

Submission

to the

WA Parliament Joint Select Committee on End of Life Choices

inquiring into

The need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices.

Submitted by Rev Dr Joseph Parkinson
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Submitted on behalf of the **L J Goody Bioethics Centre**

Note: I wish to appear before the Committee to present our position in person.

Who we are

The L J Goody Bioethics Centre was founded in 1985 as an agency of the Roman Catholic Archdiocese of Perth to provide public and private consultation, education and research in ethical aspects of contemporary health care practice and public health policy for the people of Western Australia. Our services include

- a confidential ethics advisory service for members of the public, as well as for the medical and nursing professions, and members of health ethics committees;
- on-call clinical ethics consultancy to hospitals and healthcare systems in WA;
- education in general ethics, bioethics, clinical and research ethics.

Centre staff are also members of a number of clinical and research ethics committees in the public and private healthcare sectors including the Health Department of WA and the new Perth Children's Hospital (formerly Princess Margaret Hospital). All private and clinical consultations are offered free of charge.

General Position

The L J Goody Bioethics Centre submits that

1. this Inquiry is required by its Terms of Reference [TOR] to inquire into voluntary assisted dying [VAD] in Western Australia (see Introduction);
2. voluntary assisted dying is not primarily a medical but a legal matter;
3. voluntary assisted dying has undesirable effects and raises many serious questions;
4. Parliament therefore should not, for any reason or in any circumstances, legislate assisted dying which would create an irreversible breach in the universal prohibition on one person intentionally killing another or assisting another to commit suicide;
5. Parliament should rather, as a matter of urgency, allocate sufficient funds and other resources to ensure that every West Australian – especially those in rural and remote areas – has equal access to the same excellent levels of palliative and other end-of-life care;
6. Parliament should provide greater legal certainty to health professional who deliver care solely according to medical indications and the practice standards of their professions.

Introduction

7. The Inquiry concerns citizens making informed decisions regarding their own end of life choices.
8. TOR 2 seeks review of ‘legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions.’ Legislation is currently proposed in Victoria and New South Wales to introduce so-called ‘voluntary assisted dying’ [VAD] by which is usually meant either *euthanasia* (when one person directly and intentionally kills another on request) or *assisted suicide* (when one person provides help to another who takes his/her own life). This submission will use ‘VAD’ to capture either or both.
9. Furthermore it is the stated intention of some current WA Members of Parliament to seek introduction of VAD laws in this State. In view of these facts, TOR 2 and 3 clearly require the Inquiry to examine the possibility of VAD laws in Western Australia.
10. TOR 1 enquires into practices currently utilised in the medical community. Good clinical care sometimes requires a doctor to apply treatments whose primary intention and mode of operation is to relieve pain, even if the patient’s life is shortened thereby. These are not ‘euthanasia’ because their sole intention is to relieve pain, not to kill the patient. They are totally different from VAD. Nevertheless doctors providing such treatments sometimes feel exposed. I submit that Parliament needs to strengthen legal protections for all medical professionals who act solely on medical indications and within the accepted standards and protocols of their professions

11. TOR 4 seeks to examine the role of statutory instruments currently in use in WA which have a much broader application, namely Advance Health Directives [AHD] and Enduring Powers of Guardianship [EPG]. I submit that with reference to TOR 4 and the actual reasons people seek VAD (noted below), the central focus of this inquiry is not medical but legal, in particular a person's common law right to autonomy or self-determination.

VAD is not primarily a medical matter

12. A citizen's own end-of-life decisions in general, and desire for VAD in particular, do not necessarily or even primarily concern medical matters. Research into the reasons people opt for VAD reveals that 'treatment of intractable pain' is almost never the primary reason.

13. Some research suggests that 'pain treatment' in fact comes about seventh in the list (after 'feeling tired or uncomfortable', 'loss of function', 'fear of loss of sense of self', 'desire for control', 'fear for the future' and 'bad past experiences of death').¹

14. The *Oregon Death with Dignity Act Report for 2016* notes the three most frequently mentioned end-of-life concerns were losing autonomy (89.5%), a decreasing ability to participate in activities that make life enjoyable (89.5%), and loss of dignity (65.4%).²

15. Nurses working in hospices in Oregon report that pain and pain control rated tenth in major drivers of desire for VAD among hospice patients after desire to control the circumstances of death, the wish to die at home, loss of independence or fear of such loss, and loss of dignity or fear of such loss³

16. A *2017 Position Paper* from the American College of Physicians, while acknowledging pain and nausea to be significant factors, notes that other major drivers of VAD include psychological conditions as well as interpersonal suffering due to dependency or unresolved conflict; or existential suffering based on hopelessness, indignity, or the belief that one's life has ended in a biographical sense but has not yet ended biologically.⁴

17. None of these drivers of VAD are medical conditions, and none require medical treatment.

18. One way or another, these are all expressions of a person's psychological desire to take control of the manner and timing of their own death. They represent, first and foremost, an exercise of the common law right of autonomy or self-determination which, in the assessment of one learned judge, applies without regard to the reasons for the patient's choice, and irrespective of whether the reasons are rational, irrational, unknown or even non-existent.⁵

¹ Pearlman et al (2005).

² *Oregon Death with Dignity Act. Data Summary 2016.*

³ Ganzini et al (2002).

⁴ Sulmasy et al (2017).

19. The most common reasons for seeking VAD can be managed effectively with appropriate ongoing psychological counselling and social support, and by better access to state-of-the-art palliative care which includes these services. Providing all West Australians with better access to these supports, especially equal access to palliative care for people living in rural and remote areas of the State, will be a more effective way to meet the real end-of-life decision-making needs of all WA citizens.
20. In summary : most people who seek VAD do so for non-medical reasons. With reference to TOR 4 of the current Inquiry, and whether or not the citizen is competent at the time their end of life decision is to be enacted, the key question is whether that citizen's decision has been made validly. This is not properly a medical but a legal matter.⁶ For that reason I submit that VAD properly belongs within the purview of the legal profession.

VAD abandons an essential foundation of our social order

21. Wherever in the world VAD has been introduced in any form, it has been vigorously resisted by a significant portion of the affected population. In this section I note what seems to me to be the most obvious reason for this resistance. All of the phenomena noted further in this Submission occur very commonly wherever VAD has been permitted.
22. I offer this evidence so that the Committee may be better informed about the real effects of the radical and irreversible step that VAD legislation would represent.
23. As it will be the Committee's task to make recommendations to Parliament in this regard, I wish to draw the Committee's attention to an inescapable fact. When this State abandoned capital punishment decades ago, it made a considered commitment to uphold a universal principle which stands at the heart of every civilised society, namely the absolute prohibition on one citizen intentionally killing another for any reason.
24. Were the Committee in light of this Inquiry to recommend to Parliament in favour of VAD, it would be proposing the creation of a first and irreversible breach in a principle essential to the safety and security of the people of Western Australia. And this breach once created could not be contained in practice, for reasons discussed below.
25. Therefore I ask the Committee to consider the following comments and to address each one seriously in your Report to Parliament. (I note here that a recent Report to the Parliament of Victoria refused to address these points seriously: it simply stated assertions made for and against VAD without any

⁵ *Brightwater Care Group (Inc) v Rossiter* WASC 229 [2009]. Martin CJ rightly emphasised that the Rossiter case did not concern euthanasia, but his analysis of the common law principles and the conditions under which they apply are certainly relevant here.

⁶ This is particularly true if VAD is viewed as a 'right' of all citizens. Dr Yves Robert, a senior Canadian physician and proponent of euthanasia, believes that if VAD is seen as a right, then the proper focus of VAD laws is not 'medical aid in dying' but 'legally authorised aid in dying' which, he says, could be provided not by doctors but by private enterprise, as it is in Switzerland. See Somerville (2017).

analysis of the data or reasoning behind each statement. In my view this seriously undermines the credibility of the Victorian Inquiry.)

VAD is always about disability

26. Disabled, aged and many other vulnerable people have good reason to be most apprehensive about VAD laws in this State, regardless of how carefully circumscribed those laws may be. There is much to fear. As British actress and disability advocate Liz Carr said recently:
- Whilst supporters of assisted suicide claim that the opposition of disabled people is irrelevant because these bills are only intended for terminally ill people, the top five reasons given by those using the Oregon assisted suicide law all relate to the experience of disability: “loss of autonomy” (91%), “less able to engage in activities” (89%), “loss of dignity” (81%), “loss of control of bodily functions” (50%) and “feelings of being a burden” (40%). **Assisted suicide laws are at their core, about disability.**⁷ (*emphasis added*)
27. In the same vein Craig Wallace, Convenor of Lives Worth Living, a network of Australians with disability speaking about euthanasia and eugenics from a disability rights perspective, says media portrayals describing the murder of disabled people by parents and family members as a 'mercy killing', rather than murder, are very concerning.
- This sugar-coating of murder, suicide and violence against people with a disability under euphemisms like euthanasia, is deeply disturbing to us and we worry that legalised assisted suicide might further strengthen the idea that this kind of behaviour and double standard is acceptable.⁸
28. Aged persons too have much to fear. Older people are among the most frequent users of medical services, and every older person worries about end-of-life decision making. If the older person is not medically competent to make treatment decisions autonomously, they may need to rely on an AHD or EPG. But unless an AHD is clearly applicable to the older person's particular medical condition and to the present admission, the treating health professional will normally need to seek consent for treatment from either an appointed enduring guardian or the 'responsible person' as defined in s110ZE of the *Guardianship and Administration Act 1990*. If VAD is legislated in WA, the health professional might offer VAD as a 'treatment option', and the responsible person could lawfully choose it – even if that would never have been a choice the older person would have made.
29. The fundamental question remains: if VAD laws are passed in WA, can older people – who already feel vulnerable – be guaranteed that they will remain beyond its reach? The answer is no. The only way to prevent the inevitable spread of VAD is not to cross this particular Rubicon in the first place.
30. For this reasons I respectfully submit that Parliament should not, for any reason or in any circumstances, legislate a breach in the universal prohibition on one person intentionally killing another.

⁷ Carr (2017).

⁸ Disability and Euthanasia (2014).

VAD : Elements and Effects

VAD and Depression

31. Many persons seeking VAD suffer from depression: studies identify rates as high as 40.9% and 58.8%.⁹
32. Professor Aaron Kheriaty, associate professor of psychiatry at the University of California Irvine, says that 59% of people seeking VAD suffer depression – yet in Oregon fewer than 5% of persons seeking VAD are referred for assessment.¹⁰
33. In 2011, of 71 persons seeking VAD in Oregon, only one was referred for psychological assessment.¹¹
34. In the Netherlands, rates of psychiatric assessment before VAD have plummeted from 25% in 1998 to 0% in 2010.¹²
35. It seems that although most people seeking VAD are clinically depressed, normal clinical practice standards disappear as VAD becomes established.

VAD and Suicide

36. VAD increases rather than decreases suicide rates in whole populations. Prof Kheriaty maintains that by 2010, “suicide rates were 35% higher in Oregon than the national average.”¹³
37. Other research in the United States proved that legalising assisted suicide was associated with “a significant increase in total suicides” of 6.3% and up to 14.5% for individuals aged over 65 years.¹⁴
38. Professor Theo Boer, one of the founders of VAD in The Netherlands, notes a similar effect:
Contrary to the claims made by many, the Dutch law did not bring down the number of suicides; instead suicides went up by 35% over the last six years.¹⁵
39. Canadian physician Rene Leiva asks, ‘whose suffering does VAD really eliminate?’
We do know that suicide is a symptom of intense suffering, and that the request for euthanasia is mostly the result of existential suffering and not physical pain. It follows then that euthanasia does not truly address the cause of suffering, but rather ignores it. It certainly eliminates the sufferer, whose pain **we** are not able to bear.¹⁶ (*emphasis added*)
40. It seems evident that VAD is accompanied by increased suicide rates. This creates a dilemma: can State Parliament credibly seek to lower the suicide rate in WA if it introduces a practice which will increase the rate of suicide? To put it otherwise: if all suicides are tragic, how can some suicides be considered good – and indeed, authorised by the State?

⁹ Vermeer (2017).

¹⁰ Vermeer (2017).

¹¹ Pereira (2012).

¹² Leiva (2010).

¹³ Vermeer (2017).

¹⁴ Jones (2015).

¹⁵ Vermeer (2017).

¹⁶ Leiva (2010).

VAD and trust in the medical profession

41. Years ago the proposition was put:

If a physician could save a life and, on the other hand, could end a life, it would create ambiguity in the duty of the physician. This would undermine the patients' trust in doctors and would in turn erode the medical profession.¹⁷

42. This has proved true. Prof Boer notes that in the Netherlands the public believe doctors now have a duty to become involved in assisted dying.¹⁸ Dr Leiva believes doctors' participation in euthanasia to be "a betrayal of our ultimate mandate not to cause harm and it reflects misguided compassion,"¹⁹ while the American College of Physicians goes even further:

This practice is problematic given the nature of the patient-physician relationship, affects trust in the relationship as well as in the profession, and fundamentally alters the medical profession's role in society. . . . Control over the manner and timing of a person's death has not been and should not be a goal of medicine.²⁰

VAD and 'bracket creep' : one thing leads to another

43. An inevitable effect of legislating VAD, even for a very narrowly-defined cohort in the first instance, is that other people who do not belong to that cohort come to view their exclusion from it as discriminatory. They then seek to be included among those to whom the legislation applies – and then another group claims discrimination. And so it goes on:

Once you introduce rights to one group of people, it is a political inevitability that others will soon demand to have those rights extended to them in the name of equality. Anything less than this incremental extension of rights is surely discrimination, is it not?²¹

44. Parliament – were it to make an initial breach in the universal prohibition on killing – would have no logical reason to refuse to extend its reach further and further. Indeed, regardless of any statutory restrictions in an initial VAD law, no Parliament can guarantee that a future Parliament will not remove or vary the restrictions. This has already been happening for years in jurisdictions where forms of VAD have been legislated.²²

45. Furthermore, since the operational detail of many laws is governed by regulation rather than statute, a future government could amend the reach of VAD by *fiat* without public knowledge, comment or debate on the floor of Parliament.

46. Even prior to bracket creep, there may be a trend for proponents of VAD to flout statutory regulations intended to monitor its practice: in 2010, 23% of cases of euthanasia in the Netherlands were not reported to a review committee as required by law.²³

¹⁷ Chao (2002).

¹⁸ Vermeer (2017).

¹⁹ Leiva (2010).

²⁰ Sulmasy et al (2017).

²¹ Carr (2017).

²² See the examples cited in Chao (2002).

²³ Onwuteaka-Philipsen et al (2012).

VAD : from voluntary to non-voluntary

47. It is now well known that VAD in the Netherlands has moved from being applied to the very terminally ill to the chronically ill (including those with depression, psychological distress, a 'tired-of-living' mindset, and dementia) and from a voluntary to non-voluntary (eg severely handicapped newborns) capacity.²⁴
48. This shift to non-voluntary VAD has been quantified: of 208 VAD deaths in Flanders, Belgium in 2007, including many adults, 66 were carried out without an explicit request from the patient.
49. In nearly 80% of these cases the decision was not even discussed with the patient.²⁵

TOR 4 : Requesting VAD via an Advance Health Directive or Enduring Power of Guardianship

50. In the Rossiter judgment cited earlier the same learned judge notes that in his Second Reading speech in support of the *Acts Amendment (Consent to Medical Treatment) Act*, which created Advance Health Directives and Enduring Powers of Guardianship in Western Australia, the then Attorney General, Mr Jim McGinty MLA clarified that although a patient, or someone on the patient's behalf, will be entitled to refuse lawful treatment, there will still be no legal entitlement by a patient to demand treatment.²⁶
51. So while persons seeking VAD want the right to request or 'demand' VAD as an option, the current legislation around AHD and EPG does not allow them to make such a demand, even if VAD were to become lawful. In order for AHD and EPG to encompass such a request by a citizen, the whole thrust of these instruments would have to change – and not only in regard to end of life decisions. They would have to permit a citizen to request ('demand') not only VAD but any treatment they wish, since it seems clear that to permit a citizen to 'demand' one kind of 'treatment' but not another would be unnecessarily discriminatory.
52. And contrary to TOR 1 of this Inquiry, access to VAD could not be restricted to a citizen experiencing chronic or terminal illness, since such a restriction also would be discriminatory, as noted above.
53. I submit, then, that amending the *Acts Amendment (Consent to Medical Treatment) Act* or the *Guardianship and Administration Act 1990* to permit citizens to request VAD in an AHD or via a EPG would change the nature of the way medical care is delivered in WA, which I suggest would be not at all acceptable to the medical professions.
54. And as I noted above, since any restrictions on access to VAD could and would be challenged as unnecessarily discriminatory, any form of VAD legislation would eventually make VAD available to all West Australians for any reason, not just for 'chronic and/or terminal illnesses'. This is not at all desirable.

²⁴ Leiva (2010).

²⁵ Chambaere et al (2010).

²⁶ Cited in WASC 229 [2009].

An effective alternative to VAD : better care for all West Australians

55. If the Inquiry wishes to consider legitimate options for health professionals to offer, it need look no further than the urgent need for universal access to excellent palliative care in this State.
56. It would be unseemly at best if Parliament were to legislate for VAD before ensuring that every West Australian has equal access to the best possible comfort, palliative, psychological and social supports. Hospice, hospital and home based palliative care is available to many – but not all – who are resident in the metropolitan area of Perth. It is much harder to access in outlying metropolitan, rural and remote areas of the State.
57. I submit that Parliament should, as an urgent priority, allocate sufficient funds and other resources to ensure that every West Australian has equal access to the same excellent levels of care. This is especially important as older and vulnerable citizens approach the challenge of making end-of-life decisions.
58. Leading West Australia palliative care physician Dr Doug Bridge, along with over 30 other palliative care doctors, recently issued an unequivocal statement condemning VAD and proposing palliative care as a viable alternative.
- Good palliative care helps patients and families avoid both overtreatment and neglect of treatment. It enhances patient autonomy and decision-making capacity by improving symptom control and empowering patients to participate in their care. We affirm the patient’s right to choose their therapy; decline futile therapy; choose the place of dying; choose who should be present; receive the best possible relief of symptoms, even, on rare occasions, deliberate palliative sedation (not terminal sedation); and refuse to prolong the dying process. Ideally, this should be readily available for all those with life-limiting illness.²⁷
59. I commend Dr Bridge and his group to the Committee.
60. If citizens wishing to make decisions about their own end of life choices do not have these services available, and or do not know about the possibilities achievable through palliative care, we cannot really be confident that their choices are adequately informed.

Terms of Reference 1, 3 and 4

In order not to diminish WA citizens’ certainty in making informed decisions regarding their own end of life choices, the WA Parliament should not, for any reason or in any circumstances, legislate any form of assisted dying.

²⁷ Bridge (2017).

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