

Beyond Pain

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

“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

Introduction

Go Gentle Australia is an expert advisory and health promotion charity founded by Andrew Denton.

It was established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, their families and carers.

We do this through information, education and support, and by encouraging better conversations about end-of-life-choices, **including Voluntary Assisted Dying (VAD)**.

An early focus has been bringing about **law reform around VAD** to give all Australians a right to choose what happens at the end of our lives and not to be coerced into cruel, pointless and avoidable suffering. The implementation on 19 June 2019 of Victoria's landmark Voluntary Assisted Dying law is a significant step forward for Australians seeking more compassionate end-of-life choices.

Although we see VAD laws as essential, we also understand they are just one on a spectrum of end-of-life options.

We strongly support the need for good, well resourced palliative care within the Australian community. Palliative care's aims – to alleviate suffering and to make possible a 'good death', both for the dying and their families – are also Go Gentle's aims.

In the same way, we support **greater use of advanced care directives**, with emphasis on improved education about their importance, in the community in general and in the medical professions in particular.

If laws are to be changed and new public policies introduced, Go Gentle believes it is important that **decisions are made on the basis of careful analysis, peer-reviewed evidence and established facts**, not on who shouts the loudest or has the deepest pockets.

In any debate, if no evidence can be provided to support opinions and other claims, Go Gentle believes they should be ignored.

Most importantly, if evidence is provided, how reliable is it? Who provided it and are there perhaps **undeclared allegiances that are influencing conclusions?**

To help ensure a rigorous analysis, Go Gentle Australia has developed a series of e-books.

The information they contain is drawn directly from Go Gentle's various submissions to parliamentary and other inquiries into Voluntary Assisted Dying and other matters.

The e-books are the most up to date iteration of Go Gentle's research and analysis. All convey evidence that stands up to peer review scrutiny and facts that show the full picture.

We trust you find them useful.

Go Gentle Australia

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Beyond Pain

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

The number one argument we 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]

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?

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

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 standards⁴⁴, 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.**⁴⁵ [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.⁴⁶

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.

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:

⁴³ 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.

⁴⁴ 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.

⁴⁵ 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>

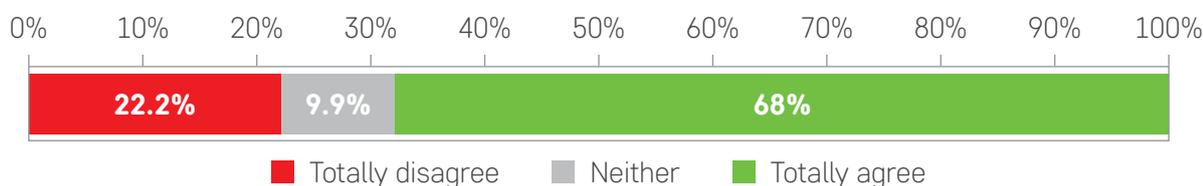
⁴⁶ Palliative Care Outcomes Collaboration, “Patient outcomes in palliative care: National Report January–June 2018”, September, 2018 – <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow252855.pdf>
Our analysis draws on Table 26, page 33 for patient numbers, and Tables 35 and 36 on pages 41 and 42 for measurements of symptom distress.

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.

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 1: 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.

Numerous testimonies from family carers, doctors, nurses and the terminally ill themselves can be found on the Go Gentle website and in the book *The Damage Done*.

Here is just one:

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.

⁵² 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>

- 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 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

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>

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

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

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. [Our emphasis]

... 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.

“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 attest to the limitations of palliative care. Here is just one:

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.

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.

- 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 a 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.

⁶⁰ 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>

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, 2008⁶¹

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*:

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.

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/y2jyl5t4>

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

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.worldrtd.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)

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

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

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

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].

The second problem the Charter⁶⁹ 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."

"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

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>

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.

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 is Rudi's advance 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]

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

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/\(Evidence+Lookup+by+Com+ID\)/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)

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

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/\(Evidence+Lookup+by+Com+ID\)/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)

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 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.

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:

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

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

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

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/>

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/\(Evidence+Lookup+by+Com+ID\)/EEC848CF38BA51AF4825821E000FBFEF4/\\$file/20171023+-+EOLC+-+Sub+530+-+Mr+Douglas+Bridge.pdf](http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/EEC848CF38BA51AF4825821E000FBFEF4/$file/20171023+-+EOLC+-+Sub+530+-+Mr+Douglas+Bridge.pdf)

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.

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-gl7g98.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 Higson⁹⁰

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 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.

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>

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.

- 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 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]

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>

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=PLXQBeKmhJGYzCVQI394Wx7WkTgxlOq1Bk&t=40>

- 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.

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]

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

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>

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 will continue.



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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

