Q1: Can you please comment on the implications for the professions of medicine and nursing and the overall medical, health and aged/residential care ecology of New South Wales by describing Voluntary Assisted Dying, as provided for in the Voluntary Assisted Dying Bill 2021, as "care" or "patient-centred care"?

# Patient centred care must focus solely on sustaining life with medical care.

Right to Life NSW is a community based organisation made up of members who value life as the supreme good of society and all things. Our membership includes medical professionals from diverse fields. The membership aligns itself with the strong voice of the medical profession which favours patient centred care.

In determining the scope of what "patient centred care" or even "care" means in a medical context we have to listen to what medical professionals are saying. International medical bodies reject the proposition that assisted suicide measures constitute patient centred care or even medical care. They see this care as posing threats to vulnerable persons and increasing the risk of patient suffering. The principles of this care are specified by the World Medical Assembly at its 70<sup>th</sup> General Assembly in October 2019:

The WMA reiterates its strong commitment to the principles of medical ethics and that utmost respect has to be maintained for human life. Therefore, the WMA is firmly opposed to euthanasia and physician-assisted suicide.<sup>1</sup>

This position has been recently supported by the College of Psychiatrists of Ireland which stated that assisted suicide "is not compatible with good medical care and that its introduction in Ireland could place vulnerable patients at risk".

Dr Eric Kelleher, from the College of Psychiatrists of Ireland commented:

"We are acutely aware of the sensitivity of this subject, and understand and support the fact that dying with dignity is the goal of all end-of-life care. Strengthening our palliative care and social support networks makes this possible. Not only is assisted dying or euthanasia not necessary for a dignified death, but techniques used to bring about death can themselves result in considerable and protracted suffering".

"Where assisted dying is available, many requests stem, not from intractable pain, but from such causes as fear, depression, loneliness, and the wish not to burden carers. With adequate resources, including psychiatric care, psychological care, palliative medicine, pain services, and social supports, good end-of-life care is possible."<sup>2</sup>

Right to Life NSW has consulted with medical professionals in our network and in supporting organisations in our response to the Committee's supplementary questions. The feedback we have received from doctors is that there is concern in relation to the emotional effects on health care workers who see or will see patients subtly encouraged towards taking their life. While proponents of the bill argue that palliative care occurs in parallel with assisted suicide, there will be many who see

<sup>&</sup>lt;sup>1</sup> <u>https://www.wma.net/policies-post/wma-resolution-on-euthanasia/</u>

<sup>&</sup>lt;sup>2</sup> <u>https://bioedge.org/end-of-life-issues/irish-psychiatrists-oppose-dying-with-dignity-bill/</u>

very little, if any, palliative care. Victoria has not seen any substantial progress in palliative care resourcing or availability since the assisted suicide laws came into effect. Turbulence and angst within palliative care services across Victoria is common as discussed by Odette Spruyt.<sup>3</sup>

Health care professionals have told Right to Life NSW in our consultation that the bill seeks to make a fundamental shift in the understanding of medical ethics to the notion that "the patient knows best", irrespective of their knowledge and emotional state. This assumes that they "will get whatever they want, whenever they want it". But this is not the basis of the public health care provision in Australia. Clinicians do not want to be seen as vending machines. Rather clinicians seek to evaluate the benefit against the risk of any intervention according to sound medical judgement. The bill seems to make this judgement less important than patient preference, and as such devalues the weight to be placed on professional medical advice in end of life care. This approach does not support the principle of patient-centred care as defined in the Australian Commission for Safety and Quality in Healthcare as

A person's care experience is influenced by the way they are treated as a person, and by the way they are treated for their condition. The ultimate goal of our health system is to deliver high-quality care that is safe, of value and to provide an ideal experience for patients, their carers and family.<sup>4</sup>

Right to Life NSW also refers to our position stated in our submission that assisted suicide legislation would fundamentally change the relationship between a doctor and their patients. No longer would the doctor or medical professional be engaged to preserve or sustain the lives of their patients but under an assisted suicide regime would face a direct tension in their medical ethics: a need to manage the extension of a patient's life without pain and with strong care and the request to end that life through a lethal drug. These two goals are antithetical and unreconcilable. A medial professional cannot fully commit to sustaining life and also be charged to end it. Assisted suicide mitigates against the necessary professional commitment to sustaining life. The medical professional must be the life saver, the life sustainer. To ask that person to also be the life taker is to place on them an impossible tension, to ask them to fulfill two opposite roles. If we want our medical professionals to be life sustainers, which we certainly want, we cannot ask them to be the agents of ending life. These two roles simply involve irreconcilable conflict. This is a key reason the international medical community opposes assisted suicide regimes.

Such a conflict involved in the role of duties of a medical professional completely violates the notion of patient centred care because it creates a conflict in the duties of a medical professional between sustaining life with medical care and actively participating in the taking of a life. Patient centred care must focus solely on sustaining life with medical care.

Q2: Further to your submission and oral evidence provided at the hearing on 10th December, what additional information and data can you provide, drawn from other states and jurisdictions that have legalised Voluntary Assisted Dying, regarding what will be the likely incidence of assisted suicide and euthanasia if the Voluntary Assisted Dying Bill 2021 is passed into law?

<sup>&</sup>lt;sup>3</sup> <u>https://insightplus.mja.com.au/2020/30/assisted-dying-push-for-removal-of-safeguards-alarming/</u>

<sup>&</sup>lt;sup>4</sup> Home | Australian Commission on Safety and Quality in Health Care

At the Committee hearing into this death bill late last year, I gave evidence that there would be many deaths in NSW from assisted suicide – over 1,200. I have been asked by the committee to provide more detail of this claim.

## Data for Oregon

I would like to draw the committee's attention to the Response to the Question I took on notice on death rates in Oregon which will been sent to the committee shortly.

## The Victorian situation

At the time of debate on the legislation in Victoria in 2017 Right to Life NSW CEO, Dr Brendan Long, speaking as an academic at Charles Sturt University, published research predicting that in by 2030 the number of deaths from assisted suicide in Victoria will be 1,000 per year. <u>https://www.theaustralian.com.au/nation/nation/its-projected-1000-people-a-year-will-access-assisted-dying-by-2030/news-story/1a39ed0cb57f6e2787bd2b1fe1c8f496</u>).

This was based on applying the measure 17% annual growth rate experience in US and European jurisdictions (where date was available) to the initial expected full year caseload.

### The Western Australian situation

On 24 November 2021, the Minister for Health, the Hon Roger Cook, stated to the Legislative Assembly that 50 people had "*completed the process under voluntary assisted dying*" (see <u>A41 S1</u> <u>20211124 All.pdf (parliament.wa.gov.au)</u>

Consequently, the assisted suicide rate in Western Australia represents 0.82% of all deaths in the State. These are alarming statistics as they constitute a much higher proportion of assisted suicides relative to total deaths (the assisted suicide death rate) than occurred in Victoria for January-June 2021. In fact, this early evidence suggests that the assisted suicide death rate in Western Australia appears to be about two thirds higher than the assisted suicide death rate in Victoria. It also appears to be about one third higher than the assisted suicide death rate for the State of Oregon over 23 years.

What is concerning is that early evidence suggests that as new jurisdictions enact assisted suicide laws the assisted suicide death rate increases. While it is too early to make clear research conclusions it seems that the less restrictive safeguards of the Western Australian Scheme (weaker requirements for specialist advice, use of nurse practitioners for the assessing the scheme and the capacity for a medical professional to introduce discussion of assisted suicide), may have led to this higher death rate. This is evidence of the so called slippery slope in Australia where we see progressive relaxation of safeguard and rapid uptake of cases numbers.

### The proposal in NSW

Using the same methodology Dr Long applied in the Victorian euthanasia debate Right to Life NSW estimates that in 2030 the annual level of deaths from assisted suicide in NSW will be approximately 1,230 persons per year – adjusting the Victorian numbers for NSW demographic factors. There were

only 359 road fatalities in NSW in 2019 – so assisted suicide in NSW is three times more deadly than the road toll.



However, given that the NSW scheme more closely reflects the Western Australian model than the Victorian model this estimate is likely to be an underestimate for NSW. As stated above early data indicates that the Western Australian model has an assisted suicide death rate two thirds higher than the Victorian assisted suicide death rate.

What is concerning is that weaker safeguards in the NSW model compared to Victoria threaten the sort of massive expansion in assisted suicide case numbers we have seen under the Canadian assisted suicide and lethal injection (euthanasia) scheme. Canada only passed its legislation in 2018 but the recent report showed that there were 7,595 assisted suicides in 2019, accounting for 2.5% of all deaths in Canada, rising at an annual rate of 34%. If this rate of assisted suicide applied in NSW there would be 1,400 assisted suicides per year.

Q3. The provisions of the Bill that relate to the poison(s) that will be used to undertake assisted suicide and euthanasia under the Voluntary Assisted Dying Bill 2021 are dealt with in clause 7 and Schedule 1, Dictionary. Further to your submission and oral evidence provided at the hearing on 10th December, what additional information and data can you provide, drawn from other states and jurisdictions that have legalised Voluntary Assisted Dying , regarding potential adverse impacts associated with poison(s) (voluntary assisted dying substances) being administered to the patient?

While there is no data in Australia to examine the effectiveness of the orally prescribed assisted suicide drug international evidence suggests failure rates of the lethal oral drug as being up to 17.5%.

There are a number recognised medical problems with the assisted suicide oral medication that is used in Victoria and Western Australia and likely to be adopted in NSW. These essentially relate to

- 1. include difficulty in swallowing the prescribed dose
- 2. a relatively high incidence of vomiting
- 3. prolongation of death
- 4. and failure to induce coma.

In Victoria, the substance prescribed for assisted suicide is a dose of <u>15g of pentobarbital</u> in a powder form. The dose to be prescribed in Victoria is different to any other jurisdiction that permits assisted suicide. There is therefore no available data on its effectiveness. Oregon data indicates that after ingesting the prescribed dose of pentobarbital (10g of pentobarbital liquid<sup>5</sup>) the time from ingestion to death was more than 60 minutes in 17.5 per cent of cases and more than six hours in 3.9 per cent of cases with the longest recorded time being 104 hours (four days, eight hours).<sup>6</sup> We do not have publicly available data on complications that may have occurred with the Victorian scheme. This is not just because the data is not published but is also related to the fact that there is no monitoring of the ingestion of the lethal oral medication so we cannot know how long patients took to die and if there were complications or significant suffering. It appears this is a deliberate design feature of the Victorian and Western Australian schemes.

I would like to draw the attention of the Committee to the important research in the journal *Anaesthesia* found:

Complications related to assisted dying methods were found to include difficulty in swallowing the prescribed dose ( $\leq$ 9%), a relatively high incidence of vomiting ( $\leq$ 10%), prolongation of death (by as much as seven days in  $\leq$ 4%), and failure to induce coma, where patients re-awoke and even sat up ( $\leq$ 1.3%). <u>https://associationofanaesthetists-publications.onlinelibrary.wiley.com/doi/full/10.1111/anae.14532</u>

On time between ingestion and death, the Dutch data indicate that after ingesting a dose of 9g of pentobarbital dissolved in a 100 ml of water:

- between 1998 and 2000 some 23% took more than 60 minutes and 13% taking 2 hours or more to die, with 1 person euthanised after 6 hours and one after 7 hours<sup>7</sup>
- in a 1994 report it is recorded that 1 patient died only after 24 hours; and 3 patients whose doctors completed euthanasia after 12, 13 and 24 hours respectively by administering a muscle relaxation.<sup>8</sup>

From 2012 the recommended dose was 15  $g^9$  to try to reduce the percentage of cases where death took more than 30 minutes. However:

<sup>&</sup>lt;sup>5</sup> Jennifer Fess and Andrea Fass, "Physician-assisted Suicide, Ongoing Challenges for Pharmacists", American Journal of Health-System Pharmacy, 68 (9): 846–849,

https://academic.oup.com/ajhp/article/68/9/846/5129756

<sup>&</sup>lt;sup>6</sup> Oregon Public Health Division, *Oregon Death With Dignity Act: 2018 Data Summary*, See Table 4 *on* p.15 www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/D ocuments/year21.pdf

 <sup>&</sup>lt;sup>7</sup> A. Horikx en P.V. Admiraal, Toepassing van euthanatica; ervaringen van artsen bij 227 patiënten, 1998-2000,
29 Dec 2000, <u>https://www.ntvg.nl/artikelen/toepassing-van-euthanatica-ervaringen-van-artsen-bij-227-pati%C3%ABnten-1998-2000/volledig</u>

<sup>&</sup>lt;sup>8</sup> Ibid.

<sup>&</sup>lt;sup>9</sup> KNMG/KNMP Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide, p. 17, p. 44 https://www.knmp.nl/downloads/guidelines-for-the-practice-of-euthanasia.pdf

 between 7 and 13% each year 2014-2018 were not dead within "the desired timeframe" (understood to be 2 hours) and were then euthanised.<sup>10</sup>

Data from Exit Switzerland indicates that after oral ingestion of 10-15 grams pentobarbital 12.4%, took more than 60 minutes to die with 8.4% taking more than 2 hours and 1 person taking more than 12 hours to die.<sup>11</sup>

Horikx and Admiraal warn that "The volume of 100 ml is too much for a small number of people to drink in one go" but that the "use of a straw should be discouraged to prevent the patient from falling asleep before the entire dose is taken."<sup>12</sup>

## The Dutch experience

The official Dutch guidelines state that oral pentobarbital is not the preferred method:

Once the patient drinks the drink, the barbiturate is resorbed by the gastrointestinal tract. The faster the resorption, the higher the peak level. If the resorption rate is too slow, then a redistribution of the barbiturate will take place, resulting in an insufficient peak level. As a result, the patient fails to lapse into a coma or can come out of a deep coma. Even when antiemetics are administered, the foul taste of the drink can sometimes cause vomiting. As a result, the whole dose is not taken. Another possible problem is that many patients use opioids at the end of their lives. Opioids result in slower gastrointestinal transit, which can mean it takes the patient longer to lapse into a coma. Due to the aforementioned unpredictability, this method is not the preferred method.

The period of time between administration and the time of death varies from person to person, but in the vast majority of cases, it takes less than 30 minutes. However, sometimes it can take longer (2-3 hours). Long periods such as these can result in uncomfortable situations.

Technical problems occurred in 5% of cases. The most common technical problems were difficulty finding a vein in which to inject the drug and difficulty administering an oral medication.

Complications occurred in 3% of cases of euthanasia (understood as lethal injection), including spasm or myoclonus (muscular twitching), cyanosis (blue colouring of the skin), nausea or vomiting, tachycardia (rapid heartbeat), excessive production of mucus, hiccups, perspiration, and extreme gasping. In one case the patient's eyes remained open, and in another case, the patient sat up.

In 10% of cases the person took longer than expected to die (median 3 hours) with one person taking up to 7 days.

From 2016 to July 2018 the Board of Procurators General <u>reported</u><sup>13</sup> on 11 cases of euthanasia with serious breach of protocols by the doctor, including:

<sup>&</sup>lt;sup>10</sup> Regionale Toetsingscommissies Euthanasie, Jaaverslag 2014-2018, see page 13 of 2018 issue at: <u>https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2018/april/11/jaarverslag-</u>2018/RTEjv2018 DEF.pdf

 <sup>&</sup>lt;sup>11</sup> Georg Bosshard et al, "748 cases of suicide assisted by a Swiss right-to-die organisation", *Swiss Medical Weekly*, 2003;133:310–317, Table 6 on p. 314, Available at: <u>https://pdfs.semanticscholar.org/291c/24458c841196b2fd967d12f5f55a6953bd75.pdf</u>
<sup>12</sup> A. Horikx en P.V. Admiraal, Toepassing van euthanatica; ervaringen van artsen bij 227 patiënten, 1998-2000, 29 Dec 2000,

https://www.ntvg.nl/artikelen/toepassing-van-euthanatica, ervaringen-van-artsen-bij-227-patienten, 1998-2000, 29 Dec 2000, https://www.ntvg.nl/artikelen/toepassing-van-euthanatica-ervaringen-van-artsen-bij-227-patienten, 1998-2000/volledig

<sup>&</sup>lt;sup>13</sup> https://www.om.nl/onderwerpen/euthanasie/beslissingen-college/

- a failed assisted suicide because the doctor ordered the wrong drug;
- seven cases of the muscle relaxant being administered when the person was not in a full coma potentially causing pain; and
- three cases where a first attempt at euthanasia failed and the doctor had to leave the person to get a second batch of lethal drugs.

# The Oregon State experience

In Oregon<sup>14</sup> there are reported complications each year:

- an overall failure rate of 0.42% in 2020.
- an overall complication rate of 6.3% in 2020 but 9.84% in 2019, and 12.12% in 2018.
- in 2020 6.94% of those for whom information about the circumstances of their deaths is available.

The interval from ingestion of lethal drugs to unconsciousness is recorded in Oregon in many cases. There have been cases of taking four hours to die in 2017. The time from ingestion to death has been as long as 104 hours (4 days and 8 hours) in a person who ingested pentobarbital. In 2019 one person took 47 hours to die after using the modified drug 'DDMP2' and another person took 19 hours to die after using the drug 'DDMA'. In 2020 one person took 8 hours to die after using DDMA (another modified drug), and another two people took more than 6 hours to die. The reality is that the Oregon authorities are struggling to find a drug cocktail that reliably leads to a peaceful death for all participants within 60 minutes.

There are some horrific stories. 8 people have regained consciousness after taking the supposedly lethal dose, including one person in 2018. In 2005, one person became unconscious 25 minutes after ingestion, then regained consciousness 65 hours later. This was lumberjack 'David Prueitt' who, after ingesting the prescribed barbiturates spent three days in a deep coma, then suddenly woke up, asking his wife *"Honey, what the hell happened? Why am I not dead?*". David survived for another 14 days before dying naturally from his cancer. <sup>15</sup>

Since 2005 seven other people have regained consciousness after ingesting the lethal medication.

"In <u>2010</u>, two patients regained consciousness after ingesting medications. One patient regained consciousness 88 hours after ingesting the medication, subsequently dying from underlying illness three months later. The other patient regained consciousness within 24 hours, subsequently dying from underlying illness five days following ingestion.

In 2011, two patients regained consciousness after ingesting the medication. One of the patients very briefly regained consciousness after ingesting the prescribed medication and died from underlying illness about 30 hours later. The other patient regained consciousness approximately 14 hours after ingesting the medication and died from underlying illness about 38 hours later."

In <u>2012</u> "one patient ingested the medication but regained consciousness before dying of underlying illness. The patient regained consciousness two days following ingestion, but remained minimally

<sup>&</sup>lt;sup>14</sup>https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGN ITYACT/Documents/year23.pdf

<sup>&</sup>lt;sup>15</sup> "Oregon man wakes up after assisted-suicide attempt", Seattle Times, 4 March 2005

responsive and died six days following ingestion". In 2017 "one patient ingested the medication but regained consciousness before dying from the underlying illness". In 2018 one person regained consciousness after ingesting the prescribed substance and later died of the underlying illness. These two occurred after using DDMP2.

## The Washington State experience

As in Oregon there have been significant challenges in finding an effective lethal oral agent.

- In <u>2009</u> two people awakened after initially losing consciousness.
- In <u>2013</u> one person took 3 hours to lose consciousness after ingesting the lethal dose and one person took 41 hours (1 day and 17 hours) to die after ingesting the dose.
- In <u>2014</u> one person suffered seizures after ingesting the lethal medication. In <u>2015</u> one person took 72 hours (3 days) to die after ingesting the dose.
- In<u>2016</u> Seven patients have regurgitated the lethal medication. Also in <u>2016</u> one person took 11 hours to lose consciousness after ingesting the lethal dose.
- In 2017 one person took 6 hours to lose consciousness after ingesting the lethal dose and one person took 35 hours to die after ingesting the lethal dose. In this year the experimental drug deployed was reported to be <u>found to be very caustic</u> and to cause a profound burning in the throat and was not longer used.

### Issues that have arisen in the use of Sodium pentobarbital as an agent in executions

A key issue that that emerged with Sodium pentobarbital that has been used for assistance to suicide in the Netherlands, Oregon and Washington (until 2015), and now in Victoria, is that it causes suffering at the time of death. There is evidence from autopsies conducted after executions in the US. The drug is now not used in the US as an agent of execution for these reasons. Additionally, there is medical concern that the drug could lead to an abiding presence of consciousness even after the body is legally dead, a potential form of cruel and unusual punishment for the criminal.

Sodium pentobarbital has been used for assistance to suicide in the Netherlands, Oregon and Washington (until 2015), and Victoria as well as by several States in the United States in the execution of prisoners.

David Waisel, MD, an anaesthesiologist, has testified about the use of this drug in executions:

... as the lethal injection commenced Mr. Blankenship jerked his head toward his left arm and made a startled face while blinking rapidly. He had a "tight" grimacing expression on his face and leaned backward. Shortly thereafter, Mr. Blankenship grimaced, gasped and lurched twice toward his right arm. During the next minute, Mr. Blankenship lifted his head, shuddered and mouthed words. Three (3) minutes after the injection, Mr. Blankenship had his eyes open and made swallowing motions. Four (4) minutes after injection, Mr. Blankenship became motionless. About thirteen (13) minutes after the injection, Mr. Blankenship was declared dead. Again, his eyes were open throughout.

Based on his lurching toward his arms and the lifting of his head and the mouthing of words, I can say with certainty that Mr. Blankenship was inadequately anesthetized and was conscious for approximately the first three minutes of the execution and that he suffered greatly. Mr. Blankenship should not have been conscious or exhibiting these movements, nor should his eyes have been open, after the injection of pentobarbital.

Given prior executions of Brandon Rhode and Emanuel Hammond in September 2010 and January 2011, respectively, during which these inmates reportedly exhibited similar movements and opened their eyes (Rhode's eyes were open throughout the execution process), Mr. Blankenship's execution further evidences that during judicial lethal injections in Georgia there is a substantial risk of serious harm such that condemned inmates are significantly likely to face extreme, torturous and needless pain and suffering. (State of Massachusetts, County of Suffolk., Affidavit of David B. Waisel, MD, p. 2-3)

Joel Zivot, another anaesthesiologist, writes:

In 2014, I watched the lethal injection of Marcus Wellons in a Georgia prison.

I noticed that Wellons's fingers were taped to the stretcher, which made little sense, given his body had already been restrained by heavy straps. I kept asking myself why. I read into the subject and came across a report of the lethal injection execution of another death row inmate, Dennis McGuire, five months earlier. During that 24-minute process at the Ohio jail, McGuire clenched his fists. Perhaps it was a final, futile show of defiance. Perhaps it was an outward display of pain. With his fingers secured, Wellons could not have made any such gesture.

In 2017, I obtained a series of autopsies of inmates executed by lethal injection, which confirmed my worst fears. Wellons's autopsy revealed that his lungs were profoundly congested with fluid, meaning they were around twice the normal weight of healthy lungs. He had suffered what is known as pulmonary oedema, which could only have occurred as he lay dying. Wellons had drowned in his secretions. Yet even my medical eye detected no sign of distress at his execution.

Wellons was executed with a chemical called pentobarbital, which caused his pulmonary oedema. If a post-mortem examination were to be performed on a body after assisted suicide, it's very likely that similar pulmonary oedema would be found.

In 2020 the media outlet NPR published a <u>review</u> of 216 autopsies conducted after execution in US States by lethal injection found signs of pulmonary oedema in 84% of the cases. The findings were similar across the states and, notably, across the different drug protocols used.

Not all states conduct autopsies after lethal injections. Texas, which has performed by far the most lethal injections of any state, has a policy of not conducting autopsies. When asked by NPR about this, a spokesperson for the Texas Department of Criminal Justice said, "We know how they died."

Euthanasia (understood as lethal injection) and assistance to suicide laws often similarly include provisions designed to preclude autopsies such as excluding such deaths from being "reportable" to the Coroner and specifying in the death certificate that the cause of death was the medical condition for which euthanasia or assistance to suicide had been requested.

It should be noted that the protocol for self-administration of a lethal poison to cause death under Victoria's law, for example, includes an anti-emetic and an anti-anxiety drug to be taken before drinking a mixture containing 15g of pentobarbital. However, the person will still be conscious when the pentobarbital is ingested.

Dr Zivot comments that "without a general anaesthetic, many will be in great discomfort, even if outwardly they don't appear to be suffering."

The matter was considered in the US Supreme Court case *Glossip v Gros*. In her 2015 <u>dissent</u> US Supreme Court Justice Sotomayor, characterised death by lethal injection as *"the chemical equivalent of being burned at the stake"*.

In a very significant study by S. Sinmyee et al. published in *Anaesthesia* in 2019<sup>16</sup> the authors warn that under all current protocols for euthanasia or assisted suicide – including the Dutch method for assisted suicide of oral ingestion of 15g of pentobarbital – there is a significant likelihood that in some cases there will be a persistence of awareness – called AAGA "accidental awareness under general anaesthetic" in the surgical context – despite perhaps apparent loss of consciousness.

In essence the data from US jurisdictions highlights the risks of the drug sodium pentobarbital as causing significant suffering in death. However, this is a key element of the drug regime applied in Victoria for assisted suicide and euthanasia. What is required here for the efficacy of lethal drugs – 'the voluntary assisted dying substance' to be reviewed by the Therapeutic Goods Administration to assess its efficacy and to ensure it is a drug that when applied does not magnify the patient's suffering and it is compliant with the requirements and objects of the Therapeutic Goods Administration Administration Act.

Q4. In the Victorian *Voluntary Assisted Dying Act 2017* there is a strict prohibition on the subject of Voluntary Assisted Dying being initiated with a patient (clause 8). An equivalent strict prohibition provision is not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include a strict prohibition provision similar to clause 8 of the Victorian *Voluntary Assisted Dying Act 2017*?

Under s10 of the Bill health care workers are allowed to suggest euthanasia and assisted suicide to a patient as long as treatment options are explained. This is problematic on several fronts.

- There is no attempt to ensure that the health care worker giving the information has the expertise to provide this information to standards normally required in the provision of health care advice. In the absence of a doctor with specialist knowledge about the patient's disease, there is no guarantee that the patient will be told of the full range of options available, and therefore the patient may not be making an informed choice. It is well known that the range of available options may vary according to the characteristics of the individual patient. However, there is no requirement that the healthcare worker discussing assisted suicide makes contact the patient's current doctors, whether GP or treating specialist. No standard medical procedure would now be legal in NSW with this level of information provision to the patient. It needs to be asked why a lower standard of medical information advice is permitted in the assisted suicide regime than would normally be required according acceptable medical standards for other forms of medical advice.
- There are risks associated with allowing a health care worker to raise the subject of assisted suicide due to the risk of possible coercion. Professor Brian Kelly, a psychiatrist at Newcastle University has shown that the doctor's attitude can have a powerful influence on the patient's decision making<sup>.17</sup> This is compounded when the clinician has no experience or training in palliative and psychological care of patients. We fear that there is a risk that information about palliative care may not be properly communicated by a health care

 <sup>&</sup>lt;sup>16</sup> S. Sinmyee et al., "Legal and ethical implications of defining an optimum means of achieving unconsciousness in assisted dying", *Anaesthesia*, 74, 630–637, <u>https://onlinelibrary.wiley.com/doi/epdf/10.1111/anae.14532</u>
<sup>17</sup> Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors. Kelly BJ, Burnett PC, and Pelusi D *Psychosomatics*. 2004 45:311–318.

professional that is ideologically committed to assisted suicide. The injunction on a health care worker raising the issue of assisted suicide is a critical safeguard that is an essential design feature of the Victorian legislation. The question can be asked why in NSW weaker safeguards are presented in legislation that were legislated in Victoria. Why should NSW legislation provide a weaker safeguard regime than provided for in Victoria? Surely NSW legislators would want to pass legislation that has no less safeguards than are provided for in another State.

• There is also credible evidence that the potential power imbalance in relationship between a health care worker and the patient may create a situation that the advice of the health care worker can be seen as directive rather than suggestive, encouraging patients to relinquish their autonomy with the notion that 'doctor/nurse knows best'.<sup>18</sup> If the Parliament truly wants to avoid the risk of coercion, it should be illegal for healthcare workers to raise the topic of assisted suicide with patients, as is the case in the state of Victoria.

• There is also the risk that safeguards will be redefined as impediments to the assisted suicide process and will be subject of further legislative amendment. The prohibition on health professionals raising the topic can also easily be ignored by some health care workers. Hints can be offered and light made of a legal requirement. Right to Life NSW doubts the ability of the appointed oversight body (Voluntary Assisted Dying Review Board) to monitor or report on breaches of such regulations. The net effect is that the potential for suggestion to vulnerable patients from health care workers is an ever-present threat. The only defence to this risk is strong criminal sanctions for health care workers for imitating a conversation on assisted suicide per se.

Q5. The Victorian *Voluntary Assisted Dying Act 2017* has, with respect to minimum requirements for co-ordinating medical practitioners and consulting medical practitioners, a requirement for the involvement of a medical specialist and an individual with relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed (clause 10). Equivalent provisions are not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include provisions similar to clause 10 of the Victorian *Voluntary Assisted Dying Act 2017*?

• The Victorian scheme offers provisions to effectively mandate specialist medical knowledge in the assisted suicide process which are a key safeguard of this scheme. Failure to include this safeguard in the NSW scheme increases the risk of poor medical decision-making (e.g. less understanding of treatment options and prognosis) and increase the risk of the patient receiving substandard care.

• Allowing GPs to be the Coordinating Medical Practitioner under the proposed scheme amounts to a reduction in the safeguards present in the NSW scheme. GPs simply don't have the expertise to answer all questions demanded of the legislation. Key diagnostic criteria are likely to missed leading to the real possibility of incorrect information being provide to the patient who will make this important decision to end their life. This undermines the principle of informed consent so critical to the legislation. This increases the risk that mistakes will be made. Prognosis of longevity is hard for anyone, let alone a non-specialist, to confidently diagnose. Without a requirement for specialist care in the assisted suicide process there is a real risk the patient will not be given accurate information in

<sup>&</sup>lt;sup>18</sup> Goodyear-Smith F, Buetow S. Power Issues in the Doctor-Patient Relationship. Health Care Analysis. 2001;9(4):449-62.

relation to viable treatment options. The question can again be asked why NSW seeks to legislate an assisted suicide regime with weaker safeguards than operative in Victoria.

• Right to Life NSW has consistently argued that there is a real risk of the so called 'slippery slope' whereby the legislative safeguards operative in assisted suicide schemes become eroded over time in legislative amendments. The reduction in safeguards by removing the effective requirement for a specialist to be a Coordinating Medical Practitioner under the proposed NSW assisted suicide regime stands as evidence of the potency of the concern relating to the 'slippery slope' argument. It can be asked what is the next step, access to the assisted suicide scheme for people with dementia, for those under 18, for those without a terminal condition? If the NSW Parliament wishes to provide for a legislative scheme for assisted suicide with weaker protections than apply in other jurisdictions it effectively concedes the concern raised in relation to the 'slippery slope' line of argument.

• Right to Life NSW agrees with the comments made in the submission by Professor Megan Best of Notre Dame University Australia in which she argued that in s6(2)(b) in this Bill, the onus on the doctor is to prove a patient *doesn't* have decision-making capacity. Professor Best has contended that cognitive function is known to be impacted negatively by factors such as organ failure, medical treatments, and psychological morbidity. Professor Best has cited research that shows that 35% of people with physical and mental illness may lack capacity to make decisions about their health. <sup>19</sup>This is a complex diagnostic area, and a high level of skill and experience is required to make this assessment.<sup>20</sup>

• Professor Best has also stated that:

"Cognitive impairment, including delirium and neurodegenerative disorders, are often not recognised, even by doctors. Cognitive impairment, no matter how subtle, does definitely impact decision making capacity. It is well recognised that, the more significant the decision, the more care must be taken with capacity assessment, and the more caution is required in signing off on capacity. Clearly there is no more significant decision than the decision to end your own life. Referral to a psychiatrist or psychologist at the very least should be included in the Bill to ensure the decision to access assisted suicide is valid, as was mandated in the 2017 Bill. We know telehealth is inadequate for full assessment of patients, much more likely to make errors if you are not a specialist and don't know specifically what to ask or look for in the patient."

• Professor Best has also indicated that if prognosis of longevity is determined only on the balance of probabilities as indicated in s16(1)(d)(ii). Professor Best has cited research<sup>21</sup> showing that it is not possible to predict life expectancy with any accuracy. This issue was raised in the Queensland Parliamentary debate and amendments were moved in relation to this question but were not seriously dealt with in debate in the Queensland Parliament by Minister Miles. In fact, Minister Miles' treatment of this important issue was rather

 <sup>&</sup>lt;sup>19</sup> Breitbart, W. Depression, Hopelessness, and Desire for Hastened Death in Terminally III Patients with Cancer. *Journal of the American Medical Association* (Dec. 13, 2000); Lepping, P, et al. Systematic Review on the prevalence of lack of capacity in medical and psychiatric settings. *J Clin Med (Lond)* 2015; 15(4).
<sup>20</sup> Agrawal M. Voluntariness in clinical research at the end of life. Journal of Pain and Symptom Management. 2003;25(4):S25-S32.

<sup>&</sup>lt;sup>21</sup> White N, Reid F, Harris A, Harries P, Stone P. (2016). A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? PLoS ONE 11(8).

dismissive of the concerns raised by Queensland doctors. NSW legislators can treat this issue more seriously than occurred in the Queensland debate, a debate it should be noted was not subject to review in a second parliamentary chamber as Queensland is a unicameral Parliament. Right to Life NSW calls on Legislative Councillors to consider the issue of uncertainty in relation to longevity of patients closely. Surely, specialist medical practitioners will be better placed to determine patient longevity, a key safeguard under the NS bill, than GPs. This is another argument for a requirement for specialist medical practitioners to be Coordinating Medical Practitioners under the proposed NSW legislation.

• s16(1)(d)(ii) in the current bill demonstrates lack of understanding regarding the degree of specialisation within modern medicine. Palliative care physicians are aware of the lack of understanding regarding what palliative care can achieve amongst the larger medical community, and the patient is unlikely to get accurate information regarding possible pathways to relieve their suffering if they are not referred to specialist palliative care ... It would be a tragedy if a patient were to choose assisted suicide because they were not accurately informed regarding their palliative care options.

• Psychological referral is not required under s27 of the bill if a person is suffering from a mental illness. This bill rightly seeks to deal with problems associated with identifying coercion and undue influence. However, failure to require medical specialist involvement in the assisted suicide assessment process exacerbates the risk present in s27 of the bill. Elder abuse has been identified as a pervasive problem in NSW by the Legislative Council's report on Elder Abuse released in 2016.<sup>22</sup> These issues were identified in the Australian Law Reform Commission's report on elder abuse released in 2017.<sup>23</sup> While the exact prevalence of elder abuse is not established in NSW, the ALRC reported that, at the international level, estimated prevalence rates of elder abuse range from 2-14% and may be as high at 20% in older women. It is imperative that in the bill provides for mandatory psychological assessment by a qualified psychological specialist where the applicant has a history of mental illness.

<sup>&</sup>lt;sup>22</sup> Report 44 – Elder abuse in New South Wales.

https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/Report44ElderabuseinNewSouthWales.pdf <sup>23</sup> Australian Law Reform Commission. Elder Abuse – A National Legal Response. ALRC 2017.

https://www.attorneygeneral.gov.au/Mediareleases/Pages/2017/SecondQuarter/Building-the-national-response-to-elder-abuse.aspx