Submission
No 87

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

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Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

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Executive Summary

Case accounts of deidentified patients who have asked about or used the Victorian Voluntary Assisted Dying (VAD) legislation over the first two years of its operation are used to illustrate the problems and dangers of such legislation to the vulnerably ill. While parliaments attempt to create safe legislation through the use of so-called safeguards to avoid such peril, the system has not been foolproof and precious lives have been forfeited.

When legislators vote for or against VAD legislation, they choose between two systems, one set up to prevent or relieve suffering by empowering physician-assisted suicide, and the second by prioritising palliative and supportive care to ameliorate such suffering. These two systems of care are fundamentally incompatible – VAD abandons hope and shortens life; Palliative Care provides hope and extends life until natural death intervenes. Palliative care is never futile as life is precious; VAD declares life pointless and worthless.

The introduction of VAD is a disproportionate response that will cause more social harm than good through failure to protect the vulnerable, the mentally ill, those who are socially disadvantaged and disabled, and who may feel an inordinate pressure to sacrifice their lives when perceived to be a burden to others. VAD normalises suicide and will increase the rate of unassisted suicide in New South Wales in the future.

Legislators will find it impossible to develop adequate safeguards that can truly protect vulnerable citizens. It is not really a law that simply gives the autonomous right to VAD to a few who seek it; rather it is a law that endangers any number of frail and elderly citizens, who in their illness become vulnerable and need the protection of the State.

Major staffing and funding deficits still exist in palliative and supportive care services across the State, especially in regional, rural and remote areas. The focus of legislators' time could be better directed to improving medical care rather than weakening it. This submission argues for a halt to the passing of this legislation in New South Wales until more can be learnt from this Australian experiment into state sanctioned death and more can be done for the development of palliative care in New South Wales.

1. With Voluntary Assisted Dying (VAD) legislation having been enacted in other states of Australia, there is no better place to begin than with a question about “what is the experience like? and “what impact does it have on the quality of end-of-life care?” I work as a cancer psychiatrist with expertise in palliative care, and as a doctor with over 47 years of medical experience, I seek to share my point of view in the hope that legislators will gain insight into the challenges they face.

A. Have legislative safeguards succeeded in the Victorian VAD legislation?

2. The VAD Review Board in Victoria has recorded six monthly reports of numbers, but no clinical account of the experience at the grass roots level. My personal experience has shown me how standards of care are placed at risk, clinical depression proves a challenge and can be easily missed, and coercion can readily occur. This experience provides evidence about how safeguards fail to protect patients who are vulnerable at the end of their lives, despite the legislators hope that safeguards would make the legislation safe. Below are case reports that I have de-identified and they illustrate my experience of the first two years of VAD being available in Victoria.

3. A case of poor medical care (deidentified)

A patient struggled with persisting cancer-induced abdominal pain and asked for VAD. The physician initiated the process for a VAD application. The patient sought referral to a different physician at another hospital to obtain a second opinion about pain relief. Opioid rotation to methadone was initiated with good effect. The patient expressed surprise at achieving good pain relief and asked why the first physician at the specialist hospital had not done this similarly. When the two physicians communicated about what had happened, the first one reflected that once VAD was requested, this distracted from attention to analgesics as the process of VAD is lengthy and felt medically stressful for the physician. The physician had stopped trying to address the patient’s needs.

4. Here we see a case of poor medical care, out of character for the initial physician involved, but brought about because of the introduction of VAD as a solution to medical care. VAD can be perceived by many in society as a potential medical treatment. When a patient is struggling, it is increasingly talked about. What patients do not realise is that a certain group of doctors are trained to deliver VAD, and when asked, they can focus solely on the application and the provision of VAD medication. In Victoria at the 30th June 2021, 41 oncologists and 5 palliative care doctors were registered in the VAD portal as providers of VAD. If you happen to be receiving your care from one of these doctors, albeit unknowingly of their philosophical commitment to VAD, the potential for VAD to take priority over other aspects of care is real.

5. **A Case of depression (deidentified)**
   An oncologist told the patient that their cancer had progressed despite the recent anti-cancer therapy. The patient became upset and asked about VAD. Wondering how they were coping, the oncologist referred the patient to a cancer psychiatrist. The patient gave a history of several weeks of feeling hopeless and fatigued, with a loss of happiness and pleasure in life, such that life felt pointless, and s(he) had entertained thoughts of an overdose for a few weeks. The patient had sensed s(he) was in trouble with their cancer and had thoughts of giving up. Their family had encouraged the patient to ask for VAD. The psychiatrist diagnosed a clinical depression with clear cut symptoms and signs, and following treatment with antidepressants, the patient's wish to live returned and several months of a fulfilling life followed. The oncologist introduced an alternative anti-cancer treatment.

6. In a very typical pattern, the oncologist had not realised the patient was depressed. Preoccupation with the cancer and what is happening with it can block awareness of the development of depression. The predicament just seemed a miserable one to all involved. Before VAD was introduced into Victoria, more of these patients were identified and referred for assessment and treatment of depression. Now they are referred because VAD is a red flag, but the quality of person-centred care, of really knowing what a patient thinks and feels has slipped. VAD has become a distractor, a nuisance, a barrier to optimal care. To ask for VAD is less stigmatised than to gain help for depression. Depression is seen as a failure of coping adequately, without awareness of the many biological and cancer-related causes of it. VAD is perceived to be straightforward, but it actually threatens the quality of medical care.

7. **A case of coercion (deidentified)**

An email arrived from a patient's partner to say that their adult child was applying pressure for VAD medication to be taken. The patient had been approved for VAD and had the medication at home. The child returned to Australia from a country in which s(he) was employed to say goodbye to her/his parent. Having arrived, s(he) wanted to know when the medication would be consumed? S(he) wanted to be present when the medication was swallowed but had only returned for a three-week visit. The spouse understood the patient could live for a few months yet and wanted to enjoy that time together. When the email arrived, the coordinating doctor returned to the patient's home to re-examine the situation. A direct question was asked of the patient: "Do you feel pressured by your child to take the medication?" Perceiving that the child was being challenged, the patient denied any sense of pressure, but took the medication the very next week so that the child could return overseas again. The bereaved spouse was left to struggle with an angry and complicated grief.

8. The coordinating physician behaved naively in asking a direct question that put the parent on the spot and created defensiveness for the benefit of the child. This type of coercive predicament does damage and left complications for the bereaved spouse, but the VAD Review Board has no process to recognise the calamity. The coordinating physician did not perceive any error. The spouse was not going to report their child. The patient accepted family coercion to advantage the child and sacrificed life for the convenience of this child. This type of coercion must be understood to be inevitable by VAD legislators. It had occurred in Oregon – see the case of Kate Cheney, published in the Oregonian newspaper[1] and further analysed by Hendin and Foley as a clear example of similar coercion.[2] I would suggest that it will occur in every jurisdiction and safeguards cannot protect against it.

9. A case of the bereaved post VAD (deidentified)

The bereaved person said, "I didn't get a chance to say goodbye. At least not properly, the way I had intended. It all happened too quickly in the end. He

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[1] Erin Hoover Barnett, A Family Struggle: Is Mom Capable of Choosing to Die, OREGONIAN, Oct. 17, 1999, at G01.

[2] Hendin H, Foley K. Physician-Assisted Suicide in Oregon: A Medical Perspective. Michigan Law Review 2008; 106(8):1613-1634. https://repository.law.umich.edu/mlr/vol106/iss8/7

had that box with the medication in it. One day, out of the blue, he said that he was ready to take the medication." The bereaved was left feeling guilty, alone, and awkward about what had happened. It had been difficult to express her ambivalence yet now the stigma became apparent. She didn't like to tell friends how he had died. A new barrier had emerged that interfered with the normal process of mourning.

10. No provision has been made in VAD legislation for the bereaved, yet some suffer and remain silent after their loss. They know that others praise and campaign for VAD in the media. It is presented as an acceptable and right thing to do. So, when people do not share this experience, they feel silenced and alone. Some have felt unable to tell the story to a bereavement group. Others are left angry and abandoned. Care of the bereaved has always been part of good palliative care, but it seems to be of little interest to the lobbyists, including medical practitioners registered in the VAD portal, who promote VAD in the media. VAD is a procedure, a medical treatment approved by an Act of Parliaments, but the process as developed offers a poor standard of whole-person and family-centred care.

11. These four clinical cases are a snapshot of everyday clinical experience, which illustrate for this author the perils of believing that adequate safeguards to protect vulnerable patients can be legislated for. In a VAD world, this type of patient experience can easily occur. It points to a lower standard of medical care unwittingly coming about because of VAD. Legislators must choose between granting autonomy to an educated minority who seek to control their dying and protecting the rights of the frail vulnerable who might be at risk because of their illness and its treatment, yet lack full insight into all of the influences at bay.

B. Are there challenges for legislators interested in introducing voluntary assisted dying or euthanasia to benefit those wanting autonomous choice over when and how they die that derive from the insights of psychiatry?

12. I want to make it clear that my motivation in making this submission is about enhancing the quality of care that we deliver as a community in caring for patients and their families with cancer and other progressive, life-threatening diseases, including during end-of-life care. **We have much still to achieve as a community to realize an optimal standard of care provision.**

13. It is conceivable that many who advocate for physician-assisted death have witnessed poor quality care to loved ones in their past. Others have limited insight into what psycho-oncology can do, rarely refer if they are clinicians, and out of pity for those perceived to be suffering, want to be able to hasten death

via medical assistance in dying (MAID). In my experience, which is informed by extensive international work, many clinicians who prescribe barbiturates to their patients to hasten their dying lack skills and confidence in restoring hope and improving quality of life in patients facing the end of their life.

14. I don’t perceive that the fundamental clinical stances of 1) supporting quality of life and optimal palliative care, and 2) supporting euthanasia are compatible. As a result, the medical community divides and two different standards of care emerge – one that promotes hope, the dignity of the person and affirms living until natural death intervenes, and the second that is neutral about the value of a person, allows them to suicide if they wish, and sees managed death as the solution to many complex and challenging medical problems.

15. Legislators need to be mindful and concerned about the disabled, the incapacitated, and those who might be pressured, albeit indirectly, by family members or a medical community that embraces physician-assisted suicide. Have legislators heeded evidence about cases of involuntary euthanasia seen in other societies that have legalized this practice?[3] Are legislators confident that they can design suitable medical and psychiatric safeguards to protect the vulnerable who become suicidal and suffer mental illness through the bylaws and gate-keeping mechanisms built into such legislation? These are some of the many very difficult issues that government must determine. Let us consider Oregon as one example.

16. 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.[4] 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. Ganzini and colleagues concluded “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.”[12]

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[3] van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-Life Practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007;356:1957-65.

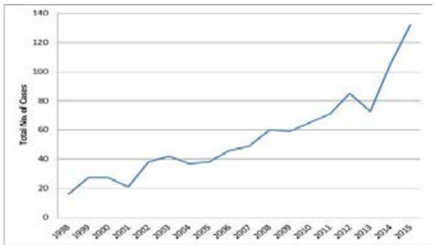
[4] Ganzini L, Goy ER, Dobscha SK. (2008). Prevalence of depression and anxiety in patients requesting physicians’ aid in dying: cross sectional survey. BMJ 2008; 337 doi: https://doi.org/10.1136/bmj.a1682

17. I had the opportunity to study the patients that Philip Nitschke cared for in Darwin when euthanasia was legal in Australia. Together, we published the clinical accounts of these patients in the Lancet in 1998.[5] The legislative gate keeping mechanisms established by the Rights of the Terminally Ill (ROTI) legislation failed to protect the vulnerable. Poor medical care was evident, with inadequate use of palliative medications, non-use of radiation therapy, inadequate treatment of depression and suicidal thinking in patients; in short, the abysmal use of palliative care.[6],[7],[8] The experience of observing the poor quality of care delivered during this period of the ROTI legislation convinced me of the legislative challenges of protecting the vulnerable while trying to meet the needs of those desiring voluntary euthanasia.

C. Are there models of medically assisted dying in operation in other countries that satisfactorily protect the vulnerable?

18. Oregon is most commonly put forward as an example that administers assisted dying to a small minority of citizens without endangering society. The evidence from the study by Ganzini et al suggests that this does not protect vulnerable people.[9] It has also been suggested that the rate of medically assisted dying is stable in Oregon. Yet when one tracks the rate of utilisation over time, its recent growth has been at 13.2% annually.[10] Such growth has been argued to represent the normalization of medically assisted dying in this society.

Oregon deaths by PAS annually.



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[5] Kissane DW, Street A, Nitschke P. (1998) Seven deaths in Darwin: studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet, 352: 1097-1102.

[6] Street AF, Kissane DW. (1999-2000) Dispensing death, desiring death: an exploration of medical roles and patient motivation during the period of legalized euthanasia in Australia. Omega, 40: 231-248.

[7] Kissane DW (2000). Case presentation: a case of euthanasia, the Northern Territory, Australia. J Pain Symptom Manage 19(6): 472-3.

[8] Kissane DW. (2002) Deadly days in Darwin. In: The Case Against Assisted Suicide, K. Foley & H. Hendin (eds). Pp. 192-209. Johns Hopkins University Press: Baltimore.

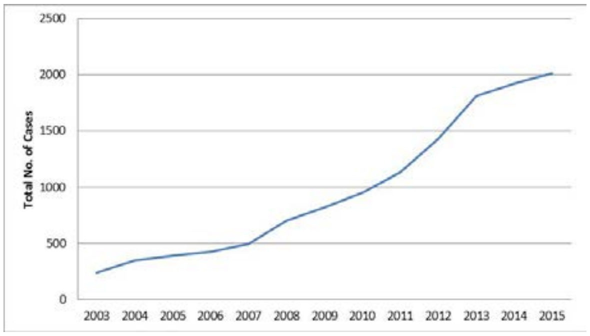
[9] Ganzini L et al. Depression in those seeking PAS. BMJ, 2008

[10] Emmanual et al, JAMA, 2016

19. Belgium has very liberal legislation that permits euthanasia for children and the mentally ill. Thus, medically assisted dying is not restricted to the terminally ill but can be used by those who decide that their sickness is intolerable. Chambaere and colleagues (2010) studied 6927 deaths across a six month period in Belgium,[11] and reported that 66 deaths occurred without any request coming from the patient**, the family providing the consent for euthanasia, and in 8% of these cases, the family cited concern that their decision would have upset or harmed the patient receiving the euthanasia. Family burden was identified in 50% of the 66 cases where no patient consent was obtained.**

20. Euthanasia of the mentally ill is also permitted in Belgium. In their second reporting period (2004-2005), 9 deaths were for chronic depression, Alzheimer's, Huntington's and Jacob-Creutzfeld disorders. In their third reporting period (2006-2007), 13 patients received euthanasia because of depression and dementia; in their fourth reporting period (2008-9), 62 mentally ill people received euthanasia; and by their fifth reporting period (2010-2011), this number had risen to 105. Patients with anorexia nervosa, schizophrenia, autism, personality disorder and prolonged grief were now included among those accessing euthanasia, alongside depression. This is a process of normalization of assisted suicide within a society.

21. The exponential rate of growth of euthanasia in Belgium is 19.6%. The process of normalization of medically assisted dying has been seen in every country, and ultimately changes forever the nature of medical practice. Legislators would be naïve to believe that they can introduce a tightly controlled process that won't increase in subsequent years once the door is opened.



Belgium's growth in euthanasia is 19.6%[12]

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[11] Chambaere K et al, CMAJ 2010. DOI:10.1503/cmaj.091876

[12] Emmanual et al, JAMA, 2016

22. In reviewing the practice of euthanasia in the Netherlands, proponents have 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 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).[13] Some 24% of these patients were aged 30-50 years. While 55% of the psychiatric disorders were clinical depression, 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.

23. **For psychiatrists who have spent their careers attempting to restore hope in the depressed and demoralized so that suicide is prevented, these trends towards physician-assisted suicide are enormously worrying and the product of society normalising the acceptability of suicide for any form of subjectively determined suffering, whether mental or physical in nature.** This flies in the face of the public education and preventive health measures which are funded to reduce suicide rates in the general community.

D. Does Voluntary Assisted Dying increase the rate of unassisted suicide in the community?

24. This is a critical question for NSW legislators to consider. I contend that it does increase the rate of suicide because it normalises suicide within the community and leads more people to commit suicide. The first body of evidence in support of this notion was published in 2015 by Dr David Jones from the Anscombe Bioethical Centre in Oxford, United Kingdom. Jones and Paton compared the rate of unassisted suicide in States in the USA that had access to medically-assisted suicide with the rest of the country.[14] As shown in the graph below, a clear trend emerged that suicide increased for such states with physician-assisted suicide compared to the rest of the USA.

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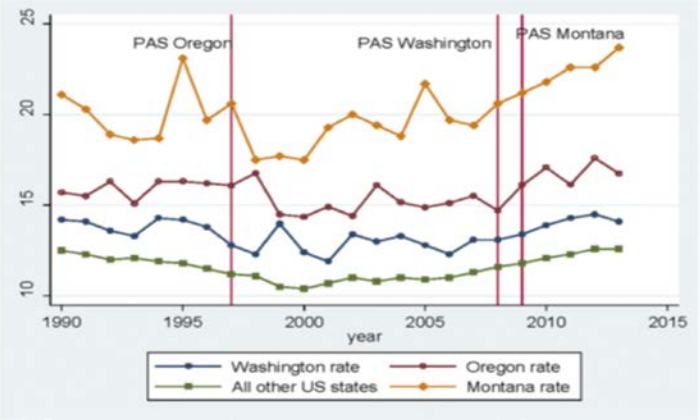
[13] Kim SYH, De Vries R, Peteet JR. (2016). Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands 2011–2014. JAMA Psychiatry, 73(4): 362–368. doi:10.1001/jamapsychiatry.2015.2887

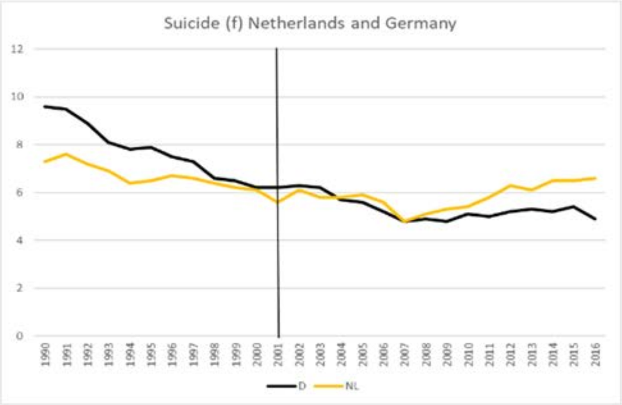
[14] Jones DA, Paton D. How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide? Southern Medical Journal 2015 Oct; 108(10): 599-604. https://doi.org/10.14423/SMJ.0000000000000349

25. Detractors have criticised this study by pointing to Jones and Paton’s careful statistical analysis that revealed loss of significant findings when the results were controlled for other socioeconomic variables. The trend was nonetheless positive and remarkable. Jones has therefore continued these studies and recently compared rates of suicide in The Netherlands and Belgium with neighbouring countries in the European Union. While the rate of unassisted suicide has steadily declined in Germany, it has clearly begun to rise again in The Netherlands as suicide has been normalised in that country. Comparing France and Belgium, rates of suicide have plateaued in Belgium, which has the third highest suicide rate in the European Union, behind only Slovenia and Lithuania.

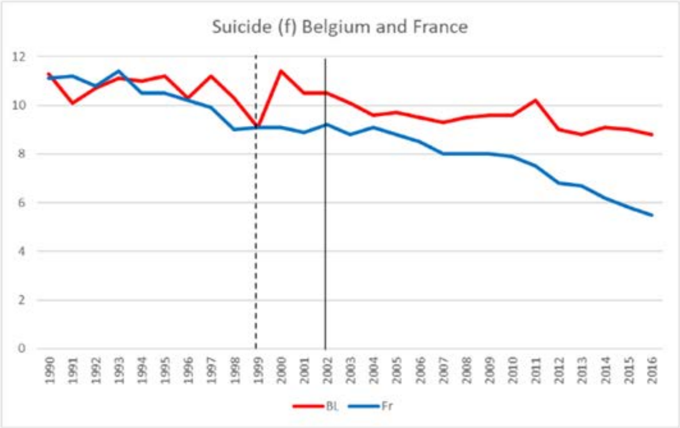
Unassisted suicides per 100,000 population comparing Oregon, Montana & Washington with all other US states 1990-2013. See Jones D et al, Southern Medical Journal, 2015



While the rate of unassisted suicide has declined steadily in Germany, the rate has begun to rise in the Netherlands[per Dr. D Jones, Anscombe Ethics Centre, UK]



While the rate of unassisted suicide has declined steadily in France, rates have plateaued in Belgium. Belgium still has the third highest rate of suicide in the European Union, only exceeded by Slovenia and Lithuania **[per Dr. D Jones, Anscombe Ethics Centre, UK]**



26. **Euthanasia and VAD create a cultural acceptance of suicide.** If suicide is acceptable for the medically ill at the end of life, why wouldn't a society begin to consider it acceptable at other times of life? When the mentally ill feel hopeless, why not allow suicide, including voluntary assisted dying, to ease their pain as The Netherlands and Belgium do? Suicide for autism, anorexia nervosa, clincial depression, prolonged grief, or schizophrenia?

27. **If legislators in New South Wales permit voluntary asissted dying, they must expect that rates of unassisted suicide will rise in NSW.** This is a very heavy responsibility that ought to be clearly understood. Canada has been grappling with whether to extend its medically-assisted dying (MAID) legislation to now include the mentally ill. Psychiatrists were surveyed about this in Canada (number = 528) and two-thirds opposed this development, declaring that, if it was brought in, **they would give up more easily in caring for their patients**, and importantly, they recognised that prior patients in their care would have been eligible for MAID and yet, with perseverance, they had gotten these patients better in the course of time.[15]

28. It is an oxymoron that we strive to prevent suicide in our community on the one hand, and then we begin to allow it for a select group. If NSW does allow VAD, it is inevitable over time that more teenagers will suicide when they feel unsure about the meaning and point of their future lives; more drug dependent patients will suicide; and more mentally ill patients will suicide. A society that normalises the right to suicide must expect that rates of unassisted suicide will rise, especially with the deficits that already exist in funding mental health care in Australia.

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[15] Rousseau S et al. A National Survey of Canadian Psychiatrists' Attitudes toward Medical Assistance in Death. Can J Psychiatry, 2017 Nov; 62(11):787-794. https://doi.org/10.1177/0706743717711174

E. The intellectual appeal of controlled dying when one is ready to die.

29. Many people in society fear the process of dying. Others have witnessed the death of a relative or friend. They are often saddened and shocked by such a process as we are a death-denying society, with little familiarity with the dying process until people become elderly. To observe a death with a terminal delirium can be frightening for the lay person, however, this is typically the result of inadequate palliative care. Legislative decisions ought not be based upon single sad case stories. The needs of the vulnerable, the elderly, the frail and disabled, those who are sick yet want to live, these are the people on which legislation ought to be framed. Too often people develop an intellectual position in favour of euthanasia “when the time is right”, only to discover that their own life is precious, and to cling to life for as long as possible when their natural death is approaching. It can be so unwise to risk forever changing medical practice based on such individual experience resulting from unfamiliarity with death; yet legislators sadly record such decision-making in Hansard reports again and again.

F. Can palliative care and physician-assisted dying comfortably co-exist?

30. Legislators must appreciate the fundamental differences in philosophy and approach that exists between the disciplines of palliative care and voluntary assisted dying practices. In Belgium, efforts have been made to integrate palliative care and euthanasia (Materstvedt, 2013).[16] The hospice unit becomes the place to stay until the time is right for euthanasia to then be delivered. The result is that patients fear admission to palliative care, and when there is pressure upon bed occupancy, it becomes economically advantageous to deliver euthanasia so that another patient has a bed to be admitted into.

31. In Australia, palliative care has never been viewed as futile. There are always treatments that can be given to optimise quality of life and sustain the focus on living life out fully, until a natural death intervenes. Suggestions made by the few to integrate palliative care with voluntary assisted dying risk damage to the reputation of palliative care as a discipline and risk increasing the public’s fear of inpatient hospice units. Palliative care maintains hope for sustained quality of life, and studies have indeed shown that optimal palliative care, in contrast to regular oncological care, increases survival. The substantial majority of palliative care physicians remain opposed to voluntary assisted dying.

G. Can the Government of New South Wales safely legislate for Voluntary Assisted Dying?

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[16] Materstvedt LJ, Progress in Palliative Care, 2013

32. Autonomy and self-determination are the key principles underpinning any consideration of VAD. John Stuart Mill stated that power should only be exercised over a civilised community when it is to prevent harm to others in society.[17] 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 smoking in public places. Legislation often restricts autonomy.

33. 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? Legislators have a responsibility to protect vulnerability, fallibility, weakness, frailty, and mortality. Avoiding harm may be a much greater legislative responsibility than permitting freedom.

34. 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? One Dutch study of people who requested euthanasia found that the request for euthanasia was **four times more prevalent among patients with Clinical Depression than patients who were not depressed.**[18] 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.[19] 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 **would be** 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.[20]

35. A separate body of work has examined the loss of morale that can arise when patients feel no longer able to control the course of their illness. This 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.[21]

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[17] Sanderson A, Holt CJ. The Report of the WA Joint Select Committee on End of Life Choices: My Life, My Choice.

[18] van der Lee ML, van der Bom JG, Swarte NB, Heintz AP, de Graeff A, van den Bout J. (2005). Euthanasia and depression: a prospective cohort study among terminally ill cancer patients. Journal of Clinical Oncology, 23: 6607-12. Doi: 10.1200/JCO.2005.14.308

[19] Kelly BJ, Burnett PC, Pelusi D, et al, (2003). Factors associated with the wish to hasten death: a study of patients with terminal illness. Psychological Medicine, 2003, 33: 75-81.

[20] Kelly BJ, Burnett PC, Pelusi D, et al (2004). Association between clinician factors and a patient's wish to hasten death: terminally ill patients and their doctors. Psychosomatics, 45:311-318. Doi: 10.1176/appi.psy.45.4.311

[21] Robinson S, Kissane, DW, Brooker, J, Burney, S. (2015). A systematic review of the Demoralization Syndrome in individuals with progressive disease and cancer: A decade of research. *Journal of Pain and Symptom Management*, 49(3): 595-610. doi:10.1016/j.jpainsymman

Medicine can inadvertently precipitate this demoralized state when physicians talk of 'no further treatment' from their own specialty if they fail to identify offerings of other disciplines like palliative medicine. 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.[22, 23, 24]

36. **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?**

37. Depression and demoralization may not be identified by cancer specialists.[25] Lloyd-Williams described depression as "the hidden symptom" in palliative care patients,[26] with clinicians' tendency to normalise grief, misinterpret the cause of somatic symptoms, or not asking about the patient's mood and coping as the key reasons.[27] A heavy emphasis on biomedical care means that busy health professionals may assign less importance to the psychosocial concerns of patients. 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%.[28] The prevalence of adjustment disorder (equivalent to demoralization) was found in this meta-analysis to be 19·4%. However, in the absence of appropriately-resourced psycho-oncology and supportive care services, there are limited options for treatment.

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[22] Fang CK, Chang MC, Chen PJ, et al. (2014). A correlational study of suicidal ideation with psychological distress, depression, and demoralization in patients with cancer. Supportive Care in Cancer, 22:3165–3174 DOI 10.1007/s00520-014-2290-4

[23] Robinson S, Kissane DW, Brooker J, Hempton C, Burney S (2017). The relationship between poor quality of life and desire to hasten death: A multiple mediation model examining the contributions of depression, demoralization, loss of control, and low self-worth. Journal of Pain and Symptom Management, 53(2). doi: 10.1016/j.jpainsymman.2016.08.013

[24] Vehling S, Kissane DW, Lo C, Glaesmer H, Hartung TJ, Rodin G, Mehnert A. (2017). The association of demoralization with mental disorders and suicidal ideation in patients with cancer. *Cancer.* 123(17): 3394-3401. doi: 10.1002/cncr.30749

[25] Walker J, Hansen CH, Martin P, et al. (2014) Prevalence, associations and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinicial data. Lancet Psychiatry, 1: 343-350. Doi: 10.1016/S2215-0366(14)70313-X

[26] Lloyd-Williams M.. (2003). Depression—the hidden symptom in cancer J Royal Soc Med, 96:577-581.

[27] Noorani NH, Montagnini M. (2007). Recognizing depression in palliative care patients. J Palliat Med, 2007, 10: 458-64. Doi: 10.1089/jpm.2006.0099

[28] Mitchell AJ, Chan M, Bhatti H, et al. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol, 12: 160–74. Doi: 10.1016/S14702045(11)70002-X

38. Capacity for informed decision-making 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 MacArthur Competence Assessment Tool is used in studies that formally test for capacity in the setting of depressive illness or psychosis.[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.[30] 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. 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 message by their physicians which they perceive implies lack of hope. The variability of capacity is of central importance.

39. 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.[31] These are studies of psychiatric patients and they 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, 39-51%) with no difference between psychiatric and medical settings.[32] These authors concluded "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."

40. 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

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[29] Grisso T, Appelbaum PS, Hill-Fotouhi C. (1997). The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. Psychiatric Services, 48(11):1415-9. DOI: 10.1176/ps.48.11.1415

[30] Kissane DW. (2004). The contribution of demoralization to end-of-life decision making. *The Hastings Center Report,* 34(4):21-31.

[31] Owen GS, Richardson G, David AS, Szmukler G, Hayward P, Hotopf M. (2008). Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study. BMJ, 30;337:a448. doi: 10.1136/bmj.39580.546597.BE

[32] Lepping P, Stanly T, Turner J. (2015). Systematic review on the prevalence of lack of capacity in medical and psychiatric settings. Clin Med (Lond). 15(4):337-43. doi: 10.7861/clinmedicine.15-4-337.

their future may hold, and who need protection. As Mills argued, the duty of legislators is foremost to prevent harm to others in society. Sanctioning medically assisted dying will not achieve this.

41. A reasonable question is whether patients change their attitude to life-sustaining treatments after their depression is treated, compared to beforehand.[33] This has been examined in repeated studies of patients with depression,[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 accept on average 6 out of 14 treatment choices, but once they have recovered from their depression, they accept on average 10 out of 14 options. Their interest in the range of life sustaining options clearly increases. Giving patients the right to an improved life is a key responsibility of good medical practice.

42. In this submission, 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 a vulnerable population that legislators need to protect. There are many other examples of the vulnerable in our society. These include the disabled, those with chronic illnesses, those who experience family violence, the homeless and those from cultural minorities as well as those with limited health literacy and financial strain. Designing adequate safeguards that can protect all of these citizens is a near impossible task.

H. Are current palliative care services adequate for New South Wales?

43. It is the contention of this submission that inadequate access to palliative care and evidence-based psychosocial care are fundamental issues affecting those facing life-limiting illness. While Australian palliative care services have been substantially developed during the last two decades, this growth focused on providing palliative care physician and nursing services, but the provision of psycho-oncology and consultation-liaison psychiatry services have never been appropriately funded. A major developmental and educational need exists within New South Wales to enhance access to psycho-oncology and consultation-liaison psychiatry services for those with life-limiting illness. **Moreover, regional, rural and remote provision of comprehensive palliative care is lacking in New South Wales.** In the absence of such

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[33] Blank K, Robison J, Doherty E, Prigerson H, Duffy J, Schwartz HI. (2001). Life-sustaining treatment and assisted death choices in depressed older patients. J Am Geriatr Society, 49(2): 153-61.

[34] Ganzini L, Lee MA, Heintz RT, Bloom JD, Fenn DS. (1994). The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. Am J Psychiatry. 151(11):1631-6.

[35] Hooper SC, Vaughan KJ, Tennant CC, Perz JM. (1996). Major depression and refusal of life-sustaining medical treatment in the elderly. Med J Aust. 1996 Oct 21;165(8):416-9.

services, patients are more likely to turn to voluntary assisted dying out of desperation to obtain relief of their suffering, when the provision of palliative, psychosocial and psychiatric care – essential supportive care services – are a basic human right.

I. Won't screening for distress adequately recognise the vulnerable and protect them from VAD?

44. A clinical model has been developed which involves the formal screening for distress. However, this is only the first step in a process of identification of vulnerable patients who may benefit from palliative and psychosocial care. There are barriers to such care including stigma, difficulty with access to services which are insufficiently staffed, and lack of understanding about the potential benefits of such care. In 2014, a major Scottish study of 21,000 cancer patients revealed that 73% of depressed patients were not in receipt of treatment.[36] This highlights the importance of developing a comprehensive program of identification, triaging, clinical referral pathways and capacity-building. Although some progress has been made in introducing distress screening in New South Wales, a major problem lies in the inadequate staffing of specialist psycho-oncology services. Many services have access to social work, however access to psychology and psychiatry services providing specialist psycho-oncology care is much more limited. **There are significant inequities across metropolitan, regional and rural zones, with major deficits in outlying sectors**.

45. Screening for Psycho-Existential Symptoms (PeSAS) in palliative care and towards the end of life is a new program that the Commonwealth Department of Health introduced in 2020. With Covid restrictions, it has only reached one palliative care program thus far in New South Wales, the Sacred Heart Hospital in Sydney. Following a model of screening for physical symptom levels (e.g., Edmonton Symptom Assessment Scale (SAS) and the PCOC SAS used in Australia), screening with the PeSAS captures 10 symptoms of psycho-existential distress and allows these to be monitored during care provision.[37] Included among these symptoms are hopelessness, pointlessness, desire for death, discouragement and depression – symptoms that identify existential suffering and the need for active treatment. Across other parts of Australia, many palliative care services use the *PalCare Medical Record*, into which the PeSAS is integrated alongside the University of Wollongong's PCOC SAS. There

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[36] Walker J, Holm Hansen C, Martin P, et al. Prevalence, associations and adequacy of treatment of major depression in 21,151 cancer outpatients: a cross-sectional analysis of routinely collected clinical data. *Lancet Psychiatry* 2014; published online Aug 28

[37] **Kissane DW**. (2020). Education and assessment of psycho-existential symptoms to prevent suicidality in cancer care. *Psycho-Oncology* vol 29, no 9; https://doi.org/10.1002/pon.5519

is a need for further funding and development of PeSAS screening throughout NSW, an endeavour that would greatly reduce suffering and enhance the quality of palliative care that could be delivered.

46. Focusing specifically on palliative care patients, Mitchell and colleagues collated data from nearly 100 studies and reported rates of Depression as **16.5%,** Adjustment Disorders (problems coping adaptively) **15%** and Anxiety Disorders **10%**.[38] Studies find higher rates of psychiatric disorder in palliative care and at the end-of-life because of the threat of death and the many cumulative losses that have taxed the coping and adaptation of these patients. Australian data by Brian Kelly's group (2004) and my own research group (Love et al, 2004) were included in Mitchell's meta-analysis.

47. **These rates of psychiatric disorder are typically three times higher than the rates of mental illness in the general community and across the lifespan**. My clinical experience points to very similar rates occurring within our Australian community in the palliative care setting. Very few of these patients receive comprehensive psychosocial care for these disorders.

J. Conclusion

48. To conclude this submission, I return to the vital need for palliative care and the related discipline of psycho-oncology to grow to improve the care that our society receives at the end-of-life. Continuity of care is a vital principle for patients and their families, and many of the strategies used in patients with early stage and curable cancers also apply to those with progressive disease. Increasingly medicine offers aggressive medical treatments for those who experience recurrence of their cancer. Medicine needs to match this zeal with access to expert supportive and psychosocial care.

49. As a psychiatrist trained to care for the medically ill, I recommend that the Inquiry recognise the many sources of vulnerability that can interfere with decision-making capacity and place people at risk in a society that normalises voluntary assisted dying. 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.

50. I recommend against the introduction of voluntary assisted dying so that legislators more adequately protect the vulnerable in our community. I believe that VAD will lower the standard of medical care delivery, increase the

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[38] Mitchell AJ et al., *Lancet Oncol* 2011; 12: 160–74; Walker J, Holm Hansen C, Martin P, et al. Prevalence of depression in adults with cancer: a systematic review. Ann Oncol 2013; 24: 895–900.

occurrence of unassisted suicides in our society, and initiate the calls for VAD for the mentally ill, as has clearly happened in other countries.

51. If it helps your Standing Committee on Law and Justice, I am willing to appear to answer any questions arising from my submission or respond to any other issues that you wish to ask about. Thank you for giving me this opportunity to address the matters dealt with in this submission.

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