

**Submission to**

**Inquiry on End of Life Choices**

**Select Committee**

**Australian Capital Territory**

**March 2018**



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*Go Gentle Australia is a health promotion charity founded by Andrew Denton to spark a national conversation about voluntary assisted dying. Go Gentle Australia was established to help relieve the distress, helplessness and suffering experienced by Australians with terminal illnesses, their families and carers. We argue for the right of all Australians to have a choice about what happens to them at the end of their lives. More at [www.gogentleaustralia.org.au](http://www.gogentleaustralia.org.au)*

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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 palliative care advocates and, especially, 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

**‘within one’s suffering is an opportunity for growth....’**

- Dr Douglas Bridge, formerly head of palliative care at Royal Perth Hospital, discussing his ‘supreme Christian calling’.

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## 1. INTRODUCTION

**When it comes to Assisted Dying in Australia we are not starting with a blank page.**

- Right now, it is legal, if you are dying, and wish to hasten an end to your suffering, to do so slowly and painfully – by starvation and dehydration, in combination with your disease. This is not considered suicide.
- When your suffering can no longer be controlled, it is legal to be drugged into a coma by a doctor, though entirely at their discretion, depending on their beliefs.
- It is legal to end your suffering by taking your own life. We know now, as a result of the extensive Parliamentary Inquiry which laid the foundation for Victoria's VAD law passed in 2017, that this is happening every week in that State. Brutal, lonely deaths that leave ineradicable scars in the families and first responders left to pick up the pieces. These same stories are now being heard by a similar inquiry currently being held in Western Australia.
- What is not legal 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 Cross-Party Parliamentary 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 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 argue that we can't trust doctors to have sufficient knowledge or skills to assist a patient to die according to strict criteria, but that we can trust them to assist people to die in secrecy, with no criteria or guidelines at all.

It is an argument that defies logic.

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 Voluntary Assisted Dying. 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.'**

Australia's most senior palliative care physician, Professor Ian Maddocks, devoted 9 months to helping write the Victorian legislation. That he did, should tell you what too many in palliative care will not: There is suffering beyond the reach of palliative care - and solely giving more resources to this sector care won't make it go away.

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 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 patients' rights at the end of life, will do so. (**PART B** of this submission – **'Beyond Pain: How Opponents of VAD Work to Make Suffering Within Palliative Care Disappear'** – addresses this in detail).

In October 2017 the World Medical Association revised the Declaration of Geneva, the modern successor to the Hippocratic Oath, which is used across the world by physicians.

The revised Declaration, makes specific reference for the first time to respecting the autonomy of the patient.

It is ironic that this is the first time the autonomy of the patient has been so recognized by doctors.

In all the noise heard from doctors who oppose these laws, we rarely hear a word for those 5% of souls beyond the help of palliative care who suffer so terribly as they die.

Barely a word for the terminally ill who have taken their lives – continue to take their lives – using guns, ropes, knives and worse.

Scarcely a mention of those who have had to watch on helplessly as their terminally ill loved ones die slowly of dehydration and starvation.

Should a VAD law be passed, none of these objecting doctors will ever have to participate.

Their silence on the demonstrated suffering of their fellow Australians - and indifference to the wishes of the vast majority of their patients for more compassionate end of life choices - is as telling as it is disturbing.

There are of course, many doctors, as well as nurses, who support this law (both the Royal Australian College of GPs and the Australian Nursing and Midwifery Federation support VAD as their official position).

While such a law affects them – by legally allowing them to help those from whom they currently have to turn away – it is not about them.

Only a small percentage of us are doctors. But all of us, including doctors will, one day, be people who are dying.

One of the first people I met when I started on this path in 2015 was Eli Stutsman, one of the architects of Oregon's Death with Dignity law (running, successfully now, for 20 years).

When I asked him if some questioned the value of the law because such a tiny number of people – less than 250 every year out of a population of 4 million – use it, he replied:

**“Yes, it’s a tiny number of people. And it always will be. But, one day, one of those people might be you or someone you love”**

It is for everyone - us - that a VAD law will be written. Very few of us will ever need it. But those who do, will do so desperately.

They are the terminally ill. The most vulnerable in our society. Those most in need of our compassion and protection.

Opponents to this law make every effort to drown out their voices in this debate. Look straight past them. Pretend their stories never happened.

But their stories did happen. And they still do. (You can hear them, as well as the testimonies of doctors and nurses scarred by such deaths, in **PART D, ‘In Their Own Words’**).

As you consider the prospect of a VAD law for the ACT, I ask that you keep their voices - and their suffering - uppermost in your mind.

**Andrew Denton**

**Director, Go Gentle Australia**



## 2. PART A: ASSISTED DYING IN AUSTRALIA - A DANGEROUSLY UNREGULATED SPACE

### 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, in different ways in Australia every week, but with almost zero oversight.**

*Please note: This submission is largely built around evidence presented over the three years of inquiries, consultation, and debate, that led to the passing of Victoria's Death with Dignity legislation in November 2017. This remains the most forensic examination of both sides of the VAD argument ever undertaken in Australia. From our extensive research, we have every reason to believe that the picture revealed of the terrible ways in which some Australians die in Victoria – and the reasons why they do - is not particular to that State but is repeated around the nation.*

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### 1. ASSISTED DYING TAKES PLACE IN AUSTRALIA TODAY, BUT WITH NO REGULATION.

The Victorian Cross-Party Parliamentary Inquiry into End-of-Life Choices (2015) found that:

**'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.'**

Research, and doctors' testimonies, over the last 20 years shows that this unregulated practice takes place around Australia

Other end-of-life practices - the foreseeable outcome of which is also death - are similarly unregulated.

According to the findings of the Committee, although widely practised, Terminal sedation - the practice of drugging dying patients into a coma in order to alleviate suffering - is:

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

In this, doctors are protected by the Doctrine of Double Effect where they can give increasing doses of medication as long as it is not their intention to hasten a patient's death.

Doctors sign certificates every day where death was the result of sedation and withholding hydration. Who would know if the doctrine of double effect is shielding abuse or cover up? No one is examining, or vouching for, the doctors' intentions, yet we are told that this system is safer than one where doctors actions are guided by regulations and held accountable by law.

In this unregulated system no questions are raised about threats to vulnerable people. We are asked to take it on trust that doctors know what they're doing and that they're doing it right.

The core of the argument against Voluntary Assisted Dying - that we can't trust doctors to have sufficient knowledge or skills to assess a patient according to strict criteria, but we can trust them to make other end-of-life decisions despite them having no criteria or guidelines at all – defies logic.

It should not be a crime for doctors to help a dying person die peacefully.

And it is not OK to say to doctors 'we think it's safer if you just keep breaking the law'.

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

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

1. Refusing all medical treatment, food, and water.
2. Committing suicide.
3. Being slowly put into a coma by doctors.

### **2 (1). Refusing all medical treatment, food and water.**

It is a person's legal right to refuse all treatment even when this may lead to their death. Such refusal is not considered suicide.

Death by this method is medically supported, with mouth, and other comfort, care. It can be long, slow, and psychologically painful for the person going through it, their family, and the medical team caring for them.

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. '**

In allowing someone the legal right to refuse life-sustaining treatment we have already accepted the principle that a dying person has a right to hasten their own death.

We are just telling them they have to do it slowly and painfully.

## 2 (2). Committing suicide.

Coroners John Olle and Caitlin English, in giving evidence to the Victorian Inquiry, brought to a 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.

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

Coroner Olle summed it up this way:

***"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"***

According to statistics gathered by the Coroner's Office over 5 years, these suicides are happening in Victoria at the rate of one a week.

This pattern was corroborated by South Australian Coroner, Mark Johns, in the podcast Series **Better Off Dead**. You can hear his testimony here:

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/14-australia-s-dark-little-secret>

There is no reason to think that Western Australia is immune from these suicides. They will continue to happen unless the law changes and people beyond the help of palliative care are offered a more compassionate option.

Please keep in mind: In allowing someone the legal right to commit suicide we have already accepted the principle that a dying person has a right to hasten their own death.

We are just telling them they have to do it violently and alone.

## 2 (3). Being slowly put into a coma by doctors.

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

- Ass. Prof. Natasha Michael, Director of Palliative Medicine, Cabrini Health.

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

Under Victorian law, decisions about terminal sedation (when 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 doctor does not require consent.

Professor Michael Cousins, Australia's foremost pain specialist, explains the incidence of terminal sedation in cancer patients:

**'About 10% 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'**

However terminal sedation is not always effective, 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.'**

## ***2 (3) (i) Terminal sedation is ethically the same as assisted dying.***

Dr Erich Loewy, writing in the Journal of American Medicine, explains that there is no meaningful ethical distinction between terminal sedation and 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.'**

**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.'**

## ***2 (3) (ii) 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.

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

We are just telling a patient that only a doctor can decide for them when they have suffered enough.

## **3. NO GOOD CHOICES: WHAT IS NOT LEGAL IN AUSTRALIA TODAY FOR A DYING PERSON SEEKING TO HASTEN THEIR DEATH.**

- It is legal, if you are dying and beyond medical help, to end your suffering slowly – either by starvation and dehydration, in combination with your disease - or by being drugged into a coma by a doctor, at their discretion.
- It is legal to end your suffering alone, and often violently, by taking your own life.
- But it is not legal to end your suffering quickly and painlessly, at a time of your choosing, with the support of your family and medical team

### **3. PART B. BEYOND PAIN: HOW OPPONENTS OF VAD WORK TO MAKE SUFFERING WITHIN PALLIATIVE CARE DISAPPEAR & WHY SIMPLY THROWING MORE RESOURCES AT PALLIATIVE CARE WILL NOT SOLVE THE PROBLEM OF PEOPLE DYING BADLY**

#### **WHAT THIS SECTION IS ABOUT**

**The #1 argument the ACT Inquiry will hear against VAD is that ‘there would be no need for it if only palliative care were properly resourced’. This is untrue. The words and statistics from palliative care tell us so, as do the many testimonies from families of those who have died badly, despite the best that palliative care can offer.**

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**“I think everybody in this committee very much values the perspective of people who are experiencing serious illness. It is going to be very much front and centre in terms of things that we consider.”<sup>1</sup>**

These were MLC Daniel Mulino’s words to Suzanne Jensen, a witness who appeared before the Victorian Parliamentary Inquiry into End-Of Life Choices in 2015.

Suzanne was diagnosed with oesophageal cancer in 2009 and underwent major surgery, chemotherapy and rehabilitation. She was later diagnosed with lung cancer. Her plea to the Committee was clear:

**“When and if the time comes, I want to be able to determine my own exit with some degree of grace and dignity. An exit that will be peaceful and on my terms with the support and assistance of my family.”<sup>2</sup>**

Daniel Mulino was one of two Victorian MLCs to dissent from the majority recommendation that their State legalise Voluntary Assisted Dying.

Suzanne Jensen isn’t mentioned in his dissenting report. She is no more ‘front and centre’ in his writing than any of hundreds of other witnesses from across Victoria who shared their suffering and trauma with members of the committee.

Making invisible end-of-life suffering across the community is a key tactic of those who oppose VAD legislation. After all, if there’s not really a problem, why try and fix it?

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<sup>1</sup> Suzanne Jensen in Standing Committee on Legal and Social Issues, Transcript: ‘Inquiry into end-of-life choices’, Parliament of Victoria, Melbourne, 16 September 2015, p 16, viewed 18 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC\\_Transcripts/Suzanne\\_Jensen-End\\_of\\_life\\_choices\\_16\\_September\\_2015.pdf](https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Suzanne_Jensen-End_of_life_choices_16_September_2015.pdf)>.

<sup>2</sup> Jensen, Suzanne, ‘Submission 549: Inquiry into End of Life Choices’, 28 July 2015, viewed 18 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/Isic/Submissions/Submission\\_549\\_-\\_Suzanne\\_Jensen.pdf](https://www.parliament.vic.gov.au/images/stories/committees/Isic/Submissions/Submission_549_-_Suzanne_Jensen.pdf)>.

## 1. MINIMISING PATIENT SUFFERING AS 'OCCASIONAL FAILURES IN BEST PRACTICE'

A reminder, from the Committee's report, of who they heard from: <sup>3</sup>

- Of 1037 submissions, 925 were from individuals in a private capacity.
- More than a third of all individual submissions, 313 in total, disclosed an experience of someone close to them either dying, or suffering from a serious illness.
- In 56 submissions, the authors disclosed a serious personal illness, the majority being forms of cancer or irreversible conditions.
- 14 of these disclosed experience of another's suicide.
- 9 disclosed experience of another's assisted dying.
- About 6 per cent of individual submissions [58] disclosed that the author is facing their own imminent death.
- 10 cases were presented in which a person was prosecuted for assisting a loved one to die.
- 31 submission authors expressed an intention to end their own life.

The stories were many – some from medical professionals - and in the Committee's own words, often "harrowing". Here are just two:

- **Leith Richards**, diagnosed with Stage 4 primary peritoneal cancer:

**'I have a husband and two sons and the idea of them watching me slowly and painfully waste away and die because there is nothing anyone can do to avert it is emotionally excruciating, almost surreal.'** <sup>4</sup>

**'It would give me enormous peace of mind to know I had some control and to know that I could hopefully spare them and myself a little suffering.'** <sup>5</sup>

- **Lachlan Smith** has glioblastoma multiform brain tumour and has undergone multiple doses of chemotherapy and radiotherapy. He told the Committee:

**'I have been injected, irradiated and infused with just about everything. The end is pretty grim when it happens. I will be victim to a creeping paralysis and increasing loss of cognitive function, until I am paralysed and delirious. There will also be quite a lot of pain from increased inter-**

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<sup>3</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Appendix 6 'Submission evidence summary', pp.293-302; Chapter 1 'Introduction', p. 4, and; Table 6.2, Chapter 6, p. 174, viewed 19 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>4</sup> Leith Richards quoted in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 7.1.1 'People with Terminal Illness', p.195, viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>5</sup> Leith Richards, 'Submission 770: Inquiry into End of Life Choices', 10 August 2015, viewed 19 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/Lsic/Submissions/Submission\\_770\\_-\\_Leith\\_Richards.pdf](https://www.parliament.vic.gov.au/images/stories/committees/Lsic/Submissions/Submission_770_-_Leith_Richards.pdf)>.



**cranial pressure. I will slip in and out of a coma until I die. This process could stretch out for quite some time.'**

In discussing his end of life options, Lachlan observed:

**'By the time life is not worth living we are going to be in no condition to do anything about it; I am going to be effectively blind and paralysed. So I have the choice: when I am still capable but I start to feel I am declining, do I take action then and deprive myself of what could be a couple more months of limited functionality, or do I roll the dice and hope it does not get any worse? Having some surety that if it does get too bad, someone could do something for me would make a very big difference.'**<sup>6</sup>

Summarising these testimonies, the Committee wrote:

**'The Committee received compelling evidence that the nature of dying for people with terminal illness and chronic and degenerative diseases under Victoria's existing end of life legal framework can be difficult and sometimes harrowing for individuals, their families and communities and for law enforcement.'**<sup>7</sup>

Mr Mulino summarised it this way:

**'The potential for very difficult situations to arise towards the end of life was reinforced by direct evidence provided to the Committee. This evidence was received in both written form and through testimony. All of the people who gave this evidence exhibited great bravery in telling their stories. This report acknowledges the importance of these peoples' experiences.'**<sup>8</sup>

Yet, in Mr Mulino's report, *not a single one* of these experiences is mentioned, even though fully one-third of submissions:

**'disclosed an experience of someone close to them either dying, or suffering from a serious illness'**<sup>9</sup>

Instead, he seeks to minimise the suffering he and the Committee have been charged to investigate by describing it like this:

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<sup>6</sup>Lachlan Smith quoted in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 7.1.1 'People with terminal illness', pp.194-195, viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>7</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 7.1.1 'People with terminal illness', p.193, viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>8</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Executive Summary', viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>9</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Figure 6.7 'Submissions that disclose a personal illness'; Appendix 6 'Submission evidence summary', p.193, viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.



**‘A very small number of cases are problematic under current arrangements.’<sup>10</sup>**

## **2. AVOIDING THE CENTRAL ISSUE OF ‘SUFFERING’ BY DEFINING IT ONLY AS ‘PAIN’**

By minimising, or failing to acknowledge, the suffering and trauma in Victoria as a result of current laws, Mr Mulino seeks to raise a question in the reader’s mind: If there’s not much of a problem, do we really need a VAD law to fix it?

He seeks to further narrow the problem by carefully defining it only in terms of ‘pain’.

In the second chapter of his dissenting report, ‘Almost All Cases of Pain Are Currently Manageable’, he 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.’<sup>11</sup> (The underlining is ours)**

Beyond his admission that there are patients for whom pain is unmanageable, 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 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.’**

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<sup>10</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 2.4 ‘Conclusion: A very small number of cases are problematic under current arrangements’, viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>11</sup> Ibid. Chapter 2.1 ‘Pain relief is effective in almost all cases’

<sup>12</sup> Roger Hunt, ‘Submission 779: Inquiry into End of Life Choices’, 11 August 2015, viewed 19 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission\\_779\\_-\\_Roger\\_Hunt.pdf](https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_779_-_Roger_Hunt.pdf)>.

This is supported by Australia's Palliative Care Outcomes Collaboration, which measures the following stressors faced by patients in the dying phase: <sup>13</sup>

- Difficulty sleeping
- Appetite problems
- Nausea
- Bowel problems
- Breathing problems
- Fatigue
- Pain

In his recent 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'.<sup>14</sup>

**Cachexia ('wasting disease'):** the slow disintegration of the body as the cancer cannibalizes 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 and anorexia (loss of appetite):** Often associated with chronic nausea. Among the most common symptoms afflicting patients with advanced cancer ... this complex 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.<sup>15</sup>

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<sup>13</sup> Palliative Care Outcomes Collaboration, 'Patient outcomes in palliative care: Results for Victoria July-December 2016 - Detailed Report', March 2017, Tables 35 and 36, pp.41-42, <<http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow231324.pdf>>.

<sup>14</sup> Martin Cohen, et al, 'Treatment of intractable dyspnoea - Clinical and ethical issues', *Cancer Investigation*, Vol. 10, 1992, p. 317.

<sup>15</sup> 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.<sup>16</sup>

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.<sup>17</sup>

American anthropologist Frances Norwood (*The Maintenance of Life*, 2009),<sup>18</sup> 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.’<sup>19</sup>**

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 body’<sup>20</sup>**

Professor Cassell 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.’<sup>21</sup>** (The underlining is ours)

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.’<sup>22</sup>**

Pain can, in most cases, be dealt with by increased doses of sedatives. This is what Mulino refers to when he says ‘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.

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<sup>16</sup> Ibid.

<sup>17</sup> Ibid., Chapter 4 ‘Advanced Incurable Illness’.

<sup>18</sup> 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.

<sup>19</sup> Frances Norwood quoted in, Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 ‘Suffering’.

<sup>20</sup> Cassell, Eric, *The Nature of Suffering and the Goals of Medicine*, Oxford University Press, 2004, p.xii. Google Books edition, viewed 19 July 2017, <[https://books.google.com.au/books/about/The\\_Nature\\_of\\_Suffering\\_and\\_the\\_Goals\\_of.html?id=BiqTtq5uZZwC&redir\\_esc=y](https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTtq5uZZwC&redir_esc=y)>.

<sup>21</sup> Ibid. p.289.

<sup>22</sup> Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 ‘Suffering’.

*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.'**<sup>23</sup>

## 2.1 Why Suffering, Not Pain, is the Worldwide Benchmark for VAD

While Mulino chooses to focus only on pain, 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 Committee; suffering of people who Victoria's current laws fail to protect. These included testimony from Coroner, John Olle, of violent and lonely suicides as a result of such suffering, happening in Victoria at the rate of one a week.<sup>24</sup>

Mr Mulino makes only passing mention of them. It is relevant to ask why – for a man focused on a balanced reading of the evidence – these cases were not important to him.

## 3. MINIMISING PATIENT DISTRESS: ASSERTIONS THAT 'VERY FEW ASK TO DIE'

Mr Mulino seeks to further 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. He 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.'**<sup>25</sup>

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<sup>23</sup> Palliative Care Australia, 'Policy statement on voluntary euthanasia', Canberra, 2006, p.2.

<sup>24</sup> 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, viewed 19 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](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.

<sup>25</sup> 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', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 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](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Dr Ranjana Srivastava:

**‘... from 15 years of experience ... there have been no more than two or three people at most, in the thousands of patients I have seen, who have said, ‘I have had enough. I want to die.’<sup>26</sup>**

and Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health, who acknowledges requests but deflects them.<sup>27</sup>

Putting aside that it is often nurses who, as primary caregivers, receive requests to die,<sup>28</sup> Mr Mulino’s assertion is contradicted by research from palliative care physicians. Roger Hunt showed that up to 25 per cent of patients considered a hastened death,<sup>29</sup> and, according to Dr Hunt, about 5 per cent asked for it ‘earnestly’.<sup>30</sup>

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.<sup>31</sup>

### 3.1 How Patients in Faith-Based Palliative Care are Discouraged from Requesting VAD

Mr Mulino doesn’t reveal that Professor Hudson and Dr Michael 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 Committee:

<sup>26</sup> Ranjana Srivastava in Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), 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](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Dr Srivastava has written publicly about her faith and her conviction that doctors should talk to their patients about God - Ranjana Srivastava, ‘The question doctors fear most: Do you believe in God?’, The Guardian, 1 September 2015, viewed 26 July 2017, <<https://www.theguardian.com/commentisfree/2015/sep/01/the-question-doctors-fear-most-do-you-believe-in-god>>.

<sup>27</sup> 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’, PP No. 174, Session 2014-16 (Document 1 of 2), 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](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>28</sup> 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>>.

Transcript at Go Gentle Australia website, viewed 19 July 2017, <<http://www.gogentleaustralia.org.au/transcripts1>>.

<sup>29</sup> Roger Hunt, *Palliative Medicine*, 1995, cited in Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 6 ‘Palliative Care’.

<sup>30</sup> 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, viewed 19 July 2017, <<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>>.

<sup>31</sup> 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, viewed 19 July 2017, <<https://www.ncbi.nlm.nih.gov/pubmed/26762669>>.

**'Being a Catholic institution, St Vincent's position is quite clear. It does not condone euthanasia.'**<sup>32</sup>

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 NSW University, 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 hospice brought to patients and their families, when it came to assisted dying he observed that the experience for many was deeply unsatisfactory:<sup>33</sup>

**'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.'**

He 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 instil particular values around what is dignity, what is a good death and can subtly disallow people's opportunity to make decisions for themselves.'**

Professor Broom 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'.**

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<sup>32</sup> 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, viewed 20 July 2017, <[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](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)>.

<sup>33</sup> Axel Broom in Andrew Denton, 'Better Off Dead: Interview with Axel Broom' embedded under the heading 'Hear More', '#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, viewed 19 July 2017, <<http://www.gogentleaustralia.org.au/transcripts2>>.



The disempowered situation patients find themselves in 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.'**<sup>34</sup>

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. Mr Mulino does not supply this context.

#### **4. AN UNDISPUTED TRUTH: NOT ALL SUFFERING CAN BE RELIEVED BY PALLIATIVE CARE**

Having minimised the problem, Mr Mulino then offers only one solution:

**4.5.5: Patients receiving inadequate pain relief or palliative care**  
**'Many situations in which a person requests a hastening of death involve pain management or palliative care that fall short of best practice.**

**... The best response to the occasional failure to maintain best practice is to provide appropriate resourcing to the health care system – including training for health practitioners'**<sup>35</sup>

In support of his claim that it is rare that pain (not suffering) can't be managed, he quotes Professor Daryl Jones from Austin Health:

**'...in 20 years as a clinical practitioner, the number of patients I've seen who die to whom that applies is the overwhelming minority'**<sup>36</sup>

*(In Section [Section 8.1.1](#) of this paper (p.66-67), we will show how this quote from Professor Jones has been taken entirely out of context, which is misleading to the reader.)*

There is no question that palliative care in Australia – amongst the best in the world<sup>37</sup> – can claim a high degree of success when it comes to managing pain. The fact that the

<sup>34</sup> 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, viewed 19 July 2017, <http://www.gogentleaustralia.org.au/transcripts2>.

<sup>35</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care', viewed 20 July 2017, [https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf).

<sup>36</sup> Daryl Jones in Standing Committee on Legal and Social Issues, Transcript: 'Inquiry into end-of-life choices', Parliament of Victoria, Melbourne, 5 August 2015, p 16, viewed 20 July 2017, [https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/FINAL\\_5\\_August\\_2015.pdf](https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/FINAL_5_August_2015.pdf).

<sup>37</sup> In 2015 *The Economist's* Intelligence Unit ranked Australia 2nd in the world (after the UK) on overall palliative care, with a rating of 91.6/100 based on 20 key indicators. (Belgium and Switzerland ranked 5th and 15th in a list of 80 countries). Source: Economist Intelligence Unit, 'The 2015 Quality of Death Index: Ranking Palliative Care Across the World - Key Findings Infographic', The Economist Intelligence

majority, apparently, die well is not the point made by the Inquiry. This debate is not about the majority, but about the small but significant minority who do not obtain adequate or requested relief from palliative care.

What's more, we have a good idea from palliative care's own statistics what that minority looks like.

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 July to December 2016 analyses the palliative care experiences of over 20,000 patients nationally.<sup>38</sup>

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

The latest PCOC report covering the period from July to December 2016, tells us that around 2.3-2.6 per cent of patients in the terminal phase suffer severe distress from pain.

It's crucial to appreciate that this single symptom – pain - would be, almost certainly, compounded by other issues causing various levels of distress. In the six months to December 2016, for example, 357 patients nationally, including 86 Victorians, suffered severe distress from breathing difficulties during their terminal phase.

Both Palliative Care Australia and the Australian Medical Association acknowledge:

**'there are some instances when satisfactory relief of suffering cannot be achieved.'**<sup>39</sup>

There is broad consensus within the medical community that palliative care cannot adequately alleviate the suffering of some patients.

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.'**

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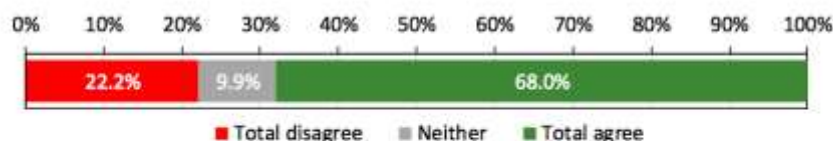
Unit, commissioned by the Lien Foundation, *The Economist*, 6 October 2015, viewed 20 July 2017, <<http://www.eiuperspectives.economist.com/sites/default/files/images/2015%20Quality%20of%20Death%20Index%20Infographic.pdf>>  
Links to full reports are here: <<http://www.eiuperspectives.economist.com/healthcare/2015-quality-death-index>>.

<sup>38</sup> Palliative Care Outcomes Collaboration, 'Patient outcomes in palliative care: Results for Victoria July-December 2016 - Detailed Report', March 2017, viewed 20 July 2017, <<http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow231324.pdf>>. Our analysis draws on Table 26, p.33 for patient numbers, and Tables 35 and 36 on pages 41 and 42 for measurements of symptom distress.

<sup>39</sup> Dr Michael Gannon, 'Review of AMA Policy on Euthanasia and Physician Assisted Suicide', Australian Medical Association, 6 October 2015, viewed 20 July 2017 <<https://ama.com.au/ausmed/review-ama-policy-euthanasia-and-physician-assisted-suicide>>. And: Palliative Care Australia, 'Policy statement on voluntary euthanasia', Canberra, 2006, p. 2.



Nearly 70 per cent of respondents agreed.<sup>40</sup>



**Figure 11:** Palliative care and medical treatment cannot adequately alleviate the suffering of some patients

Source: AMA Member Consultation Report.

### **Figure 9: Australian Medical Association Member Consultation Report - Palliative Care**

Mr Mulino blames the small but significant number of Australians who suffer unendurable pain at the end of their lives on 'occasional failures' of palliative care to 'maintain best practice'.<sup>41</sup> The implication is that if governments just threw more money at palliative care they could make the problem go away. As Penrith doctor, Peter Johnson, said in a letter to *The Age* in 2014:

**'No one working in the medical profession could sensibly deny that good, well-resourced palliative care is a great advance. Sadly, even those who work in palliative care realise, however, the limits to the benefits some patients receive, leaving them distressed, in pain, or otherwise facing a miserable time.'**

**It is about time those who ignore the existence of such patients came up with a practical solution not couched in platitudes, philosophy or the solution that more funding might produce even better palliative care in the future. The simple acceptance of the fact that, sadly, for some there are worse things than dying would be a start.'**<sup>42</sup>

Dr Roger Hunt, palliative medicine specialist and a life member of the Palliative Care Council of South Australia adds further clarification. Like Dr Johnson (above), 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 have multiple concurrent symptoms and other forms of suffering'**

<sup>40</sup> Australian Medical Association, 'Review of AMA Policy on Euthanasia and Physician Assisted Suicide - Member Consultation Report', 2016.

<sup>41</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care: Cases involving inadequate pain management', viewed 19 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>42</sup> Johnson, Peter, 'Worse things than dying', Letter to the Editor, *The Age*, Melbourne, 19 November 2014, viewed 20 July 2017, <<http://www.theage.com.au/comment/the-age-letters/behaving-like-the-spoilt-child-who-wont-share-20141118-11p4o7.html>>.

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.'*<sup>43</sup>

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).'**<sup>44</sup>

There is no, definitive figure for the proportion of terminal patients in Australian palliative care clinics who endure unmanageable pain and suffering. Unlike jurisdictions where VE and VAD are legal, there are no detailed, ongoing, peer-reviewed studies about end-of-life practices in Australia.

But, based on their professional experience - and, informed by relevant data from the PCOC and from overseas - Dr Hunt, Dr Rodney Syme, Dr Rosemary Jones<sup>45</sup> and the late Clive Deverall<sup>46</sup> (founder of Palliative care WA) agree the figure is somewhere in the vicinity of 4 and 8 per cent.

Mr Mulino does not refer to this small but significant cohort of people who suffered as they died, preferring instead to explain their deaths as an:

**'occasional failure to maintain best practice'**<sup>47</sup>

<sup>43</sup> NI Cherry 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>>.

<sup>44</sup> Roger Hunt, "Re P.C. Figures", email to Andrew Denton, Go Gentle Australia, 23 July 2017.

<sup>45</sup> Rosemary Jones quoted in Yasmin Noone, "Doctors in Support of Voluntary Euthanasia", *Australian Ageing Agenda*, 7 March 2013, viewed 20 July 2017, see also Dr Syme's observation in 'comments', viewed 20 July 2017, <<http://www.australianageingagenda.com.au/2013/03/07/doctors-in-support-of-voluntary-euthanasia/>>.

<sup>46</sup> Deverall, Clive quoted in Claire Moodie, 'Cancer pioneer Clive Deverall's death puts spotlight on voluntary euthanasia laws', *ABC News*, 22 March 2017, viewed 20 July 2017, <<http://www.abc.net.au/news/2017-03-22/cancer-pioneer-clive-deveralls-death-spotlight-on-euthanasia/8376890>>.

<sup>47</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care', viewed 20 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

## 5. THE UNACKNOWLEDGED PROBLEM: MEDICAL, RELIGIOUS, AND ETHICAL, QUESTIONS SURROUNDING TERMINAL SEDATION

### 5.1 Terminal Sedation: Unregulated, not Monitored, and without Guidelines

Mr Mulino's case that VAD is not necessary rests on his assertion that virtually all pain (not suffering) can be accommodated by palliative care. However, palliative care can only treat intractable cases by using terminal sedation, a practice defined to the Committee by Dr Rodney Syme as:

**'continuous delivery of analgesics and sedatives by titration\* — a slow and incremental increase — without the provision of hydration, to slowly induce over some days a deep continuous sedation which can only result in death.'**<sup>48</sup>

*\*Continually measured and adjusted.*

Dr Natasha Michael, Director of Palliative Medicine, at Cabrini Health explained its use:

**'Continuous deep sedation is sometimes instituted in people where we feel they have intractable pain that we just cannot manage.'**<sup>49</sup>

In essence, it means that, when faced with unmanageable pain and suffering, the patient is slowly placed into a coma – sometimes, of necessity, without their consent - and kept there, medically supported, until they die.

In the absence of a legal alternative, the use of terminal sedation is not surprising and can, indeed, be described as 'best practice'. As Professor Michael Cousins, an anaesthetist and Australia's foremost pain specialist explained in 2010:

**'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 then, or as much as a week [before the person dies].'**<sup>50</sup>

<sup>48</sup> Rodney Syme in, Standing Committee on Legal and Social Issues, Transcript: 'Inquiry into end-of-life choices', Parliament of Victoria, Melbourne, 14 October 2015, p 25, viewed 21 July 2017

<[https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC\\_Transcripts/Dying\\_with\\_Dignity - FINAL - SCLSI End-of-life choices\\_14\\_October\\_2015.pdf](https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Dying_with_Dignity_-_FINAL_-_SCLSI_End-of-life_choices_14_October_2015.pdf)>.

<sup>49</sup> 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', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 3.10.2 'Continuous palliative sedation', viewed 21 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Quote is from: Standing Committee on Legal and Social Issues, Transcript: 'Inquiry into end-of-life choices', Parliament of Victoria, Melbourne, 16 September 2015.

<sup>50</sup> Michael Cousins, quoted in Julia Medew, 'Pain follows many cancer patients to the end', *The Age*, 12 February 2010, (sourced from News Store archive), viewed 21 July 2017,

<[http://newsstore.fairfax.com.au/apps/viewDocument.ac?page=1&sy=age&kw=michael+cousins&pb=all\\_ffx&dt=enterRange&dr=1month&sd=12%2F02%2F2010&ed=12%2F02%2F2010&so=relevance&sf=text&sf=headline&rc=10&rm=200&sp=adv&clsPage=1&docID=AGE1002129R7957FBJMF](http://newsstore.fairfax.com.au/apps/viewDocument.ac?page=1&sy=age&kw=michael+cousins&pb=all_ffx&dt=enterRange&dr=1month&sd=12%2F02%2F2010&ed=12%2F02%2F2010&so=relevance&sf=text&sf=headline&rc=10&rm=200&sp=adv&clsPage=1&docID=AGE1002129R7957FBJMF)>.

But, as Australia's most senior palliative care physician, Professor Ian Maddocks, explains, terminal sedation is not always effective at relieving suffering:

**'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.'**<sup>51</sup>

Mr Mulino does not mention terminal sedation in his chapter discussing the management of pain. It's a surprising omission considering the Committee's finding that, in Victoria, it is:

**'widely accepted as an appropriate way to relieve suffering for someone at the end of life.'**<sup>52</sup>

In another part of his report, however, Mr Mulino seeks to make much of similar deaths in Belgium and the Netherlands, implying they constitute a 'grey area' which brings into question the safeguards around euthanasia laws.<sup>53</sup>

Beyond the fact that it is not always effective, it is likely that Mr Mulino did not wish to discuss terminal sedation in Victoria for three reasons:

*Firstly*, its existence is proof that there is some suffering at the end of life that can only be relieved by death and which has nothing to do with the 'occasional failure of best practice'.

*Secondly*, we have no way of knowing how widely it is being applied (and, therefore, how often it is needed) because, as the Committee found:

**'Its use is not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it.'**<sup>54</sup>

*And thirdly*, even within palliative care, there are ethical concerns about leaving a dying patient to die slowly rather than helping them, at their request, to die quickly. Ray Godbold, a palliative care nurse who, himself, died painfully of oesophageal cancer (and whose children appeared before the Committee) described it like this:

<sup>51</sup> 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, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

<sup>52</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Chair's foreword', p.xvi, viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>53</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.7 'Failure to monitor what occurs outside the law', viewed 20 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>54</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, 'Chair's foreword', p.xvi, viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

**'I think everybody - if we all sat down on a Friday night and had a few drinks together and people were honest on what their beliefs were, a lot of them would come out and say, 'Look, that was a shocking death. We should have done something else to help', you know... I've been there when lots of people have had terrible deaths that - no matter what palliative care people say, the last 24 to 48 hours of somebody's life can be completely unexpected, you know, and there's only - the only options you've got is to make that person unconscious and then you've got - the family's sitting there looking at this person who's been in terrible suffering, is now unconscious and is going to take hours or days or weeks to die. You know, that's not acceptable I don't think.'**<sup>55</sup>

The question of terminal sedation is ethically vexing for many in palliative care. In a *Lancet* 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'.'**<sup>56</sup>

And the question of whether or not there is any meaningful ethical distinction between terminal sedation and assisted dying continues to be debated. As Dr Erich Loewy writes:

**'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. 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. Most patients are, in fact, sedated and given analgesics at the end of life. Thus the term 'terminal sedation' is, at the very least, misleading and euphemistic.**

**When patients ask for and seem to require sedation sufficient to render them unconscious at the end of their life, there can, in selected cases, be little ethical objection. Patients injected with overdoses of a drug with the intention of causing their deaths or patients kept unconscious with the intent of keeping them unconscious until death ensues are in the end both**

<sup>55</sup> Ray Godbold in Andrew Denton, 'Better Off Dead: #12 Velvet Ray' podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 22 March 2016, (audio) <<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/12-velvet-ray>>. Transcript at Go Gentle Australia website, viewed 21 July 2017, <<http://www.gogentleaustralia.org.au/transcripts2>>.

<sup>56</sup> Janet Hardy, 'Sedation in terminally ill patients', Letter, *The Lancet*, 356 (9245), 2 December 2000, pp. 1866-7.

very much dead. To say that in the former case (the injecting of a drug to directly cause death) death was the intended consequence but in the latter to deny that death was the intended consequence seems, at the very least, disingenuous. 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.’<sup>57</sup>

## 5.2 Terminal Sedation: Total Power in the Hands of the Doctor

Under Australian law, decisions about terminal sedation (when it is employed and the speed at which drugs are administered) are entirely in the hands of the treating doctor.

As Sheila McLean says in the *QUT Law Review*:<sup>58</sup>

**‘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.’**

We confirmed this with Professor Lindy Willmott from the Faculty of Law at QUT who specialises in this area. Professor Willmott replied:

**‘the use of terminal sedation falls within the discretion of the individual doctor based on what he or she regards as good medical practice. This will be influenced of course on the circumstances of the patient. But the practice is not specifically regulated by the Victorian ‘law’. That is, there is no law in Australia that specifically defines or specifically regulates ‘terminal sedation’ or ‘palliative sedation’.’**<sup>59</sup>

If the doctor or institution holds a core belief that assisting someone to die is killing them, the dying patient, too, must face a slow death, regardless of how clear and persistent their request for a quick death may be. Palliative Care Australia acknowledges that there are patients who make rational and persistent requests for help to die.<sup>60</sup>

## 6. THE INFLUENCE OF PERSONAL AND INSTITUTIONAL BELIEFS ON MEDICAL PRACTICE

Having argued that the problem of intractable pain is so small it doesn’t really need fixing - and that the only *real* need is to address the ‘occasional failure to maintain best practice’ - Mr Mulino goes on to suggest that:

<sup>57</sup> Erich H Loewy MD, ‘Terminal Sedation, Self-Starvation, and Orchestrating the End of Life’, *JAMA Internal Medicine*, 161(3), 2001, pp.329-332, viewed 21 July 2017, <<http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/647177>>.

<sup>58</sup> Sheila A. M., McLean ‘Terminal Sedation - Good Medicine?’, Good Ethics? Good Law?, *QUT Law Review*, Volume 16, Issue 1, pp. 113-134, 2016, viewed 24 July 2017, <<http://www.austlii.edu.au/au/journals/QUTLawRw/2016/7.html>>.

<sup>59</sup> Lindy Willmott, ‘Question re Victorian Law on Palliative Sedation’, email to Andrew Denton, Go Gentle Australia, 24 July 2017.

<sup>60</sup> 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.’



**'Before legislating for euthanasia or assisted suicide, it would be appropriate to provide greater support to health care providers dealing with patients at the end of life.'**<sup>61</sup>

There is great merit in the idea of greater resources for end-of-life care. The majority report spent considerable time in discussing – and recommending – just that. Recommendations Mr Mulino supported.

However, in advocating greater support for health care providers working in end-of-life care, he ignores, not only the medical limitations of that care but, also, the elephant in the room.

As Ray Godbold put it succinctly:

**'the doctors have all got their own beliefs and a lot of them have got religious beliefs and that comes into the clinical area at times. I've seen it.'**<sup>62</sup>

According to Cardinal George Pell, Catholic healthcare providers account for 55 per cent of Australia's palliative care.<sup>63</sup> The Catholic church is deeply opposed to any form of assisted dying. Their core belief is in the sanctity of life. For many, the example of Christ's suffering on the cross is extremely powerful, as evidenced by Pope Benedict's (2009) statement on euthanasia which venerates the 'power of life in suffering':

**'Jesus, suffered and died on the cross out of love. In this way, viewed properly, he gave meaning to our suffering, a meaning that men and women of every age have understood and made their own, experiencing profound serenity even in the bitterness of harsh physical and moral trials.'**<sup>64</sup>

Similarly, his predecessor, Pope John Paul II, spoke of the **'salvific value in suffering'**.<sup>65</sup>

The idea of salvation in dying, in a medical context, is best captured by Dr Douglas Bridge, formerly head of palliative care at Royal Perth Hospital.

In March 2017, Dr Bridge wrote a passionate article in the *Medical Journal of Australia* attacking proposed VAD legislation in Victoria on the grounds that it is not a doctor 'assisting someone to die', it is a doctor 'killing someone or assisting them to commit suicide'. The article was co-signed by more than two dozen medical health practitioners, including Dr Natasha Michael.

<sup>61</sup> Daniel Mulino, 'Minority Report', 'Executive Summary', in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care', viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>62</sup> Ray Godbold in Andrew Denton, 'Better Off Dead: #12 Velvet Ray' podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 22 March 2016, (audio) <<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/12-velvet-ray>>. Transcript at Go Gentle Australia website, viewed 21 July 2017, <<http://www.gogentleaustralia.org.au/transcripts2>>.

<sup>63</sup> George Pell quoted in Jane Cadzow, 'Our Man in Rome', *The Sydney Morning Herald*, 16 June 2012, viewed 21 July 2017, <<http://www.smh.com.au/lifestyle/our-man-in-rome-20120610-204wh.html>>.

<sup>64</sup> Catholic News Agency, 'Euthanasia a 'false solution' to suffering, Pope says', 1 February 2009, viewed 21 July 2017, <[http://www.catholicnewsagency.com/news/euthanasia\\_a\\_false\\_solution\\_to\\_suffering\\_pope\\_says/](http://www.catholicnewsagency.com/news/euthanasia_a_false_solution_to_suffering_pope_says/)>.

<sup>65</sup> John Paul II, 'Apostolic Letter: Salvifici Doloris of the Supreme Pontiff John Paul II to the Bishops, to the Priests, to the Religious Families and to the Faithful of the Catholic Church on the Christian Meaning of Human Suffering', Apostolic Letters, Vatican, 1984, viewed 21 July 2017, <[https://w2.vatican.va/content/john-paul-ii/en/apost\\_letters/1984/documents/hf\\_jp-ii\\_apl\\_11021984\\_salvifici-doloris.html](https://w2.vatican.va/content/john-paul-ii/en/apost_letters/1984/documents/hf_jp-ii_apl_11021984_salvifici-doloris.html)>.

In an online profile for the Uniting Church, Dr Bridge explained his personal philosophy of care, one inspired by his 'supreme Christian calling to be a missionary' to interviewer, Heather Dowling:

**'Much about his work, Doug says, is to do with healing a patient so they are ready to die. [Quoting a Canadian physician who has influenced his philosophy on palliative care, Dr Bridge says,] 'Indeed, it is possible to die healed.'**

**'... Doctors are trained to cure diseases and I'm trying to say, 'what about healing people?' Not that we shouldn't cure diseases, but as well as curing disease, it would be really good if we could heal people.'**  
**As Doug says, within one's suffering is an opportunity for growth....'**

Dr Bridge goes on to explain how this can happen:

**"It's interesting that people facing death grow spiritually,' Doug said. "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.'" <sup>66</sup>**

Whether all his patients feel this way, Dr Bridge doesn't say.

In similar vein, Australian GP, Dr Colette Livermore, describes how this view of the sanctity of suffering played out in her work as a nun with Mother Teresa's Missionaries of Charity.<sup>67</sup>

Livermore says she was taught that '[s]uffering and hardships were purifying ... redemptive':

**'I understood that suffering was an unavoidable part of life but I believed that it should be relieved as much as possible.'**

She assumed that was also the Society's aim. But, Mother Teresa believed human suffering was necessary to 'quench the thirst of Jesus'. Obedience to God, the Church, its leaders and its doctrine, Livermore learned, took priority over peoples' suffering; and, if they suffered it was a beautiful, sacred thing. Ultimately, Dr Livermore left the order and set aside her faith, saying:

**'I had been taught that a suffering human being was sacred, the embodiment of Christ Himself. Nevertheless I was expected to ignore the pleading of a man whose friend lay dead among metho bottles, to send dying children away, to ignore a man dying in the street with dysentery, and to shut up and submit no matter what I was told to do or how stupid the order was ... [The Society] did all this in God's name.'**

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<sup>66</sup> Heather Dowling, 'Healing at Journey's End', Uniting Church in Australia, Western Australia, 7 February 2013, viewed 21 July 2017, <<http://unitingchurchwa.org.au/blog/2013/02/healing-at-journeys-end/>>.

<sup>67</sup> Colette Livermore, *Hope Endures: Leaving Mother Teresa, Losing Faith, and Searching for Meaning*, Free Press, New York, 2008, Chapters 2, 3, 7, 8 and 10.



Mother Teresa tried to persuade Dr Livermore to stay, imploring her to accept suffering in imitation of Christ:

**“Ill-treated and afflicted he never opened his mouth, like a lamb led to the slaughter house, like a sheep dumb before its shearers he never opened his mouth.”**

If a doctor or institution holds a core belief that there is value in suffering then the patient whose suffering cannot be relieved has little choice but to keep suffering.

Professor Alex Broom observed the influence of religious thinking on treatment decisions during his six months of observations in a Catholic hospice:

**‘The idea of an afterlife and the sort of dying process as, essentially, a rite of passage is very powerful.**

**What occurs, then, is that you get a very idiosyncratic values-driven form of dying, so it all comes down to what the collective around you thinks is appropriate or not. Then it is not systematic. It opens us up to all sorts of problems of people who have much greater degrees of suffering than they should’** <sup>68</sup>

What does this mean in practice for a patient who is dying, and suffering, and who may, or may not, share the same beliefs as their doctor?

Professor Richard Chye, head of palliative care at St Vincent’s Scared Heart Hospice, Sydney (and another co-signatory to Dr Bridge’s anti-VAD letter) explains what happens when there is no longer a way to control a patient’s symptoms:

**‘I walk with the patient. I say to them, ‘Yes, we have done our best to control your pain, yes, the pain is still there, but I will help you live with that pain’. The patients who have committed suicide on my watch were not in pain, not in physical pain. The patients who committed suicide on my watch feared that they will have pain.’**

Professor Chye says that assisting a patient to die is **‘against his morals and ethics’**. When asked for whose benefit such a dying patient is being kept alive, he responded:

**‘I think that patients who live do provide some benefit for the rest of the family and for themselves.’** <sup>69</sup>

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<sup>68</sup> Axel Broom in Andrew Denton, ‘Better Off Dead: Interview with Axel Broom’ embedded at ‘Hear More’, ‘#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, viewed 21 July 2017, <<http://www.gogentleaustralia.org.au/transcripts2>>.

<sup>69</sup> 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, viewed 21 July 2017, <<http://www.gogentleaustralia.org.au/transcripts2>>.

Mr Mulino says the solution to the trauma of patients dying in pain is to give **'greater support to health care providers'**.<sup>70</sup> In this, he ignores the reality that, for a substantial portion of those providers, personal or institutional beliefs dictate how a patient's suffering is to be treated, regardless of what the patient may need, want, or request.

No amount of extra training or resourcing is going to change that.

Palliative care physician Michael Ashby says this of the influence of religion on end-of-life care:

**'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'** <sup>71</sup>

That doctors hold strong personal beliefs is not at issue. 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 patients who are suffering and who wish to end their suffering quickly; a law which offers patients no power to control the speed of their dying, short of refusal of food and fluids, or suicide.

Distressing evidence of how vulnerable a dying patient can be in this situation is provided in the case of Victorian man Rudi Dobron, 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.'** <sup>72</sup>

Seeking support in this difficult choice, Rudi Dobron entered the Caritas Cristi palliative care unit, having been assured that he could expect to die quickly and with minimal physical suffering.

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<sup>70</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care', viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>71</sup> 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>>.

<sup>72</sup> Rudi Dobron quoted in Julia Medew, 'A Wish Before Dying', *The Sydney Morning Herald*, 25 September 2010, viewed 21 July 2017, <<http://www.smh.com.au/national/a-wish-before-dying-20100924-15go9.html>>.

Rudi's medical records, obtained through Freedom of Information, are detailed in the book *A Time to Die* (2017) by Dr Rodney Syme. 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.<sup>73</sup>

All this, as the book's author says, taking place, not in a desert, but:

**'in Kew, with all amenities at hand.'**<sup>74</sup>

In their majority report, the Committee commented on:

**'The trauma experienced by patients and their families when palliative care does not provide an adequate solution for their situation.'**<sup>75</sup>

As long as the religious elephant in the hospital room remains unaddressed, this imposed level of trauma and suffering will continue.

## 7. PALLIATIVE CARE VS ASSISTED DYING: A FALSE BINARY

Both Mr Mulino and the majority report praise the 'many benefits of palliative care'. This praise is merited: Palliative care's deeply admirable purpose is to alleviate pain and suffering at the end of life and much of what they do does exactly that.

Chief amongst their palliative tools is the ability to provide dying patients with comfort in the face of pain. Mulino writes:

**'Knowledge about pain relief options can provide considerable comfort**

**... Many health practitioners who provided evidence to the Committee spoke of the considerable potential to provide patients with peace of mind by clearly communicating the pain relief options available to them.'**<sup>76</sup>

What Mr Mulino doesn't acknowledge is that the choice of assisted dying also has a proven palliative effect which provides comfort to dying patients.

This was emphatically underlined, in December 2016, in a judgement handed down by the Victorian Civil and Administrative Tribunal, in the case of *Syme v Medical Board of Australia*.

Dr Syme brought his case to the tribunal after the Medical Board had sought to prevent him from engaging in:

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<sup>73</sup> Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 1 'Is this the best we can do?'.

<sup>74</sup> Ibid.

<sup>75</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Section 7.1 'The legal framework and peoples' end of life experiences', p.194, viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>76</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 2.2 'Knowledge about pain relief options can provide considerable comfort', viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

**'the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner that has the primary purpose of ending a person's life.'**<sup>77</sup>

The Medical Board had taken this action after learning that Dr Syme had offered to supply the illegal drug Nembutal to Bernard Erica who was dying of throat and tongue cancer.

In a submission to the tribunal, Syme explained his actions:

**'It is widely accepted in palliative medicine that, consistent with this clause, doses of medicine may be given to patients to relieve their pain and suffering even though it is foreseeable and indeed inevitable that those doses will also have the effect of hastening the patient's death. The use of morphine and sedatives for this purpose is widely accepted and meets the needs of many patients. However, not all patients wish to receive that form of palliative care because of the loss of dignity, control and comfort which can be associated with it.**

**Dr Syme's practice is a form of palliative care that is directed to the palliation of the psychological and emotional suffering experienced by some patients in the end stages of terminal disease.**

**... Mr Erica sought that control so that he could spend his final weeks in a calm and peaceful manner without fear and distress about the future.**

**The provision of advice and assistance which has the sole intention of relieving psychological suffering is properly to be seen as a legitimate form of palliative care. Dr Syme does not intend Mr Erica to end his life though he recognises that there are circumstances in which Mr Erica might choose to do so. His care of Mr Erica is directed not to the ending of Mr Erica's life but to the improvement of the quality of Mr Erica's life.'**<sup>78</sup>

In two submissions to the tribunal, Bernard Erica confirmed the palliative value of Syme's assistance:

**'I am suffering from a number of symptoms which are either unpalliatible or currently resisting palliation ...**

**These symptoms are certain to continue and increase, unpalliated, until my death.'**<sup>79</sup>

**My psychological suffering relates to my extreme loss of control over my own destiny and my fear of extreme suffering and loss of choice as my**

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<sup>77</sup> Rodney Syme 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. 4, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

<sup>78</sup> Rodney Syme, 'Applicant's submission to IAC dated 2 February 2016' excerpted 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), p.4, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

<sup>79</sup> Statement of Bernard Erica to the Chairman of the IAC, dated 4 March 2016, TB 72-73, excerpted 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. 23, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

**disease progresses. I want to die at home surrounded by family and friends. I do not want to be hospitalised under palliative care and die by slow sedation and dehydration.**

**... The effect of his support and advice has been extremely valuable. None of the other doctors who have attended me have provided such benefit and peace of mind. My psychological suffering has diminished to a large degree. I am calm and accepting of the reality of my situation. Dr Syme's care has had a profound palliative effect.'**<sup>80</sup>

In finding in favour of Dr Syme, the tribunal supported the following:

1. The right of any individual of sound mind to seek reassurance that they will be able to, if they wish, control the manner of their dying.
2. The palliative effect on a patient, knowing that they are dying; and
3. That the reassurance of the promise or actual possession of the drug does not, from the patients' perspective, place them at any risk.<sup>81</sup>

There is abundant evidence from Oregon to demonstrate that providing legal, regulated access to life-ending medication has strong palliative power and likely helps *prolong* life.

Statistics from the last 20 years from the Oregon Department of Health show that more than 30 per cent of terminally ill patients who are written a prescription for life-ending medication under their Death with Dignity Act, ultimately choose not to take it.<sup>82</sup>

The VCAT hearing was the first time in Australia that Voluntary Assisted Dying has been judged in a legal setting. Its palliative value – and the right of a dying patient to seek such palliation – were unanimously upheld.

(You can read the full judgement here: <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/vic/VCAT/2016/2150.html?stem=0&synonyms=0&query=health%20or%20doctor%20or%20nurse%20or%20hospital%20or%20clinic%20or%20surgeon%20or%20dentist%20or%20psychologist%20or%20clinic#disp1>)

<sup>80</sup> Statement of Bernard Erica to the Chairman of the IAC, dated 30 January 2016, TB 70, excerpted 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.22, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

<sup>81</sup> '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. 44, viewed 21 July 2017, link to document file here <<https://tinyurl.com/y88ac64f>>.

<sup>82</sup> Oregon Public Health Division, 'Oregon Death with Dignity Act: 2015 Data Summary', Oregon Health Authority, 4 February 2016, p.2 viewed 21 July 2017,

<<http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>>.

"Since the [Oregon] law was passed in 1997, a total of 1,545 people have had prescriptions written under the DWDA, and 991 patients [64%] have died from ingesting the medications."

Professor Ian Maddocks confirms that 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.’**

In Belgium, assisted dying is integrated into palliative care; in the Netherlands, palliative care has grown remarkably beside assisted dying; 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 2016, 90% of Oregonians who accessed Voluntary Assisted Dying were also in hospice care.

(For more, 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. <https://www.churchilltrust.com.au/fellows/detail/3763/Linda+Sheahan>)

## **7 (i) Palliative care will improve in Australia with the introduction of Voluntary Assisted Dying.**

Professor Ian Maddocks:

**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.**

**Some colleagues maintain that only trained Palliative Care staff have the skills to communicate with and respond effectively to the comprehensive needs of dying individuals. I contest that. Most Palliative Care is simply good, everyday medical and nursing practice, and in the great majority of situations is well within the professional compass of every practitioner.**

**The practice of Palliative Care is demanding, but its separate special status is difficult to justify. Palliative Care is ‘everyone’s business’, a responsibility to which all health care practitioners can contribute. When Palliative Care is practised more widely by all health care disciplines, it will be available in familiar surroundings – the home, aged care facility, and small private hospital, as well as hospice – and not in the hurly-burly of the acute major hospital where most dying happens.’**



## **8. PALLIATIVE CARE IN AUSTRALIA, BEYOND SUFFERING – *IN THEIR OWN WORDS***

For an insight into the realities of how some people die within Australian palliative care, here are links to two episodes from the podcast ***Better Off Dead***.

They feature the voices of palliative care doctors and nurses, as well as of families recounting the deaths of loved ones.

### **Episode 10: Neither Hasten nor Prolong Death. Palliative Care in Australia Pt. 2**

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death>

### **Episode 11: Whose Life is it Anyway? Palliative Care in Australia Pt. 2**

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway>

### **Episode 12: Velvet Ray**

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/12-velvet-ray>

This episode tells the story of palliative care nurse Ray Godbold, diagnosed with Stage 4 gastro-oesophageal cancer. Ray knows what some doctors prefer not to admit. He knows that, even in palliative care, not everything can be taken care of; that a patient's choices about how they die are very limited; and that, sometimes, their dying involves a wildness nobody can predict.

What Ray doesn't know is that his own death will turn out to be everything he was hoping that he and his family would be spared.



## 4. PART C: BUSTING 5 KEY MYTHS ABOUT ASSISTED DYING

### WHAT THIS SECTION IS ABOUT

**While ‘better funding of palliative care means there’s no need for VAD’ is the number #1 falsehood used to discourage politicians from legalising it, there are other pervasive, and persuasive, myths used to do the same.**

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### **MYTH #1: ‘GRANNY WILL COERCED TO DIE FOR THE INHERITANCE.**

Using the laws framed by the Ministerial Advisory Panel (Victoria), chaired by Professor Brian Owler:

To access VAD a patient has to, first of all, make a request for assistance themselves. No one else can do it for them. To be eligible they have to be suffering from an illness, disease or medical condition that is incurable, advanced and progressive and likely to cause death within weeks or months (but not longer than 12 months)

Their suffering has to be judged by them, and accepted by their doctors, as intolerable. They must have mental capacity to make such a decision, and must demonstrate that their decision is well considered and enduring, by making three separate requests, separated by at least ten days.

Two highly skilled and experienced doctors must both agree that these conditions are met. A patient turning up feeling vulnerable and coerced, because of heartless, greedy relatives, is not going get past square one.

What *will* happen is this: when a patient presents saying “I want help to die”, the doctor is going to ask, “why?” They’re going to look at all that patient’s symptoms. They’re going to want to know what’s going on in that patient’s life that’s making them feel like they no longer want to live.

By law, both doctors have to explore all other reasonable treatment options, including palliative care, before they can declare a patient’s suffering untreatable and intolerable. Faced with a patient who does not meet all the criteria, but who is expressing a wish to die, what they’re going to do is refer them to psychiatric help and, most likely, a social support network.

Surrounding this framework and these principles and conditions is a complex administrative structure involving 68 safeguards. It will not be an easy matter to obtain assistance to die. Nor for a doctor to sign off on it.

In addition to the written safeguards, there are two critical matters which cannot be proscribed in legislation. The first is that placing control over the final decision to ingest the medication in the hands of the suffering person prevents non-voluntary acts, and recognises that suffering people will not end their lives unless in severe distress. People want to go on with their lives as long as possible.

The second major safeguard is the conservatism of the medical profession - the professions' ethic to help their patients to go as far with their lives as possible while respecting their autonomy, and their concern to protect the vulnerable, which includes suffering, dying people. This conservatism should not be under-estimated.

When the mythical granny, whose relatives are after the inheritance, presents herself, what these doctors are *not* going to do is recommend that she be helped to die. Firstly, because they are trained to adhere to best medical practice. And, secondly because, if they do, they're going to get caught.

Remember, also, not only is there a second independent doctor against whom the first doctor can be checked and vice-versa – but, by law, the patient has to put their request in writing in the presence of two independent witnesses.

Both doctors have a series of mandatory reporting forms that must be sent to The Voluntary Assisted Dying Review Board throughout the assessment process. This puts them on notice that – unlike any other end-of-life decisions made in Australia – their work will be put under close scrutiny.

The Review Board will get the patient's written request, the case notes of the two doctors, the patient's medical records, and the authorization forms for prescribing of medication from the Department of Health and Human Services

If a breach is detected, either doctor can be reported to the relevant authority, be that Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency.

Elder abuse is a genuine problem in Australia. It is something that the Ministerial Advisory Panel who helped frame this law looked at very closely. By its very nature it happens in secret, where no one can see. Under this legislation it is going to be difficult for elder abuse to remain hidden.

This is because voluntary assisted dying will never occur in isolation. Beyond the mandatory involvement of two assessing medical practitioners, a pharmacist, a nominated contact person, two witnesses, the Department of Health and Human Services, and the Voluntary Assisted Dying Review Board, there will be many others in a person's treatment team – including, most likely palliative care doctors and nurses – as well as friends and family, to offer support, advice, and comfort, in their final weeks and months.

The request and assessment process in this legislation is also far more rigorous than any existing process in Victoria for medical treatment and provides greater opportunity to identify instances of elder abuse. Medical practitioners are not ordinarily required to specifically consider the risk of elder abuse, but will be asked to do so during their

assessment. This will be part of specified training which will have a particular focus on identifying elder abuse.

Further, it will be a criminal offence, punishable by up to 5 years in prison, to induce another person to request Voluntary Assisted Dying.

Finally, while legitimate concerns about elder abuse and coercion must be taken into account in assessing requests for access to voluntary assisted dying, it is important to remember that most people who are dying have loving and supportive families.

**Repeated, independent, peer-reviewed, and exhaustive, reviews have shown no evidence of abuse of the vulnerable overseas.**

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’**

Justice Lyn Smith, British Columbia Supreme Court, 2012. (upheld unanimously on appeal by the Supreme Court of Canada):

**“This evidence serves to all the fears of a practical slippery slope...[it] 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”**

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”**

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’**

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’**

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 testimonies here: <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/13-now-they-re-killing-babies>

These safeguards work because it is very hard to coerce a vulnerable person into a serious, untreatable, illness they don't have. Even harder to coerce two doctors, whose work is subject to close scrutiny and who face heavy penalties for breaches, to agree with them.

## MYTH #2: VAD GOES AGAINST A DOCTORS' OATH TO 'DO NO HARM'

According to the AMA's code of ethics, 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”***

A survey of their 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”

Some doctors object to Voluntary Assisted Dying on the basis of the Hippocratic Oath which instructs ‘do no harm’. Others see leaving a dying patient to suffer as the opposite of ‘do no harm’.

Doctors who object portray it as though they are being asked to ‘kill’ a patient. In reality, what they're being asked to do is what they already do - make a careful diagnosis that a patient's condition is terminal, and at its end stages, and their suffering intolerable, and go through with them 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 doctors' mission statement doesn't suddenly change under this law. They still want to alleviate suffering. Determining whether a patient is eligible for 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 patients' death, the offer of assistance to die has no such certainty. We know this from Oregon where more than 30% of those written the lethal prescription choose not to take it.

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 of 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.

### **Why offering protection under this law is good for doctors and even better for their patients.**

When doctors, such as AMA Federal President Michael Gannon, argue against a voluntary assisted dying law on the grounds that it can never be safe, what they are actually arguing for is that it's OK for doctors to keep breaking the law. The secrecy this must, of necessity, entail leaves their patients vulnerable as a result.

And even when doctors abide by the law, their patients remain vulnerable.

The 2016 Parliamentary Inquiry heard many accounts of “irremediable pain despite receiving palliative care”. It reported that:

**“health practitioners are uncertain about the law relating to administration of pain relief which may have the unintended consequence of ending life”.**

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, but 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.

In October 2017, the World Medical Association revised the Declaration of Geneva, the modern successor to the Hippocratic Oath, which is used across the world by physicians.

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, which is not included in the current text.

Only a small percentage of us are doctors. But all of us will, one day, be patients who are dying.

It is for patients, not their doctors, that this law is being written.

### **MYTH #3. VAD / VE LAWS OVERSEAS HAVE LED TO A SLIPPERY SLOPE**

It is claimed that voluntary assisted dying legislation always results in the law being changed over time to allow more people and more conditions to access voluntary assisted dying. This is the “slippery slope”.

These are the facts. The numbers of patients in each jurisdiction has increased over time – this is to be expected given aging 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. Less than 0.5% in Oregon).

In Oregon, which has been in operation for 20 years, the numbers have increased until last year when they went down slightly. The actual numbers themselves remain small with last year only 204 prescriptions being written and 133 deaths with a population of about 4 million people.

In Belgium and the Netherlands there has been an increase in the number of people with mental illness and dementia who have accessed euthanasia laws. As a percentage of the total who access the legislation in those countries, these cases remain a tiny minority.

However, the most important fact here, one often overlooked, is that all of those cases occur within the scope of the existing legislation in those countries.

The legislation in those two countries has always been based on unbearable suffering, not whether a person has a terminal illness.

The legislation in Oregon has been in operation for 20 years and has never been changed. It has formed the basis for other legislation in California, Vermont, Colorado, Washington and Washington DC.

The legislation in Belgium and the Netherlands has been in place since 2002. There has only ever been one change to the legislation. (For more, Listen to **Better Off Dead, Episodes 5, 6, 7,8 & 9**, which tells the story of VAD laws in The Netherlands, Belgium and Oregon, in the words of those who live there and work under them):

[https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show\\_all=true#about](https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show_all=true#about)



It is not that people don't campaign for or talk about changes, they do and will always do it as part of a democratic society, but the notion that once a law for voluntary assisted dying is passed, it will invariably change is simply not supported by the evidence from overseas jurisdictions.

Legislation most recently proposed in Victoria, 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. Each society writes laws according to what that society will tolerate.

#### **MYTH #4: VAD LAW IS AN ATTACK ON THE SANCTITY OF LIFE.**

It is important to acknowledge that people of religious faith have a right to their deeply-held views in opposition to voluntary assisted dying.

VAD legislation acknowledges and enforces this right by allowing anybody to conscientiously object to participation in it.

Surveys consistently show that these objectors are in a very small minority, even within their own religions.

- A 2012 Newspann survey showed that 88% of Anglicans and 77% of Catholics agreed that a doctor should be allowed to meet a request from a hopelessly ill patient for help to die.
- The 2013 ABC Vote Compass policy tool found that out of 1.4 million Australians, 75% supported the legalisation of assisted dying for the terminally ill.
- It also provided a breakdown based on religion, and the rate of support among Catholic respondents was 69.8%.

While the hierarchies of our major religions are opposed to voluntary assisted dying, they do not speak for a majority of their congregations, let alone the majority of Australians.

#### **MYTH# 5: VOLUNTARY ASSISTED DYING WILL LEAD TO MORE SUICIDES**

Opponents cite a phenomenon they call “suicide contagion”, to suggest that the legalisation of voluntary assisted dying will lead to an increase in suicides.

This is a deliberate, and false, conflation of two very different acts.

Suicide is entirely distinct from voluntary assisted dying. The first – suicide - is an irrational impulse, acted on in secret, in response to a problem that, with treatment, could most likely be fixed. The second - – voluntary assisted dying - is a rational response, taken in consultation with doctors and family, to a condition that cannot be fixed.



This difference was clearly understood by the Chief NY 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, agonizing 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’.

There is no credible evidence of increased suicide rates as a result of assisted dying laws overseas. You can read more here:

<http://www.dyingforchoice.com/docs/SomervilleIndefensibleSCclaimApr2017.pdf>.

You can also hear Oregon’s State Health Officer, Katrina Hedburg, dismiss allegations of a connection between Oregon’s suicide rate and their Death with Dignity Law here

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/9-death-with-dignity-in-oregon>

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 that - faced with the fear of an agonizing death, or with unmanageable suffering - terminally ill Victorians are committing suicide at the rate of one a week.

You can also hear the South Australian Coroner, Mark Johns, confirm the same phenomenon in his state here:

<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/14-australia-s-dark-little-secret>

VAD legislation will provide those people with a more compassionate choice at the end of life. It will help many of them to live longer. As well, they will end their lives peacefully and without leaving behind the kind of trauma and emotional damage now evident in families and first responders.

## 5. PART D. IN THEIR OWN WORDS: PRIMARY SOURCES IN AUSTRALIA AND OVERSEAS EXPLAIN HOW VAD LAWS WORK, AND WHY THERE IS A NEED FOR THEM IN AUSTRALIA.

Go Gentle is dedicated to providing factual and verifiable information to the debate around Voluntary Assisted Dying.

We identify all our sources and are more than happy for them, and their provenance, to be further investigated.

As well as working from peer-reviewed evidence, we have spent thousands of hours recording and documenting primary testimonies. These come from doctors, nurses, palliative care specialists and others who work in end of life care.

They are also from families who have been impacted by VAD/VE laws overseas – or by the lack of them in Australia.

The primary testimonies collected by Go Gentle are available from three, key sources:

1. **BETTER OFF DEAD.** A 17-part podcast series, recorded over 8 months in Belgium, the Netherlands, Oregon and Australia. It tells the story of VAD / VE laws from all angles, featuring interviews with opponents and proponents.

You can find it here:

[https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show\\_all=true](https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show_all=true)

2. **THE DAMAGE DONE.** A collection of 72 testimonies from doctors, nurses, families, and the terminally ill documenting the cost to our community created by the absence of a VAD law in Australia.

You can download a free PDF here:

[https://d3n8a8pro7vhmx.cloudfront.net/gogentleaustralia/pages/35/attachments/original/1521614939/The\\_Damage\\_Done\\_ePDF.pdf?1521614939](https://d3n8a8pro7vhmx.cloudfront.net/gogentleaustralia/pages/35/attachments/original/1521614939/The_Damage_Done_ePDF.pdf?1521614939)

3. **GO GENTLE AUSTRALIA STORY WALL.** Contains stories and video testimonies from families, doctors and nurses explaining the need for a VAD law in Australia.

You can find them here:

<http://www.gogentleaustralia.org.au/resources>

## **6. PART E. TECHNIQUES COMMONLY USED TO CREATE A MISLEADING AND ALARMIST PICTURE OF VAD/VE LAWS OVERSEAS.**

### **WHAT THIS SECTION IS ABOUT**

**For 20 years, opponents of VAD in Australia have run similar arguments, using misleading and distorted information – and quoting ‘experts’ with a clear, but undeclared, anti-VAD bias – to persuade politicians not to support legislation.**

**A perfect summary of these were captured in the dissenting report by Victorian MLC Daniel Mulino, to the Victorian Parliamentary Inquiry into End-of-Life Choices (2015), which recommended that that State legalise VAD.**

**A full copy of it was included in the [Final Report](#) of the Inquiry into End of Life Choice by the Parliament of Victoria, from page 387 onwards.**

**Mr Mulino’s report is extensively footnoted and looks authoritative. Go Gentle has been through it carefully to analyse the techniques used throughout to create a misleading and alarmist picture of VAD and VE laws overseas.**

**These techniques, and many of the sources quoted (such as Dr David Kissane), will be sure to be part of submissions to the ACT Inquiry. This section is to help identify them and to give them a greater, and more accurate, context.**

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## ACRONYMS

VE - Voluntary Euthanasia

VAD - Voluntary Assisted Dying

PAD - Physician Assisted Dying

DWD - Dying with Dignity

DWDA - Death with Dignity Act (Oregon)

LAWER - Life-Ending Acts Without Explicit Request

NVE - Non-voluntary Euthanasia (same as LAWER)

## 1. EXECUTIVE SUMMARY

In 2015 the Victorian Cross-Party Parliamentary Inquiry into End-of-Life Choices handed in its majority report which recommended, by a majority of 6-2, that Victoria legalise Voluntary Assisted Dying.

This paper deals with the Minority Report by Daniel Mulino MLC: A paper which is flawed, ignores, misreads or misrepresents the evidence, and fails to acknowledge extensive examples of suffering across the Victorian community as a direct result of existing laws.

In summary, a report which fails to achieve his stated objective of 'a balanced reading of the evidence'.

The Minority Report does not deal with key evidence presented to the Committee. Unlike all other Committee members (bar the other dissenting MLC, Inga Peulich), Mr Mulino declined to hear firsthand how VAD laws are working in other jurisdictions. The Report also uses material taken out of context, or presents as evidence "claims made by known VAD opponents (without disclosing their bias).

The Victorian Committee of Inquiry into end-of-life choices voted in support of a law for Voluntary Assisted Dying after a 10-month long inquiry into end of life care in Victoria. This included travel to jurisdictions where VAD and VE laws exist.

Their report, which was comprehensive, was based on an exhaustive review of evidence, both for and against VAD. Much of the evidence they considered was peer-reviewed, and from independent and primary sources.

However, Mr Mulino rejected the majority findings of the Committee on the basis that their report did not represent a 'balanced reading of the evidence'.

His dissenting report is rich in detail and extensively footnoted. It looks like a well-researched and argued document. The likelihood is that few, if any, politicians or journalists have the time or resources to check that detail see if what he is saying is balanced, let alone correct.

Taking his measure of a 'balanced reading of evidence', and applying it to his own work, we have conducted a detailed review of Mr Mulino's report. Our analysis shows that it contains repeated examples of:

- Distortion and misrepresentation of statistics that do in fact show VAD / VE laws are working safely
- Omission of critical facts
- Cherry picking of evidence to support misleading conclusions
- Significant and undeclared bias from many of his key sources
- Disproportionate weight given to opponents of VAD
- Dismissal of clear evidence of suffering in the Victorian community
- Dismissal of clear evidence that palliative care cannot ease all suffering



We note his decision not to visit other jurisdictions with the Committee and the fact that unlike other Committee members Mr Mulino did not witness whether or not their laws are operating safely.

We note, too, that Mr Mulino's Minority Report does not include a single quote from the extensive submissions, or numerous testimonies, to the public Inquiry from witnesses of the intolerable and unrelievable suffering that some people experience at the end of their lives.

## 2. A RIGHT TO DISAGREE

After an exhaustive investigation, a clear majority (6-2) of the Victorian Inquiry into End-of-Life Choices concluded that voluntary euthanasia (VE) and voluntary assisted dying (VAD) laws overseas are:

**‘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.’<sup>83</sup>**

In his dissenting report, Mr Mulino asserts that vulnerable people cannot be protected under euthanasia and VAD legislation, and that the safeguards which exist are subject to **‘widespread failure’**.<sup>84</sup> He does so on the basis of his statement that a **‘balanced reading of the evidence’ shows the majority findings are ‘not true’**.<sup>85</sup>

Mr Mulino has a clear right to disagree with the majority conclusions of the committee.

But, having claimed as his standard a ‘balanced reading of the evidence’, it is incumbent upon him not to distort, manipulate, conceal, or omit, evidence in order to support his argument.

As an elected representative of his community it is also incumbent on Mr Mulino to acknowledge credible evidence, presented to the committee, of suffering within that community and not to minimise, or step around, it.

On both these counts, Mr Mulino’s dissenting report fails.

### 2.1 THE FINDINGS OF THE MAJORITY COMMITTEE REPORT

The majority report of the committee, informed by an unprecedented 10-month long inquiry into end-of-life choices held across the State, established these critically relevant facts about the impact of existing laws on the Victorian community:

1. People experiencing an irreversible deterioration in health are taking their own lives, often in horrific circumstances.<sup>86</sup>

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<sup>83</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 8.4 ‘The Committee’s decision — An assisted dying framework’, p.212, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>84</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, ‘Executive Summary’ and Chapter 4.6 ‘The widespread failure of safeguards’, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>85</sup> Ibid., Chapter 4.6 ‘The widespread failure of safeguards’ and 4.6.1 ‘Systemic non-reporting’.

<sup>86</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, ‘Chair’s Foreword’, p. xvi, Section 7.1.3 ‘People are choosing suicide over dying with irremediable pain’ pp.197-200, Section 8.2 ‘The problem’, p.206, Section 8.3.2 ‘Enforce the current legal framework’, p.209, Table A6.1, point 9, Appendix 6, p.297, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

2. Doctors practice unlawful assisted dying despite its prohibition. This is happening without regulation, without support, without transparency or accountability, and sometimes without the patient's consent.<sup>87</sup>
3. The nature of dying for people with a serious and incurable condition can sometimes be harrowing for individuals, their families and communities. Inadequate pain treatment as a consequence of health practitioners' uncertainty about the law was a repeated theme.<sup>88</sup>
4. Despite its many benefits, palliative care does have limitations, as described by Palliative Care Victoria, who explained that palliative care can sometimes be ineffective at relieving all suffering.<sup>89</sup>
5. Some people are choosing to stop having treatment, knowing that this will result in their imminent death.<sup>90</sup> Others spoke of the trauma of watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.<sup>91</sup>
6. There is strong and credible evidence, in legislations where VAD/VE is legal, of robust regulatory frameworks that focus on transparency, patient-centred care and choice.<sup>92</sup> There is no evidence of institutional corrosion or the often cited 'slippery slope'.<sup>93</sup>

Having weighed up this evidence – and having listened carefully to arguments for and against - the Committee rejected, outright, the option of maintaining the status quo. Doing nothing, they determined, was:

**'an inadequate, head-in-the-sand approach to policy making and to the plight of the Victorians described in this Report.**

**To maintain the status quo risks ignoring the evidence of the harm that occurs within it. In light of the evidence submitted, the Committee has determined that this is not an acceptable outcome.**

**The status quo is, if not causing, then facilitating or allowing great pain. The Committee does not wish this to continue.'**<sup>94</sup>

They recommended by a majority of 6-2 that voluntary assisted dying (VAD) be legalised in Victoria.

<sup>87</sup> Ibid., Section 6.3 'Unlawful medical practice', pp.181-186, Table A6.1, point 13, Appendix 6, p. 297.

<sup>88</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Chair's Foreword', p. xvi, Section 7.1.3 'People are choosing suicide over dying with irremediable pain' pp.197-200, Section 3.10.4 'Working with end of life law', pp. 111-112, Section 7.2.1 'Protecting lawful medical practice of doctors', p. 202., viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>89</sup> Ibid., Section 3.2, 'Benefits and limitations of palliative care', pp.49-51.

<sup>90</sup> Ibid. Section 7 'How the existing legal framework shapes end of life experiences', p.193; Section 6.4, p.187.

<sup>91</sup> Ibid. Section 3.10.2 'Continuous palliative sedation', p.103; Section 7 'How the existing legal framework shapes end of life experiences', p. 193; Section 8.62 'Janine Truter, personal submission', p.221; Table A6.1, Point 14, Appendix 6, p.297.

<sup>92</sup> Ibid. 'Chair's foreword', p. xvii; Section 8.5 'Overview of proposed assisted dying framework' p.216.

<sup>93</sup> Ibid. 'Chair's foreword', p. xvii; Section 8.4 'The Committee's decision - An assisted dying framework: sidebar Professor Julian Savulescu, Director, Oxford Uehiro Centre for Practical Ethics', p.212; Appendix 7.6.1 'Refuting the slippery slope and risks to vulnerable people argument', p.312.

<sup>94</sup> Ibid. Section 8.3.1, 'Maintain the Status Quo', p.208.

In Mr Mulino's dissenting report, the facts accepted by the majority of the committee are either avoided, minimised so as to appear insignificant, or heavily contested. In reaching his conclusions Mr Mulino uses a number of methods which appear to fail basic ethical requirements.

## **2.2 WHAT THIS REPORT WILL DEMONSTRATE: TECHNIQUES OF OMISSION, DISTORTION, CONCEALMENT, AND MANIPULATION OF EVIDENCE USED TO CREATE A DISTORTED AND ALARMIST PICTURE OF VE/VAD LAWS OVERSEAS.**

To analyse Mr Mulino's conclusions, and the techniques used to reach them, this document will focus on the following:

1. Misleading allegations of the widespread failure of safeguards.
2. Exaggerated and alarmist allegations of a sharp upward trend in VAD/VE deaths.
3. Allegations, which are contradicted by the evidence, of failures in Oregon's Death with Dignity laws.
4. Inaccurate reporting of deaths under the Northern Territory *Rights of the Terminally Ill Act*.
5. Methods used by Mr Mulino throughout his report to create a distorted picture of VAD/VE legislation overseas.

### 3. CONTRADICTED BY THE EVIDENCE: ALLEGATIONS OF 'A WIDESPREAD FAILURE OF SAFEGUARDS'

In Chapter 4.6 of his dissenting report, Mr Mulino states:

**'The Majority Report asserts that the evidence is "clear" that safeguards work in jurisdictions with legalised euthanasia and assisted suicide. A balanced reading of the evidence would lead one to conclude that such an unequivocal statement is not true.'**<sup>95</sup>

There is a vast amount of literature which can be quoted, often selectively, in support of one or other position about assisted dying and euthanasia. The literature that is important is that which is from primary research sources of an independent nature, particularly those established by government to investigate and report on end of life actions.

Before looking more closely at some of Mr Mulino's evidence in support of his allegations, it is worth examining how the committee majority reached the conclusion that the safeguards used in existing VAD/VE legislation are working as they should.

#### 3.1 EVIDENCE CONSIDERED BY THE COMMITTEE

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.'**<sup>96</sup>

what sources did the committee draw on?

##### 3.1.1 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*

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<sup>95</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.6 'The widespread failure of safeguards', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>96</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Section 8.4 'The Committee's decision - An assisted dying framework', p. 212, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

*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*

### 3.1.2 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<sup>97</sup>
- 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)<sup>98</sup>
- The report of the UK Commission on Assisted Dying (2011)<sup>99</sup>
- The Québec Select Committee on Dying with Dignity report from the National Assembly of Quebec (2012)<sup>100</sup>
- The final report from the External Panel on Options for a Legislative Response to Carter v. Canada, (2015)<sup>101</sup>
- The final report from Canada's Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (2015)<sup>102</sup>
- A bioethical report and recommendations on the Canadian hearing from the University of Toronto (2015)<sup>103</sup>
- 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)<sup>104</sup>

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.

<sup>97</sup> 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.

<sup>98</sup> 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.

<sup>99</sup> The Commission on Assisted Dying, 'The current legal status of assisted dying is inadequate and incoherent...', Demos, London, 2011.

<sup>100</sup> Select Committee on Dying with Dignity, *Dying with Dignity*, National Assembly of Québec, Québec, 2012.

<sup>101</sup> 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.

<sup>102</sup> Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final report*, 2015.

<sup>103</sup> 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, 2015.

<sup>104</sup> 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, viewed 11 July 2017, <<http://eol.law.dal.ca/wp-content/uploads/2016/05/Special-Joint-Committee-on-PAD-Final-Report.pdf>>.

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.

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.'**<sup>105</sup>

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."**<sup>106</sup>

This deep archive of empirical research and literature, conducted and created by independent authorities laid a foundation for the Victorian Committee's conclusions.

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<sup>105</sup> Carter v. Canada (Attorney General), 2012 BCSC 886, para. 685.

<sup>106</sup> Ibid., para. 684.



### 3.1.3 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 Advisor, 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)
- 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 Advisor, 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 Advisor, 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.<sup>107</sup>

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.**

**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.’**<sup>108</sup>

The combination of all these sources – independent committees of review, peer-reviewed academic literature, and primary evidence from those who work within VAD/VE regimes<sup>109</sup> – informed the Committee’s majority conclusion that there is *clear evidence* the robust safeguards in the proposed legislation<sup>110</sup> will **‘protect patients from potential abuse’**.<sup>111</sup>

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.

<sup>107</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, “Inquiry into end of life choices: Final Report”, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 8.4 ‘The Committee’s decision - an assisted dying framework’, p. 213, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](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].*”

<sup>108</sup> Ibid., Section 8.9.3 ‘Chair of end of life care’, p.235.

<sup>109</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, “Inquiry into end of life choices: Final Report”, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Appendix 4 ‘Legislation in jurisdictions that allow assisted dying’, pp.283-287, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Specific safeguards are set out in Appendix 4.

<sup>110</sup> Ibid., Section 8.5.3 ‘Criteria and safeguards’ and 8.7.3 ‘Request must be properly considered’, pp.217-227.

This section of the Report details the robust safeguards in the proposed legislation.

<sup>111</sup> Ibid., Section 1.2.3 ‘Overseas research’, p.8.

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.*”

### 3.2 MR MULINO DID NOT TRAVEL OVERSEAS WITH THE COMMITTEE

In [Section 8.2](#) of this paper (pp. 69-72), we will look at how Mr Mulino's sources – their independence, credibility, and his use of the information they contain – compare with those of the majority report.

For now, it should be noted that Mr Mulino did not join five other Committee members on the fact-finding journey to Canada, the Netherlands, Switzerland and Oregon. (Neither did the other dissenting report author, Ms Peulich, MLC).

In so doing, he missed out on meeting:

**'academics, regulators, health care professionals, supporters and opponents of the different legalised assisted dying frameworks [as well as] doctors, medical and legal experts, palliative care specialists and disability rights groups in jurisdictions where assisted dying is legal'** <sup>112</sup>

Whatever Mr Mulino's reasons for not going, the fact that he did not take the opportunity to learn, first-hand, how these laws work, or to test the truth (or otherwise) of his allegations, must be taken into account when weighing up the merits of his argument.

Having recused himself from a crucial part of the Inquiry in which participating Committee members learned, first-hand, about **'the rigorous safeguards, monitoring procedures and high levels of compliance'** in jurisdictions which allow VE and VAD,<sup>113</sup> Mr Mulino disregards his colleagues' findings in his dissenting report. He makes, instead, serious allegations about how such laws are working.

It is to two of these – 'systemic non-reporting' and 'cases in which explicit consent is not given' – that this paper now turns.

### 3.3 ALLEGATIONS OF 'SYSTEMIC NON-REPORTING'

#### 3.3.1 Belgium

In Chapter 4.6.1 'Systemic non-reporting' Mulino states:

**'In Belgium, mandatory notification of euthanasia to the Federal Control and Evaluation Commission is a cornerstone of the regulatory arrangements. However, recent reports suggest that around half of all euthanasia cases are not reported.'** <sup>114</sup>

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<sup>112</sup> Ibid., 'Chair's Foreword', p.xvii.

<sup>113</sup> Ibid., Section 8.4 'The Committee's decision - an assisted dying framework', p.213.

<sup>114</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.6.1 'Systemic non-reporting', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

The 2010 study he refers to is peer-reviewed and credible.<sup>115</sup> However, the picture, as Mulino paints it, is far from complete. In it lies another piece of information: that 77 per cent of those doctors who failed to report did not perceive their action to be euthanasia.<sup>116</sup>

Mulino notes this but says nothing more of it. It's a crucial omission because it speaks to a practice commonly used in many countries, including Australia: palliative (or terminal) sedation. Here's how this 'anomaly' in reporting is explained in the paper; a clarification which Mulino chose not to use.

**'Reported cases of euthanasia were almost always performed with barbiturates, neuromuscular relaxants, or both (95.6%), whereas the majority of unreported cases (90.5%) were performed with other drugs, mainly opioids, sedatives, or both. However, in about half (52.7%) of the unreported cases in which opioids were used with the explicit goal of hastening death, physicians indicated that they did not administer a higher dose than necessary for pain and symptom alleviation.'**<sup>117</sup>

The unreported cases were seen by doctors, not as euthanasia, but as palliative sedation to alleviate suffering, with an explicit intention, also, to shorten life.

For Mulino this failure to report is a matter of 'serious concern'. He writes:

**'A requirement to report instances of euthanasia and assisted suicide is seen by some advocates as a key strength of a legalised regime. They argue that it will bring opaque practices more into the open. The experience in Belgium suggests otherwise.'**<sup>118</sup>

But, in fact, the opposite is true. Belgium's law has done exactly what Mulino claims it hasn't; it has brought a previously opaque practice more into the open.

Here is Assistant Professor Kenneth Chambaere, from the End-Of-Life-Care Research Group at Vrije University, Brussels - his work is cited by Mulino on three occasions – writing in response to Mulino's report:

**'It's easy to pin this all down on the fact that euthanasia is legalised. But Belgium (and the Netherlands) are among the very few countries to research end-of-life practice in such a systematic and rigorous way.'**

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<sup>115</sup> Tinne Smets, Johan Bilsen, Joachim Cohen, Mette L Rurup, Freddy Mortier, Luc Deliens et al., "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases", *British Medical Journal*, 5 October 2010, 341:C5174, viewed 11 July 2017, <<https://doi.org/10.1136/bmj.c5174>>.

<sup>116</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.6.1 'Systemic non-reporting', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>117</sup> Tinne Smets, Johan Bilsen, Joachim Cohen, Mette L Rurup, Freddy Mortier, Luc Deliens et al., 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *British Medical Journal*, 5 October 2010, 341:C5174, viewed 11 July 2017, <<https://doi.org/10.1136/bmj.c5174>>.

<sup>118</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.6.1 'Systemic non-reporting', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

**Yes, these cases constitute something of a grey area between euthanasia and palliative sedation with intent to speed up death. Two different practices, but doctors see the latter as palliative sedation and therefore do not report.**

**Those before the law [existed] also were not declared. What has euthanasia law changed? Data on reporting rates. When doctors label their case as euthanasia they report it in 95% of cases. For completeness, they sometimes label their life-ending act otherwise and then of course don't report it. Overall, two-thirds of life ending acts upon request are reported. Before the law this was 0%.'**<sup>119</sup>

### 3.3.2 The Netherlands

How does reporting in the Netherlands compare? On this there is very good data, because researchers there have undertaken repeated, nationwide studies of all deaths every five years since 1990. So we know from research that:

**'The reporting rate ... gradually increased from 18% in 1990 to 80.2% in 2005, indicating a trend towards more societal control over the practice.**

**Most euthanasia cases that are not reported in the Netherlands are performed with opioids or sedatives and are often not perceived as euthanasia by the physicians themselves.'**<sup>120</sup>

In 2015, ethicist Professor Theo Boer - for nine years a member of one of the Netherlands' euthanasia review committees, but always a self-declared 'sceptic' of such laws - nonetheless explained that:

**'The law on assisted dying has in fact led to a practice that is transparent. Review committees report a reporting rate of close to one hundred percent. Practices that formerly took place in hiddenness are now more or less controllable.'**<sup>121</sup>

Rather than systemic non-reporting in Belgium and the Netherlands, as Mr Mulino claims, the level of reporting of euthanasia deaths and other life-ending acts (palliative sedation) in both countries has *risen* since the introduction of these laws and is high. What was once hidden has been brought into the light.

### 3.3.3 Australia

By comparison Australia's reporting rate for cases where doctors intentionally hasten someone's death is 0 per cent.

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<sup>119</sup> Kenneth Chambaere, Email to Go Gentle Australia responding to Mr Mulino's Dissenting Report, 6 May 2017.

<sup>120</sup> Tinne Smets, Johan Bilsen, Joachim Cohen, Mette L Rurup, Freddy Mortier, Luc Deliens et al., 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *British Medical Journal*, 5 October 2010, 341:c5174, viewed 11 July 2017, <<https://doi.org/10.1136/bmj.c5174>>.

<sup>121</sup> Theo Boer, video speech recorded at HOPE International anti-euthanasia convention, May 2015, audio reproduced in Andrew Denton, 'Better Off Dead: #5 The keys to life and death in someone else's hands: the Netherlands part 1', podcast, 23:23-24:00, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 23 February 2016, accessed 12 July 2017, <<https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/5-the-keys-to-life-and-death-in-someone-else-s-hands-the-netherlands-part-1>>.

Transcript at Go Gentle Australia website, viewed 21 July 2017, <<http://www.gogentleaustralia.org.au/transcripts1>>.

### 3.3.4 Irrelevance of Allegations to Proposed Victorian Law

Finally, there is a deeper point about Mr Mulino's claim of systemic non-reporting in Belgium and the Netherlands: Even were it true, it has little, or no, relevance to the law recommended for Victoria.

Whereas, in those countries euthanasia is by lethal injection provided by a doctor, the committee's recommendation is that assisted dying in Victoria be by self-administration of a lethal drink, except in rare circumstances where the patient is incapable of self-administration.

Remember that doctors in Belgium and the Netherlands who didn't report, failed to do so because they did not perceive their life-ending actions (injection) to be euthanasia. The proposed Victorian law removes that difficulty as the act of self-administration requires that a doctor write a prescription for life-ending medication once all the criteria of the law have been met. It is up to the person the prescription is written for whether or not – and when - they drink it.

This allows for the reporting of dispensation of the prescription to be traced to the reporting of an assisted death. In this way, there should be no confusion in doctors' minds. Any failure of reporting of assisted dying can be reduced to a negligible (but traceable) minimum.

### 3.4 'LIFE-ENDING ACTS WITHOUT EXPLICIT REQUEST' IN EUROPE: MISLEADING ALLEGATIONS

Mr Mulino's dissenting report is rich in detail and extensively footnoted. It looks like a well-researched and argued document. The likelihood is that few, if any, politicians or journalists have the time or resources to check that detail to see if what he is saying is balanced, let alone correct.

Yet it is in the detail that questions about Mr Mulino's methodology arise, particularly his careful omission of important information that, when presented, undermines his insinuations of sinister developments under VE and VAD laws.

For example, in Chapter 4.5.4 'Cases in which explicit consent is not given', Mr Mulino cites the work of Belgian end-of-life researcher Kenneth Chambaere:

**'In a large-scale death certificate survey, Chambaere et al find that "life-ending acts without explicit request [LAWER] are significantly different from those provided in euthanasia and similar to those provided in standard palliative care." This suggests that some of the worst fears that have been expressed in this area are based more on poor reporting than systemic abuse.'**



**However, they also argue that legalisation of euthanasia or physician-assisted dying did not put an end to the practice of non-voluntary or involuntary termination of life ...<sup>122</sup>**

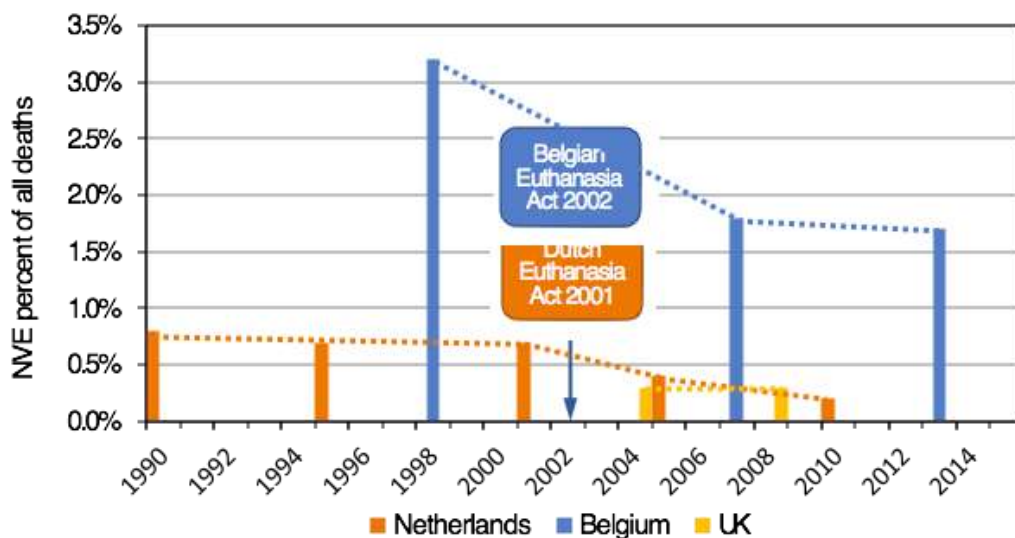
In response, Mr Chambaere points out a significant omission by Mulino which casts the impact of euthanasia laws on LAWER (life-terminating acts without explicit request) deaths in a very different light:

**‘Nowhere does [he] mention that the numbers have dropped since legislation!’<sup>123</sup>**

And indeed they have. How do we know?

In the Netherlands and Belgium large scale nationwide studies into the frequency and characteristics of voluntary euthanasia, physician assisted suicide and other medical end of life decisions began in 1990. All medical behaviour that shortens life is studied using death certificates. The results give a transparency to clinical decisions and practice - the palliative techniques - of doctors caring for dying patients. No other countries in the world have an archive as detailed and as comprehensive on end of life medical decision-making.

The table below shows the sharp decline in LAWER rates since the Netherlands began the process of legalising VE, and, since both the Dutch and Belgian VE Acts were introduced in 2002.



**Figure 1: Empirical trends in NVE rates before and after legalisation of assisted dying<sup>124</sup>**

<sup>122</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.4 'Cases in which explicit consent is not given', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>123</sup> Kenneth Chambaere, Email to Go Gentle Australia responding to Mr Mulino's Dissenting Report, response to point 4.5.4 'Cases in which explicit consent is not given', 6 May 2017.

<sup>124</sup> Dying for Choice, 'Figure 2: Empirical trends in NVE rates before and after legalisation of assisted dying' in 'The F Files', Dying for Choice UK, 8 August 2016, viewed 12 July 2017, <<http://www.dyingforchoice.com/categories/united-kingdom>>  
Data in graph sourced from the following studies:

1. J Bilsen, J Cohen, K Chambaere, G Pousset, BD Onwuteaka-Philipsen, F Mortier, & L Deliens, 'Medical end-of-life practices under



In the Netherlands, from 1990-2005, LAWER deaths dropped from 0.8 per cent to 0.4 per cent of all deaths.<sup>125</sup>

Rietjens et al (2009) explain that:

**'analyses of the cases of ending of life without an explicit request show that these concern nearly always patients who are very close to death, are incompetent but with whom the hastening of death has been discussed earlier in the disease trajectory and/or with their relatives, and for whom opioids [rather than barbiturates] were used to end life.'**<sup>126</sup>

Dutch research, confirmed by Professor Hans (JJM) Van Delden in evidence to the Canadian Supreme Court in 2012, shows about one-third of these cases can be described as terminal sedation, in which higher doses of sedatives are given without hydrating patients.<sup>127 128</sup>

By 2010 LAWER deaths in the Netherlands had dropped further to 0.2 per cent, or 270 out of a total of 136,058 deaths.<sup>129</sup>

Similar to the Netherlands, in Belgium the rate of LAWER deaths has fallen since the introduction of euthanasia and palliative care laws in 2002. Whereas, in 1998, LAWER deaths accounted for 3.2 per cent of total Belgian deaths, they have since fallen to a stable rate of 1.7 per cent.<sup>130</sup>

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the euthanasia law in Belgium', *New England Journal of Medicine*, 361(11), 2009, pp.1119-1121, viewed 12 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJMc0904292#t=article>>.

2. C Seale, 'End-of-life decisions in the UK involving medical practitioners', *Palliative Medicine* 23(3), 2009, pp.198-204, viewed 12 July 2017, <<https://www.eutanasia.ws/hemeroteca/t301.pdf>>.

3. BD Onwuteaka-Philipsen, A Brinkman-Stoppelenburg, C Penning, GJF de Jong-Krui, JJM van Delden and A van der Heide, 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey', *The Lancet*, 380(9845), 2012, pp.908-915, viewed 12 July 2017, <<https://www.ncbi.nlm.nih.gov/pubmed/22789501>>.

<sup>125</sup> Judith A. C. Rietjens, Paul J. van der Maas, Bregje D. Onwuteaka-Philipsen, Johannes J. M. van Delden, and Agnes van der Heide, 'Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?', *Journal of Bioethical Inquiry*, 6(3), September 2009, **Table 1:** Frequency of euthanasia and other end-of-life practices in the Netherlands, in 1990, 1995, 2001 and 2005', pp.271-283, published online 28 July 2009, viewed 12 July 2017, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733179/>>.

<sup>126</sup> Judith A. C. Rietjens, Paul J. van der Maas, Bregje D. Onwuteaka-Philipsen, Johannes J. M. van Delden, and Agnes van der Heide, 'Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?', *Journal of Bioethical Inquiry* 6(3), September 2009, pp.271-283, published online 28 July 2009, viewed 12 July 2017, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733179/>>.

<sup>127</sup> G. Van der Wal et al 'Medical Decision Making at the end of Life: The Practice and the Evaluation Procedure' [in Dutch], 2003, cited in JJM Van Delden and E Borst-Eilers, 'Thirty Years' Experience with Euthanasia in the Netherlands', in Timothy E Quill and Margaret P Battin (eds), *Physician Assisted Dying: The Case for Palliative Care and Patient Choice*, Johns Hopkins University Press, Baltimore and London, 2004, p.208, viewed Google Books version 12 July 2007,

<[https://books.google.com.au/books?id=Gt6WlpqFbYC&printsec=frontcover&source=gbs\\_ge\\_summary\\_r&cad=0#v=onepage&q&f=false](https://books.google.com.au/books?id=Gt6WlpqFbYC&printsec=frontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false)>.

<sup>128</sup> Professor Hans (JJM) van Delden, Evidence, in *Carter v. Canada (Attorney General)*, 2012 BCSC 886, para. 485.

<sup>129</sup> BD Onwuteaka-Philipsen, A Brinkman-Stoppelenburg, C Penning, GJ de Jong-Krui, JJ van Delden, A van der Heide, 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey', *The Lancet*, 380(9845), 8 September 2012, pp.908-15, viewed 12 July 2017, <<https://www.ncbi.nlm.nih.gov/pubmed/22789501>>.

<sup>130</sup> Kenneth Chambaere and Luc Deliens, 'Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium', Letter to the Editor, *New England Journal of Medicine*, 372, 19 March, 2015, p.12, viewed 13 July 2017, Ghent University website, <<https://biblio.ugent.be/publication/7037428/file/7037435.pdf>>.

See also: Johan Bilsen, Joachim Cohen, Kenneth Chambaere, Geert Pousset, Bregje D. Onwuteaka-Philipsen, Freddy Mortier, Luc Deliens, 'Medical End-of-Life Practices under the Euthanasia Law in Belgium', *New England Journal of Medicine*, 361, 10 September 2009, pp.1119-1121, viewed 13 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJMc0904292#t=article>>.

Peer-reviewed research by Bilsen, Chambaere et al, published in the *New England Journal of Medicine* in 2009 supports this:

**‘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.’<sup>131</sup>**

And, as in the Netherlands, more specific research into LAWER deaths in Belgium further clarified that physicians were, in fact, describing standard clinical management practices of dying patients in the last days and hours of life. These findings raised questions about whether these acts are truly equivalent to non-voluntary termination of life.

For example, in 2014 Chambaere et al explain how their study:

**‘elaborates on the results of previous studies that have shown that the medications provided in life-ending acts without explicit patient request are significantly different from those provided in euthanasia and similar to those provided in standard palliative care. In addition, the terminology used by physicians suggests that their focus was not on hastening death, and other studies have presented similar results ...’<sup>132</sup>**

The welter of detail, which is likely to remain unexamined and unquestioned, conceals other omissions too.

For example, he refers to a study in *The Lancet* by Agnes Van der Heide et al who undertook surveys in six European countries to contrast end-of-life decision making.<sup>133</sup>

He states:

**‘Two countries with the highest rates of this type of end-of-life [LAWER] (Belgium at 1.5% and the Netherlands at 0.60%) allowed the practice of euthanasia and assisted dying.’<sup>134</sup>**

<sup>131</sup> Johan Bilsen, Joachim Cohen, Kenneth Chambaere, Geert Pousset, Bregje D. Onwuteaka-Philipsen, Freddy Mortier, Luc Deliens, ‘Medical End-of-Life Practices under the Euthanasia Law in Belgium’, *New England Journal of Medicine*, 361, 10 September 2009, pp. 1119-1121, viewed 13 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM0904292#t=article>>.

<sup>132</sup> Kenneth Chambaere, Jan L Bernheim, James Downar and Luc Deliens, ‘Characteristics of Belgian “life-ending acts without explicit patient request”: a large-scale death certificate survey revisited’, *Canadian Medical Association Journal Open*, Oct-Dec; 2(4), 2014, pp. E262–E267, published online 1 October 2014, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4257563/>>.

<sup>133</sup> A Van der Heide, L Deliens, K Faisst, T Nilstun, M Norup, E Paci et al, ‘End-of-life decision-making in six European countries: descriptive study’, *The Lancet*, 362, 2003, p.347, viewed 13 July 2017, <<http://image.thelancet.com/extras/03art3298web.pdf>>. Mr Mulino (2017, footnote no. 96) refers also to: K. Meeussen, L. Van den Block, N. Bossuyt et al., ‘The end of life in the absence of explicit patient request in general practice in Belgium’, *BMC Public Health*, 10, 2010, p.186, viewed 15 July 2017, <<https://www.ncbi.nlm.nih.gov/pubmed/20380710>>.

Mr Mulino does not mention the conclusion drawn by this study: “*The practice of using life-ending drugs without explicit patient request in general practice in Belgium mainly involves non-competent patients experiencing persistent and unbearable suffering whose end-of-life wishes can no longer be ascertained. GPs do not act as isolated decision-makers and they believe they act in the best interests of the patient. Advance care planning could help to inform GPs about patients' wishes prior to their loss of competence.*”

<sup>134</sup> Daniel Mulino, ‘Minority Report’, in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.4 ‘Cases in which explicit consent is not given’, viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Here is the relevant data (highlighted) from the original study. It was not published by Mulino:

	Country					
	Belgium	Denmark	Italy	Netherlands	Sweden	Switzerland
Number of studied deaths	2950	2939	2604	5384	3248	3355
Sudden and unexpected death*	34 (32–36)	33 (32–35)	29 (27–31)	33 (32–34)	30 (29–32)	32 (30–34)
Non-sudden death, no end-of-life decision	27 (26–29)	26 (24–28)	48 (46–50)	23 (22–25)	34 (32–36)	17 (16–19)
Total end-of-life decisions	38 (37–40)	41 (39–42)	23 (22–25)	44 (42–45)	36 (34–37)	51 (49–53)
Doctor-assisted dying	1.82 (1.40–2.36)	0.79 (0.53–1.18)	0.10 (0.03–0.34)	3.40 (2.95–3.92)	0.23 (0.11–0.47)	1.04 (0.75–1.45)
Euthanasia	0.30 (0.16–0.58)	0.06 (0.01–0.26)	0.04 (0.00–0.27)	2.59 (2.19–3.04)	..	0.27 (0.14–0.51)
Doctor-assisted suicide	0.01 (0.00–0.28)	0.06 (0.01–0.26)	0.00 (..)	0.21 (0.12–0.38)	..	0.36 (0.20–0.63)
Ending of life without the patient's explicit request	1.50 (1.12–2.01)	0.67 (0.44–1.04)	0.06 (0.01–0.29)	0.60 (0.43–0.84)	0.23 (0.11–0.47)	0.42 (0.25–0.70)
Alleviation of pain and symptoms with possible life-shortening effect	22 (21–24)	26 (24–28)	19 (17–20)	20 (19–21)	21 (20–22)	22 (21–23)
Non-treatment decisions	15 (13–16)	14 (13–15)	4 (3–5)	20 (19–21)	14 (13–16)	28 (26–29)

Data are weighted % (95% CI). \*Including all people for whom the reporting doctor had his or her first contact with the patient after he or she had died.

Table 2: Frequency of end-of-life decisions

**Figure 2: Frequency of end-of-life decisions, Europe**

Closer scrutiny shows Mr Mulino's assertion that the Netherlands and Belgium are the two countries with the highest rate of LAWER deaths is contradicted by his own source. While it is true that Belgium and the Netherlands are at the higher end of the scale, so is Denmark, which ranks in second position. Denmark doesn't have a euthanasia law.

Also, while focussing on the Netherlands and Belgium, Mulino disregards Switzerland, which sits at the lower end of the rankings with a LAWER rate of just 0.42. VAD has been permitted in Switzerland for 75 years without many of the safeguards which exist elsewhere. Yet, its LAWER rate is one of the lowest. That's hard to explain when you're trying to insinuate a connection between euthanasia laws and an inevitable escalation in the number of life-ending-acts without explicit request.

But, the most important thing missing from Mulino's report is any reference to the period to which these statistics refer. Clearly stated in his source document, but not disclosed, is that they derive from surveys conducted before the Dutch or Belgian euthanasia Acts were introduced in April and September 2002 respectively - and are, therefore, irrelevant.<sup>135</sup>

These may seem like small examples, but they are indicative of repeated omissions of evidence used by Mr Mulino to support his case. There are others, and of far greater significance, which this report will turn to shortly. All of them run contrary to his self-declared standard of a 'balanced reading of the evidence'.

<sup>135</sup> See also: Neil Francis, "Mr Mulino must withdraw his minority report", Dying for Choice, 6 August, viewed 6 August 2017, <<http://www.dyingforchoice.com/blogs/daniel-mulino-must-withdraw-his-minority-report>>.

These and other concerns about Mulino's dissenting report are also raised by Neil Francis of Dying for Choice. Go Gentle Australia was provided with an earlier, unpublished draft of Mr Francis' paper.

### 3.5 'LIFE-ENDING ACTS WITHOUT EXPLICIT REQUEST' IN AUSTRALIA: A TRUTH OMITTED

To his credit, when talking about LAWER deaths, Mulino does acknowledge that:

**'... it is clear that wherever the legal line is drawn, activity occurs in the grey area around that line that is difficult to monitor.'**<sup>136</sup>

But in so doing, he points to one of his biggest omissions – the fact that LAWER deaths happen in Australia too; some (and likely most) of them in that grey area - endorsed by palliative care and currently unregulated in Victoria; it is known as 'terminal (or palliative) sedation'.

Research into such deaths here, by comparison with Belgium and the Netherlands, is limited. (No central record of terminal sedation in Victoria is kept, for example). What research there is shows that, even without a law, Australian doctors also respond to patients' suffering and will administer drugs knowing - *intending* - that to do so will accelerate the final phase of dying:

- A national survey of Australian doctors in 1996 showed 3.5 per cent of all deaths involved doctors administering drugs that they knew would hasten death, without the explicit consent of their patients.<sup>137</sup>
- In a 1999 survey of Australian surgeons over one-third said they had hastened death by giving more medication than was necessary. Twenty percent of this group did so without the explicit consent of the patient.<sup>138</sup>

The reality of LAWER deaths in Australia was confirmed by Professor Richard Chye, Head of Palliative Care, at St Vincent's Hospital in Sydney. Here is an excerpt from the transcript of Richard Chye's (RC) podcast interview with host, Andrew Denton (AD):

**AD: If I am looking at this from the outside ... is it technically correct to say that it is not always possible to get the explicit consent of the patient for terminal sedation?**

**RC: Yes, very much so. And in New South Wales, where you get the 'consent' - in inverted commas - is then from families, from the wife, from the spouse, from the children. It is a term that we call 'person responsible' in New South Wales. If a patient is unable to give their consent, then we go on to the next person to get consent in a way, or rather to tell them, 'This is what I think is the best treatment, this is the way I think the medication should be used', and I am bringing the patient and I am bringing the family along with me.**

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<sup>136</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.5.4 'Cases in which explicit consent is not given', viewed 11 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>137</sup> H Kuhse, P Singer, P Baume, M Clark and M Rickard, 'End-of-life decisions in Australian medical practice', *Medical Journal of Australia*, 17 February, 166(4), 17 February 1997, pp.191-6, viewed 13 July 2017, <<https://www.ncbi.nlm.nih.gov/pubmed/9066548>>.

<sup>138</sup> CD Douglas, I Kerridge, K Rainbird, J McPhee, L Hancock, A Spigelman, 'The intention to hasten death: a survey of attitudes and practices of surgeons in Australia', *Medical Journal of Australia*, 175 (10), 2001, pp.511-515, viewed 13 July, <<https://pdfs.semanticscholar.org/0d1f/416fe8821e88c9d11dcfd6c985544e19a236.pdf>>.

**AD: And this sounds to me like exemplary palliative care practice. Is it your understanding that this is what palliative care does in most advanced countries in the world, that this is standard practice?**

**RC: Yes, I think so, and the thing that confuses it that a lot of people think that because we are sedating patients and giving lots of medications, humongous doses of medications, then that must be the same as euthanasia, which it is definitely not.**<sup>139</sup>

Why does Mulino not mention identical deaths in Australia? Because it runs contrary to the impression he's trying to create; that once a country legally allows doctors to compassionately end the lives of competent patients requesting their help, the culture shifts to something darker and potentially deadly. Something that can't be controlled. A 'normalisation of death'. A slippery slope.

Nowhere are Mulino's efforts to do this more obvious, or more discreditable, than in Chapter 3 of his report 'The Frequency of Euthanasia and Assisted Dying is Rising Rapidly'.

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<sup>139</sup> Andrew Denton, 'Voices from the Frontline', Submission to Victorian Parliament's Legal and Social Issues Committee Inquiry into End of Life Choices, Submission No. 969, 2015, pp.26-27, viewed on 14 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission\\_969\\_-\\_Andrew\\_Denton.pdf](https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_969_-_Andrew_Denton.pdf)>.

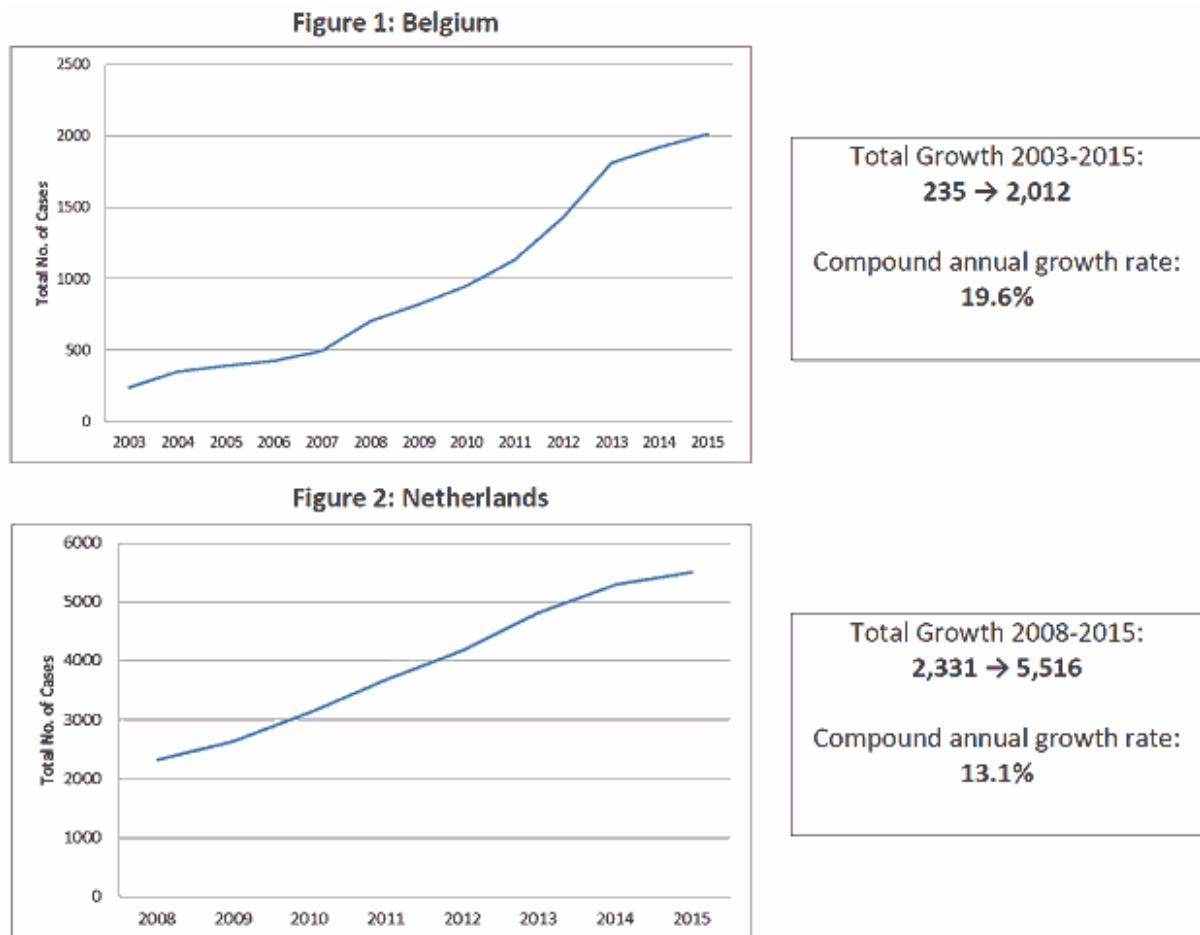
## 4. MISLEADING ALLEGATIONS THAT THE FREQUENCY OF EUTHANASIA IN EUROPE IS RISING RAPIDLY

### 4.1 MANIPULATION AND OMISSION OF FIGURES

Mr Mulino opens Chapter 3 of his dissenting report 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.’<sup>140</sup>**

The following charts are used by Mulino to illustrate his claim of a sharp and sustained rise in Belgium and the Netherlands:



### **Figures 3 and 4 (Figures 1 and 2 in Mr Mulino’s minority report): *Assisted deaths in Belgium and the Netherlands***

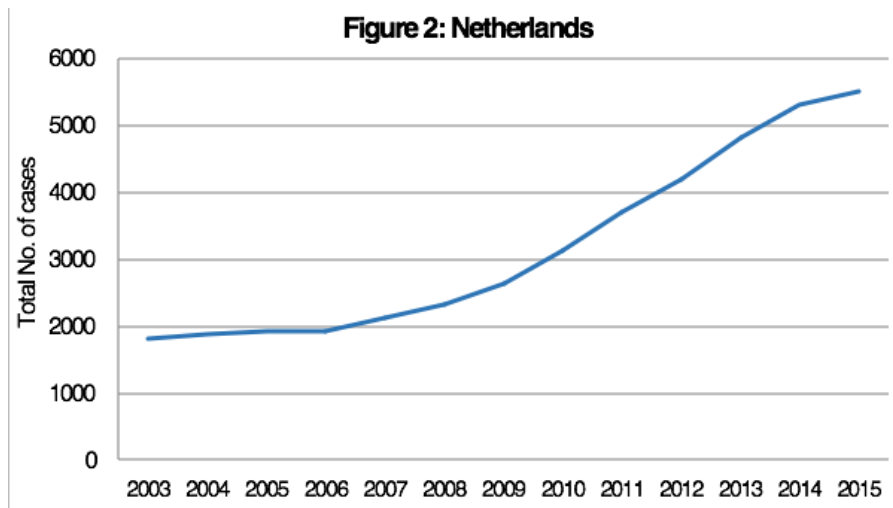
Taken at face value, they appear to confirm his claims. But, once again, closer inspection reveals crucial information which contradicts his analysis has been omitted.

<sup>140</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 3.1 ‘The frequency of euthanasia and assisted dying is rising rapidly’, viewed 11 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.



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 5 years? He offers no explanation.

But, when you factor in all the relevant data for the Netherlands (Figure 3), not just the years 2008-13, the reason becomes clear.



**Figure 5: The full Netherlands assisted dying data, 2003-15. Source: Official Euthanasia Commission reports** <sup>141</sup>

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

<sup>141</sup> Regional Euthanasia Review Committees (RTE), Annual Reports, 2002-2015, <https://english.euthanasiacommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports>.



- 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) <sup>142</sup>
- terminal illness frequency
- reporting improvements
- the corresponding decrease in LAWER (ending of life 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'.

#### **4.2 A VERY DIFFERENT PICTURE: PUTTING EUTHANASIA AND VAD 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.*

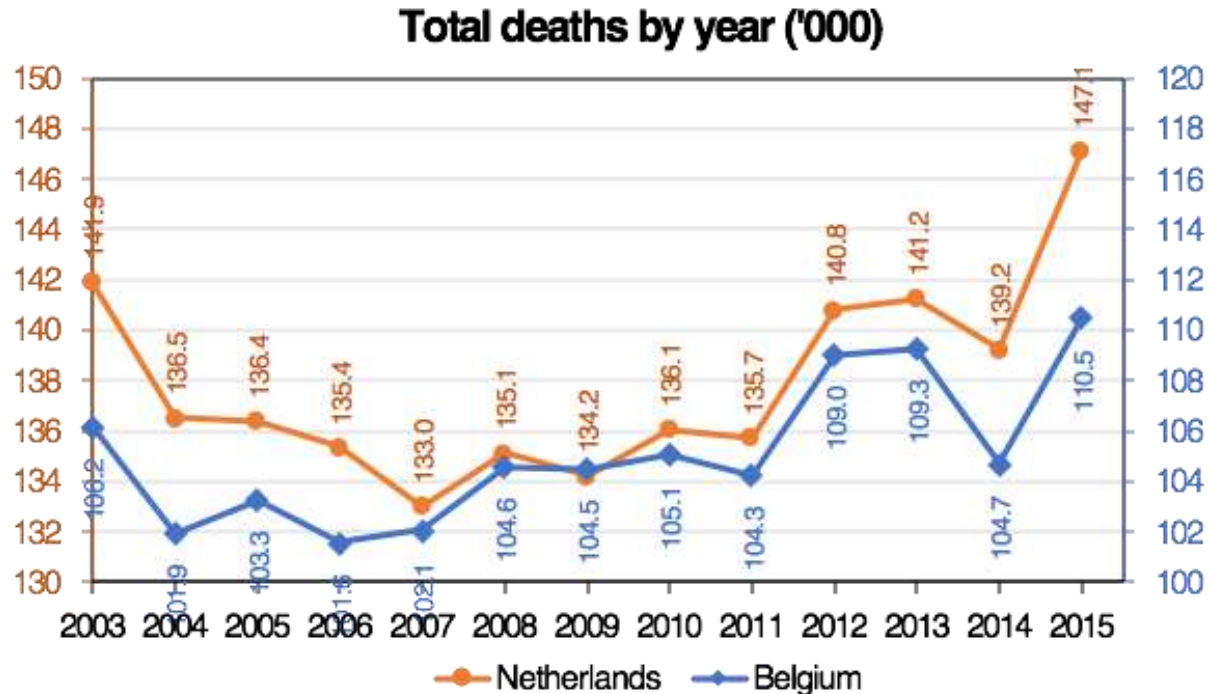
It is only within this context that the data can be properly understood. An increasing number of VE deaths may look alarming in isolation, but it's misleading to show it this way; VE numbers will inevitably rise as the population and total number of deaths increase. So, the fairest and most accurate expression of the data is as a proportion of overall deaths.

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<sup>142</sup> 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, viewed 23 July 2017, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/>>.

#### 4.2.1 A Very Different Picture: Belgium and the Netherlands

Here is the official data for deaths each year, 2003-15:

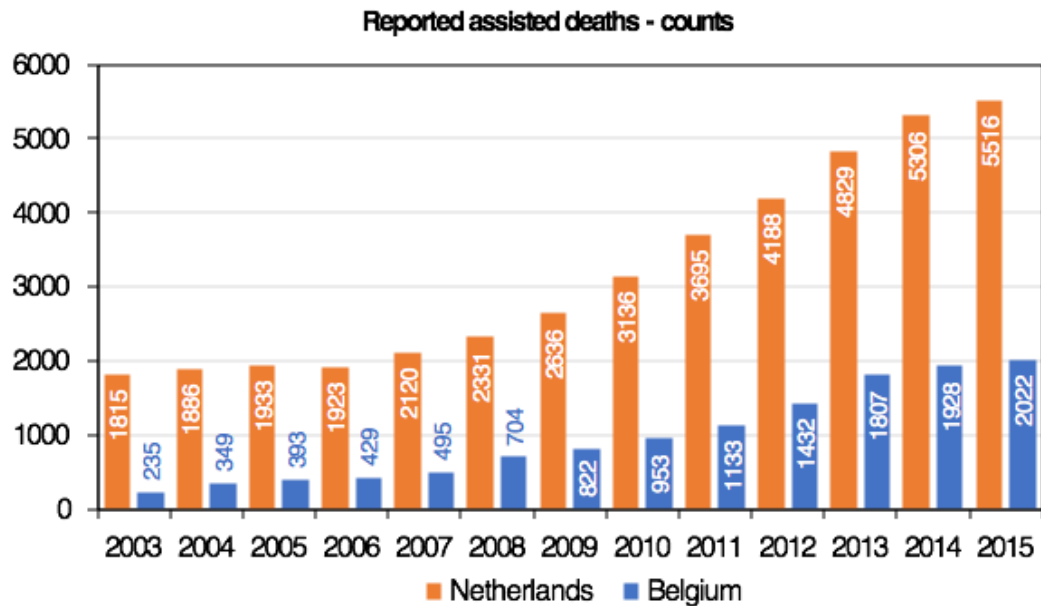


**Figure 6: Total deaths by year in the Netherlands and Belgium ('000) Source: Official government mortality data**<sup>143</sup>

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.

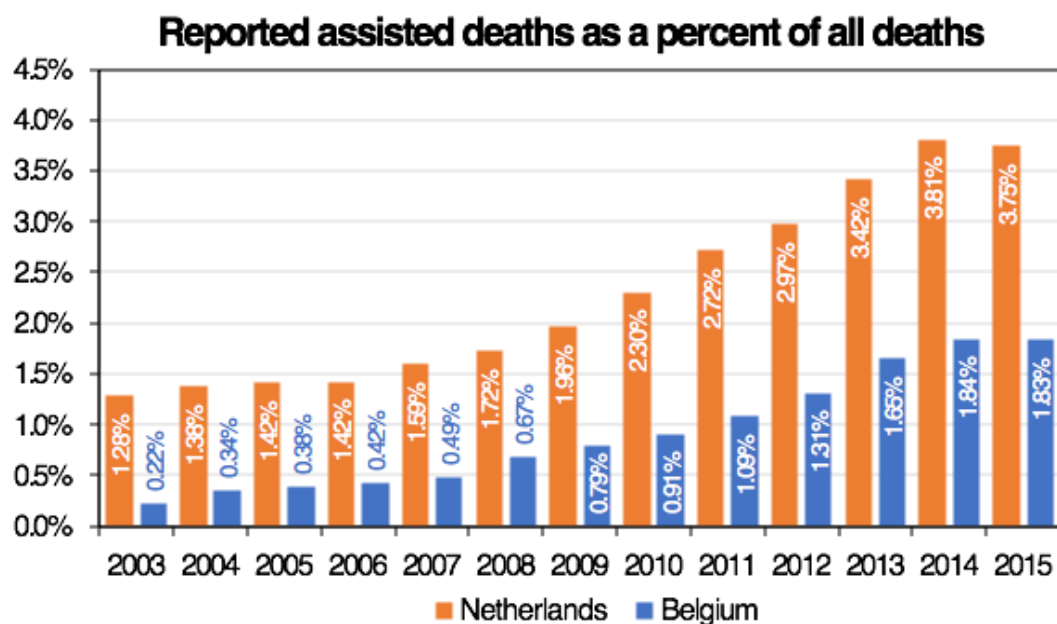
Now here is the official data for euthanasia deaths in the years, 2003-15 (not 2008-13 as shown in Mulino's chart of the Netherlands):

<sup>143</sup> The three graphs, Figures 6-8, 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 website, 15 December 2016, viewed 14 July 2017, <<http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>>.



**Figure 7: Reported assisted deaths in the Netherlands and Belgium, raw counts** Source: Official Euthanasia Commission reports<sup>144</sup>

And, finally, putting both together, euthanasia deaths as a percentage of all deaths:



**Figure 8: Reported assisted death rates in the Netherlands and Belgium as a percentage of all deaths.**<sup>145</sup>

<sup>144</sup> The three graphs, Figures 6-8, 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 website, 15 December 2016, viewed 14 July 2017, <<http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf>>.

<sup>145</sup> Ibid.

When all the data is tabled the following becomes clear:

1. 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.
2. Euthanasia deaths have remained statistically tiny despite an upward trend in total deaths in both countries.
3. 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.'**<sup>146</sup>

The facts – all on the public record - contradict him. As does the 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.'**<sup>147</sup>

#### 4.2.2 A Very Different Picture: Switzerland

Mr Mulino makes the same deliberate omission of important qualifying information with Switzerland. He points only to a total growth in euthanasia numbers, between 1998-2014, from 50 to 836 deaths.

*(We will discuss Mr Mulino's use of an end figure for Switzerland, gleaned, without reference or provenance, from an anti-euthanasia blogger, in [Section 8.1.3](#) (p. 69) below. The official, figure from the Swiss Federal Statistical Office - unavailable at the time Mr Mulino wrote his report - is 742).*<sup>148</sup>

A closer look at Switzerland tells us why Mr Mulino has been careful not to go into deeper detail.

Switzerland has the world's oldest assisted suicide law, in effect since 1942. It is also the least prescriptive: the only specific statutory requirement is that any assistance rendered must not be for reasons of self-interest. Having none of the complex requirements demanded by Dutch and Belgian law, according to slippery slope theory, the rate of euthanasia in Switzerland should be very high.

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<sup>146</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Section 3.3 'Challenges for the palliative care workforce in Victoria', viewed 11 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>147</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Introduction', p. 8, viewed 1 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>148</sup> Federal Statistical Office, 'Suicide and assisted suicide in Switzerland 2014', Press Release, 11 October 2016, viewed 1 July 2017, <<https://www.bfs.admin.ch/bfs/en/home.assetdetail.1023146.html>>.

When we add in the fact that Swiss law allows foreigners to travel there for assistance to die, the potential for numbers to ‘run out of control’ would seem obvious to someone concerned with the slippery slope.

By citing a rise, over 16 years, from 50 to ‘836’ deaths, this is what Mr Mulino wants us to think.

But, as a proportion of all deaths in Switzerland, euthanasia – including that of foreign nationals – makes up about 1.7 per cent of deaths overall, lower than that of both Belgium and the Netherlands.<sup>149</sup>

#### 4.3 THE ‘NORMALISATION’ OF EUTHANASIA: PROOF OF A LAW THAT IS WORKING

By excluding crucial statistical data in order to suggest a slippery slope, Mr Mulino is also attempting to substantiate his claim that:

**‘There is evidence of a “normalisation” of euthanasia and assisted suicide’**<sup>150</sup>

He defines ‘normalisation’ as being a situation whereby, once legalised:

**‘euthanasia and assisted suicide are increasingly taken for granted and seen to be unexceptional both within the medical profession and more broadly within society.’**<sup>151</sup>

We take issue with Mr Mulino’s claim that euthanasia deaths are now ‘unexceptional’. This is contradicted, for example, by the Royal Dutch Medical Society Report ‘Euthanasia in Figures’ (2017) which reveals:

Of the average number of cancer deaths in the Netherlands each year (44,000), doctors were involved in care prior to death in the following ways (our underlining) –

- Pain and symptom control (36%)
- No life-sustaining treatment (17%)
- Palliative sedation (18%)
- Euthanasia and physician assisted suicide (4.6%)<sup>152</sup>

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<sup>149</sup> Calculated using official and aggregated figures.

<sup>150</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, Chapter 4.4 ‘There is evidence of a “normalisation” of euthanasia and assisted suicide’, viewed 18 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>151</sup> Ibid.

<sup>152</sup> Marjolein Reezigt, ‘Euthanasia in figures’, KNMG [Royal Dutch Medical Society], June 2017, viewed 18 July 2017, Weblink to PDF - <<https://www.knmg.nl/zoekresultaten.htm?searchstring=euthanasia+in+figures+2015#gsc.tab=0&gsc.q=euthanasia%20in%20figures%202015&gsc.page=1>>.

It is also at odds with the majority committee finding that:

**'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.'** <sup>153</sup>

It is revealing of the thinking underpinning Mr Mulino's report that he regards a medical practice, codified in law and in operation for almost two decades, as not 'normal'.

What is more, Mr Mulino's central thesis - that safeguards do not and cannot work – is at odds with his assertion that euthanasia and assisted suicide have become normalised.

It is hard to imagine laws that leave vulnerable people in the danger Mr Mulino asserts they are in being viewed by legislators and the medical profession as 'normal'. Yet VAD and VE laws sit, as they have done for many years, squarely within the medical and legal systems of the countries where they exist.

Evidence shows that Dutch people do not live in fear of their doctors and relatives; of being euthanised against their will. Providing euthanasia as an end-of-life option has not eroded the bond of trust between patients and their doctors and nurses. In fact, the opposite is true. Dr Gerrit Kimsma (2010) describes anthropologist, Frances Norwood's (2009), observation of the relationship as follows:

**'a request for euthanasia changes not only the doctor–patient relationship, but also the relationships between patients and their families and friends. This change is a deepening and strengthening of the emotional commitments and relations.'** <sup>154</sup>

There is statistical evidence for this. In Belgium and the Netherlands, health care workers rank at the top of those countries' most trusted professionals. In 2014, the GfK Group, reported that, in the Netherlands, where the average trust rating for professionals is 70 per cent, 95 per cent of Dutch citizens have confidence in nurses. Doctors scored a rating of 88 per cent. <sup>155</sup>

In Belgium, where the average professional rating for trust is 71 per cent, GfK reports that 'Belgians bestow particular trust on healthcare professions'. Ninety-five per cent of the population rates nurses as trustworthy and 93 per cent has confidence in doctors. <sup>156</sup>

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<sup>153</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Executive Summary', p.xx, viewed 1 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>154</sup> Frances Norwood, *The Maintenance of Life: The Maintenance of Life: Preventing Social Death Through Euthanasia Talk and End-of-life Care: Lessons from the Netherlands*, Carolina Academic Press, 2009, p.48, paraphrased in GK Kimsma, 'Death by request in the Netherlands: facts, the legal context and effects on physicians, patients and families', *Medical Health Care and Philosophy*, 13, 2010 pp. 355-361.

<sup>155</sup> GfK, 'Professions with the highest trust rating per country', Vereen, Netherlands, 2014, p.8, viewed 22 July 2017 <<https://tinyurl.com/y8zyx9k7>>. Note: this link will download a PDF.

<sup>156</sup> GfK, 'Trust in Professions Report 2016 - Firefighters are ranked first place whereas politicians occupy last place', Press Release, Leuven, Belgium, 19 May 2016, viewed 22 July 2017, <<http://www.gfk.com/en-be/insights/press-release/trust-in-professions-report-2016-firefighters-are-ranked-first-place-whereas-politicians-occupy-last-place/>>.



In Switzerland in 2016, nurses and doctors earned the confidence of 95 per cent and 89 per cent of Swiss citizens, respectively.<sup>157</sup>

The so-called 'normalisation' of euthanasia has not eroded the trust that Dutch and Belgian citizens have in their health systems or their governments.

For example, a 2015 OECD report on the Netherlands notes that:

**'Satisfaction with health care in the Netherlands is high – 86% – compared to 71% across the OECD'**<sup>158</sup>

Of Belgium in 2017, the OECD reports:

**'Citizen satisfaction is among the highest ... health care – at 90% of citizens satisfied ... significantly higher than the OECD [average], which amount[s] to 70% in the case of health care.'**<sup>159</sup>

Similarly, in Switzerland, whose government presides over the world's most liberal approach to VAD, the OECD reports in 2017 that:

**'The share of [Swiss] citizens who have confidence in the national government was close to 80% in 2016 (based on Gallup World Polls), almost double the OECD average of 42%'**<sup>160</sup>

These statistics are not indicative of health systems in crisis, of widespread medical malpractice, or of a law derailing the sacred trust between patients and health care providers. Indeed, a balanced reading of the evidence shows no evidence of a widespread failure of safeguards with the inevitable erosion in public trust that would follow as a consequence.

In questioning the wide acceptance of voluntary euthanasia in the Netherlands, Mr Mulino questions the Royal Dutch Medical Society, who helped frame Dutch laws and who continue to support them; also the caring doctors who supervise these deaths in homes, hospitals, hospices and in residential care facilities.

He questions the Belgian palliative care system, within which more than 70 per cent of euthanasia deaths take place.<sup>161</sup>

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<sup>157</sup> GfK, 'Trust in Professions 2016 – a GfK Verein study: From firefighters to politicians', Verein, Belgium, viewed 22 July 2017, <[http://www.gfk.com/fileadmin/user\\_upload/dyna\\_content/CH/documents/Medienmitteilungen\\_2016/Mai\\_16/Trust\\_in\\_Professions\\_2016\\_Switzerland\\_EN.pdf](http://www.gfk.com/fileadmin/user_upload/dyna_content/CH/documents/Medienmitteilungen_2016/Mai_16/Trust_in_Professions_2016_Switzerland_EN.pdf)>.

<sup>158</sup> OECD, 'Government at a Glance 2015: Country Fact Sheet - Netherlands', 2015, viewed 22 July 2017, <<https://www.oecd.org/gov/Netherlands.pdf>>. NB: The latest 2017 report does not show 'satisfaction with health care' data.

<sup>159</sup> OECD, 'Government at a Glance 2017: Country Fact Sheet - Belgium', 2017, viewed 22 July 2017, <<http://www.oecd.org/gov/gov-at-a-glance-2017-belgium.pdf>>.

<sup>160</sup> OECD, 'Government at a Glance 2017: Country Fact Sheet - Switzerland', 2017, viewed 22 July 2017, <<http://www.oecd.org/gov/gov-at-a-glance-2017-switzerland.pdf>>.

<sup>161</sup> Kenneth Chambaere and Luc Deliens, 'Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium', Letter to the Editor, *New England Journal of Medicine*, 372, 19 March, 2015, p.12, viewed 13 July 2017, Ghent University website, <<https://biblio.ugent.be/publication/7037428/file/7037435.pdf>>.



He questions too, the Parliaments, and also the citizens, of these countries who - surveys show - support these laws in vast numbers.<sup>162</sup>

The 'normalisation' of euthanasia and assisted suicide speaks to the success, not the failure of legislative reform in the Netherlands, Belgium and elsewhere. It affirms that the legislation is working to the growing satisfaction of all stakeholders.

That an increasing number of incurably ill people are freely choosing to end their suffering with the assistance of expert medical advice is not evidence of a legislative or moral failing, but its opposite.

## 5. MISREPRESENTATION OF OREGON'S DEATH WITH DIGNITY LAW

### 5.1 OREGON: TWO VERY DIFFERENT PICTURES

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.'**<sup>163</sup>

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 deaths<sup>164</sup> - 133 out of nearly 36,000 deaths<sup>165</sup> - or fewer than 4 in every 1000 people<sup>166</sup>.

<sup>162</sup> *The Economist*, 'Attitudes towards assisted dying: An idea whose time has come', 27 June 2015, viewed 17 July 2017, <<https://www.economist.com/news/briefing/21656121-idea-whose-time-has-come-attitudes-towards-assisted-dying>>. Cached version:

<<https://webcache.googleusercontent.com/search?q=cache:ioDHEFnrrgJ:https://www.economist.com/news/briefing/21656121-idea-whose-time-has-come-attitudes-towards-assisted-dying+&cd=1&hl=en&ct=clnk&gl=au&client=safari>>.

<sup>163</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 3.3 'The sustained and long-term nature of growth', viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>164</sup> Public Health Division, Centre for Health Statistics, 'Oregon Death with Dignity Act: Data Summary 2016', Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017,

<<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Document/s/year19.pdf>>.

<sup>165</sup> Oregon Government, 'Deaths by Age Group and Country of Residence: Oregon Residents 2016, Final Data', viewed 31 July 2017, <<http://www.oregon.gov/oha/PH/BIRTHDEATHCERTIFICATES/VITALSTATISTICS/DEATH/Documents/dage16.pdf>>.

<sup>166</sup> Death with Dignity National Centre, 'Debunking Myths and Falsehoods About Death with Dignity Legislation', Fact Sheet.

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:<sup>167</sup>

- Since the law was passed in 1997, a total of 1,749 people has had prescriptions written.
- Of that number, 1,127 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.<sup>168</sup>

Speaking from his long experience with the legislation, Doctor Blanke said that ‘***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,”** says Dr Blanke.

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 to the account given by Mr Mulino (who, it must be remembered, did not travel to Oregon with the rest of the Committee).

<sup>167</sup> Public Health Division, Centre for Health Statistics, ‘Oregon Death with Dignity Act: Data Summary 2016’, Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>>.

<sup>168</sup> 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, viewed 25 July 2016, <<http://www.medscape.com/viewarticle/869023>>.

## 5.2 ALARMISM: RAW DATA 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.<sup>169</sup>

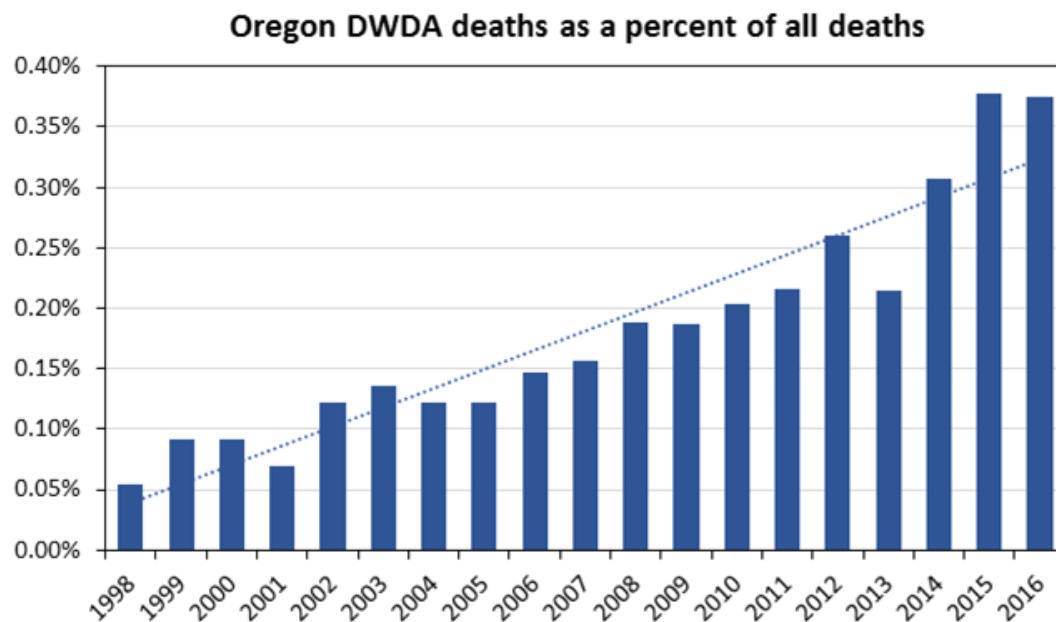
In 2016, that equated to 37 out of 10,000 deaths.

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.’<sup>170</sup>**

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 .15 per cent in 2007 to .37 per cent of total deaths in 2016.



**Figure 10: Oregon DWDA deaths as a per cent of all deaths. - 1998-2016<sup>171</sup>**

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.

<sup>169</sup> Public Health Division, Centre for Health Statistics, ‘Oregon Death with Dignity Act: Data Summary 2016’, Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>>.

<sup>170</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 3.3 ‘The sustained and long-term nature of growth’, viewed 21 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>171</sup> Graph plotted by Neil Francis, Dying for Choice, using data from Public Health Division, Centre for Health Statistics, ‘Oregon Death with Dignity Act: Data Summary 2016’, Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>>.

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.<sup>172</sup>

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),<sup>173</sup> and patients' lack of access to affordable health care in the early (treatable) stages of disease.

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 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 20 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.

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<sup>172</sup> 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.

<sup>173</sup> 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, viewed 23 July 2017, <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/>>.

### 5.3 'FEAR OF BEING A BURDEN': TELLING ONLY HALF THE STORY

Mr Mulino raises concerns about people who may hasten their deaths, either because they feel pressure from their family or, because they don't wish to burden their loved ones.

He references a 2006 review of the empirical literature on Oregon and asserts **'fear of being a burden is common in patients who die by lethal prescription'**.<sup>174</sup>

**'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.'**<sup>175</sup>

The information is correct. But, stripped of its context, the conclusion he points to is misleading.

On this question there are two other issues at play: Where 'being a burden' sits on a patient's list of concerns, and 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. Only 42.2 per cent of patients considered it a factor in contrast with the 91.4 per cent of patients, overall, for whom 'losing autonomy' was their important concern.

	2016	1998-2015	Total
End of life concerns <sup>4</sup>	(N=133)	(N=994)	(N=991)
Losing autonomy (%)	119 (89.5)	906 (91.6)	1,025 (91.4)
Less able to engage in activities making life enjoyable (%)	119 (89.5)	888 (89.7)	1,007 (89.7)
Loss of dignity (%) <sup>5</sup>	87 (65.4)	680 (78.8)	767 (77.0)
Losing control of bodily functions (%)	49 (36.8)	475 (48.1)	524 (46.8)
Burden on family, friends/caregivers (%)	65 (48.9)	408 (41.3)	473 (42.2)
Inadequate pain control or concern about it (%)	47 (35.3)	249 (25.2)	296 (26.4)
Financial implications of treatment (%)	7 (5.3)	31 (3.1)	38 (3.4)

**Figure 11: Characteristics - End of Life Concerns, Oregon Death with Dignity Act Data Summary 2016**<sup>176</sup>

<sup>174</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.1 'People who feel as though they are a burden', viewed 24 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>175</sup> Ibid.

<sup>176</sup> Public Health Division, Centre for Health Statistics, 'Oregon Death with Dignity Act: Data Summary 2016', Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf>>.



Read together, and *in context*, these two statistics support a different explanation of ‘fear of being a burden’ to the one Mr Mulino wishes 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 PAD.

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.’** <sup>177</sup>

Working to Mr Mulino’s own benchmark, 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.

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

Under Oregon law you can only access PAD if, according to the independent assessment of two doctors, you are terminally ill with six months or less to live. 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 facing the end of their life.

The implication that people are choosing to end their life because they feel they are a burden is clearly untrue.

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<sup>177</sup> George Eighmey, email to Andrew Denton, Go Gentle Australia, 16 May 2017.

### 5.3.1 A Full Accounting: The Story of Kate Cheney

To illustrate his point about people being made to feel a burden, Mr Mulino provides the story of Kate Cheney as a case study:

**Kate Cheney, a terminally ill 85-year-old widow, sought access to a lethal drug, made accessible to qualifying patients under Oregon's (then new) Dying with Dignity Act. Mrs Cheney's physician refused her request but referred her to another doctor. The second doctor insisted on a psychiatric assessment. The psychiatrist felt she was not fully committed and implied her daughter was more invested in a positive assessment than Ms Cheney, herself. A second opinion was sought and the independent psychologist also raised doubts about Ms Cheney's competence and felt she may have been under some pressure from her daughter but, ultimately, decided she was able to make her own decision. An 'administrator' from the health care service then saw Ms Cheney and confirmed she was competent and able to make her own decisions. A prescription was written and filled and sometime later, Ms Cheney took the medication and died.\***

*\*Mr Mulino's slightly longer version can be read in his dissenting report at 4.5.1 'People who feel as though they are a burden: Box 2: Kate Cheney - Case Study, Oregon'.*

The full first-person story, direct from Ms Cheney's family and the health care provider involved, is available at the link provided below.<sup>178</sup> It contains important details omitted in Mr Mulino's account. Here is a *precis*:

**In mid-1999, Kate Cheney, a terminally ill 85-year-old widow with untreatable stomach cancer, sought access to a lethal drug, accessible only to those who met the strict criteria of Oregon's (then new) Dying with Dignity Act. Ms Cheney's physician refused her request but referred her to another doctor in the same facility. The doctor's refusal was probably because he had an ethical objection to the new law, rather than concerns about Ms Cheney's competence or independence. That suspicion is strengthened by the fact the physician referred Ms Cheney to another GP in the same facility.**

**The second doctor insisted on a psychiatric assessment; not because of any doubts about Ms Cheney's competence or independence, but because it was standard procedure for that particular health care service.**

**Understandably cautious about the new law, the psychiatrist interpreted Ms Cheney's gentle manner as a lack of commitment to the process. He felt her daughter was more invested in a positive assessment than Ms Cheney, herself. Yet, he also noted that assisted suicide was consistent with Ms Cheney's values throughout her life.**

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<sup>178</sup> Erin Hoover Barnett, 'Physician-assisted suicide: A family struggles with the question of whether mom is capable of choosing to die', Oregon Live, 4 February 2015 (originally published in *The Oregonian* on 17 October 1999), viewed 24 July 2017, <[http://www.oregonlive.com/health/index.ssf/2015/02/physician-assisted\\_suicide\\_a\\_f.html](http://www.oregonlive.com/health/index.ssf/2015/02/physician-assisted_suicide_a_f.html)>.



**A second opinion was sought (again, through the same health care facility). Ms Cheney met one on one with a clinical psychologist. After questioning her extensively, he determined she suffered no severe impairment that would limit her ability to make a medical decision. He found Ms Cheney ‘demonstrated the capacity to ... articulate her own values.’**

**But, the psychologist did not write Ms Cheney a prescription. The health service assigned an ethicist to the case and the ethicist and her doctor made the decision in consultation with each other. This decision was made only after the ethicist made an independent assessment after meeting with Ms Cheney, alone, away from the ‘influence’ of her daughter. According to the ethicist, Ms Cheney articulated clearly under what circumstances she would assess her condition as being ‘unbearable’.**

**‘I had no reason to believe that this was anyone’s agenda but hers,’ he said.**

**Ultimately, having satisfied a clinical psychologist, a doctor and an ethicist of her competence and independence, Ms Cheney received a prescription for the lethal drug.**

**But, she did not just ‘take it’. In an interview with the local newspaper prior to her death, Ms Cheney said:**

**“It’s not that I have any plans to use it right away. I may never use it. But it’s just to have the decision in my hands, rather than anyone else’s.”**

**She dismissed the notion she was being pressured or coerced:**

**“She [Erika, her daughter] makes more noise than I do. But that doesn’t make me any less serious.”**

**“They [the family] all feel I should do what I want.”**

**Ms Cheney explained part of the family’s values was respecting one another’s views.**

**It was two months before Ms Cheney finally decided to avail herself of the lethal drug. She had spent a week in a nursing home and contemplated that option but, ultimately, she decided she preferred to die at home. At that stage she was weak and barely eating. She was having trouble managing her waste bag and was suffering the indignity of having to be cleaned up by her daughter. She was at the stage she had initially stated she would find unbearable.**

**When requested, her daughter did not just give her the drug. She asked her to repeat the request to other family members. Yet more family was assembled to say goodbye. The contents of the capsules was mixed with apple sauce and given to Ms Cheney who not only consumed it of her own**

**accord, but ‘shovelled it in’, despite having had no appetite for food for months. She died an hour later.**

It is concerning that the full facts of this case have been available on the internet since 2015, yet the voices of Ms Cheney, her family and her health care providers are not heard in Mr Mulino’s version of the story. There is no doubt Mr Mulino was aware of the interview in *The Oregonian*; it is mentioned in his own account.<sup>179</sup>

Instead of corroborating the evidence from the source document it appears that Mr Mulino simply cut and pasted a story from *The Case Against Assisted Suicide* (2002), an anti-euthanasia book by Doctors Kathleen Foley\* and Herbert Hendin.<sup>180</sup>

*\*(Further information on Dr Foley and her background can be found in on p 6 Part E-57 of this submission)*

Ms Cheney’s story is a testament to how the checks and balances of the Act worked; not about how they failed. Ms Cheney’s daughter’s anger and frustration were the result of the safeguards *working* not failing. Erika wanted her mother’s last wish fulfilled and represented her as a passionate advocate as any loving daughter would do.

There is no substance to the imputation that family self-interest or coercion played any role in Kate Cheney’s death.

## **5.4 DEPRESSION AND DECISION MAKING CAPABILITY**

Mr Mulino refers to a study by Linda Ganzini et al<sup>181</sup> which found that 20 per cent of patients who had accessed Oregon’s DWD law had symptoms of depression. He writes:

**‘These studies raise questions about what safeguards need to be in place in legalized euthanasia or assisted suicide regimes to protect people from making decisions that might be affected in the short term by depressive mood that might be manageable or treatable with additional support.’<sup>182</sup>**

Avoiding the fact that all patients eligible under Oregon’s law have been diagnosed with a terminal illness and 6 months or less to live, Mr Mulino adds:

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<sup>179</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, 4.5.1 ‘People who feel as though they are a burden: Box 2: Kate Cheney - Case Study, Oregon’, viewed 26 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>. Specifically, within Mr Mulino’s account are the words: ‘the family released his report to the *Oregonian*’s reporter.’

<sup>180</sup> K Foley and H Hendin, ‘The Oregon Experiment’, Chapter 7 in K Foley and H Hendin, (Eds.), *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002.

<sup>181</sup> 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, viewed 27 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>>.

<sup>182</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, 4.5.2 ‘Depression’, viewed 26 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

**‘A number of studies have shown that physicians find it difficult to diagnose depression in patients with terminal conditions, let alone to determine whether that depression is impairing judgement.’<sup>183</sup>**

The allegation ignores an important safeguard provision of Oregon’s DWD law which mandates mental health examinations. As the current, revised statute says:

**127.820 s.3.02. Consulting physician confirmation.**

Before a patient is qualified under ORS 127.800 to 127.897, a consulting physician shall examine the patient and his or her relevant medical records and confirm, in writing, the attending physician's diagnosis that the patient is suffering from a terminal disease, and verify that the patient is capable, is acting voluntarily and has made an informed decision. [1995 c.3 s.3.02]

**127.825 s.3.03. Counseling referral.**

If in the opinion of the attending physician or the consulting physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling. No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. [1995 c.3 s.3.03; 1999 c.423 s.4] (Underlining is ours)

**127.830 s.3.04. Informed decision.**

No person shall receive a prescription for medication to end his or her life in a humane and dignified manner unless he or she has made an informed decision as defined in ORS 127.800 (7). Immediately prior to writing a prescription for medication under ORS 127.800 to 127.897, the attending physician shall verify that the patient is making an informed decision. [1995 c.3 s.3.04]<sup>184</sup>

It is important to note that depression, even severe depression, does not necessarily impair decision making capability.<sup>185</sup> It is also important to understand the difference between an individual with a long-term life-expectancy and a patient in the final stages of a terminal illness making decisions about hastening their death.

What is essential for the purposes of assessing a patient’s eligibility for physician assisted dying is not so much ‘depression’ as the presence of ‘adequate decision-making capacity’. There are specific criteria and guidelines for making this kind of assessment and doctors (not just psychiatrists and psychologists) are competent to make these kinds of judgements.<sup>186</sup>

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<sup>183</sup> Ibid. 4.5.2 ‘Depression’

<sup>184</sup> Oregon Health Authority, ‘Oregon Death with Dignity Act: Oregon Revised Statute, Chapter 127’, Oregon Government, viewed 31 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ors.aspx>>.

<sup>185</sup> Thomas Hindmarch, Matthew Hotopf and Gareth S Own, ‘Depression and decision-making capacity for treatment or research: a systematic review’, *BMC Medical Ethics*, 14:54, 13 December 2013, viewed 25 July 2017, <<https://bmcmethics.biomedcentral.com/articles/10.1186/1472-6939-14-54>>.

<sup>186</sup> Joshua M. Baruth and Maria I Lapid, ‘Influence of Psychiatric Symptoms on Decisional Capacity in Treatment Refusal’, *AMA Journal of Ethics*. Volume 19, Number 5, May 2017, pp.416-425, viewed 25 July 2017, <<http://journalofethics.ama-assn.org/2017/05/ecas1-1705.html>>.

What is essential for the purposes of assessing a patient's eligibility for physician assisted dying is not so much 'depression' as the presence of 'adequate decision-making capacity'. There are specific criteria and guidelines for making this kind of assessment and doctors (not just psychiatrists and psychologists) are competent to make these kinds of judgements.

Finally, Mulino's concerns about patients with depression accessing PAD is directly contradicted by his own source (Ganzini et al, 2000).<sup>187</sup>

According to Mulino:

**'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.'** <sup>188 189</sup>

But, 'the patients' referred to in this quote are patients who *requested* a prescription; not patients who received one. There is no suggestion that patients exhibiting symptoms of depression were given access to lethal drugs; in fact, the reverse. The abstract of the article states this unequivocally:

**'Twenty percent of the patients had symptoms of depression; none of these patients received a prescription for a lethal medication.'** <sup>190</sup>  
(Underlining is ours)

In fact, Ganzini et al conclude:

**'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.'** <sup>191</sup>

Once again, Mulino has sought to cherry pick evidence in support of an argument not otherwise supported by the facts.

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<sup>187</sup> 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, viewed 27 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>>.

<sup>188</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.2 'Depression', viewed 27 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>189</sup> Following the discussion about Ganzini et al in this Section, Mr Mulino's treatment of evidence from this source is discussed in more detail at Section 8.1.2 (pp. 67-68) below.

<sup>190</sup> 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, Abstract, viewed 27 July 2017 - Article: <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=abstract>>.

<sup>191</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.2 'Depression', viewed 27 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

## 5.5 INADEQUATE PALLIATIVE CARE AND PAIN RELIEF

Mr Mulino raises concerns that patients may be choosing to hasten their deaths because of failures in palliative care and pain relief:

**‘The 2016 Report of the Oregon Health Division indicates that 28.7% expressed inadequate pain control or a concern about it as a reason for wanting assisted suicide. This was the second least commonly cited reason in 2015. It would be useful to know, of the 28.7%, what proportion were experiencing unendurable pain at the time the lethal dose was prescribed and administered and what proportion were suffering from an anticipation of future pain. It would also be useful to know, of those patients experiencing unendurable pain at the time the dosage was administered, how many were not benefiting from best practice pain relief of palliative care.’**<sup>192</sup>

Patients in Oregon have shown clearly that pain ranks well below other important factors behind their decisions to seek physician assisted dying:

End of life concerns <sup>1</sup>	(N=133)	(N=994)	(N=991)
Losing autonomy (%)	119 (89.5)	906 (91.6)	1,025 (91.4)
Less able to engage in activities making life enjoyable (%)	119 (89.5)	888 (89.7)	1,007 (89.7)
Loss of dignity (%) <sup>5</sup>	87 (65.4)	680 (78.8)	767 (77.0)
Losing control of bodily functions (%)	49 (36.8)	475 (48.1)	524 (46.8)
Burden on family, friends/caregivers (%)	65 (48.9)	408 (41.3)	473 (42.2)
Inadequate pain control or concern about it (%)	47 (35.3)	249 (25.2)	296 (26.4)
Financial implications of treatment (%)	7 (5.3)	31 (3.1)	38 (3.4)

**2016                      1998-2015      Total**

**Figure 12: Characteristics - End of Life Concerns, Oregon DWDA Data Summary 2016**<sup>193</sup>

As George Eighmey, explains:

**‘patients are *ranking* their concerns; so that to say 35% rank pain as a reason does not mean 35% of the patients use the law because of pain, but simply that 35% say it is their *sixth* reason for using the law.’**<sup>194</sup> (The italics are ours)

As the Committee heard in evidence from doctors, palliative care specialists, patients and their families: pain is just one aspect of the suffering endured by some patients at the end of their lives.

<sup>192</sup> Ibid., Chapter 4.5.5. ‘Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: Oregon’.

<sup>193</sup> Public Health Division, Centre for Health Statistics, ‘Oregon Death with Dignity Act: Data Summary 2016’, Oregon Public Health Authority, 10 February 2017, p.10, viewed 25 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Document%20year19.pdf>>.

<sup>194</sup> George Eighmey, email to Andrew Denton, Go Gentle Australia, 16 May 2017.



Canadian physician, Dr Harvey Chochinov, for example, describes the final stages of patients with cancer and also, AIDS:

**‘the burden of both physical and psychological symptoms becomes staggering.**

**... Distress of this kind may express itself as an overwhelming sense of hopelessness, existential or spiritual angst; loss of sense of dignity; sensing oneself a burden to others; or a waning of one's will to live and a ... wish to no longer carry on living.**

**... within one-to-one interactions with dying patients, few care providers remain unaware that there are aspects of distress that defy even the most sophisticated of medicinal or technological modalities.**<sup>195</sup>

(Underlining is ours.)

As was shown earlier in this report in the section titled, 'Avoiding the Central Issue of Suffering by Defining It Only as Pain' (pp. 17-21), Mr Mulino makes every effort, when discussing Victoria, to keep the conversation focused entirely on pain. He does the same with Oregon, ignoring, too, another important reality – that 9 out of 10 patients who access Oregon's DWD law are also in hospice care.<sup>196</sup>

## 5.6 SYSTEMIC NON-REPORTING

Mr Mulino alleges that, Oregon **'systemic non-reporting' is rife**. He criticises the Oregon Health Department for limiting its yearly reports to 'general epidemiological data' and complains that only limited data is collected from physicians who prescribe the lethal medication.<sup>197</sup>

The State collects data from mandatory reporting forms required to be completed by attending and consulting physicians, pharmacists, patients and when necessary psychologists or psychiatrists. These forms are required to be submitted under penalty of law. If any of the persons required to complete the forms fails to do so they are reported to the appropriate enforcement agency, which has been done only in a handful of cases generally for Scribner errors.

Here is the current list:

- Attending Physician Form (2 pages) or Attending Physician Short Form - must be accompanied by copies of the patient's chart notes.
- Consulting Physician Form
- Psychiatrist/Psychologist Form
- Pharmacy Dispensing Record Form
- Attending Physician Follow-Up Form

<sup>195</sup> Harvey Max Chochinov, 'Dying, Dignity, and New Horizons in Palliative End-of-Life Care', CA: A Cancer Journal for Clinicians, Vol. 56, Issue 2, March 2006, viewed 25 July 2017, <<http://onlinelibrary.wiley.com/doi/10.3322/canjclin.56.2.84/full>>.

<sup>196</sup> Public Health Division, Centre for Health Statistics, 'Oregon Death with Dignity Act: Data Summary 2016', Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Document/s/year19.pdf>>.

<sup>197</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.6.1 'Systemic non-reporting', viewed 25 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

- Data collected from follow-up interviews with physicians (may be completed in lieu of a follow-up interview).
- Oregon Health Authority Form (internal use only) - Chronology and Death Certificate Extract Form<sup>198</sup>

Apart from data which may be private and confidential, the State of Oregon issues comprehensive annual collations of statistics for public scrutiny.<sup>199</sup>

In questioning Oregon's reporting under its DWD law, the onus is on Mr Mulino to explain why, in 20 years, there have been no moves for major legislative review or amendment of its operation.

A balanced reading of the evidence would suggest that is because the legislators of Oregon are satisfied that the law is operating safely and as it should be.

## 5.7 UNCERTAINTY ABOUT TERMINAL DIAGNOSIS

Under Oregon law, a patient is deemed eligible if they are diagnosed with a terminal illness and, in the independent judgement of two doctors, has six months or less to live. However, Mr Mulino writes:

**'When surveyed, over 50 per cent of Oregon physicians indicated that they were not confident that they could make such a prediction. It is unclear at present how this uncertainty is communicated to patients seeking assisted suicide.'**<sup>200</sup>

That physicians are not always able to accurately pinpoint a patient's prognosis within a specific time-frame<sup>201</sup> is no argument against easing the suffering of people who are, without doubt, going to die in the foreseeable future.

As the statistics show, 80 per cent of the people who use Oregon's law are dying of cancer. A further 14 per cent either from Motor Neurone Disease or complications from heart failure.

While death for all those under this law may be certain, the path towards death may not. A Death with Dignity law is not simply about assisting a dying patient to die peacefully. It is also about assisting a dying patient to live well in their final weeks and months.

This is evidenced by the high proportion (more than 30 per cent) of Oregonians who have had access to lethal medication under the law but who chose not to take it.<sup>202</sup>

<sup>198</sup> Oregon Health Authority, 'Death with Dignity Act: Death with Dignity Forms', Centre for Health Statistics, viewed 25 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/paforms.aspx>>.

<sup>199</sup> Public Health Division, Centre for Health Statistics, 'Oregon Death with Dignity Act: Data Summary 2016', Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017, <<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Document/s/year19.pdf>>.

<sup>200</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.6.3 'The difficulty of deciding whether a case is terminal', viewed 25 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>201</sup> Ibid., Chapter 4.6.3 'The difficulty of deciding whether a case is terminal'.

<sup>202</sup> Public Health Division, Centre for Health Statistics, 'Oregon Death with Dignity Act: Data Summary 2016', Oregon Public Health Authority, 10 February 2017, p.10, viewed 24 July 2017,



They died naturally - some, later than expected. For many terminal patients, just knowing they had some control over their destiny helped them endure their suffering longer.

As Oregon oncology specialist, Dr Charles Blanke says:

**'It could be that just knowing that they have the option is enough. It's there if they need it, and it may relieve their fear of loss of control.'**<sup>203</sup>

Kate Cheney said much the same thing:

**'It's not that I have any plans to use it right away. I may never use it. But it's just to have the decision in my hands, rather than anyone else's.'**<sup>204</sup>

That some people have the medication but don't take it - or live longer than six months - indicates that people do not rush into using the law or in consuming the medication. They want to live as long as their quality of life is acceptable.

The alternative, as the Committee heard from the Victorian Coroner, is that people faced with the same illnesses, but not the comfort of a DWD choice, take their own lives, **'often in horrific circumstances'**.<sup>205</sup>

## 5.8 'DOCTOR SHOPPING'

Mr Mulino raises general concerns about 'doctor shopping', whereby patients who may be refused access to DWD law by their consulting physician, are encouraged to seek out other physicians who may be more likely to give them the 'green light'.

The law specifically permits physicians to 'opt out' without sanctions or criticism. This may be on the grounds of religion. It may be because he/she is unwilling to participate in a process that is unfamiliar to him/her 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 physician who is not opposed to, or uncomfortable with, his/her decision to seek access to the law. This is called exercising one's right, not doctor shopping.

Every patient has the right to pursue a legal medical intervention to relieve their suffering and to seek a second opinion.<sup>206</sup>

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<http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Document%20year19.pdf>.

<sup>203</sup> Charles Blanke quoted in Roxanne Nelson, 'Death With Dignity in Oregon: No Evidence of Abuse or Misuse', Medscape, 20 September 2016, viewed 25 July 2017, <<http://www.medscape.com/viewarticle/869023>>.

<sup>204</sup> Kate Cheney quoted in Erin Hoover Barnett, 'Physician-assisted suicide: A family struggles with the question of whether mom is capable of choosing to die', Oregon Live, 4 February 2015 (originally published in *The Oregonian* on 17 October 1999), viewed 24 July 2017, <[http://www.oregonlive.com/health/index.ssf/2015/02/physician-assisted\\_suicide\\_a\\_f.html](http://www.oregonlive.com/health/index.ssf/2015/02/physician-assisted_suicide_a_f.html)>.

<sup>205</sup> Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, 'Chair's foreword', p.xvi, viewed 21 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>206</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.6.4 'Doctor shopping', viewed 25 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

It is what a well informed patient does when facing his/her options at the end of life.

Regardless of how many doctors a person sees, the bar for access to the law remains the same: Two doctors, making independent assessments of the patient, must determine that they are terminally ill with 6 months or less to live.

We can see from the Oregon Public Health Division's published statistics, exactly what diseases (cancer, heart failure, neurological) the people who access this law in Oregon are dying of.

To cast doubt on their right to seek a second opinion in the face of such illnesses seems, at best, thoughtless.

## 5.9 FAILURE OF LIFE ENDING DRUGS

Mr Mulino raises the issue of 24 cases in which patients regurgitated some of the legal dose, and six regained consciousness after taking the drugs and died later, as evidence of the failure of the life-ending drug.<sup>207</sup>

The facts are:

- The life ending drugs have worked in 1127 cases out of 1133 cases in Oregon and all cases in Washington.
- A success rate in Oregon of .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.

A .997 level of success is extraordinarily high. In questioning it, Mr Mulino has looked at evidence of success and sought to convey it, instead, as failure.

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<sup>207</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.6.8 'Failure of drugs performing as designed', viewed 25 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

## 6. MISREPORTING OF DEATHS UNDER NORTHERN TERRITORY'S *RIGHTS OF THE TERMINALLY ILL ACT*

In a domestic context, Mr Mulino cites the Northern Territory's short-lived euthanasia legislation as 'highly instructive':

**The experiences of people whose lives ended under the Northern Territory regime casts doubt on the effectiveness of the types of safeguards proposed in the Majority Report. During the 9 months that euthanasia was legal in the Northern Territory (July 1996 – March 1997), seven people made formal use of the Rights of the Terminally Ill (ROTI) Act, four of whom died. All seven patients had cancer, most at an advanced stage.<sup>208</sup>**

This is factually incorrect. Only four, not seven, people made formal use of the Rights of the Terminally Ill Act. Two patients sought euthanasia but died before the Act became law, and one died after its repeal. So only four patients pursued intervention within the framework of the Act.<sup>209</sup>

As Dr Rodney Syme pointed out in a letter to *The Lancet* in 1999:

**'The first patient did no more than make a request for euthanasia but she did not qualify under the Act, mainly because she did not have severe pain and had not been terminally ill. I know this to be true because Philip Nitschke sought my opinion about her request. Why she is included in the paper is a mystery, unless it is in an attempt to damn the Northern Territory Act.**

**The second patient died through a process of extreme cachexia and asthenia. In addition, his psychological distress, based partly on the rejection of his wish to die earlier and with dignity, was obvious. Anyone who saw the television footage of this tragic man, by then little more than a living skeleton, being bodily transported in and out of bed because of his inability to do anything himself could only be astonished to see his death described as peaceful. Obviously some physicians believe a death in coma is peaceful, no matter how drawn out it might be, whether it is medically induced and irrespective of the extreme anguish and loss of dignity before and during coma.<sup>210</sup>**

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<sup>208</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: the Northern Territory', viewed 26 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>209</sup> Information provided to Go Gentle Australia by Marshall Perron, formerly Chief Minister of the Northern Territory at the time the Rights of the Terminally Ill Act was introduced. Mr Perron was instrumental in devising the Rights of the Terminally Ill Bill and has an intimate, first-hand knowledge about how it was used.

<sup>210</sup> Rodney A Syme, 'Seven deaths in Darwin', Letter to the Editor, *The Lancet*, Volume 353, Issue 9158, 27 March 1999, p.1098, viewed 26 July 2017, <[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(05\)76455-2/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(05)76455-2/fulltext)>.

Expressing further concerns, Mr Mulino continues:

**In a paper by Kissane, Street and Nitschke<sup>211</sup>, it was found that three of the seven patients were socially isolated and depressive symptoms were present in four of the seven.<sup>212</sup> Failure of pain management did not appear to be the motivation for the patients. Of the seven patients, four had controlled pain and the remaining three did not have prominent pain.<sup>213</sup> This is in contrast to the way this issue is often framed by advocates of euthanasia and assisted dying.’** (For transparency, we have added Mr Mulino’s sources in footnotes.)

Mr Mulino does not disclose the highly contested nature of his source material, nor the [strong religious beliefs of Dr David Kissane](#), which bring into question his neutrality on this issue.<sup>214</sup> In his submission to a 2008 Senate Inquiry into the Rights of the Terminally Ill Bill, co-author of the report, Dr Phillip Nitschke said:

**‘Professor Kissane had held views opposed to voluntary euthanasia legislation long before he took on the exercise of reviewing the patient records of the people who made use of the ROTI Act. The role he played in the “Euthanasia No” campaign was known to me and I believed his views were influenced by his strong religious beliefs. I agreed to his request to visit Darwin as I felt the issue would be served if close investigation of the issue were made by a known opponent of voluntary euthanasia.**

**I was wrong.**

**The article published in *Lancet*, by Kissane, Street and Nitschke was essentially correct. Unfortunately Professor Kissane immediately then set out to misrepresent his own article. In a press release that followed the *Lancet* publication he replaced “signs of depression” with “serious evidence of depression” and promoted himself as one who intimately understood the people and events that had taken place in Darwin. His “Deadly Days in Darwin” provided to the Senate enquiry is an account of his deliberate selection and misrepresentation of the “facts” he claims to have had revealed to him during his short Northern Territory stay.’<sup>215</sup>**

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<sup>211</sup> David Kissane, Annette Street and Philip Nitschke, ‘Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia’, *The Lancet*, Vol. 352, 3 October, 1998.

Mr Mulino notes: This paper, which appeared in the *Lancet*, was based upon, inter alia, 18 hours of interviews with Nitschke by Professor David Kissane, a psychiatrist and professor of palliative care and Annette Street, a medical sociologist. In addition, the authors had access to documents from the coroner’s court, public texts created by the patients and other public commentary (eg in the media).

<sup>212</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.5 ‘Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: the Northern Territory’, footnote #106, viewed 26 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

Mr Mulino notes in footnote #106: Two had depressive symptoms (one of whom was on antidepressants), one had a history of depression and was experiencing suicidal thoughts, and another was suicidal (this person ultimately died as a result of suicide).

<sup>213</sup> Ibid. ‘Cases involving inadequate palliative care: the Northern Territory’.

<sup>214</sup> See [Section 8.2.1](#) (pp. 69-70) below for information about Dr David Kissane’s involvement as a Knight of the Catholic Order of Malta, whose members pledge to ‘practice and defend’ their faith ‘against the enemies of religion’.

<sup>215</sup> Nitschke, Phillip, ‘Submission to the Standing Committee on Legal and Constitutional Affairs: Inquiry into the Right of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008’, Australian Parliament House, 27 April 2008, viewed 26 July 2017, <<https://tinyurl.com/y8bdavum>>. Note: Clicking this link downloads a PDF.

Mr Mulino, relying only on the opinions of Dr Kissane, questions the ability of psychiatrists to make accurate assessments of patients' mental capacity. He suggests that some may have had 'unrecognised' depression.

Dr Syme addresses Dr Kissane's concerns in his letter to *The Lancet*:

**Kissane implies a diagnosis of depression in four of the cases on the basis of some symptoms, without ever having known the patients in question personally, and despite the fact that patients 3—7 all had expert psychiatric diagnosis (from three different psychiatrists), which indicated that there was no treatable clinical depression. One would expect to find some symptoms of depression in a person dying with unrelievable pain. The key question addressed by the Act was whether any symptoms of depression were out of proportion to the physical situation, and thus whether treatment by psychological means would have any influence on the patient's request. In any event, as Philip Nitschke has said, these patients would have refused psychiatric treatment which was their right.**

**Finally, it is surprising that Kissane and Annette Street did not reveal their antagonism to voluntary euthanasia in the text, which would have allowed readers to place their interpretation.'**<sup>216</sup>

Mr Mulino quotes Dr Kissane's concern that some patients may have been demoralised by their terminal prognosis. Had more sensitive language been used, Dr Kissane suggests, this mental malaise may have been avoided.

It is difficult to know what is being suggested here: That physicians should speak to terminally ill adults in euphemisms or vague language? Adults have a right to be fully informed about their medical condition. It is surely not surprising that some find this information demoralising; that is not an unreasonable reaction to news that your death is imminent.

The fact that most people do not respond to this news with a request to hasten their death shows that 'demoralisation' is not, in itself, a condition that leads to a request for an early death. Instead, like pain, it may be one of numerous factors that add up, in a small percentage of individuals, to a crescendo of unendurable suffering.

Once again, Mr Mulino creates a misleading picture by applying the narrowest possible frame to a much broader canvas.

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<sup>216</sup> Rodney A Syme, 'Seven deaths in Darwin', Letter to the Editor, *The Lancet*, Volume 353, Issue 9158, 27 March 1999, p.1098, viewed 26 July 2017, <[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(05\)76455-2/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(05)76455-2/fulltext)>.

## 7. METHODOLOGY USED THROUGHOUT THE DISSENTING REPORT

### 7.1 THREE EXAMPLES OF SERIOUS BREACHES IN PRESENTING EVIDENCE

#### 7.1.1 Associate Professor Daryl Jones - An Answer Falsely presented as a Response to an Entirely Different Question

In Chapter 2.1 of his report - in a discussion titled 'Pain relief is effective in almost all cases' - Mr Mulino says:

**'A number of expert practitioners in palliative care gave evidence to the Committee in relation to the frequency of cases in which it was possible to manage pain at the end of a patient's life. While it is not possible to put a precise percentage on this proportion, the experts were unanimous in their assessment that it was rare that pain couldn't be managed. This included the following evidence:**

In support of this he quotes Associate Professor Daryl Jones of Austin Health from his appearance before the Committee:

**'... in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority.'**<sup>217</sup>  
(Underlining is ours.)

Reading this, it appears as though Professor Jones is responding to a question about unmanageable pain. He was not. In fact, he was responding to an entirely different and unrelated question.

The question, from Senator Patten, was about non-terminal patients, with disabilities they deemed unendurable, seeking access to euthanasia. There was no reference in it to unmanageable pain.

For transparency, here is the relevant part of the transcript in its entirety (the underlining is ours):

**Ms PATTEN — This has been a very interesting inquiry, and it has been great looking at all aspects of it. We have received hundreds of submissions, as you would not be surprised to hear, and many of them are talking about the more proactive decision about ending their life, whether it is talking about very sad stories about a bad death and wanting to have that good death and that is being able to say goodbye at the time that they choose and at the point that they choose. Do you think there is room in where we are going that we can have those more proactive decisions in advance care so it is not just about refusing treatments but actually saying, 'If I get to this level of disability, I'm not**

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<sup>217</sup> Daryl Jones, evidence given to Standing Committee on Legal and Social Issues, Transcript: 'Inquiry into end-of-life choices', Parliament of Victoria, Melbourne, 5 August 2015, p.16, viewed 20 July 2017, <[https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/FINAL\\_5\\_August\\_2015.pdf](https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/FINAL_5_August_2015.pdf)>.



**going to die from that disability but that is not the life that I want to lead'? Do you think we can take more proactive decisions?**

**Assoc. Prof. JONES — I just want to be clear: are you talking about euthanasia?**

**Ms PATTEN — I would be talking about physician-assisted dying in some form. Yes.**

**Assoc. Prof. JONES — Okay. I just wanted to be clear. In my experience, and I do not work in the community so I probably do not see these patients, in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority.**

The transcript provides no room for doubt that Professor Jones was not talking about pain.

Juxtaposing Professor Jones' answer with an entirely different question, in a way which lends weight to an argument, is disturbing.

Mr Mulino's academic credentials are impressive. He is an experienced and respected legislator. It is surprising that he appears to have used evidence, given in a public inquiry, to suggest that someone has responded to a question that was never actually put to them.

### **7.1.2 Linda Ganzini et al: Selective Quoting from an Academic Report which Contradicts the Findings of the Original Authors**

In his Chapter 4.5.2 'Depression' Mr 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.<sup>218</sup>:

**'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:

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<sup>218</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.2 'Depression', viewed 27 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

**‘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.’**<sup>219</sup>

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.<sup>220</sup>

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.’**<sup>221</sup>

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.’**<sup>222</sup>

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.

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<sup>219</sup> 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, viewed 27 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>>.

<sup>220</sup> 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, **Abstract**, viewed 27 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>>. <http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=abstract>>.

Ganzini states this specifically in the abstract of the article (see below at footnote #223).

<sup>221</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.2 ‘Depression’, viewed 27 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSIC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf)>.

<sup>222</sup> 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, viewed 27 July 2017, <<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 (underlining is ours):

**Twenty percent of the patients had symptoms of depression; none of these patients received a prescription for a lethal medication.**<sup>223</sup>

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.'**

Once again, Mr Mulino fails his own standard of a 'balanced reading of the evidence'.

### 7.1.3 The 2014 Swiss VAD Death Rate: Using a Statistic from an Activist Blogger, rather than Official Data

As prefaced in [Sections 4.2.1](#) and [4.2.2](#) (pp. 21-23), we question Mr Mulino's judgement in basing his calculation of Swiss VAD deaths in 2014 on an end figure for 2014 of 836.

This statistic comes, not from the official figures from Switzerland's Federal Statistical Office (FSO) - but on a statistic, provided with no reference or provenance, by the anti-euthanasia blogger, Alex Schadenberg.<sup>224 225</sup>

The incorrect data is less significant than the ethical issue of a statistic with no provenance being passed off as evidence.

To make a balanced reading of the evidence, you must first make every effort to make sure the evidence you are working from is correct. Mr Mulino has failed to do so.

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<sup>223</sup> 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, **Abstract**, viewed 27 July 2017, <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article>> <<http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=abstract>>.

<sup>224</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June 2017, See Footnote #17 in Chapter 3.2 'A summary of empirical trends in the number of cases of euthanasia and assisted suicide across major jurisdictions', viewed 23 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

See next footnote for a direct link to the source of Mr Mulino's data.

<sup>225</sup> Schadenberg, Alex, "Assisted suicides jump 34% in 2015", Life Site News, viewed 23 July 2017,

<<https://www.lifesitenews.com/news/switzerland-assisted-suicides-jump-34-in-2015>>.

Note: Alex Schadenberg refers to the statistic as 'around 836'. He provides no hyperlink, source or explanatory comment.

## 7.2 UNDISCLOSED BIAS OF EXPERT SOURCES

The standard by which Mr Mulino found the majority report wanting was a ‘balanced reading of the evidence’.

In [Section 3.1, ‘Evidence considered by the Committee’](#) this report showed the exhaustive range of evidence (both for and against) considered by the Committee before they voted strongly in favour of a VAD law for Victoria.

This included peer-reviewed evidence, evidence from independent inquiries, and evidence from primary sources.

Let us turn now, to some of the key sources Mr Mulino has used to inform his dissenting report.

### 7.2.1 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.<sup>226</sup> 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.<sup>227 228</sup>

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’**<sup>229</sup>

### 7.2.2 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.<sup>230 231</sup>

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<sup>226</sup> Daniel Mulino, ‘Minority Report’ in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, ‘Inquiry into end of life choices: Final Report’, PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.5 ‘Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: the Northern Territory’, viewed 27 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>227</sup> 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, viewed 27 July 2017, <[http://orderofmalta.org.au/wp-content/uploads/2015/07/2014\\_Australian\\_Hospitalier\\_Online.pdf](http://orderofmalta.org.au/wp-content/uploads/2015/07/2014_Australian_Hospitalier_Online.pdf)>.

<sup>228</sup> 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, viewed 26 July 2017, <[http://orderofmalta.org.au/wp-content/uploads/2015/07/2014\\_Australian\\_Hospitalier\\_Online.pdf](http://orderofmalta.org.au/wp-content/uploads/2015/07/2014_Australian_Hospitalier_Online.pdf)>.

<sup>229</sup> *Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta* ‘Welcome’, 2014, p.3, viewed 26 July 2017, <[http://orderofmalta.org.au/wp-content/uploads/2015/07/2014\\_Australian\\_Hospitalier\\_Online.pdf](http://orderofmalta.org.au/wp-content/uploads/2015/07/2014_Australian_Hospitalier_Online.pdf)>.

<sup>230</sup> Opus Dei, ‘Cardinal Bertello ordains 31 priests from 16 countries’, 29 April 2017, viewed 26 July 2017, <<http://opusdei.org.au/en-au/article/ordinations-priestly-opus-dei-2017/>>.

<sup>231</sup> Etienne Montero Redondo, Staff Directory Page, University of Namur, Belgium, viewed 27 July 2017, <[https://translate.google.com.au/translate?hl=en&sl=fr&u=https://directory.unamur.be/staff/emontero%3F\\_LOCALE\\_%3Den&prev=search](https://translate.google.com.au/translate?hl=en&sl=fr&u=https://directory.unamur.be/staff/emontero%3F_LOCALE_%3Den&prev=search)>.

Included to verify that the Etienne Montero Redondo mentioned by Opus Dei is the same person referenced by Mulino.

At Professor Montero's recent 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.

### 7.2.3 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 (discussed in [Section 6.3.1](#) (pp. 54-56), above).<sup>232</sup> 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 recent 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.<sup>233</sup>

### 7.2.4 Professor Alan Johnson

Mr Mulino presents evidence provided to the House of Lords Select Committee on Assisted Dying by the late Professor Alan Johnson.<sup>234</sup> The late 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'.<sup>235</sup>

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<sup>232</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, 4.5.1 'People who feel as though they are a burden: Box 2: Kate Cheney - Case Study, Oregon', viewed 27 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>233</sup> Junno Arch Esteves, 'Pope names members for renewed Pontifical Academy for Life', Catholic News Service, 27 July 2017, viewed 24 July 2017, <<https://www.ncronline.org/news/vatican/pope-names-members-renewed-pontifical-academy-life>>.

<sup>234</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.5.6 'Summary of evidence in relation to vulnerable people', viewed 27 July 2017 <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>235</sup> Liz Croton, 'Beyond the Bleep 2001 - Wisdom Which Works' in Christian Medical Fellowship Newsletter, No. 161, October 2001, p.3, viewed 27 July 2017, <<http://admin.cmf.org.uk/pdf/cmfnews/cmf161.pdf>>.

### 7.2.5 European Institute of Bioethics

Mr Mulino's discussion on voluntary euthanasia in Belgium is informed by insights from the European Institute of Bioethics, specifically to support his assertion that euthanasia is becoming 'normalised'.<sup>236</sup>

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'** <sup>237</sup>

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.<sup>238</sup>

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.

### 7.2.6 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.<sup>239</sup>  
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<sup>236</sup> Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, 'Inquiry into end of life choices: Final Report', PP No. 174, Session 2014-16 (Document 1 of 2), June, 2017, Chapter 4.4.1 'Belgium', viewed 27 July 2017, <[https://www.parliament.vic.gov.au/file\\_uploads/LSiC\\_pF3XBb2L.pdf](https://www.parliament.vic.gov.au/file_uploads/LSiC_pF3XBb2L.pdf)>.

<sup>237</sup> European Institute of Bioethics, website, viewed 27 July 2017, <<http://www.ieb-eib.org/en/>>.

<sup>238</sup> 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, viewed 27 July 2016, <<http://www.heidihautala.fi/wp-content/uploads/2017/01/SRHR-Europe-Study--Elena-Zacharenko.pdf>>.

<sup>239</sup> Vermont Alliance for Ethical Health Care, 'About Us', website, viewed 27 July 2017, <<http://www.vaeh.org/who-we-are/>>.

<sup>240</sup> Center for Bioethics and Human Dignity, 'Who is Robert D Orr?', undated, viewed 27 July 2017, <<https://cbhd.org/orr-fellowship/robert-d-orr>>.



### 7.2.7 Conclusion

There is no doubt many of Mr Mulino's sources are highly trained medical professionals and academics. But, highly trained professionals are also complex human beings. A passionate belief in a particular ideology can fundamentally colour one's perception and ability to accept contrary evidence. If the belief is strong enough, even the most highly educated may reinterpret evidence through the filter of their worldview.

Neither does it follow that people of faith are always opposed to voluntary euthanasia. In fact, Australian polls suggest around 75 per cent of Catholics support the notion of euthanasia or physician assisted dying.<sup>241</sup>

But, as Neil Francis argued recently 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.'**<sup>242</sup>

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Mr Mulino set the standard for a proper consideration of VAD as "a balanced reading of the evidence"

For many of Mr Mulino's key sources, their faith instructs them that Voluntary Assisted Dying is wrong in any form and for any reason. There is no evidence, no matter how credible, that can be put before them that will change their view.

In choosing to give their views disproportionate weight, so as to contradict, minimise, or deny the views of the Committee majority, Mr Mulino has damaged the credibility of his own report.

Because of their core beliefs, it is impossible for many of his sources to bring a 'balanced reading of the evidence' to the discussion. Mr Mulino does not disclose this bias. Nor does he explain why he has chosen to favour this evidence over the peer-reviewed and independent evidence sought, and accepted, by the Committee.

When compared with the careful and wide-ranging work of the Committee Majority it is Mr Mulino's work, not theirs, which fails to meet the standard.

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<sup>241</sup> Newpoll, 'Dying with Dignity Summary Report', Prepared for Dying with Dignity Victoria, Inc, February 2007, viewed 31 July 2017, <<https://tinyurl.com/ybsjglo8>> and Newpoll, 'Dying with Dignity', Prepared for [yourlastright.com](http://yourlastright.com), November 2012, viewed 31 July 2017, <<https://tinyurl.com/yamf4uug>>.

<sup>242</sup> Neil Francis, 'Opposition to Assisted Dying in Australia is Largely Religious, and Shrinking', ABC Religion and Ethics, 25 July 2017, viewed 27 July 2017, <<http://www.abc.net.au/religion/articles/2017/07/25/4707589.htm>>.

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