Commentary on

The Report of the Joint Select Committee on
End of Life Choices
My Life, My Choice
Presented by Ms A Sanderson MLA and Hon CJ Holt, MLC
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written by

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Australian Care Alliance
“Care and Compassion: Opposing Assisted Suicide.”
Brief bio-sketch about the author of this commentary

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Professor Kissane’s academic interests include group, couples and family psychotherapy trials, communication skills training, studies of existential distress, and the ethics of end-of-life care. He is best known for his model of family therapy delivered to ‘at risk’ families during palliative care, which prevents complicated grief and depression in bereavement. His work on demoralization as a variation of depression in the medically ill has prompted interventions to promote meaning-based coping. He is the author of over 350 publications, including booksabout Communication in Cancer Care, Depression and Anxiety, Psychotherapy in Cancer Care, and Bereavement Care for Families.

Prof Kissane has been recognised by the International Psycho-Oncology Society with its Sutherland Award for lifetime achievement, by Cornell University with its Klerman Award for psychotherapy research, and by King’s College, London with its Dame Cecily Saunders lecture. In 2018, he was made a Companion in the General Division of the Order of Australia for his contribution to the development of the disciplines of Psycho-oncology and Palliative Care.

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EXECUTIVE SUMMARY

The Joint Select Committee (JSC) on End of Life Choices through its majority report recommends in favour of the development of Voluntary Assisted Dying (VAD) Legislation, recommending that the Minister of Health establish an expert panel to develop this legislation in accordance with the framework recommended by the JSC. A minority report submitted by the Hon Nick Goiran, MLC recommends against this.

This commentary is offered to provide a critique of the framework developed by this JSC Majority Report. As an academic psychiatrist and palliative care physician who published with Dr Philip Nitschke a Lancet report (1998) on the patients accessing euthanasia in the Northern Territory of Australia, and as a scholar who has studied end-of-life care across more than forty years, these reflections are offered in the interest of achieving optimal patient care. Legislators are invited to consider the needs of the vulnerable alongside the needs of those advocating for freedom of choice. This critique aims therefore to speak specifically to legislators who may be asked to introduce the legislation recommended in the JSC Report.

A commentary is therefore offered on each chapter of the JSC Report, highlighting key challenges that arise from each perspective that is presented, following the sequence of the JSC Report. Key findings are offered that arise from this commentary on each chapter, and these are also presented for ease of access in this executive summary.

Key finding based on Chapter 1, the Context:
The AMA reported that individual doctors in Western Australia are not best positioned to make the assessments required under the proposed VAD framework and that considerable training would be needed to establish safe practices if the Government remains committed to introducing VAD.

Key finding based on Chapter 2, Advanced Health Care Planning and Dementia
The use of an advance care plan to direct the future use of VAD in a patient with dementia presents many societal problems for Residential Aged Care Facilities and the community in the years ahead. The JSC Report appears to expect dementia to be an illness for which VAD is delivered under their framework, yet no in-depth consideration of the many issues involved has been presented.

Key finding based on Chapter 3, Palliative Care
Palliative care is inadequately funded and resourced in Western Australia, with no beds servicing the northern suburbs of Perth, inadequate funding for community services, and major deficits in rural, regional, remote and Indigenous services. This inequity of palliative care service needs to be urgently addressed by the Minister of Health.

Key finding based on Chapter 4, Lawful options at the end of life
Proportional palliative sedation is a necessary and useful symptomatic treatment for anxiety states, agitation and delirium across any illness journey, including at the end of life. Use of the pejorative terminology “terminal sedation” is politically based and unwise. Moreover, most suicides, even when medical illnesses are co-morbidly present, occur because of mental illness, and suicidal patients require psychiatric assistance as the mental health focus of care provision.

Key finding based on Chapter 5, International experience with Voluntary Assisted Dying
Commentary on WA JSC Report on End of Life Choices

There are published findings of depressed patients accessing physician-assisted suicide in Oregon, growing numbers of the mentally ill being euthanised in the Netherlands and Belgium, and pressure mounting in Canada for euthanasia of the mentally ill. Legislators might be naïve to not expect such future pressure from euthanasia advocates in Australia. The proposed safeguards in the JSC recommended framework are unlikely to protect the vulnerable such as the mentally ill, the frail elderly and the disabled.

**Key finding based on Chapter 6, Legislation in other Australian jurisdictions**

The evidence from the ROTI Legislation in the Northern Territory is that the safeguards did not protect the vulnerable. Depressed patients accessed euthanasia. Suboptimal medical care was provided. Doctor shopping occurred. The coroner of the day failed to ensure adherence to the regulations under the Act. Processes of review in every jurisdiction appear to have failed to protect the vulnerable. The JSC Report suggests that doctors be able to propose VAD to their patients as an available treatment, risking that patients sense their physician believes they would be better dead. The JSC Report places its emphasis on less restrictive access to VAD rather than safety.

**Key finding based on Chapter 7, Voluntary Assisted Dying**

Depression and demoralization in the medically ill are common reasons that bring about a desire to die. This is confirmed by Australian studies. Depression and demoralization often pass underdiagnosed and undertreated in oncology and palliative care. Depression and demoralization have a significant impact on decision-making capacity, and if unrecognised, the vulnerable are put at grave risk by VAD legislation. Treatment of depression restores interest in life-sustaining treatments or living until natural death intervenes. An additional factor is that doctors do make errors in diagnosis and treatment. Furthermore, prognosis is not an exact science. Protection of the vulnerable, the frail elderly, the disabled and the mentally ill is a crucial responsibility of society and its legislators. Legislators ultimately must make a choice between autonomy sought by a few vocal advocates and the safety of the wider community, whose lives may be put at risk through the difficult regulation of state sanctioned death.
Commentary on Chapter 1 Introduction and Context

In setting the context for this Joint Select Committee (JSC) Report, the committee noted the ageing of the Australian population, with the development of chronic illness as a common pathway that now leads to death in Australia.

The JSC noted that 56% of the submissions it received opposed Voluntary Assisted Dying (VAD), with only 35.5% being supportive. They further noted that the Western Australian Branch of the Australian Medical Association is opposed to such VAD legislation, and that the AMA recommended that the Government and Minister for Health approve more funding for palliative care, to improve the delivery of palliative care, especially in regional, rural and remote parts of the State. Such increased resourcing of palliative care appears to be a crucial current need for WA.

The AMA (WA Branch) indicated that individual doctors are not best placed to make the end of life assessments proposed by the JSC’s proposed framework for VAD. They therefore recommended that if the Government wishes to proceed with VAD legislation, approval should be agreed upon by a panel, which could be established under a civil and administrative tribunal. The JSC’s report did not recommend adopting this telling advice offered by the AMA.

Finding: The AMA reported that individual doctors are not best positioned to make the assessments required under the proposed VAD framework and that considerable training would be needed to establish safe practices if the Government remains committed to introducing VAD.

Commentary on Chapter 2 on Advance Health Care (AHC) Planning and Dementia

In its report to the WA Parliament, the JSC makes several recommendations about the development of AHC plans. It distinguishes between a legally binding AHC Directive, an Enduring Guardian, a non-binding AHC plan, and a common law AH directive/plan, which could be orally communicated.

The JSC’s recommendations seek a central register of AHCDs, with education and promotion of their development. The push is for the steady recognition of legally binding AHCDs.

Three common clinical settings are evident where AHCDs are used:

1. The cancer death: When a person is clearly dying, whether from advanced and irreversible cancer (or other progressive illnesses in comparable circumstances), and the intent is to respect natural dying. This type of AHC plan is welcomed by the palliative care community as it has promoted communication about and eventual acceptance of dying.

2. The ICU death: When an emergency arises (e.g. fulminant pneumonia) that proves life-threatening to an elderly person with several accumulated chronic illnesses, an Intensive Care Unit (ICU) admission on a ventilator is the only prospect of life. Evidence given by Dr Hennessy (ICU specialist, Sir Charles Gairdner Hospital, 10/2017) was that this management carries a 2 percent rate of success and a high prospect of very poor subsequent quality of life for survivors. This type of AHC plan
is welcomed by ICU physicians as it potentially protects them from a program of care that they often perceive as futile.

3. **The dementia death**: This is the most feared form of dying by our society, yet one that is becoming the second commonest cause of death after cardiac disease (when cancers are not clustered together, but listed by discrete tumour types). Bodies like Alzheimer’s WA argue that patients should not be discriminated against, as lawful options should exist for all people in all of society. This type of AHCD might be helpful to not extend dying by allowing a pneumonic dying process to bring about a natural death. However, expectations could be raised that these AHCDs be used to introduce VAD to such patients.

From the perspective of VAD, the AHCD that provides the pre-considered option that a patient be administered a lethal medication in the future (for instance, when he or she has dementia and no longer recognises their loved ones, or becomes bed bound) is strongly likely to become a very large group of VAD deaths, albeit involuntary when that time occurs. The AHCD instructions for treatments are used instead of consultation with the enduring guardian. In the absence of an AHCD, the enduring guardian is called upon to make personal, lifestyle and medical treatment decisions. It is noted that an enduring guardian can be the same person as the patient’s enduring attorney.

Problems beyond the sheer numbers of such patients in the future include:

1) The capacity to make a binding AHCD may be problematic in the setting of mild cognitive decline;

2) The timing of activation of the wishes expressed in the AHCD become a judgement for the person with the medical power of attorney or enduring guardianship. They can be influenced by a multitude of factors like carer fatigue, demoralization, burden, or financial hardship. Because the enduring guardian is not independently appointed and will often be a relative/friend and a beneficiary under the dying person’s will, they could consent to VAD even if the dying person had not wanted this. Inheritance impatience could lead to involuntary euthanasia.

3) The staff in the Residential Aged Care Facility (RACF) will also be asked to join in a subjectively-timed decision, may have mixed views about the moral grounds, feel coerced to cooperate, and subsequently bear the burden of the outcome.

4) The resultant ethos in RACFs that are compelled to accept that VAD becomes a normative form of dying in their facility, when issues like elder abuse, inadequate care provision, poor nutrition and substandard care might prevail.

The frail elderly who develop some form of mild cognitive impairment become a very vulnerable group in any legislation of VAD that includes dementia as a chronic illness causing grievous and irremediable suffering, which through an AHCD could require VAD to be administered.

The staff and institution delivering the aged care are also identifiable as vulnerable individuals under VAD legislation, as their ability to conscientiously object may by impeded by circumstances that prohibit the movement to another residential site of care provision for a patient with dementia, whose AHCD may have been completed several years before, yet deemed binding by statutory authorities.

The WA JSC on End of Life Choices appears to include dementia deaths as very appropriate for VAD and has failed to adequately consider the many complexities that will arise in this clinical setting.
Countries such as Belgium and the Netherlands routinely deliver non-voluntary euthanasia to patients with dementia at the request of relatives. The absence of adequate oversight of such practices has raised concern for other countries, whereas such dying is normalised by the societies in which they occur. Without oversight by a very carefully administered civil and administrative tribunal process, safeguards about not delivering VAD to the vulnerable will break down in these clinical circumstances.

Legislators may see wisdom in initially excluding such patients from accessing VAD, but societal fears of dementia as an unworthy form of dying will steadily apply pressure on future governments to amend legislation to include such people.

Society’s ability to protect the vulnerable would appear to be very slender for patients with dementia.

Finding: The use of an advance care plan to direct the future use of VAD in a patient with dementia presents many societal problems for Residential Aged Care Facilities and the community in the years ahead. The JSC Report appears to expect dementia to be an illness for which VAD is delivered under their framework, yet no in-depth consideration of the many issues involved has been presented.

Commentary on Chapter 3 on Palliative Care

Surprisingly, the authors of this chapter wrote as if they were learning about palliative care for the first time. They offered a series of definitions, including some quite old views, as they came to grips with the goals of palliative care, differing levels of expertise, its framework of care delivery, timing of referral and outcomes achieved from its care. They tended to describe care provision as either/or, contrasting curative care with palliation, instead of realizing that the two paradigms can operate in parallel from the first time an illness is diagnosed. They appeared to have joined a committee to examine VAD, and then struggled to make sense of what palliative care is. It became apparent that palliative care is inadequately resourced and funded in Western Australia, with no beds servicing the northern suburbs of Perth, inadequate funding for community services, and major deficits in rural, regional and remote areas. Inequity of service provision was glaringly obvious.

The committee struggled to understand the funding of palliative care services, and despite needing to issue a summons to the Director General of WA Health to obtain appropriate data, it was still difficult to understand what was presented. They recommended that the Minister of Health establish an independent audit of palliative care funding, and that WA Health conduct an independent review of palliative care services, equity and models of care. In this manner, the committee may not have fulfilled its own responsibilities to examine end-of-life care.

With the JSC’s focus on patient autonomy, they misunderstood the difference between clinicians developing clinical “Goals of Patient Care” with each patient and family, which might focus on symptom relief, family support, psychological or even spiritual care, and the completely different concept of Advance Health Care Directives, which describe a patient’s wishes and values if they lose decision-making capacity. They reported in Finding 15 that for clinicians to create clinical goals of care (which are relevant to every medical or surgical encounter) was “inconsistent with respect for patient autonomy” (p.80 JSC Report). These very different concepts seemed to be poorly understood.
The alarming news for the State was that access to specialist palliative care was limited for Western Australians. The State has the lowest number of palliative care beds per head of population in the country. Rural and regional services are at crisis point. Medical oversight for palliative care is lacking across WA Country Health services. Indigenous people are badly neglected. The JSC recommended that Minister of Health should prioritise policy development, governance structures and adequate funding, although no mention was made of urgency. The committee recommended that this situation needed an independent audit to discover where to start to rectify this abysmal situation.

Legislators should be reminded of Senator Dodson’s words to the Senate on 15 August 2018, as recorded in Hansard,

“There is a desperate need for culturally appropriate palliative care services in regional and remote areas. A review recently commissioned by the Australian government confirmed that more needs to be done to ensure that First Nations people are receiving palliative care within their communities. Where First Nations people are already overrepresented at every stage of our health systems, it is irresponsible to vote in favour of another avenue to death. Paving the way for euthanasia and assisted suicide leaves First Nation people even more vulnerable, when our forces should be working collectively to create laws that help prolong life and restore their right to enjoy a healthy life.”

Senator Dodson went on to offer a most informative commentary on the approach of our Indigenous people to a communitarian morality, where interconnectedness brings responsibilities for our common humanity, and where respect for life is a central principle. Again, he is quoted directly from Hansard,

“In Yawuru we have three concepts that guide our experience of life. They shape our ways of knowing and understanding, and are the collective approach to our existence on this earth and, to that extent, any afterlife that may come. They are: mabu ngarrunngu(nil), a strong community—the wellbeing of all is paramount; mabu buru, a strong place and a good country—human behaviour and needs must be balanced in their demands and needs of what creation provides; and mabu liyan, a healthy spirit and good feeling. Individual wellbeing and that of our society not only have to be balanced but be at peace with each other within the context of our existence and experience.

This concept of interconnectedness is one that transcends across many First Nations groups. It is grounded in our understanding that human resilience is based on our relationships with each other and our connectedness with the world around us. The quality of life for individuals and for our communities are intertwined, not limited to the wellbeing of an individual. We are fundamentally responsible for honouring our fellow human beings. We are called to carry responsibilities, to exercise duties and to honour those who are in need, who are ill, who are elderly, who are dependent and those of the next generation to value life with love, respect and responsibility. This is true of family members and unknown individuals. Moving away from such principles and values begins to reshape the value of human beings and our civil society, in my view.

We exist not as solitary individuals; we exist within a family, a community, our cultures and ethos, and in the kinship landscape. I’m a great admirer of those who have cared for loved ones and made personal sacrifices to do so. Not everyone is able to do this, I know, and I do not condemn them for the choices that they make. In the

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1 Senator Patrick Dodson, Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015, Second Reading, Hansard, p. 12, Wednesday 15 August 2018, 10:53.
broad sense, we are part of a common humanity. If we give one person the right to make that decision—that is, to assist in committing suicide—we as a whole are affected. If we give one family that right, we as a whole are affected. If we give one state or territory that right, we as a country are affected. If we give one nation the right to determine life, our common humanity is affected. I cannot support this legislation."²

Not only is palliative care desperately needed by our First Nation people in the Kimberley and across the State, but it is also clear that our Indigenous oppose the development of VAD.

**Key finding:** Palliative care is inadequately funded and resourced in Western Australia, with no beds servicing the northern suburbs of Perth, inadequate funding for community services, and major deficits in rural, regional, remote and Indigenous services. This inequity of palliative care service needs to be urgently addressed by the Minister of Health.

**Commentary on Chapter 4: Lawful options at the end of life**

In this chapter, the committee reviews the refusal of medical treatment, food and fluid, palliative sedation and suicide. The discussion appears slanted to argue for a conclusion that Western Australians want to be able to control their dying.

In this chapter, the authors observe that palliative care continues when a person accepts that he or she is dying, and declines food and drink. Although not discussed, the section carries forward the implication that palliative care could also continue when a person adopts the practice of VAD. This is an extraordinarily complex area that merits further detailed exploration. There is a difference between palliative care services continuing to provide service to a person who has accessed medication from elsewhere for a potential future suicide while that person is focused on their continued living, and palliative care services being present when a person suicides.

The authors displayed a limited understanding of palliative sedation, and cited case examples of patients with agitated delirium, neither naming this clinical condition nor displaying an understanding of its management. It can be distressing and frightening for a relative or friend to watch a loved one experience agitated delirium, even though the patient lacks a normal conscious state, and later awareness of what happened. Poor medical care of delirium occurred without comment. Moreover, there was no differentiation of a delirium from which the patient can fully recover and a terminal delirium, which can accompany approximately 80 per cent of deaths in the final days. With no real sense of the complexity of delirium, the authors biased their discussion through a focus on “terminal sedation” rather than “palliative sedation.” This failed to appreciate the commonness of proportionally administered palliative sedation in treating patients for anxiety, agitation or delirium. They argued as a result for the use of the words “terminal sedation” in the medical record, showing a clear bias in their line of reasoning. Poor understanding of palliative care leads to a flawed recommendation about using the word “terminal” when sedatives are being discussed.

In examining suicides in the chronically medically ill, there was no consideration of mental illnesses such as depressive disorders and adjustment disorders with demoralization. They cited examples from the coroner where “the deceased remained anxious and depressed about his

symptoms” (p.141) without any consideration of appropriate treatment of mental illness, concluding the chapter with the implication that tragic suicides ought to be avoided by VAD. The neglect of any consideration of psychiatric reasons for suicide revealed bias in writing this chapter.

**Key finding:** Proportional palliative sedation is a necessary and useful symptomatic treatment for anxiety states, agitation and delirium across any illness journey, including at the end of life. Use of the pejorative terminology “terminal sedation” is politically based and unwise. Moreover, most suicides, even when medical illnesses are co-morbidly present, occur due to mental illness, and suicidal patients require psychiatric assistance as the mental health focus of care provision.

**Commentary on Chapter 5: International experience with Voluntary Assisted Dying**

Through examination of aspects of euthanasia laws in the Netherlands, Belgium, Luxembourg, Switzerland, Oregon, Washington, California and Canada, the authors argue that there is no evidence of a slippery slope, no expansion to include psychiatric illness and children, no risk to the disabled, aged or vulnerable, no impact on suicide prevention or the development of suicide contagion, and that safeguards can be developed that won’t be subsequently changed by future legislators.

Oregon is presented as the safest model because proponents of euthanasia describe it as the most restrictive, including its exclusion of the mentally ill. Oregon has been the most secretive of all jurisdictions, releasing very little medical data about those using the legislation. However, Compassion in Dying, Oregon did fund the psychiatrist, Dr Linda Ganzini, to study patients seeking to make use of the legislation to prove that it was being safely administered and the depressed were being excluded. Ganzini followed 58 patients, finding that 26% of them were in fact depressed. Eventually 18 patients obtained prescriptions, and 33% of those who used the medication to suicide were clinically depressed. Ganzini and colleagues published these data in the British Medical Journal in 2008. Why did Dr Ganzini not develop a larger sample for this study? The reason offered by Dr Ganzini is that Compassion in Dying withdrew her funding when they realised that her findings revealed flaws in their processes. And so we discover that this apparently safe piece of legislation conceals the reality that it fails to protect some vulnerable citizens. Ganzini and colleagues concluded in their abstract that “the current practice of the Death with Dignity Act may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug.”

In reviewing the practice of euthanasia in the Netherlands, the authors argued that there was no evidence of a slippery slope because the Dutch legislation had accepted euthanasia for the mentally ill and children from its inception in 2002. However, the first Dutch case of euthanasia for the mentally ill occurred in 1991 when Dr Boudewijn Chabot euthanised a 50-year-old bereaved woman whose son had died four months earlier. He declared to the Supreme Court in 1994 that she suffered incurable grief and claimed a “defence of necessity” as he perceived it was his duty to relieve her suffering. By 1997, more cases of euthanasia of the mentally ill started to occur, and by 2012, there were 14 notifications for psychiatric disorders.

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and 42 for dementia. By 2016, there were 60 notifications for psychiatric disorder and 141 for dementia. More than half of the euthanasia for the mentally ill was delivered by the Levenseindekliniek, the public End-of-life Clinic. Kim and colleagues summarised 66 of these cases, whose details were published by the Regional Euthanasia Review Committee in the Netherlands (Kim et al, 2016). Some 24% of these patients were aged 30-50 years. While 55% of the psychiatric disorders were clinical depressions, others included autism, anorexia nervosa, grief and psychotic disorders. No psychiatric second opinion had been obtained in 11%, while 21% of these 66 patients had received the euthanasia from the End-of-Life Clinic.

In Belgium, a similar story exists where euthanasia for the mentally ill has included not only people with depressive and anxiety disorders, but also anorexia nervosa, autism, prolonged grief, personality disorders, neurocognitive and post-traumatic stress disorder. Through the second (2004-5), third (2006-2007), fourth (2008-2009) and fifth (2010-2011) reporting periods, the number of mentally ill people receiving euthanasia has crept up from 9 to 13 to 62 to 105. This steady rise is associated with reduced questioning about how remediable these disorders are. An insidious normalisation of killing the mentally ill has occurred in Belgium. Psychiatrists and other clinicians have been voicing protest at such unfettered practices, with 476 signatures to the REBEL (Review Belgium Euthanasia Law for Psychiatric Suffering) petition, being exemplified by Professor Dr. Dr. Ariane Bazan of the Université Libre de Bruxelles declaring, "Allowing euthanasia to prevent suicide is a bizarre reasoning." Furthermore, Materstvedt has criticised Belgium’s model of integrated palliative care with euthanasia, declaring how these units have become dumping grounds for helping patients come to accept that it is “time to die.” The economic pressure on beds renders the practice of palliative care futile, and makes the hospice unit no longer a specialist centre to alleviate suffering, but rather the place to go to receive euthanasia.

In both the Netherlands and Belgium, children with autistic disorders, spina bifida and other handicaps have been permitted to access euthanasia when this is requested by their parents. In 2014, legislators in Belgium amended their 2002 euthanasia law to permit access to minors. Similarly, the Netherlands adopted the Groningen Protocol in 2005 as a further development of their 2002 legislation. Dutch legislators subsequently responded to the pressure of advocates by establishing a Committee of Experts to advise the Public Prosecutor

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about individual cases of euthanasia being delivered to minors. History provides this clear evidence for how legislators are asked to eventually modify initially restrictive legislation to allow more liberal access. The authors of the JSC report acknowledge that “deliberate and considered legislative reform” may occur after the initial introduction of VAD legislation (p.173).

The Canadian legislation came about after the Canadian Supreme Court found that their Charter of Rights and Freedom guaranteed the right to life, liberty and security and the right not to be deprived thereof. Where a competent person consents to the termination of their life, and has a grievous and irremediable medical condition that causes suffering that is intolerable, they may receive euthanasia. While the Canadian Parliament was creating its legislation, in Alberta, a 58-year-old woman was allowed Medical Assistance in Dying (MAID) by the Alberta Supreme Court for a psychiatric condition known as a Conversion Disorder, in which spasms of her eyelid muscles over a nine-year period had caused her eyelids to stay shut, a condition known as blepharospasm. She had complained of migraines, insomnia and weight loss with deconditioning, such that she became wheelchair dependent, and needed others to transport her about. She was administered euthanasia (Alberta Court of Appeal Canada v EF, 2016 ABCA 155). The Canadian Parliament subsequently legislated to exclude mental illness as a reason to access MAID, but active political campaigns are currently being waged by euthanasia advocates to permit this.

Rousseau and colleagues published a survey of attitudes of Canadian psychiatrists to MAID for mental illness, with 21% of psychiatrists taking part in the survey, and only 29.4% recording their support for euthanasia for mental illness. The significant factors that were associated with psychiatrists opposing euthanasia for mental illness were clinicians having treated patients who would have met the proposed eligibility criteria for euthanasia at one stage during their illness and yet had later recovered from this illness; secondly, psychiatrists perceived that clinicians would reduce their commitment to treat a challenging patient and would be less likely to persist with treatment when symptoms were prolonged. These are very telling ways in which the vulnerable would receive a lower standard of care provision when their symptoms were proving difficult.

The authors of the JSC Report on End-of-Life Choices rejected many submissions that argued that vulnerable individuals would not be protected by safeguards proposed in any legislation favouring euthanasia and VAD, including concerns about elder abuse, the disabled, the mentally ill, and many elderly and disabled people who might feel they are a burden to their families and society. They argued on p.176 that there was no evidence of the mentally ill accessing physician-assisted suicide in Oregon, which Ganzini’s study clearly refutes. They also suggested that the 20% of referrals from the mentally ill seeking assisted dying in the Netherlands were not able to access euthanasia. Again, this is clearly an incorrect judgement. In contrast with what the authors of the JSC Report suggest, the proposed safeguards will not protect the vulnerable such as the mentally ill, the elderly and the disabled. Once legislation is introduced, strong pressure will emerge on legislators to relax safeguards and permit more people to access VAD. Canada looks likely to see over 3000 citizens receive euthanasia in 2018 in what is emerging as a very liberal framework there, and the WA proposal looks very similar in its language to Canada.

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Key finding: There are clear published findings of depressed patients accessing physician-assisted suicide in Oregon, growing numbers of the mentally ill being euthanised in the Netherlands and Belgium, and pressure mounting in Canada for euthanasia of the mentally ill. Legislators might be naive to not expect future pressure from euthanasia advocates in Australia. The proposed safeguards in the JSC recommended framework are unlikely to protect the vulnerable such as the mentally ill, the frail elderly and the disabled.

Commentary on Chapter 6: Legislation in other Australian jurisdictions

The first jurisdiction to be reviewed was the Rights of the Terminally Ill (ROTI) legislation in the Northern Territory in 1995. The Joint Select Committee interviewed the then Chief Minister of the Northern Territory, Marshall Perron, and the doctor who delivered the euthanasia, Philip Nitschke.

I published Nitschke his medical records of these patients in the Lancet in 1998. These cases included two who died receiving Nitschke’s care before the regulations of the Act were made law, four who died under the Act, and one who subsequently died after the Act was repealed by the Federal Parliament. The findings summarised in the Abstract were: “All seven patients had cancer, most at advanced stages [one had early stage cancer at post mortem]. Three were socially isolated. Symptoms of depression were common. Having met criteria of the Act, some patients deferred their decision for a time before proceeding with euthanasia. Medical opinions about the terminal nature of illness differed.” The key conclusion was “Provision of opinions about the terminal nature of illness and the mental health of the patient, as required by the ROTI Act, created problematic gatekeeping roles for the doctors involved.”

The JSC Report failed to acknowledge the failures of this legislation. Four of the seven patients cared for by Nitschke had inadequately treated clinical depression, were vulnerable, and not kept safe by this legislation. Doctor shopping was very evident until a second opinion certifying that the patient’s prognosis was terminal was obtained. The legislation required that the person offering this second opinion had expertise in the illness from which the patient was suffering. When a haematologist certified that a patient with lymphoma was not terminal, an orthopaedic surgeon provided the requisite second opinion about the terminal nature of this person’s illness (gatekeeping role). Although this behaviour was in clear breach of the legislation, the coroner who had responsibility to provide oversight of the application of the legislation choose to ignore this breach. Thus, the vulnerable were not protected as the legislators had intended.

Why might the coroner in the Northern Territory not have fulfilled his obligations under the ROTI legislation? His records were inspected, and all the data existed on his files. One might assume that he perceived that the Government wanted the legislation to succeed. To establish a hearing would have created a national media furore. Much simpler to ignore the safeguards built into the legislation. He behaved in a similar manner to international legislatures in the Netherlands and Belgium. Whether legislators establish a review board or

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set the coroner up to have oversight to ensure the legislation operates appropriately, there is a high likelihood that such a mechanism will not be able to protect the vulnerable from direct breaches of the legislation.

The JSC report details the recent Victorian Voluntary Assisted Dying Act 2017, its eligibility requirements and the operation of its Review Board. The JCS were silent about the likelihood of the legislation’s safeguards proving operational, but included suggestions from advocates for euthanasia that these safeguards be relaxed. It does point out that much of the Act appears bureaucratic, leaving open the question of whether the Review Board will function as intended, or fail to protect the vulnerable as many have suggested.

The JSC report reviews and contrasts proposals for legislation in New South Wales and Tasmania with the Victorian legislation, and recommends that WA legislation should be proposed by the government. They further advise that medical practitioners should not be prohibited from suggesting VAD to their patients, where this prohibition exists in the Victorian legislation. The JSC want assisted dying to be “considered as one of many clinical options available to patients for responding to terminal illness” (p.200), and therefore a treatment that clinicians in WA should be able to propose to their patients.

In discussing the “expected time until death” (p. 199) and whether this ought be a prognosis of six or twelve months, or be unrestricted, they note that there is “an undeniable political element to the inclusion of these timeframes in the legislation.”

The overarching sentiment brought forth by the authors in this chapter is that legislation ought to ensure that any safeguards “impede as little as possible on the ability of a competent person to exercise their autonomy in a timely fashion” (p. 201). Rather than view safeguards as necessary to protect the vulnerable, an emphasis is introduced that they not impede autonomy.

**Key finding:** The evidence from the ROTI Legislation in the Northern Territory is that the safeguards did not protect the vulnerable. Depressed patients accessed euthanasia. Suboptimal medical care was provided. Doctor shopping occurred. The coroner of the day failed to ensure adherence to the regulations under the Act. Processes of review in every jurisdiction appear to have failed to protect the vulnerable. The JSC Report suggests that doctors be able to propose VAD to their patients as an available treatment, risking that patients sense their physician believes they would be better dead. The JSC Report places its emphasis on less restrictive access to VAD rather than safety.

**Commentary on Chapter 7 Voluntary Assisted Dying**

Autonomy and self-determination are the key principles underpinning the JSC’s recommendation for VAD. The authors remind legislators of John Stuart Mill’s statement that power should only be exercised over a civilised community when it is to prevent harm to others in society (p.204). This tension is a familiar one to legislators who make road regulations to keep the community safe, who restrict access to firearms for the greater good of the community, and who even make laws restricting nicotine smoking in public places. Legislation often restricts autonomy.
The key question before legislators is therefore whether legislation can be safely designed to permit some people to access VAD without harm being brought to others who may be vulnerable and die unwittingly through their unintended access to such legislation? Society can of course be seduced by the principle of individual autonomy, and have a limited understanding of the ethic of interdependence. We can pervert autonomy when we forget that the human being is incomplete without the mutuality of others. Legislators have a responsibility to protect vulnerability, fallibility, weakness, frailty, and mortality. Avoiding harm may be a much greater legislative responsibility than permitting freedom.

To consider this question carefully, we must ask what are the key reasons that lead human beings to seek to end their lives, to hasten death, or to suicide? Studies have examined this most carefully and provide informative information. Mental illness has been strikingly prominent as it occurs co-morbidly with medical illness, exemplified by one Dutch study of people who requested euthanasia, where they found that the request for euthanasia was four times more prevalent among patients with Clinical Depression than patients who were not depressed. In Australia, Kelly and colleagues found that 14% of 256 patients referred to a palliative care inpatient unit for an advanced medical illness had an initial wish to hasten their death. The significant predictors were higher depressive symptoms, higher anxiety symptoms, lower family cohesion, lower social support, a greater perception of being a burden and poorer symptom control when first admitted. Importantly, in this Brisbane study, the referring GPs were independently asked if they were willing to offer physician-assisted suicide to these patients? Such willingness was significantly associated with their own sense of feeling poorly trained to offer psychological support to a patient whom they perceived to feel pessimistic about their future.

A separate body of work has examined the loss of morale and poor coping that can arise when patients feel trapped and no longer able to control the course of their illness. This mental state has been called Demoralization, and across ten years of study, its prevalence among 2,295 palliative care patients has been found to lie between 13 and 18 percent. Demoralization finds expression when patients talk of losing hope and sense of the point of their continuing lives. Thus, hopelessness and meaninglessness lie at the heart of becoming demoralized. Medicine can inadvertently precipitate this demoralized state when physicians talk of ‘no further treatment’ from their own specialty, presenting a one-sided perspective without due attention to the offerings of other disciplines like palliative medicine. Poor communication skills can wrongly generate this hopeless and trapped predicament. Furthermore, demoralisation has been found to be an important mediator of patients developing a desire to hasten their death. Studies in Taiwan, Germany and Australia have all found that demoralization is more powerful than

depression in generating this desire to die or suicidal thinking, and the risk ratio has been consistently three times as powerful.\textsuperscript{22, 23, 24}

Two questions arise from this state of knowledge. Firstly, can clinicians readily diagnose these mental illnesses of depression and demoralization in patients who inquire about euthanasia or VAD? And secondly, do these mental states interfere with a patient’s capacity for decision making? Neither of these questions were considered adequately by the JSC.

A recent Scottish study screened 21,000 cancer patients for depression over three years and reported that 73\% of the depressed patients had not received any treatment for their depression. It had been missed by their treating cancer specialists.\textsuperscript{25} Why? Lloyd-Williams described depression as “the hidden symptom” in palliative care patients,\textsuperscript{26} with clinicians’ tendency to normalise grief, misinterpret the cause of somatic symptoms, and often simply avoid asking about the patient’s mood and coping as the key reasons.\textsuperscript{27} Clinicians with the pressure of time may choose to not open what could be a Pandora’s box, and hence poorly assess for the presence of depression and related mental symptoms. Such a model of care is typically focused on the disease rather than the person. These data point incontrovertibly to the medically ill who become depressed as vulnerable patients who may not receive quality care towards the end of their life. They may need legislators to protect them.

Careful studies documenting the level of depression that occurs in patients receiving palliative care for cancer and other medical illnesses have found a prevalence rate of depression of 16.5\% (95\%CI 13.1–20.3).\textsuperscript{28} The prevalence of adjustment disorder (equivalent to demoralization) was found in this meta-analysis to be 19.4\% (95\% CI 14.5–24.8). Combined, these mental health issues have a quite high prevalence. Considerable skill, knowledge and understanding of the existential challenges of life are needed, yet medicine struggles to deliver this quality of care. Psycho-oncology services are very lacking in Western Australia. More funding to extend and train the palliative care workforce could remediate this predicament. There is so much to do.

The second question was the loss of capacity to make a competent decision about VAD because of cancer or other medical illness if the patient is also depressed or demoralized. Capacity changes with the context, the patient’s understanding of their illness, their prognosis, treatment options, and the impact all of this has on their mood and morale. The JSC Report offers the most basic commentary on the assessment of capacity. The MacArthur Competence

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Assessment Tool is used in studies that formally test for capacity in the setting of depressive illness or psychosis.\textsuperscript{29} This tool examines 1) a person’s capacity to understand and remember the diagnosis and treatment options; 2) ability to reason about risks and benefits of treatment options; 3) capacity to appreciate their predicament (prognosis) and the consequences of their choice; and 4) ability to communicate or express a choice. Of these four parts, the appreciation test is the most commonly disturbed by depressive and demoralization disorders. It becomes clear that a person’s appreciation of the worth and value of their future may be darkened by a negative worldview when depressed or demoralized.\textsuperscript{30} When it comes to a decision about continuing life, the highest standard of appraisal is needed to avoid error in this assessment. Moreover, recognition is needed of the way capacity can change, for it can be recovered and lost again. Thus, a person could have capacity when they ask for VAD medication but not use it at that time, and then lose capacity in the future if given a hopeless message by their physicians, only to ingest a fatal medication while they lack capacity. The changeability of capacity was overlooked by the JSC.

Advocates from Dying with Dignity and other Voluntary Euthanasia Organizations like to point out that, while studies show that more than 80\% of psychotic patients with an illness like Schizophrenia lose their decision-making capacity, when a unipolar depression is present, only 31\% have been confirmed to lose capacity.\textsuperscript{31} What is easily overlooked when these studies are cited is that the majority have involved psychiatric patients with reference to mental health treatments. Studies have not been undertaken in the palliative care setting. A recent meta-analysis however compared studies of incapacity in psychiatric and medical settings, concluding that the average proportion of patients with incapacity was 45\% (95\% confidence interval (CI) 39-51\%), with no difference between psychiatric and medical settings.\textsuperscript{32} These authors concluded their abstract with the comment that “Clinicians should be more alert to the possibility that their patients may lack decision-making capacity. Assessment of capacity should be frequent using the appropriate legal frameworks to act in the best interest of patients.”

If up to half of the patients with depression or demoralization can lack capacity at some stage during their palliative care illness, and many of these patients have their depression pass unrecognised or undiagnosed, we begin to see a significant subgroup who are indeed very vulnerable, may not appreciate what their future may hold, and may need the wise protection of legislators to ensure they do not sacrifice their lives prematurely. As Mills argued, the duty of legislators is foremost to prevent harm to others in society. Sanctioning medically assisted dying will not achieve this.

A very reasonable question is whether patients change their attitude to life-sustaining treatments after their depression is treated, compared to beforehand?\textsuperscript{33} This has been examined


in repeated studies of patients with depression,\textsuperscript{34, 35} who are asked to select from a list of 14 life-sustaining treatments what treatments they would agree to. Options include treatments like a blood transfusion, receipt of antibiotics for infection, oxygen therapy, through to the use of a ventilator and cardiopulmonary resuscitation. When depressed, patients only average 6 out of 14 treatment choices, but once they have recovered from their depression, they average 10 out of 14 options. Their interest in the range of life sustaining options clearly increases. Giving patients this right to an improved life is a key responsibility of good medical practice.

Although the JSC Report rejects the sole experience of mental illness as a sufficient cause of suffering to permit access to VAD on the grounds that this mental illness is remediable, the report is silent on the co-occurrence of mental and medical illness. There is an assumption carried throughout the report that when medical illness has death as a reasonably foreseeable consequence, the described ‘grievous and irremediable suffering’ is being caused by the medical illness, when often it is co-morbid mental illness that is causing the suffering, and the latter is indeed remediable if it is recognised and treated appropriately.

In this critique, the issue of mental illness and its capacity to interfere with decision-making capacity in the medically ill has been developed as one example of the vulnerable that legislators need to protect. There are unfortunately many other examples of the vulnerable in our society. These include the disabled, those afflicted with chronic illnesses, those who are poorly treated medically with missed diagnosis or inadequate treatment, those who see a doctor with limited medical skills, those with dysfunctional families and poor sources of support, those who feel a burden when their offspring are busy with their own lives, and those who carry many fears, whether a fear of dementia, unworthy dying, or dying alone. Designing adequate safeguards that can protect these citizens is a near impossible task.

In Finding 50, the JSC Report includes the criterion of “chronic illness” as well as advanced and progressive or neurodegenerative illnesses as an acceptable cause of grievous and irremediable suffering, without any prescribed timeline. This inclusion of chronic illness is extraordinarily broad and opens the door to people with many forms of chronic medical illnesses, who only need to state that for them, subjectively, there is suffering that is not acceptably alleviated, such that they can request VAD.

The JSC Report concludes by recommending that a VAD Framework be established by a Health Department Panel, which is to bring back to Parliament a piece of legislation to introduce VAD legislation into Western Australia. This step, of course, usually sets an unstoppable process in motion, and brings all the marketing powers of the Department of Health into play to reassure the State that this legislation will be safe and properly managed. The Cabinet is poised therefore with a most influential decision. If it accepts this JSC Majority Report in favour of the Minority Report written by the Honourable Nick P Goiran, MLC, and ignores this cautionary commentary on JSC Majority report, it will set the State of Western Australia on a pathway to accept medically sanctified death within society, a most grave and serious step for the State.

Medically assisted dying may be a disproportionate response that causes more social harm than good. Vulnerable people will be placed in difficult situations in which they have to make irreversible, complex choices under a great deal of pressure. To protect the vulnerable, legislators may need to subordinate individual patient autonomy to the interests of the wider


community. Legislators are making a choice between two imperfect systems in which some suffering will be difficult to treat or manage, and in which regulation of state sanctioned death will be difficult to perfectly enforce. Which system will do more harm to our community?

**Key finding:** Depression and demoralization in the medically ill are common reasons that bring about a desire to die. This is confirmed by Australian studies. Depression and demoralization often pass underdiagnosed and undertreated in oncology and palliative care. Depression and demoralization have a significant impact on decision-making capacity, and if unrecognised, the vulnerable are put at grave risk by VAD legislation. Treatment of depression restores interest in life-sustaining treatments. Unfortunately, doctors make errors in diagnosis, prognosis and treatment. Protection of the vulnerable, the frail elderly, the disabled and the mentally ill is a crucial responsibility of society and its legislators. Legislators ultimately must make a choice between autonomy sought by a few vocal advocates and the safety of the wider community, whose lives may be put at risk through the difficult regulation of state sanctioned death.