

Submission to  
**Inquiry into Elder Abuse**

Royal Commission into Aged Care Quality and Safety | May 2019



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# Contents

<b>THIS SUBMISSION</b>		<b>Page 5</b>
<b>PART 1</b>	<b>The Right To Refuse Treatment And/Or Sustenance</b>	<b>Page 9</b>
	1.1 Outline of the law	Page 9
	1.2 Abuse and mistreatment	Page 14
<b>PART 2</b>	<b>Palliative Care At The End Of Life</b>	<b>Page 19</b>
	2.1 End-of-life suffering and palliative care	Page 19
	2.2 Care should be patient and family-centred	Page 20
	2.3 Sedation in end-of-life-care	Page 22
	2.4 Guidance for end-of-life medication in residential care	Page 26
	2.5 Personal accounts from the Western Australian inquiry	Page 28
	2.6 Abuse and mistreatment	Page 32
<b>PART 3</b>	<b>A Growing Concern In Aged Care</b>	<b>Page 35</b>
<b>PART 4</b>	<b>Why Is Abuse And Mistreatment Occurring In Aged Care?</b>	<b>Page 39</b>
<b>PART 5</b>	<b>Some Possible Solutions</b>	<b>Page 47</b>
	5.1 Exposure of the issue	Page 47
	5.2 Improve education, training and staffing	Page 47
	5.3 Improve end-of-life planning in aged care	Page 48
	5.3.1 Advance care directives	Page 48
	5.3.2 Addressing the disparity in knowledge	Page 48
	5.3.3 Ensuring compliance	Page 49
	5.4 Improve regulation and recording of terminal sedation	Page 49
	5.5 Improve data on palliative care in aged care	Page 50
	5.6 Disclosure of religious beliefs and how they may affect end-of-life care	Page 51
<b>ANNEXURES</b>		<b>Page 53</b>

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# This submission

**Go Gentle Australia has been established to help relieve the distress, helplessness and suffering experienced by Australians with untreatable or terminal illnesses, their families and carers.<sup>1</sup>**

Our early focus is on bringing about change to laws around Voluntary Assisted Dying to give all Australians a right to have a choice about what happens to us at the end of our lives and not to be coerced, when we are at our most vulnerable, into cruel and avoidable suffering.

Although we see Voluntary Assisted Dying as being essential to our choices, Go Gentle Australia understands that it is just one choice on a spectrum Australians should be aware of.

We strongly support the need for good palliative care within the Australian community. The aims of palliative care – to alleviate suffering and to make possible a ‘good death’, both for the dying and their families – are also the aims of Go Gentle Australia.

We also support greater use of advance care directives, with emphasis on improved education about their importance among the community at large, and the medical professions in particular.

Go Gentle Australia understands that the Royal Commission into Aged Care Quality and Safety is not examining the possible introduction of Voluntary Assisted Dying laws. This submission does not seek to make the case for such laws.

However, we believe that the testimonies in this submission lend weight to our view that Voluntary Assisted Dying – along with palliative care and advance care directives – should be offered as a valid part of end-of-life care.

Rather, this submission addresses two particularly significant problems we have encountered through hearing the stories of people’s experiences of end-of-life care in aged care:

- Refusal to recognise a person’s exercise of their right to refuse treatment and/or sustenance
- Inadequate palliative care, particularly pain management and sedation at end of life.

Both of these situations result in mistreatment and abuse of people accessing aged care services at the end of life.

Both of these problems reflect a denial of autonomy, dignity, choice and control to those accessing aged care services at the end of life.

Mistreatment and abuse at end of life occurs in aged care settings and in other settings, such as hospitals, hospices and in the community. However, it is clear that this mistreatment and abuse is and will continue to be a growing problem in aged care settings unless it is urgently addressed.

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<sup>1</sup> Go Gentle Australia’s philosophy is set out in full in Annexure 1

This is because:

- Australia's population is growing and ageing
- older age groups have a higher burden of disease, with higher prevalence of cancer and other chronic conditions
- most end-of-life care is provided by services targeted towards older Australians, with around four in five deaths each year occurring for people aged 65 and over
- most Australians experience end of life in institutional settings, with only one in five deaths occurring outside hospitals or residential aged care facilities
- the provision of palliative care in residential aged care facilities is currently increasing with the Australian Government's provision in the 2018–19 Budget of increased funding for palliative care for older Australians living in residential aged care
- increased end-of-life choices for some Australians – through Voluntary Assisted Dying laws commencing shortly in Victoria and those soon to be considered by the Western Australian Parliament – may focus more attention on whether people's end-of-life choices generally are being respected.

This submission includes five individual accounts of end-of-life experiences in or related to aged care which we have been authorised to submit on behalf of those who told us of their experiences.

At the end of this submission, we make some preliminary suggestions about ways to improve the quality and safety of end-of-life care in aged care services so that this mistreatment and abuse at end of life does not occur.

We urge the Royal Commission to examine these end-of-life issues.

They go to the heart of many people's greatest fear of aged care – the loss of autonomy and dignity – and the terrible suffering that occurs for those who die a 'bad death' and their families. We would appreciate the opportunity to speak to these issues at a public hearing or roundtable consultation.

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## CASE STUDY: AUDREY'S STORY

Audrey's story, told by her daughter Carol, is set out in full in Annexure 2.  
This is a summary.

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**In the 1990s, Audrey was diagnosed with severe dystonia (involuntary muscle contractions) of the tongue, which left her with difficulties swallowing and unable to communicate clearly.**

In 2006, at the age of 80, and now suffering from a number of debilitating medical conditions, Audrey was admitted to hospital for treatment and to have a temporary PEG feeding tube inserted.

After her operation, Audrey was diagnosed with a condition which it was thought she would not survive. In accordance with her documented 'Do Not Resuscitate' wishes and in consultation with Audrey's daughter Carol, Audrey was given small amounts of morphine to keep her comfortable.

It was then discovered that there had been a mistake and Audrey was not dying.

However, by the time her care was corrected, it was too late: the temporary PEG tube had to be made permanent and Audrey was left incontinent, barely able to swallow, with even more limited speech, and able to walk only with close supervision and the aid of a Zimmer frame.

Audrey moved to a rehabilitation nursing home in the hope that she might recover enough to live independently again, but this was not possible.

Carol found her mother an aged care home in Perth. It was a religious institution with excellent facilities and caring staff.

As Audrey continued to decline, she requested that her PEG tube be removed and she be allowed to die.

Audrey said she couldn't walk unaided, drink, eat, swallow or toilet herself, and could barely speak so many staff could not understand her. She was unable to read her beloved books as her cataracts were deemed inoperable because of her tremors.

**Most of all, the indignity of having to lie in a faeces-filled 'smelly' nappy until a staff member was available to clean her up was more than this fiercely independent woman could bear.**

For her, life was no longer worth living and she said so – frequently.

She was informed by staff (not her GP) that it was her legal right to refuse food and water but the staff (institution) would probably not accede to her wishes.

Audrey made the request to remove her PEG tube repeatedly over several months. Instead of honouring her request, Audrey's GP increased her antipsychotic and antidepressant medication.

Carol became increasingly distressed by her mother's situation. Carol requested that the aged care home arrange a psychiatric assessment of Audrey to determine if she was capable of making an informed request to have her PEG tube removed and to confirm that this was what she wanted.

The geriatric psychiatrist confirmed Audrey wanted her PEG tube removed so that she

would die and that she understood that this would not be an easy or quick process.

However, instead of recommending that the PEG tube be removed, the psychiatrist increased Audrey's antipsychotic and antidepressant medication. Carol later discovered he was deeply religious. It is unclear whether his personal views influenced his professional recommendation.

Audrey was given increased sedation which meant that she shifted in and out of consciousness and she was no longer capable of making requests about her care.

Despite Audrey's prognosis, the GP contracted by the nursing home refused to provide palliative sedation and would not administer morphine due to concern of legal consequences because Audrey was not 'in agony' and did not have terminal cancer.

Carol continued to try to convince the GP that terminal sedation should begin, but the GP appeared reluctant to engage in any discussion about Audrey's impending death.

As Carol told us:

***“They didn't think about the mental and emotional pain that she was going through – she knew exactly what was happening, that her body was failing, and how undignified it was for her. They couldn't accept that the pain for my mother wasn't necessarily physical, but it was very real ...”***

Just under a week after Audrey was finally given palliative sedation with morphine – thanks to Carol's dogged persistence – but several months after entering the home, Audrey died in her sleep, aged 81 years.

## Part 1

# The Right To Refuse Treatment And/Or Sustenance

### 1.1 OUTLINE OF THE LAW

Recent parliamentary inquiries into end-of-life care and Voluntary Assisted Dying have confirmed that the law recognises a person's right to relieve suffering at the end of life by a number of means, independent of the introduction of Voluntary Assisted Dying.<sup>2</sup>

Leaving aside suicide, a person, in order to hasten death, may exercise:

- the right to refuse further medical treatment; and/or
- the right to refuse food and water.

The Australian Centre for Health Law Research provides extensive information on end-of-life law in Australia.<sup>3</sup>

## **The law is clear that every adult has the right to refuse medical treatment if the adult has 'capacity' or is 'competent'.**

Medical treatment given without consent is unlawful, unless it was provided in an emergency in order to save the person's life, and it was not possible to obtain consent from the person or their substitute decision-maker.<sup>4</sup>

In relation to adults with capacity, the Centre states:

It is lawful for an adult with capacity to make their own decisions to refuse or accept medical treatment, even if the decision they make results in their death.

Doctors must respect those decisions to refuse treatment and, if directed to do so, doctors can legally withhold (not start treatment) or withdraw (stop treatment already started) life-sustaining treatment from adults, even if this might result in the person's death.

It can also be lawful for a substitute decision-maker to ask that life-sustaining treatment be withheld or withdrawn from someone who can no longer make treatment decisions for themselves.<sup>5</sup>

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<sup>2</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, pp. 187-8. Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 109.

<sup>3</sup> Australian Health Law Centre. End of life law in Australia. Legal overview – <https://end-of-life.qut.edu.au/legal-overview> (accessed 11 March 2019)

<sup>4</sup> Australian Health Law Centre. End of life law in Australia. Legal overview – <https://end-of-life.qut.edu.au/legal-overview> (accessed 11 March 2019)

<sup>5</sup> Australian Health Law Centre. End of life law in Australia. Legal overview – <https://end-of-life.qut.edu.au/legal-overview> (accessed 11 March 2019)

The Centre provides the following relevant questions and answers:

***Can an adult with capacity refuse life-sustaining treatment?***

Yes. A fundamental principle of health law is an adult's right to decide what is or is not done to their bodies. This includes the right to consent to or refuse medical treatment. An adult who has capacity can choose to refuse medical treatment even if failure to receive treatment will result in death. An adult can refuse medical treatment on any grounds including for example, religious reasons or personal beliefs about what is an acceptable quality of life. So long as an adult has capacity there are few restrictions on the right to refuse medical treatment ...

***Must health professionals follow a decision to withhold or withdraw treatment made by a patient with capacity?***

Yes. A person's right to bodily integrity cannot be violated. A health professional who provides treatment despite an adult with capacity refusing it may be liable in criminal or civil law.<sup>6</sup>

We acknowledge that the law is more complicated in relation to adults who lack capacity. It is likely to involve consideration of the position in legislation in the particular state or territory, including in relation to guardianship legislation and common law.<sup>7</sup>

However, generally, and subject to specific legislation, adults who lack capacity have the legal and moral right to refuse medical treatment, including life-saving treatment, through advance care planning, using mechanisms such as Advance Care Directives and substitute decision-makers.<sup>8</sup>

**Brightwater Care Group v Rossiter (2009)**

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

Brightwater Care Group v Rossiter [2009] WASC 229

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

The Court decided that as Rossiter had capacity he was entitled to decide the treatment he wished to receive or refuse. The Court noted that the principle of autonomy prevailed over the sanctity of life, and decided that the duty of the facility to provide Rossiter with the necessities of life did not apply given he was a competent person refusing treatment. A declaration was made that the facility caring for Rossiter could lawfully withdraw the treatment if Rossiter requested it.<sup>9</sup>

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

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

<sup>6</sup> Australian Health Law Centre. *End of life law in Australia. Withholding and withdrawing life-sustaining treatment for adults, and guardianship law. Withholding and withdrawing life-sustaining treatment from adults with capacity*. <https://end-of-life.qut.edu.au/stopping-treatment/adults> (accessed 11 March 2019)

<sup>7</sup> Australian Health Law Centre. *End of life law in Australia. Withholding and withdrawing life-sustaining treatment for adults, and guardianship law. Key cases: Withholding and withdrawing life-sustaining treatment from adults who lack capacity*. <https://end-of-life.qut.edu.au/stopping-treatment/adults> (accessed 11 March 2019).

<sup>8</sup> Cartwright, Colleen Maria, White, Ben P., Willmott, Lindy, Williams, Gail, & Parker, Malcolm Holbrook (2016) "Palliative care and other physicians' knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment: Survey results". *Palliative Medicine*, 30(2), pp. 171-179.

<sup>9</sup> Australian Health Law Centre. *End of life law in Australia. Withholding and withdrawing life-sustaining treatment for adults, and guardianship law. Key cases: Withholding and withdrawing life-sustaining treatment from adults who lack capacity*. <https://end-of-life.qut.edu.au/stopping-treatment/adults> (accessed 11 March 2019).

the right, described as long ago as 1914 in the United States by Justice Cardozo, as the right of **'every human being of adult years and sound mind ... to determine what shall be done with his own body'**: *Schloendorff v Society of New York Hospital* [211 NY 125](#) [1914], 129.

**That right has been recognised in Australia and referred to with approval by the High Court:**

*F v R* [\[1983\] 33 SASR](#) 189, 192 - 193 (per King CJ); *Rogers v Whitaker* [\[1992\] HCA 58](#); [\[1992\] 175 CLR 479](#), 487. **That right also underpins the established legal requirement that the informed consent of the patient is required before any medical treatment can be undertaken lawfully.**

That principle has been affirmed by the High Court on a number of occasions: *Secretary of Department of Health and Community Services v B* [\[1992\] HCA 15](#); [\[1992\] 175 CLR](#) 218 (*Marion's case*), 233 and *Rogers v Whitaker*, 489. Also see the English case of *Airedale NHS v Bland*, 857.

The corollary of that requirement is that **an individual of full capacity is not obliged to give consent to medical treatment, nor is a medical practitioner or other service provider under any obligation to provide such treatment without consent, even if the failure to treat will result in the loss of the patient's life.** That principle has been established by decisions in each of the major common law jurisdictions, including the United States (*Bouvia v Superior Court of Los Angeles County* 179 [Cal App 3d 1127](#) [\[1986\]](#), 1137 and 1139 - 1141); Canada (*Nancy B v Hotel-Dieu Quebec* [\[1992\] 86 DLR \(4th\) 385](#); *Malette v Shulman* [\[1990\] 67 DLR \(4th\) 321](#), 328); the United Kingdom (*Airedale NHS Trust v Bland*, 857 (Lord Keith) and 864 (Lord Goff); *Ms B v An NHS Hospital Trust* [16] - [21]); New Zealand (*Auckland Area Health Board v Attorney General* [\[1993\] 1 NZLR](#) 235, 245) and Australia (*Hunter and New England Area Health Service v A*, [9] - [15]).

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

...

Another corollary of the principles to which I have referred is that **a medical practitioner or service provider who provides treatment contrary to the wishes of a mentally competent patient breaks the law by committing a trespass against the person of that patient:** *Marion's case*, 264 and 309 - 310.<sup>10</sup> [Emphasis added]

## H Ltd v J & Anor (2010)

The Australian Centre for Health Law Research summarises another case involving a resident of an aged care facility in South Australia.

[H Ltd v J & Anor](#) [2010] SASC 176

J was a 74-year-old woman who suffered from post-polio syndrome and Type 1 diabetes. She resided in a high care unit of an aged care facility run by H Ltd. She spent her waking hours in a wheelchair and required assistance for all of her basic toileting and hygiene needs. J's quality of life was unacceptable to her, and she advised H Ltd that she had decided to end her life by ceasing to take any food, water or insulin. H Ltd asked the court whether it would be lawful to comply with J's decision.

The court reviewed the *Rossiter* decision, and concluded that H Ltd had no legal duty to provide sustenance to J.<sup>11</sup>

J wished to instruct the aged care home not to provide hydration other than for the purpose of oral hygiene and to palliate pain and discomfort.<sup>12</sup>

<sup>10</sup> *Brightwater Care Group v Rossiter* [2009] WASC 229 [24]–[27], [31].

<sup>11</sup> Australian Health Law Centre. *End of life law in Australia. Withholding and withdrawing life-sustaining treatment for adults, and guardianship law. Key cases: Withholding and withdrawing life-sustaining treatment from adults who lack capacity.* <https://end-of-life.qut.edu.au/stopping-treatment/adults> (accessed 11 March 2019).

<sup>12</sup> *H Ltd v J & Anor* [2010] SASC 176, [7].

Kourakis J adopted the statements of principle from Rossiter, which we set out above.<sup>13</sup> He also discussed the decision of McDougall J in 2009 in *Hunter and New England Area Health Service v A*, which we outline below.

Returning to J's particular circumstances, Kourakis J concluded in relation to her state of mind in deciding to bring her life to an early close:

J has been examined by a specialist Geriatrician and a specialist Palliative Care practitioner. Both were satisfied of her mental competence. There is no indication that J is depressed.

She showed significant insight into her condition and explained to them, rationally and dispassionately, the reasons for her decision. Both doctors explained to J in some detail the physiological consequences of her decision and the palliative care she could be given.

... On the basis of the medical reports I have just referred to and my own observations of J, I am satisfied that she has a full understanding of the consequences of her decision. I am satisfied that she has made her decision after long reflection ... **My impression is that J is a sensible person who has formed a considered decision based on the importance to her of an independent and dignified life.**

She has arrived at the decision independently, freely and rationally on the basis of a full understanding of her condition and the consequence of her decision.<sup>14</sup> [Emphasis added]

Kourakis J was also required to consider the relevant statutory provisions in South Australia, and the *Aged Care Act 1997* (Cth). In relation to the relevant provisions of the *Aged Care Act*, he concluded:

It would be inconsistent with those parts of the Care Principles and the Charter which enshrine the independence of residents and their rights to make choices affecting their personal lives to extend the responsibility to provide food and hydration to those residents who exercise a lawful choice not to accept them.

**The Charter and Care Principles recognise that residents remain in control of their personal lives.**

However, it must again be observed that the duty on aged care residential providers is owed to persons who are dependent on the proper discharge of their responsibilities. The duty therefore extends to ensuring that the refusal is voluntary, rational and informed.

It does not advance the objects and purpose of the Act and the particular function served by the Care Principles to construe them to require the provision of care which the resident rationally refuses. The purpose is to manage the quality of care provided through statutorily approved, and government assisted, aged care providers for the protection and benefit, of residents.

**That purpose is not advanced by requiring the provision of food, hydration and medicine to residents who rationally refuse to take it.**

The imposition of the obligations in the Care Principles is premised on their being sufficient co-operation from the resident to allow the service to be provided.

**There is no indication that the Act intended to alter the common law position and deny residents their common law rights. Certainly, there is no indication that the purpose of the Act was to authorise the use of force against the considered wishes of the resident in the provision of those services.**<sup>15</sup> [Emphasis added]

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<sup>13</sup> *H Ltd v J & Anor* [2010] SASC 176, [36].

<sup>14</sup> *H Ltd v J & Anor* [2010] SASC 176, [45]-[46].

<sup>15</sup> *H Ltd v J & Anor* [2010] SASC 176, [87]-[88].

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

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

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

- a competent adult's right of autonomy or self-determination – the right to control his or her own body; and
- the interest of the State in protecting and preserving the lives and health of its citizens.<sup>16</sup>

McDougall J stated:

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

[I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. ... [t]o this extent, **the principle of the sanctity of human life must yield to the principle of self-determination.**<sup>17</sup>  
[Emphasis added]

McDougall J identified a number of principles that resolve the conflict between sanctity of human life and self-determination at common law, relevantly including:

(1) Except in the case of an emergency where it is not practicable to obtain consent (see at (5) below), **it is at common law a battery to administer medical treatment to a person without the person's consent** ...

(2) Consent may be express or, in some cases, implied; and whether a person consents to medical treatment is a question of fact in each case.

...

(5) Emergency medical treatment that is reasonably necessary in the particular case may be administered to a person without the person's consent if the person's condition is such that it is not possible to obtain his or her consent, and it is not practicable to obtain the consent of someone else authorised to give it, and if the person has not signified that he or she does not wish the treatment, or treatment of that kind, to be carried out.

(6) A person may make an 'advance care directive': a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive ...

...

(10) It is not necessary, for there to be a valid advance care directive, that the person giving it should have been informed of the consequences of deciding, in advance, to refuse specified kinds of medical treatment. **Nor does it matter that the person's decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit. Indeed, it**

<sup>16</sup> *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 90 [5].

<sup>17</sup> *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 92 [17].

**does not matter if the decision seems to be unsupported by any discernible reason**, as long as it was made voluntarily, and in the absence of any vitiating factor such as misrepresentation, by a capable adult.<sup>18</sup> [Emphasis added]

### Re JS (2014)

The Australian Centre for Health Law Research summarises a third case as follows.

[Re JS](#) [2014] NSWSC 302

JS was a 27-year-old man who had been a quadriplegic since an accident when he was seven. Since that time JS needed full ventilator support through a tracheotomy. His health had deteriorated significantly over the last two years to the extent that JS regarded his quality of life as adversely affected. JS decided he did not want to reach his 28th birthday. He requested his mechanical ventilation be withdrawn. The hospital sought orders from the Supreme Court that it would be lawful to do so.

The Court agreed that the hospital could comply with JS's request, and decided it would be unlawful for a doctor to provide medical assistance if it was refused by a competent adult. The Court also noted that JS's actions in refusing medical assistance, even knowing that death would result, did not constitute suicide. Therefore, the doctors involved with his medical care would not commit the criminal offence of aiding or abetting suicide.<sup>19</sup>

## 1.2 ABUSE AND MISTREATMENT

The law is clear that every adult has the right to refuse medical treatment and the right to refuse food and water.

These rights must be respected, whether they are described by reference to principles of:

- autonomy
- respect for the individual human being
- self-determination
- choice and control or
- dignity.

### Why was Audrey's choice to refuse medical treatment (the PEG tube) and food and water denied?

The psychiatrist – called in at Carol's insistence to try to make the aged care facility comply with her mother's wishes – confirmed she was of sound mind.

Audrey, a dignified and well-educated woman, did everything she could to exercise her rights, but her decisions were overridden by the aged care services that should have been helping her, at a time when she was very vulnerable and, save for her daughter's determined advocacy on her behalf, totally dependent on them for care.

The aged care facility failed to meet Audrey's needs.

An experience like Audrey's of having her decisions to refuse medical treatment and food and water overridden can only be understood as unlawful abuse and mistreatment.

<sup>18</sup> *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 97-8 [40].

<sup>19</sup> Australian Health Law Centre. *End of life law in Australia. Withholding and withdrawing life-sustaining treatment from adults, and guardianship law. Key cases: Withholding and withdrawing life-sustaining treatment from adults who have capacity.* <https://end-of-life.qut.edu.au/stopping-treatment/adults> (accessed 11 March 2019)

We also note the evidence given to the Royal Commission in its first hearing about over-treatment or unwanted treatment causing great distress at the end of life. On 11 February 2019, Mrs Spriggs told the Royal Commission about her husband Bob's experience in Oakden Older Persons Mental Health Service and Royal Adelaide Hospital, and her reflections on how the aged care system needs to change in relation to end-of-life care. Mrs Spriggs said:

End-of-life care plan. Aged care and hospital staff also need to respect the wishes of family members, especially when it comes to end-of-life care plans. My family and I had previously made an end-of-life plan for Bob. We knew that he was – wasn't going to recover and that life for him would get progressively more distressing. We decided that he not be given resuscitation or antibiotics unless he was in pain. I remember we had spent so much time on all of that. There was a lot of paperwork involved and it was a very difficult decision to make. We made the decision as a family.

This plan was ignored by the system, or at least did not follow him from Oakden to the RAH, where he was given antibiotics for pneumonia. Although I questioned this at the hospital, the process went ahead. I was so distressed by Bob's condition and neglect that I felt helpless and numb and frightened and was in no state to insist that the documented end-of-life care plan be followed.<sup>20</sup>

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### CASE STUDY: MURRAY'S STORY

Murray's story, told by Dawn, is set out in full in Annexure 3.  
This is a summary.

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**At the age of 58, Murray was diagnosed with early-onset Parkinson's disease, which progressed to Lewy-body dementia. When he ceased to be safe at home, he moved into a nursing home, where he lived for eight years.**

Towards the end of his life, Murray was fading away but a palliative care service was not engaged to see him through to the end of his life.

Dawn could see Murray's pain was not being managed properly. She asked nursing staff to increase the amount of painkiller. They refused.

Dawn told us:

***I don't know whether it was a legal thing, or fear of getting into a bother, but he went through several weeks of really very little painkiller, until I said Look you've got to do something, he's in a lot of discomfort here. You can't let this go on.***

*So they gave him some morphine but it could only be administered by a doctor, and they were very hesitant to increase it and I had to get quite determined, and one particular RN was very anti-doing it.*

*Whether that was her own religious tendency against it or what, I don't know. But I had to go over her head a bit, and speak to the doctors directly. And eventually, they upped the morphine and administered it through a driver.*

*It was another five days before Murray died, at the age of 73."*

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<sup>20</sup> Royal Commission into Aged Care Quality and Safety, Transcript, 11 February 2019, TP-40:39-P-41:5.

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## CASE STUDY: MARGARET'S STORY

Margaret's story, told by her daughter Ann, is set out in full in Annexure 4.<sup>21</sup>  
This is a summary.

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### Margaret was diagnosed with lung cancer at the age of 90.

She refused further tests and treatment and lived for more than two years, largely symptom free until the final eight weeks of her life. On admission to hospital, it was found that the cancer had spread to Margaret's liver and bones. Margaret moved to a palliative care unit run by a Catholic hospital.

As Margaret's condition deteriorated, Ann and her brother discussed Margaret's advance care directive and her wishes that "she drift away on an opium cloud" with the unit. Ann told us "the doctor nodded knowingly" in response, and Ann took that to mean that palliative sedation was an acceptable practice at the unit.

In her fifth week at the unit, Margaret told Ann to go home. Ann told us:

*"I was exhausted. I was out of fight. "There will be no death bed scene," she said bluntly because she and I both thought she would be sedated.*

*The doctors at least were now acknowledging her deterioration and that really was the worst of it: to recall the relief I felt that she was safe is hard. But they still refused to give a prognosis claiming that it might take weeks and I doubted that wasn't true. I touched her feet and hands on the day I left and could see she was passing into what they call the active dying stage.*

*I wanted to go home. I fell back on the excuse of their expertise (despite not trusting them) because it brought me relief and in the end it was my call and I cannot blame them for that. But they promised to ring me if she faded further and they never did.*

*My brother rang me ... 36 or so hours after I had left, telling me if I wanted to see her to come back now. I got there ten minutes before she died conscious, bright yellow, staring hard, as if concentrating very deeply whether on her breathing or the process I don't know. My brother and I each held a hand and kissed her goodbye. Her grip was intense and she tried to talk but we couldn't understand her.*

***“Later, my brother told me that she had complained of pain before I arrived but when the doctor came in and she couldn't explain where it was he had wandered off without doing anything.”***

*The doctors were pointlessly hovering by the door when I arrived. Why hadn't they increased the morphine twenty minutes before her death?"*

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## **CASE STUDY: DAPHNE'S STORY**

Daphne's story, told by her daughter Carol, is set out in full in Annexure 5.  
This is a summary.

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**Daphne was living independently until her early 90s, when she started having falls and contracted pneumonia.**

After a brief stint in hospital, Daphne's daughters, Carol and Dawn, found her a place at a residential aged care facility, where she stayed for the next six months.

Regrettably, they now consider it one of the greatest mistakes they ever made.

One night, Daphne fell over when no one answered the bell to help her go to the toilet, and she smashed her ribs and shoulders. Daphne's injuries meant she needed to be transferred to a high-care ward. Everything went rapidly downhill.

Daphne had a negative reaction to the painkillers she was prescribed for her physical pain and began having terrifying hallucinations that caused her to shout out in fear.

This was a cruel Catch-22: managing Daphne's physical pain meant causing her great mental distress, but withholding pain relief meant she was in agony.

**No one seemed to be putting much effort into finding a solution.  
Daphne never got enough pain relief. She was given paracetamol.**

Carol and Dawn were horrified. They urgently looked for an alternative nursing home for their now 93-year-old mother. Eventually, they found her a bed at another facility.

By the time Daphne was transferred there, she only had another two weeks to live.

Dawn lay in the bed beside Daphne for her final few days, as her breathing became more and more laboured, until finally – after much futile pleading with the palliative care nurse to 'stop this' – Daphne died.

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## CASE STUDY: GLORIA'S STORY

Gloria's story, told by her daughters Jo and Sherie, is set out in full in Annexure 6.  
This is a summary.

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**Gloria was only in her 30s when she was diagnosed with multiple sclerosis, but for the next 50 years, despite a physical decline that eventually saw her depend on a wheelchair, she did not let her condition define or constrain her.**

Gloria was 80 when she first felt she had lost control of her life, after fracturing her spine and spending months recovering in hospital, before returning home for in-home care.

At 82, Gloria had another fall. After a stay in hospital, she was moved into a nursing home, where she lived for another two years.

According to her daughters, Jo and Sherie, it was at this point that she became seriously distressed by her predicament. She was bitterly sad, and in physical pain that was not adequately relieved.

Eighteen months into her stay, Gloria's wheelchair – her means of mobility for decades – was taken away, and Gloria was confined to a bed. The next six months were torturous.

Long before she'd entered the home, Gloria had written a living will. It laid out, very clearly, a 'No Revive' instruction and a request that if she should no longer be able to take food and liquid orally, or not be able to direct her care, then she was not to be provided nutrition nor fluids nor life supporting therapies of any kind. Her daughters said:

***Mum wanted to be allowed to suicide with the aid of medication before she got 'too bad', but this was denied her.***

Gloria also stated that any and all pain-killing medication would be gratefully accepted and that if legal, she wanted the doctors to give her something to end her life peacefully.

But that was not to be. Gloria suffered horrendous delusions, she was absolutely terrified and in severe mental distress.

At the very end, it took more than ten days for Gloria to die. The doctors were reluctant to increase her sedation, seemingly out of fear of the legal repercussions. Gloria was forced to endure the prolonged death she had always feared.

After spending 83 years overcoming life's seemingly insurmountable challenges with great dignity, she was made to suffer at its end, a traumatic experience that left her loving daughters scarred.

## Part 2

# Palliative care at the end of life

### 2.1 END-OF-LIFE SUFFERING AND PALLIATIVE CARE

Opponents of Voluntary Assisted Dying commonly focus on arguments that such laws cannot be safe and that the solution to people dying badly is to give more resources to palliative care. They commonly promote palliative care as having all the answers.

Australia's palliative care is well regarded by international standards,<sup>22</sup> and we have heard many accounts of people receiving good palliative care that has eased pain and suffering.

However, we have drawn on the many accounts we have heard of 'bad' deaths in spite of the provision of palliative care to argue that palliative care cannot help everyone.

This is now accepted by Palliative Care Australia,<sup>23</sup> doctors surveyed by the Australian Medical Association,<sup>24</sup> the Parliament of Victoria Legislative Council Legal and Social Issues Committee *Inquiry into end of life choices: Final report* (the Victorian inquiry),<sup>25</sup> and the Western Australian Legislative Assembly Joint Select Committee on End of Life Choices Report: *My Life, My Choice* (the Western Australian inquiry).<sup>26</sup>

### **Both the Victorian and Western Australian inquiries accepted that some palliative care patients are beyond meaningful help from palliative care.<sup>27</sup>**

The Western Australian inquiry referred to "somewhere in the range of 2–5 per cent" of patients for whom palliative care was ineffective in relieving their symptoms as being consistent with the evidence, and also referred to "evidence from some health professionals that the figure may be even higher, perhaps as high as 30 per cent"<sup>28</sup> (references omitted). These are the people for whom we argue voluntary assisted dying is most needed.

Accepting that around five per cent of people who receive palliative care cannot be helped sufficiently by that care (an important issue which we understand will not be addressed specifically by this Royal Commission), this still leaves many people for whom palliative care should be able to help by effectively easing their pain and suffering as they die.

<sup>22</sup> Australian Institute of Health and Welfare. Australia's health 2016. *Australia's health* series no. 15. Cat. no. AUS 199. Canberra: AIHW, 2016, p. 3.

<sup>23</sup> Palliative Care Australia, *Policy statement on voluntary euthanasia*, 2006, Canberra, p. 2, quoted in Neil Francis, *AMA uncovered: How its own review exposed its assisted dying policy as indefensible*, March 2017, p. 20, <http://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf> (accessed 11 March 2019).

<sup>24</sup> Australian Medical Association. *Member Consultation Report – Palliative Care*, 2016, Figure 11. See also Neil Francis, *AMA uncovered: How its own review exposed its assisted dying policy as indefensible*, March 2017, p. 2, <http://www.dyingforchoice.com/docs/AMAUncoveredFullReport27Mar2017.pdf> (accessed 11 March 2019).

<sup>25</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. xvi.

<sup>26</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. xxii.

<sup>27</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, pp. 194, 204-7. Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 92.

<sup>28</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 92.

However, accounts from family members of the extreme pain and suffering endured by people who have been denied adequate palliative care at the end of life are distressing and alarming.

Particularly in the final weeks and days of life, common symptoms experienced by the person who is dying include:

- Pain
- Breathlessness
- Anxiety
- Agitation and restlessness
- Hallucinations
- Dysphagia (difficulty swallowing)
- Nausea
- Vomiting
- Respiratory secretions.<sup>29</sup>

In discussing the limitations of palliative care, the Western Australian inquiry stated:

end-of-life symptoms are broad and can include laboured breathing, nausea, vomiting, pain, respiratory tract secretions, terminal restlessness or agitation, delirium and fatigue.

Individuals experience these symptoms subjectively, meaning that no two people will have the same sense of suffering as a result of similar symptoms.

In addition, illness trajectories differ from patient to patient, making treatment more complicated. These complex symptoms at end of life are treated by palliative care specialists using a “holistic” approach encompassing physical, psychological and spiritual responses as needed.<sup>30</sup>

Patients at the end of life may experience suffering that goes beyond physical pain and the symptoms listed above. Dr Rodney Syme, a urological surgeon and President of Dying With Dignity Victoria, has discussed in detail the profound psychological suffering, including fear and even terror, and existential suffering, arising from losses that relate to our fundamental existence as human beings.<sup>31</sup>

The Western Australian inquiry found that suffering at the end of life is not confined to pain:

suffering is not simply about the physical experience and manifestation of pain. Many of the other symptoms experienced by people suffering life-limiting illnesses are harder for the medical profession to measure, even as health professionals acknowledge the symptoms.<sup>32</sup>

## 2.2 CARE SHOULD BE PATIENT AND FAMILY-CENTRED

For many years now, guidance for end-of-life care in aged care has made clear to aged care providers and staff the importance of autonomy, dignity, choice and control for end-of-life care. The 2006 Guidelines for a Palliative Approach in Residential Aged Care state:

The quality of end-of-life care can vary from person to person, due to differing beliefs, values, culture, spirituality and basic assumptions. This makes the term ‘optimal end-of-life care’ difficult to define, and even more difficult to accurately measure.

Despite these obstacles, various theories abound as to what are the common factors that exist when optimal end-of-life care is achieved. The following list should help aged care team members

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<sup>29</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 2.

<sup>30</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 91.

<sup>31</sup> Syme, Rodney. *Time to Die*, Melbourne University Press, 2016, pp. 68-79.

<sup>32</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 103-4.

raise their awareness about some of these common factors for optimal end-of-life care. Residents who are dying may need to:

- know when death is coming, and to understand what can be expected;
- **be able to maintain a sense of control and have their wishes given preference;**
- **be afforded dignity** and privacy;
- **have control over pain relief and other symptom control;**
- have choice over where their death occurs (RACF, home or elsewhere);
- have access to information and excellent care;
- have access to spiritual and emotional support as required;
- have access to a palliative approach;
- have control over who is present and who shares the final moments;
- **be able to issue advance care plans, which ensures that their wishes are respected;**
- have time to say goodbye; and
- not have life inappropriately prolonged.

(Adapted from the Centre for Policy on Ageing, 1999).<sup>33</sup> [Emphasis added; reference omitted.]

Other national guidance about end-of-life care that is not specific to aged care also requires person-centred care. *The National Consensus Statement: essential elements for safe and high-quality end-of-life care* includes the following guiding principles:

2. **Patients must be empowered to direct their own care**, whenever possible. A patient's needs, goals and wishes at the end of life may change over time.

...

6. **Safe and high-quality end-of-life care is patient and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers.** Such care should consider the patient's expressed wishes regarding the circumstances, environment and place in which they wish to die.

...

9. Care of the dying is urgent care. Timely recognition of a patient's transition to the terminal phase of life must be documented and communicated to patients, families, carers and other health professionals by the interdisciplinary team. The care plan must be specifically revised to meet the unique needs of the patient, family and carers during this phase.

10. **End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient's expressed wishes and/or jurisdictional legislation.**

11. The interdisciplinary team has a responsibility to:

- provide timely and accurate information regarding the patient's clinical condition and its severity or stage, the expected disease trajectory, the available treatments, and the likelihood of response to such treatments
- **clearly communicate information to support patients (or substitute decision makers, families and carers) to make decisions about care, and to check that they understand the implications, consequences and risks associated with such decisions**

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<sup>33</sup> National Health and Medical Research Council. *Guidelines for a Palliative Approach in Residential Aged Care*, enhanced version, prepared by Edith Cowan University, Western Australia for the Chronic Disease and Palliative Care Branch, DoHA, Canberra, 2006, p. 161.

- invite patients to participate in the process of advance care planning, and create opportunities for patients to make decisions and to communicate their values, goals and wishes regarding their end-of-life care
- offer support, expert opinion and advice so that patients (or substitute decision-makers, families and carers) can participate in fully informed, shared (or supported) decision-making
- identify existing advance care plans and provide care in accordance with the patient's expressed wishes
- document, communicate and hand over the agreed plan of care and any limitations of medical treatment to other clinicians involved in the patient's care.<sup>34</sup> [Emphasis added.]

## 2.3 SEDATION IN END-OF-LIFE CARE

The 2006 *Guidelines for a Palliative Approach in Residential Aged Care* provide that:

**Sedation in end-of-life care is warranted when symptoms are unrelieved (including existential or psychological distress).** There are, however, various levels of sedation, and medications should be titrated according to effect. For recommended doses of sedating medications see the *Therapeutic Guidelines: Palliative Care*.<sup>35</sup> [Emphasis added; references, including levels of evidence, omitted.]

Evidence in the Victorian and Western Australian inquiries makes clear that some people are enduring unnecessary pain and suffering because they are not being provided with effective sedation in their end-of-life care. Both inquiries made recommendations designed to improve the provision of effective sedation.<sup>36</sup>

The issue arises particularly in relation to terminal sedation (sometimes referred to as continuous or palliative sedation), which is seen as contentious among some health professionals,<sup>37</sup> who may regard it as akin to euthanasia.

The Australian and New Zealand Society of Palliative Medicine Specialists (ANZSPM) supports the European Association for Palliative Care (EPAC) framework for use of sedation in palliative care.<sup>38</sup>

EPAC uses the term palliative sedation rather than terminal sedation. It defines palliative sedation as:

the use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers.<sup>39</sup>

Its 2009 framework for sedation for patients at end of life recommends:

Continuous deep sedation should only be considered if the patient is in the very terminal stages of their illness with an expected prognosis of hours or days at most. Transient or respite sedation may be indicated earlier in the patient's trajectory to provide temporary relief whilst waiting for treatment benefit from other therapeutic approaches.<sup>40</sup>

<sup>34</sup> Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high quality end-of-life care*. Sydney: ACSQHC, 2015, pp. 4-5.

<sup>35</sup> National Health and Medical Research Council. *Guidelines for a Palliative Approach in Residential Aged Care*, enhanced version, prepared by Edith Cowan University, Western Australia for the Chronic Disease and Palliative Care Branch, DoHA, Canberra, 2006, p. 166.

<sup>36</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, recommendations 26-28. Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, recommendation 18.

<sup>37</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 123-4.

<sup>38</sup> Australian and New Zealand Society of Palliative Medicine Specialists, *Guidance Document. Palliative Sedation Therapy*, 2017 <http://www.anzspm.org.au/c/anzspm?a=da&did=1005077> (accessed 11 March 2019), p. 1.

<sup>39</sup> Australian Health Law Research Centre. *End of life law in Australia. Palliative medication*. <https://end-of-life.qut.edu.au/palliative-care> (accessed 11 March 2019).

<sup>40</sup> European Association for Palliative Care (EPAC), *Recommended framework for the use of sedation in palliative care*, p. 584, quoted by Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 124.

The Australian Centre for Health Law Research describes the purpose of palliative (ie terminal) sedation as follows:

It is used in palliative care for several reasons, including to manage refractory symptoms (symptoms which cannot be otherwise adequately controlled) at the end of life. The primary purpose of palliative sedation is to sedate a patient near the end of their life in order to relieve their symptoms, not to cause or hasten their death.<sup>41</sup>

The End of Life Directions for Aged Care (ELDAC) project is described as a national specialist palliative care and advance care planning advisory service. It is funded by the Australian Government Department of Health,<sup>43</sup> and is:

conducted by a national consortium of eight partners – three universities and five national agencies: Queensland University of Technology (QUT), Flinders University of South Australia (FUSA), University of Technology Sydney (UTS), Palliative Care Australia (PCA), Aged & Community Services Australia (ACSA), Leading Age Services Australia (LASA), Australian Healthcare and Hospitals Association (AHHA), and Catholic Health Australia (CHA).<sup>44</sup>

In its fact sheet *Medication for pain and symptom relief for people with a life-limiting illness*, ELDAC refers to medication for pain and symptom relief (palliative medication) being “important to ease suffering and improve the quality of life of a patient with a life-limiting illness”, but it also states that “uncertainty can arise for those giving palliative medication about whether it is lawful, particularly where a patient is close to death”.<sup>45</sup>

The fact sheet describes palliative medication, including morphine and sedatives, as a “key part of good palliative care”.<sup>46</sup>

While it refers to there being “varying clinical views about whether or not some palliative medication may hasten death”, it states unequivocally that:

the law recognises that **palliative medication used for pain and symptom relief is lawful in Australia** so long as the intention of the person giving the medication is to relieve the patient’s pain and suffering and not to cause death.<sup>47</sup> [Emphasis original.]

It describes this “doctrine of double effect” – giving medication to a person will be lawful, even if it may hasten death, so long as the intention is to relieve pain and not hasten death – and states that it can apply whether a person dies in a hospital, residential aged care facility, other health service or at home.<sup>48</sup> In relation to who the doctrine protects, it states:

The person giving the medication does not need to be a doctor for double effect to apply. Other health professionals and care givers, including nurses, aged care workers, paid or unpaid carers, or family members may also be protected by double effect so long as there **is medical authorisation and supervision of the medication plan** by a doctor, and death was not intended.<sup>49</sup> [Emphasis original.]

The only limitation it notes is that double effect is likely to apply only when a person is near death, or under the legislation in South Australia, where the person is in the terminal phase of a terminal illness.<sup>50</sup>

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<sup>41</sup> Australian Health Law Research Centre. *End of life law in Australia. Palliative medication*. <https://end-of-life.qut.edu.au/palliative-care> (accessed 11 March 2019).

<sup>42</sup> ELDAC End of Life Directions in Aged Care. *About ELDAC. About the Project*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>43</sup> ELDAC End of Life Directions in Aged Care. *About ELDAC. Acknowledgments*. <https://www.eldac.com.au/tabid/4896/Default.aspx> (accessed 11 March 2019).

<sup>44</sup> ELDAC End of Life Directions in Aged Care. *About ELDAC. About the Project*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>45</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>46</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>47</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>48</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>49</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>50</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

In relation to a person who refuses food and water, ELDAC states:

**Everyone has the legal right to refuse food and water**, even if this results in their death. When a **person decides to stop eating and drinking, palliative medication can be given** to reduce any pain or suffering they experience from this.<sup>51</sup> [Emphasis original.]

The ELDAC fact sheet states unequivocally that palliative medication is not euthanasia. It says:

**Appropriate medication is not euthanasia.**

A common misconception about palliative medication is that it is the same as euthanasia if it causes the person's death. *'If I give my patient medication and she dies I will have euthanased her'*. Sometimes these concerns have resulted in people not getting enough pain and symptom relief.

**Appropriate palliative medication which is intended to relieve pain and suffering is not euthanasia.** The law views this as appropriate palliative care and, if the palliative medication also has the effect of hastening the patient's death, protects those providing the medication through double effect.<sup>52</sup> [Emphasis original.]

The ELDAC fact sheet provides the following 'Key points to remember' in relation to terminal sedation and double effect:

1. Giving appropriate palliative medication for pain and symptom relief is lawful in Australia.
2. The doctrine of double effect provides legal protection if a person dies after receiving palliative medication. It applies if the person who gave the medication intended to relieve pain and not hasten death.
3. Double effect will only apply if the medication is administered by a doctor, or by someone else (for example a nurse, aged care worker, carer, family member) under the doctor's supervision; and the person was already close to death.
4. Palliative medication given with the intention of relieving pain and symptoms is not euthanasia.
5. People with capacity have the right to refuse food and drink, even if it results in death. Medication to relieve the person's pain and symptoms can be given in these situations.<sup>53</sup>

The Australian Centre for Health Law Research's guidance on terminal sedation is expressed in less unequivocal terms than that provided by ELDAC, but it accepts that the doctrine of double effect is likely to be part of Australia's common law and is generally accepted in the legal and medical professions and by medical professional bodies, and that it will likely only apply to a person who is near death. It also states that "some doctors consider that properly administered palliative medication does not hasten death, and that the doctrine is not needed."<sup>54</sup>

The Centre's guidance differs more in relation to whether terminal sedation is permitted when a person has refused food and drink (sometimes referred to as palliated starvation). The Centre suggests that the issue is unclear as it has not been decided by Australian courts.<sup>55</sup> It references an article which argues that providing palliative care in these circumstances is both legal and ethical, including by reference to the cases discussed above in relation to refusing treatment which generally accepted that palliative care would be provided while the person died.<sup>56</sup> The authors argue that health professionals should be able to make a conscientious objection to providing terminal sedation, but they state that if they do object, they must respect the patient's autonomy and refer them to another practitioner.<sup>57</sup>

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<sup>51</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>52</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>53</sup> ELDAC End of Life Directions in Aged Care. *Medication for pain and symptom relief for people with a life-limiting illness*. <https://www.eldac.com.au/tabid/4895/Default.aspx> (accessed 11 March 2019).

<sup>54</sup> Australian Health Law Research Centre. *End of life law in Australia. Palliative medication*. <https://end-of-life.qut.edu.au/palliative-care> (accessed 11 March 2019).

<sup>55</sup> Australian Health Law Research Centre. *End of life law in Australia. Palliative medication*. <https://end-of-life.qut.edu.au/palliative-care> (accessed 11 March 2019).

<sup>56</sup> White, Benjamin P., Willmott, Lindy, & Savulescu, Julian (2014) "Voluntary palliated starvation : A lawful and ethical way to die?" *Journal of Law and Medicine*, 22, pp. 376-86.

<sup>57</sup> White, Benjamin P., Willmott, Lindy, & Savulescu, Julian (2014) "Voluntary palliated starvation : A lawful and ethical way to die?" *Journal of Law and Medicine*, 22, pp. 376-86.

In relation to the doctrine of double effect, the Victorian inquiry concluded:

The Committee's view on the doctrine of double effect is that there is evidence that **patients may be receiving sub optimal care because of fear on the part of health practitioners about their legal position.**<sup>58</sup> [Emphasis added.]

In relation to continuous palliative sedation (ie terminal sedation), the Victorian inquiry noted that it was used in Victoria and stated:

The Committee's view is that, as it has been advised by medical experts, **continuous palliative sedation has a place in appropriately administered end of life care.** However, the current lack of clarity and consistency around its administration in the mind of doctors is problematic. This issue combined with a lack of data about the extent or circumstances of its use contributes to a lack of accountability and transparency that the Committee sees as undermining high-quality patient-centred care.<sup>59</sup> [Emphasis added.]

The Victorian inquiry made three relevant recommendations:

Recommendation 26: That the Victorian Government establish a taskforce to create appropriate guidelines for the administration of continuous palliative sedation to address the existing absence of data on continuous palliative sedation which undermines transparency.<sup>60</sup>

Recommendation 27: That the Victorian Government establish a requirement for all cases of continuous palliative sedation to be reported to the Department of Health and Human Services, and for the Department to include this data, de-identified, in its annual report.<sup>61</sup>

Recommendation 28: That the Victorian Government enact in legislation the common law doctrine of double effect to strengthen the legal protection for doctors who provide end of life care.<sup>62</sup>

The Western Australian inquiry concluded that terminal sedation "is practiced in Western Australia for patients at the end of life, but that it is not offered consistently across palliative care settings".<sup>63</sup> It stated:

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

**The uncertainty among some health professionals regarding the legal status of terminal sedation at the end of life may lead to patients receiving less than optimal treatment, and continuing to suffer pain and other symptoms. ...**<sup>64</sup> [Emphasis added.]

The Western Australian inquiry made the following finding and recommendation:

#### Finding 28

The committee received evidence from government agencies, medical professional bodies and medical educators providing a consistent explanation of terminal sedation and its use as **an appropriate and lawful treatment option** for patients suffering refractory symptoms at end of life.

There remains some confusion amongst health professionals as to the legal status and reasonableness of the clinical practice of terminal sedation and this **confusion is likely to result in the denial of adequate symptom relief to some patients at end of life.**

<sup>58</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 119.

<sup>59</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 107.

<sup>60</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 107.

<sup>61</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 107.

<sup>62</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 119.

<sup>63</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 128.

<sup>64</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 129.

## Recommendation 18

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment.

As per any other medical treatment, the requirement for informed consent must be clear.

The treatment must be specifically noted in the medical record as 'terminal sedation'.<sup>65</sup>  
[Emphasis added.]

In relation to a person's right to receive palliative care following their decision to refuse food and water, the Western Australian inquiry made the following finding and recommendation:

### Finding 26

In the case of a refusal of food and water by a competent person at end of life, there is clinical and legal support for the position that it is similar to the refusal of medical treatment and therefore is not suicide.

Accordingly, **in circumstances where a competent patient at end of life has elected to refuse food and water, it is appropriate that the person be provided with palliative care.**

## Recommendation 16

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. **Training should also include those working in aged care.**<sup>66</sup> [Emphasis added.]

## 2.4 GUIDANCE FOR END-OF-LIFE MEDICATION IN RESIDENTIAL AGED CARE

ELDAC's online toolkit for residential aged care includes a section on managing dying. In relation to end-of-life medications, it states that "[a]ssessment and management of symptoms is critical for dying residents" and links to the specific guidance available for the residential aged care sector in relation to medication to manage dying.<sup>67</sup>

The *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents* was produced by the Brisbane South Palliative Care Collaborative in 2013, and was:

developed as part of the National Rollout of the Palliative Approach Toolkit for Residential Aged Care Facilities Project. The Project was funded by the Australian Government Department of Social Services under the Encouraging Better Practice in Aged Care (EBPAC) Initiative.<sup>69</sup>

It was prepared with the assistance of, among others, the Australian and New Zealand Society of Palliative Medicine (ANZSPM).<sup>70</sup>

The Guide describes its context as follows:

Residents who are dying commonly experience distressing symptoms in the last days and hours of life. High quality end of life (terminal) care requires ongoing assessment of the resident and timely use of pharmacological and non-pharmacological strategies to address emerging symptoms. Failure to do so can result in poor resident/family outcomes as well as poor health system outcomes if dying residents are inappropriately transferred to emergency departments/

<sup>65</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 130.

<sup>66</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 119.

<sup>67</sup> ELDAC End of Life Directions in Aged Care. *Toolkits: Residential Aged Care. Clinical Care. Manage Dying*. <https://www.eldac.com.au/tabid/5026/Default.aspx> (accessed 11 March 2019).

<sup>68</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013.

<sup>69</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, Acknowledgements.

<sup>70</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, Acknowledgements.

hospital wards.

Residential aged care staff responsible for managing/administering medications to control end of life (terminal) symptoms require:

- High level and up-to-date knowledge regarding end of life symptom management and the appropriate uses of palliative care medications.
- Immediate access to these medications in order to relieve symptoms as they occur.
- Locally specific policies and procedures, linked to the continuous quality improvement and risk management programs of their residential aged care facility, to allow safe and effective medication management.<sup>71</sup> [References omitted.]

The Guide “focuses on the medication management of end of life (terminal) symptoms commonly experienced by residents in the last days and hours of life”.<sup>72</sup>

The Guide provides the following “Key Principles Guiding Quality Pharmacological Management of End of Life (Terminal) Symptoms”:

Residents who are in the terminal (or dying) phase are clinically unstable – symptoms can emerge at any time which may require pharmacological intervention. **To ensure a good death, residents require proactive pharmacological management.**

Key principles underlying this pharmacological management include:

- Medications are prescribed, obtained, charted and administered according to the Australian National Medicines Policy and in accordance with regional jurisdictional requirements and local facility policies and procedures.
- **Knowledge by the resident, or their substitute decision maker if appropriate, that the dying process is occurring and that medication administration may improve the quality of death.**
- **Consent given by the resident, or their substitute decision maker if appropriate, to receive medications for the treatment of terminal symptoms.**
- If a medication is considered necessary, the most appropriate medicine is chosen and used safely and effectively.
- **Medications are immediately available to ensure optimal symptom control.**
- **Charted medication doses are based on frequent assessment of the resident and are appropriate to the severity of the symptom(s). Persistent symptoms are treated with regular doses of medication while as-needed doses of medication are charted to cover ‘break through’ symptoms. Medications are administered by the most reliable route ...**<sup>73</sup>

[Emphasis added.]

The Guide provides examples of strategies that can be implemented to ensure timely access to medications for the terminal phase, and suggests using a combination of these three strategies:

- **Prioritise excellent proactive clinical care** as the goal of care. Best practice clinical care involves **early recognition of signs and symptoms** that indicate the dying process allowing residential aged care staff to **pre-emptively organise the prescription, charting and delivery of necessary medications** for subsequent administration.
- Development of professional relationships with medical officers, nurse practitioners and local specialist palliative care services that can act as prescribing resources in partnership with community pharmacists who agree to stock and deliver, in a timely fashion, commonly

<sup>71</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 2.

<sup>72</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 3.

<sup>73</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 4.

prescribed palliative care drugs for use in the terminal phase. This strategy requires particular consideration of how to ensure timely access to medications after hours, during weekends and over holiday periods.

- Establishment of an on-site medication imprest or emergency stock of palliative drugs according to requirements set out by the Medication Advisory Committee of the residential aged care facility and in accordance with national and jurisdictional regulatory legislation ...<sup>74</sup>

The Guide then provides:

- A consensus-based list of medications, endorsed by The Australian and New Zealand Society of Palliative Medicine (ANZSPM), suitable for use in residential aged care for the management of terminal symptoms.
- A table summarising the uses, doses and routes of administration of the medications endorsed by ANZSPM that can be used in the education and training of residential aged care staff.
- Flowcharts summarising the pharmacological management of four common end-of-life symptoms – Nausea and Vomiting, Pain, Respiratory Distress, and Restlessness and Agitation.<sup>75</sup>

The recommendations in the flowcharts are passed on a number of key points to consider in the pharmacological management of end-of-life (terminal) symptoms experienced by residents in residential aged care facilities as follows:

- The resident and/or their substitute decision maker should be aware that the resident is dying and support the use of medications to manage end of life (terminal) symptoms.
- Medications and doses prescribed should be based on careful assessment of the dying resident's condition and symptoms.
- **Doses should be proportionate to the severity of symptoms and response to treatment should be regularly reassessed.**
- Medications that have minimal therapeutic benefit in the terminal phase of life should be ceased.
- The burden of how medications are given and of potential side effects should be minimised.  
**Palliative care medications at the end of life are usually given via the subcutaneous route, which is generally the least invasive and most reliable route in the dying resident.**
- **Persistent symptoms require regular rather than PRN (as needed) orders.**
- **Use of regular medications to manage symptoms does not preclude the need for appropriate breakthrough dose orders.** PRN orders should be written for intermittent symptoms and to cover possible breakthrough events for persistent symptoms.
- **Anticipatory PRN prescribing for problems which may occur during the dying process is important for good end of life (terminal) care** as it will ensure that medications are easily accessible when required.<sup>76</sup> [Emphasis added.]

## 2.5 PERSONAL ACCOUNTS FROM THE WESTERN AUSTRALIAN INQUIRY

Particularly concerning evidence emerged in the Western Australian inquiry about the lack of information given to people and their families about terminal sedation and the terrible pain and suffering experienced when adequate sedation was not provided.

The Western Australian inquiry said it had “heard evidence from some individuals who indicated they would have asked sooner for better pain relief for their loved ones – **had they been aware that it was available**”.<sup>77</sup>

<sup>75</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 3.

<sup>76</sup> Brisbane South Palliative Care Collaborative *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*, Brisbane, State of Queensland (Queensland Health), 2013, p. 11.

<sup>77</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, p. 126.

The Western Australian inquiry set out at length a case study that illustrates the inadequacy of end-of-life care and the lack of control for people and their families when they are not given proper information about sedation. Due to length, we include only excerpts from it here:

The committee received confidential evidence from a witness regarding the protracted and painful death of her partner. Her partner had been admitted to a metropolitan hospice in Western Australia, and promised a peaceful death by his treating team. However, he endured many days of abject, appalling suffering. Finally, one of the nursing staff indicated to her that another treatment was available for her partner and that it would address his pain and distress. The witness recounted the final 17 days her partner spent in the hospital for the committee, and her evidence is reproduced at length over the following pages.

#### Case Study 4.1

In her own words, **a witness explains the suffering of her partner until provided terminal sedation:**

Sometime during that period, he stopped drinking. He was no longer able to swallow so he was not allowed to drink in case he aspirated, although he was at that point still terribly thirsty, often begging for water. Our other child stayed on, and with our children and me by his side, my partner prepared for what he described as the good part – the restful, pain-free sleep.

Only it did not happen. Under sedation with an ever-changing cocktail of drugs, **he was sometimes semiconscious, sometimes very anxious, restless, confused and disoriented. Most of all, he was in pain and completely bewildered by how far from what he had asked for his experience of dying actually was – how far from what he and we had believed could be achieved. And it just went on and on.** It was interminable for us; I cannot imagine how he bore it. Attached to his body were four medication pumps, two butterfly ports for breakthrough medications, and a catheter.

He wore a nappy. The usual regular blood pressure, blood oxygen level et cetera checks were made. He was washed daily, moved and moved again in an attempt to provide some sort of relief ... Even under such heavy sedation, he cried out, he groaned, he said no.

**I protested and was told that it was in his best interests and he was not really in pain and that perhaps if it worried me I should leave the room.**

...

Then there were the secretions. This is the polite term for the thick yellow liquid that builds up in the lungs and needs to drain once it reaches the throat. Again, my partner would be heavily sedated and we would prop him on his side and I would spend hours swabbing the flow and wiping his face and neck until eventually the level dropped sufficiently and stopped and he could be laid back on his back [...].

Eventually his communication was limited to, "I love you", and "Get me out of here".

He indicated that he wanted to go home and take all the medication we had left in the house – anything to stop what was happening. I was beside myself; I was so tired, stressed, sad and desperate that I could not think straight.

**Finally, in conversation with my friend, after I had conveyed to her our desperate situation she said, "you are too bloody polite. Go out into that corridor and make a fuss. Do whatever you have to do to get help for him. It must surely be possible to place him under some sort of anaesthetic – something that will put him in a coma."**

So, I went out into the corridor and **by chance, a senior nurse was on her way around with the drugs trolley.** She called another nurse to take over and went and sat with me.

**I conveyed our desperation:** the fact that my partner wanted to get out of there and that we had lost faith in the hospice's ability to help us. **She told me that there was another drug which, she believed, would have the effect that my partner wanted, but that our doctor did**

**not believe in. I am not sure if she said, “believe in” or “agree with using it”.** She told me its name, but I cannot remember what it was; I only heard it once. She said she was going to seek advice from a more senior doctor.

At the regular meeting of the doctors and nurses in staff the next day, when my partner’s doctor reported on his condition and the steps that were being taken to alleviate his suffering, she said, “Yes, but it’s not working, is it?” Discussion followed and it was agreed to place him on this other drug. **Thank goodness for that nurse. We had never before been told by anyone that there were any other options available; we believed totally that everything had been laid out before us, that we had been provided with all the information and all the options, yet crucially important information had not been given us. We just could not believe it.**

**The drug was then administered and finally my partner was at peace;** finally, he seemed to be without pain, in a deep, relaxed sleep. I hope that inside he was as comfortable as he appeared to us. Some days later – I cannot remember how many – he quietly passed away in his sleep, on his own.<sup>78</sup> [Emphasis added; references omitted.]

The Western Australian inquiry included another personal account in relation to end-of-life care in a hospice as follows:

Very powerful evidence of one patient’s pain and suffering not being alleviated by treatment in a specialist palliative care unit was provided in closed session. The witness told of her mother’s death in a palliative care facility with access to top-quality specialist palliative care. The witness’s mother was diagnosed with breast cancer; unfortunately, the presentation of her symptoms was unusual so by the time she received medical attention she was already very ill. She moved into a hospice just a few months after her initial diagnosis, and at first her symptoms seemed to improve, but soon:

She was sleeping up to 22 hours a day. She got weaker and weaker physically. People were coming to visit her, and we could not even wake her up.

The witness then recounted the last few weeks of her mother’s life:

**She was still in a lot of pain and a lot of discomfort** in this period here because, because if she is not using her muscles and stuff, then she is basically wasting, and that comes with discomfort. You are talking about continence as well. She could not eat a lot of food anymore. Her stomach was rejecting food. **I would not say she had any quality of life from here on in.**

[the day she died] I was at home. It was 4.00 am. I got a call from my auntie, who had flown in. She was with my mum. [...] “You need to come now, because your mum looks different.” I went in, and it was dark because they had the nightlight on. My mum’s eyes were pointing in different directions. They were grey. My mum had dark brown eyes. Her skin was grey and blue and yellow. She was sweating, but she was cold.

Her mouth was open. She stank. Her teeth were apart, and her tongue was sticking that far out of her mouth. Her hands were twisted. Her back was twisted. Her shoulder was twisted. Her feet were twitching. She was dancing in her own bed, and she was making this choking sound that you see in horror movies.

I went up to her and grabbed her hand and tried to get her to say something to me. [...] My mum looked at me with one of her eyes. She looked straight at me. My mum knew what was going on, and her teeth were chattering and she was choking, but I swear she said my name. [...]

**That killed me, knowing that she could have been aware of what is going on in those final hours.**

[a nurse spoke to the witness] “Look, it’s her last, final hours, you want to just clear your schedules for the day. What’s going to happen **is we’re going to give her morphine when she starts twitching.** She will settle – give it some time to kick in – and **just keep calling us when she twitches.**”

**So it was four or five cycles of madness. So my mum twitches, we call the nurse, they come within five minutes, they press a button to give her more morphine through a drip, or whatever the machine is that is in her – [...]**

**It takes her 15, 20 minutes to settle. There is peace and quiet for a little while – maybe half an hour if we are lucky – and then she starts twitching again, and then we call the nurse again and then they inject her again, and then we wait and then she twitches and then we inject and then we wait and then she twitches and then they inject and then we wait!** It was the [sic] absolutely pointless. Then my mum was pronounced dead at 8.20.

Despite this experience, the witness still stated the ‘utmost respect for every single doctor and medical staff who came into contact with my mum’.<sup>79</sup> [Emphasis added; references omitted.]

The Western Australian inquiry also included a detailed account of a person’s experiences in obtaining palliative care after she had refused food and water. It reported:

The committee received several personal stories about individuals choosing to refuse food and water in order to hasten an unavoidable death. One compelling case was provided by Dr Robert Edis, a neurologist, who told the story of one of his patients, Melanie, who suffered with advanced motor neurone disease (MND). The illness took a severe toll.

She was a very intelligent young woman, from a big professional background. The loss of autonomy; the loss of dignity ...

Melanie could no longer tolerate her extreme suffering and elected to stop all food and water to hasten her death. She was provided with palliative care at Hollywood Hospital. Another hospice (where she had previously been an inpatient) refused to admit her again because staff were reluctant to provide palliation for her as she dehydrated, and starved herself to death. Fortunately, for Melanie, Hollywood Hospital agreed to take her in, and hospital staff provided her with palliation. Dr Edis described Melanie’s transfer of care in her final days ...<sup>80</sup> [References omitted.]

Dr Edis described Melanie’s discharge to the high-dependency unit in “what was considered a very good nursing home”, her inability to cope with the discomfort she was experiencing in the nursing home, and the three attempts she had to make to be transferred to a public hospital. Dr Edis described seeing Melanie in the public hospital and her subsequent experiences as follows:

where she said, “Well, how can I end my life? I will not go back to a nursing home. I refuse.” We said, “Well, you have to. There isn’t anywhere else you can go.” So she said, “What can I do?”, and I said, “Well, **there is this thing called terminal dehydration**, stopping nutrition, and we can do that, and **I will negotiate with the hospice to get you there, and you will die within eight to 14 days, but we will cover your symptoms.** We will cover the distress of thirst in the first day or two and anything else, and when you are ready to go, you let us know, and I am sure I can get the palliative care people to turn it on.”

**So I rang the [hospice] head and she said, “If she comes back here, I’ll have nurses going on sick leave. We can’t take her back.”** So I said, “All right; I’ll try Hollywood palliative care, because she has got private health cover.” ... **I had an interview with the palliative care physician at Hollywood, who was very supportive, and she talked to her team about it**

<sup>79</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 93-4.

<sup>80</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 117-8.

and said, “We’ve got this young woman who is in distress. She’s in the terminal phase of her motor neurone disease. She wishes to end her life in this way. Will you agree to participate?”

**The nursing staff all agreed.** If anyone disagrees, they can opt out of the team. The palliative care people do it that way. **She came over. She then died under those circumstances. It was a very peaceful death.**<sup>81</sup> [Emphasis added; references omitted.]

The Committee concluded in relation to Melanie’s experience that:

Melanie was exercising a lawful right in very difficult circumstances and **it is regrettable that she was forced to go to such lengths, and had to endure additional suffering before she died.**<sup>82</sup>

## 2.6 ABUSE AND MISTREATMENT

Although we accept that it could be confirmed in legislation, the law allows the use of sedation in end-of-life care, including terminal sedation that is given for the purpose of relieving a person’s symptoms, and not to cause or hasten their death.

In advocating for Voluntary Assisted Dying, we have been critical of the default to the doctrine of double effect as sufficient protection for a dying person’s rights because it relies on the doctors’ intention, an intention which can be influenced: by personal religious beliefs; by ignorance of what protections doctors are offered under the law; or by fear of being reported for appearing to hasten death. Nonetheless we support its continued application to allow sedation in end-of-life care, although we consider that there should be clearer guidelines and greater scrutiny.

It is clear that people can experience unbearable suffering, including through pain and other physical symptoms, as they approach the end of their lives.

**We have argued more than most that palliative care does not work for everyone and that it cannot relieve all pain and suffering for all those who receive it. However, we strongly support the provision of the most effective possible palliative care for all who need it.**

A key part of making palliative care as effective as possible is focusing on the wishes of the dying person and their family, carer or substitute decision maker.

The guidance on palliative and end-of-life care makes clear the importance of providing person-centred and family-centred care. The person who is dying should have their autonomy and dignity respected, and – together with their family members or carers – they should have choice and control in relation to their end-of-life medication.

In order to exercise choice and control, the person and their family members or carers must be given adequate information about options for medication, including terminal sedation, and they must be given this information sufficiently early so that the pain and suffering of dying can be managed as effectively as possible in accordance with the person’s wishes.

Available guidance for the residential aged care sector makes clear the importance of pro-active management and provision of end-of-life medication.

Consideration of the need for increased sedation, including terminal sedation, should not depend on family members in anger and desperation demanding that something be done when the suffering has become unbearable even to the family members.

The provision of adequate end-of-life care should not depend on the “luck” of having a compassionate member of staff quietly tell a family member that there is more effective treatment that could be provided.

<sup>81</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 118-9.

<sup>82</sup> Joint Select Committee on End of Life Choices (WA) *My life, my choice*. Parliament of Western Australia, 2018, pp. 119.

**Why was Audrey not given adequate sedation? Why was her need for end-of-life medication not assessed proactively, taking account of her views and those of her daughter, Carol?**

Why did the GP contracted by the nursing home refuse to provide palliative sedation for Audrey? Why did he refuse morphine? Why did he not recognise her extreme pain and suffering?

Why did Carol have to push for weeks to convince the GP that Audrey should be allowed morphine?

Once the morphine was finally provided, Audrey was allowed a peaceful ending, but only after the most dreadful and unnecessarily prolonged experience of her life. How much worse would her experience have been without her daughter's knowledge as a nurse giving her the confidence to keep pushing for adequate end-of-life care?

The aged care system failed to meet Audrey's needs. It failed to provide her with adequate end-of-life care. It failed to allow Audrey what she and Carol could have accepted as a 'good death' in the circumstances.

An experience like Audrey's can only be understood as abuse and mistreatment.

**Why was Murray not given adequate sedation? Why did the nursing home staff not assess his need for end-of-life medication proactively, taking account of his views and those of his wife, Dawn?**

If the nursing home staff did not have adequate knowledge, why did they not obtain proper end-of-life advice to help manage Murray's dying? Why did Dawn have to keep pushing for adequate pain relief for Murray?

Why was a nurse able to block the provision of adequate pain relief, without escalating Dawn's concerns to the doctors? Why did Dawn have to go around the nurse to get to the doctors directly?

Once the morphine was finally provided, Murray was able to die in peace. But Dawn cannot understand why he had to suffer as he did for the last few weeks of his life. Dawn now lives with a huge fear that she may have to suffer that pain and indignity at the end of her life.

The aged care system failed to meet Murray's needs. It failed to provide him with adequate end-of-life care. It failed to allow Murray what he and Dawn could have accepted as a 'good death' in the circumstances. It has left Dawn living with fear of what her own end of life experience will be.

An experience like Murray's can only be understood as abuse and mistreatment.

**Why was Margaret's deteriorating condition not recognised by the hospice? Why was the possibility of her discharge raised in spite of her deterioration? Why was her anxiety not better managed, in spite of her daughter Ann raising concerns?**

Why was Margaret not given adequate end-of-life medication? Why did the hospice not assess her need for end-of-life medication proactively, taking account of Margaret's views and those of her son and Ann?

Why did the doctors not increase Margaret's morphine before she died so that she did not have to die in pain? Why was Margaret left to die conscious, against her wishes?

Why did Ann have to keep pushing to be heard in relation to her concerns about her mother?

Margaret was not able to die in peace; she was not given medication that would have allowed that at the end of her life.

The hospice failed to meet Margaret's needs. It failed to provide her with adequate end-of-life care. It failed to allow Margaret what she and Ann could have accepted as a 'good death' in the circumstances.

An experience like Margaret's can only be understood as abuse and mistreatment.

**Why was Daphne's pain not better managed? Surely there was something that would have been more effective than paracetamol for Daphne?**

Why was specialist advice not obtained to help find a medication that would more effectively address Daphne's pain without causing her terrible hallucinations?

Daphne, Dawn and Carol were put through the additional distress of finding another facility and moving Daphne for her final two weeks of dying.

The aged care services failed to meet Daphne's needs. It failed to provide her with adequate end-of-life care. Daphne was not allowed a 'good death'.

An experience like Daphne's can only be understood as abuse and mistreatment.

**Why was Gloria's pain not better managed, both throughout the palliative care and at the end-of-life stage?**

Why was Gloria left to suffer horrendous delusions, in absolute terror? Why were her requests for "any and all pain-killing medication" not met, at least by providing a level of sedation that would have given her the peaceful end to life that she sought?

Why were the doctors fearful of legal repercussions when providing sedation to ease pain is lawful, particularly as Gloria asked for the most effective pain-killing medication and was enduring terrible suffering?

After all the challenges Gloria had dealt with in life, why was she forced to suffer a 'bad' death, leaving her daughters Jo and Sherie scarred?

The aged care service failed to meet Gloria's needs. It failed to provide her with adequate palliative care, including adequate end-of-life care. Gloria was not allowed a 'good death'.

An experience like Gloria's can only be understood as abuse and mistreatment.

## Part 3

# A growing concern in aged care

These forms of abuse and mistreatment in end-of-life care in aged care are and will continue to be a growing problem in aged care settings unless they are urgently addressed.

As we noted at the start of this submission, this is because:

- Australia's population is growing and ageing
- older age groups have a higher burden of disease, with higher prevalence of cancer and other chronic conditions
- most end-of-life care is provided by services targeted towards older Australians, with around four in five deaths each year occurring for people aged 65 and over
- most Australians experience end of life in institutional settings, with only one in five deaths occurring outside hospitals or residential aged care facilities
- the provision of palliative care in residential aged care facilities is currently increasing with the Australian Government's provision in the 2018–19 Budget of increased funding for palliative care for older Australians living in residential aged care
- end-of-life choices are – or at least should be – increasing for some Australians through Voluntary Assisted Dying laws commencing shortly in Victoria and being prepared for consideration by the Western Australia Parliament, and which are subject to consideration by a parliamentary inquiry in Queensland.

To expand on this summary, the Australian Institute of Health and Welfare (AIHW) in its report *Australia's Health 2016* included a section reporting on end-of-life care. AIHW described the need for appropriate end-of-life care and palliative care as important. It stated that Australia's growing and ageing population means that "the number of people who will die each year will rise substantially over the next 50 years, and more people will die due to chronic progressive diseases, increasing the need for an end-of-life care system that meets the needs and expectations of individuals and their families."<sup>83</sup>

In its report *Australia's Health 2018*, AIHW included a short section on palliative care services. AIHW stated that the "demand for palliative care services is likely to increase in Australia in future years due to a growing and ageing population as well as to the high burden of disease, related to the higher prevalence of cancer and other chronic conditions, in older age groups".<sup>84</sup>

In 2016, AIHW reported that, while end-of-life care is provided in a variety of settings, most end-of-life care is provided by services targeted towards older Australians, with around 80 per cent of deaths each year occurring for people aged 65 and over.<sup>85</sup>

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<sup>83</sup> Australian Institute of Health and Welfare *Australia's health 2016*. Australian Institute of Health and Welfare, 2016, Section 6.18 "End-of-life care", p. 2.

<sup>84</sup> Australian Institute of Health and Welfare *Australia's health 2018*. Australian Institute of Health and Welfare, 2018, Section 7.21 "Palliative care services", p. 1.

<sup>85</sup> Australian Institute of Health and Welfare *Australia's health 2016*. Australian Institute of Health and Welfare, 2016, Section 6.18 "End-of-life care", p. 4.

AIHW described the end-of-life experience for Australians as having become “increasingly institutionalised” over the last century, with only around 20 per cent of Australians dying outside of hospital or residential aged care in the first decade of the 21st century.<sup>86</sup> This is one of the lowest rates in the developed world.<sup>87</sup>

The AIHW report *Palliative care services in Australia*, updated in 2019, provides data in relation to permanent residents (that is, a person who is receiving long-term (permanent) care in a residential aged care facility) who were assessed and funded for palliative care in residential aged care. The data is based on the Aged Care Funding Instrument (ACFI). The AIHW reports:

- There were about 239,600 permanent residents of aged care facilities in Australia in 2016–17 with completed Aged Care Funding Instrument (ACFI) appraisals, and about 1 in 50 of these residents (4,509) had an ACFI appraisal indicating the need for palliative care and subsequently received palliative care funding.
- The number of aged care residents and admissions appraised as requiring palliative care has trended downwards since 2012–13. The number of residents appraised as requiring palliative care decreased from 12,107 to 4,509 and admissions from 5,488 to 2,811 between 2012–13 and 2016–17. The number of residents and admissions assessed as requiring other care increased over the same period.
- The decrease over time in residential aged care permanent admission and residents appraised as requiring palliative care is most likely related to changes in the application of the ACFI for palliative care in recent years.
- In practice, it is possible to receive palliative care in residential aged care without having received an ACFI assessment indicating the need for palliative care.
- The data available to the AIHW cannot confirm the extent or nature of palliative care actually provided for those who were assessed and funded for palliative care.<sup>88</sup>

It is therefore safe to assume that the ACFI understates – and possibly substantially understates – the current need for and provision of palliative care in residential aged care facilities.

In relation to palliative care and the reasons permanent residents leave aged care facilities, AIHW reported that the most common reason for separation from the facility for their last care episode was due to death, whether or not they received palliative care (97.6% for palliative care and 83.9% for other care).<sup>89</sup>

Leaving aside the inadequacies of the ACFI data, it is clear that the provision of palliative care in residential aged care facilities is planned to increase.

In the 2018–19 Budget, the Australian Government announced increased funding for aged care of \$32.8 million over four years from 2018–19 to 2021–22 to improve palliative care for older Australians living in residential aged care. The Australian Government explained the importance of this measure in the following terms:

Caring for people at the end of life is one of the most important elements in a truly compassionate society. This measure will facilitate the development and implementation of new models of palliative care in aged care facilities.

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<sup>86</sup> Australian Institute of Health and Welfare *Australia's health 2016*. Australian Institute of Health and Welfare, 2016, Section 6.18 “End-of-life care”, p. 4, referencing Broad JB, Gott M, Kim H, Boyd M, Chen H & Connolly MJ 2013. “Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care setting in 45 populations, using published and available statistics”. *International Journal of Public Health* 58(2):257–67.

<sup>87</sup> Australian Institute of Health and Welfare *Australia's health 2016*. Australian Institute of Health and Welfare, 2016, Section 6.18 “End-of-life care”, p. 4.

<sup>88</sup> Australian Institute of Health and Welfare *Palliative care services in Australia 2018* (web only report). Australian Institute of Health and Welfare, 2018, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary> (accessed 11 March 2019). “Palliative care in residential aged care – Key points”, “Characteristics of residential aged care residents needing palliative care”, and “Residential aged care residents and admissions over time”.

<sup>89</sup> Australian Institute of Health and Welfare *Palliative care services in Australia 2018* (web only report). Australian Institute of Health and Welfare, 2018 <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary> (accessed 11 March 2019). “Separation mode”, “Length of stay” and “Hospital leave”.

Quality palliative care plays a vital role at the end of life for Australians, reducing the physical and emotional distress of dying for individuals and the carers, family and friends supporting them.

Many older Australians living in residential aged care facilities transfer in and out of hospital multiple times as they approach the end of their lives. This measure will provide early access to specialist palliative care support in aged care facilities that will reduce the need for many of these hospitalisations and may limit the associated emotional and financial impacts on older Australians and their families.

It will further enable people to die in their place of choice, supported by increased capacity in aged care, improved care coordination, and better clinical governance.

Through this measure, older Australians will receive appropriate support from the entire spectrum of health services in order to more effectively meet their medical and personal needs, as they approach end of life.<sup>90</sup>

Finally, concerns around denial of autonomy, dignity, choice and control may become more acute as a result of an increase in the end-of-life choices some Australians will have through the introduction of Voluntary Assisted Dying laws.

From 19 June 2019, under the *Voluntary Assisted Dying Act 2017* (Vic), Victorians approaching the end of their life who meet strict eligibility criteria will be able to request access to Voluntary Assisted Dying.

The Western Australian Government has appointed an expert panel to help draft assisted dying legislation, which it plans to introduce into Parliament later this year and which it has said will be subject to a conscience vote.<sup>91</sup>

The Queensland Parliament has established an Inquiry into aged care, end-of-life and palliative care, which is being conducted by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee. It is to consider, among other things, "Queensland community and relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons" and it is to report by 30 November 2019.<sup>92</sup>

Providing an additional choice at end of life for some eligible people may focus more attention on end-of-life choices generally, including what choices are available and whether the choices people make are being respected.

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<sup>91</sup> Eliza Laschon, "Voluntary euthanasia bill set to be introduced to WA Parliament in bid to legalise assisted dying", 12 Nov 2018 <https://www.abc.net.au/news/2018-11-12/voluntary-euthanasia-legislation-announced-by-wa-government/10488400> (accessed 11 March 2019).

<sup>92</sup> Parliament of Queensland, Legislative Assembly. *Hansard*, 14 November 2018, p. 3477.

<sup>93</sup> Royal Commission into Aged Care Quality and Safety, Transcript, 18 February 2019.

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## Part 4

# Why is abuse and mistreatment occurring in aged care?

The abuse and mistreatment in aged care that we highlight in this submission is abuse and mistreatment in end-of-life care, particularly:

- overriding people's exercise of their right to refuse medical treatment and/or their right to refuse food and water
- leaving people to experience unnecessary pain and suffering at the end of life through failing to provide adequate pain medication, including where appropriate terminal sedation, and failing to provide adequate information on options for end-of-life medication.

In both cases, we submit that the care provided denies a person's autonomy, dignity, choice and control, whether exercised themselves or through their family, carer or substitute decision maker.

We have already noted above concern about uncertainty over the legal position in relation to these issues. It is hard to understand how those involved in providing health and aged services – including medical practitioners – could be uncertain as to something as fundamental as the need for a competent person's consent to provide medical treatment, although we accept that the doctrine of double effect might be harder to understand. We would have no objection to the common law on these points being confirmed in legislation where this has not already occurred.

The personal accounts we have heard, the Victorian and Western Australian inquiries, and even some of the evidence in the Royal Commission's first hearing, particularly that given by Dr Harry Nespolon, President of the Royal Australian College of General Practitioners,<sup>93</sup> suggest that these forms of abuse and mistreatment in end-of-life care will share some of the causes of other forms of abuse and mistreatment in aged care more generally.

Thus, lack of funding, staffing shortages, inadequate training, insufficiently qualified staff, gaps in services between aged care (on the one hand) and primary and acute care (on the other hand) might all play a part.

We particularly note Dr Nespolon's evidence about the adequacy with which aged care services are currently able to cater for end-of-life care:

### DR NESPOLON

Certainly, the discussions I've had preparing for this is that most of my colleagues who are working in – in residential aged care facilities believe that palliative care or end of life care should occur in the nursing home. It's often desired by the relatives because it's something where the patients have been, it's their "home", and that nursing homes – if I can, sorry, use the old term, are – should be in – should be resourced to allow patients to die and to have good deaths, to use

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<sup>93</sup> Royal Commission into Aged Care Quality and Safety, Transcript, 18 February 2019.

the terminology, in their nursing home. Palliative care services are often very good at dealing with patients in their own homes and for dealing with often cancer-type pains. Within nursing homes, not all patients are dying from cancer. They're dying from chronic illnesses, things like heart failure, strokes, lung disease. It's a different – it is a different sort of death, and nursing homes, in my view, should be adequately resourced to be able to allow people to die, and as my colleagues have said to me, it's often where most non-cancer deaths are occurring nowadays.

#### MR GRAY

Is there a gap in the equipment at nursing homes, in the skills mix? Is there some issue you perceive there? You seem [to be] saying that should be the aspiration but I'm not sure whether you're saying that it actually is the actuality now.

#### DR NESPOLON

Look, I was chatting to one of my colleagues this morning and often using a pump to pump things like morphine into patients subcutaneously, that sort of – I would see it as sort of as an absolute minimum sort of piece of equipment. That's worth about \$10,000. So that's quite a significant investment by a nursing home in a particular – just in one piece of equipment. It can be done manually. You don't have to have the machine, the machine makes it easier, but it does require someone to be coming and seeing the patient regularly and once again you run into this problem, the number of staff members within the nursing home. If you've got – I don't know what the number is, two or three people on, if you've got one of those people just dealing with one patient it means there is a whole lot of other patients who aren't being seen.<sup>94</sup>

We also note the following observations in Counsel Assisting's summary on the final day of the first hearing:

Dr Nespolon also identified issues of concern relating to hospital transfers. Dr Nespolon also spoke of the related issue of the need for improvement in end-of-life care available in residential aged care settings. Residential aged care facilities are of course not hospice facilities. Funding is available in limited circumstances for end-of-life care. However, we have heard evidence from various witnesses that such funding is difficult to obtain and is often received too late. It has been suggested by a number of medical professional and provider peak group witnesses that funding arrangements should be amended to allow for end-of-life services in residential aged care. This might involve funding appropriate equipment and services or funding for palliative care specialists to offer appropriate solutions in residential aged care.<sup>95</sup>

The Victorian inquiry heard evidence about problems with access to medication and medication management, including after hours, and a lack of clarity in the law as to who may administer medication in residential aged care. It stated:

The Committee recognises the issues raised surrounding access to medication. Any solution to ensure greater access to medication may not be straightforward. There are some possible solutions which the Victorian Government may consider investigating. For example, requiring residential aged care facilities to employ staff able to administer appropriate palliative care medication, and/or amending legislation or regulation to increase the ability of nurses, carers, and patient care workers to administer appropriate palliative care medication. However, these or other measures require further investigation, including targeted consultation with key stakeholders.<sup>96</sup>

The Committee recommended:

Recommendation 12: That the Victorian Government update the regulations regarding the storage of and access to medications at home and in residential aged care facilities for palliative care patients so that unnecessary barriers to treatment and pain relief are removed,

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<sup>94</sup> Royal Commission into Aged Care Quality and Safety, Transcript, 18 February 2019, TP-380:20-47.

<sup>95</sup> Royal Commission into Aged Care Quality and Safety, Transcript, 22 February 2019, TP-654:21-30.

<sup>96</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 76.

while mitigating the risk of potentially dangerous and addictive medications being accessed inappropriately.<sup>97</sup>

It is not clear that these concerns need prevent adequate medication being provided, given the guidance in the *Guide to the Pharmacological Management of End of Life (Terminal) Symptoms in Residential Aged Care Residents*.<sup>98</sup> However, if there are provisions in particular state or territories that prevent adequate end-of-life medication being given, then we agree that they should be removed.

The Victorian inquiry also recognised issues with education about end-of-life care in residential aged care. It recommended:

Recommendation 22: That the Victorian Government develop an education package for residential aged care workers on end-of-life care.<sup>99</sup>

We expect that all of these factors contribute to abuse and mistreatment in end-of-life care in aged care to some extent. Some of them – such as staffing levels, training and expertise, and interaction with primary and acute health services – presumably contribute to other forms of abuse and mistreatment in aged care.

However, we do not accept that these factors can be the full story. As Audrey's and Murray's stories show, adequate sedation was able to be provided, but only after Carol and Dawn respectively had exhausted themselves demanding that their loved ones be properly cared for. There were staff with the necessary knowledge, such as the nurse who tipped off Dawn as to what better treatment Murray could be receiving.

It is also the case, as Margaret's story shows, that this abuse and mistreatment occurs in what are supposed to be specialist palliative care services. That is, the failings are not only occurring in aged care settings, and factors that relate to the staffing levels and skills of aged care staff cannot be a full explanation for abuse and mistreatment at end of life.

Our experiences in advocating for Voluntary Assisted Dying and improved palliative care have led us to believe that there is another factor that particularly affects the adequacy – or otherwise – of end-of-life care, including in aged care.

**That factor is the determination of some who work in palliative care and aged care to provide end-of-life care in accordance with their own religious beliefs and not in accordance with the choices of the person who is dying or their family, carer or substitute decision maker.**

Many of the accounts we have heard, including through the Victorian and Western Australian inquiries, relate to Catholic hospitals, hospices, aged care facilities, doctors and nurses. Catholic health and aged-care services form the largest non-government grouping of health and aged-care services.<sup>100</sup> However, the accounts are not limited to Catholic providers. For example, Audrey's experience occurred in an aged care facility operated by another religion.

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

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<sup>99</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. 92.

<sup>100</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript, Mrs Suzanne Greenwood, Chief Executive, Catholic Health Australia, 28 February 2018, p. 1.

In 1985, Pope John Paul II founded the Pontifical Council for Pastoral Assistance to Health Care Workers. Said to be inspired by faith and hope, he intended to offer a response to the challenges arising in the world of health care. In 1994, the first president of the dicastery, the late Fiorenzo Cardinal Angelini, published the *Charter for Health Care Workers*, translated into nineteen languages.<sup>101</sup>

According to the *Charter for Health Care Workers*, released by the Vatican in English in 1995:<sup>102</sup>

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

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

**The most important assistance is “loving presence” at the bedside of the dying person.** There is a proper medical-health presence which, though not deceiving him, makes him feel alive, a person among persons, because he is receiving, like every being in need, attention and care.

This caring attention gives confidence and hope to the patient and makes him reconciled to death. **This is the unique contribution which doctors and nurses, by their being human and Christian – more than by their expertise – can and should make to the dying person,** so that rejection becomes acceptance and anguish gives way to hope. [Paragraph 117] [Emphasis added; references omitted.]

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

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

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

However, it then refers to two problems with the use of painkillers with the dying. The first problem essentially describes the doctrine of double effect. The doctrine of double effect is very well recognised in the Catholic moral tradition.<sup>103</sup> However, the Charter requires that there be “proportionate reasons” before it is permitted to use narcotics to alleviate suffering even though they hasten death [Paragraph 123].

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<sup>101</sup> Bioethical Committee of the World Federation of Catholic Medical Associations, “A New Charter for Health Care Workers”, 23 November 2017 <https://bioethicsfiamec.com/2017/11/23/a-new-charter-for-health-care-workers> (accessed 11 March 2019).

<sup>102</sup> Pontifical Council for Pastoral Assistance, *Charter for Health Care Workers* <http://www.ewtn.com/library/curia/pcpaheal.htm#3> (accessed 11 March 2019).

<sup>103</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Archbishop Timothy John Costelloe, Catholic Archbishop of Perth, 8 March 2018, p. 2.

The second problem the Charter identifies is terminal sedation:

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

Without serious reasons, the dying person must not be deprived of consciousness. Sometimes the systematic **use of narcotics which reduce the consciousness of the patient is a cloak for the frequently unconscious wish of the health care worker to discontinue relating to the dying person.** In this case it is not so much the alleviation of the patient's suffering that is sought as the convenience of those in attendance. The dying person is deprived of the possibility of "living his own life," by reducing him to a state of unconsciousness unworthy of a human being. This is why the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is "a truly deplorable practice".

It is a different matter when there is a serious clinical case for the administration of analgesics which suppress consciousness, as **when there is violent and unbearable pain. In this case the anesthetic is said to be licit, provided certain conditions are fulfilled: that the dying person has fulfilled or could still fulfill his moral, family and religious obligations.** [Emphasis added; references omitted.]

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

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

An updated *New Charter for Health Care Workers* was adopted in 2016 and published in English in 2017. The provisions in relation to dying are substantially the same as the original charter.

While the provisions outlined above suggest that the Charter does not prohibit sedation, including terminal sedation, or the acceptance of a person's decision to starve to death, it cautions against them in terms that empower the (Catholic) health care worker to make the decision, without any real regard for the wishes of the dying person or their family or carers. Everything is assessed through the prism of the health care worker and their faith, and not through the wishes of the dying person. It applies without regard to whether the dying person is religious or not, and if they are, whether they are Catholic or of another faith.

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

Illness, disability and suffering are never good in themselves: health care properly seeks to relieve them. There are, however, limits to what health care can achieve. **Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.**<sup>104</sup>

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

Advances in palliative care are now such that the control of pain should not normally lead to side effects such as loss of lucidity or consciousness or to the shortening of life.<sup>105</sup>

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

<sup>104</sup> Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 2001 <https://www.cha.org.au/images/resources/Code%20of%20ethics-full%20copy.pdf> (accessed 11 March 2019), p. 9.

<sup>105</sup> Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 2001 <https://www.cha.org.au/images/resources/Code%20of%20ethics-full%20copy.pdf> (accessed 11 March 2019), p. 46.

lives, the Rev Dr Parkinson said:

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

...

If you are able to provide consciousness, if you are able to preserve consciousness with pain relief, that is great. But you will also have heard, I am sure, reference to palliative sedation – so dealing with if not the pain, then the agitation that can accompany pain at the end, that can be managed; patients can be given relief from that. It is not, as we have discussed, about killing a patient, it is about controlling pain. **The beauty of palliative sedation is that it is temporary, so it is reversible. A patient can be given a break, get relief, have a couple of days good solid sleep and then be brought out of that and be able to continue making their autonomous health care choices.** I think there might be a bit of a myth floating around that somehow medicine ought to be able to provide everything that I want. The fact is, it never has been able and probably never will be able to provide both full consciousness and complete freedom from pain.<sup>106</sup>

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

- Catholic aged care services would support the decision of a competent and “mentally stable” person who requested palliated starvation, but they would look at why the person wished to end their life and they would address their distress or mental health issues and support them and their family to make “informed decisions”.<sup>107</sup>
- Catholic Health facilities rarely see people who are so severely distressed at the end of life that sedation is the only option. Sedation is considered at the last 24 or 48 hours of life to alleviate suffering.<sup>108</sup>
- Patients or their substitute decision-makers sometimes request an increase in palliative medication, knowing the risk is to hasten death, but this is usually “a reflection of levels of distress and a signal for us as a team to spend more time with patients and families and explore that distress, and often with intervention and time and the multidisciplinary approach, we are able to support people through that”.<sup>109</sup>
- This is the case in aged care too, where a request for an increase in palliative medication is “an opportunity for people to give families information around what is available as well. Often people are so distressed and they think medication is the only answer to that distress. There may be other interventions we can make to address psychological distress, spiritual distress, issues around meaning and family relationships that would be adding to that distress. It is a multidisciplinary conversation that needs to take place as well.”<sup>110</sup>

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

In advocating for Voluntary Assisted Dying, we have often been on the other side of the debate to some senior palliative care doctors who share a belief that there is spiritual growth to be found in suffering

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<sup>106</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript, Rev Dr Parkinson, 8 March 2018, p. 4.

<sup>107</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA, 28 February 2018, p. 12.

<sup>108</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Ms Natalie Joseph, Catholic Homes, Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA, Mrs Suzanne Greenwood, Chief Executive, Catholic Health Australia, Dr Alison Parr, Director Medical Services, St John of God Health Care; Palliative Medicine Consultant, 28 February 2018, pp 13-4.

<sup>109</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Dr, Dr Alison Parr, Director Medical Services, St John of God Health Care; Palliative Medicine Consultant, 28 February 2018, p. 17.

<sup>110</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA, 28 February 2018, p. 17.

as you die. They argue for the sort of palliative care that the Charter promotes and their authority, as 'experts on the care of the dying', has been accepted without question by many politicians.

Their arguments are seldom presented as religious ones – only as medical – but they represent nonetheless a powerful belief system. The palliative care that they campaign to preserve enables them to continue practising according to those beliefs, without scrutiny or censure, regardless of whether or not those beliefs are shared by the dying patients dependent on their care.

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

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

There are quite a significant number who view the hospice model as inhumane because it doesn't allow them to, essentially, be the masters of their own demise.<sup>111</sup>

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.**<sup>112</sup> [Emphasis added.]

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

What people don't realise is that on entering into the hospice you're entering into a contract, essentially, about how you can die. Hospices in Australia have a set of parameters around what is acceptable and what is ethical, and those are embedded in a particular series of moral structures which have religious underpinnings and certain ideas about what is okay or not okay and the nature of suffering.

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

I think we need to acknowledge the fact that if we overvalue this so-called natural course of dying and we normalise suffering – as Pope Benedict said, assisted suicide is this false solution to the drama of suffering. I would suggest that that suggests he has not seen much suffering, because it's not much of a drama if you ask me. It's something much more malevolent than that. **If we overvalue suffering, which I think has very religious puritan roots around the virtue of stoicism, there's not much virtue in it when you see it happening.** There's not much virtue in it when you are in that space. In fact if anything, **it's degrading of a person and all of those around the person.**

So, **I think we have a set of values, but they're highly compromising in terms of other really important values, which are choice, expressing one's preferences, agency, and the most important one, which is dignity.**<sup>113</sup>

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<sup>111</sup> Better Off Dead Podcast, #10 *Neither hasten nor prolong death: palliative care in Australia, part 1* <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death> (accessed 11 March 2019).

<sup>112</sup> Better Off Dead Podcast, #10 *Neither hasten nor prolong death: palliative care in Australia, part 1* <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death> (accessed 11 March 2019).

<sup>113</sup> Better Off Dead Podcast, #10 *Neither hasten nor prolong death: palliative care in Australia, part 1* <https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death> (accessed 11 March 2019).

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

An example of this is provided by palliative care physician, Dr Douglas Bridge of Western Australia. Dr Bridge has spoken publicly of his "supreme Christian calling" in his work, and of his belief that "within one's suffering is an opportunity for growth..."<sup>114</sup>

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

The possibility of such an outcome highlights the need to make every effort to deal with psychological "skeletons in the cupboard" before the patient becomes too weak to address them. A few, however, resist every attempt to share what they have been hiding.<sup>115</sup>

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

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

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<sup>114</sup> Online profile for the Uniting Church Western Australia, page no longer available.

<sup>115</sup> Christian Medical and Dental Fellowship of Australia Inc., (2018), *Luke's Journal*, Vol 23(1), pp. 38-40, p. 38.

## Part 5

# Some Possible Solutions

The abuse and mistreatment in end-of-life care in aged care that we have highlighted in this submission goes to the heart of many people's greatest fears of aged care – the loss of autonomy and dignity – and the terrible suffering that occurs for those who die a 'bad death' and their families.

Go Gentle Australia will continue to advocate for change to laws around Voluntary Assisted Dying to give all Australians a right to have a choice about what happens to us at the end of our lives and not to be coerced, when we are at our most vulnerable, into cruel and avoidable suffering.

However, as we understand that the Royal Commission into Aged Care Quality and Safety is not examining the possible introduction of Voluntary Assisted Dying laws, we have not sought to make the case for assisted dying laws in this submission.

We discuss our current ideas about possible solutions below. We are not experts in the aged care sector, and we acknowledge that there may be better ways of achieving the objectives we identify than the ways we suggest. We are keen to continue to contribute to the development of possible solutions as the Royal Commission continues its work.

### 5.1 EXPOSURE OF THE ISSUE

We consider that exposing the types of abuse and mistreatment in end-of-life care we have highlighted through the work of this Royal Commission, particularly in its public hearings, will raise awareness of the problem and focus attention on the need for solutions.

We do not think that awareness raising alone will be sufficient, but it is an important first step.

As noted at the start of this submission, we would appreciate the opportunity to speak to these issues at a public hearing or roundtable consultation. We will also be very interested to hear any possible solutions proposed by other witnesses.

### 5.2 IMPROVE EDUCATION, TRAINING AND STAFFING

We consider that education and training about end-of-life care needs to be improved for those working or providing services in aged care, including relevant health professionals.

In particular, there needs to be clear education and training about:

- the law relevant to end of life, including the person's right to refuse treatment and/or food and water (whether under common law or legislation)
- pain medication and sedation approaching and at the end of life, including the need for a proactive approach, for ensuring adequate supplies of medication and the best methods of delivering it
- the importance of Advance Care Directives and the need to observe them.

A need for education of more general application in relation to patient-centred and family-centred care and what this really requires in practice arises from both the types of abuse and mistreatment we have highlighted and through evidence of other types of abuse and mistreatment that the Royal Commission is receiving. Insufficient understanding and respect for the autonomy, dignity, choice and control of aged care recipients, either directly or through their families, carers or substitute decision makers, needs to be addressed, both in end-of-life care and more generally in aged care.

Staffing levels, or the qualifications of staff, may also need to be addressed if current arrangements impede the administration of effective medication and sedation at the end of life.

### 5.3 IMPROVE END-OF-LIFE PLANNING IN AGED CARE

We consider that one of the most effective ways to reduce mistreatment and abuse in aged care may be to improve end-of-life planning in aged care.

#### 5.3.1 ADVANCE CARE DIRECTIVES

All Australians should be aware of what Advance Care Directives are and how they can work to support their wishes at the end of life. They are important, also, because in requiring the appointment of an enduring guardian or substitute decision maker, they begin a discussion within families about the often-avoided subject of dying.

We consider that residential aged care facilities should be required to hold a current Advance Care Directive for every resident, unless there are circumstances particular to the resident that make this impossible. Requiring fairly regular update or confirmation of the Directive should help to improve the facility's understanding of the resident's wishes, and it should help to improve awareness of the Directive and its legal effect.

Residential aged care facilities should be required to ensure that all relevant staff are aware of the existence of an Advance Care Directive and its relevant contents as a resident receives palliative care and as they approach the need for end-of-life care.

We note that our suggested improvements to the use of Advance Care Directives will only be effective if laws in each state make such directives legally enforceable.

#### 5.3.2 ADDRESSING THE DISPARITY IN KNOWLEDGE

We consider that a significant factor in the personal accounts annexed to this submission, and in the many other personal accounts we have heard of abuse and mistreatment at end of life, is the disparity in knowledge between the dying person and their family or carer (on the one hand) and the health care professionals and aged care staff (on the other hand). This is particularly important in relation to palliative care, including sedation, at end of life.

That is, the health and aged care staff know what medication is available and how it can be administered most effectively, but the dying person and their family, carer or substitute decision maker do not.

For example, in relation to terminal sedation, the Western Australian inquiry observed:

Terminal sedation is another lawful option at end of life. **Ordinarily, it is an option chosen by the treating doctor and may not be fully discussed with the patient. This option is usually only available in the last days and hours of life and is not widely offered, nor understood.** Several witnesses described the sedation of a loved one right at the end of their life as the only effective means to relieve unremitting and distressing symptoms until death.<sup>116</sup> [Emphasis added.]

This disparity in knowledge adds to the disparity in power: in residential aged care, a dying person and

their family, carer or substitute decision maker is reliant on the aged care facility for most aspects of their care and their experience of dying, subject to what their family, carer or substitute decision maker are able to add.

One way to address the disparity in knowledge might be to require aged care facilities to provide residents, or substitute decision makers, and their families and carers with clear information about end-of-life care, including options to refuse treatment and/or food and water and available pain medication, including sedation and terminal sedation.

This information should be provided in the form of an information sheet with mandated content approved by an appropriate professional or regulatory body, rather than leaving the content to the discretion of the facility. It should be required to be provided at the time a resident or their substitute decision maker is asked to prepare, update or confirm an Advance Care Directive, so that the information can help to inform the Advance Care Directive. It should also be available online and in the facility for residents, families, carers and substitute decision makers to review at any time, including when they may be spending more time with the resident as the resident nears the end of their life and may be in the best position to observe the resident's need for more effective medication.

### 5.3.3 ENSURING COMPLIANCE

These proposed requirements for Advance Care Directives and the provision of information about end-of-life care need to result in better planning and decision-making about end-of-life choices, and in the facility respecting and observing the resident's end-of-life choices. It is important that they are not regarded simply as 'tick-a-box' compliance exercises.

A facility's compliance with these requirements should be assessed as part of a facility's on-going accreditation. If necessary, randomly selected records of residents should be audited to assess whether the Advance Care Directive was obtained and kept current and whether the end-of-life care provided complied with the Directive.

## 5.4 IMPROVE REGULATION AND RECORDING OF TERMINAL SEDATION

Sheila McLean, an Emeritus Professor of Law and Ethics in Medicine, writes:

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.<sup>117</sup>

This is confirmed by Professor Lindy Willmott from the Faculty of Law at QUT who specialises in this area. Professor Willmott writes:

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>118</sup>

Nor is there any record of how often, or in what circumstances, it is used – or denied – as the Victorian inquiry found:

Its use is not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it.<sup>119</sup>

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<sup>117</sup> McLean, Sheila, "Terminal Sedation - Good Medicine? Good Ethics? Good Law?" 2016. *Queensland University of Technology Law Review*, 16(1), pp. 113-24, p. 116, quoting David Orentlicher, "Principle and Practice for Palliative Sedation: Gaps Between the Two" in Sigrid Sterckx, Kasper Raus and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press, 2013) 116, 122.

<sup>118</sup> Lindy Willmott, "Question re Victorian Law on Palliative Sedation", email to Andrew Denton, Go Gentle Australia, 24 July 2017.

<sup>119</sup> Victoria. Parliament. Legislative Council. Legal and Social Issues Committee and O'Donohue, Edward *Inquiry into end of life choices: final report*. [Melbourne, Victoria] Victorian Government Printer, 2016, p. xvi.

We believe that guidelines should be developed to regulate the use of terminal sedation. This will provide a standard by which doctors' actions can be measured, and against which complaints of poor, or abusive, treatment can be made.

## **We also believe that reporting of the use of terminal sedation in hospitals, hospices, and aged care facilities should be made mandatory.**

Such reporting should include the circumstances in which terminal sedation was used; the rate at which it was employed; and a formal record of any request by the dying person, their family, or their carer for terminal sedation to be used in order to end suffering. This will enable a clear picture to develop of either over- or under-use of the practice in particular institutions.

However, we believe that this reporting scheme should be designed and implemented in a way that makes it clear that the scheme's purpose is to understand the use of terminal sedation, and not to reduce its use.

### **5.5 IMPROVE DATA ON PALLIATIVE CARE IN AGED CARE**

Patient outcome data is collected on palliative care, but not in aged care settings. We support the extension of this data collection to aged care, but note that it appears to have some important limitations.

The Palliative Care Outcomes Collaboration (PCOC) is a national palliative care project funded by the Australian Government Department of Health. It reports on patient outcomes in palliative care. Palliative care services working with the program agree to use a data set established by PCOC and this data is analysed and reported every six months. The PCOC describes the purpose of benchmarking as being to drive improvement and palliative care service innovation.<sup>120</sup>

Palliative care services participate in the PCOC project on a voluntary basis. The most recent report relates to information from January to June 2018, gathered from 129 services who provide palliative care in hospital / hospice or in the person's home and who were then participating in PCOC.<sup>121</sup>

PCOC does not currently collect data on palliative care in aged care. Having received funding through to 2020, PCOC aims to broaden its scope in collecting information on patients receiving palliative and end-of-life care in settings other than specialist palliative care and within different subgroups, including in aged care.<sup>122</sup>

The PCOC assessment tools collect data from patients and families or carers (as well as physicians) on the level of distress being experienced from specified symptoms on a scale of one to 10. It appears that only clinicians are able to provide ratings on the 'Palliative Care Problem Severity Score'.

The Clinical Manual states:

The Palliative Care Problem Severity Score (PCPSS) is recommended as a clinical tool which can be used for initial screening and ongoing coordination of specialist palliative care. Clinician rated, it facilitates the global assessment of four palliative care domains: pain, psychological/spiritual, other symptoms and family/carer. The family/carer domain measures problems associated with a patient's condition or palliative care needs ...<sup>123</sup> [Emphasis added; references omitted.]

If PCOC is extended to aged care, and sufficient aged care services agree to participate in it, the process of collecting the data on levels of distress being experienced from specified symptoms seems likely to

<sup>120</sup> Palliative Care Outcomes Collaboration. *Patient Outcomes in Palliative Care in Australia: National report for January - June 2018*, September 2018, p. 1 <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow252855.pdf> (accessed 11 March 2019).

<sup>121</sup> Palliative Care Outcomes Collaboration. *Patient Outcomes in Palliative Care in Australia: National report for January - June 2018*, September 2018, p. 1 <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow252855.pdf> (accessed 11 March 2019).

<sup>122</sup> Palliative Care Outcomes Collaboration. *PCOC 2017 Annual Report*, 2017, p. 11 <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow249343.pdf> (accessed 11 March 2019).

<sup>123</sup> Palliative Care Outcomes Collaboration. *Clinical manual*, April 2018, p. 33 <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf> (accessed 11 March 2019).

improve awareness of these symptoms and the degree to which a resident is suffering from them. Over time, reviewing benchmarked data should encourage individual services to improve the palliative care they provide.

However, there does not appear to be any measure of the patient's (i.e. the resident's) or substitute decision maker's view, or that of the patient's family or carer, as to whether their wishes are being or were followed or how satisfied they are or were with the palliative care provided, including towards and at end of life.

## 5.6 DISCLOSURE OF RELIGIOUS BELIEFS AND HOW THEY MAY AFFECT END-OF-LIFE CARE

Aged care facilities should be required to make clear, up-front disclosures in all their advertising and promotional material if the religious beliefs of the people who operate the facility may limit or otherwise adversely affect a person's palliative and end-of-life care. Presumably, many if not all facilities operated by religious organisations already promote what they see as the beneficial effects of those religious beliefs on the care provided. Limitations or adverse effects should also be made clear.

The introduction of Voluntary Assisted Dying rights in Victoria has clearly raised the need for disclosure.

On the day the Victorian legislation completed passage through Parliament in November 2017, the Archbishop of Melbourne released a statement, which included the following:

Catholic health and aged care providers will continue to accompany those who face death, always striving to provide the best care to them and their loved ones. Assisted suicide and euthanasia are not part of their practice and are incompatible with the provision of quality palliative care.<sup>124</sup>

Victoria's largest palliative care provider, St Vincent's Health, independently ruled out involvement in Voluntary Assisted Dying.<sup>125</sup>

Catholic Health Australia's Chief Executive Officer, Ms Suzanne Greenwood, was reported as saying:

For Catholic palliative care providers, VAD [Voluntary Assisted Dying] is not a part of our practice and is not something that we can assist any person within their home, in our residential aged care facilities, or in our hospitals.

For those who may choose to access VAD, we would explore the reasons for that but will not be changing the way in which Catholic services currently deliver compassionate palliative and end of life care; we will continue to optimise quality of life and support people and their families.

...

For those people who may choose to access VAD, we would explore the reasons for that request, however we would not assist in any way.

Catholic providers of health and aged care services will seek to ensure that staff and volunteers receive counselling and support required if a person they have been caring for makes such an irreversible decision to access VAD.<sup>126</sup>

The Western Australian inquiry heard evidence from representatives of Catholic Health Australia, Catholic Homes, Catholic Homes WA and St John of God Health Care about how Catholic health and aged care services would respond if Voluntary Assisting Dying was introduced in Western Australia.

In summary, Catholic hospitals would seek to exercise conscientious objection rights. They would not allow clinicians to undertake Voluntary Assisted Dying in Catholic hospitals. If patients in Catholic

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<sup>124</sup> A Statement from the Archbishop of Melbourne, Denis Hart, on Euthanasia and Assisted Suicide in Victoria, 29 November 2017 <http://cathnews.com/media-releases/media-releases-2017/1126-171129-melb-arch-statement-from-the-archbishop-of-melbourne-denis-hart-on-euthanasia-and-assisted-suicide-in-victoria/file> (accessed 11 March 2019).

<sup>125</sup> Samantha Hutchinson, "Euthanasia legal in Victoria from 2019, but Catholics refuse to participate", *The Australian*, 30 November 2017 <https://www.theaustralian.com.au/national-affairs/health/euthanasia-legal-in-victoria-from-2019-but-catholics-refuse-to-participate/news-story/f6fc5964b0b1e572bbf14f06d055167f> (accessed 11 March 2019).

<sup>126</sup> Aged Care Guide, "Religious providers won't facilitate assisted dying", 19 December 2017, <https://www.agedcareguide.com.au/talking-aged-care/religious-providers-wont-facilitate-assisted-dying>, (accessed 11 March 2019).

hospitals wished to exercise a right to assisted dying, they would have to go to another institution, although they acknowledge that sometimes people may be too unwell to move. This approach would apply to public and private patients.<sup>127</sup>

They gave evidence that there are a number of services that Catholic hospitals do not currently provide, namely IVF, pregnancy termination and sterilisation procedures. If a patient has to transfer from a Catholic public hospital, the hospital would assist them to be comfortably transferred. However, unlike the position with end-of-life care, patients seeking the services they currently do not provide are usually physically well; they are more likely to be discharged from the Catholic hospital and would then make their own arrangements.<sup>128</sup>

In answer to the Chair's question whether potential residents and patients are fully informed of the restrictions before entering into a care home or hospital, the representative of Catholic Homes WA told the Committee:

Catholic Homes does not have any restrictions really. Some of the restrictions that the hospitals have are not relevant to aged care, such as contraception. Other than that, we do not have any restrictions that we need to notify anyone of.<sup>129</sup>

The Chief Executive Officer of Catholic Health Australia added:

Not to cut you off there, but if I could just offer: we have what we call our "Code of Ethical Standards for Catholic Health and Aged Care Services in Australia". That is a document that is available on our website – [cha.org.au](http://cha.org.au). It does outline our position on those kinds of matters. It is a publicly available document and freely available.<sup>130</sup>

We note that the Code is some 100 pages in length, although this is not all text, and the main content of the Code is covered in some 68 pages.

We do not think such a lengthy and detailed document would serve the purpose we have in mind here. The issue is that potential residents and their families or carers must have highlighted to them any services relevant to aged care that a facility will not provide. Obviously, this should include the right to Voluntary Assisted Dying in any state or territory where this is available and the facility will not permit it to occur within the facility.

We think it should also make clear any reluctance to provide the full range of pain medication, including sedation and terminal sedation.

People will not always be able to anticipate what pain and suffering they will experience towards the end of their lives when they enter an aged care facility. If the beliefs of those who operate the facility might limit their palliative and end-of-life care options – for example, by providing sedation to unconsciousness reluctantly and only for short periods of time after which the resident will be woken up again – those looking for a residential aged care facility should be given this information so that they can take it into account if it is important to them.

We also consider that if the religious beliefs of those who operate an aged care facility limit the adequacy of a resident's palliative or end-of-life care, the facility should be required to take steps to enable effective palliative or end-of-life care if the resident or their family, carer or substitute decision maker wants this care to be provided, at least in circumstances where it would be difficult for them to make the necessary arrangements themselves.

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<sup>127</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Mr John Fogarty, Executive Director, St John of God Health Care, and Dr Alison Parr, Director Medical Services, St John of God Health Care; Palliative Medicine Consultant, 28 February 2018, pp 10-1.

<sup>128</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Mr John Fogarty, Executive Director, St John of God Health Care, 28 February 2018, p 11.

<sup>129</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA, 28 February 2018, p 11.

<sup>130</sup> Parliament of Western Australia, Joint Select Committee on End of Life Choices, Transcript of Mrs Suzanne Greenwood, Chief Executive, Catholic Health Australia, 28 February 2018, p 11.

This obligation might require an aged care service to facilitate access to its residential aged care facility for doctors who do not object to providing the necessary care, or to facilitate the transfer of a resident to another facility that does not oppose the provision of the necessary care.

This obligation is particularly important if the resident does not have the benefit of support from a sufficiently healthy, knowledgeable and well-resourced family member, carer or substitute decision maker to make alternative arrangements to obtain the necessary care themselves.

If a person resides in an aged care facility and is receiving palliative care, they are likely to be very dependent on the facility for the arrangement and provision of their care unless they have fairly regular contact and support from a family member or carer. If the facility will not arrange the necessary care, the reality is that they will not receive the care they want and need.

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## ANNEXURE 1

# Go Gentle Australia's philosophy

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

In the face of evidence released in the Parliament of Victoria's Inquiry into End of Life Choices (2016) which documents the suffering, trauma, and harm being inflicted on the community by our existing laws around Voluntary Assisted Dying – evidence supported by hundreds of personal testimonials we have gathered from across Australia – our early focus is on bringing about change to these laws.

This is to:

- Palliate and empower those who are suffering with greater choices
- Reduce the suicide rate among elderly Australians faced with chronic and irreversible illnesses
- Provide options within palliative care when, despite their best efforts, it is no longer possible to relieve all suffering
- Remove the current legal uncertainty which has led to many documented cases of inadequate pain relief being delivered to patients as they suffer
- Create a law that protects – and gives clarity and guidance to – doctors and nurses faced with human suffering that is beyond meaningful medical treatment
- Relieve the suffering of families and carers forced to endure the traumatic and painful deaths of their loved ones.

Go Gentle Australia does not argue for a 'right to die'.

We see death not as a right, but as a fact at the end of life.

What we do argue for is a right to have a choice about what happens to us at the end of our lives and not to be coerced, when we are at our most vulnerable, into cruel and avoidable suffering.

We argue for the right of all Australians not to have that choice dictated to them by the ethics, morals, or religious beliefs of another.

We respect the beliefs of all those who find the idea of assisting a suffering person to die to be morally or ethically unacceptable. We also accept their right not to participate in, or support, Voluntary Assisted Dying if it conflicts with those beliefs.

We ask, in return, that they accept the rights of other Australians, who may not share their beliefs, to seek a death that fully reflects the person they have been and the life they have lived – not just in their own eyes, but in the eyes of those who love and care for them.

Although we see Voluntary Assisted Dying as being essential to our choices, Go Gentle Australia understands that it is just one on a spectrum Australians should be aware of.

These include:

### **1. Palliative Care**

We strongly support the need for good palliative care within the Australian community, both in hospitals and at home. In providing dying individuals and their families with holistic support, good nursing, and pain control, palliative care provides an essential service for many Australians at the end of life.

We do not argue that Voluntary Assisted Dying is a substitute for good palliative care. However, Palliative Care Australia acknowledges that they “cannot relieve all suffering at the end of life, even with optimal care”. This acknowledgement was supported by evidence presented to the Parliament of Victoria’s Inquiry into End of Life Choices. In light of this, we do argue that Voluntary Assisted Dying should be available as a choice for those patients whose suffering they cannot relieve.

The aims of palliative care – to alleviate suffering and to make possible a ‘good death’, both for the dying and their families – are also the aims of Go Gentle Australia.

### **2. Advance Care Directives**

Regardless of whether or not they may ultimately seek Voluntary Assisted Dying, all Australians should be aware of what Advance Care Directives are and how they can work to support their wishes at the end of life. They are important, also, because in requiring the appointment of an enduring guardian or substitute decision maker, they begin a discussion within families about the often-avoided subject of dying.

### **3. Refusal and Withdrawal of Treatment**

Even should they qualify under a law, not all Australians who are eligible will seek the option of Voluntary Assisted Dying. It is important that people have a good understanding of their rights under the law, to either refuse, or request withdrawal of, medical treatment as a means of hastening their death. An important part of this is also understanding the obligations of medical professionals to respect and support them in their wishes.

Go Gentle Australia is also about a better conversation in Australia around dying and death. This includes among doctors and nurses as well as patients, their families and carers.

We are working with professionals across all sectors of our community – palliative care workers, nursing unions, individual doctors and their representative groups, cancer support organisations, representatives of the disability community, elderly support groups, Dying With Dignity organisations, political representatives from all parties, legal experts, as well as individuals who are suffering and their families – to shed more light on a subject that, even within the medical community, often remains taboo.

In encouraging all these groups to talk more, not just among themselves but also to each other, we aim to educate Australians about how to approach a ‘good death’ and, in so doing, reduce harm and suffering across our community.

Go Gentle Australia’s work in this area will be supported by information on – and links to – good palliative care, appropriate advance care directives, and supportive organisations and resources.

Every single one of us faces eventual death.

We are all in this together.

We can help each other to go gently.

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## ANNEXURE 2

# Audrey's story, told by her daughter Carol

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Carol's mother, Audrey, was a well-educated woman who adored classical music and the fine arts. Her house was full of books, the works of Shakespeare and Tennyson and other writers who knew how to transport or transform a reader with language. She was a qualified teacher who lived in many countries before settling in Australia in the 1960s. Audrey was a proud and dignified woman who went to the hairdresser once a week to have her hair set and was always immaculately presented. She was a mother of two and grandmother.

Audrey was alone when her house was demolished during Cyclone Tracy. Once she was evacuated to her daughter and son-in-law's house the family discussed their wishes about end-of-life care. During these debates Audrey and her then husband (a medical practitioner) said they did not want to be kept alive if they developed a terminal illness or any condition which deprived them from living independently or with dignity. After Audrey's divorce her daughter assumed the role of next-of-kin and eventually guardian. Audrey lived for another 35 years although in the 90s she had been diagnosed with severe dystonia of the tongue (probably neuroacanthocytosis). She found her inability to communicate clearly especially distressing. Despite this she continued to teach children with learning difficulties and those who spoke English as a second language until 2005, when her failing health and speech meant she had an increased need for family and care-giver support. This was provided in Audrey's home in accordance to her wishes.

Audrey lived independently until early 2006 when at the age of 80 she contracted an intractable UTI and found it increasingly difficult to swallow, eat and speak. Suffering from the UTI, sepsis, dehydration and malnutrition, Audrey was admitted to a tertiary hospital for treatment and to have what was supposed to be the insertion of a temporary PEG feeding tube to help her regain some weight. She was reassured by the multi-disciplinary team that with intensive therapy she would probably "go home" to live independently and so she gave informed consent to the procedure believing that it would be a temporary measure. It was a simple procedure and seemed to go well – but on her first post-operative night the medical staff called Carol to advise that her mother was bleeding internally and was not expected to live until morning. The registrar acknowledged the Do Not Resuscitate in her hospital paperwork. Family members who lived interstate and overseas flew home. In consultation with Carol and accordance with her wish first expressed in 1974 Audrey was given small amounts of morphine to keep her "comfortable". The next day Audrey was still alive and after significant pressure from Carol it was determined that her laboratory results had been incorrectly reported. This information was not relayed to the entire medical team. This meant that Audrey was not expected to die in the immediate future but for more than four days she was not fed, toileted, mobilised or taken off her morphine. By the time her care deficits were corrected, it was too late: the temporary PEG tube was now permanent, she was now incontinent, she could barely swallow, her speech was even more limited and she could only walk with close supervision and with the aid of a Zimmer frame.

Audrey couldn't go home so she was sent to a rehabilitation nursing home in the hope that she might recover enough to live independently again but this was not possible. Furthermore, the dystonia had been exacerbated. It was clear that Audrey needed full time care and much against her wishes she consented to moving to an aged care residence.

Carol found her mum in an aged care facility in Perth. It was a religious institution with excellent facilities and caring staff. Audrey (unlike most residents) was not significantly cognitively impaired. She did not share the facility's 'faith', and this was documented in her records. Carol was informed about the facility's dietary prohibitions etc but there was no discussion about Audrey's end-of-life care or her wishes. The facility provided expert care and mostly treated Audrey with kindness – but the staff were unable or unwilling to respect her wishes in one crucial way.

As Audrey's health declined she began to ask that she be allowed to die. She wanted her PEG feeding tube removed to hasten her death. Audrey said she couldn't walk unaided, drink, eat, swallow or toilet herself, and could barely speak so many staff could not understand her. She was unable to read her beloved books as her cataracts were deemed inoperable because of her tremors. Most of all, the indignity of having to lie in a faeces-filled "smelly" nappy until a staff member was available to clean her up was more than this fiercely independent woman could bear. For her, life was no longer worth living and she said so – frequently. She was informed by staff (not her GP) that it was her legal right to refuse food and water but the staff (institution) would probably not accede to her wishes. At no stage did her GP choose to discuss her end-of-life wishes with her even though she could understand these complexities. Following intervention by her daughter, instead of removing her feeding tube to honour her request the GP ordered additional antipsychotic and antidepressant medications. This meant that Audrey's ability to communicate became even more difficult. Carol became increasingly distressed by her mother's situation and tried to advocate for her mother's wishes to be respected. She grew concerned that staff in the home might think she was the one pushing for her mother to die and so Carol requested the facility arrange for a psychiatric assessment of Audrey, to determine if she was capable of making an informed request to have her PEG tube removed and to confirm that was what she wanted.

The facility arranged for a specialist in geriatric psychiatry to visit Audrey. The first question he asked her was "What is it that you want, Audrey?" Audrey replied, "Just shoot me, take the PEG tube out, I want to die". Carol then chose to leave the room. After he had finished, the psychiatrist informed Carol that Audrey was able to understand him and said she wanted to die and the PEG tube removed so she would die. She understood that this would not be an easy or quick process. The psychiatrist estimated that Audrey would die within 6–8 weeks even if she was still fed by the PEG tube. The psychiatrist told Carol how painful and slow dying by starvation would be for her mother. Instead of recommending the feeding tube be removed he increased her antipsychotic and antidepressant medications. (Carol would later discover this man was deeply religious and opposed to assisted dying in all forms. It is unclear whether his personal views influenced his professional recommendation.) The increased dosage meant that Audrey shifted in and out of consciousness and she was no longer capable of making requests about her care. Even when she was awake and lucid the staff couldn't understand her speech.

As Carol put it:

***“She was so heavily sedated she couldn't really ask anymore – increasing her sedation so much was tantamount to slowly killing her, but that wasn't the point – the doctors were very careful to keep her semi-conscious and quiet but not sedated enough to bring about death.***

***The treatment regime aimed to keep her from asking these rather difficult questions because it really upset some of the doctors and nurses in the nursing home. So, it kept everybody quiet including her. That was the idea.”***

Despite Audrey's prognosis, the GP contracted by the nursing home refused to provide her with any other palliative sedation such as morphine. He was a kindly man but, oddly for a doctor working in an aged care facility, had very little experience dealing with end of life choices including palliative sedation. (When Audrey finally died, hers was the first autopsy and cremation certificates he had signed.) The GP had never administered terminal sedation and was reluctant to administer morphine because he feared on autopsy it would be discovered she had been given narcotics and that he would face legal consequences with AHPRA because, as he put it to Carol, your mother is not in "agony" and does not have "terminal cancer". Carol continued to try to convince him that terminal sedation should begin. The GP appeared reluctant to engage in any discussion about Audrey's impending death and any communication tended to occur in the corridor. Carol commented:

*They didn't think about the mental and emotional pain that she was going through – she knew exactly what was happening, that her body was failing, and how undignified it was for her. They couldn't accept that the pain for my mother wasn't necessarily physical, but it was very real. They didn't understand how terribly distressing it was that she had to wear a nappy and sometimes not wear knickers (because it was quicker to change her).*

*In less than six months she'd gone from this very proud, dignified, well-dressed woman, to having her body exposed to strangers and being unable to communicate her needs because her tongue protruded and moved uncontrollably.*

Finally, just under a week after first being given palliative sedation with morphine – thanks to Carol's dogged persistence – Audrey died aged 81 years. A peaceful ending to what had been a most undignified (for Audrey) and unnecessarily prolonged experience.

Carol feels there are three things that need to change when it comes to end-of-life care in nursing homes: the first is that there should not be a circumstance where an institution funded or partially funded by the Commonwealth is able to override patients'/residents' rights and beliefs because of the institution's and their employees' faith and belief systems. These beliefs, especially concerning end-of-life decisions, should be clarified before the resident is admitted to the institution. If there is conflict about the prospective resident's faith, needs and wishes, the resident should not be admitted to the institution.

The second is that management and medical and nursing staff employed by nursing homes must be educated about evidence-based practice concerning end-of-life decisions and remain up-to-date about legal processes around assisted dying, palliative care and palliative sedation, so that people aren't denied treatment because of a clinician's religious faith, values or lack of current knowledge or fear of professional sanction. Medical and nursing staff employed in aged care facilities should be expected to undertake educational programs and competency-based assessments, as are hospital staff, to ensure they are competent to provide evidence-based medical and nursing care for people at the end of their lives.

And third, that it should be recognised that pain isn't necessarily physical – that mental, emotional and spiritual modes of suffering can be just as real and unbearable to a human being.

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## ANNEXURE 3

# Murray's story, told by his widow Dawn

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Dawn's husband Murray loved cars. He loved cars so much that over the course of their marriage they owned 53 in total. Some he'd have for just three weeks before they found a new home, others were vintage English models that he spent months lovingly restoring.

Murray also loved motorbikes. And trains. He sometimes entered train layout competitions, putting his creative and technical skills on display through carefully arranged tracks and bridges and switches and crossings. Murray loved jazz, his family and his job as an electrical design draftsman. He was interested in and enthusiastic about every topic that crossed his radar and was the kind of person who always put his hand up to volunteer on the school committee or a community group. Murray lived a full life.

At the age of 58, Murray was diagnosed with early-onset Parkinson's. A tremor in his hand was the first noticeable sign, but as the disease progressed he began to experience the hallmark symptoms of Lewy-body dementia, which is commonly associated with the condition, though nobody would diagnose it for some time. Murray began to exhibit strange behaviours and occasionally had violent outbursts. It got to the stage that he wasn't safe at home so, in 2006 at the age of 65, Murray moved into the Sandpiper Lodge Nursing Home in Goolwa. He was there for eight years as his body and mind succumbed further to the disease.

On a few occasions when Murray became "too much to handle" for staff at the nursing home, he was sent to the geriatric ward at the Repatriation General Hospital in Adelaide, where Dawn says the treatment was superb. It was there that he was diagnosed with Lewy-body dementia, which Dawn felt was a huge relief and explained much of Murray's behaviour over the previous years. The hospital had wonderfully caring staff and volunteers, but Murray could not stay there indefinitely. He would always have to be returned to the nursing home, where Dawn felt the standard of care was unfortunately "second rate". She often got the impression that the staff put on a "caring face" but didn't always follow through.

Towards the end, Murray wasn't eating well. He had always been a well-built man, but had become little more than skin and bones. Dawn had difficulty getting there at meal times during the weekdays so asked the staff to make sure he was fed – they said they would try but staff shortages limited much extra help. And as Murray wasted away, it was clear he wasn't eating enough to sustain himself.

Towards the end of his life, Murray was often placed into a Princess Chair, and left there all day. Dawn felt it was a way of restraining someone without actually tying them down – the chair was designed in such a way that, once a person was reclining in it, they would not have the strength to pull themselves out of it on their own. It soon became clear staff were not moving Murray around very much. He had developed terrible bedsores that had no hope of healing. He lost the ability to speak. He was skeletal. It was clear he was fading away, but a palliative care service was not engaged to see him through to the end. Nobody, it seemed, was especially concerned with making sure Murray's dying was handled compassionately. The attitude – whether deliberate or not – seemed to be "just sit down, and shut up, and die – get on with it".

Dawn could see Murray's pain wasn't being managed properly, that he was suffering. For

weeks, he had been on a very low dose of painkiller and she asked the nursing staff to increase the amount. They were hesitant to do so and needed to be pushed and coerced into phoning the doctors for approval.

*I don't know whether it was a legal thing, or fear of getting into a bother, but he went through several weeks of really very little painkiller, until I said 'Look you've got to do something, he's in a lot of discomfort here. You can't let this go on'. So they gave him some morphine but it could only be administered by a doctor. They were very hesitant to increase it and I had to get quite determined, and one particular RN was very anti-doing it. Whether that was her own religious tendency against it or what, I don't know. But I had to go over her head a bit, and speak to the doctors directly.*

And eventually, they upped the morphine and administered it through a driver. Murray was tough, he had a strong heart. It was another five days before he died, on 29 December 2014, at the age of 73. Dawn was barely ten minutes down the road, having just left after sitting by his side all of that day, when she was called back to the home.

*The doctor hadn't been yet, but the room had been rearranged and there was subdued lighting. I sat there with him for quite some time and the peace was deafening. I had never experienced anything like it. I will never understand why he had to suffer for those last few weeks.*

*I now have a huge fear that I may have to suffer that pain and indignity at the end of my life. There must be a better way.*

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## ANNEXURE 4

# Margaret's story, told by Ann\*

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My mother was diagnosed with lung cancer at the age of 90. They found it while doing routine tests. She refused all further tests and treatment despite being so phenomenally healthy and fit that a surgeon was keen to operate, claiming she seemed more like eighty than ninety. She thought long and hard about the recovery time of surgery and the complications of chemo and radiation and decided against it. She lasted more than two years and, until the final eight weeks of her life, was largely symptom free. She had in fact sat and passed her drivers licence one week before she was admitted to Goulburn Base Hospital on 27 October with hypoxia and a blood oxygen reading of 89.

Her specialist was surprised that she had been experiencing signs of mental confusion and the speed with which the disease was advancing. They put her on oxygen and started the opiates. As she began to breathe more easily, her mental function returned. The specialist also convinced Mum to have a Cat scan which is how he discovered that the cancer had spread to an advanced stage into her liver and bones. I did not see the scans but was told that these sites showed multiple metastasizes. He gave her a prognosis of three weeks and advised us that my brother and I would not be able to care for her at home because it would take too long for us to set up the services to which she was entitled, in theory, as a war widow, and that she needed to go into hospice or stay in hospital.

Goulburn Hospital was grim. The food was slops and they had put her at the end of a long corridor in the geriatric ward which looked out onto a brick wall. She told her doctor that she didn't want to die in that room and, when he asked her why, she pointed to the brick wall and said "it's the outlook". She asked to be referred to a palliative care hospice in Canberra which she knew about through a friend. The doctor found her a bed there remarkably quickly. I knew nothing about the hospice, but it was our understanding that she was being admitted for end-of-life care.

Mum arrived at the hospice by ambulance on 1 November and my brother and I followed by car. I was impressed by the contrast to Goulburn Hospital. Her room was freshly painted and had a generous bathroom. Large sliding windows looked out onto a terrace and beyond that the Molonglo River where it turns into the lake. The food, while bland, was edible.

I spoke with the doctors that first day. At that stage they appeared to agree with her specialist's prognosis, or that is how I interpreted their pained faces and nods when I asked questions. There were no direct statements. They were not forthcoming nor at any stage did they invite my observations, rather their body language actively discouraged my involvement. Even the most basic and least invasive of tests such as blood oxygen were eschewed in favour of what they called clinical observation, which they based on the daily rounds and the opinion of the nurses as they rushed in and out without pause. The doctors were a study in remoteness, experts in dying, or like priests with absolute authority. Because although Catholicism was never mentioned its influence was everywhere: through its hierarchical model and down to the very tolerance to alcohol and provision of an indoor atrium where patients could smoke. I liked that tolerance but it made me think that the body was somehow insignificant.

Mum was relieved to be there and her appetite and mood improved in the first few days although she was highly anxious. She was terrified of death, an imagined experience

which she had once compared to the claustrophobia she suffered from and had managed untreated through avoidance and being incredibly busy. She set up her table as her command centre ordering essentials such as her mobile phone, books, tv remote (used exclusively for News 24) and her note book within easy reach. She wrote endless lists of jobs that needed doing around her house, which were passed on as instructions to my brother and myself, and kept details on her medications to the irritation of the doctors and nurses.

She had a horror of being alone in the afternoons and the nights and for the first nine days by brother and I alternated sleeping with her in her room. And those long nights with three night nurses on duty and the bells going off were a lesson in staffing shortages.

Palliative care might talk about helping people cope with something it calls “existential” anxiety but in my experience those claims are meaningless. All they offered was a sequence of anti-anxiety and antipsychotic drugs which either did not work or to which she reacted badly, inducing insomnia and causing shaking, not observed by the nurses, it needs to be said, but by me.

There were a number of medical stuff ups such as her severe constipation which made her extremely ill from the opiates and prescribing the antinausea drug Maxolon, to which, as she and I had both reported, Mum was allergic, a fact which ought to have been on her notes. Questions put to the RN and the Director about what happened there were never answered and I scrawled allergic to Maxalon on her white board in red pen.

The nurses seemed a little thrown by mother’s mental agility and it was only after a few days of being there day and night that I began to notice that the majority of patients were in the active dying phase. She was no doubt an unusual case. Despite the bone cancer she was never in severe pain. She was bedridden and needed help washing and going to the toilet but I don’t think they knew what to make of a patient who was reading a biography of William Dampier, following the Vanuatu referendum and doing the cryptic crossword, at least for the first week. She did not conform to their check list of dying. I think now that her engagement with the world must have created the false impression in their minds that she was not really dying and am reminded of a comment made by a nurse that they had been startled to see her trying to get off the trolley and walk in that first day. The meaning of that remark began to nag at me by day four when the pastoral care worker dropped the concept of discharge to a nursing home into the conversation. “Oh, don’t worry,” she said smiling brightly. “It’s for the bean counters. There are ways of delaying the process”.

It was when the social worker raised discharge again several days later and I was told that there was a timeframe of 31 days for dying that I really got upset. I was told that it was about “equity and access” as if that superseded their duty of care to my slowly dying mother. The social worker made me feel as if my Mum had somehow slipped through the system and was hogging a bed.

The decision that my mother had become incontinent and was put in nappies sowed further doubt about the quality of care. I had been a witness to so many occasions of her ringing the bell in order to be helped by two nurses to the toilet (a not insignificant burden given the quota of four day nurses to 19 beds) and waiting ten to fifteen minutes. I knew, too, that on another occasion when they were busy, my daughter had been on the point of pulling down Mum’s pants and attempting to take her to the toilet at my mother’s request. I lost my temper and was forced into two meetings with the RN and the pastoral care worker who lectured me on respecting my mother’s dignity.

Of course, I was not privy to my mother’s conversations with the nurses and do know that she was a pragmatic person who might well have sized up the situation and minimised any fuss. She had worked as a hospital social worker for many years; knew how the system

worked. She knew it was vital to her peace of mind to be if not be completely compliant then to pick her fights.

*It is hard, though, to describe the effect of those 'conversations' I had with staff. Anything that worried their claims of expert care was deflected with kindly comments about my exhaustion skewing my perception. It was simply a matter of their being right and my being wrong. I wasted so much energy in pointless argument.*

The issue of her continence also raised questions about whether she was in fact deteriorating because you can't have it both ways. You can't be both stable and losing bodily control. I insisted on yet another meeting with one of the doctors and the head of nursing where all requests to understand their processes or see their guidelines for admission and discharge were artfully ignored. I did, however, make my mother's wishes about not going into a nursing home very clear for the record and said that if needs be my brother and I would care for her at home. A discussion was also had about her advance care directive and her request for "sufficient medication to control pain and/or anxiety when at the terminal stage of illness, even if this hastens my death". I also repeated to them a recent conversation with my mother on how she wished to die and her saying that she wanted "to drift away" and not be conscious. The doctor had nodded knowingly, which I took to mean that palliative sedation was an acceptable practice there.

Nothing changed for the better. It was around this time that the doctors and nurses started claiming that Mum was there to stabilise her symptoms. To remind myself of the evidence that she was in fact dying, I rang her specialist and told him about the talk of discharge. "But they have seen the scans," he said. I was on edge, constantly worrying that they would broach the subject of discharge with my mother which indeed they did the following week when I briefly returned to Melbourne.

My mother was extremely upset when I rang her, telling me that the doctor that day had mentioned discharge. I brought that up with the Director in their so-called 'family meeting' the following day in which I participated by phone. "Oh no nothing of the sort had happened", I was told. My mother "had said she felt much better and had raised her desire to go home". Mum had made her wishes to die in the hospice fully known. She was admitted there with end-stage cancer to die. She knew she was dying. Even when I had sentimentally raised the possibility of taking her home she had abruptly put an end to the conversation with "that's not going to happen". I mean, what was there to say to these people? That meeting was a painful exercise in being told what to think.

By the time I returned to Canberra in week three, Mum was visibly deteriorating. Her appetite was greatly reduced, although for my benefit she was putting that down to the dullness of the food. She looked jaundiced and had lost significant weight. Her ability to concentrate on reading and the crossword was failing, although she kept News 24 on with the sound off, reading the subtitles. But all attempts to communicate this was ignored and the doctors and the nurses kept up their patter about stabilising symptoms.

Over time, the atmosphere of that place became more and more oppressive. In the four weeks I spent there, the turnover of patients was startling but the only evidence of death or discharge was the changing family faces or the little groups you would see huddled outside privately crying. According to the ACT inquiry, the average stay is 11 days but my reckoning in the period I was there it was more like 3–5 days. It appeared to me that they were only admitting people in the very last days of life and that by then they were too ill to notice the lovely views or enjoy the slightly better food. Those final days were brutal though. Family members told me again and again that their loved ones simply wanted to die. Looking back,

I cannot see the point of moving people at that stage of their lives at all, because it is not as if the medical care was superior to a hospital or even a nursing home, whatever the claims. I also wonder why so many people in terrible a pain were conscious enough to plead for death.

It was the silence about the deaths I found unsettling, more so because of the claims made by Palliative Care Australia that we lay people are disconnected from death with its unstated implication that death is best managed by the experts. And you never heard people weeping or remonstrating. There were no goodbyes with people with whom one had forged relationships, however superficial, through those long days and nights taking a break from their vigils. They just disappeared. It was a culture which you picked up on and imagined one should model. A good death is a quiet one. The place felt like a cult.

My mother told me to go home to Melbourne on the Monday of the week she died. She was a formidable character. I was exhausted. I was out of fight. "There will be no death bed scene" she said bluntly because she and I both thought she would be sedated. The doctors at least were now acknowledging her deterioration and that really was the worst of it: to recall the relief I felt that she was safe is hard. But they still refused to give a prognosis claiming that it might take weeks, which I sensed could not be true. I had touched her icy feet and hands on the day I left and could feel her temperature had dropped and knew she was passing into what they call the active dying stage. I wanted to go home and fell back on the excuse of their expertise (despite not trusting them) because it brought me relief and, in the end, it was my call and I cannot blame them for that. But they promised to ring me if she faded further and they never did.

My brother rang me Friday morning 30 November, 36 or so hours after I had left, telling me if I wanted to see her to come back now. I got there ten minutes before she died conscious, bright yellow, staring hard, as if concentrating very deeply whether on her breathing or the process I don't know, but the look on her face came close to horror. My brother and I each held a hand and kissed her goodbye. Her grip was intense and she tried to talk but we couldn't understand her.

***Later, my brother told me that she had been terrified of being left alone all day. She had also complained of pain half an hour or so before I arrived but when the doctor came in and she couldn't explain where it was had wandered off without doing anything. The doctors were pointlessly hovering by the door when I arrived. Why hadn't they increased the morphine so she was free of anxiety on the day she died? Or topped it up twenty minutes before her death to alleviate her physical pain?***

***Instead, she died frightened, conscious and in pain against her stated wishes.***

I left the room for five or so minutes as I was told to do and when I came back the nurses had laid her flat and had placed a flower between her hands. I found that particularly upsetting as if I hadn't already been a witness to my mother's distressing end and they could expunge that memory with the flower. I stayed there as long as I could before my brother, sensing that we had out-stayed our welcome, started packing up all of her belongings and we left. She had been dead for less than half an hour. It was a Friday afternoon around three and nobody except the nurses offered any form of condolence then or since, such is the fallacy of their family centred care.

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## ANNEXURE 5

# Daphne's story, told by her daughter Carol

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Daphne Maxine Mills was the kind of woman movies are made about. In the 1950s, she was the first female racing driver to hit the track at the Claremont Speedway in Perth. She drove one of the first school buses in Mandurah, running the bush kids in and out of town each day. She and her husband owned the local 24 hour taxi service – Daphne drove one of their two taxis, a rare job for women, even back then. In her later years, right into her 80s, Daphne worked in home care, paying home visits to the sick and elderly, cleaning their houses, or taking them on outings to brighten their days. She accompanied her daughter, Carol, on visits to the sick and dying. They'd take food for the family. They'd sing and pray. Afterwards, Daphne would sit and hold the patients' hands, just to be there, to talk and to cry with them, to say nothing if that's what felt right. She had the compassion and sensitivity to sense what people needed. Throughout her long life, Daphne was widely known as a hard worker, an impeccable dresser, and a strong, independent, classy lady. Daphne was the kind of person you never forgot.

Daphne was living independently until her early 90s, when she started having falls and contracted pneumonia. After a brief stint at Peel Health Campus she recovered, but not enough to return to her independent living. Her daughters, Carol and Dawn, found her a place at Coolibah Residential Care, where she stayed for six terrible months.

Dawn had worked for many years in geriatric hospitals and palliative care, and was appalled by what she saw:

***“It was definitely a nightmare for mum. We'd go down there and I'd find her sitting in her own faeces, calling out for help. And I'd have to go and find the staff because they weren't coming. We'd stand on the alert mat around the bed to see if anyone came and no one would. I'd make them clean mum up and ask when they'd last showered her because it didn't seem to happen very often.”***

On one occasion, Daphne needed to go to the toilet in the night. She called for help but no one answered the bell, so she tried to go by herself. She fell, at 2am, onto hard tiles in the bathroom. She was put back into bed with her injuries then at 7am again needed to go to the toilet. And again, no one responded, so Daphne tried herself – with her injuries – and fell a second time. This time the injuries were so serious an ambulance needed to be called to take her to hospital.

A doctor explained that Daphne's injuries – two badly broken shoulders and broken ribs – could not be repaired and meant she would never walk again. She needed to be transferred to a high-care ward, lifted in and out of bed with a hoist, and showered by carers. Most of the carers were male, which made Daphne especially uncomfortable. Daphne found the indignity of soiling herself, and having to wait hours to be cleaned up, so distressing that she would cry. She began to develop continuous kidney and bladder infections because of these delays. Dawn urged the staff to take special care with her mother's skin because she was at high risk of developing bed sores. It did no good. The skin on Daphne's back broke open, and things went rapidly downhill from there. Apparent dementia began to set in, and combined with a negative reaction to the painkillers she was prescribed for her physical pain, Daphne began having terrifying hallucinations that caused her to shout out in

fear. This was a cruel Catch-22: managing Daphne's physical pain meant causing her great mental distress, but withholding pain relief meant she was in agony. No one seemed to be putting much effort into finding a solution. According to Dawn:

*“She certainly never got enough pain relief. I'd tell them mum's in so much pain, and they'd come in and give her a panadol, but she was in extreme pain. Every time they moved her she'd be screaming.”*

Carol says Daphne was always asking to die.

*“Every time I went in there, Mum would pray and say 'ask God to take me, God help me, take me, get me out of here, I'd rather be dead!'. She used to scream – I'd be in the corridor, and she would be screaming that she wanted God to take her. 'I want to die, I can't do this,' and they all heard, they just ignored it because they'd say 'oh she's a bit demented'.*

*But she'd always said she would rather be dead than go into a nursing home. She said that to me several times: 'I'd rather be dead than have to go into one of them'.*”

Dawn and Carol were horrified. They urgently looked for an alternative nursing home for their now 93-year-old mother. Eventually, they found her a bed at the Bethanie Peel Aged Care Home. By the time Daphne was transferred there, she had deteriorated so much that it was evident she had only weeks – possibly just days – left to live. Carol had to return to New South Wales for her own medical treatment and asked the palliative care nurse whether her mother could be helped to die before she left. The nurse said Daphne would be OK until Carol returned. Sadly, she wasn't. Carol received a call in NSW a few days later to advise her mother was dying. She was devastated, and remains intensely sad and angry to have been robbed of the opportunity to support her mother while she died and say goodbye.

Meanwhile, Dawn was so distressed by her mother's condition that she lay in the bed beside Daphne for her final few days, traumatised to hear the 'death rattles' as her breathing became more and more laboured, until finally – after much futile pleading with the palliative care nurse to 'stop this' – Daphne died.

Both daughters find the memory of their mother's end-of-life experience unnecessarily painful and traumatic. For Carol, this was an especially confronting experience given her own diagnosis with a neurodegenerative brain disease which will eventually render her unable to control her own life. Carol plans on leaving the country, if she has to, to ensure her own ending is on her own terms. She firmly believes in having a choice on how to go, and doesn't see how that option in anyway diminishes the value of life, saying:

*“Life is a precious gift. None of us desire to give up that gift until we need to.”*

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## ANNEXURE 6

# Gloria's story, told by Jo and Sherie

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Gloria was only in her 30s when she was diagnosed with Multiple Sclerosis, but for the next 50 years, despite a physical decline that eventually saw her depend on a wheelchair, she did not let her condition define or constrain her. She had a big family – five children, who brought her great joy. Sadly she lost her husband at the age of 44. As Gloria's disease progressed, she became unable to complete most normal household chores and struggled to look after her own personal needs. And still she managed to find great pleasure in appreciating the simple things in life: sitting in the sunshine on the back verandah, watching a rabbit hop around the paddock, delighting in a bougainvillea flush with purple flowers, listening to classical music and reading books. She was an intelligent woman, accepting of her situation – never bitter about her lot in life. At the age of 49, despite her physical challenges, she flexed her mind by taking a university course and completing a BA in Philosophy. Gloria was a person who, driven by circumstance and character, very clearly thought a lot about the meaning of life.

Gloria was 80 when she first felt she'd lost control of hers, after fracturing her spine and spending months recovering in hospital, before returning home for in-home care. That, she felt, was when the "indignities" began. She was unable to toilet herself adequately, and found it horribly uncomfortable when her pad or bedding or seat became urine-soaked. She was unable to take even a few steps unaided. Her muscles had wasted, her knee bent backward when she was assisted to stand, and her back and neck began to give her serious grief. Macular degeneration blinded her completely in one eye, and cataracts in the other meant that she was denied even her love of reading.

At 82, Gloria had another fall. She had suffered muscle and nerve damage, causing her severe pain and leaving her "like a floppy doll". After a three-week stay at Nepean Hospital she was moved into Governor Phillip Manor, an RSL Life Care aged home in Penrith, where she lived for another two years. According to her daughter, Jo, it was at this point that she became seriously distressed by her predicament.

***“She was bitterly sad. This accompanied her physical pain and her deteriorated physical capacity. Mum was given constant pain relieving medication but it didn't ease all the pain and she was commonly in severe pain before more medication would relieve it for a few hours. Mum's independence was gone, her privacy was gone, her ability to direct her own life was all but gone and she didn't want to exist anymore.”***

But the worst was yet to come. Eighteen months into her stay, Gloria's wheelchair – her "artificial limb", her means of mobility for decades, was taken away. It was an inconvenience to the nursing staff, an obstruction to their routine. Jo tried to explain to them that even if she couldn't use it regularly, Gloria needed to be able to see it, to know that it was there if she needed it. But the staff won out. The wheelchair was gone and Gloria was confined to a bed. The next six months were torturous. She couldn't sit or lie for long periods of time without it becoming painful and distressing, but staffing shortages meant Gloria was not moved from bed to chair, or from side to side, as frequently as she needed. So she sat, or lay, often urine-soaked, for hours in pain, with no one to help her and no ability to help herself. Gloria's daughters spent considerable time visiting her at the

home, so witnessed first-hand their mother's day-to-day existence.

Long before she'd entered the home, Gloria had written a living will. It laid out, very clearly, a No Revive instruction and a request that if she should no longer be able to take food and liquid orally, or not be able to direct her care, then she was not to be provided nutrition nor fluids nor life supporting therapies of any kind. She wanted to starve/dehydrate to death, rather than continue with life under those conditions – though she'd always hoped it would never get to that.

***Mum wanted to be allowed to suicide with the aid of medication before she got 'too bad', but this was denied her. She considered euthanasia for at least 40 years. At home, she kept plastic bags in the drawer next to her bed, telling me that when it was time she was going to tie one around her head. She couldn't lift a brush to brush her own hair, so I don't think this was a very thought out solution. It did, however, seem to be a comfort to her to think she could do something if the situation got to that point.***

Gloria also stated that any and all pain-killing medication would be gratefully accepted and that if legal, she wanted the doctors to give her something to end her life peacefully. But that was not to be. The combination of her physical decline due to MS, the medication she was on, and a depression triggered by the hopelessness of her situation combined to induce what can only be described as psychological torture. Jo would frequently answer the phone to hear her mother's terrified voice on the other end:

***She was suffering horrendous delusions such as being locked in a concrete floored shed and left there to starve, she was cold and frightened. This may have been a delusion but her mental state was very real; Mum was absolutely terrified and in severe mental distress. Mum would tell me to come and get her and told me that she would bang really hard on the corrugated iron walls so that I could find her. She was mentally tortured by these delusions and in absolute distress.***

Gloria had often said, "But you don't just die, do you?". She was right. At the very end, it took over ten days for Gloria to die. There was no palliative care service involved, and the doctors were reluctant to increase her sedation, seemingly out of fear of the legal repercussions. She stopped eating the food that was brought to her and was forced to endure the prolonged death she had always feared. After spending 83 years overcoming life's seemingly insurmountable challenges with great dignity, Gloria was made to suffer at its end, a traumatic experience that also left her loving daughters scarred. As Jo puts it:

***As I write this I'm crying, my feelings of inadequacy are still overwhelming. It's 18 months since Mum passed away and I wonder if this feeling will ever leave me. I looked after Mum all my adult life, I was 50 when she died and we were very close. My mental torture at seeing Mum's decline, knowing she wanted to pass peacefully and my inability to help will never stop tormenting me. On numerous occasions, Mum begged me to help her die, and I would have if I had been stronger. She wanted to end her life at a time of her choosing in a peaceful controlled way but spent month after month in mental distress and physical pain trapped by her own withering body and mental torment. I still feel I should have, I really should have helped her regardless of the consequences.***

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