

# Exit International ACT Branch

Submission to the ACT Government on

# Voluntary Assisted Dying in the ACT

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# 1. EXECUTIVE SUMMARY

1. We advocate that the ACT Government legislate for voluntary assisted dying (VAD) based on a VAD Human Rights Model as defined in this submission (see Chapter 4).

2. First, individual autonomy is a human right, so each person has the right to make decisions about their own body and access VAD. We make the case that VAD is ethically right because it is about mitigating suffering consistent with a person's wishes. We all die, but VAD allows for the desirable option of a peaceful death.

3. Second, we strongly object to the ACT's proposed VAD model. In the ACT Discussion Paper on Voluntary Assisted Dying, the ACT Government states that it:

will be pursuing a model consistent with Australian states in that voluntary assisted dying is only an option for those approaching death because of an advanced and progressive condition, illness or disease. However, how this is defined and who this is available for are questions we are seeking your views on.<sup>1</sup>

4. It would be poor policy to base ACT legislation on the restrictive, conservative, discriminatory VAD legislation in the states. Moreover, if elements of the ACT VAD legislative model have been predetermined—a plausible inference from the statement above—the ACT consultation process appears insincere and disingenuous.

5. Third, if the ACT Government's consultation is, however, genuine, then it should be concerned about people's well-being and develop world-leading VAD legislation based on the Human Rights Model (see Chapters 4, 5). The Human Rights Model respects and endorses individual autonomy and, as it supports a person's well-being or quality of life, allows all people to mitigate their suffering. The ACT Government should base VAD policy on a Human Rights Model policy objective of the form:

that all people have the right to access VAD so that their quality of life is not reduced below what they consider to be an acceptable threshold.

6. That objective is ethical, consistent with human rights principles and legislation, and best practice. No person is a second-class citizen and automatically excluded from VAD. The Human Rights Model's key features are the following:

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<sup>1</sup> The ACT Discussion Paper on Voluntary Assisted Dying (February 2023) can be found at <https://yoursayconversations.act.gov.au/voluntary-assisted-dying-in-act>.

- (a) All people are treated equally and there is no discrimination on a person's type or degree of suffering, life expectancy, age, residency or citizenship status, or other attributes.
- (b) The only VAD eligibility criteria should be that a person has decision-making capacity, is well informed, and can make a voluntary decision to access VAD. These criteria are supported by the Ethical Rights VAD Survey 2021, the most comprehensive survey of VAD advocates around the world, including from the ACT and Australia (see Appendices 2, 3).
- (c) Survey respondents, and most countries with VAD legislation, consider that unbearable suffering is a sufficient, but not necessary, criterion to access VAD. People who either have a VAD specific advance directive, are in palliative care, or are of advanced age should be able to have immediate access to VAD.
- (d) As each person is responsible for their own life, they should self-administer any lethal substances (unless that is not possible).
- (e) Doctors are not required in the VAD process. We know what the lethal drugs are and, as individual autonomy underpins the Human Rights Model, doctors should never be able to assess and overrule a person with decision-making capacity as ineligible to access VAD.

7. Fourth, if the ACT legislates VAD as Australian states have done, it will be legislating VAD based on forms of a Medical Model (see Chapter 4). Forms of the Medical Model in the states have a discriminatory policy objective 'that doctors will counsel and refer *adult resident* patients, and at least another doctor will assess patients and prescribe the drugs *to patients suffering unbearably, terminally ill and with limited life expectancy*.'<sup>2</sup>

8. This submission rejects any form of the Medical Model being implemented in the ACT for many reasons (see Chapters 4, 5):

- (a) The Medical Model is outmoded, because it is not focussed on individual autonomy and ensuring a person's quality of life does not deteriorate below what they consider acceptable. Doctors are legislated as the arbiters of whether a person's life is worth living, not each person themselves.
- (b) It discriminates based on degree and type of suffering, life expectancy, age, and residency and citizenship status. Unjust discrimination cannot be justified when the outcome is that some people are ineligible to have their suffering mitigated. People of advanced age, or people who are in palliative care, will suffer, contrary to their wishes.
- (c) It leads to perverse outcomes. A person who will experience many years of suffering must suffer, but a person who has a short life expectancy can access VAD. It is unethical that adults can access VAD, but terminally ill children will be

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<sup>2</sup> Italicised text indicates specific conditions in Australian state legislation based on the Medical Model.

ineligible and forced to suffer.

Individual autonomy means a woman with individual autonomy can have an abortion at 20, but doctors would assess her as ineligible for VAD when she has locked in syndrome at 50. At what age does a woman lose the right to her body?

- (d) The Medical Model is not best practice—it is administratively burdensome and rejected by VAD advocates and supporters in the ACT and Australia. Survey respondents overwhelmingly rejected the eligibility criteria of citizenship, 2-doctor approval, being terminally ill and having limited life expectancy.

9. In summary, the model proposed in the Discussion Paper based on the Medical Model as legislated in the states should be rejected as ethically unsound and a violation of individual rights. The Medical Model does not allow all individuals to mitigate suffering.

10. The Medical Model philosophy has arisen from the old-fashioned thinking that only an unbearably suffering, terminally ill adult resident would have any reason to die. That is patently false; people other than terminally ill adult residents can suffer and want to access VAD. The only reason that the ACT might have proposed basing legislation on the Medical Model is that it has already been legislated in the states. If the ACT enacts legislation based on the discriminatory Medical Model, it will have reneged on its commitment to uphold Canberrans' rights to equality and non-discrimination. The ACT can do better than duplicating discriminatory, outmoded legislation.

11. Unlike the legislation based on the Medical Model, ACT VAD legislation based on the Human Rights Model allows all individuals to access VAD if they deem it is in their best interests. The Human Rights Model upholds the primacy of individual rights and does not permit other people, doctors, or governments to overrule competent individuals on whether they are sick enough or their quality of life is poor enough to access VAD. Only legislation based on the Human Rights Model will allow people to access VAD so that they will not need to suffer and have their quality of life deteriorate below a threshold of what they can bear.

12. Individuals are responsible for their lives. If they have decision-making capacity, are well informed, and make a voluntary decision to access VAD, they should be able to access VAD. As people can suicide legally and ethically, accessing VAD to ensure a peaceful death is an ethical, humane policy for progressive, civilised societies.

## 2. INTRODUCTION

### Background

13. This submission to the Australian Capital Territory (ACT) Government's consultation process in response to its Discussion Paper on Voluntary Assisted Dying (February 2023)<sup>1</sup> is jointly from Exit International ACT branch (Exit ACT) and Ethical Rights and prepared by Dr David Swanton.<sup>3</sup>

14. Both Exit and Ethical Rights are particularly concerned with the objectives and eligibility criteria for voluntary assisted dying (VAD) legislation in the ACT (Chapters 3–5). We discuss the roles of health professionals, processes, and regulatory monitoring (Chapters 3–5). We also address the Discussion Paper's consultation questions and other aspects of VAD legislation (Chapter 6).

15. This submission includes valuable tables that summarise or highlight critical points. These tables:

- (a) challenge conservative, conventional state-based VAD policy through considering VAD scenarios that ought to be covered by comprehensive VAD legislation (Table 1, p. 22)
- (b) compare the VAD eligibility criteria for the predetermined ACT VAD legislation (based on Victorian legislation, see Discussion Paper, p. 8 and Appendix 3) with the preferred ACT legislation based on a Human Rights Model (Table 2, p. 24)
- (c) compare international VAD regulatory systems, most of which do not discriminate to the same extent as state VAD legislative schemes (Table 3, p. 28)
- (d) contain responses to the consultation questions listed in the ACT Discussion Paper Appendix 1 (Table 4, p. 39).

16. This submission has similar objectives to the submission from Dying with Dignity ACT Inc.: to seek an ethical, compassionate, model for ACT VAD legislation, Their proposal for an Elective Death Unit—similar in concept to how the regulatory regime in Switzerland works—is supported. The Elective Death Unit would be the most efficient and effective means of delivering VAD services to the ACT community.

17. Information about the author is available in Appendix 1. I am available to discuss any issues raised in this submission or relevant to VAD.

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<sup>3</sup> Information on Exit International can be obtained from <https://www.exitinternational.net>. Information on Ethical Rights can be obtained from <https://www.ethicalrights.com>.

## **Some definitions**

18. The World Federation of Right to Die Societies notes that VAD is an Australian term (based on how it has been used in the Australian states) that is defined as:

the provision of medical assistance to a terminally ill person for self-administration of a drug which will cause their death; if the person can no longer self-administer, a doctor can administer the drug.<sup>4</sup>

19. This definition is restrictive as there must be assistance, it must be medical, it involves a terminally ill person and so on. The World Federation defines euthanasia more broadly as a:

deliberate termination of life by someone else, on the explicit request of the person involved. “Voluntary” euthanasia is a term to emphasise the voluntariness of the request for euthanasia.<sup>4</sup>

20. As Australian states have used the restrictive VAD definition above, their VAD legislation is discriminatory and deficient (see following chapters). We can remove these discriminatory restrictions and define VAD more broadly as:

a deliberate act intended to cause the death of an individual, at that individual’s request, for what they see as being in their best interest.<sup>5</sup>

21. The ACT should be trying to legislate VAD based on this broad definition. If it uses the more restrictive definition, it unnecessarily limits its policy options.

22. In this submission, VAD is taken as an umbrella term with as broad a meaning as possible. Hence, VAD encompasses what is often described by the terms voluntary euthanasia, physician-assisted suicide, medical aid in dying, and suicide (with or without assistance). With this broad definition, VAD does not discriminate and does not specify who can be involved or who is eligible. That is, there is no requirement that VAD requires medical assistance or doctor involvement, that a person be terminally ill, have a short life expectancy or be an adult. VAD is simply an intentional act to cause a peaceful death done voluntarily in a person’s best interests, which is usually to end suffering.

## **Note on rational suicide**

23. It is important to draw a distinction between rational suicide and irrational suicide. Rational suicide refers to suicide that can be justified ethically, for example, by preventing an inevitable decrease in a person’s well-being. All cases of VAD should be rational suicide or rational assisted suicide. That is, well informed people with decision-making capacity have voluntarily determined that VAD would eliminate their suffering

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<sup>4</sup> See <https://wfrtds.org>.

<sup>5</sup> See <https://www.ethicalrights.com/euthanasia/euthanasia-faqs>.

or otherwise prevent a decline in their quality of life below their self-determined threshold of what is acceptable.

24. In contrast, irrational suicide includes the suicides often caused by depression or mental illness and occurs too frequently, especially among young people. These deaths are tragic as their illnesses or conditions are treatable and these people could have had fulfilling and productive lives with a good quality of life.<sup>6</sup>

25. To be clear, for the purposes of this submission, VAD is not concerned with tragic situations of irrational suicide. Instead, it is concerned with rational suicide where an individual's well-being is unsatisfactory, occasionally worsening, and often with no hope of improvement.

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<sup>6</sup> Australian organisations such as Lifeline ([www.lifeline.org.au](http://www.lifeline.org.au)) and Beyond Blue ([www.beyondblue.org.au](http://www.beyondblue.org.au)) offer support and suicide prevention services to people suffering from anxiety, depression, and mental health issues. Similar organisations in other jurisdictions, as well as medical professionals, should be contacted for advice on treatable suicide prevention.

## **3. ARGUMENTS FOR THE BEST VAD REGULATORY SYSTEM**

### **3.1. BACKGROUND**

26. This submission makes the case that the ACT should legislate for VAD based on a Human Rights Model (see Chapters 4, 5). The Human Rights Model is one of two main models that can be used for VAD legislation, the other being the Medical Model.

27. In short, the arguments for the Human Rights Model are ethically justifiable and consistent with individual autonomy and human rights principles. Desirable ACT legislation based on the Human Rights Model will mitigate suffering without discriminating on a person's type or degree of suffering, life expectancy, age, residency status or other factors.

28. However, the ACT Voluntary Assisted Dying Discussion Paper states that the ACT Government will legislate by

pursuing a model consistent with Australian states in that voluntary assisted dying is only an option for those approaching death because of an advanced and progressive condition, illness or disease. However, how this is defined and who this is available for are questions we are seeking your views on.<sup>1</sup>

29. Rather than legislating based on the Human Rights Model, the Australian states have instead based their legislation on forms of the VAD Medical Model (see Chapters 4, 5). Forms of the Medical Model are unethical, discriminatory, and are not supported by VAD advocates and supporters in the ACT or Australia.

30. If elements of the ACT VAD legislative model have been predetermined—a plausible inference from the statement above—the ACT consultation process would be insincere and disingenuous, and its legislation would be flawed and unfit for purpose.

31. If, however, consultation is genuine and stakeholder views can be supported by argument, as we hope and suspect is the case, then the ACT can be progressive and enact VAD legislation that benefits all people who want or need it. In doing so, the ACT should develop a VAD policy objective that is ethical, does not discriminate and is best practice.

32. In this chapter, and before we can reach the conclusions above, we consider the criteria for good VAD regulation. In Chapters 4 and 5 we consider the arguments and issues surrounding legislation based on the Human Rights Model and legislation based on forms of the Medical Model.

## **3.2. CRITERIA FOR GOOD VAD REGULATION**

33. The best VAD regulatory system for the ACT ought to be:

- (a) ethical
- (b) consistent with human rights principles and legislation
- (c) best practice and reflect the views of VAD supporters in the ACT.

34. These criteria for good VAD regulation are appropriate. In an article in the Canberra Times on 3 December 2022, ‘ACT govt lays out plans for VAD debate’, both Tara Cheyne MLA and Shane Rattenbury MLA expressed their views on the ACT’s VAD legislative process. Ms Cheyne said that the legislation would ‘take into account the views of the Canberra community’ and Mr Rattenbury said that ‘he wanted the territory to put in place the most advanced and “modern version” of the laws’.

35. The ACT Government would also be expected to acknowledge that VAD legislation ought to be ethical (concerned with a person’s well-being and thus effective at mitigating their suffering) and consistent with human rights principles and legislation (including that it ought not be discriminatory).

### **3.2.1 Ethical regulation**

36. Ethics is concerned with how each of us should act and what constitutes right and wrong behaviour. Ethics is about well-being. Behaving ethically and implementing ethical legislation will lead to improved well-being. If well-being includes all things we reasonably desire, then pain and suffering refer to things that we do not.

37. VAD legislation ought to be ethical, which means it should be about achieving what is in a person’s best interests. Ethical VAD legislation gives all people the option of mitigating suffering and preventing a decline in their well-being or quality of life below what they consider to be an acceptable threshold. VAD legislation cannot be ethical if some people with decision-making capacity cannot mitigate their suffering. Similarly, it would not be ethical if only some women were permitted to have an abortion, or that only some people could live in LGBTIQ+ relationships.

38. Suffering affects all people. A person's well-being is important—each person should have the right to access VAD to mitigate any suffering that they deem to be unacceptable.

### **3.2.2 Human rights principles**

39. VAD regulatory systems should be consistent with human rights principles and legislation. VAD legislation should uphold equality and allow all people to maintain their dignity without discrimination, amongst other things.

40. From a human rights perspective, VAD legislation should not discriminate on the type or degree of suffering, life expectancy, age, residency or citizenship status, pregnancy status, disability, race, sexual orientation, religion etc. People who are not terminally ill (including quadriplegics, people with locked-in syndrome and convicted criminals), people who will suffer for a long time, as well as children, people with disabilities, non-residents, non-citizens, or any other groups of people should be eligible to have their suffering mitigated and access VAD.

41. No discrimination can be justifiable because 'All human beings are born free and equal in dignity and rights'.<sup>7</sup>

42. We can consider some unethical discriminatory VAD legislation that violates human rights. State VAD legislation only allows adults (18 and over) with less than a year to live to access VAD. This means children will suffer when adults need not.

43. If governments actively discriminate in VAD legislation, then they can offer no ethical argument against discrimination. That is, if discrimination is allowed in VAD legislation, arguments against discrimination are arbitrary. Whatever the government of the day decides is 'bad' discrimination can be banned, but all other discrimination is OK. Government policy ought to be justifiable and ought not discriminate.

### **3.2.3 Best practice regulation**

44. VAD regulatory systems should be best practice. Best practice VAD legislation should achieve outcomes consistent with the policy objective (effectiveness) and be economically efficient without unnecessary bureaucratic controls. Essentially, VAD should be inaccessible to people who should not use it, such as people without decision-making capacity, see eligibility criteria, section 5.1. It should not be so onerous as to deter people, particularly anyone with poor well-being and facing a decline in their well-

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<sup>7</sup> Universal Declaration of Human Rights, see <https://www.un.org/en/about-us/universal-declaration-of-human-rights>.

being, who may wish to use it, as is the case with the administratively burdensome state legislation. That balance should not be difficult to reach.

45. If VAD legislation in the ACT is to be best practice and based on a Human Rights Model, it should be supported by VAD advocates and supporters in the ACT and Australia. The Medical Model, as used in the states, is not. Respondents to the most comprehensive survey of VAD advocates and supporters worldwide confirmed this result.

46. The Summary Report and Results documents of the Ethical Rights VAD Survey 2021 of VAD advocates and supporters around the world, including from Australia and the ACT, are presented in Appendices 2 and 3, respectively. Survey responses reflected an ethical and non-discriminatory approach to VAD, consistent with the Human Rights Model (section 4.2). Respondents to the Ethical Rights Survey were mostly over 50 (84% of respondents), 72% had at least one university degree, 61% were female and 75% were not religious. In Australia, respondents were shared amongst political groupings.

47. The results in the appendices were obtained from all survey respondents around the world. At the level of detail discussed in this submission, the responses across the world, Australia, and ACT are quantitatively similar and qualitatively the same. ACT and Australia specific results can be viewed on request.

48. VAD regulatory systems should reflect the views of VAD supporters in the ACT community, including on VAD eligibility criteria (see section 5.1). The most supported eligibility criteria are that a person has decision-making capacity, is well informed, and makes a voluntary decision to choose VAD.<sup>8</sup> These eligibility criteria underpin the Human Rights Model.

49. Forms of the Medical Model rely on four additional eligibility criteria: that a person be a resident (citizen was used in the survey), have 2 doctors approve a request for VAD, be terminally ill, and have limited life expectancy. Survey respondents considered these to be the four least supported eligibility criteria ( $\leq 25\%$ ). VAD supporters reject legislation based on the Medical Model.

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<sup>8</sup> If a person has decision-making capacity, we can usually infer that they are well informed and making a voluntary decision.

## 4. VAD LEGISLATIVE OPTIONS AND POLICY OBJECTIVES

50. We cannot know if a particular VAD action is good and desirable or bad, unethical, and discriminatory unless we can assess it against a policy objective, or guiding principle for legislation. Consequently, it is critical that the ACT Government specify their VAD policy objective, otherwise the merits of policy decisions cannot be assessed.

51. There are two main VAD legislative schemes with two different policy objectives that the ACT Government could adopt:

- (a) Legislation could be based on a form of the Medical Model (section 4.1), as used in Australian states and many jurisdictions overseas.
- (b) Legislation could be based on the Human Rights Model (section 4.2), of which the Swiss VAD regulatory system comes closest.

### 4.1. THE MEDICAL MODEL

#### 4.1.1 Definition

52. VAD regulatory systems based on a Medical Model require that:

it is doctors who will counsel and refer patients—and assenting doctors who will do assessments and prescribe the drugs.<sup>9,10</sup>

53. The Australian states, and some jurisdictions overseas (see Discussion Paper, Appendix 3), have legislated forms of this Medical Model,<sup>11</sup> with a specific objective:

that doctors will counsel and refer *adult resident* patients, and at least another doctor will assess patients and prescribe the drugs *to patients suffering unbearably, terminally ill and with limited life expectancy*.<sup>12</sup>

54. Legislation based on the Medical Model has problems.

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<sup>9</sup> See British Medical Journal 2021;374:n2128 <https://www.bmj.com/content/374/bmj.n2128/rr-9>.

<sup>10</sup> The ACT Discussion Paper uses the terms coordinating and consulting health professionals.

<sup>11</sup> Australian states have different VAD legislative systems, all of which are forms of the Medical Model.

<sup>12</sup> Italicised text indicates specific conditions in state legislation based on the Medical Model.

## **4.1.2 Problems with state VAD regulatory systems**

55. We can consider how the Medical Model has been legislated in the two jurisdictions closest to the ACT: Victoria and New South Wales (NSW).

56. In Victorian VAD legislation, ‘voluntary assisted dying’ refers to ‘administering a medication for the purpose of causing death in accordance with the steps and process set out in law. Voluntary assisted dying must be voluntary and initiated by the person themselves and is usually self-administered. Only people who are already dying from an incurable, advanced and progressive disease, illness, or medical condition are able to access voluntary assisted dying.’<sup>13</sup>

57. In New South Wales, VAD means ‘an eligible person can ask for medical help to end their life.’<sup>14</sup> Eligible persons include adult residents and citizens who will die within a short, specified timeframe.

58. Victorian and NSW VAD regulatory systems are based on forms of the Medical Model. As implemented across Australia, eligibility criteria for legislation based on the Medical Model might include that 2 doctors are required to assess that a person has decision-making capacity, has an advanced and progressive disease or illness, is suffering intolerably, has a limited life expectancy (6 months) but longer for neurodegenerative conditions (12 months) and, in addition, is an adult (over 18 years), and resident in the state (12 months). People might be ineligible if they have a mental illness or disability unless they meet all other criteria.

59. The Victorian and the New South Wales VAD regulatory systems, based on the Medical Model, are unethical and violate human rights because they discriminate on many attributes, including suffering. In these legislative schemes, a person is ineligible for VAD if they:

- (a) have not been assessed by 2 doctors (why should doctors, and not the person themselves, be arbiters of a person’s well-being and determine whether they can access VAD?)
- (b) do not have an advanced and progressive disease or illness (why should a person who is suffering from a disease that is not ‘advanced’ or ‘progressive’ be required to suffer?)
- (c) are not suffering intolerably (why should suffering have to be intolerable; each individual should determine how much suffering they can bear?)
- (d) have a longer than 6 months life expectancy or 12 months for neurodegenerative conditions (why should a person who could suffer for many years before dying,

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<sup>13</sup> See <https://www.health.vic.gov.au/patient-care/voluntary-assisted-dying-overview/overview>.

<sup>14</sup> See <https://www.health.nsw.gov.au/voluntary-assisted-dying/Pages/voluntary-assisted-dying-in-NSW.aspx>.

regardless of the disease or condition, be excluded from mitigating their long-term suffering?)

- (e) are not an adult (over 18 years, why should a child suffer when an adult need not?)
- (f) have not been resident in the state for more than 12 months (why should non-residents or non-citizens be required to suffer?)
- (g) have a mental illness or disability unless they meet all other criteria (why should some illnesses be excluded; all suffering adversely affects well-being?).

60. In addition, we can question why it should be medication and why it should be medical help, and not for example a spouse who can help?<sup>15</sup> Puzzlingly, if a person is not well informed about VAD options—all persons ought to be well-informed of all treatment and VAD options—they might be unable to initiate discussion on VAD themselves.<sup>16</sup> This is a classic catch 22 situation—a person can only be well informed if they are sufficiently well informed to ask about options they do not know about.

61. Furthermore, the VAD legislation in Victoria has been administratively burdensome, because even with its (exaggerated) 68 safeguards, it has deterred people from using it. Western Australia even proclaimed 102 safeguards for its legislation, in a race to the bottom to see which jurisdiction could make it more administratively burdensome and difficult for people who are suffering to access VAD.<sup>17</sup> The result is that with these restrictions on VAD access, people have suffered and will suffer.

62. If the ACT legislates VAD as in Victoria and NSW, it will be beset by the same problems. The Medical Model, as legislated in Australia, unjustly discriminates not only on the type and degree of suffering, life expectancy and age, but also on residency and citizenship status.<sup>18</sup> Discrimination on these attributes is just as ethically wrong, and should be just as legally wrong, as discrimination on sexual orientation or race.

### **4.1.3 VAD legislation should not unjustly discriminate**

63. The ACT Discussion Paper states that, in Australia, VAD refers to:

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<sup>15</sup> In the absence of regulation, some people have used gases to die through hypoxic hypoxia. That might not be classified as ‘medication’. Most VAD advocates do not want medical help, see Appendices.

<sup>16</sup> There are ways to ensure that doctors do not coerce people to die. Furthermore, according to the Australian Medical Association, ‘The community should continue to trust that Medical Practitioners will compassionately and ethically safeguard human health (including dignity, comfort and safety) and life.’ See <https://www.ama.com.au/tas/euthanasia-voluntary-assisted-suicide-vas-and-physician-assisted-suicide-pas>.

<sup>17</sup> See McDougall R, Pratt B., Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation, *BMC Medical Ethics* 21(1), 2020. <https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-020-00483-5>.

<sup>18</sup> Residency is not a medical issue, but many VAD regulatory systems based on the Medical Model also require residency or citizenship for eligibility.

a safe and effective medical process that gives an eligible person the option to end their suffering by choosing how and when they die.

64. In the ACT definition, the term ‘eligible person’ should be correct if it is defined correctly. If, however, it were being used euphemistically to disguise a very restrictive VAD regime—for example, a regime based on the Medical Model where doctors only permit terminally ill adults with less than 12 months to live to access VAD and be alleviated of suffering—then it would be discriminatory. This discriminatory model is that which the Discussion Paper (p. 8) leads us to believe is likely to be implemented in the ACT. Further, VAD is stated to be a ‘medical’ process, but it should not require that health professionals administer drugs or overrule a person’s decision about their own body.

65. Fortunately, the ACT Government opposes discrimination. The ACT Government stated in its Discussion Paper (p. 6) that it is ‘committed to respecting and upholding all Canberrans’ rights to equality, non-discrimination, and freedom of religion, conscience and belief’. If it enacts legislation like that in the states, it will have reneged on its commitment to uphold Canberrans’ rights.

## **4.2. THE HUMAN RIGHTS MODEL**

### **4.2.1 Definition**

66. In contrast to the Medical Model where decisions are made by doctors, legislation based on a Human Rights Model accepts individual decisions as a human right. In treating people equally, it avoids all discrimination. Legislation based on a Human Rights Model could have a policy objective of the following form:

that all people have the right to access VAD so that their quality of life is not reduced below what they consider to be an acceptable threshold.

67. This model gives autonomy to each person so that they can use their legally acquired drugs at a time and place of their choosing. This is an ethically sound model and aligns with John Stuart Mill’s libertarian principle that ‘over himself, over his own body and mind, the individual is sovereign.’<sup>19</sup> The Human Rights Model of voluntary euthanasia provides individuals with the rights and means to make end-of-life decisions about their own lives, without requiring the involvement of doctors at the implementation stage.

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<sup>19</sup> Mill, JS 1974, *On Liberty*, Penguin, Melbourne.

## **4.2.2 The Human Rights Model is justifiable**

68. The Human Rights Model applies equally to all people because each person has the right to determine what is right for their body and how much suffering they can bear.

69. VAD legislation based on the Human Rights Model is justifiable—ethical, consistent with human rights principles and legislation and best practice (reflecting the views of VAD supporters in the ACT community). It does not include the unjust discrimination and medical bias explicit in the Medical Model. There would be no discrimination against any classes of people, regardless of their type or degree of suffering, life expectancy, age, residency status, etc.

70. To be absolutely clear, a person would not need to be terminally ill or suffering unbearably, have a limited life expectancy, be an adult and no doctors would be required to approve VAD requests or be involved in the administration of VAD drugs (they are unnecessary—we know the drugs to be dispensed and administered, with the exception noted in paragraph 107) and no unjust discrimination. Individuals would be responsible for their own lives, not doctors.

## **5. COMPARING THE HUMAN RIGHTS MODEL AND MEDICAL MODEL**

### **5.1. ELIGIBILITY CRITERIA SUPPORT AND RATIONALE**

71. We can compare support for legislation based on the Human Rights Model with legislation based on any one of many forms of the Medical Model. Best practice legislation must meet the needs of VAD advocates and supporters, that is, the people who would use the legislation.

72. The Ethical Rights VAD Survey 2021 (Appendices 2, 3) surveyed VAD advocates and supporters on VAD issues, including eligibility criteria (see survey Q4, p. 62). The only eligibility criteria needed in VAD legislation based on the Human Rights Model are the survey's three most supported VAD eligibility criteria, namely that the person:

- (a) has decision-making capacity (70% support)
- (b) makes a voluntary VAD decision (no coercion 95% support)
- (c) is well informed (71% support).

73. Being an adult received 61% support, but only 35% considered that a child should be automatically ineligible for VAD. Being of sound mind also attracted only 35% support. Most people who did not support being of sound mind supported immediate access to VAD if a person had a VAD advance directive (82%).

74. The other four key eligibility criteria that underpin state VAD legislation—criteria designed to achieve Medical Model objectives—are that a person be a resident (citizen was used in the survey),<sup>18</sup> have 2 doctors approve a request for VAD, be terminally ill, and have limited life expectancy. These were the least supported eligibility criteria (all ≤25% support). VAD advocates overwhelmingly reject eligibility criteria that limit their access to VAD.

### **5.2. FALLACIOUS ARGUMENTS AGAINST VAD AND THE HUMAN RIGHTS MODEL**

75. We should consider why these four eligibility criteria—rejected by VAD advocates and the Human Rights Model—are fundamental criteria of state VAD legislation.

76. First, legislators might not have considered that the mitigation of suffering is the ethical priority; otherwise, conservative, restrictive legislation would not have been developed. Second, conservative VAD legislation would seem to be an overreaction to the fallacious slippery slope argument against VAD. That argument suggests that regulating voluntary death through VAD could lead to calamitous situations where people are being routinely killed against their will. Conservative regulatory legislation probably emerged from the belief that the slippery slope argument was true.

77. The slippery slope argument is fallacious and unsound. There is no evidence for such situations internationally, and nor should there be. There is no slippery slope simply because there is no 'slope'. Regulation provides a firm barrier beyond which VAD is illegal. A person will be ineligible for VAD if they do not have decision-making capacity, are not well informed, and do not make a voluntary decision to access VAD. These are straightforward policy directions for legislative drafters to convert to effective and efficient legislation.

78. There are two other fallacious arguments that reject the Human Rights Model and VAD for all people (not just terminally ill people). For many years they underpinned most arguments against VAD. They should be quickly debunked: the religious arguments that everyone has a right to life and that life is sacred.

- (a) Everyone has a right to life. People choosing VAD are choosing to not to exercise that right, just as they might not exercise their right to freedom of speech and choose not to speak up at a public meeting. When people suicide—a legal act—they are choosing to not to exercise their right to life. Staying alive is not a duty, it is a choice.
- (b) That life is sacred is a religious argument, because sacred is a religious term. The argument could only ever apply to people of that religion. Depending on which gods a person might worship, a common conclusion is that VAD is morally wrong because the gods decree it. Those conclusions are premised on gods existing; the existence of which have yet to be demonstrated. Therefore, with a premise that has not been demonstrated as true, the argument is not sound, and the sanctity of life argument can be rejected.

79. The Human Rights Model rejects these religious arguments. In general, forms of the Medical Model align with these religious arguments, except for the futile situation where a person is on death's door.

### **5.3. VAD SCENARIOS**

80. Table 1 lists VAD scenarios that ought to be covered by comprehensive VAD legislation. The table indicates whether VAD should be allowed in each scenario,

consistent with the Human Rights Model. Where appropriate, scenarios include the percentages of respondents to the Ethical Rights VAD Survey who support VAD in each scenario. Raw survey data is in Appendix 3.

81. The scenarios are designed to challenge conventional thinking, because many people and many governments have been mired in old-fashioned Medical Model philosophy that only terminally ill adults would ever want to die—and they had better be residents. That too is fallacious, but that philosophy was incorporated into the Medical Model. A person is suffering or wants to die in all Table 1 scenarios.

82. Legislation based on forms of the Medical Model would allow VAD for adult residents in scenario 1 in Table 1, but nothing else. Many people who are suffering unbearably but not terminally ill want to access VAD now (scenario 2). There have been occasions in Australia and the ACT where a healthy person has chosen to die when they are of advanced age (scenario 4) or when their terminally ill partner has died (scenario 5). Although some people think that should not occur, they have no right to demand that individuals who are grieving and suffering must live contrary to their wishes. Either everybody has individual autonomy and the right to determine what is best for themselves, or they do not. VAD is not about governments exercising control over individuals; it is about people managing their own well-being.

83. In other scenarios, conventional discriminatory thinking dictates that a person with a VAD advance directive (scenario 8) or an infant (scenario 11) cannot ethically access VAD. However, if individual autonomy and well-being are priorities, then these people ought to be able to access VAD.

84. Table 2 compares the eligibility criteria and some other features of the Victorian VAD legislation based on a Medical Model (using conditions from Appendix 3 of the Discussion Paper) with preferred eligibility criteria based on a Human Rights Model. The main difference between them is that legislation based on a Human Rights Model is free of discrimination on the type or degree of suffering, life expectancy, age, residency or citizenship status, and have no requirement that doctors be involved. The differences in the two models are considered in the following sections.

85. The Discussion Paper states that the ACT Government could pursue ‘a model consistent with Australian states’. Victorian legislation is typical of the legislation that could be used (Discussion Paper, Appendix 3). The rationale for rejecting the Victorian legislated Medical Model is included in the rightmost column of Table 2. Many Victorian conditions are either unethical, discriminatory or do not mitigate suffering. On that basis, the ACT should not legislate based on state legislation.

**Table 1. VAD scenarios that should be covered by comprehensive VAD legislation based on a Human Rights Model.**

VAD scenario	Should well-informed persons with decision-making capacity (unless stated otherwise) be able to access VAD? (percentages are respondents' support for that scenario in the Ethical Rights VAD Survey, where applicable) <sup>20</sup>
<b>Criteria: unbearable suffering, palliative care, advanced age, not ill, burden, depression, advance directive</b>	
1. Person who is terminally ill, short life expectancy, poor quality of life.	Yes, can access VAD so that their quality of life will not deteriorate. Likely, the most common scenario. (100%)
2. Person who is not terminally ill, many-year life expectancy, suffering unbearably with poor quality of life, including persons, e.g., with locked-in syndrome.	Yes, can access VAD so their well-being will not deteriorate. Unethical to discriminate based on the type or degree of suffering or life expectancy. An individual can make choices about their own life. A common scenario. (80%)
3. Person in palliative care (short time to live).	Yes, can access VAD immediately as they are in palliative care. A common scenario. (60%)
4. A person who is of advanced age (see cases of David Goodall (chose to die in Switzerland at 104) and Lisette Nigot (chose to die at 80)). <sup>21</sup>	Yes, can access VAD immediately if they are of advanced age. Canberrans should not have to go to Switzerland to prevent a reduction in their quality of life. Occurs now in Australia. (58%)
5. Person who is not ill but wants to die when their seriously ill spouse dies.	Yes, can access VAD. Their life is their life. Might often default to scenario 4. Occurs now in Australia.
6. A person (with many afflictions) who considers that they are a burden on society.	Yes, can access VAD if they have decision-making capacity. Regardless of whether they are a burden, they consider themselves to be a burden. To maintain their dignity, they do not want to vomit or be cleaned, fed, medicated, changed etc. They have responsibility for their life. (77%)
7. A person with long-term clinical depression.	Yes, can access VAD, if they have decision-making capacity and even if treatment does not suit them. (48%)
8. A person who is not terminally ill, a candidate for dementia, with an advance directive specifying VAD at a specified level of incapacity.	Yes, can access VAD if they have an advance directive specifying circumstances under which VAD should occur, including, for example, advanced dementia. See survey, Appendix 3. (82%)
<b>Criteria: doctor involvement, minimum age, role of parents, mental condition</b>	
9. A person who wants to die in the presence of their spouse or family members.	Yes, can access VAD and spouse or family can be present; doctors are not required. The person will have been provided with the lethal drug. It is their life, their choice. (78%)

<sup>20</sup> Some scenarios are not exactly the same as survey questions. If a value is given, then it is a reasonable quantitative approximation. Survey data is in Appendices 2 and 3.

<sup>21</sup> See <https://www.exitinternational.net/about-exit/exit-remembers/>.

<b>VAD scenario</b>	<b>Should well-informed persons with decision-making capacity (unless stated otherwise) be able to access VAD? (percentages are respondents' support for that scenario in the Ethical Rights VAD Survey, where applicable)<sup>20</sup></b>
10. A child with a terminal illness.	Yes, can access VAD, if they, their parents/ guardians agree (only parents/ guardians required if child does not have decision-making capacity), acting on doctors' advice. Suffering can be avoided, and it is unethical to discriminate on age. A child's well-being is paramount. (65%)
11. An infant born with fatal condition, such as inoperable multiple intestinal atresia. They will suffer and vomit for 2 weeks before dying.	Yes, can access VAD, but as they do not have decision-making capacity, their parents/ guardians should agree, acting on doctors' advice. Suffering can be avoided, and it is unethical to discriminate on age and require that an infant must suffer. An infant's well-being is paramount. (74%)
12. A person who is suffering with a mental health condition.	Yes, can access VAD if they are well informed and have decision-making capacity when they voluntarily choose VAD. (74%)
<b>Criteria: pregnancy, prisoners, residency status, VAD telehealth</b>	
13. A pregnant woman who has been told she is terminally ill with a short time to live.	Yes, can access VAD. It is her body, her life. Whether the foetus is born or dies with her is her decision. (52%)
14. A person in the ACT's prison with a severe illness.	Yes, can access VAD, as we should not discriminate against prisoners and make people suffer because they are prisoners. (84%)
15. A person in the ACT's prison. The person has showed no remorse for their many murders and refuses to tell police where their remaining murder victims are buried.	No, cannot access VAD if there is a social contract that requires people answering all police questions before they become eligible to access to VAD. Otherwise, they can access VAD. Some complexities here. (67%)
16. A person in the ACT's prison suffering with the mental anguish of a lifetime sentence but no other illness.	Yes, can access VAD. Depends on whether the objective of prison is to torture, rehabilitation, or something else. The former is unethical, and rehabilitation is moot if they have a life sentence. Some complexities here.
17. A person who has recently relocated to the ACT, with a short time to live.	Yes, can access VAD. Discrimination based on residency status is unethical. (Citizenship had only 15% support.)
18. A person who lives in rural or remote areas wants telehealth advice on VAD.	Yes, should be able to access VAD, but this is currently not possible. Accessing VAD telehealth services is illegal. It is an offence to use a carriage service for suicide-related material, see s474.29A of the <i>Criminal Code 1995</i> (Cth). The Commonwealth Criminal Code should be amended to allow VAD telehealth advice.

**Table 2. Comparison of the eligibility criteria and request provisions in the Victorian VAD legislation (from Discussion Paper, Appendix 3) and preferred ACT legislation based on a Human Rights Model.**

Regulatory condition		Condition included in Victorian legislation (Medical Model)	Condition required in preferred ACT legislation (Human Rights Model)	Rationale for rejection of the Victorian VAD legislation and support for the Human Rights Model
<b>VAD eligibility criteria</b>				
1	Guiding principles in legislation	Yes	Yes	It is good regulatory practice to specify the ethical, non-discriminatory, and best practice objective for VAD legislation. The recommended objective, based on the Human Rights Model, should be 'that all people have the right to access VAD so that their quality of life is not reduced below what they consider to be an acceptable threshold.'
2	18 years or more	Yes	No	No, discrimination based on age is unethical. We would not think about discriminating based on Indigenous heritage or sexual orientation. Children should not have to suffer when adults need not.
3	Resident in jurisdiction	Yes (12 months)	No	No, all people suffer, regardless of where they reside. There is no ethical reason that new residents, immigrants, tourists, vagrants should be required to suffer. Cost recovery can cover costs.
4	Person has decision-making capacity in relation to assisted dying	Yes	Yes	Yes, the most important criterion. Decision-making capacity with respect to VAD is necessary to make a voluntary decision. This should allow for the option of advance health directives specifying VAD when a person has dementia and for parent/guardian to make decision when a person cannot, including when a child is suffering.
5	Person is acting voluntarily and without coercion	Yes	Yes	Yes, if it is not voluntary it could be unethical. This allows for the option of advance health directives specifying VAD and for parent/guardian to make decision when a person cannot, including when a child or infant is suffering.
6	Diagnosed with an eligible disease, illness or medical condition (e.g., advanced, incurable, progressive, will cause death)	Yes	No	No, suffering can occur regardless of the disease, even if it will not cause death, e.g., locked in syndrome. It is unethical and discriminatory if some people are required to suffer. All suffering should be able to be mitigated by VAD. We cannot be arrogant and demand that another person's illness is not sufficient to access VAD. Should also allow option for non-ill spouse to die at same time.

Regulatory condition		Condition included in Victorian legislation (Medical Model)	Condition required in preferred ACT legislation (Human Rights Model)	Rationale for rejection of the Victorian VAD legislation and support for the Human Rights Model
7	Disease, illness or medical condition is expected to cause death within a specified timeframe	Yes (6 months, 12 months for a neuro-degenerative condition)	No	No, it is unethical that a person who is expected to suffer for a short time can access VAD, but a person who would suffer longer, even 40 years, needs to suffer. The person most in need of VAD, to avoid the greatest amount of suffering, would be excluded. There should be no life expectancy limit.
8	Person is suffering	Yes	No (suffering is not necessary, but it is sufficient for VAD)	No. Suffering is not necessary (hence not a VAD eligibility criterion), but it should be sufficient to access VAD. Should not exclude situations where a person is not sick: including a person who is elderly but not sick (Dr David Goodall), a person with locked in syndrome, a person who has a life prison sentence, or a healthy spouse (who should be permitted to die at same time as suffering person).
9	Express provision that mental illness or disability alone is not an eligible disease, illness or medical condition	Yes	No	No, there is no reason to discriminate based on disease. All suffering, regardless of what it is, should be able to be mitigated by VAD. Employers would not exclude people with mental illness from accessing sick leave; similarly, no person with mental illness should be excluded from VAD.
10	All criteria must be met	Yes	No	No, if using Medical Model criteria. People in palliative care, advanced age can have immediate access. Suffering is sufficient but not necessary for VAD. See all comments above.
11	Review by tribunal of some criteria (e.g., residency, decision-making capacity or voluntariness)	Yes	No	No (depends on criteria). Reviews are good public policy, but a review here suggest that an unethical system will be established and then reviewed later to get it right. Being voluntary, having decision-making capacity are given, definitions might change. Discrimination on age or residency status is unethical discrimination. If the ACT legislation is erroneously unethical, then yes, review required. Act should be evaluated regularly. Definitions and criteria could be disallowable instruments. The ACT should develop ethically right legislation now. Given the Human Rights Model objective, it is straightforward to determine policy actions.

Regulatory condition		Condition included in Victorian legislation (Medical Model)	Condition required in preferred ACT legislation (Human Rights Model)	Rationale for rejection of the Victorian VAD legislation and support for the Human Rights Model
<b>Request to access VAD</b>				
12	Health practitioner must not initiate discussion about voluntary assisted dying	Yes	No	No, eminently sensible for information on all options, including VAD, to be available to everybody. So, VAD information can be provided at same time as treatment and palliative care options. Health practitioner need not be a doctor.
13	Person themselves must make request	Yes	Yes	Yes, except if the person does not have decision-making capacity, such as a child or infant who will suffer until they die. Parent/ guardian request, on doctors' advice, then required.
14	Person can make a request in an advance directive	No	Yes	Yes, eminently sensible, occurs overseas (see Table 3). A person should be able to decide about their future life. Most people do not want to think of themselves living with severe dementia. Advance directive is required before a person loses decision-making capacity.
15	Person must make three requests	Yes	No	No, three is excessive. Two is better for a person with decision-making capacity. Don't need to make three or even two requests about starting an LGBTIQ+ relationship or having an abortion. Only one request required if person is in palliative care, suffering unbearably, very elderly (only one request required then) or advance directive in place.
16	One request must be in writing	Yes	Yes	Yes, this would constitute evidence that it was voluntary. AV recording could also obviate 'requirement' for more requests.
17	Two witnesses to written request	Yes	Yes	Yes, best practice, two witnesses are not hard to obtain.
18	Waiting period between first and final requests	Yes (unless likely to die)	Yes (unless likely to die or elderly)	Yes, cooling off period between first and second (final) requests is good. VAD should be immediately available to people suffering unbearably, in palliative care, very elderly, or with an advance directive.
19	Any interpreter must be independent and accredited	Yes	Yes	Yes, best practice regulation, consistent with being well informed.
20	Person may withdraw request at any time	Yes	Yes	Yes, best practice regulation, consistent with individual rights.

## **5.4. TYPE OR DEGREE OF SUFFERING AND LIFE EXPECTANCY**

86. ACT VAD legislation should not discriminate based on a person's type or degree of suffering or their life expectancy. Unbearable suffering is a sufficient but not necessary condition for VAD, and anybody with unbearable suffering should have immediate access to VAD.

87. State legislation based on forms of the Medical Models discriminates unjustly. Only adults whom doctors consider are terminally ill and suffering unbearably will be eligible for VAD. Consider if one person has chronic pain after unsuccessful surgical interventions to address cancer. Another person might have more minor issues and complications arising from incontinence, impotence, diabetes, osteoporosis, shortness of breath, cardiovascular problems and hearing and sight impairment. Both want to access VAD because their quality of life is less than what they both consider to be acceptable.

88. Under legislation based on the Human Rights Model, both persons can access VAD. However, under the state-based legislation based on the Medical Model, doctors might not assess the second person to be sufficiently ill to die. The catch 22 situation is that if a person is sufficiently ill to qualify for VAD, they might be too ill to navigate the regulatory obstacles to access VAD. State legislation is not best practice.

89. Significantly, survey respondents did not support being terminally ill or having limited life expectancy as VAD eligibility criteria. Only 22% of respondents considered that terminal illness should be a VAD eligibility criterion, although 100% said that being terminally ill was sufficient to access VAD. For unbearable suffering, these figures were 34% and 80% respectively. That is, it should be unnecessary for a person to be terminally ill or even suffering unbearably to access VAD, but if they are, that should be sufficient for them to access VAD. That majority view is consistent with a Human Rights Model. It would be wrong to unjustly discriminate against people because they are not terminally ill or suffering unbearably. They are suffering and want their suffering mitigated.

90. Table 3 compares some international VAD regulatory systems. Many international regulatory systems are ethically more acceptable than those in the Australian states because more suffering can be mitigated. Most countries (9 of 13) do not require that a person be terminally ill. There is acknowledgement and acceptance of the role of VAD in mitigating suffering because 11 countries consider that unbearable suffering is sufficient to access VAD (only Australian states and some states in the United States do not). In 2 countries, a person need not be ill to access VAD.

Table 3. A comparison of international VAD regulatory systems.

	Australia	Austria	Belgium	Canada	Colombia	Germany	Italy	Luxembourg	Netherlands	New Zealand	Spain	Switzerland	USA	
<b>Eligibility Requirements</b>	'Healthy' - not ill	X	X	X	X	✓	X	X	X	X	X	✓	X	
	Terminal Illness required	✓	X	X	X	X	✓	X	X	✓	X	X	✓	
	Unbearable suffering	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	
	Psychiatric illness	X	X	✓	✓ <sup>3</sup>	X	✓	X	✓	✓	X	X	✓	X
 Must be resident	✓	✓	✓ <sup>a</sup>	✓	✓	?	✓	✓ <sup>a</sup>	✓ <sup>a</sup>	✓	✓	X	✓	
	 Must be 18+	✓	✓	X	✓	X	?	✓	✓	X	✓	✓	✓	✓
		 Cooling off Period	✓	✓	✓	✓	✓	X	✓	X	X	X	✓	X
	 Request in writing		✓	✓	✓	✓	X	X	✓	✓	✓	✓	✓	X
		 Request can be included in AHD	X	X	✓	X	X	X	✓	✓	✓	X	X	X
	 Single Doctor sign-off		X	X	X	X	✓	X	X	X	X	X	X	✓
		 Multiple Doctors sign-off	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	X
<b>Means of Administration</b>	Drink		✓	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓
	Lethal Injection	✓ <sup>1</sup>	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	X
	Self-activated infusion	X	X	X	X	X	✓	✓	X	X	X	X	✓	X
	Rectal	X	X	✓	✓	X	✓	✓	✓	✓	X	✓	X	✓
 Affordable	✓	✓	✓	✓	✓	?	?	✓	✓	✓	✓	✓	X	✓
	 Expensive	X	X	X	X	X	?	?	X	X	X	X	✓	X

**Notes**

- \*1 - Injection is possible if the patient unable to self-administer
- \*2 - Only Oregon has dropped residential requirements
- \*3 - Psychiatric illness permitted from 03/23
- \*a - In Benelux countries one does not need to be a resident but must have a long-standing relationship with the treating doctor



Reference. P. Nitschke and F. Stewart, The Peaceful Pill Handbook. The only correction (as of 1 March 2023) to this table is that Note 3 should be amended: '3–Psychiatric illness permitted from 03/24'.

91. The Medical Model also discriminates based on a person's life expectancy. Australian states have legislated that doctors can assess people as being ineligible for VAD. If doctors assess that a person might suffer for 20 years before dying, then that person will be ineligible for VAD for 19 years, as state VAD eligibility requires that a person has a maximum 12-months life expectancy. However, a person who might suffer for 3 months before dying can access VAD. It is egregious policy that state VAD legislation demands that people who could suffer the most cannot access VAD, and so must suffer the most. The unjust discrimination against people based on life expectancy and rejection of individual rights should not be a feature of ACT legislation.

92. Furthermore, it is wasteful to use scarce taxpayer funds to keep people alive against their will if they have a poor quality of life and would rather choose VAD and die. That money could be better spent on health care for people who do want to live longer.

## **5.5. AGE**

93. ACT VAD legislation should not discriminate based on age. All people, regardless of age, should be able to access VAD. No child must be forced to suffer when an adult need not.

94. In the Human Rights Model, all people are treated equally, independent of age. In most forms of the Medical Model, it is inhumane and unethical that seriously ill adults can access VAD, but children (people under 18) should suffer. A child's well-being is paramount, yet suffering does not begin in adulthood. Civilised societies can do better.

95. The unsound counterargument used to exclude children from VAD involves decision-making capacity. The argument states that younger children do not have decision-making capacity and that people should be excluded from serious medical interventions if they do not have decision-making capacity. This second premise is clearly false, otherwise children would be excluded from all surgery.

96. When children are not sufficiently well informed and do not have decision-making capacity, then their parents or guardians, acting on advice from doctors, can make decisions in the child's best interests. If, tragically, a child's unbearable suffering cannot be mitigated, then parents or guardians can act in the child's best interest.

97. About 65% of survey respondents thought that a child suffering unbearably could access VAD. About 74% of respondents thought that an infant in similar situations could access VAD. These are sensible, non-discriminatory responses, see Table 1, scenarios 10 and 11. At least 3 countries do not require a person to be 18 years old or over.

98. Age discrimination in VAD in Australian states and many jurisdictions means we have an irrational, unjustifiable situation. A woman can have an abortion and any person can have an LGBTIQ+ relationship when they are 20. But if these people were suffering from locked-in syndrome or any other serious non-terminal illness at 50, they would be excluded from accessing VAD.

99. We can only speculate at what age state legislators consider that a woman or other person loses the right to their own body. A common human rights and feminist maxim is that ‘Every person has the right to make decisions about their own body’. Yet state legislators have selectively applied that maxim, excluding many people from accessing VAD.

100. While writing this submission, we have had need to visit our local veterinarian regarding our much-loved cairn terrier, Indy, who is elderly and suffering from some ailments. Our dog does not have decision-making capacity with respect to VAD. When our dog’s quality of life is below a threshold that is acceptable, we will make the incredibly sad decision, in consultation with our veterinarian, that it will be better for our dog to die. While dying is inevitable, suffering need not be.

101. Regrettably, given the current discriminatory VAD legislation in Australia, dogs can have a better death than any suffering, terminally ill Australian child. While our dog’s suffering can be mitigated, a child’s suffering cannot. The ACT should legislate to ensure that nobody and no child need die worse than a dog.

## **5.6. DOCTOR INVOLVEMENT**

102. ACT VAD legislation does not require the involvement of doctors.

103. The Medical Model focuses on the active involvement of doctors in the VAD process. During the early VAD debates over the past 30 years, there has been strong opposition to VAD from some doctors and medical associations, arguing that ‘we can’t have doctors killing people’. As recently as 2018, after Victoria had passed VAD legislation, the president of the Australian Medical Association (AMA) said that ‘asking doctors to kill patients—that is very, very difficult, and it’s at odds with what we’ve been taught since day one.’<sup>22</sup> According to the AMA, doctors were not keen on being involved with VAD. This statement has two perspectives.

104. First, doctors talk of ‘patients’—with connotations that ‘patients’ are people that doctors should always tend to and are responsible for—rather than seeing them as

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<sup>22</sup> AMA President, Dr Michael Gannon, ABC Radio Brisbane, *Breakfast with George Roberts and Rebecca Livingston*, Friday 11 May 2018, <https://www.ama.com.au/media/transcript-dr-gannon-abc-radio-ethanasia-and-physician-assisted-suicide>.

individuals or persons responsible for their own lives. In most cases, people do want doctors to take responsibility for the advice they provide to them when they are sick. But when people choose to die, they do not want doctors overruling them and assessing them as not sick enough to die. Doctors do not own patients and people. People are responsible for their own lives. We cannot uphold the primacy of individual rights and permit doctors to overrule individuals on whether they are suffering sufficiently to access VAD.

105. Second, it is apparent that doctors don't want to be involved in VAD—they have been taught to keep 'patients' alive, regardless of the person's quality of life or wishes. Moreover, VAD advocates do not want them involved (see Appendices 2, 3). If best practice regulation is to be developed then doctors are not required, don't want to be involved, are not wanted by VAD advocates, and should not be involved. Yet the states have legislated forms of the medical model that give primacy to the role of doctors.

106. A person will not usually be seeking access to VAD unless they have exhausted all options to improve their well-being. Hence, there is no need to involve doctors in VAD processes because we know what lethal drugs cause a peaceful death. The best drugs to cause a peaceful death are the well-known 5-drug mix and Nembutal. Pharmacists could dispense these drugs to eligible people (people who are suffering, meet eligibility criteria, completed paperwork etc). It is not as if medical advice is required to avoid side-effects for lethal drugs. If people take these drugs they will die and die peacefully.

107. There is a minor exception to the need for doctors in VAD. That exception is if a person is unable to administer a drug themselves. A person might require medical assistance to insert a cannula for drug administration, but a qualified nurse could do that. In many cases, a spouse, relative or friend might be able to assist with turning a valve or lifting a drink to a person's lips. If a doctor is required to assist with administration, a volunteer could be found.

108. Self-administration of a lethal drug was supported by 89% of survey respondents. Aside from the exception noted above, self-administration of a drug should be a mandatory requirement of any VAD regulatory system. VAD is ethically right because every person has responsibility for their own lives, including at the end of life (if it can be managed). If people self-administer, it counters any criticism that doctors are killing people and that people are being killed against their will.

109. In the ACT definition of VAD (section 4.1.3), and consistent with the definition of a Medical Model, a medical process implies doctors counselling, referring, assessing, and prescribing patients. While doctors "counselling", "referring", "assessing" and "prescribing" sound like familiar and innocuous medical tasks, acting as society's arbiter of what makes a life worth living is not.<sup>9</sup> Each individual is their own judge of whether their life is worth living, not doctors.

110. Only 18% of VAD advocates in the Ethical Rights VAD Survey supported 2 doctors approving a VAD request (see Appendix 3). Doctors can and should advise individuals on all treatment and VAD options, but no more. A better, alternative framework involves the establishment of an ACT Elective Death Unit, discussed in the submission from Dying with Dignity ACT. In short, an Elective Death Unit would be staffed by health professionals, be able to assess that a person has decision-making capacity and would respect human rights as it would not permit doctors to overrule a person's decision. An appropriately certified pharmacist would be required to dispense the lethal drugs, under secure best practice arrangements.

### **Decision-making capacity**

111. We ought to ensure that a person seeking access to VAD has decision-making capacity, but this should be straightforward and may not require doctors. Shaw et al.<sup>23</sup> write that 'Four criteria for medical decision-making capacity are widely accepted: the ability to understand the relevant information, the ability to appreciate the disorder and the medical consequences of the situation, the ability to reason about treatment choices and the ability to communicate a choice.'

112. To those criteria, Kaspers et al. would add 'deliberation based on personal values'.<sup>24</sup> They further argue that<sup>24</sup>:

'For patients at the end of life, decision-making capacity evaluations should be relatively straightforward, even if they have mental health issues. For those who are not yet at the end of life, evaluating capacity can be more difficult and a higher standard may be justified, but care must be taken to avoid letting other considerations contaminate the decision-making capacity evaluation. Most importantly, doctors should not let any personal qualms about assisted suicide to infect the objectivity of the decision-making capacity evaluation.'

## **5.7. RESIDENCY STATUS**

113. ACT VAD legislation should not discriminate on a person's residency or citizenship status.

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<sup>23</sup> Shaw, D., Trachsel, M., & Elger, B. (2018). Assessment of decision-making capacity in patients requesting assisted suicide. *The British Journal of Psychiatry*, 213(1), 393-395. doi:10.1192/bjp.2018.81.

<sup>24</sup> Kaspers PJ, Onwuteaka-Philipsen BD, Deeg DJ, Pasman HR. Decision-making capacity and communication about care of older people during their last three months of life. *BMC Palliat Care*. 2013 Jan 10;12:1. doi: 10.1186/1472-684X-12-1.

114. The Victorian VAD legislation and many Medical Models discriminate based on residency status. Residency or citizenship is not a medical issue, but these requirements are incorporated within many legislated forms of the Medical Model worldwide.

115. If residency were an eligibility criterion in ACT legislation, non-ACT residents who were not granted an exemption to access VAD would be excluded. Suffering does not stop at the ACT border. If people from elsewhere in Australia or overseas were to come to the ACT for the purposes of accessing more progressive VAD legislation and to die, or if they were tourists, new residents or vagrants, the mitigation of their suffering and desire to die would not be any less compelling than that of suffering ACT residents. Economic costs should not be a deterrent; there would be no cost imposition if non-residents were charged at least cost recovery on services offered.

116. We can see how discriminatory it would be to ban non-residents or non-citizens from accessing VAD in the ACT. Consider an analogous thought experiment. As an ethical principle, would the ACT refuse people who may be discriminated against elsewhere, whether they are political, LGBTIQ+ or other refugees, from coming to Canberra? Hopefully not. Similarly, there is no reason for the ACT to discriminate against non-residents or non-citizens if they cannot access VAD in their own jurisdiction. The ACT should help people who cannot be helped in their own jurisdiction, whether it is offering political refuge or access to VAD. The ACT can make the world a better place at no additional cost.

## **5.8. PALLIATIVE CARE AND ADVANCED AGE**

117. ACT VAD legislation should allow all people who are in palliative care or are of advanced age to have immediate access to VAD.

118. The author's mother, Betty, died in 2015 from pancreatic cancer. She spent her last weeks in a very good palliative care facility in Sydney, where no food and nil water were and are a wretched means for hastening death. About 3 days before her death, she had suffered 2 episodes of breakthrough pain and indicated that she wanted to die. I wrote at the time<sup>25</sup>:

As well as these pain events, there is also a lack of dignity associated with this disease. She was toileted and showered, there was a cocktail of pills and suppositories, ongoing and frequent injections of painkillers and antiemetics, cannulas, little vomiting episodes, dryness, artificial saliva sprays (because drinking was nil or minimal), lack of appetite, nil food for the last week, emaciation, and gurgling respiratory infections.

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<sup>25</sup> See [https://www.gogentleaustralia.org.au/david\\_swanton](https://www.gogentleaustralia.org.au/david_swanton).

And that was in addition to the bowel blockage, the appearance of being six-months pregnant, the threat of possibly vomiting faecal matter, and knowledge that she would not be sedated so that scenario could never arise. And perhaps she should have buzzed the nurses every half an hour for extra pain relief, rather than waiting...

Until the last three days she still had a bit of spark. At that stage she indicated she would be happy to die then.

119. Even if VAD had been legal in NSW when my mother died, it would have been impossible to meet all regulatory requirements in less than 3 days. In the VAD survey, 60% of respondents thought that a person in palliative care should be able to immediately access VAD—meaning as fast as possible and desirably within a day. This is a sensible response to a situation where suffering is occurring, death will occur imminently, and a person wants to avoid undignified episodes like vomiting faecal matter. Immediate access while in palliative care means a single request and providing a lethal drug to the person in the shortest time possible. There is no advantage to be gained from keeping somebody alive against their will in these circumstances.

120. In the survey, 58% of respondents thought that a person of advanced age could also immediately access VAD. Again, this makes sense. In 2018, David Goodall, a 104-year-old Perth scientist, who had been actively working until 103, prioritised his quality of life and well-being. He was not sick and not terminally ill. He travelled from Australia to Switzerland to die because of Switzerland's supportive legislative regime. Although Switzerland forbids inciting or assisting a person to suicide for selfish motives, assisted suicide from non-selfish motives is not prohibited. Lethal drugs are made available in facilities that people can then administer themselves. Before he died, Goodall remarked that his 'recent life has not been enjoyable'. In response to the question of whether he was certain he wanted to die, he 'laughed and replied, "Oh yes, that's what I'm here for"'.<sup>26</sup>

121. David Goodall prioritised his quality of life and well-being. He chose to die. His death was received in the media with understanding and compassion. He should not have had to travel overseas. Rational suicides such as Goodall's challenge politicians and policy makers. His death, an individual act with his well-being a priority, is a wake-up call to governments. The well-being of citizens is a matter for which governments have legal and ethical responsibility. The ACT should legislate so that people like David Goodall do not need to travel to Switzerland and can access a peaceful death in the ACT.

122. There is always an interesting thought experiment. If a terminally ill person were being treated at Calvary Hospital or a palliative care facility, and were about to drink the lethal and legal substance they had obtained under new ACT legislation (and secretly

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<sup>26</sup> See <https://www.abc.net.au/news/2018-05-10/david-goodall-ends-life-in-a-powerful-statement-on-euthanasia/9742528>.

brought from home), would hospital or facility management instruct their staff to forcibly prevent the person using their lethal substance?

123. They ought not, but they could. Suicide is legal, but under s.18 of the *ACT Crimes Act 1900*, a person can intervene to prevent a suicide. Provisions in the Crimes Act will need to be changed to address this situation and to avoid conflict with VAD legislation.

## **5.9. ADVANCE DIRECTIVES**

124. ACT VAD legislation should allow people to develop VAD advance directives so that they can access VAD when they no longer have decision-making capacity.

125. The 82% of survey respondents who supported VAD for somebody who had drafted a VAD advance directive is an acknowledgement that people want to ensure that they do not suffer when they no longer have decision-making capacity. People without decision-making capacity—the critical eligibility criterion—can suffer as they would not be able to choose VAD. That is why a VAD advance directive would need to be drafted when a person does have decision-making capacity.

126. A VAD advance directive should be straightforward to legislate because advance directives are already legal. We can compare the current situation with advance directives with a future VAD advance directive.

- (a) Currently, a person can develop an advance directive that specifies that—in certain circumstances, including that they do not have decision-making capacity—treatment be withheld, life support be withdrawn, etc.
- (b) A future VAD advance directive will also specify that—in certain circumstances, for example, a loss of ability to manage personal care, respond to their environment, communicate, move, swallow, etc.—a legal lethal drug can be administered.

127. In both cases, the person's intention, and the consequence of the action—whether withdrawal of life support, rejection of treatment or administration of a lethal drug—is that the person will die consistent with their wishes. The two situations, with the same intention and consequence, are ethically equivalent.

128. Furthermore, if a person had drafted an advance directive, 'this could dramatically reduce concerns about coercion (especially when dementia is a nominated reason).<sup>27</sup> This would add weight, if more were ever needed, to the person's conviction and desire for VAD.

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<sup>27</sup> Roy Harvey, *ACT voluntary assisted dying laws can help others avoid appalling deaths*, Canberra Times, 25 March 2023.

129. VAD advance directives will give peace of mind to many people who are concerned that they will suffer later in life but might not then have the VAD decision-making capacity. Without a VAD advance directive, many people will choose to die early,<sup>28</sup> because in considering options to alleviate their suffering, they know that ‘it is always too early, until it is too late’. That is, people are choosing to die early before they lose decision-making capacity and the option of dying later.

130. Advance directives for VAD would prevent this. People will be comforted to know that they need not suffer, even if they lose VAD decision-making capacity in the future.

## **5.10. SUICIDE**

131. If suicide is ethical, VAD should be ethical. It must be appropriately regulated.

132. Suicide is legal. In most jurisdictions where VAD is illegal, suicide is probably the only legal act that becomes illegal if assistance is obtained. Ethically that is wrong, but legally and historically, we can understand why that has often been the case.

133. Decades ago, if somebody had been found dead, there would have been no evidence for VAD aside from the admissions of the person who caused the death. A person would be found, dead, obviously ‘assisted’ to die, and the perpetrator could have claimed, ‘well yes, they wanted to suicide, and they wanted my help’. Without evidence for VAD, including paperwork and state-dispensed drugs, and without an understanding that some people who are suffering want to die, murder could not be discounted. Even if a person were innocent of murder, no jury would have believed that somebody really wanted to suicide and needed help. So, murder was assumed.

134. In more enlightened times, where VAD is now legal in many places, that would not be the case. In a legislated Human Rights Model, there would be relevant paperwork attesting to the person’s VAD eligibility, decision-making capacity, desire for VAD, a history of suffering, a state-dispensed lethal drug, and other evidence. The evidence would be sufficient to meet legislative requirements and satisfy authorities that the well-informed person with decision-making capacity was making a voluntary decision to suicide (or be assisted with suicide) and at that moment had the capacity to do so (or at an earlier time had developed an advance care directive with directions for VAD). A death in a house, hospital, or in an ACT Elective Death Unit (logistically or physically attached to a hospital), with sufficient evidence, would be identifiable as VAD and distinguishable from murder. If there were a breach of regulatory conditions, serious penalties would apply.

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<sup>28</sup> See, for example, the people who have taken their own lives at <https://www.exitinternational.net/about-exit/exit-remembers/>.

## **5.11. REGULATORY CONSIDERATIONS**

135. Best practice VAD regulatory systems would come with penalty provisions, compliance, enforcement and monitoring systems, and legislated reporting and evaluation requirements. VAD has been successfully legislated overseas and can be successfully legislated in the ACT. The Swiss model (paragraph 120) allows individuals to exercise their autonomy

136. . If individual rights are a priority, then there would need to be a good argument as to why the evidence for a request for VAD should be more onerous than, for example, when we make our own last will and testament. Best practice legal and regulatory options should be employed, but that should be balanced against them not being so onerous that they deter people from accessing VAD.

## **5.12. CONCLUSION**

137. From a public policy perspective, regulated VAD is highly desirable. Regulatory systems should allow all people the right to choose the time and place of their death. Otherwise, some ACT residents might choose to die using substances acquired outside the regulatory system. Or people will suffer. In either case, ACT VAD regulation would have failed.

138. Legislation based on the Medical Model should be rejected as ethically unsound and a violation of individual rights. It does not allow all individuals to mitigate suffering.

139. We are mostly concerned about VAD eligibility criteria that do not discriminate and allow all people to mitigate their suffering. Decision-making capacity, being well informed and making a voluntary decision are the key eligibility criteria in the non-discriminatory Human Rights objective and supported by VAD advocates in the ACT.

140. The ACT government has an excellent opportunity to develop ethical, advanced, and world-leading VAD legislation. Legislation, based on an ethical Human Rights Model and involving an Elective Death Unit, would respect individual rights, not discriminate, and allow all people the option of mitigating suffering. That is what we all should want and what many need now.

## **6. RESPONSES TO CONSULTATION QUESTIONS**

141. Table 4 contains responses to the consultation questions in Appendix 1 of the ACT Government's Discussion Paper: Voluntary Assisted Dying in the ACT.<sup>1</sup> Responses, especially for eligibility questions 1–7, are based on rationale, arguments and evidence presented in Chapters 3–5 and data from the Ethical Rights VAD Survey (Appendices 2, 3). They are justifiable because the Human Rights Model will result in legislation that is ethical (mitigates suffering), consistent with human rights practices and legislation (does not discriminate) and best practice, including being consistent with the views of VAD advocates in the ACT.

142. Questions 8–36 are bureaucratic in nature. Policy responses to questions 8–36 should reflect regulatory best practice and be consistent with achieving a Human Rights policy objective (section 4.2). The criteria for good VAD regulatory systems should be met (section 3.2), including that individual rights are upheld, no discrimination occurs, and regulatory processes are best practice. For example, there are standard requirements about witnessing documents and these standard legal processes should be used where they are effective and efficient.

143. Given the policy objective for the Human Rights Model, we can determine which policy actions can most effectively and efficiently achieve that outcome. That does not mean that the ACT should be automatically duplicating state or international legislation; it means that sound (justifiable, ethical) arguments should be developed to justify policy actions.

**Table 4. Responses to ACT Discussion Paper consultation questions. Responses, where appropriate, are based on a Human Rights Model.**

Consultation question	Response
<b>Eligibility criteria</b>	
1. What should the eligibility criteria be for a person to access voluntary assisted dying?	A person ought to have decision-making capacity, be well informed and make a voluntary decision to access VAD, see arguments in Chapters 3–5. VAD advocates supported these three criteria more than any others in the Ethical Rights VAD Survey 2021 (Appendices 2, 3). That a person be resident/citizen, have 2 doctors approve a request for VAD, be terminally ill, and have limited life expectancy were the least supported eligibility criteria. These criteria also discriminate based on type or degree of suffering and life expectancy.
2. What kind of suffering should a person be experiencing or anticipating in order to be eligible to access voluntary assisted dying?	A person can have any type of suffering to access VAD. That is, no suffering should be excluded because there should be no discrimination on type or degree of suffering. Doctors should not be judging whether a person is sufficiently sick to die and overruling persons with decision-making capacity. When and how an individual chooses to die is an individual’s decision, not a doctor’s decision. That’s why VAD is ethically right; it is a decision for each individual.
3. Should a person be expected to have a specified amount of time left to live in order to be eligible to access voluntary assisted dying? If so, what timeframe should this be? Should there be a different timeframe for different conditions, for example for neurodegenerative disorders? If there is no timeframe required, what should a prognosis be instead?	No, discriminating on life expectancy is unethical. Any life-expectancy, that is, length of suffering, should be able to be mitigated, whether it is 3 days (e.g., in palliative care), 1 month or 40 years. If the objective of VAD legislation is to mitigate suffering, then we cannot require people to suffer for 39 years before becoming eligible to access VAD. A person who could suffer more must not be required to suffer more. A prognosis is not required. Each individual will determine if they are suffering more than they can bear.
4. How should a person’s decision-making capacity be defined or determined in relation to voluntary assisted dying?	A key role for the ACT Government is setting standards for determining decision-making capacity. A person only needs decision-making capacity with respect to VAD—they might not have decision-making capacity with respect to financial matters or anything else. They also need decision-making capacity if they were to draft an advance directive. For VAD, a person need only an understanding of the facts involved in the decision, appreciation of the nature and importance of the decision, understanding the benefits and risks of the decision,

Consultation question	Response
	<p>communication about the decision, and deliberation based on personal values.<sup>24</sup> These criteria are not and should not be onerous. A competent person with decision-making capacity should be easily able to satisfy these criteria. The ACT Government should seek advice from psychiatric and legal professionals on best practice processes for assessing VAD decision-making capacity. It will be important to identify situations that could be classified as irrational suicide so that they can be prevented.</p> <p>Note, decision-making capacity is assumed in most other activities, for example, if a person commits a crime. A sound argument would be needed to counter that presumption for VAD.</p>
<p>5. Should voluntary assisted dying be restricted to people above a certain age (for example, people 18 and over)?</p>	<p>No, it is unethical to discriminate based on age. Suffering does not begin in adulthood. If the policy imperative is to allow all people to mitigate their suffering, then all people should be allowed to do so, regardless of age. Children must not be required to suffer when adults need not.</p>
<p>6. Should a person be an Australian citizen or a long-term resident of Australia to access voluntary assisted dying in the ACT?</p>	<p>No, suffering knows no borders. Citizenship (least supported eligibility criterion in the survey) and residency are irrelevant. There is no sound reason to not mitigate suffering. If people were to come to the ACT from other states or overseas (where there might not be regulated VAD) to die, we should assist them to die. Mitigation of suffering is a priority, just like accepting human rights refugees is a priority. The same argument applies to ‘VAD refugees’—people who cannot access VAD in other jurisdictions. If cost considerations were a factor, the ACT could cost recover VAD services.</p>
<p>7. Given every Australian state now has voluntary assisted dying laws, is there any need for voluntary assisted dying in the ACT to be restricted to people who live in or have a close connection to the ACT?</p>	<p>No, see point 6.</p>
<p><b>The process for request and assessment</b></p>	
<p>8. What process should be in place in the ACT to ensure that an eligible person’s access to voluntary assisted dying is safe and effective?</p>	<p>Question is broad. Best regulatory practice should be used. The key point is to act to achieve the VAD Human Rights policy objective. There should be paperwork and witnesses to ensure a request is voluntary, the person is well-informed and has decision-making capacity (when they choose VAD or when they draft a VAD advance directive). The process should not be burdensome, and it would not be if the ACT established an Elective Death Unit (physically or logistically attached to a hospital).</p>

Consultation question	Response
<p>9. If a coordinating health professional or consulting health professional declines to be involved in a person's request for voluntary assisted dying, should they be required to take any particular action?</p>	<p>1. These health professionals should not be required, certainly not a consulting health professional. We do not need a doctor to confirm a person is suffering or acting as society's arbiter of what makes a life worth living, we only need to confirm the person has decision-making capacity. We want to ensure that a person has exhausted options for treatment/staying alive that are acceptable to them (that they are well-informed). A person will not be usually seeking access to VAD unless they have spoken to health professionals and exhausted all options to improve their well-being.                  2 If doctors do not want to be involved, they should refer the person to supportive doctors.                  3. Another issue is doctors in public hospitals that receive public funding should be acting in a person's best interests, not discriminating against them because they might not share the doctor's or hospital board's (usually religious) beliefs.</p>
<p>10. Should witnesses be required for a person's formal requests for voluntary assisted dying? If so, who should be permitted to be a witness?</p>	<p>Yes, use best regulatory practice. Two witnesses are usually sufficient for all other activities. It would be appropriate if carers or recipients in a person's will were ineligible to be witnesses, to reduce risk of coercion.</p>
<p>11. Should the process for seeking access to voluntary assisted dying require that a person take time to reflect (a 'cooling off' period) before accessing voluntary assisted dying?</p>	<p>Yes, sensible regulatory practice. Not much time should be required if they are in palliative care (less than one day) or of advanced age. People are suffering in palliative care and will die soon.</p>
<p>12. Should a person have a choice between self-administration and administration by an administering health professional of a voluntary assisted dying substance?</p>	<p>VAD is ethically right because all people are responsible for their own bodies. Thus, it should be mandatory that people self-administer lethal drugs (e.g., drink lethal solution or turn valve to administer IV fluid) unless self-administration is not possible.                  If assistance is needed or requested, it need not be a health professional. A spouse or loved one can help a person sip a drink or turn a valve. Doctors do not need to be involved, and doctor associations do not want doctors to be involved, so there is no need to involve them.</p>
<p>13. Should one method of administration be prescribed as the default option, or should methods differ depending on the circumstances? Does this need to be prescribed in legislation, or is it a matter best determined between the registered medical practitioner and patient?</p>	<p>Use best practice regulatory processes. Methods should depend on the circumstances. Some people might need administration through a peg tube, some can drink, some might need a cannula, some might prefer using a gas. If VAD is about individual rights, then it is up to the person, and, in unusual situations, in discussion with a medical professional. There should be no prescribing for individuals; it is a matter for the person. That said, recommended/ preferable drugs and methods of administration could be included in subordinate legislation.</p>
<p>14. Are additional safeguards required when an</p>	<p>Self-administration ought to be the first option. Health professionals should only be engaged if self-</p>

Consultation question	Response
eligible health professional administers the voluntary assisted dying substance (as compared with self-administration) and, if so, what safeguards would be appropriate?	administration is not possible. If health professionals have a view on safeguards, they should be consulted.
15. Should administration of the voluntary assisted dying substance to an eligible person be witnessed by another person? If so, who should be permitted to be a witness?	Not necessarily ethically, but probably required for legal protection. A person might want to die alone and that should be their choice. However, many people could be liable if something goes wrong, so having somebody present (for example, the health care worker from the Elective Death Unit that they have been dealing with) would offer legal protection. As would having an AV recording and being recorded remotely via CCTV; whatever is necessary to provide legal surety to protect everybody involved in the process.
16. What safeguards are necessary to determine whether or not a person has taken the voluntary assisted dying substance, and to return the voluntary assisted dying substance if it has not been taken?	Follow best practice regulatory procedures and safeguards. Witnesses, if any, might need to sign declarations, excess lethal substance would need to be returned to dispensing pharmacist for disposal etc. See also response to question 15.
<b>The role of health professionals</b>	
17. Who should be permitted to be a person's coordinating health professional or consulting health professional? For example, a registered medical practitioner, a nurse practitioner, or someone else?	Workers in an Elective Death Unit would be health professionals (need not be doctors) and would have that role. VAD supporters and people seeking access to VAD do not want anyone telling them that they are not sick enough to die.
18. What minimum qualification and training requirements should there be for health professionals engaged in the voluntary assisted dying process?	Use best regulatory practice. People in an Elective Death Unit would be health professionals, nurses, maybe doctors, and they would provide all necessary information that a person can use to make an end-of-life decision. This assumes that all persons who are ill would already have exhausted all treatment options with their general practitioner and/or specialists. They should be trained to accept decision of a person with decision-making capacity to die, even if they are not ill.
19. Which health professionals should be able to administer the voluntary assisted dying substance? For example, a registered medical practitioner, a	Self-administration must be the first option. A person's life is their responsibility, that's why VAD is ethically right, and that's why a person should self-administer. If self-administration is not possible, then it is the individual's choice and it need not be a health professional. The person might want a

Consultation question	Response
nurse practitioner, registered nurse, or someone else?	spouse to turn a valve or bring a drink to their lips. They might also need medical assistance if a cannula is required. It is each individual's choice.
20. Should registered health practitioners or other health professionals be free to initiate a discussion about voluntary assisted dying, providing information alongside other treatment and management options such as palliative care, where appropriate?	Yes, a person accessing VAD ought to be well-informed about all options to help improve their lives and well-being or end their lives via VAD. A person's GP or specialist could provide VAD information via a standard pamphlet.
21. Should health professionals be required to provide certain information to a person who asks about voluntary assisted dying, in addition to providing information about other treatment and management options such as palliative care?	Yes, health professionals ought to act in a person's best interest. That means that they should answer all questions and ensure that everybody is well informed about all treatment and VAD options.
22. What categories of persons or professions should be permitted to conscientiously object to being involved in voluntary assisted dying? Should this be limited to registered health practitioners?	If anybody does object to being involved, they should refer the person to somebody who can help, just as they should for somebody requiring specialist surgery. Nobody should object if they are working in the Elective Death Unit (workers are choosing to work there), noting that ACT might only need two such units.
23. Should health professionals who conscientiously object or who choose to not participate in the voluntary assisted dying process be required to declare their objection or non-participation to a person who is or may be interested in accessing voluntary assisted dying?	Yes, and they should refer them to somebody else. Noting that this will not occur in an Elective Death Unit (workers will choose to work there). Regarding other health professionals, full personal disclosure should be required.
24. Should health professionals who conscientiously object to voluntary assisted dying be required to refer a person to other health professionals? Is there anything else that health professionals should be required to do if they conscientiously object, such as provide certain information about voluntary assisted dying?	Yes, conscientiously objecting health professionals should refer people seeking access to VAD to the Elective Death Unit or somebody else. Noting that this will not occur in an Elective Death Unit (workers will choose to work there).

Consultation question	Response
<b>The role of health services</b>	
<p>25. Should a health service be permitted to not facilitate voluntary assisted dying at its facilities, for example at a residential aged care facility, a hospital, or accommodation for people with a disability?</p>	<p>This will not be a problem with an Elective Death Unit. The person's best interests are paramount. If they are already living or being treated at a health facility or residential aged care facility etc, and it is not in the person's best interests that they be moved, the facility ought to be required to facilitate VAD or otherwise act in a person's interests (e.g. find them a better place to live or stop taking their money under the false pretence that they are caring for them). They could also state that their policy is that they do not offer VAD, and everybody who moves in after that policy begins would be aware of the limitations, but that should not apply to a large public hospital. But they should care for the people already there. There should be no opt-out option for a major public health facility like Calvary Hospital. People should never be transferred between health facilities against their will in their last days just so a major public hospital can ignore a person's VAD requests. If the Calvary Board and Hospital cannot accommodate people requesting VAD, they should be required to pass management of the hospital over to a more ethical and considerate group that will accommodate legal requests for VAD.</p>
<p>26. If a health service wishes to not facilitate voluntary assisted dying at its facilities, what is the minimum the provider should be required to do so that a person's access to voluntary assisted dying is not hindered?</p>	<p>Not a problem with an Elective Death Unit. All health facilities should be acting consistent with a person's best interests. This is serious. In a person's last days, if they were taken by ambulance to a major public hospital (e.g., Calvary), they should not have to be transferred to another hospital to access VAD. A person who wants VAD in Canberra or Calvary Hospital, hospitals in receipt of public funds, should be able to access it. People should not have to change hospitals at the end of life.</p>
<b>Death certification and notification</b>	
<p>27. Should information about the Registrar-General's discretion for death certificates under section 44 of the Births Deaths and Marriages Registration Act 1997 (ACT) be made available to families who may require support after a person dies by accessing voluntary assisted dying?</p>	<p>If that is in the family's best interests, then yes. Use regulatory best practice and determine what is best considering the VAD policy objective.</p>
<p>28. What should be recorded as the cause and manner of death for a person who has died by accessing voluntary assisted dying?</p>	<p>In all, or at least most, cases, the underlying cause of death should be recorded, given that 'Medical certificates of death are used as a source of data for mortality statistics that then inform the allocation of resources, for example, guiding the allocation of health services or health research</p>

Consultation question	Response
	<p>resources.<sup>29</sup> That will be the reason a person has chosen VAD. The subsequent antecedent cause might also need to be listed.</p> <p>The person's view is also important. If the person had no disease but were suffering, then the person might have a view about how that was recorded. Think rationally, consider best practice overseas regulatory frameworks, and develop best practice policy based on evidence, consistent with the VAD policy objective.</p>
<b>Oversight, reporting and compliance</b>	
<p>29. What sort of oversight mechanisms are needed to ensure voluntary assisted dying is safe and effective? In particular, should oversight focus more on retrospective compliance or prospective approval? Should oversight mechanisms be independent from government?</p>	<p>Use best practice regulatory oversight. For example, there should be reporting provisions and an Act review every few years. There should be compliance, enforcement and monitoring provisions that should not impact on people seeking VAD. These can be streamlined if an Elective Death Unit is developed. Retrospective oversight does not impact on people seeking VAD, so is preferred. Complex, but would need to consider the arguments to make an informed decision. Legislative reporting and evaluation are important.</p>
<p>30. If an oversight body is established, should this body review or approve compliance with key stages in the voluntary assisted dying process as a person is progressing through the process? If so, what should these key stages be?</p>	<p>No, it would be an administrative burden if used as a person is progressing through the VAD process. It would take longer and it is unclear whether it would add value. An Elective Death Unit would facilitate processes. If a person has decision-making capacity, and there is no discrimination on suffering, age, residency or citizenship status, then it is difficult to see what an oversight body would do.</p>
<p>31. Should mechanisms be available to review the decisions of a coordinating health professional or consulting health professional in relation to a person's eligibility to access voluntary assisted dying? If so, what kind of mechanisms, and what aspects of health professionals' decisions should be reviewable?</p>	<p>1 This question is premised on doctors finding some people (with decision-making capacity) as ineligible. No reviews need be required because doctors should not overrule the decision of a person with decision-making capacity.</p> <p>2 An Elective Death Unit is administratively simpler.</p> <p>3 The ACT does not need coordinating, or especially consulting, health professionals, this is unnecessary bureaucracy. Governments should think laterally about what produces the most ethical and efficient regulatory system.</p> <p>4 All people, regardless of their type or degree of suffering or doctors' assessments of life expectancy, should be able to access VAD. They would be seeking VAD if other options to keep</p>

<sup>29</sup> Downie J, Oliver K. Medical certificates of death: First principles and established practices provide answers to new questions. CMAJ. 2016 Jan 5;188(1):49-52. doi: 10.1503/cmaj.151130. Epub 2015 Dec 14. PMID: 26668191; PMCID: PMC4695354. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4695354/>.

Consultation question	Response
	<p>them alive are not desirable and their well-being is poor.                      5 Doctors must never overrule a person with decision-making capacity and tell them they are not sick enough to access VAD. It is not their life and not their decision. Doctors are not arbiters for people's lives.</p>
<p>32. What protections might be necessary for health professionals, and potentially others, who act in accordance with voluntary assisted dying legislation in good faith and without negligence?</p>	<p>Use regulatory best practice. Whatever other protections apply when health professionals give advice to the best of their ability. Note, as doctors should not assess people and determine that they are not sick enough to die, we do not need doctors involved.</p>
<p>33. Should there be specific offences for those who fail to comply with these requirements?</p>	<p>Use regulatory best practice. Health professionals should be protected if they give advice to the best of their ability and note where they might not have expertise. If people assisting with VAD processes do not comply with regulatory conditions, they should be subjected to appropriate penalty provisions under any VAD Act.</p>
<p><b>Other issues</b></p>	
<p>34. What other laws might need to change in the ACT to enable effective access to voluntary assisted dying?</p>	<p>Legislation may be required to ensure that anyone involved in providing information about or facilitating VAD is not subject to s.18 of the ACT Crimes Act which deals with aiding/inciting suicide.                       It is an offence to use a carriage service for suicide-related material, see s474.29A of the <i>Criminal Code Act 1995</i> (Cth). The Commonwealth Criminal Code ought to be amended to allow VAD telehealth advice.</p>
<p>35. Are there experiences elsewhere in Australia or internationally that the ACT might usefully learn from in the development of its own approach to voluntary assisted dying?</p>	<p>The Swiss model is closest to a Human Rights Model. It is closest to the concept of an Elective Death Unit. See the Dying with Dignity ACT submission for more information on the Elective Death Unit.</p>
<p>36. Are there any other matters you think should be considered in implementing voluntary assisted dying in the ACT?</p>	<p>VAD legislation should be ethical, non-discriminatory, and best practice. If it discriminates on type or degree of suffering, life expectancy, age, residency or citizenship status, it is unethical. If it has doctors overruling people and telling them they are not sick enough to access VAD, that is unethical. The ACT should develop an ethical VAD objective and use best practice regulation to achieve that.</p>

# APPENDICES

144. Appendix 1 provides information about this submission's author.

145. Appendix 2 contains the Summary Report of the Ethical Rights Voluntary Assisted Dying Survey 2021. Appendix 3 contains the Results of the Ethical Rights Voluntary Assisted Dying Survey 2021. The results quoted are from all survey respondents around the world. At the level of detail discussed in this submission, the responses across the world, Australia, and ACT are quantitatively similar and qualitatively the same.

146. Both the Summary Report and the Results can be found at the Ethical Rights Website: <https://www.ethicalrights.com>.