she was comatose. Her mouth was ulcerated, her lips were so dry. She wasn't awake or aware, we didn't know what pain she was suffering, she couldn't swallow, we couldn't give her fluids. What's the point in keeping someone alive like that when they're not going to get better?

My mum weighed 32kg when she died, you couldn't even help her in bed without her screaming in pain. I have PTSD as a result of everything I've been through.

Marcelle Van Soust – Ex-husband (Willem). Mesothelioma.

Each time he had a course of chemotherapy the aftermath was so appalling and made him so ill and weak that after a time we decided that if he continued down that path then the time he was told he had left would be spent so debilitated and weak, with an immune system destroyed by the very treatment meant to prolong his life. It just wasn't worth it.

At this point he was taking prescribed doses of Oxycontin, Oxynorm, Movicol and various other drugs for pain.

Silver Chain nurses had been assisting with his daily hygiene and the doctor prescribed his drugs which Silver Chain nurses administered via the push pump in his chest.

As the days went on the drugs became less and less effective and so the dosage was increased. The build-up of fluid in his abdomen was

excruciatingly painful and was extracted by syringe from time to time; a very painful procedure.

The morphine causes bowel loops, which in turn causes excruciating pain, so not much use to anyone. The bowel loops caused by the morphine were just a further agonising part of this hideous process; a vicious cycle of pain and suffering. Morphine ceases to have any effect whatsoever and does not relieve pain in a patient with a terminal illness such as mesothelioma or any cancer for that matter.

Van had a locked push-pump in his abdomen which delivered his medication but because at that stage he had no fat under his skin, the very thing that was delivering supposed relief was itself, causing more pain.

Seeing a person lying in a bed, wasted away to a skeleton, who cannot breathe and is struggling and groaning and gurgling day after day, making hideous noises which can be heard out in the street is the most harrowing thing for both patient and carer.

Three days before he died, he was in such agony that it was decided to take him to Sir Charles Gairdner Hospital to see if a small procedure could be performed to relieve the pain in his abdomen. After many hours it was decided he was too weak for an anaesthetic. He was taken by ambulance back to my house where, after the worst three days of unimaginable hideous suffering, he died.

Suffering such as this is criminal and is totally unacceptable especially in a person for whom there is no cure and is going to die.

Gabrielle Rose – Friend Dylan.

I will email you Dylan regarding the death by starvation made necessary by the suffering of a dear friend. This cannot be shoved into the 'zed file', overlooked, or in the 'too hard' basket any longer. Our Premier needs to stand up for what is decent, just and more important than football stadiums, more roundabouts and all the other 'follies' on the list. The people are suffering. Mark McGowan needs to be a leader on this right now. Mark my words he'll garner the respect of the whole nation by doing so.

Jackie McCallum – Mother-in-law.

It is tragic watching them die. I watched my mother-in-law virtually starve to death until her organs failed. All I kept saying was “we wouldn’t be allowed to let this happen to one of our pets”.

It was the most heartbreaking thing I have ever had to watch..

Lyn Godier – Sister, Michelle. Adenocarcinoma.

She fought for 18 months. Had chemo which didn’t work. Eventually the cancer was almost everywhere and she finally had to agree to be admitted to hospital, because her pain had become too hard to manage at home. She had been a nurse so she knew what was to come.

She had signed the paperwork for no medical intervention except pain relief. **For five weeks she ate nothing. Willing herself to pass away.**

We were so aware of her pain and suffering because we were there constantly.

Her pain increased as the cancer advanced. She was allergic to morphine.

Watching the nursing staff, the majority of whom did their utmost to keep her comfortable, holding back the tears because they could do no more.

My sister-in-law, who is a nurse, pressed the buzzer for more and more pain relief when Michelle’s daughter and husband became distraught with watching the pain she was in.

I cannot fully express the horror of watching a loved sister die so wracked by pain, and by law nothing else could be done. Her son, in the end, couldn’t face being there. Her beloved grandchildren were kept away because it would have been too much for them. Her youngest daughter couldn’t bear to come and is now dealing with the grief of losing her mother as well as a sense of guilt.

She had lost the sight in her right eye and could barely see from her left eye so invasive was the cancer. She had tumours that could be felt on her arms, near her collarbone and on her thighs. She was so frail but she just had to suffer it out. How cruel is that?

Joan Smith – Husband, 61. Aggressive lymphoma.

He was diagnosed with aggressive lymphoma which was strangling his intestine.

His final three days were spent in hospital and on the third night he lapsed into semi-consciousness. He had been having litres of fluid drained from his abdomen at intervals during the treatment process, and in the early hours of the fourth day fluid in large quantities continued to rise into his throat and he was gurgling and drowning while he struggled dreadfully to get a breath. **All the while he kept raising his hand to his head imploring someone to help him. This inhumane action continued without ceasing for seven hours!!!**

Towards the end, one and a half litres of blood-soaked fluid gushed out of his mouth before he took his final breath. Those hours will haunt me forever. Why should anyone die that horribly?

As a practising Christian couple, we viewed the present law as ungodly. We are God’s hands and feet, he has no other, and while we do nothing this horrendous practice will continue.

Bettina Arndt – Mother, 87. Broken hip. Pulmonary embolism.

She had a fall, broke her hip and ended up in a surgical recovery ward. Then she had a pulmonary embolism, which should have delivered the fast, peaceful death she so wanted. She lingered for two horrible weeks. Everything went wrong. She screamed every time the nurses turned her over.

But one evening a palliative care nurse happened to be on night duty. She asked what was going on. It turned out my mother was in terrible pain, having grown tolerant of her morphine level and missing the medication for her crippling arthritis. That superb nurse tried to fix things. She had her moved to a ward which had proper palliative care, arranged for higher morphine levels, less regular turning. But then my mother got terrible diarrhoea, which led to more pain, intrusion, endless assaults on her dignity.

It was devastating struggling so ineffectually to provide that peaceful death my mother so deserved. Here I was, an educated, assertive person, thoroughly familiar with the medical

system having for many years taught both doctors and medical students. Yet I failed dismally.

Wandering the hospital corridors with me were other families totally crushed by their impotence to ease their parents' suffering.

It is a total nonsense to suggest that the solution to a peaceful, dignified death is now available through palliative care.

And palliative care experts acknowledge that even with state-of-the-art palliative care, terminally ill patients can still experience distressing symptoms that make their lives unbearable – weakness, breathlessness, nausea, suffocation, psychological distress, confusion.

Spencer Ratcliffe – Partner, Deb. Cancer.

The doctors can only administer, as you would know, a certain amount of morphine over certain hours otherwise that can put the patient to sleep permanently, and obviously that's not allowed. So **as much as the patient may want that, the doctors are understandably – and nurses – scared stiff of overdosing their patients.**

The pain was getting so intense on this particular night that Deb sort of called out to me and said, 'Spencer, I need to walk. I must walk. I've just got to do something.'

We walked around the corridors of this hospital for six hours until she was allowed to have more morphine and **during those six hours – I've probably still got the marks – her nails were clawed into my back through sheer hell. We walked past doors that led into utility rooms and she'd scratch at the door.**

She had to do something to alleviate the horrendous pain she was in. I've never seen pain like it. I've been a journalist for 49 years.

They said, 'We're not allowed to give any more for another two hours and 14 minutes,' or whatever. 'It's all written down on the chart.' 'Why not?' I'd say. 'Because that's the amount the doctor says. We're not allowed to give any more than that.' 'Why not?' 'Because it's the legal limit that we're allowed to give.'

Deb was only allowed a certain amount every hour or two hours or whatever. But because the

pain just keeps growing and growing and growing, the amount of morphine grows too but not in accordance with the pain. It's very hard to measure that, but you can tell **when someone's screaming in pain and they're just crying. 'Please can she have some more?' 'No.'**

I said, 'How can you just tell me that? How can you sit and watch her in such pain and tell me she can't have more morphine?' 'Because the doctor says I can't.'

Jessie Edney – Husband, John. Bowel cancer.

John had suffered for five years with terminal bowel cancer. He had had more than 60 per cent of his liver and half his bowel removed in two separate operations. He was on chemotherapy for most of that time. He then got cancer in his femur and it broke, another operation and weeks of rehabilitation to walk again.

We had heard positive things about palliative care at home and thought that would be for us. Unfortunately, it has left me regretting our decision. While the people from palliative care who visited were wonderful, caring and pleasant, John had a terrible, painful and frightening death.

John was struggling to breathe, arms flailing, trying to speak but all that came out for ages was terrible gurgling noises. In final desperation I called an ambulance and by the time they arrived John was still in that terrible state. They said that it was too late to take him to hospital as he would be dead-on-arrival.

My wonderful husband died a terrible death and left me with a terrible image.

John had suffered for five long years and to watch him suffer so much for hours at the end was terrible.

Sandra McEwen – Friend, Graham. Brain lesions. CNS lymphoma.

Graham chose to have only enough mild chemotherapy to get him home to sort out his affairs. He knew he was aiming for a good time, not a long one, but sadly only had one day. A series of seizures sent him straight back to a small regional hospital, unable to communicate effectively for another six weeks.

He talked constantly, but his words jumbled, leaving him frustrated and angry. His eyes said it all, but occasionally complete sentences sneaked out. He'd say, 'This is hell!' and 'I'm over this mate! I've had enough. I want this finished.' He clearly understood everything we said to him.

At my request, the doctor withdrew the steroids that were 'calming' inflammation in his brain. Why prolong this palliative nightmare?

Ten days before he died Graham stunned his doctor by saying, 'I want this ordeal over by 3pm, and if not then ... by sundown.' I'd been relaying his scarce comments for weeks, but perhaps it was this clear statement from him that confirmed Graham's desire to die.

Drug regimes changed and things moved faster from there.

The next day Graham fell while trying to walk, and probably broke his hip. That hip remained a source of extreme pain until the morning he died, despite increasing doses of morphine.

Palliative sedation and medication for seizures were his only treatments. It was all his doctor could legally do.

Eventually pneumonia carried Graham off before the brain lesions did. I will never again hear anyone call it the 'old man's friend'. **There is nothing friendly about drowning in one's own phlegm. There is nothing good about listening to desperate, healthy lungs gasping and grasping at air for two days.**

I was left shocked and traumatised by witnessing Graham's death from pneumonia. But I walked out of that hospital and didn't have to go back. What of the poor nurses who helped us? They were clearly shaken.

They were the kindest, most compassionate people I've ever met. How often are they traumatised by bad deaths? Daily? Weekly? How can we, as a society expect them to carry such an appalling burden in their own lives?

Robyn Taubert – Mother, Betty, 84.
Stomach cancer.

Then at 84, she got stomach cancer, which blocked

the exit of food from her stomach. She felt fine as long as she didn't eat; she was simply not hungry. She asked them to help her die. But no, **she had to remain in hospital while her body starved to death. By law, she had to have intravenous fluids, which only served to prolong the starvation process.**

In the last four weeks, her veins began to collapse so she was put through daily agony having someone constantly trying to find another vein. Being bedridden meant she was plagued by discomfort and bedsores.

She should not have been subjected to all that pain and indignity of the last four weeks – hurting her to keep her alive until she died.

Judith Daley – Mother, Catherine, 73.
Lung cancer.

She was literally walloped with a very virulent form of lung cancer. It was six weeks from diagnosis to death and it was as though she had been shoved off the cliff of wellness and was plummeting into a chasm where there was no safety net.

During those last few days she was frequently incoherent with pain and pleaded with us to 'make it stop', or to 'get something' for her.

By day 40 after her diagnosis she was ... restless and unable to remain still, tossing and turning and groaning and moaning.

My sister and I cornered this poor young doctor and demanded to know, 'Why is she suffering so much?' And he said, 'If I give her any more it will hasten her death.' My sister and I didn't even look at one another. We both said, 'Well do it.' He didn't react to those words but suggested we should go and have a coffee.

We all knew her condition was incurable and her pain was clearly intolerable.

When we returned, Mum gave every appearance of being at peace. She was no longer thrashing around and moaning but was serene and apparently in a deep coma. Kay and I stayed with her for the next nearly 20 hours until she died.

Her suffering could have gone on for days or weeks but for the kindness of that young doctor. We are eternally grateful to him.

Denise Kapernick – Father. Parkinson's and oesophageal cancer.

Due to the staph, he was not a suitable candidate for chemotherapy and the idea of operating was also eliminated as it was a major operation that would involve cracking his chest open and removing a considerable amount of the oesophagus and stomach, which would have been too much for his already unfit condition.

It was decided that he would instead undergo a course of radium to try to shrink the tumour enough so he could swallow (and keep) his food down, which he was now unable to do.

Unfortunately, this treatment did not reduce the tumour, so he continued to lose weight and strength until he eventually was unable to even swallow his own spit.

At this stage Dad knew his time was limited so, in an attempt to hasten his death, he stopped taking his staph medication in the hope the infection would return and end his time on earth quickly and painlessly.

... at 2am he suffered a catastrophic stroke, paralysing him completely down his left side, weakening his right side and leaving him totally bedridden.

He was unable to do anything for himself and was reliant on the nursing staff, my sister and me to feed him, wipe his face, clean him, roll him over, massage his legs and wipe away his tears. **As the weeks passed, his pain increased as the fluid built in his limbs and the morphine was not enough.** The Parkinson's was also a factor for his pain as his muscles seized and spasmed.

The doctors tried fentanyl patches, increased his morphine doses and eventually commenced a morphine driver but his pain was still unbearable. He stopped asking the nurses to hoist him into a chair so he could be wheeled outside as the slightest movement would bring him to tears, even when we tried to trim his fingernails.

He put up an incredible fight against the staph, Parkinson's and the cancer, but the stroke robbed him of any quality of life and it was only at this time that he had no fight left and no desire to 'live' another day.

Dad lived seven weeks and three days after the stroke and this whole time he suffered, both mentally and physically.

He did not pass away peacefully like the movies portray though. He drowned in his own phlegm and the noise of this is something I can never describe. His eyes were rolled back in their sockets and he was groaning and gurgling and his breaths were laboured, shallow and frantic. My sister and I cried at his side, hoping that each breath was his last, but as the hours passed, he continued his struggle for air until his body finally gave up and went silent.

Sue Hayward – Brother, Paul. Advanced pancreatic cancer.

Paul had been diagnosed with advanced pancreatic cancer that had spread to his liver. Wednesday, he was told by his GP that he would benefit from palliative support.

In the emergency room he was very stressed and frightened. A blood test confirmed an infection in his liver. His kidneys were failing, as well as a thought that the cancer had gone to his brain.

Paul was put on fluids and antibiotics, which were both stopped the following day when I had spoken with the doctor stating that I wanted Paul to be made comfortable and allowed to pass with dignity.

A pump providing regular bursts of morphine was provided and sedatives given but they did not have any desired effect and, in my mind, were not given quickly enough. **Medication was administered only when Paul was in agony rather than topping it up before it got too severe. Once given it took a good 30 minutes to kick in.**

The morphine pump was again increased, as it was clear that nothing was keeping the pain at bay. More shots of sedatives were given every hour but nothing seemed to work. Paul was moaning and his arms were reaching out in agony, his hands clutching in fists. His eyes, a sight I will never be able to get from my mind, showed sheer terror as pain wracked his body.

I was sobbing and pleading for help...to do something...let me sign something...I wouldn't let an animal suffer so! I have never been more frantic and felt so utterly useless. I could not help my brother and I just wanted to run away. I couldn't

even pump a fatal dose of morphine into him as the pump was locked up solid within a casing, the keys locked away in a cupboard somewhere.

For six hours this went on. Even the darling young nurse looked desperate as she explained hospital policy.

John Acton – Mother. Stroke.

Eleven years ago, my mother had a stroke and took seven months to die. As her principal carer I divided my days into good days and bad days.

A good day for me was when she said, ‘John, I want to die.’ A bad day was when she said, ‘John, please kill me.’

That was the only thing in her whole life that she had ever asked of me, and I didn’t love her enough to do it because of the legal consequences.

Eventually, she starved herself to death.

Jane Morris (nurse) – Mother. MND.

As my mother’s MND progressed we were, on several other occasions, **assured that her death would be comfortable and pain free.**

We placed our trust, and in fact our mother’s life, in a system which only now I can say failed her dismally.

As it was my dear beautiful mum went to palliative care to die. Her and our intention and understanding was that she would be cared for right up until the moment of death.

And up until a few days before her death I cannot emphasise how exemplary her care was.

... not for a second did we envisage the horrific, inhumane and tortuous death to which she would succumb.

Mum was no longer under the care of her two neurologists but the palliative care specialist.

Yet again we were assured that Mum would not suffer in the end and that terminal sedation would provide her with the least amount of pain and discomfort.

She would supposedly be given adequate sedation to prevent any pain or associated anxiety.

She would not, we were told, experience any

thirst or hunger as a result of the withdrawal of fluids and nutritional supplements. I promise you, you will not suffer at the end.

Mum did suffer. She had pain, breakthrough pain, because her prescribed dose was unable to adequately palliate her pain at all times.

She managed to express to us her fear and in one of her conscious moments was able to convey to us that she wanted to be fed through her PEG tube.

This was so very traumatic for all of us, many staff included.

We had been assured that Mum would be devoid of hunger and thirst, but no, the dying process is not a templated one and whilst her case may have been unusual it was nevertheless real and it was happening to my mother.

Mum suffered what I deem to be unnecessarily for days. Family members requested that her analgesia be increased.

A request I made pleading for her analgesia to be substantially increased even if it meant hastening her obviously imminent death was directly replied to by the question, ‘Are you asking me to kill her?’

No, I was not trying to have my mother murdered I simply wanted her tortuous pain and existential suffering to end.

We are told that death can be peaceful and that we should not fear it but no-one, even staff members, could leave her bedside unscathed.

We chose not to allow young grandchildren and close friends to see Mum in her final hours.

This hideously prolonged death was visually ugly and this once beautiful, vibrant and radiant individual should not have been subjected to the haunting and unforgettable images that we were privy to.

To end suffering when palliative care cannot is not an act of killing, it is an act of compassion and love and one that we should all aspire to.

My beautiful mum did not deserve to die the way she did.

I promise you, she did suffer at the end.

Sandie Wands – Mother, Dulcie, 73.

Neuroendocrine cancer.

She had a neuroendocrine tumour in her abdomen and a life expectancy of two months if she elected not to have chemotherapy. She had suffered a lifetime of major illnesses, but given her history and the prognosis even with treatment, she decided the fight would be too hard, and she chose to die.

She was transferred to hospital two weeks prior to her death where **she was given a blood transfusion, which was in contradiction to her express wishes that nothing be done to prolong her life.** By this stage, the pain was becoming unbearable and she was drugged to the eyeballs all the time.

My beautiful mother lay in that bed, rotting in front of my eyes for an entire week. Once they stopped taking her obs and said she was nil by mouth, it meant that medications that she had been so heavily dependent on (and was addicted to) were no longer being administered. In my opinion, that sent her into a violent withdrawal and **she spent a lot of time thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing. She was starving to death and by this stage was skeletal, and her dehydration was obvious. Her mouth was caked with thrush** and because she had suffered very severe respiratory illnesses in her lifetime, the infected mucus was pooling on her chest, further preventing her from breathing.

I spent that whole entire week (day and night) by my mother's side, speaking on her behalf to try and get her more pain relief or a sip of water (until nil by mouth).

In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time.

Finally, she sat bolt upright in bed and her eyes flashed wide open with a look of terror on her face, then she fell back on the pillow and took her last breath. The mucus that had been pooling on her chest began to ooze out of her mouth, putrid, green sludge that just kept coming and coming.

That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through.

Anne-Louise Kitto – Mother, 87. Heart failure and pulmonary fibrosis.

My mum had heart failure and pulmonary fibrosis. She was admitted to hospital in a very distressed state and with breathing difficulties. She was probably about 4'9" and 38 kilos by this stage.

Anyone who came into her hospital room – nurse, doctor, pink lady, dinner person – she would gently grab their wrist and say, 'Please let me die'. I turned up to the hospital one day and she was so distressed. I crawled into bed next to her and held her while she chanted forever, 'I'm so sick. What day is it today? I want to die today. Why can't I die today?'

The only way I could honour her wishes was to sign a 'nil by mouth' form, which I did. Can anyone explain to me what the difference is between me signing a form consenting to my mum being given a needle that would peacefully end her life surrounded by family who could say their final farewells and me signing a 'nil by mouth' form, which meant my mum had a very slow, seven-day death? They are both a death sentence, except one is humane and the other is cruel.

After a couple of days, she lost her voice, which was so frustrating for her. She couldn't even lift her arms so she could only communicate by frowning and opening and closing her eyes.

I had to watch her fingers and toes turn black. She died alone in the middle of the night.

Annie Sobey – Best friend, Rhoda, 72. MND.

When first diagnosed with motor neurone disease, her life expectancy was one year to 18 months. She did not realise the disease would become so debilitating in such a short space of time.

First bodily function to shut down was her swallowing. She could only eat puréed food and then thickened drink, progressing to not being able to swallow at all. A PEG tube was then inserted directly into her stomach to give her sustenance

and keep her alive. Her speech was badly affected, her frustration intense.

She was being kept alive by the PEG feeding directly into her stomach. Her quality of life was nil. She was fully alert and conscious but trapped in the prison of a non-functioning body. The last week of her life was a horror I will never forget.

My dear friend's eyes were full of fear and terror. We requested more morphine for her, and the nursing staff agreed she needed it but by the time permission was given by the palliative care doctor hours would pass. She did not seem to get enough to calm her. The fact she was fully conscious and aware was the worst. Her suffering defied belief.

As her friend, I felt so very inadequate that I could not do something, anything, to take away the terror in her blue eyes that still sparkled, beseechingly begging for help.

She was a spiritual and quite religious being, who believed in the hereafter. She deserved a peaceful passing. The horror in her eyes in those last days will always be with me.

John Paynter – Partner, Mary-Anne Paynter. Stage 4 cancer.

My partner had stage 4 cancer and had many medical issues including a broken hip that was causing her much pain. She was rushed to the hospital on Easter Sunday with a high temperature.

On the last scan where she was making sense a clerical error meant that she did not receive her pain medication before the scan.

The last thing she said to me with tearful wide blue eyes was, 'I'm scared'. I will never be able to get over that.

It turned out that all the scans and all the pain were in vain since a later brain scan revealed that she had suffered a massive stroke ... 1 April I was told that it was too late to do anything about the stroke and that 'she is dying'. I and other family members were told that there was little chance of saving her and that surgery would likely be fatal. I begged them to perform the surgery since if she died on the operating table under general anaesthetic it would be a peaceful death. But they

refused stating that they could 'do no harm'. They said they would keep her comfortable and she would probably be gone in 12 to 24 hours.

I had no idea what palliative care involved. They remove anything that would help her stay alive, including saline drips and antibiotics. One staff member told me that she will virtually die of thirst and that it can take several days or even weeks. She was given a steady infusion of morphine, a sedative a few times a day and a drug to help dry out her throat.

Days One to Four: For the first few days she was constantly gurgling and coughing in an attempt to clear her throat. She appeared terrified.

After much complaining on my part they finally included the sedative in her continuous feed and allowed 'breakthrough' sedation and pain medication once per hour instead of a longer period earlier. It was horrible to watch her with her face scrunched up in pain.

I begged too much for her to be euthanised to the point where the palliative 'care' nurse suggested that other family members should request breakthrough medication since the nurses did not trust my judgement and thought that I might 'do her harm' with a morphine overdose. The complete lack of any logic is in itself unbelievable.

Day Five: Still groaning and trying to cough, sometimes almost screaming. I asked the palliative 'care' nurse who was very sympathetic and doing what she could to stay and watch my partner. After a few minutes she went and spoke with the palliative 'care' senior doctor. They tripled her dosage of sedation and pain medication – too little too late.

Day Six: She was getting weaker and sometimes just couldn't get a breath. Fighting for life not knowing she had no chance – so incredibly cruel.

She fought the whole day. At about midnight when I asked for more relief to stop her needing to cough up the liquid

I was told 'we can only give that three times a day and she had some an hour ago'. My god! Were they afraid it might make her sick? I felt I was living in a Stephen King horror novel.

Day Seven: She finally got so weak that she stopped trying to cough and just breathed more and more shallowly. **At last the poor thing had some peace – after seven days of unnecessary and unbelievable cruelty.**

Anne Woodger – Father, 59. MND.

Over a space of six years he gradually lost the use of his fingers, hands, arms and legs. He lost his power to speak and to swallow food. He had to be toileted, usually by his wife who nursed him for the full duration of his illness. He dribbled and so, as an intelligent civil engineer he spent his long, long days in one chair by a window with a large bib on.

As his speech became difficult to understand and then non-existent, he would communicate using an E-Tran board. When my father could no longer eat food, he elected to have a feeding tube inserted into his stomach. This enabled PEG feeding and it is how he consumed his food and drink.

Approximately five years into his disease, my father asked me, via the E-Tran board, whether he could end his life. ... approximately six months later he asked me to contact his palliative care doctor to discuss his options. ... I understand my father indicated to the doctor that he wanted to cease PEG feeding.

The palliative care doctor then organised a family conference at our family home. My father, mother, brother, the doctor and myself attended. During this meeting, my father and the rest of the family talked about what he wanted to do.

The decision-making remained my father's. He knew that the muscles in his eyes were weakening and once he could no longer keep his eyes open and indicate letters on the E-Tran board, he would have no effective way to communicate his wishes. The palliative care doctor suggested that if and when my father was ready to act on his plans to contact him.

Sadly, the compassionate and considered decision-making about my father's end of life choices was followed with the cruel reality of his death. While the law respected his right to decide to end his life, it gave him no help to do it and insisted that he must die slowly of starvation and dehydration.

Dying this way can take days or even a fortnight, so my father needed access to reliable palliative care to relieve his suffering.

Accordingly, he asked to be admitted to the local palliative care hospice where he knew he would have quick access to pain relief if he needed it. He did not want to risk being without necessary pain relief at home.

While the staff at the hospice were kind and considerate, there was no escaping the necessary steps of dying in this way. **Mucus solidified in the back of his throat and needed to be regularly prised out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water. Nurses, unfamiliar with his routines, tried to turn and bathe him and struggled to get him comfortable. He was eventually sedated when muscle cramps were so overwhelming and painful for him. I hope the sedation was effective in managing that pain. He died after 12 days.**

Shayne Higson – Mother, Jan, 77.

Terminal brain cancer.

Mum had an aggressive form of glioblastoma multiforme, and with multiple tumours they could not operate or do radiation therapy for fear of causing severe brain damage.

As the months passed Mum lost her ability to walk, she lost words and struggled to communicate, she was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort. She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

Each day her condition worsened. We did everything we could to try to keep her comfortable. Every day I would rub her legs and feet because she said it felt like they were already dead. The anti-nausea medication did little to ease her discomfort and as Mum's right side became more and more affected she could not even lie in bed peacefully. She was agitated and distressed.

Mum started to ask for some form of medication

that would just knock her out but nothing the doctors prescribed achieved a peaceful state. **She had had enough. She kept asking, 'Why are they doing this to me?' 'Why are they torturing me?'**

By 14 November Mum no longer wanted to eat and each day she asked, 'When will it end?' 'Just give me something to end it', but I couldn't. I was so afraid.

Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this. That is, until the end.

By the time she was admitted to hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night my worst nightmare came true and Mum suffered another seizure. It took nearly an hour and a half to get the seizure under control because the nurses were only authorised to give small doses of medication, 15 minutes apart.

I won't describe all the other things that Mum had to endure over the next four days but I want to point out that **under the current law, medical practitioners can only treat symptoms as they occur. That means a terminally ill patient, like Mum, has to suffer, whether it be nausea, pain, or other symptoms.**

Nothing is given in doses high enough to prevent suffering, all for the fear of giving too much and perhaps hastening the death.

Joan, Julie, Mark, Jo, Christine, Bradley and Jason – Father, Ken, 81. Terminal oesophageal cancer. Suicide.

Dad was diagnosed with terminal oesophageal cancer and wasn't expected to live three months, but instead he suffered another 12 months. This cancer is a slow and painful death sentence. Although Dad was on a lot of medication there were days when it just wasn't enough and the side effects of the medications were unbearable. Dad got down to a weight of just 45 kilos.

Our beautiful Dad took his own life on Friday, 9 October 2015 at the home he shared with Mum

and Down syndrome son, Jason. Dad left behind a note expressing his desperation to the end. All he wanted was for someone to help end his suffering so that he could die in peace with dignity which is what he deserved.

What Dad went through, especially in the end, was horrific. He made the heartbreaking decision to take his own life, hanging himself in the backyard. Jason, who is Down syndrome, was the one to find Dad and that made the situation even worse, if that was possible.

Ronda McCarthy – Husband, Wayne, 65. Progressive supranuclear palsy Suicide.

PSP is an insidious brain disease slightly affecting the mind but particularly affecting the ability over around three to eight years to walk, talk, write, eat and see properly – those with it often die from choking. There is no cure. Wayne was a very active person, doing triathlons, the Ironman, marathons, and went annually on bicycling, motorbike and heli-skiing holidays. All those things came to a halt as the PSP progressed slowly but steadily. Eventually he could only walk outside with me holding on to him.

Three years into the disease, Wayne told me he would eventually have to take his own life. I told him he would have to tell me when as I would be terrified every time I came back into our apartment that I would find him dead. He said of course he wouldn't do that as it would spoil our home for me and I would afterwards have to leave.

I'll never forget that walk from the lift to our room. I opened the door and saw Wayne lying flat on his back with his eyes open. I hadn't imagined he'd have his eyes open. I could feel myself falling to pieces as I phoned Reception and asked for someone to come as my husband was dead. They came and soon after two ambulance men arrived. By that time, I was in deep shock. One of them tried for about 20 minutes to calm me down. I was taken to another room nearby where there was a young policeman. Our room had become a 'crime scene'.

If Wayne was alive today, he would be in a terrible state. He would no doubt be in a wheelchair, unable to speak or see properly,

and being fed through a tube. Just waiting for a long, lingering death.

If voluntary euthanasia had been legal, Wayne would not have had to take his life so early and we would have had him a little longer. Our family and his close friends would have been able to know what he was intending and to say goodbye. They had all understood and it turns out goodbyes are important.

Jess Cushing – Grandfather, 70s. Terminal cancer.

Suicide My grandfather was diagnosed with cancer during his 70s, and while he fought it off for a few years, he was eventually given a diagnosis of terminal cancer. So, **as the cancer took its usual toll of damage and destruction, his life became increasingly unbearable. He was in incredible pain, had become incontinent, lost his appetite and could often barely eat. He was unable to do any of the things that he loved and valued in life** and began struggling to stay awake or hold a conversation for any great length of time.

He documented his failing health – ‘very hard to get up, hard to swallow, breathlessness, weak’. And later his wife would share with the police investigating that matter that he’d said ‘life is hell, this isn’t living’ and he was in total despair due to his increasing state of infirmity.

One Friday night, when he could take it no more, he ended his life. We didn’t know his plans, nobody did. One of his sons was a GP, and as such my grandfather had to be very careful not to implicate him in any of his actions. He decided not to stockpile any medication of any sort, or try and get hold of a barbiturate that might potentially implicate his son.

So instead he was left with a much more horrific means of dying if he was to do so at a time and way of his own choosing: **he cut an artery in his leg with a serrated kitchen knife.** He did it on a Friday evening so no-one would be interrupted from work the next day. He did it quietly, he did it totally alone, in his room with his foot in a bucket and a black plastic rubbish bag wrapped around it so as not to make a mess.

And as he cut deep into an artery, and his life

slowly bled out of him, I dread to consider the thoughts that ran through his head, the loneliness he must have felt, the emotions – perhaps of relief, perhaps of panic, perhaps of fear, undoubtedly of pain.

His wife found him the next morning; she’d been asleep in the room next door. He’d left a note: ‘I love you all more than words can say, look after one another’.

Three cases of suicide presented to the Victorian Inquiry into End of Life Choices by Coroner John Olle

Case 1: The first individual is a **59-year-old man**. He had a wife of 38 years, survived by his children and his wife, with whom he shared close and loving relationships. He had no mental health documented, **a medical history of metastatic colorectal carcinoma, multiple confirmed colorectal and liver metastases.** About two years before his death he underwent a liver resection for confirmed liver metastases and was subsequently treated with chemotherapy. **He underwent 22 cycles of treatment, and unfortunately a CT scan performed not long before his death showed evidence of progressive disease with a new liver lesion, which resulted in the cessation of his trial treatment. His GP informed the court that the cancer had now spread to his liver and his prognosis was not good.**

He was admitted to hospital with a fever, dry cough. Ultimately, he wished to go home. He would inform his son and family members he would rather take his life than live a life dying in a bed.

He was well aware of his suffering and what was ahead of him. So, he would rather die than stay in a ward. Ultimately, he was observed by a motorist on a major freeway in Victoria hanging from a bridge. A note indicated his intention to take his own life.

Case 2: A **75-year-old**. He lived with his wife, with whom he maintained a good relationship despite their divorce. He is survived by his daughters, with whom he shared close, loving relationships. He had no documented mental health history, and again a very long, complex medical history.

Not long before his death, some years, he was

diagnosed with prostate cancer, treated – radical treatments – sadly without improvement and increasing pain with poor prognosis. He expressed to others his belief that his life would be so much easier if someone could help him die.

He could not face his lot. **He ultimately obtained a firearm which he discharged by holding the tip of the barrel against his chest and reaching for the trigger. He was found by family.**

Case 3: Finally, a **90-year-old man**, survived by his family, again with whom he shared close, loving relationships. He was described as a delightful gentleman. He was extremely fit for his age and a proficient iPad user. He had no documented mental health history.

A very lengthy history included back pain, chronic obstructive pulmonary disease, asbestos exposure and the like. Not long before his death he was diagnosed with a solitary brain metastasis in a setting of metastatic melanoma. He expressed his wishes very clearly to his treating clinicians; he did not wish to have any invasive procedure done. His main priority was quality of life.

In the final four weeks of his life, his doctor explained, he remained frail. He had lost approximately six kilograms in the previous four weeks. He had a poor appetite. He looked malnourished and had nausea. His family stated that from about mid-December 2014 his wellbeing deteriorated. He felt generally unwell. He was dehydrated and had diarrhoea. He was vomiting uncontrollably. He had fevers. He was wobbly on his feet, even with the assistance of walking aids. He was diagnosed with likely viral gastroenteritis and was commenced on IV fluids for rehydration therapy. He improved as a result of the rehydration therapy markedly and was discharged home to the care of his grandson in January this year.

The family explained that when he learnt of his cancer he went downhill emotionally. He was depressed and angry that there was no cure. He often told his family he would rather do something to end it straightaway and that if he could no longer drive, he might as well be dead.

He mentioned a nail gun.

He was subsequently found dying with nail gun wounds to his head and to his chest. He died ultimately from the injuries sustained from the nail gun.

Coralie Richmond – Father, 72. Asbestosis. Westmead Hospital, NSW. Suicide.

My father's lungs were shot to pieces and when he reached the age of 72, fluid built up in those lungs and he was in excruciating pain. I took him to have blood tests and X-rays and finally the doctor said to take the X-rays to Westmead Hospital to have them read. My father had had enough. He was terrified of dying like a lot of his friends and on this night, he decided to take his own life. **He used a shotgun to his right temple. It did not kill him immediately; his brain was shot to pieces as the bullet ricocheted within his skull.**

He was taken to Westmead and was given medication, oxygen and tube feeding. Then they wanted to perform a tracheotomy on him. I was appalled ... I said he wanted to go, just let him go. But no, that wasn't what they wanted to do. I checked for myself to see how his wishes should be carried out. I found out that I could have his medication stopped.

It took a week for my father to eventually pass away; at least he was finally at peace.

Tracey Walker – Father, Russell, 73. Parkinson's. Suicide.

He had noticed little things – for instance, it became difficult to comb his hair and to clean his teeth. When he walked he didn't swing his right arm. When he was finally diagnosed, Dad was devastated.

He enrolled in a six-week Catholic adult education seminar, and seemed to get some comfort from this.

Dad did everything he could to find an answer. He went to more doctors and lung specialists, had PET scans, MRIs and numerous blood tests. He completed a rehabilitation program for Parkinson's disease patients at Calvary Hospital, and changed his medication (which unfortunately made him vomit and created a metallic taste in his mouth).

Everything my dad loved to do – surfing, swimming, cooking, **walking his granddaughter to school – had been taken away from him. He became totally debilitated, unable to do more than sit in a chair, for days and weeks at a time.**

On Sunday 12 April 2015, my beautiful generous father hung himself in his bathroom

It's bad enough that my dad had a progressive neurological illness and a range of other medical complications. Much worse than that was the terrible way that he ended his life.

Di Hatfield – Father. Inoperable prostate cancer. Suicide.

On 14 June 1994, **our father shot himself in the heart with a rifle.**

He was in the bedroom; our mother was in the kitchen no more than five metres away, my 12-year-old nephew in the lounge.

Dad was diagnosed with inoperable prostate cancer at the age of 54 with a 10 to 15-year prognosis.

And so began his long battle with an exploratory operation that ended in a careless removal of the catheter that left him 'leaking' constantly, but he didn't give up due to that little hurdle. He devised his own special 'nappy' so that he could continue to play his beloved golf. I don't think they had Tenas then!

I can't remember the exact point when he started to decline but I do remember distinctly his last couple of months. **He had been admitted to the palliative care ward of our local private hospital and was cared for so wonderfully by the nursing staff.** At the beginning, he would entertain other patients, and us when we came to visit, by playing the piano (totally self-taught and unable to read music). **But he was being given painkilling drugs that had him hallucinating and we could sense his frustration at his lack of control. He couldn't conduct a reasonable conversation when friends came to visit.**

Even though he had the best of care at the hospital, he was desperate to come home and, in the end, refused to go back. I learned after his death that he had begged his doctor to give him enough

medication to allow him to safely and gently end his life when he knew all hope was lost.

He had written a note which I still have; a small piece of paper roughly torn from a page, upper case letters, obviously written with a shaking hand:

I LOVE YOU ALL. ALWAYS DO YOUR BEST. DAD.

I can only wonder at the beautiful memory we could have had of Dad's last moments; whether he had chosen to have us present when he passed or not, at least he would have died with the dignity that was rightfully his.

Terri Eskdale – Partner, Mark, 66. Multiple Sclerosis. Suicide.

MS is a mystery illness, it manifests differently for everyone. Mark's walking and balance were affected and were the most obvious symptom. His feet and toes had no feeling, and while he still could walk, he would walk barefoot down the street to our boat and not notice he had taken chunks out of his skin on the rough gravel road. In contrast to his feet, his skin elsewhere became extremely sensitive, making wearing clothes uncomfortable.

Mark experienced shooting pains through the left side of his body. He had spasms that often came at night. He had short sharp pains that would wake him. Pains under the skin that he called snakes and spiders. He had bladder infections. He gradually became incontinent. His bowels stopped working and he relied on fierce medications, which would suddenly send him exploding to the toilet, too bad if you were out and about! Some days his eyes were reluctant to focus.

By December 2013 he was assessed as high needs which meant **if he was admitted to nursing care, he would have been in the high care side of the nursing home, and they would have kept him alive against his wishes. The most devastating loss to him was when he began to lose the dexterity of his hands.** He never complained about pain but experienced a lot. Towards the end he was unable to sleep in a bed due to the pain and spasms when he lay down. He slept in an electric recliner chair.

His greatest fear was that he would get to a stage where he would not be able to end his life

because his hands would not work.

Mark had always been an advocate for assisted dying, dying with dignity. It was not a rash or spontaneous act, rather the considered position of a highly intelligent person facing a disease that wouldn't let up.

Mark died alone and without a word of goodbye because he had to protect me.

That is what upsets me the most – **he had to die alone and in an unnecessarily violent way.**

Miriam Meikle – Mother, Dorothy, MND. Mercy killing.

Sadly, at the age of 70 she contracted motor neurone disease shortly after an accident/fall whereby she broke her ankle. Unfortunately, at the time of her diagnosis, my mother was given a prognosis of about five years. She was faced with the prospect of the next five years whereby this disease would travel up her body and she was likely to die slowly and possibly painfully. She would slowly lose muscle functions and they would be depleted in her lower and upper limbs. We all knew that this would progress until she was unable to talk, swallow or breathe.

My mother really came to her decision to die at home with dignity shortly after the death of her loving husband of 55 years (he was aged 87). I watched him in agonising pain – **he was gripping my hand and groaning to his last breath in the early hours of the morning.**

Our requests for more morphine were often denied and to this day, those two days can only be described as appalling and horrific. Our family had felt they had witnessed an inhumane and horrific way to die.

... with the progression of her disease, there was now very little muscle holding her small frame together. It was frightfully painful and debilitating. She had been confined to a wheelchair for years, **she was receiving 24-hour pain relief and 24-hour home care and she knew that within months she would choke to death.**

The legal implications and repercussions made my decision to be with my mother the day she wanted to die extremely distressing.

I wanted my mum's death to be a better experience for her, but overall simply wanted them both to not die alone. For them and me both, my most simple and purest wish was for them to not suffer. My want to hold their hand so tightly so that they knew I was with them was essential.

I was arrested a few days after my mother's passing, on a murder charge. I was interrogated by a police officer and received many abusive threatening phone calls. I was constantly harassed by news magazines. My family abandoned me. I was reduced to only a few close friends and I had to vacate my home.

Two years later I was informed that the DPP had decided that I had assisted in my mother's death, however, no further charges were to be laid. I endured two years of quite extreme distress.

Dr Michael Cameron – Mother, Cle, 40s. Metastatic cancer.

She took my advice, and as a result she died as planned. Later I discovered that what I had done was illegal.

Three years earlier Cle had undergone an operation for bowel cancer. When she consulted me, she had just been told that the cancer had returned, in the form of secondary tumours in her liver and lung. These were discovered during routine antenatal care. A termination at 20 weeks had been performed so that she could access further treatment for her cancer. She understood treatment was unlikely to be curative.

Her greatest fear was of losing control over her body in the final hours and days leading up to her death. She asked me to advise her on a way she could end her life, at a moment of her choosing. She said she would know when that moment came.

I did some research and **advised her that an overdose of barbiturate was the best way to achieve a reliable, painless death.** Since I could not prescribe for her, I coached her on how she could obtain a supply of barbiturates, for a fictitious insomnia, from her general practitioner. Within a few weeks she had a supply, which she hoarded. I calculated the dose she would require, based on her body weight and the potency of that particular

drug. When she had saved enough tablets, she stashed them away in a safe place. She was ready.

Three months later, Cle had tried every avenue she could to find a cure. She had completed the palliative therapy prescribed by her oncologist without any apparent benefit. She had flown to Germany to try laetrile therapy. She had spoken to alternative practitioners at home in Brisbane. Nothing she tried had any benefit. **She became weaker, lost weight, lost energy, and lost hope. She now spent most of her time resting at home, supported by her family.**

An episode of shortness of breath saw her admitted to hospital with a diagnosis of heart failure brought on by the tumours in her lungs. Oxygen and medication to make her heart beat more strongly relieved her symptoms. At visiting time that night, her family were treated to a vibrant, energised Cle. She wore make-up, she did her hair and she told jokes and stories, laughing as she had not done for weeks. Each of her family members had time with her alone, to share their thoughts and feelings at an intimate level. When visiting hours were over, she stayed in the hospital and slept well.

The first visitor the following day was her partner, Bill. Cle told him that she had taken the tablets ten minutes earlier. He knew which tablets, and he rushed to a public telephone to call me.

Fifteen minutes later when I arrived at the hospital, she was dead. No autopsy was performed. Cle was buried a few days later.

Dr Barbara Westwood – Mother. Emphysema.

My mother suffered from emphysema and **the last few weeks of her life were just a torture for her** and also for those who loved her, especially for me. During that time, **she begged me to end her suffering.** I didn't do it, but the guilt is still with me.

Dr Geoff Wall – Patient. End stage neuromuscular disease.

A fully paralysed patient on life support with end stage neuromuscular disease who could only communicate through eye movements. Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die.

His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died. If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder.

The potential for litigation is always present and may influence outcome, as in this case where a conflicted family could not reach a consensus and whatever medical staff did would be criticised. The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24-hour machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death.

Current laws failed to protect both this patient's right to control his own fate, and the medical staff's freedom to implement his wishes.

Dr Geoff Tresize – Two patients.

He developed a rapidly aggressive form of multiple sclerosis and within eighteen months had become very disabled and only able to walk with difficulty using a walking stick. **At a visit to his home, in the presence of his wife, he asked me if I would assist him to die. I wanted to but my mind froze with the thoughts of a possible murder trial and the loss of my licence to practice.**

He was a practical man so did without my input. He asked his wife to go into the town to buy some magazines then called the police to say he was going to kill himself so that his wife would not find his body. **He then shot himself. That a man should have to do this in civilised society is a great indictment of the maturity of that society.**

Another case which has worried me is a man in his sixties with late stage pharyngeal carcinoma with all its horrors. I was looking after him in the local 20-bed hospital but I did not bring up to him the possibility of my hastening his death and he was unable to speak due to the choking

effect of the malignancy.

I spoke to his wife after as to whether he would have liked me to help him out and she said, 'Didn't you see him jabbing at his arm like you injecting him?' By this stage I would have **arranged something. There is no palliative care for pharyngeal carcinoma apart from long-term complete sedation.**

Nurse Coral Levett – Various patients.

People's bodies at end of life do amazing things. Bones break. Organs fail. Even our neural receptors, our pain receptors, are hypersensitive, so we may have apparently little reason for pain but yet feel it and experience it. And **often we see at end of life no amount of pain relief can relieve that**, and people will ask the question. They ask you to help them end it, to finish it, to kill them. They will use all sorts of language but there is no mistake about it. People know when they've had enough. It can be very difficult for the nursing staff to, I guess, experience that imploring and begging to assist them to end their suffering when it happens.

Many of the deaths I've seen are extremely undignified. I can assure you **starving to death or dying of dehydration is not dignified**. It's just not. And the levels of pain – **people can scream for the last hours of their death in agony despite very high doses of opiates, morphine and other forms of relief**. It's less than dignified I think when you're in a public place surrounded by people that you may not know very well, when other people can hear you, hear your trauma, hear your suffering, and you're generally in a strange environment. To me that's not dignified.

Nurse Flora Metcalf – Friend. Asbestosis.

I have been overcome with inner distress over the **prolonged inhumane, unrelieved suffering, particularly of the incurable patients known to be terminally ill and in their final stages of life**. Even more sadly, several of my friends have become such patients.

One friend was diagnosed with end stages of asbestosis and was in an acute general hospital for around six weeks then transferred to a nursing home, where he died within weeks.

For the above period he suffered terribly. He never got relief from the constant cough that sounded like he was choking, nor relief or way of removing the huge ribbons of yellow-green-brown tenacious mucus accumulating and dripping from his mouth, throat and nose, and was constantly soiling his pyjamas and bedding. He had no energy. Continuous oxygen via nasal tubes seemed to add discomfort and annoy him with his unbearable, unrelieved, dreadful pain. Loudly he yelled out with the pain, and for staff who rarely responded to him, perhaps knowing they couldn't help him.

After being transferred to the nursing home he continued to thrash around the bed so much that his leg nearest the wall was bleeding from deep abrasions, caused by him desperately and repeatedly hitting it. He did a lot of screaming out with the pain, and 'can't someone help me?'

Too often pain breakthrough occurs in the suffering, terminal patients already receiving analgesia. With disbelief I observed the above situations also in acute public and private hospitals, some also under palliative care, and in 'modern' aged-care facilities.

Dr X – Mother. Stomach cancer. Woman with vulval cancer.

I have witnessed the illness, suffering and deaths of many patients over the years. Many deaths have been well managed with palliative care but **there is a misconception that modern palliative care can alleviate most suffering and allow a dignified and reasonably comfortable death in nearly all cases. This is simply not so.**

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients. **Patients can suffer both physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids.**

In my mother's case of linitis plastica (a form of stomach cancer), she had absolutely intractable and intolerable nausea and could not eat, and **this was not adequately palliated despite maximum**

involvement of palliative care services. It was dreadful to see her suffer without adequate relief. She asked me several times to be put out of her misery but she had to endure it to the end.

I can recall several other patients who were unable to be adequately palliated. In particular, I vividly recall one unfortunate young woman. She was dying of advanced vulval cancer and had the most awful ulceration with severe pain at the slightest movement or touch and offensive discharge, bleeding and odour. **Fifteen years on her suffering still makes me feel sick. Nothing except death gave her release and death did not come peacefully despite morphine and palliative care.** Patients dying of advanced motor neurone disease are also faced with unbearable suffering, witnessing in full alertness a body that is paralysed and fearing choking to death as they lose every last vestige of independence and dignity. For some this is intolerable, yet our society demands that they endure the full course of their illness no matter what their wishes.

Dr Alida Lancée – Patient, 80. Emphysema.

Some five years ago, a 55-year-old woman came to see me in my clinic. She was distraught and desperate for help. She explained that her mother, who was in her 80s, had severe emphysema, was breathless at rest and any activity caused her to gasp for air. The respiratory physician had suggested home oxygen and inhalers, none of which relieved her severe breathlessness.

She went on to explain, through tears of distress, that on three occasions she had found her mother in bed with a plastic bag over her head. The bag had not been tied effectively and her mother's suicide attempts failed each time. Did I have any suggestions to help, she asked?

What to do? **My bags of tricks in my palliative care repertoire are mostly useless for severe breathlessness. I could try low dose morphine, but this would create hypoxia and confusion which would be very distressing in itself.**

I went to visit the mother, who lived with her daughter on a rural property, and confirmed her medical condition to be terminal and associated with severe distress. The mother confirmed a

passionate wish to die and end her suffering, and a mental state examination confirmed she was of sound mind.

Over the coming weeks I did try the morphine to allow at least an attempt at symptomatic treatment and to give me, the patient, and her family, time to consider her options. The treatment did not relieve her symptoms and the mother was persistent in her wish to die.

After confirming the family's support of the mother's decision and their support for my position from a legal point of view, it was decided for me to arrive at 6.00 one morning to provide a lethal injection with the family by her side. The mother died a beautiful peaceful death with a smile on her face.

Dr Cheryl Wilson – Friend, Diane. Metastatic breast cancer.

My friend, Diane, would not follow the doctors' advisement to go home to die when she was diagnosed with advanced metastatic breast cancer.

She was determined to fight this cancer. She had two young boys, a loving husband and a life worth living. The second oncologist agreed with the first but finally supported Diane's decision to fight and arranged for the chemotherapy and radiation. She was given four to six weeks to live. She lived ten years. We made a joke about doctors' prognoses; 'You've had so many expiration dates stamped on you!' I said. And we laughed as she lived past those dates. It was a hard ten years. Repeatedly the cancer returned and she fought back again and again.

I am still deeply affected by the memory of how she had to die. When her time came, **her bones were riddled with metastases and fractures. Breathing broke her ribs.** Can you imagine this type of pain? Multiple fractures throughout her body. I can't imagine it. No-one should be forced to live through it. I will never forget her words the day I called her at the hospital. Without saying hello or the usual pleasantries one begins a phone call with, my dear friend, the strongest, most courageous woman I have known immediately said, **'Oh my God Cheryl, my body won't stop. My body won't die. Oh God, Cheryl.' I'll never forget**

my friend begging for her agony to end.

She had lived with a great deal of pain and suffering from chemotherapy, radiation, surgeries and metastatic fractures and met it head-on with humour and strength. She was inspiring.

I cannot comprehend the torture she would have gone through. She didn't deserve that. No-one does. It was completely unnecessary. No-one benefited by forcing her to have to live that last month.

Jason Tangen – Wife, Melanie, 38. Pancreatic cancer.

I am an Associate Professor in cognitive science and my wife, Melanie, is a Lecturer in Science Communication... well... she was. At the moment, she's lying next to me in her hospital bed slowly dying from pancreatic cancer. She's 38. She was happy, authentic, fiercely intelligent, and loved her friends, food, wine, and words. It was a privilege to share the last 20 years with her.

It has been 10 days without any food or drink and she has now deteriorated to just a shell of the woman she used to be. She's not in pain. We've ensured that there's enough methadone coursing through her veins to soothe a small nation, but it's hardly dignified—she would not have wanted to go out like this.

I spend my days teaching The Science of Everyday Thinking, and it turns my stomach to hear Melanie's nurse ask whether we're waiting for anyone to arrive—because that must be why Mel continues to 'hold on'. As if she could slip out of consciousness simply by wishing it.

There was no explicit 'decision' to stop food and drink per se. Melanie just gradually stopped eating and drinking. First, she could only tolerate mango, apple sauce, or an icy pole. Eventually, she'd end up just throwing them up, even with her nausea medication. She could tolerate sips of water or ice chips for a bit, but eventually stopped asking for either. She just slept for longer and longer periods, and eventually she just didn't wake up. She was on a syringe driver by this point, which slowly administered methadone, a sedative, and anti-nausea meds subcutaneously. I asked the palliative care doctors to increase her methadone because

she'd wake up at night groaning and distressed – it seemed like she was in pain. They were happy to oblige.

From that point on – about 5 or 6 days – she just slept and got weaker and weaker, and just withered away.

I should say that I don't want to vilify her palliative care doctors and nurses. They were absolutely heroic during this entire process.

They genuinely cared for Melanie and myself and wept by my side when she eventually passed. This hands-off process where they just treat her pain, symptoms and keep her as comfortable as possible is just standard care. Everyone knew about the timeline of symptoms as she approached death: the 'death rattle', mandibular motion, radial pulselessness, etc. They explained them all and kept reassuring me that she wasn't suffering.

I have no doubt that she'd prefer to die much earlier in this process, but I honestly don't know when that would be. There's no easy decision rule, even in hindsight. I'm actually struggling with this at the moment because I want to leave very explicit instructions for my loved ones and doctors if I'm ever in the same situation. But I'm finding it nearly impossible to point to the precise moment where I'd say enough is enough. **The last five days or so were particularly bad. There were very few signs that Melanie was conscious at all, and letting her lie there gasping for air just seemed cruel.** But then her eyes might open a bit and I'd get a faint sign that someone was in there, and I just couldn't imagine making a decision to end that glimmer right up until her last breath. If the shoe was on the other foot, and I was in Melanie's position and had to decide when to pull the plug, I don't know if I'd sacrifice those last intimate moments we had together in her final days, snuggling in her tiny bed and weeping in the dark.

Graham Lovell – Wife, Susan. Melanoma / metastatic cancer. Victorian Inquiry.

My beautiful wife, Susan, my dearly loved wife of 40 years and mother of our three children, **died a terrible death in the Alfred hospital on 24 October two years ago. She died of thirst. She had no liquids for six days until she died.** I stayed with her day and night at the Alfred hospital

and had to fight to get morphine for her to prevent pain and suffering. It was a very difficult period.

This committee has already heard about doctors and nurses being afraid to provide sufficient pain relief medication to dying patients, and that was my experience.

Susan's story has been documented extensively in a confidential submission to this inquiry. The reason I am presenting today is that I do not want to see other totally vulnerable people suffer and die in pain, as Susan did. It is not appropriate.

The cancer spread to her brain, and she had brain surgery in August 2012, November 2012, February 2013 and September 2013. She had radiotherapy and terrible chemo treatment with interferon and temozolomide, as well as a range of other medicines. I can assure you interferon is a very nasty drug. It drove her to suicidal depression.

I found a knife, a boning knife, in the glove box of her car.

Susan had a hip operation to bolt her femur together two days later. The shock of the two operations was too much for her. Her system could not handle it. Her digestive system shut down, a condition known as ileus, and stopped food passing through and just blocked up. Over the next two weeks all attempts to get Susan's digestive system working failed and she became progressively weaker. She went from a situation where she was able to push herself up in bed using one leg to not even having the strength to do that.

Susan was declared palliative by the Alfred medical staff on 15 October 2013. At 1 o'clock on Friday, 18 October, Susan started shaking and had a seizure. She was no longer able to move, to talk or swallow, but she was able to respond to questions by squeezing fingers placed into her hands. There was no hope for Susan, and the medical decision was made that she was to die of dehydration – that is, given no fluids until she died. I have no problem with the decision that she was to die. She was finished. I have no issue with that. It is how she died that is of great concern.

Everyone was shocked to find that Susan was in pain and we were ignorantly sitting there, believing everything was all right and her pain relief was

being controlled, and the hospital staff were not providing adequate pain relief to prevent suffering.

After that I insisted on morphine for Susan, as she cried out in pain due to the broken hip whenever she was turned in bed. In addition, **Susan's tongue was raw, as the skin had come off, her lips were cracking as she was breathing through her mouth and could not moisten or close it. The frequency and dosage of morphine was much less than the 5 milligrams per hour authorised by the medical staff, as Susan was typically given parsimonious 2.5 milligram doses at extended intervals, so she was effectively going in and out of pain. Instead of proactively working to prevent Susan's pain, the staff gave Susan very little morphine because she did not and could not tell them that she was in pain. I would be there with her, and she would be crying and calling out in pain every time she was moved.**

At 2.00 am on Sunday a nurse took exception to my request for more morphine and summoned the doctor.

On Sunday morning I asked for a syringe driver for Susan, which I only learnt about from a nurse through the night, so she could have continuous morphine. After much delay and procrastination this was fitted, but with a token dose of 10 milligrams per 24 hours, which would basically shut me up.

On Monday, 21 October, the palliative care staff were back and they tripled the syringe driver dose to 30 milligrams per 24 hours at my request, but Susan was still crying out in pain when moved. It is not only the moving, of course; it is the pain that she was experiencing between the moves, which we had no ability to assess, but from what had happened previously we were pretty sure she was in pain through that.

As Susan's body dehydrated it tried to extract every possible bit of liquid in her system. Her stomach, which had been bloated and very firm due to the blocked digestive system collapsed and became concave. As her body tissue dehydrated, her loose skin was pixelated, with numerous small flat spots, so cream was applied. Her urine flow progressively slowed,

and the concentrated urine was a dark orange colour before the flow finally stopped. Susan's mouth and tongue were raw and her lips cracked, so water spray and cream were applied regularly.

On Wednesday night Susan was desperately gasping for breath, as her desiccated body tried to pump her thickened blood through her system. This gasping became progressively worse in the early morning, and she was given morphine and a sedative. My beautiful Susan died at 3.00 am on Thursday, 24 October, as I was stroking her hair.

After watching Susan die so horribly over six days, I consider that she died a barbaric death.

I hate to think of how terribly Susan would have died if I was not with her for those days. In a civilised society human beings should not be forced to endure such pain and suffering when they are most vulnerable before death.

In a situation like Susan's, I see nothing at all achieved by having her die for six days from thirst and putting that person in such a vulnerable situation at the end of life through that trauma. I say nothing is gained for her, for the family. It is just devastating for everyone, and she had a terrible death.

Bev McIntyre – Partner, Rudi Dobron, cancer.

Victorian man Rudi Dobron, dying of cancer, whose suffering had reached such a crescendo he determined that he wanted to die.

With no quick means to end his life – the disease meant he could no longer swallow – Rudi invoked his legal right to end it as quickly as he could, by refusing all food and fluids.

He described his decision this way:

'I am dying of cancer of the throat. I can no longer control my bowels nor eat or drink. If I was a pet, I would have had a peaceful injection days ago. But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks.'

Seeking support in this difficult choice, he entered the Caritas Christi palliative care unit, having been assured that he could expect to die quickly and with minimal physical suffering.

Rudi's medical records, obtained through Freedom of Information, are detailed in the book *A Time to Die*. They show that, **despite exhibiting ongoing symptoms of physical, psychological and existential suffering, he did not receive 24-hour sedation until 32 days after he entered hospital. He eventually died a further 15 days later.**

All this, as the book's author says, taking place, not in a desert, but:

'In Kew, with all amenities at hand.'

Debbie Smith – Mother, 53.

Metastatic breast cancer.

My mother was diagnosed with breast cancer in 2005. She was 45. She had an emergency mastectomy, chemotherapy and radiation. For a time, she was in remission, but the cancer returned with a vengeance after it metastasised. Mum fought cancer for a period of eight years, with everything she had.

Her biggest complaint was her bowel, it just wasn't working due to her abdominal tumours and it gave her more pain than any person should ever have to endure. My mum would often say to me that she was scared of how she would die; she did not want to die in pain. I assured her that she would not and that we would trust that the system would take care of her and I would not leave her side. Well I was half right, I didn't leave her side, but the system did not keep her from suffering. **At that time, I didn't realise what our current palliative care system is legally bound by; I assumed that people would not be in pain and suffering at their end. A perfectly reasonable presumption, as it was common sense. I was wrong!**

We trusted that the system here in Australia would protect mum and provide relief from suffering, until nature took its course. That's what we were promised when she entered the Palliative Care facility in her final months. We were assured that mum would receive what she needed. We were told what we wanted to hear, but as the weeks went on we realised there was a catch. Mum had to be well enough to ask for pain relief and express her symptoms: i.e. pain, nausea, insomnia, anxiety, migraines, etc.

The problem with this was that the very same

drugs that were given to relieve her suffering, also made her incoherent and drowsy, limiting her communication to crying and moaning in pain, and unable to speak. Although, her pain was evident even when she was incoherent. Each time the drugs wore off, she would become lucid, terrified and traumatised from her experience, with the pain and the side-effects from the drugs, which included hallucinations.

Each time she came around, the process began again. There came a point where she was so highly medicated and so close to death she couldn't communicate verbally, let alone open her eyes. This rendered her unable to ask for more pain relief. From this point the pain went on without intervention, as it was assumed she was no longer suffering, because she couldn't tell us with her words, but she would squeeze my hand in a desperate attempt to communicate.

Before she became incapacitated, she had shared the intricate details of what she was experiencing. Her bowel had not worked for some weeks she was completely compacted. The pain in her abdomen alone was excruciating. She had cancer in her bones, she was so fragile that when she rolled over in bed one day, she broke her ribs. Her head ached, as the cancer was also in the bone of her skull. She experienced a blood clot in her upper thigh, which naturally alarmed us, but the shock of the words of her doctor truly floored us. He said 'we can't do anything about the clot, and it might speed things up for you'. Only more painkillers were offered and mum was left waiting in fear of what would get her first. She shuddered at the sound of the elderly man in the room next door, who was drowning within. His guttural coughing and painful moans left us all distressed. Unfortunately, that sound was all too familiar to mum as she had nursed her own mother to her death, from the same disease (breast cancer), in the midst of her own cancer battle.

... you get to a point where a person you love is starving, scared beyond relief and suffering excruciating pain but you can't help. There was nothing we could do, except drip feed her enough drugs to keep her momentarily knocked out, but

not enough to put her in a coma as this is illegal.

There are no words that adequately capture the helplessness we felt. It was soul destroying. A tightrope of fear and doubt, that at any moment we would find ourselves in regret, that perhaps we should have done more. The reality is, her fears became fact.

Even in a state of sleep she was suffering, she just wasn't able to tell us. Any person watching on could see that she was in pain. Her face was twisted, her body twitched and she moaned and whimpered. We know she was in pain, because she told us many times in her lucid moments. Often, that is all she could say.

My mother died after almost 6 weeks without food and I will be forever haunted by this experience. By the end she was a skin-clad skeleton.

Mum went on for over a month, on a diet of painkillers and ice chips. **During our interview with ABC, another man told me his grandfather was in his 90s and went 90 days without food waiting to die.**

It's worth noting that the doctors were as helpless as we were. They said they couldn't do anymore for mum, as it was not legal. Bound by protocols, they wanted to help end mum's suffering, but would have to face charges and risk losing their medical license if they did. After this experience it is now crystal clear to me that law reform is the only way we can give palliative care doctors the protection they need to act and most importantly, comfort and ease the burden of suffering for those who await an unavoidable death.

Heather Bell – Mother, Alison. Neurodegenerative illness.

In the space of two weeks [my mother] had become completely bedbound. She couldn't eat solid foods at all. She was struggling to speak and she was being put on a lot of painkillers. So, for the next seven days I slept on the floor next to her bed. She became in steadily increasing more pain and came to the point where we needed to put in a butterfly clip for morphine and then of course those morphine injections became more and more

frequent until it in the last few days I had an alarm set on my phone every two hours that was titled 'morphine', **and I would wake up every two hours to my mother's screaming in pain.** And we would rush around finding the one registered nurse in that whole building. She would have to come and bring the morphine and I would spend 15, 20 minutes trying to soothe my mother, stop her screaming, stop her crying, stop her writhing around while the morphine kicked in. And then she would sort of go slack-jawed for another two hours, moan a lot in her sleep. So, I'm not under any delusion that she wasn't in pain during her sleep; she certainly was. And then sort of just lie there for the next two hours and wait for it to start again. And then on her last day I was holding her, because I think I knew and the nurse knew – we all knew it was the last night. **She weighed about 30, 35 kilograms; her shins were like razorblades under the bed. There was just – you could feel and see every bone in her body.**

HB: That was about seven days that this whole injections of morphine thing went on.

AD: Do you think there's any way in that last week where your mother could've been helped and not had any pain?

HB: I can absolutely tell you – **my father's a doctor, I'm a medical student – we were surrounded by the absolute best doctors, the best nurses. No-one wanted her to be in pain. If there was anything that could have in this world been done to alleviate her pain even the tiniest bit more, it would have been done.** There is absolutely no way, and I can say that absolutely.

HB: I was standing there watching my mother take last breaths and groaning even as she did so, and I watched the grey creep up her fingers until her entire body went grey. And then I came back half an hour later after they'd removed the catheters and everything and wiped the blood off her lips, because **her lips were so cracked and dry and everything was bleeding and there was conjunctivitis – just layers of pus – around her eyes because her body was just so susceptible to infection and nothing could be done. She couldn't close her eyes for the last week they would never close even when she**

was sleeping. And I mean that's something I see all the time I mean I'm terrified of those images. I didn't sleep for an extremely long time. You can't put into words the toll that it takes on someone to see anyone in that state, let alone, you know, the person who brought you into the world.

AD: To whose benefit is someone like Alison kept alive in that situation?

HB: It's not to anyone's frigging benefit. No-one benefited. **The nurses were horrified, and they obviously will go through it again and again.** I certainly didn't benefit. My mum didn't benefit. I can't think of a single person who got anything out of that except for maybe the proverbial man on the moon who got a kick out of the fact that my mother didn't take her own life and so she's not a sinner, I suppose. I mean is that who we're running this little show for?

Anne Hammond – Uncle, Multiple Sclerosis.

My uncle was chief engineer on merchant ships all his life. **MS reduced him to a shell of a man, incapable of doing anything for himself, barely able to speak, who needed to be spoon fed, toileted and put to bed. Eventually he managed to use a kitchen knife to cut his own throat.**

Sadly, his stepson found him, called an ambulance and 'saved' him from dying. Later at the hospital he succeeded in pulling out the IV line and ending his life. It should never have come to that. He should have been able to die quietly with dignity.

Betty Ogle, 84. Pancreatic cancer.

Although the hepatobiliary surgeon said she was medically fit to operate, he advised that the tumour was too advanced for curative surgery. Mum chose not to proceed with surgery. She was then referred to an oncology doctor for discussion about types of chemotherapy, their side effects and unlikelihood of cure or prolonged life span. After a few days pondering her position Mum chose not to proceed with chemotherapy, her rationale was that she already felt nauseated, didn't want to eat and was very tired so she wanted to make the most of her time without chemo side effects.

When it was time for the palliative care nurses to visit, Mum's first request was that she 'go with dignity'. At the time I did not ask Mum to verbally

outline exactly what she meant by 'going with dignity' but I knew her well enough to know that not being able to wash or toilet herself, having bouts of pain requiring morphine and the incredible weakness that end stage pancreatic cancer delivers ... that Mum had reached her point of NO dignity. That's when she asked and HOPED that she could receive an injection to let her pass quietly and quickly on (die).

After being denied her request for an injection to relieve her suffering my mother endured another couple of weeks of intense bouts of pain and wasting of her body known as cachexia. When a continuous morphine infusion was commenced, she turned to me with a hope in her eyes and said, 'Does this mean I will go to sleep now?' I replied 'No, not instantly it may take some time yet Mum, perhaps a few more days'.

Eventually severe dehydration set in, pressure areas formed on her boney hips and she experienced terrible sensitivity and pain from simply trying to reposition her for comfort.

Next came the dreadful night of watching her struggle to breathe with the 'death rattle' and knowing she was still partially aware of all of this. This was not her idea of 'going with dignity' and all I could do was kneel beside her bed and apologise for not being able to do any more for her.

Brett and Diane Godden – Daughter, Cassie. Metastatic Melanoma.

Further tests showed the melanoma had moved into her bone marrow. Doctors said there was nothing else they could do and Cassie bravely made the decision to refuse any further treatment. She knew she was going to die.

She asked for a week to say her goodbyes; doctors gave her four days, saying they could now only make her 'comfortable'.

What rubbish.

Cassie was on huge doses of painkillers and was outwardly unresponsive – but could still feel pain. She regained consciousness long enough to acknowledge she was being given painkillers and occasionally speak to us.

Cassie asked the nurses for 'the biggest dose they

could give'.

On the third morning, she begged the nurse: 'Please tell me this is going to kill me'.

She was in excruciating pain and distress.

She had said her goodbyes, and wanted to go. The distress extended not just to her family and boyfriend, but to the medical staff.

Cassandra passed four days after ceasing treatment. The question of how she wanted to end her life was never broached. It was illegal to help her to die, so the question was never asked.

But having watched her die, hearing her ask for the biggest painkilling dose, and beg 'Please tell me this is going to kill me', we have no doubt Cassie would have welcomed the choice to make an end-of-life decision. Whether she would have acted and ended her life earlier, we will never know. **But if all palliative care can do is keep you in an induced coma until your body gives out, it is not enough.**

Kelly Somerville (Nurse) – Mother, Eileen, 63. Amyloidosis.

Kelly Arnett Somerville says her mother had the epitome of a bad death — drowning in her own blood in a hospital bed in front of her children.

Lucid and in pain, 63-year-old Eileen Keogh succumbed to a rare disease her daughter said robbed her of her quality of life and dignity.

Ms Somerville, a nurse, said there was nothing palliative care specialists could do to relieve her mother's suffering from amyloidosis and months of nauseating agony.

"She was alert, she was in pain and she was suffering, suffering terribly," Ms Somerville said.

"My mum died what I call the epitome of a bad death, she drowned in her own blood ... whilst watching me, her 'nursey', beseeching me with her eyes to help her.

"She was the most important patient I ever had in my entire life and I could not help her. I will live with that for the rest of my life."

Anne Korner (Nurse) – Husband. Metastatic cancer.

My husband had metastatic cancer from Melanoma and died a shocking death, though **he**

was administered morphine but not enough as he was under the palliative care doctors, who really only want to prolong life, which is very upsetting for the relatives.

Lee Packer – Mother.

My mum has just passed after 32 days on morphine, I was so distraught, an animal had more rights.

Pam Miller – Father, 94.

I have spent the last 5 years visiting my 94-year-old father in Queensland ... he died in 19 November.

He lingered unnecessarily for 3-4 days and 'comfortable palliative care' was not carried out for the second day as he was very distressed and quite able to talk to us, and if not for the fact that I was with him, it would have been more distressing for the staff at the nursing home.

At the end of the day I rang his GP and demanded more sedation as he was gasping for air and the doctor was repeatedly telling me he was comfortable.

My daughter experienced the distress of watching him choking for air for 12 hours. I said we would never put her through that.

The nurses at the aged care facility were wonderful. They felt as distressed as us that there was no end of life medication available in 2016.

I feel it is our duty as Baby Boomers to speak up and try to do something so that our children do not have to go through all this when our time comes.

Carolyn Masel – Neighbour, Magda, 81.

In January this year, **my 81-year-old neighbour starved herself to death while living in a nursing home. It took her 56 days to achieve her goal. She died a slow, painful death and her last words to me were 'no-one should try this'.**

Then she had a stroke which paralysed her down the right side. This made her frustrated and angry. She had to sell her car and rely on others (she was fiercely independent).

The weekend after her niece departed, Magda decided to commit suicide using an old blade to cut her wrists, but she cut them the wrong way and the blood clotted.

I could not fault her logic when she told me she didn't want to live any more. She couldn't turn the page of a book, prepare a meal, wash herself or walk unaided more than a couple of meters.

David Cade – Mother. Cancer.

Palliative care did not comfort David Cade's partner's mother, who had a tumour at the back of her mouth. **For six weeks she struggled with the pain of hunger and fought to breathe.**

"It was utterly cruel, inhumane and unmerciful for her to be forced to endure such a situation for those last six weeks," David wrote. "No doubt the nurses and doctors who administered 'palliative care' as the patient moaned in hunger and gasped for breath felt they were doing the best they could to make her comfortable, but in this case her agony continued. 'Palliative care' wasn't good enough. It did not relieve her suffering. The medical staff should have had the power to quickly end what must surely be one of the most awful ways to die."

Carmel Hurst (Nurse) – Mother.

Nurse Carmel Hurst's mother had not only an Advance Care Directive, but had paid for her own funeral. After a cardiac arrest, she was taken to hospital and put on a medical regime to suppress her pain and make her comfortable. Carmel agreed with this treatment, but her mother's pain got worse and worse.

Two doctors agreed 'in an unspoken way' to not do anything that might not lead to a change in care, which would be a de facto means of adhering to her Advance Care Directive and letting her die. But a third doctor ordered more tests as, he said, it was 'the right thing to do', even if it wouldn't lead to a change.

A series of confrontations resulted, as senior doctors ignored Carmel and her mother's Advance Care Directive. Doctors insinuated to Carmel that she was acting selfishly; she believed they saw her not as her mother's advocate but as their opponent. Her mother wanted to die, and eventually did.

But **she was kept alive in unnecessary pain, Carmel believed, because of the arrogance of**

doctors who thought it was ‘all about them’.

**Genevieve Allison – Mother, Alice.
Breast cancer.**

We helplessly waited almost three weeks for our dear Mum to slowly die.

Three weeks too long.

When my mother lost her brave battle with breast cancer earlier this year, she had endured the painful disease for almost six years.

At 170cm tall and just 37 kg, she looked as anyone who was dying would look.

She fought so hard for so many years to stay just that little bit longer with us.

But eventually she made her final decision – she was too tired to keep fighting.

She told us through tears from her hospital bed and we said the only thing that she needed to hear: ‘It’s OK, you can let go.’

I’ve lost count of how many times we would repeat that phrase over the coming weeks. Because even after she had made her decision and we brought her home, the uphill battle had only just begun.

For three heartbreaking weeks, we watched her slowly fade. Her skin greyed and she lost her expression. She couldn’t speak and began suffering from terminal restlessness.

She was constantly anxious and scared going to sleep at night for fear of being alone.

There were several close calls where we assembled on the bed to soothe her cries and tell her it was okay for her to stop fighting. But each time, her body would defy her and she would draw another breath.

We slept in shifts and rarely got dressed, too nervous to leave the house in case we were gone too long.

Angelique Flowers – Bowel cancer.

Angelique Flowers, young Melbourne woman **who dies horribly of bowel cancer despite having sought death with dignity** – a death which horrified her siblings but was ‘approved’ of by her religious parents who believed that a medicated death was against God’s will. As featured in

documentary *35 Letters*: <https://www.youtube.com/watch?v=5DqXGLwmJsc>

**Susan Wragg – Husband, Colin.
Multiple illnesses. Suicide.**

In the weeks before Colin took his own life, **I begged the doctors to put Colin in hospital on a morphine drip because the pain medication was not working any more. All the specialists that Colin saw said that there was nothing they could do any more.** I was refused and told that it would be illegal. The only legal alternative that we were given was nothing short of medical torture.

How can it be legal to keep someone alive to suffer another day but it is not legal to let them go?

Every day was worse than the last and I would like to point out that keeping someone ‘alive’ is not the same as ‘living’.

Colin’s quality of life was zero. I have never known or even heard of someone who had so many diseases some of which contradicted each other.

Colin did not want to die alone and asked me to stay with him and that is just what I did. 20 minutes after Colin told me he had taken the tablets he was unconscious. It took a total of three hours before Colin died and it was horrible.

If that wasn’t enough to deal with, I had four police officers turn up on my door and amongst other things telling me that I would probably go to jail. I must stress I did not help Colin commit suicide I just didn’t stop him. There are many other people like Colin and people should have the right to say how they want to die and have their wishes carried out. In a hospital it would take minutes even seconds and be pain free. On their own the outcome is unpredictable and loved ones are put through the horrible aftermath.

Dean Ingerswen – Father. MND.

At present my father is dying a cruel and miserable death at the hands of Motor Neuron Disease (MND). In the space of just eight months he has gone from an independent, healthy and vital 75-year-old who lived on his own to someone who requires 24-hour nursing. **He can no longer use his arms, meaning he requires someone else to dress him, feed him, shower him,**

toilet him and care for him. He can no longer walk far and recently has switched to using a wheelchair to go further than 5m. He has also reached the point where he cannot stand up without assistance. In the next little while he will lose the ability to walk completely and become bed-ridden, susceptible to bed sores and similar ailments. But worse than that, MND has no cure or effective treatment. Those with MND die due to two reasons – an inability to breathe, or an inability to swallow. So, my father is staring down the barrel of dying via suffocation or starvation, and myself and my family will have to sit by his bedside and watch him suffer. Most frustrating of all, for his whole life he's been an advocate of assisted dying. How cruel that in his ultimate time of need he is stuck in a situation where his worst fears are playing out right in front of us all.

Tony Paul – Wife. Cancer.

My wife was a cancer patient for 12 months. She went through a whole process of going in and out of hospital, because they could not get the medications right. She had a host of allergies. But at the very end, with the cancer generating a lot of fluid, she was getting fluid drained from her body; she was getting fluid drained from her lungs – 2.25 litres out of one lung three days before Christmas.

It made a huge difference once they got it out. That is like three bottles of wine out of one lung. She went and had some fluid drained on the Thursday. On the Friday she was due for chemo, but she could not handle it, so we cancelled it. On the Saturday she collapsed, and by this time she had had a gutful of the hospital where she was being treated. At her express instructions we took her down to another hospital, and they were brilliant. They were up-front and said, **'Your lung's three-parts full of water now. It was only drained 36 hours ago. The more frequently it gets drained, the faster it will refill. We can drain your lung tonight, but it will need draining again tomorrow. What you want to do?'** She said, **'I want to go home and die'**.

It is a shame that she did not have the facility of having her life terminated when she wanted it terminated. **Why did she have to come home on**

the Saturday night and drown, and drown again on Sunday? She was gasping for breath – I could hear her bubble, bubble, bubble – and on the Monday night she passed away. So, there is a lot to it. Basically, a patient should have, especially when death is imminent, that right to say, 'Yes, I have had enough, and my family is around me'. We were lucky we had our two daughters living within a few hundred yards of the house. That was our caring team – the four of us: my son-in-law, two daughters and me. We had a daily roster up at the hospital. It worked well, but it just did not work for my wife, that is all.

Brian – Father. Cancer.

My father starved to death as the tumour in his stomach could not be removed, and no food could get in through the feeding tube. It was slow and painful, **each day he begged for it to end.** Good people are being made to be criminal bringing in illegal suicide drugs. We deserve the liberal value of a choice to end this suffering. I don't want a system where some doctors give extra happy drugs to send you off and some do not. I want euthanasia not to be a lottery, but taken out of the shadows and transparently regulated. People have a right to die peacefully.

Manda Quin – Father, Nana.

I tell everyone this: unless you've lived the dream of looking after a terminally ill loved one and watched them slowly, painfully die day by day, you'll never know the nightmare it really is. I've lived the nightmare. **My dad and nana both would have gone on their terms, not a slow agonising death.** My dad was in so much pain even the bed sheet touching him and the hospital gown hurt him a lot.

Kathleen Skidmore – Mother. Liver failure.

I lost my mother three years ago to liver failure. **I had to watch an active, intelligent woman suffer through losing her mind and her ability to take care of herself.**

Anna Lam – Father. Pancreatic cancer.

I will never forget Grand Final Day two years ago when, at the ripe age of 25, I saw my father take his final, gargled breath. He had been battling pancreatic cancer. **In the weeks before his death,**

I listened to his moans of pain and witnessed him struggle with the simplest things – breathing, going to the toilet, opening his eyes.

I heard my once strong-as-an-ox Chinese father whisper in Mandarin (so that my Australian mother could not understand) that he wanted to die. Everyone should be able to make informed choices about their own life.

Anna Swards – Father. Pancreatic cancer.

I am sorry, but I get cross when people like cancer patient Julie Morgan say she opposes the proposed assisted dying laws ('I don't want to feel like I have to go', 9/12). I am sympathetic towards her pain but she is free to make her choice. I watched my 54-year-old husband die from pancreatic cancer.

In vain he begged for release. The experience has strengthened my resolve to say: You can only decide for yourself.

Lyn Rostirolla – Sister, Nicole, 46. Huntington's Chorea.

Words are insufficient to describe this slow and cruel debilitating degenerative disease. Initially loss of balance, trouble swallowing and slurred speech, closely followed by mental health issues where terrible nightmarish episodes in your mind convincingly become your reality. You believe what you are thinking is real, although to everyone else it is obvious this is not so.

Fast forward four or so years and you can no longer talk, walk, shower, voluntarily move, eat independently or communicate, as you now stay forever more trapped in your mortal body.

This mere existence eventually transformed our beautiful girl into a skeleton shell of a person who relied solely on carers to puree spoon feed, toilet, wash and clothe her. This mere existence lingers and lingers for another four long and hopeless years.

Finally, her jaw refused to open and syringing food and water was no longer an option. It took eight agonising days for her body to shut down completely.

After painfully experiencing her Mother's debilitating disease, our beautiful Nicole pleaded with her family 15 years ago, not to let the disease take her in this same way.

Sitting beside her over the last 24 hours of her life, we were painfully aware that we could not honour her most important wish.

Norma Kelly – Nurse.

Appearance before Victorian Committee.

Sometimes they are not really right at the end, as everyone believes they are. It is only a few weeks since one lady came into hospital, a very old lady who had had mega amounts of treatment because she was advised that this was very near the end, she only had a few days left. She lived for nearly four weeks in awful pain, in awful suffering, and just wanting to go. She said, 'I can't even hear'. Right to die in five minutes, sort of thing. She said, 'Here I am', and she ended up like a limp little rag doll in the bed. I am sorry, but **sometimes it does not matter how much medication you give people, when you turn them over – and you must turn people, you must move them in the bed, otherwise they get dreadful pressure sores – they do respond and they do become kind of conscious for that little while. I have people looking right into my face and begging me, 'Why am I still here? Please can't you do something'.** It is not a very good thing to have happen to you.

Another lady – who was not an old lady; she was in her 60s – had stayed at home, lived on her own, had no family and was going to stay home. Palliative care went there and she could not even get out of bed, so they said, 'You have to go to the hospital; we can't walk away and leave you here'. She agreed; she said, 'Yes, all right. I will'. That went on and on, too. Because – I do not know – she was obviously a strong lady and her heart was strong, **we could not get rid of her pain. Out in the corridor we could hear her groaning and saying, 'Oh, pain'. It was just awful.**

Which brings about another issue. Junior doctors are not in a very good position about this. They are very hesitant to order large amounts of morphine or haloperidol or any of these drugs that are really going to knock the patient out, which is what we really need. They are just fearful of it. The patient keeps what we call breaking through with extra pain, and we cannot get it under control. At 11 o'clock at night I am sitting there with a lady looking at me, begging me to end it – 'Please,

can't you do something? I know you can't, but can somebody?' That is really not good enough.

People are in pain and there are people you just cannot get out of pain.

That is where I am coming from.

Rod Henney – Three family members.

Appearance before Victorian Committee.

I saw my grandfather suffer. **My father-in-law, every time I saw him he would say, 'Shoot me. For God's sake, shoot me!'** I saw my brother-in-law die, and I know for a fact – he had cancer, and they say three months is quick; it is not when you spend three months with someone with cancer – I know exactly what he would have done if he was well aware of where he was headed. He would have stopped it a lot sooner, because they say you are not in pain, but when you get shifted – and I know how tough this bloke was and his face was screwed up like you would not believe – there was something going on. He was not doing it just for the sake of doing it.

Kate Roach – Mother, Zelda. Emphysema.

'You wouldn't let your dog suffer the way I am suffering.'

Those were the words my maternal grandfather said to my mum shortly before he died of cancer in 1985. Full circle to 2016 and my mum was saying the same to me. She had been a strong advocate for euthanasia from when she had to watch her father dying by small degrees over weeks and weeks of endless pain.

My mum, Zelda, had emphysema and an irrational fear of hospitals and doctors. I believe this fear stemmed from watching her father go through such horrifying pain and the doctors not being able to put him out of his misery, even though he was begging them to day after day.

On the 15th of August 2016 my mum, not for the first time, sat on the side of her bed thinking about taking her own life. What stopped her was not knowing how to make sure as she said she 'did the job properly to leave this mortal coil' without medical assistance to support her. She was terrified that if she didn't do it properly, she would be worse off than she already was.

For my mum her worst nightmare came to pass on 8 September when she couldn't breathe and I had to call an ambulance. This was to be her one and only trip to hospital during her extended illness and it was weeks and months after the time she had long had enough of existing. If not for the terror of not being able to breathe, due to contracting a chest infection, she would never have allowed me to call an ambulance that night.

Over the next week she deteriorated, both mentally and physically, in the hospital until on the 15th of September she took her last breath.

At the end she was only 28 kilos, a skeleton with skin, who finally let go. It breaks my heart all over again to think how long she suffered, how often she had said she wanted to die, how that last month in particular was its own kind of torture for her every day.

Chris Cable – Mother, 83. Peritoneal cancer.

In January 2016 my mother was diagnosed with [final] stage peritoneal cancer – a type of cancer that was both inoperable and terminal. Initially her oncologist said that without chemotherapy she would have 'weeks not months' to live, and that without chemotherapy, there was no hope that she would make her 60th wedding anniversary in January 2017.

After accepting the hope that chemotherapy gave to prolong her life, the initial treatment started in early February, and lasted for a period of nine weeks. Every couple of weeks, Mum would get a report from the oncologist, indicating that the progress was 'going well'. However, at the end of her treatment, the prognosis was that the chemo had made very little difference, if any, and that perhaps a further treatment of a heavier duty chemo might be appropriate. The doctor advised this may or may not assist, but would also most likely impact on her health adversely for the duration of the treatment, including the normal chemotherapy side effects (hair loss, nausea etc).

At this stage (April 2016) Mum was 83, and decided that enough was enough – and that the treatment she already completed was all that she was prepared to put up with. For the next period she wanted to just be as healthy as possible,

not have the side effects that the treatment would inflict. Mum wanted to be with the family. However long she had left.

At that stage palliative care was arranged, with a number of doctors assisting her with pain relief and dealing with the side effects of the cancer including (but not limited to) stomach problems, bowel problems, blood clots and sleeplessness. At one stage she was taking around 20 tablets each day for a range of issues that were the result of her cancer.

While Mum was well for a few months she deteriorated very quickly in late August–early September 2016. **During this time, the family watched her waste away in pain and discomfort. It got to the stage where she could not walk and even struggled to eat or drink.**

Watching someone go through this period has fundamentally changed my life and approach to how much people can suffer despite the best attempts by doctors. **‘It’s very hard to die’ was the palliative care doctor’s candid assessment of her progress during the last part of her life.**

Mum knew that at some stage she would get to a point of not wanting to be around. While some people think that this might be at the diagnosis stage of the illness, Mum had quite a few nice months of a largely comfortable existence enjoying the family, and spending up big on the grandchildren.

Toward the end of her life, while she was still of very sound mind, **Mum had clearly had enough of the consequences of her illness, and wanted things to end.** She asked me numerous times how she could end her life. We all had to back away for fear of being an accessory to suicide. **In the end I got the 3:00am call from Dad saying that Mum wasn’t breathing well and was coughing up blood. No one should see their loved ones suffer like that.** Mum never woke up on that day.

Anne Holland – Parkinson’s Disease.

My mother, Anne Holland, had Parkinson’s disease. She knew that this would eventually kill her but she wanted to get the maximum out of life before that happened. She arranged her affairs and spent four years in nursing home care before she deteriorated.

When she could no longer walk and because my father was also infirm, we moved her to a nursing home where her husband could visit daily. After four years and on one of her ‘good days’, she asked her GP – ‘Can you help me die when I say I have had enough?’ The obvious answer was no, of course, and I saw both fear and disappointment on her face. Just before she got to the stage of not being able to swallow and straight after a speech therapy session she said (read: shouted) to the GP – **‘I’ve had enough! Let me go. I’m hungry, thirsty, incontinent and can’t move, have ulcers and have said goodbye, now let me go!’** I heard her repeat this at least three times in the months before she died. I could see the fear in her eyes and I really wanted to help. Eventually when we could no longer give her food or water because she couldn’t swallow and because she had requested that she not be fed by a tube, **the doctor asked permission to put her on palliative care and explained that this would dull the hunger and thirst issues while they starved her to death (my words) and that she would, if she was lucky, quickly get pneumonia and die in her sleep.**

We gave permission for palliative care since we felt there was no legal alternative. **We are still suspicious that her palliative care was there to make the onlooker feel good, not to substantively help mum. We can’t tell what that was like from her side of the drugged fog but she only cried and moaned a little for about 10 days before she died – the documents would have said of pneumonia but that was far too simplistic.**

When supporting euthanasia, we have to be careful that it’s not the onlookers we are pleasing but the patients. I’m convinced that Mum suffered, she knew she would and no-one knows what went on in her consciousness while waiting to starve.

David Swanton – Mother, Betty. Pancreatic Cancer.

She said, in one of her last phone calls to me, that ‘I was told that it would be painless, and I’m so cranky’.

My mum, Bet to her friends, had pancreatic cancer. From her diagnosis in April until her death in

September there were some bright moments, but we all knew there would ultimately be a downward slide. Even though **she was told that her death by cancer would be made painless, she interpreted that as meaning that there would definitely be no pain or suffering, and was confident that would be the case. Unfortunately, she was wrong.**

After medical advice, mum opted against major surgical intervention (though a couple of stents were inserted), chemotherapy or radiotherapy, not that those were really options for someone who was otherwise healthy, but was in her eighties and somewhat frail.

Her poor quality of life in the last months was not the fault of her palliative carers.

Her doctors and nurses at her hospital were professional, compassionate, and according to mum, 'excellent'. All staff were committed and sensitive to the needs of patients in pain and suffering. However, more money is needed for the palliative care hospital system.

Perhaps it is now moot, but **it is interesting to speculate what mum would have done if she knew that she would eventually have two episodes of excruciating breakthrough pain: one requiring dramatic ambulance attendance, and the other while in palliative care.** As well as these pain events, there is also a lack of dignity associated with this disease.

She was toileted and showered, there was a cocktail of pills and suppositories, ongoing and frequent injections of painkillers and antiemetics, cannulas, little vomiting episodes, dryness, artificial saliva sprays (because drinking was nil or minimal), lack of appetite, nil food for the last week, emaciation, and gurgling respiratory infections. And that was in addition to the bowel blockage, the appearance of being six-months pregnant, the threat of possibly vomiting fecal matter, and knowledge that she would not be sedated so that scenario could never arise. And perhaps she should have buzzed the nurses every half an hour for extra pain relief, rather than waiting...

Until the last three days she still had a bit of spark.

At that stage she indicated she would be happy to die then. She was then consumed by the disease, her optimism and vitality overrun as she drifted in and out of light sleep, signalling the onset of the inevitable. There was lots of hand-holding, lots of support, and distress at the discomfort of our loved one.

After her many pain events (minor events though were well managed in palliative care) and suffering, she died in the company of a nurse, while her loving husband and I, her eldest son, were but ten minutes away from being with her. She would have preferred dying in the company of her loving family and relatives, and preferably at home. Who wouldn't? If she could have chosen her time of death, then the family could have been there for her. The extended family has been devastated.

Bet suffered more than I could or would wish to endure.

Many patients would benefit if increased funding were made available for the palliative care system, which is more likely if voluntary euthanasia were a legal option. If I were in my mum's position, I would have chosen, intentionally, to die earlier, rather than suffer as mum did. If mum had been better informed and had chosen that option, she would not have suffered as much.

Bill Grace, 60. Lung and liver cancer.

The biopsy confirmed what we'd suspected, it was indeed metastatic. And they told us then that **there was nothing that could be done.**

We were referred to an oncology centre, where it was also confirmed that this was indeed terminal and they concurred with the time frame given. It was suggested that perhaps some chemo might give him a little more time, but even that was uncertain. Bill decided that he would rather take it as it came, rather than undergoing chemo that may make him sick and lessen the quality of life for possibly a bit more quantity.

I have to say that all Drs and staff that we dealt with were wonderful, and supportive. Medication was prescribed for comfort and to alleviate symptoms as much as possible, and we set about making the best of the time we had left together.

The next appointment at the oncology centre

it was suggested that perhaps another dose of chemo might be considered, Bill said no and on this appointment it was suggested that they refer him to palliative care, which they did.

Our palliative care team was wonderful; I am at a loss for words to express my gratitude to each and every team member that joined 'our' journey. During our first visit Bill expressed his desire to remain at home, which they took on board and helped make it a reality.

August came and went and Bill was still with us. Most days were good, a few were not so good, pain relief was available and used when necessary.

He deteriorated further and in August (2 years from diagnosis) and September he was to the point of being hospitalised to investigate sources of pain and re-assessing his meds. By the time a bed was available he had rallied and only went in for a chest x-ray and some blood work, he stayed part of one day and called and said 'come get me', we returned the following morning for the x-ray and when it was determined that his lungs were not filled with fluid he opted to come home and remain on the same pain meds.

The following week, Bill's 60th birthday was upon us, one we never thought he'd see and he decided he wanted to go on a 'cruise'.

Bill began to deteriorate more quickly at this point, and needed additional pain relief. Once again, our palliative team stepped up and introduced us to another amazing Dr, our final palliative team member.

Pain killers became Bill's best friend making life tolerable, but not always pleasant, with me administering injections as needed. We had one last Christmas, and again made more memories surrounded with family and friends.

The final descent began just after the New Year, and decision was made that a syringe driver was necessary to manage the pain, with break through pain managed with additional meds.

Bill's children got to come and see Dad one last time, and we lost him a few days after these final visits.

In this day and age, we are looked upon as inhumane if we don't end the suffering of a much-

loved pet, we should be able to do the same for suffering loved ones. I find it unimaginable that our society does not allow terminal patients at the end of life to have the choice to end their suffering on their own terms.

Justine Martin – Mother. Multiple Sclerosis.

It was a cruel death, and happened over a 24-hour period. She had fluid in her lungs, and my brother and I had to sit there with her. It was traumatic for both of us.

She had a peg [feeding tube] in her stomach, and a breathing tube. She had no quality of life. She had lost the will to live a long time prior to that because of the MS.

She often spoke of ending her own life. She just didn't have the means to do it. Her biggest fear was becoming incontinent.

Brandi Galpin – Father, Neville. MND.

He was diagnosed in June 2015. He died in April 2016.

From the beginning, we were worried about Dad ending up as just a pair of eyes on the couch, and not be able unable to talk or do anything for himself; he was so proud and capable.

We'd never seen him be vulnerable and weak and were scared about that, for him. I had reassured him that I would do anything I could so he wouldn't suffer. And I started looking into assisted dying, and what the possibilities were. I did all the research online and we ended up with a bottle of Nembutal in the cupboard.

The MND affected his lungs mostly, his breathing, so he could still move. But he was getting progressively worse; he started using a walker, and needed help going to the toilet. Mum's a trained nurse and she was able to keep him at home with **visits from the palliative carers; they tried really hard and they did what they could.**

Dad asked the doctor to help him die at one stage, and the doctor said he couldn't help him.

He could only try to make him comfortable. We had the Nembutal on hand but he had so many drugs at the end, it got beyond the point where we could say he was making that decision for himself. He was suddenly on a breathing machine, and it

all went too quickly for us to discuss it. We hadn't planned ahead. We thought we'd know when the time was right and it got away from us.

In some ways, at the end, it was merciful because it was quick. But **he really suffered. We'd hearing this primal groan for air. The machine wasn't giving him any air. It couldn't help him. He had a very horrible last night. He was contorted across the bed. He must have been drowning.**

Eleanor Marsh – Mother, Beverley. Lung cancer.

Eleanor remembers her mother as strong, independent and caring. But Beverley's last days were harrowing.

"It was a horrible experience watching my mum go through it", Eleanor says, "I just wished I could help her.

"She wasn't the type of person to put any pressure on anyone else to look after her. She hated relying on other people."

The last eight days of Beverley's life were horrific for Eleanor and her brother as they witnessed their mother slowly deteriorate.

"It was the most horrifying and painful eight days of my life, and hers. I was told on the first day that she would die and it was just a matter of hours. But she didn't, **she lay gasping for air on a ventilator that was forcing her lungs open.**

"My brother and I were there through the eight days, and we just wanted her to pass because we could see her suffering," she says. "She was not conscious enough to talk but conscious enough just to breathe and moan. It was horrible."

When doctors finally removed Beverley's oxygen mask, Eleanor and her brother watched as she struggled for air. **"At one point she was saying help me, help me.** I gave her a drawing board so she could write down what she was saying, it was all scrambled, but I could still read it, it said "Endone", which was her daily medication that helped ease her pain. **The doctors wouldn't give it to her. They had taken her off all medications, because she was dying.**

"All they could do was supply her with intravenous morphine. Each dose was every two hours, and **when it would wear off my mum would start**

moaning and her eyes would roll. It was so painful to watch.

"I know that her body had started to shut down, as there was only blood in her urine catheter. In the end, at day eight, I asked them if there was anything more they could do. The nurse came in and took off her oxygen mask, we then watched my mum painfully take her last breaths, and then giving up.

"It took about five minutes of her gasping. We watched her take her last breath."

Eleanor says her mum endured an unnecessarily cruel and painful death.

Samantha Lancey – Multiple family members.

Over the past seven years my family has gone through hell watching loved ones suffer. I've lost three grandparents, an aunty and a close friend and they all suffered in the end, some more than others.

My grandfather was the first to go, he had cancer and it spread to his brain. I remember lying on the bed with him at his home looking at photos and laughing, then he screamed in pain. **His whole body was tense and you could see the tears running down his face from the pain,** I cried with him. He told me that if he was a dog, I would be charged with cruelty for letting him go on like this. **Pa was put into hospital and lived for another few months and the pain and suffering got worse, the more advanced the cancer got on his brain the more my grandfather became someone I didn't recognise mentally and physically.**

My grandfather was a very intelligent, kind and artistic man who **died a very confused, agitated and nasty man of skin and bones.** He would have been so ashamed of that.

My beautiful independent aunty was diagnosed with Motor Neurone Disease. It took them 16 months to diagnose it and she died within seven months, she was only 62. I'm not even sure I can put into words how debilitating this disease is and to watch someone go through it knowing there is no hope is just heart breaking. The problem with this disease is that your mind is still perfect but your body lets you down.

My aunty was put into care and we would visit regularly. I will never forget the day when I went to see her (at this stage she couldn't talk anymore and was getting fed through a PEG) she was just lying in bed and when I walked in the door she didn't even smile. She always smiled when I saw her. She leant over to get her note pad and her gown slipped off her back a bit, **I could see her spine and it looked like something from a horror movie.** I still have nightmares of it. She got her note pad and wrote 'I wish I was brave enough and capable to stop this'. **She died alone in palliative care, in pain** and not surrounded by people that love her. How can this be right?

My other grandfather died on the 3rd September 2016. This broke me. It's the first time in my life that I thought I could actually kill another person.

These are just a few things and feeling that we went through over the years, it's hard to put it all into words. **I must tell you that all the doctors, nurses and care staff that we have dealt with over the years have been amazing and I feel sorry for them as well, it must be very frustrating to watch people suffer knowing they would do something if they were allowed.**

My Pa and I always had a special bond, I just adored him. He fought in World War II and was my hero.

I myself am not scared of death but I'm petrified to think that I could suffer like they did.

Julie Wearing-Smith – Father, Ian, 86. Multiple Myeloma. Suicide.

On 2 September 2015, after writing a letter each to my brother and me, compiling a list of people and services to contact, and writing a letter to the police, my father set about the lonely business of ending his life. **It would have taken him some time to set everything in place and I can only imagine how alone he felt.** He'd planned an easier ending that in the end he was unable to facilitate.

Dad was 86 years old on the day he became a Queensland Masters Squash Champion in June 2014. A month later, he was diagnosed with Multiple Myeloma.

Dad was never depressed; he was a fighter and he battled that disease. But he could not bear to lose

his autonomy; this to him would be a complete loss of self-dignity. For Dad anything less than being able to care for himself, to walk with ease, to cook without dropping things, anything less was not a good quality of life. To have carers washing him, to lie in a bed for weeks at a time, to be incontinent or incapacitated was not part of his life plan.

I had been staying with Dad, leaving to come home eight days before he decided to take his last journey. He was very unwell; he could only walk a few steps without becoming incredibly breathless and distressed. We had a beautiful weekend in spite of this; I asked him to return home with me and encouraged him to come: he could have lots of good company, I would ensure he would be comfortable and cared for.

'Dad, I am really good at palliative care, I have lots of experience,' I said.

He smiled at me, then gently declined.

Dad saw the oncologist again a couple of days later; he was told that there was nothing more they could do: he was now 'palliative'.

I can only think that on 2 September 2015, or perhaps the day before, he realised he was deteriorating very quickly. He had to act quickly or he'd have been too ill to carry out his elaborate plan. The loneliness of it appals me.

Pam Parker – Father, John. MND, brain tumour.

Dad was 64 and in the throes of planning his retirement when on 10 May 2013 he was diagnosed with Motor Neurone Disease (MND), with the prognosis of 1 to 5 years life expectancy.

Dad kept working for as long as he could however due to his deteriorating health he finished up work and arranged house renovations for his future needs. At this point he had started using leg splints and crutches to move around but nothing was going to stop him from achieving his and Mum's dream of seeing more of the Australia that they loved. So, in April 2014 they set off travelling in their caravan.

Just a few weeks into their journey, on the 10th May 2014, while in Hervey Bay Qld. Dad was taken to the Emergency Department of the local hospital. He was experiencing numbness down his left

arm with a burning sensation towards his fingers, accompanied by dangerously high blood pressure which was hard to bring under control. He was eventually airlifted to the Prince Charles Hospital in Brisbane, where he was examined over several days for suspected heart problems. A full body scan was carried out, and a growth was found in his brain. He was referred to the Royal Brisbane Hospital where he was diagnosed with a brain tumour in a location that was easy to be removed. He was told that without treatment, he could expect to live 3–12 months, with treatment his life expectancy was anywhere from 18 months to five years, and this was based on the tumour alone.

He underwent surgery and the tumour was formally diagnosed as a Stage 4 Glioblastoma Multiforme, the most aggressive of all brain tumours.

Dad's outlook on life didn't wain and he chose to have both surgery and treatment. At this stage, he had no pain and he wanted to live as long as he could.

Since his MND diagnosis in 2013 and during this period Dad's MND progressed up his legs, into his chest, throat and arms. He went from using walking sticks, to crutches, to a scooter, and finally a motorised wheelchair as his strength in his muscles deteriorated.

Dad had notably deteriorated by the time they returned from their travels in September with less core strength to hold himself upright. He was now more reliant on his ventilator due to the muscles weakening around his lungs which meant his lungs wouldn't inflate. He had previously only required this when he was resting in his chair or at night.

Dad's reduced strength meant that he required assistance, even to move slightly in his chair to relieve the pain of pressure from sitting. We would do this as a team, grabbing him by his pants on the front and back and lifting him. Dad wanted his legs stretched and his knees bent to relieve the stiffness, this was also painful.

In mid-October Dad was at serious risk of pneumonia as he did not have the strength to cough up the phlegm from a simple cold. On his way to hospital with breathing difficulty, Dad

described to the ambulance officers what he thought was an anxiety attack about his inability to breathe, as well as a fear of falling when being lifted using a hoist or being rolled over in bed.

Around this same time, it was apparent to those around him that something else was occurring as Dad's speech became more slurred and the left side of his lip was starting to droop. It was assumed to be a result of the brain tumour. On 21 October 2015 after a follow up MRI, Dad was told that the tumour he had been treated for in April had now doubled in size. Treatment was no longer offered. Just seven days later Mum was advised that the tumour was 3.5 x 5.1 x 4.3 cm in size and that we should be planning for a Christmas with Dad in November.

During October and November Dad became even more reliant on the ventilator and needed it most of the time. However, as the muscles weakened in his throat and voice box, he was less able to project his voice, and communicating his needs through the ventilator's mask was even more difficult.

He was constantly sucking on lozenges as his lack of saliva production led to a constantly dry mouth. He was now incontinent and also required support to eat and drink.

In the three days before he went to hospital, Dad developed a severe bladder infection and also had an enlarged prostate. On 10 November 2015, in significant pain from his UTI, Dad was admitted to Calvary Health Care Bethlehem Caulfield (specialist MND hospital) where his pain and deteriorating condition was managed. On arrival at the hospital, we were told to prepare for Dad to pass at any time. His kidneys were starting to shut down and he was passing a significant amount of blood through his urine.

Dad was in hospital for another 18 days until he passed, and over that time he deteriorated such that he could no longer eat, his inability to swallow put him at risk of choking and he didn't have the strength to cough anything up. His bowels had become impacted and he was no longer able to suck on lozenges to relieve his dry mouth which now required regular wetting with a sponge but this had to be done quickly as he needed his mask on to breathe.

He had lost all movement apart from his right arm but eventually even this reduced to a 'thumbs up or down', or a squeeze.

He was in pain from not being able to move his body and then in pain from being gently moved and stretched.

Eventually, he was unable to express if he needed moving, what he wanted moved, if the pain from being moved was too much or what else might be hurting. This inability to communicate was due to the MND and brain tumour and not that he was unconscious or heavily medicated.

One day my brother and I were sitting next to Dad and heard him making noises but we weren't sure if he was in pain or if he was upset. From a 'thumbs up or down' we were able to establish that **he was upset and crying, which was the first time throughout his journey that we had witnessed him cry.** We did not feel we were able to offer much comfort as we could not determine if they were tears of fear or tears of pain or if, in fact, he had something he wanted to say.

On 21 November, seven days before he died, Dad developed small blisters around his right eye, which were diagnosed as shingles. The blisters spread down part of his face and although he was not able to communicate, the pain he was feeling was obvious as the mask he needed for breathing lay directly across the shingle blisters. Upon checking Dad's swollen eye, the doctors advised us that as a result of the shingles, an abscess was eroding the back of his eyeball. His medication was increased to deal with the pain.

During his final two days, Dad pushed off his breathing mask and survived on extremely shallow breaths. On the day of his passing I asked the nurse if today would be the day as his fingertips were turning purple due to a lack of oxygen. She said that it would be, and it was.

Dad died on 28 November 2015 in a room filled with love.

**Lawrie Daniel – Multiple Sclerosis.
Took his own life.**

https://www.gogentleaustralia.org.au/lawrie_daniel

Jessica Edwards – Father, Tim. Mesothelioma.

Tim Edwards passed away 16 February 2018, after fighting mesothelioma to the bitter end for the better part of two years. Tim acquired meso (as he called it) from being exposed to asbestos during a summer job when he was 18 to fund the cost of his university. Almost five decades later the disease took over his body and he could no longer breathe.

Tim approached death as he approached everything in life, practically and with extreme clarity of mind even though throughout his disease he suffered from depression, extreme breathlessness and a never-ending list of painful symptoms from the multiple rounds of chemotherapy and the disease itself. In the final months of Tim's life, **he was in a great deal of pain, could barely eat or drink and could not breathe or function without the support of the oxygen machine. His heart and lungs were surrounded by the cancer, he had multiple pulmonary embolisms and a plethora of secondary medical issues.**

Tim was an outspoken advocate for assisted dying and believed strongly in having the right to choose when and how he ended his life. Tim's passions in life were his family, his dogs, the outdoors and changing the world for the better. Tim's disease progressed to a level that these passions were taken away from him and it was at this point that Tim should have rightly been entitled to call it quits. His disease was terminal. He had only two choices remaining to him – dying well or dying horribly.

In the end, Tim's position on assisted dying worked strongly against him, **with his palliative care doctors and nurses, in my view, under-treating him and one of them repetitively lecturing a grieving family about the illegality of assisted dying (even the day before he passed away). In the final days of his life, we took turns sitting with him and watching his sleep and at one point when he woke up, he looked at me and asked me when they were going to let him go and by them, he was referring to the palliative care staff. All I could do was look at him in tears and say I don't know – this is not the way it should be.**

When Tim passed away the first feeling I had was

not sadness, it was a feeling of immense relief. Relief that his suffering was done, relief that he no longer needed to be **poked and prodded by palliative care staff for no good reason** and relief from a feeling that we had somehow failed him by letting him suffer the way he did in his final days.

<https://dwdnsw.org.au/tim-edwards-choosing-the-moment/>

Yvonne McChlery – Mother, 73. Multiple Sclerosis.

Mum died aged 73 in May 2012, having suffered from MS since 1981. **For the last three years she could barely see or speak, couldn't walk, and was incontinent in both bladder and bowel. As my aunt said, the only thing of Shona's that works is her ears.** I flew to NZ three weeks before her death and met with her GP and the nursing home representative. I put it to them that Mum had signed a NZ Dying with Dignity form that said, in part, 'I fear indignity more than I fear death', and yet **here she was in possibly the most undignified state one could imagine.**

They agreed to take her off all medication at that point. I noticed then she had a little rattle in her chest, and hoped that it might end up in pneumonia. Sure enough, it did. Three weeks later I got a call from the home asking me whether I'd like her to be put on drugs for pneumonia. My brother and I said no, and she died the next morning. At the viewing of her body I was struck by how peaceful she looked. Still a bit wonky from the strokes she'd had, but finally she was no longer suffering.

Hannah Baker – Mother. Renal Cell Carcinoma.

When I was 18, I became the full-time carer for my mother who passed away horribly and tragically from renal cell carcinoma (a form of kidney cancer). **It took 10 months for her to die and not one moment of that consisted of any kind of respite or quality of life,** once she got sick, she stayed sick and I'm sure it was sheer determination and stubbornness that allowed her to live for as long as she did after diagnosis.

I was so young and completely unprepared for what faced us and it has inherently changed who I am as a person.

Sarah McDonald – Father.

My father, a Dr, died last year. **His death was everything he didn't want** but he didn't want to break the law. Eventually the Drs did help us fulfil his wishes but I am **still traumatised by the horror and with guilt about the medicalised torture** that went on. He was a humane, compassionate, loving good man who respected his patients to have the birth they wanted and have autonomy and power as they brought new life into the world.

Dr Alida Lancee – Three Stories.

I was in a meeting with a senior palliative care specialist. She had just completed a ward round in the palliative care ward. She received a call from the ward nurse that a dying patient in her 90s had reduced breathing rate and had become unresponsive after the morphine injection, which she had administered 20 minutes prior for severe pain. The palliative care specialist asked the nurse to administer an injection of Narcan (a morphine antidote) to reverse the effects of the morphine. I asked the specialist why she had asked for the Narcan as this is known to potentially lead to severe rebound pain and distress and the patient was very elderly and dying. **She replied that she did not want the family to think that she had caused the patient to die with the morphine. She agreed that in her opinion the woman was better off not having the Narcan and be allowed to die comfortably, but she did not want any trouble for her or the hospital.**

One of the doctors in our group describes the last days of his father:

"My father died 10 years ago in a Perth Palliative Care Unit. He had terminal bowel cancer and was admitted for terminal care, knowing he would not be coming out – short of breath, emaciated, great discomfort. After a few days, it was decided to relieve his pain via subcutaneous morphine. This essentially put him to sleep, and he was not given any intravenous fluids.

"After 24 hours, he was clearly very dehydrated and I enquired of the treating palliative care specialist as to whether the morphine could be increased as **he seemed to be suffering – restlessness, gasping, dry as a chip. He made it clear that**

this would be seen as hastening death and was not allowed. We therefore plodded on for another 24-hours before eventually he succumbed."

I spent three months working in the Palliative Care Unit at a Perth Hospital. People in the last days/weeks of their terminal illness would be transferred from nearby hospitals. They would have their malignant ascites drained, or an excruciating bone metastasis irradiated, and would die, more comfortably, a few days or weeks later. The situation however was different for one lady. She had pancreatic cancer, was stick-thin, had no pain, no appetite and no energy. She paced the ward (slowly), a quiet but frustrated observer. Toward the end of my placement, she tearfully implored the consultant "when is my time..?" With the permission of his patient (of course) and her family, the head of the unit commenced terminal sedation, and his patient died a day or two later.

Two nurses objected strongly to what he had done and threatened to report him. I don't know whether or not they did, as I left the unit shortly afterwards.

Kay Setches – Friend. Oesophageal cancer.

My dearest friend is now dying! **She has cancer of the oesophagus and is starving to death.** This critical stage has been continuing now for 1 week. Even prior to that Margaret was very incapacitated. It is horrible.

Dr Janet Fitzpatrick – Husband.

Cancer of the liver, pancreas and throat.

A peaceful death at that stage would have been wonderful. Instead **he had 10 days in hospital when he was in pain, his tracheostomy tube was constantly blocked with thickened mucus,** he could not communicate or recognise us.

Jane Haberfield – Uncle, Paul, end-stage cancer. Suicide.

My uncle killed himself this year, Paul. My mum's brother. He had run the end road with cancer. He was 86 ... He lived in Canberra. He was facing palliative care, he was in dreadful pain. So sadly, **he went to a reserve near his home in Canberra and set fire to himself, he was not recognisable** ... and his family went through a lengthy process included DNA matching of one of my first cousins

(his children) to identify his body knowing it could not possibly be otherwise. His wife, my auntie Kay and my first cousins feel strongly, if another humane option was available, he may have chosen this action, he may have chosen palliative care, who knows. There are no words for this anguish.

Dr. Doug Gaze – wife, 53, pancreatic cancer. Mother, 88, stomach cancer.

[Over 26 years] I have witnessed a lot of changes with the growth of palliative care, and that has certainly been a great development and should be supported and improved.

Over my time I have been involved in the care of quite a number of people in their final illnesses, the majority of those being cancer deaths, and some of those deaths have been pretty grueling.

Some of those deaths were very drawn out and very difficult for all involved, and symptoms of course include intolerable pain – but in some respects pain is not the worst symptom because it can be managed generally pretty well – nausea, vomiting, bowel obstructions, severe oedema of the legs, jaundice with the unbearable itching that goes with it, pressure sores, faecal impaction and incontinence, ulcers, confusion, haemorrhage, choking et cetera.

The majority of deaths that I have witnessed have been well managed with good palliative care. It is the ones that were not so well managed that stick in the memory, and those are the ones that drive my views.

One gentleman I particularly remember who had advanced prostate cancer and had been to his specialist. He had secondaries in his spine. His specialist told him there was a risk he would become paraplegic, following which he went home and shot himself. I would rather patients have another way out.

It is important, in my opinion, that the committee understands that although palliative care can well manage the majority of patients, it cannot manage the suffering of all patients, and that suffering is not just physical; some of it is psychological or existential or spiritual.

We do currently practice a form of passive physician-assisted death by withdrawing

treatments and increasing doses of morphine and midazolam, but that process can still take days, sometimes weeks, and can be quite grueling. I do not see a fundamental difference from a more active form of physician-assisted death; I think the intent is what is crucial. But that said, personally I would have great difficulty giving somebody an injection which I knew had the effect of killing them.

I do not see this as a slippery slope, but rather a compassionate response of a progressive and caring society to a very difficult issue

Sue Hendy, CEO, Council of the Ageing, Victoria

We have experiences of that whether that is in the medical system, helping people along with the extra morphine and that fine line between whether that is an assisted death or not versus circumstances where one of our peer educators – we have older people who work as our presenters, and we call them peer educators – had breast cancer return after some years and did not want to go through the full extent of that death, but could not get assistance, **so she took a huge amount of medications and her husband put a plastic bag over her head and a pillow over her head because she did not want to come alive after this medication.**

He was charged, and I think he got a nine-month good behaviour bond or something.

Imagine what his life was like, that that was the only choice they had.

So, there are examples where people, because of the lack of choices, are having shocking deaths, and people around them have to go through that experience.

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PO Box 992 St Ives Sydney NSW 2075
0468 464 360 | contact@gogentleaustralia.org.au

gogentleaustralia.org.au

ABN 61 613 668 643

Go Gentle Australia Limited is a registered charity.

Go Gentle Australia is a health promotion charity founded by Andrew Denton. It was established to help relieve the distress, helplessness and suffering experienced by Australians with terminal illnesses, their families and carers. We are about a better conversation around death, dying and end of life choices, including voluntary assisted dying. More at www.gogentleaustralia.org.au

