

Exit International ACT Branch

Submission to the ACT's Select Committee on the Voluntary Assisted Dying Bill 2023

7 December 2023

Submission prepared by
Dr David Swanton
Exit ACT Chapter Leader and
Director, Ethical Rights
<https://www.ethicalrights.com>



Ethical Rights

CONTENTS

1.	Executive Summary	3
1.1.	Recommendations	5
2.	Introduction	6
2.1.	Overview of the Bill	7
2.1.1	Exit ACT's take on the Bill's shortcomings	7
2.1.2	Exit ACT's take on the Bill's positives	8
3.	The focus of this submission	10
4.	Exit ACT	11
5.	A justifiable ethical approach to VAD	14
6.	Part 2 of the Bill	16
6.1.	Clause 6	16
6.2.	Clause 7	18
6.3.	Clause 8	21
6.4.	Clause 9	21
6.5.	Clause 10	21
6.6.	Clause 11	22
6.7.	Clause 12	26

1. EXECUTIVE SUMMARY

1. The ACT Government should be congratulated for introducing the Voluntary Assisted Dying Bill 2023. A great deal of work has gone into it, and the Government should be congratulated for getting this far.
2. Exit ACT and Ethical Rights support any efforts that respect individual autonomy and allow all people to access voluntary assisted dying (VAD) to mitigate their suffering. In this submission, we challenge the Government to make the ACT's VAD legislation the best it can be, without unjust discrimination.
3. VAD is ethically right because it respects individual autonomy—a person's right to make decisions about what is best for their own body. On this basis, all women can have abortions and all people, including persons identifying as LGBTIQ+, can choose their life partner. All people choosing VAD should have similar rights to their own bodies.
4. Although the Bill and Explanatory Statement claim otherwise, the Bill does not respect individual autonomy, the key feature of any ethically desirable VAD human rights model. In the human rights model, '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'.
5. The Bill, unfortunately, has been based on the discriminatory Australian VAD medical model legislated in the Australian states. Although the Bill is a solid improvement on state VAD legislation, it unjustly limits who is eligible for VAD, does not respect everyone's personal beliefs, does not allow all people to maintain their dignity, is not international best practice VAD legislation, and is not what voluntary assisting dying advocates want according to a worldwide VAD survey (see Attachments 4, 5).
6. In the VAD medical model, individual autonomy is rejected. That is because doctors can assess individuals as not sick enough and judge them as ineligible for VAD. State VAD legislation unjustly discriminates as it is limited to *terminally ill, adult residents with limited life expectancy*. That last condition has thankfully not been included in the ACT Bill.
7. This Bill's discrimination is clear. Limiting VAD to terminally ill, adult residents is ethically equivalent to limiting abortion to raped women only, organ transplants to adults only, and restricting medical services to only residents, but not refugees. The hollow arguments in the Explanatory Statement can be applied logically to these scenarios.
8. No rational Canberran can justify such discrimination. Unless the Government thinks Canberrans support unjust discrimination—they abhor it—it should amend the Bill to remove discrimination and ensure individual autonomy.
9. In addition, no provision has been made for VAD-specific advance care directives. There are two likely outcomes. Canberrans will either suffer with dementia, against their

will, or some elderly Canberrans will take legal lethal substances in the absence of VAD legislation that respects individual autonomy (as happens now). ACT police are well-respected, but further police welfare checks on elderly Canberrans who might buy legal lethal substances will continue to be an inefficient use of police resourcing.

10. People who will suffer under the Bill include persons whose disease is not advanced, progressive and expected to cause death (they are not terminally ill), suffering children and infants, non-ACT residents, as well as people in palliative care homes, of advanced age, with mental illnesses and conditions such as motor neurone disease, locked-in syndrome etc. Again, no rational Canberran can justify discrimination that results in people suffering. All people can suffer. Suffering is not limited to terminally ill, adult, ACT residents.

11. There are specious arguments aplenty in the Explanatory Statement. One is that a 'person's condition is advanced and terminal' to ensure 'that VAD is only an option for those near the end of life'. Such fallacious circular arguments must be rejected.

12. Another is that children should not have access to VAD to protect the 'rights of young people to life and protection'. That is nonsense. A child's well-being is critically important. When children are terminally ill, and unbearable suffering and death await them, VAD might be the only way to mitigate their suffering. It should not be denied to anyone. The Bill requires children to suffer when adults need not. The Bill should be amended to reduce children's suffering and help make the world a better place.

13. According to the worldwide VAD Survey, and consistent with the VAD human rights model, only three eligibility criteria are needed for VAD. Persons must make a voluntary decision, they should be well-informed, and they should have decision-making capacity. Each person knows what is best for their bodies, not doctors. Doctors should be unable to overrule their decisions. Only then can individual autonomy be properly respected.

14. There are many scenarios that are problematic, especially given the inconsistency between the Bill's principles and its eligibility criteria. These include scenarios involving a suffering terminally ill criminal who has not cooperated with police, a 17-year-old terminally ill pregnant woman who will be 8 months pregnant when she is eligible for VAD at 18, and a person in a palliative care facility who wants to use their own legal lethal substance because of their inability to meet VAD regulatory timeframes.

15. The Bill's discrimination, problematic scenarios and other shortcomings can be addressed by legislating a Bill that is consistent with ethical VAD objects and principles that respect individual autonomy, rather than a Bill that pretends to do so. It should not be hard to amend.

16. Exit ACT is available to discuss any of these matters.

1.1. RECOMMENDATIONS

17. The Bill should be amended now, as outlined in this submission, so 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. If amended, then some Canberrans will not be forced, through absence of ethically satisfactory legislation, to suicide early.

18. The Bill can be improved by:

- (a) respecting individual autonomy—ensuring the Bill aligns with ethically appropriate VAD objects and principles consistent with the VAD human rights model and removing all unjust discrimination based on degree or type of suffering, terminal illness, age, or residency status, including in the eligibility criteria.
- (b) preventing doctors or any health professional from overruling the voluntary, well-informed decision of a person with VAD decision-making capacity.
- (c) including provisions for VAD-specific advance care directives so that a person's well-being will be improved knowing that options are in place if they were to suffer from dementia etc.
- (d) amending cl 159 so that a review in 3 years will include whether a person's suffering must be 'advanced, progressive and expected to cause death', that is that they be terminally ill.

2. INTRODUCTION

19. The ACT Government's Voluntary Assisted Dying Bill 2023 (the Bill) is a robust improvement on the voluntary assisted dying (VAD) legislation in the Australian states, all of which has been based on the Australian VAD medical model.¹ The ACT Government, and in particular, the responsible minister, Tara Cheyne MLA, should be commended for its work. Despite opposition from VAD detractors, it has been a marvellous effort by Ms Cheyne to introduce a Bill that will prevent many Canberrans from suffering against their will. This is a significant achievement.

20. The Government's good work in introducing the Bill must be balanced against the fact that more work can and should be done now. The Bill is ethically unsatisfactory because no rational Canberran could justify the rejection of a person's individual autonomy, represented by the unjust discrimination in the Bill.

21. If no rational Canberran could support all clauses of the Bill in its current form, then the Government should amend the Bill. Canberrans are sensible and abhor discrimination more than the ACT Government probably thinks they do. No rational Canberran would accept similar discrimination in abortion or gay marriage legislation.

22. This submission challenges the ACT Government to amend the Bill to develop ethically acceptable VAD legislation that respects individual autonomy and does not unjustly discriminate on the degree or type of suffering (including terminal illness, mental illness etc), age, or residency status. This submission argues for Bill amendments, focussing on VAD objects, principles, and eligibility criteria.

23. The robust and rational positions argued for in this submission are not meant as criticism of the Bill's development. There has been an impressive amount of work to get the Bill this far. It is simply that the Bill can and should be ethically better to meet the needs of Canberrans. The VAD medical model is discriminatory, rejects individual autonomy, and a poor starting point for legislation. The Government should not let VAD detractors deter it from legislating the most ethically desirable legislation. People will suffer if they do.

¹ The Australian medical model has 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.*' It gives doctors rights over patient lives. See the Exit ACT Submission to the ACT Government 2023 at Attachment 1.

2.1. OVERVIEW OF THE BILL

2.1.1 Exit ACT's take on the Bill's shortcomings

24. Despite some specious claims in the Bill's Explanatory Statement and Human Rights Compatibility Statement, the Bill does not respect individual autonomy. Respect for a person's individual autonomy is a fundamental ethical principle in philosophy and medicine. However, individual autonomy is not respected if a health practitioner can judge and overrule the choice of any person with decision-making capacity for VAD.

25. The Bill's shortcomings have arisen because it is difficult to develop ethically satisfactory VAD legislation from a flawed Australian VAD medical model. The Bill might meet the needs of some people, but not all people will have the opportunity to choose VAD and have their suffering mitigated. Any rational Canberran would accept that all competent persons with VAD decision-making capacity should have the right to mitigate their suffering.

26. The general impression from even a cursory reading of the Bill and states' VAD laws is that the legislation is consumed with regulatory and administrative constraints with little compassion for people who are suffering. Certainly, the Bill is a legislative instrument, and regulatory controls are required.

27. However, the Bill's so-called safeguards for eligibility—mostly euphemisms for unjust discrimination—make the suffering person jump unnecessary hurdles that can only increase their anguish. The Bill is so consumed with comprehensive regulatory checks and balances that it loses its humanity. Voluntary assisted dying advocates and rational Canberrans would classify the Bill as ethically unsatisfactory and effectively useless in some end-of-life scenarios.

28. Many people will be forced to suffer against their will or suicide prematurely if doctors assess them as ineligible or they fail to meet the Bill's regulatory provisions. These include people who:

- (a) could suffer for many years but do not suffer from a condition that is advanced, progressive, and expected to cause death (are not terminally ill), including people suffering, or likely to suffer, from dementia (including Alzheimer's Disease), motor neurone disease, locked-in syndrome, or who have physical or mental conditions or disabilities causing suffering.
- (b) are in palliative care with days or weeks to live.
- (c) are suffering unbearably with a short time to live.
- (d) are of advanced age, for example, elderly people whose well-being is poor (their quality of life is below a threshold of what they consider to be acceptable) and is

likely to deteriorate.

- (e) choose to die when their terminally ill partner of many years dies.
- (f) are terminally ill children and infants²—while the plight of children is not a specific legislative priority for Exit members given Exit's elderly membership, the welfare of children is a concern for all rational Canberrans—suffering terminally ill children and infants must suffer until they die, when terminally ill adults can access VAD and need not.
- (g) are suffering non-ACT residents.

29. Nobody should be able to deny these people's choice of VAD—it would prevent any deterioration in their well-being—but the Bill either marks them as ineligible for VAD or gives doctors the right to overrule them. No rational Canberran would endorse a violation of a person's individual autonomy if doctors could assess any woman as ineligible for abortion or politicians could overrule any LGBTIQ+ person's choice of a life partner.

30. Finally, people who are likely to be ravaged by dementia or similar conditions must suicide early as the Bill lacks provisions for VAD-specific advance care directives. Humane, civilised societies do better. Belgium, Italy, Luxembourg, and the Netherlands allow VAD-specific advance care directives.

31. The Bill (cl 159) addresses some of these failings by stating that issues of eligibility based on a person's age and residency status, as well as matters relating to VAD advanced care planning, will be reviewed 3 years after the Act's commencement. That is welcomed, but no changes would be effective until at least 2030. The issue of whether a person's suffering must be 'advanced, progressive and expected to cause death'—that is, that they be terminally ill—should also be reviewed in 3 years.

32. Until then, people will suffer, or people will take their own lives so they do not suffer. More can and should be done now in the Bill to mitigate people's suffering.

2.1.2 Exit ACT's take on the Bill's positives

33. The Bill improves on the ethically unsatisfactory VAD medical model implemented in the Australian states.

34. First, there is no limit on a specific timeframe until death, that is, life expectancy. This is an excellent outcome. The Australian states have mostly legislated a 6-month timeframe to death (12 months for neurodegenerative conditions). A person who could suffer for 40 years—unfortunately, their condition must still be advanced, progressive, and expected to cause death—could theoretically access VAD under the ACT Bill. No rational

² A child or infant, and some adults, will not have VAD decision-making capacity. In which case, a decision should be made by parents/guardians acting on doctors' best advice and in the person's best interest.

Canberran would accept that a person who could suffer more must suffer more.

35. Second, one nurse practitioner can be involved rather than a doctor. This is certainly an improvement on states' medical models, but no nurse practitioner or doctor should ever be able to overrule a suffering person's decision for VAD.³

36. It is helpful to consider the puzzling change of heart by doctors' groups on VAD. As recently as 2018, even 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.'⁴ Indeed, before VAD legislation was introduced, doctors' groups had been vigorously opposed to legalised VAD. They claimed that they should 'do no harm', although from a suffering person's perspective, staying alive and suffering was doing harm.

37. Yet now VAD legislation has been developed, doctors have been advocating to control VAD and act as arbiters of whether a person's life is worth living. This rejection of individual autonomy is unethical and unacceptable. Each competent person should be responsible for whether they have an abortion, who they have a sexual relationship with, and whether they choose VAD. That's what individual autonomy demands. The world is not a better place if some people are denied individual autonomy and prevented from alleviating their suffering.

38. VAD is ethically right because it respects individual autonomy. Each person should be responsible for their own life, and for ending it. Consequently, the only role that health practitioners ought to have in VAD is certifying VAD decision-making capacity and, if a person is unable to self-administer and family or friends do not wish to assist, administering a lethal substance.

39. Third, there is some capacity for non-residents who are being treated in Canberra hospitals to access VAD, but only if they have a 'substantial connection' to the ACT. That is an improvement, however, suffering does not begin at the ACT border.

40. Fourth and finally, there is some protection for patients who live in institutions that oppose VAD. That too is encouraging and appropriate.

41. These are all highly commendable improvements on the restrictive, discriminatory, and ethically unsatisfactory Australian VAD medical model.

³ Throughout this submission, all persons eligible for VAD must have decision-making capacity with respect to VAD and make a voluntary, well-informed decision. Other eligibility criteria are unnecessary, discriminatory and have been rejected by VAD advocates and supporters (see [Ethical Rights Voluntary Assisted Dying Survey 2021](#) at Attachments 4 and 5).

⁴ 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-euthanasia-and-physician-assisted-suicide>.

3. THE FOCUS OF THIS SUBMISSION

42. Given Exit ACT's elderly membership, the focus of this submission will be on Part 2 of the Bill, concerned mainly with the Bill's objects, principles, and important concepts, including eligibility criteria.

43. This submission is supported by 5 attachments.

- Attachment 1 is the comprehensive Exit ACT and Ethical Rights submission to the ACT Government during the Bill's consultation phase. It includes details of the VAD medical model and human rights model, rational arguments against unjustly discriminating in eligibility criteria, international VAD comparisons, and responses to the ACT Government's VAD consultation questions.
- Attachment 2 is a letter from Exit ACT written to Tara Cheyne MLA and all ACT MLAs in September 2023. It clarifies Exit ACT's position on rejecting the medical model as a basis for VAD legislation, advocates legislation based on a VAD human rights model that respects individual autonomy, and rejects unjust discrimination based on a person's degree or type of suffering, life expectancy (not discriminated against in the Bill), age, or residency status.
- Attachment 3 is the response from Tara Cheyne MLA to Exit ACT's letter.
- Attachment 4 is the Summary Report and Attachment 5 is the Results of the [Ethical Rights Voluntary Assisted Dying Survey 2021](#).⁵ VAD advocates in Canberra, Australia and worldwide overwhelmingly rejected the Bill's key eligibility criteria of being terminally ill and having 2 doctors approving VAD requests, amongst others.

44. It should be noted that other changes to the Bill regarding regulatory and administrative procedures will be required if Exit ACT's amendments to eligibility criteria are adopted to make the Bill ethically satisfactory. For example, if doctors are not required to certify that a person's illness is terminal, as occurs in the ethically progressive VAD nations of Austria, Belgium, Canada, Colombia, Germany, Luxembourg, the Netherlands, Spain, and Switzerland, then doctors cannot overrule people who are not terminally ill from accessing VAD.⁶ The role of doctors in other people's lives is lessened.

⁵ The Ethical Rights Voluntary Assisted Dying Survey 2021 Questions and Supplementary Material can be found at <https://www.ethicalrights.com>.

⁶ Only Australia, Italy, New Zealand, and the United States require that a person be terminally ill to be eligible for VAD.

4. EXIT ACT

45. Exit International is the voluntary euthanasia/voluntary assisted dying advocacy and information organisation founded by Dr Philip Nitschke in 1997. Dr Nitschke was the first doctor in the world to assist with the administration of a legal lethal substance in 1996, when the Northern Territory had effective VAD legislation. That law was subsequently overturned by the Australian Government's *Euthanasia Laws Act 1997*.

46. Exit International 'provides information and education about practical do-it-yourself end of life choices to rational adults' (aged 50 years and over).⁷ Exit prioritises individual autonomy, as it believes that control over one's life and death is a fundamental human right.

47. Exit ACT has over 200 mainly elderly members in the ACT. Exit members, as every person should be, are well informed about end-of-life options. Exit ACT and Dying with Dignity ACT (DWDACT) have been advocating for VAD legislation in the ACT since 1997. Both organisations represent people who would use ACT VAD legislation. This submission is a result of 26 years of advocacy by Exit ACT and DWDACT for people to obtain the right to end unnecessary suffering and achieve a peaceful death.

48. The Bill does not meet all Exit ACT members' needs. Since 1997, many suffering people in Canberra, Australia, and around the world have taken end-of-life substances to achieve peaceful deaths. They have done so because VAD regulation has been either lacking or inadequate. Many suicides were peaceful and desirable, many were mis-managed and not so.

49. With respect to VAD legislation, Exit ACT is advocating for eligibility criteria that align legislatively with the VAD human rights model,⁸ in which individual autonomy is properly respected and no discrimination occurs. We argue in this submission that there should be no restrictions on a person's:

- (a) degree or type of suffering—to be eligible, a person could have physical or mental suffering or both and need not be terminally ill.
- (b) age—children must not be forced to suffer when adults can access VAD (all people should be eligible, not just adults).
- (c) residency status—all people should be eligible, regardless of whether they reside in the ACT.
- (d) capacity to legally draft an advance care directive—a document that specifies the option of VAD in specific circumstances—and to have instructions in that advance care directive implemented.

⁷ See <https://www.exitinternational.net>, accessed 22 November 2023.

⁸ See the Exit ACT Submission to the ACT Government 2023 at Attachment 1.

50. For completeness, we note that the Bill improves on the Australian medical model as it does not discriminate on life expectancy (time to die).

51. Exit ACT is particularly concerned with the fate of elderly Canberrans. Many elderly people suffer from degenerative or deteriorating conditions relating to ageing. For these people, the concerns about suffering with dementia are manifold, and with good reason. Dementia is the largest killer of Australians over 85 years old and second largest killer for people 75–85 years old. Exit ACT members are all too aware of the maxim ‘it’s always too early until it’s too late’. This refers to the fact that many people will suicide prematurely rather than waiting until they have dementia and lack the capacity to suicide. A VAD-specific advance care directive could prevent these premature suicides.

52. If the current Bill were enacted in the ACT, given that it has deficiencies, many Canberrans would likely obtain legal lethal substances and suicide outside of the regulatory system. It should be noted that there are many legal ways of achieving peaceful deaths. Anyone with a good medical or science degree has the knowledge and intellectual skills to research options for themselves.

53. In the [Ethical Rights Voluntary Assisted Dying Survey 2021](#) (see Attachments 4, 5), 85% of respondents indicated that their quality of life would be improved if they had ready access to an end-of-life substance. In 24% of cases, respondents indicated that the substance should be legal, but 61% of respondents indicated that their quality of life would be improved if the substance were legal or illegal. Moreover, the proportion of respondents whose life would be improved if they had access to legal or illegal end-of-life substances increased with respondents’ age. That is, as people age, they are more likely to want something, anything, to avoid the possibility of suffering, regardless of legality. The Bill does not provide that option.

54. During 2023, the ACT’s Federal Police have conducted welfare checks on elderly Canberrans late at night, after 11 pm. These elderly women were alleged to have acquired some legal lethal substances from overseas. These women have VAD decision-making capacity and are not ‘vulnerable’, but these welfare checks were counterproductive as these women were, as all people would be, stressed by police interrupting their sleep. The ACT police are well respected, but late-night police visits would be stressful to anybody. Police resources can be more effectively deployed.

55. Until the ACT introduces VAD legislation that meets the needs of Canberrans, there should be no need for these police welfare checks. If the Bill is enacted without amendments that properly respect individual autonomy and reject unjust discrimination, then people will continue to acquire legal lethal substances. The police do not need to be involved—nothing illegal is occurring.

56. Alternatively, Canberrans and Australians who are suffering can go to Switzerland to die. A new book, *Going to Switzerland—How to plan your final exit* (Figure 1), describes

what is required if a person wants to die in Switzerland.

57. In 2018, David Goodall, a 104-year-old Australian scientist, who had been actively working until 103, prioritised his quality of life and well-being. He was not sick or terminally ill but had been suffering from some elderly ailments. He travelled from Australia to Switzerland to die because of Switzerland's supportive VAD 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"'.⁹

58. If Australians go to Switzerland to die, that will be a reflection that VAD legislation based on the VAD medical model does not meet Australians' needs.



Figure 1. The book, 'Going to Switzerland—How to plan your final exit'

⁹ See <https://www.abc.net.au/news/2018-05-10/david-goodall-ends-life-in-a-powerful-statement-on-euthanasia/9742528>, accessed 29 November 2023.

5. A JUSTIFIABLE ETHICAL APPROACH TO VAD

59. VAD is ethically right because it is an expression of individual autonomy: that each person has the right to determine what is proper for their body. VAD is an option that a person can choose to mitigate their suffering.

60. John Stuart Mill, one of the architects of democratic and utilitarian philosophy, argued that individual autonomy is fundamental. He wrote that 'Over himself, over his own body and mind, the individual is sovereign'. That is, nobody can overrule the individual decision of a competent person on whether they choose to have an abortion, live in an LGBTIQ+ relationship, drink alcohol, follow a religion, or even to suicide. Yet the Bill limits, through restrictive eligibility criteria and the empowering of doctors, an individual's right to choose VAD.

61. Mill also expressed, his so-called harm principle, 'That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.' As a competent person's choice of VAD does not harm others, it should be nobody's concern but that of the person themselves. If the ACT Government is going to violate this principle, it begs the question of what other aspects of an individuals' lives it will choose to interfere in.

VAD's ethical equivalence with abortion and LGBTIQ+ relationships

62. No rational Canberran would accept a doctor interfering in a woman's individual choice to have an abortion or a politician interfering in a person's choice to live in an LGBTIQ+ relationship.

63. A 10-year-old or 17-year-old woman can have an abortion because she has individual autonomy. But subsequently, as she is not an adult according to the Bill, she cannot have VAD even if terminally ill. A 17-year-old person can engage in an LGBTIQ+ relationship because they have individual autonomy. But subsequently, according to the Bill, they cannot have VAD if they were suffering with locked-in syndrome but not terminally ill. This begs the question: when do these people lose the right to their own bodies?

64. If we accept Mill's ethical arguments, then governments ought not interfere in any of these individual matters. If it interferes in some, it takes the moral low ground: its decisions are arbitrary, and it has no sound basis for interfering in some individual matters but not in others. If abortion and LGBTIQ+ relationships are ethically right because of individual autonomy and liberty, then so is VAD. Individual autonomy demands their ethical equivalence.

VAD policies must be based on evidence and argument

65. In public policy debates, including on VAD, people are only entitled to what they can argue for. They are not entitled to their opinions. This means that as a person, you are not 'entitled to have your views treated as serious candidates for the truth'.¹⁰ Flat-earthers, anti-vaxxers, climate change deniers, god believers, and people who oppose a person's right to access VAD to mitigate their suffering, must provide evidence or argument to support their conclusions. Without evidence their arguments must be rejected. We are deluding ourselves if we accept conclusions of flawed arguments without evidence.

66. The ethical VAD policy objective, based on a VAD 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.' This policy objective will allow all people to mitigate their suffering. Given a set of policy principles, we can also answer questions about whether a child, an infant, a non-resident, an incarcerated criminal with a life sentence, a person with locked-in syndrome, motor neurone disease, or dementia, an LGBTIQ+ person, a pregnant woman, a religious person, or any other person can access VAD. All people can suffer, and no rational Canberran would accept that we should impose discriminatory eligibility criteria. No rational Canberran supports the Bill's discrimination, so the Government should remove it.

67. In the next section, we will focus on whether Part 2 of the Bill respects individual autonomy and is ethically consistent. We will use similar comparisons to other recent ethically contestable issues, including abortion and LGBTIQ+ relationships, to highlight ethical inconsistencies in political thinking. We will consider what a rational person might consider as a sound or cogent argument for a policy position.

Political perspectives

68. Politically, individual autonomy with respect to VAD should be not contentious. Politicians Australia-wide from the Labor Party and the Greens have, rightly, generally been supportive of individual autonomy given their broad or party-based support for abortion and LGBTIQ+ relationships. The Liberal Party promotes that it believes in individual freedom¹¹: 'we work towards a lean government that minimises interference in our daily lives' and 'we simply believe in individual freedom and free enterprise'. All politicians should respect individual autonomy and support ethical VAD legislation.

69. Politicians must think critically about the principles that underpin their policy decisions, otherwise their decisions are arbitrary, do not meet the needs of Australians and do not make the ACT, Australia, or the world a better place.

¹⁰ See <https://theconversation.com/no-youre-not-entitled-to-your-opinion-9978>, accessed 22 November 2023.

¹¹ See <https://www.liberal.org.au/our-beliefs>, accessed 22 November 2023.

6. PART 2 OF THE BILL

6.1. CLAUSE 6

70. The Bill's clause 6 lists its objects. Cls 6(a), 6(c)(i)(A), and 6(c)(ii) might seem straightforward and sensible objects for a VAD Act. However, cl 6(a) assumes that people are dying, which excludes people who are suffering but not dying (not terminally ill). That should be amended. Clauses 6(d) and 6(e) are consistent with what the Act is trying to achieve.

71. The Explanatory Statement relating to the Bill's objects is a forlorn attempt to justify the unjustifiable. It states that 'The purpose of introducing VAD is to promote the human rights of individuals who are suffering and dying by enabling an eligible individual to both 'enjoy a life with dignity' and 'die with dignity', and by providing choices for a person about the circumstances of their death'. The Bill does not achieve those outcomes.

72. No rational Canberran could justify why some suffering people—people not terminally ill—should be excluded from mitigating their suffering. Children and non-residents are also ineligible for VAD, without justification. Nobody will enjoy a life with dignity if they are suffering against their will.

73. Cls 6(b) and 6(c)(i)(B)—VAD is accessible by individuals that 'have been assessed as meeting the requirements to access VAD under this Act'—are seemingly innocuous. However, taken with elements of cl 11, it underscores the Bill's problems. It suggests that some people can be assessed as ineligible for VAD. A good VAD Bill must specify eligibility requirements, but exclusions from Mill's libertarian principle must be supported by argument. Exclusions should not be inserted at the behest of the clergy or groups that cannot make sound ethical arguments. Blindly copying the eligibility criteria of other Australian states is unsatisfactory. The arbitrary eligibility criteria in cl 11 cannot be justified.

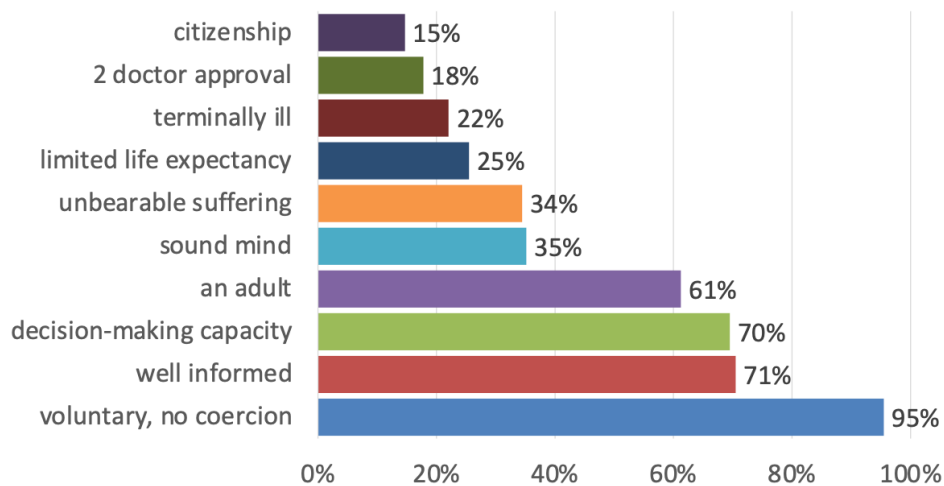
74. We can make a case that there should just be a few eligibility criteria, consistent with Mill's philosophy. People must have VAD decision-making capacity, be well-informed and make a voluntary decision to access VAD. To have VAD decision-making capacity, a person does need to be well informed and make a voluntary decision (explicit, given the 'V' in 'VAD'). These eligibility criteria can be justified because they allow only appropriate people—those capable of making decisions about their lives—to mitigate their suffering. It is good VAD public policy.

75. These are also the three most supported eligibility criteria in the [Ethical Rights Voluntary Assisted Dying Survey 2021](#) (Figure 2). Note that most survey respondents who

did not respond positively to the 'sound mind' and 'decision-making capacity' options, did respond positively to a subsequent question allowing immediate access to VAD for people with an advance care directive. That is, at the time of death, the person might not be of sound mind or have decision-making capacity, but they would have had a valid advance care directive specifying the conditions under which they would want VAD.



Q4. Which of the following would you consider NECESSARY for a person to be ELIGIBLE for voluntary assisted dying?



Voluntary Assisted Dying Survey 2021. Results (World)
© Ethical Rights

5

Figure 2. Responses to Q4, Ethical Rights Voluntary Assisted Dying Survey 2021.

76. In addition, 82% of respondents supported *immediate* access to VAD if a person had a VAD-specific advance directive and 80% supported immediate access for people with unbearable suffering (regardless of being terminally ill) (Figure 3). VAD advocates' strong preferences are not reflected in the Bill, but they should be.

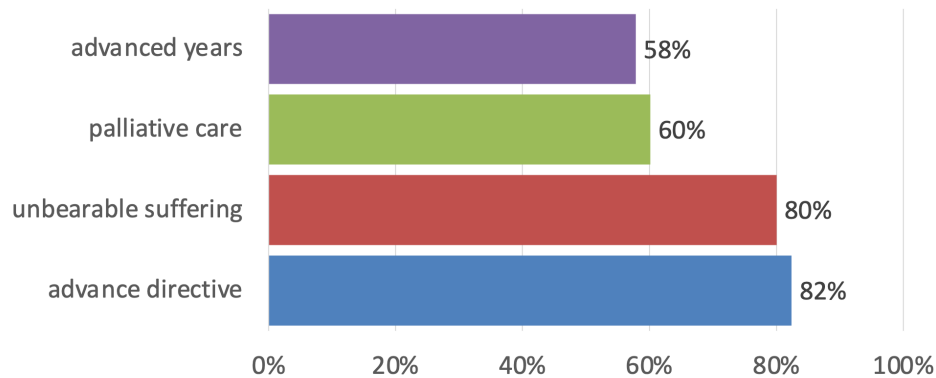
77. Children and infants,¹² non-residents, or persons who are not terminally ill, or who have a disability, mental disorder or mental illness do not lose their VAD decision-making by virtue of being so categorised. No rational Canberran can justify excluding them from eligibility and requiring them to suffer.

78. The excuse to exclude these groups might be based on outdated religious beliefs. Religious people generally believe that only their god (in Canberra, usually the god called God) can take a life, and when a person is terminally ill, assisting a little might be considered by them to be barely acceptable. But these fallacious arguments have no merit as the clergy, or anyone else, has yet to demonstrate that their god called God exists.

¹² A child's or infant's parent or guardian, or an adult's guardian, acting in the person's best interest and on the best advice of doctors, can decide on their behalf.



Q5. Assuming that a person has decision making capacity and requests voluntary assisted dying, which of the following should make someone immediately eligible?



Voluntary Assisted Dying Survey 2021. Results (World)
© Ethical Rights

6

Figure 3. Responses to Q5, Ethical Rights Voluntary Assisted Dying Survey 2021.

79. The ACT Government should not pander to religious or other groups who seemingly want people to suffer according to their moral framework. They have not argued their case. The ACT should not be a society where some people are arbitrarily excluded from mitigating their suffering.

6.2. CLAUSE 7

80. The Bill's principles are fundamental to determining all aspects of what should happen under the Bill. They should be appropriate and consistent with the Government's overall policy objective, ethical, and self-consistent (not contradict one another). Ethical principles mean that they are non-discriminatory and improve people's well-being. They might also include a utilitarian objective stating what ought to be achieved—possibly improving the well-being of Canberrans or just of making the world a better place.

81. Consider cl 7(a), 'human life is of fundamental importance'. This is generally true, especially when we talk of people in war zones. In the context of VAD, it is false if it means that human life must be protected regardless of its quality. Existing for the sake of existence, as cl 7(a) could imply, is clearly wrong, otherwise we would ban VAD.

82. For VAD, the principle should be 'the quality of a person's life is of fundamental importance'. VAD is ethically right because of individual autonomy, and all people should have the option to avoid suffering to sustain a good quality of life. The Bill is inconsistent with the principle at cl 7(a), and both should be amended.

83. Cl 7(b) states that 'every individual has inherent dignity and should be treated with compassion and respect. The Explanatory Statement states that 'the right to enjoy a life with dignity is a core element of the right to life'. However, ineligible persons will lose their dignity as the Bill will force them to suffer against their will. The only people who can die with dignity are *adult residents* who are *suffering unbearably* and *terminally ill*. These are exactly the specific criteria (as well as the right for doctors to assess patients as ineligible) that comprise the VAD medical model and that are rejected by VAD advocates (see Figure 2). For many people, there goes a core element of the right to life. The Bill is inconsistent with the principle at cl 7(b).

84. That any of the above people must suffer is inhumane, cruel, and unethical.

85. Cl 7(c), respecting a person's individual autonomy, is clearly misleading. Individual VAD choices by competent persons can be overruled. That is a resounding rejection of individual autonomy. All people either have individual autonomy or, consistent with the Bill's principles, do not. It is disingenuous to claim that the Bill supports individual autonomy.

86. We can draw an analogy. This Bill's discrimination and rejection of individual autonomy is clear. Limiting VAD to terminally ill, adult residents is ethically equivalent to limiting abortion to raped women only, organ transplants to adults only, and restricting medical services to residents only, but not refugees. The specious arguments in the Explanatory Statement can be applied logically to these scenarios. No rational Canberran can justify such discrimination.

87. The Bill's provisions mean that the following people will be ineligible for VAD because their right to individual autonomy will have been overruled. They will have a poor quality of life, their dignity will be undermined, and they will suffer. Suffering people include people who:

- (a) are not terminally ill but are suffering due to locked-in syndrome, motor neurone disease, mental illnesses, physical disabilities, Huntington's disease, or other conditions. They will suicide with legal lethal drugs they acquire, or they will suffer unless the Bill is amended.
- (b) have early-stage dementia but do not wish to exist for years before dying while not recognising their family. They will suicide early, or they will suffer unless the Bill is amended.
- (c) are suffering in palliative care. They will suffer unless the Bill is amended.
- (d) have life sentences in prison and are suffering because of the stress of having to spend the rest of their lives in prison. They will suffer unless the Bill is amended.
- (e) are of advanced age. They will suffer unless the Bill is amended.
- (f) a terminally ill infant born with inoperable multiple intestinal atresia (who will vomit and suffer for two weeks before dying) or a terminally ill 5, 10 or 15-year-

old child.¹³ They will suffer and die unless the Bill is amended.

- (g) live outside the ACT, who will suffer or suicide unless the Bill is amended.

88. The Bill's principles are such that we are either not sure how the people in the following scenarios would be assessed or the scenarios are problematic:

- (a) suffering prisoners if they have not fulfilled all their obligations to divulge where their murder victims may be buried—would a terminally ill Ivan Milat type serial killer be allowed to access VAD under the Bill?
- (b) a woman, who after becoming pregnant, is found to be terminally ill, and who will be 8 months pregnant when she turns 18—would Canberrans accept that she could suicide at 17 or must she wait until 18 to access VAD and die with an 8-month-old foetus?
- (c) a terminally ill person who does not have VAD decision-making capacity, as they have a severe intellectual disability—can their guardian act on their behalf, as should also be the case for children?
- (d) a suffering person who wants to access VAD, but as they are overruled by a doctor, they then announce that they will suicide (either in a private home, or in a Sarco,¹⁴ or in a secluded nature park) in a few days' time—would Canberrans accept that?
- (e) a suffering person in palliative care who wants to take their own legal lethal substance and suicide in their palliative care facility because they will not meet the regulatory timeframes for VAD. Should a doctor or care provider be allowed to stop them from suiciding?
- (f) a suffering person who wants to die, has been assessed as not sick enough, and has decided to travel and die in Switzerland. Would Canberrans want to be forcing their own people overseas to mitigate their suffering?

89. The bad news for cl 7 does not end here.

90. Cl 7(d) states that every person 'should be provided with high quality' care, including palliative care, to 'minimise their suffering and maximise their quality of life'. The last part of this principle is ethically what VAD is about, but unfortunately some people will be assessed as ineligible. Many people do not want high quality care or palliative care, they just want the VAD option. The principle should be amended to indicate that people 'should have the option to be provided with high quality' care.

91. Cls 7(e), 7(f) are satisfactory.

92. Cl 7(g) is unsatisfactory. The personal beliefs of Exit members, and rational

¹³ If a person does not have VAD decision-making capacity, is not well informed and cannot make a voluntary decision for VAD, then their parent or guardian, acting in the person's best interest and on the best advice of doctors, can decide on their behalf.

¹⁴ A Sarco is a new assisted suicide pod that a person can use to suicide.

Canberrans who support a woman's right to an abortion, and the choice of life partner by a person identifying as LGBTIQ+, prioritise individual autonomy. Individual autonomy is not respected if a competent person's decision for VAD can be overruled. That is contrary to the meaning of individual autonomy and to many person's beliefs and values. That can be written as a principle, but it is only given lip-service if no attempt is made to make it so.

93. The Bill does not respect individual autonomy, respect personal beliefs, maintain dignity for people, and it discriminates. The Bill should be amended and improved.

6.3. CLAUSE 8

94. Cl 8 states that VAD is not suicide for the purposes of territory law, etc.

95. That is satisfactory. But it is almost irrelevant for telehealth services. Accessing VAD telehealth services is currently illegal. It is an offence to use a carriage service for suicide-related material, see s 474.29A of the *Criminal Code 1995* (Cth). We are aware that Commonwealth law renders Territory law inoperative to the extent of any inconsistency.

96. The Commonwealth Criminal Code should be amended to allow VAD telehealth advice, and the Prime Minister is not keen.

6.4. CLAUSE 9

97. Cl 9 reflects individual autonomy and is appropriate. A person with VAD decision-making capacity can choose to not take any further steps in relation to a request for VAD. The rest of the Bill should also reflect individual autonomy without exception.

6.5. CLAUSE 10

98. Cl 10 details the regulatory hurdles that people must jump, and health practitioners must traverse, for somebody to be eligible for VAD.

99. According to cls 10(b), 10(c) and 10(f), consulting and coordinating practitioners can assess a person as ineligible, given they are making assessments against cl 11. The Bill should be amended so that nobody in cl 10 can overrule a person with VAD decision-making capacity.

100. VAD is ethically right because of a person's individual autonomy, but health

practitioners assessing and potentially overruling people who choose VAD is the antithesis of individual autonomy. The Bill does not achieve its objects.

6.6. CLAUSE 11

101. Cl 11 contains the eligibility criteria for VAD in the Bill. If cl 7 is a true reflection of the principles, then no rational Canberran would want any suffering person to be excluded from accessing VAD. However, the eligibility requirements require that some people must suffer contrary to the principles in cl 7.

102. The desirable VAD policy objective:

‘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’

has been supplanted by the discriminatory VAD medical model objective, as defined in the British Medical Journal¹⁵. The Bill’s policy objective is now:

‘that health practitioners will counsel and refer *adult resident* patients, and at least another health practitioner will assess patients and prescribe the drugs to patients *suffering unbearably who are terminally ill (have a condition that is advanced, progressive and expected to cause death)*’.

103. Cl 11 effectively discriminates against children, non-residents, and people who are suffering but not terminally ill. Again, no rational Canberran can accept that discrimination or rejection of individual autonomy.

104. We must consider the following questions:

- does excluding terminally ill children and infants, non-residents who are suffering, and all people who are not terminally ill, and all people with a disability or mental disorder or illness improve their well-being or mitigate their suffering?
- should people who could suffer longer (because they are not terminally ill) be required to suffer longer?
- can the ACT or the world be a better place if some people are forced to suffer against their will?

105. Any rational Canberran would answer ‘no’ to all these questions. That is not what the Bill would indicate.

¹⁵ See Attachment 1.

Clause 11(1)(a)

106. Cl 11(1)(a) states that an eligible person must be an adult. This discrimination means children must suffer. Suffering does not begin at adulthood. A child's or infant's parents or guardians should, with the child as appropriate, and acting on the best advice of doctors, make a decision in the child's best interests. This is what happens in other circumstances, such as when the child needs cancer treatment, blood transfusions or an organ transplant. We should always be acting in a child's best interests, but requiring children to suffer when adults need not is unethical and abhorrent.

107. The Explanatory Statement is what would be expected if somebody were trying to justify the unjustifiable. It says that 'The approach in this Bill, to limit access to VAD for only adults aged 18 years and over, aligns with ACT Government's obligation to protect the rights of young people.' Requiring terminally ill children to suffer does not protect the rights of young people. Requiring that a new-born infant with inoperable multiple intestinal atresia must vomit and suffer for 2 weeks before dying is inhumane. There are more civilised and rational solutions that can mitigate any child's suffering.

108. Individual autonomy is independent of age on significant matters, especially if parents or guardians are acting in the best interests of a child or infant.

Clause 11(1)(b)

109. Cl 11(1)(b) states that an eligible person must have a condition(s) that is advanced, progressive, and expected to cause death'.

110. What this means is the following. People who could suffer longer (because their condition is not expected to cause death), must suffer longer. That is irrational. A person could have locked-in syndrome for 40 years, and they will be forced to suffer against their will, because their condition is not advanced, progressive, and expected to cause death. That is not humane and does not respect their individual autonomy. Another perspective is that they are being discriminated against because they are incapable of suicide.

111. The Explanatory Statement says that:

A key safeguard is the eligibility requirements that a person's condition be expected to cause their death, causes intolerable suffering, and is advanced and progressive. This means that VAD will still only be available to those who are in the advanced stage of illness, or the final part of a person's life where quality of life becomes unacceptable and where treatment (if available) is no longer effective. Requiring that a person's condition is both advanced and terminal provides flexibility for an assessing health professional, while ensuring that VAD is only an

option for those near the end of life who wish for an end to intolerable suffering.

112. This statement suggests that it is a 'safeguard' that a person's condition is expected to cause their death, causes intolerable suffering, and is advanced and progressive (suffering unbearably and being terminally ill). The Explanatory Statement assumes, as the VAD medical model assumes, that somehow it is wrong for a person to access VAD if they are not terminally ill. A person's quality of life is not only unacceptable at the end of life—there is untreatable suffering. The case has not been made that people who are not terminally ill will not benefit from VAD.

113. The Explanatory Statement argument is also fallaciously circular. Requiring that a person's condition is terminal *is equivalent* to ensuring that VAD is an option only for those near the end-of-life! Terminal illness is not a 'safeguard'; that statement is trying to justify unjust discrimination of people who are not terminally ill. No rational Canberran would accept such fallacious arguments.

114. There is no need for the condition to be advanced, progressive, or expected to cause death. The only thing that matters ethically—and ethics is concerned with well-being—is that the person is suffering, and their well-being is below a threshold of what they consider acceptable. Even if their motor neurone disease is not advanced, not progressive, and not expected to cause death sometime soon, they might be suffering. No rational Canberran could sanction a policy that requires people to suffer against their will. Rational governments should reject such policies.

Clause 11(1)(c)

115. Cl 11(1)(c) states that the person must be 'suffering intolerably in relation to the relevant conditions'.

116. People with VAD decision-making capacity will not be seeking VAD if their well-being is fine. We all would like to stay alive with a good quality of life.

117. If a person has some condition, for example arthritis, they might not be suffering 'intolerably'. But let us assume that their arthritis causes them great distress. If individual autonomy is to be respected (cl 7(c)), then a person with VAD decision-making capacity should be able to access VAD without fear of any health professional overruling them. If the persistent suffering is, according to the person, intolerable, then according to the definition in cl 11(3), they should be eligible for VAD, subject to meeting all the other eligibility requirements. Given that arthritis is unlikely to lead to death, they will still be denied VAD and forced to suffer.

118. Dr David Goodall died in Switzerland while having many elderly ailments, but it would have been cruel and a violation of his individual autonomy to insist that he must

have lived and suffered.

119. People who want to access VAD will generally be suffering. According to them, they will be suffering more than they can bear. That should be sufficient for VAD. It should not be possible for any health practitioner to rule that 'sorry, you're ineligible because you're not sick enough'. That overrule is permitted in the Bill.

120. We must consider the question: 'whose life is a person's, if a doctor can overrule the person's decisions about their own life?'

Clauses 11(1)(d), 11(1)(e)

121. Cl 11(1)(d), that a person has VAD decision-making capacity, and cl 11(1)(e), that a person's decision is made voluntarily, are appropriate and acceptable criteria.

Clause 11(1)(f)

122. Cl 11(1)(f), that a person must have been living in the ACT for the previous 12 months, or has an exemption, is unjustified. Suffering does not begin at the ACT border.

123. According to the Explanatory Statement, this is so the 'Bill strikes a fair balance between the need to protect the ACT health system from being unable to meet demand for ACT, and the need to enable access to VAD for individuals who should reasonably expect it'. That is a poor argument.

124. On that basis we would not allow external students or patients come to the ACT. However, if they do, the ACT would be seeking cost recovery for services provided. Hence, there should be no imposition on the ACT health system meeting demand, despite the Bill's self-imposed burdensome regulatory requirements.

125. Similarly, the Explanatory Statement's argument could be used to prevent refugees coming to the ACT. It makes the world a better place if the ACT helps mitigate suffering, and cost recovery policies can ensure that the ACT health system is not overloaded.

Clause 11(2)

126. Cl 11(2) is seemingly discrimination against people who have a disability, mental disorder, or mental illness. The only criteria for VAD should be that a person is suffering, has decision-making capacity, is well informed and makes a voluntary decision to access VAD. Noting the comments in the Bill's Human Rights Act Compatibility Statement, cl 11(2) might not be necessary unless a person living with these conditions also lost their VAD decision-making capacity, which should not be the case.

Clauses 11(3), 11(4)

127. The definitions in cls 11(3) and 11(4) seem appropriate given the Bill's requirements.

6.7. CLAUSE 12

128. Clause 12 gives a good description of VAD decision-making capacity. There is an acknowledgement that a person might not always have VAD decision-making capacity.

129. It is important to comment that if a person (or their parent/guardian) has decision making capacity, then that person is not vulnerable.

130. The Explanatory Statement makes a point about balancing access to VAD. It says, 'Alternatively, reducing the safeguards to access VAD would increase the risk that vulnerable members of the community may be subject to coercion and exploitation.'

131. That is, reducing the safeguards (relaxing the eligibility criteria) could increase the risk that vulnerable people could be exploited. That is wrong.

132. The only people who are listed as ineligible for VAD, the only people to which that statement could be referring, are suffering but not terminally ill persons, the parents or guardians who would be making decisions on behalf of terminally ill children and infants, and non-ACT residents. All these people are assumed to have VAD decision-making capacity. None of these groups of people are 'vulnerable' or loses VAD decision-making capacity by virtue of their being categorised in these groups. It is discriminatory and insulting to suggest they do. It is disappointing that the Government has adopted a baseless line from state VAD legislation and VAD opponents without reason.

133. There does not seem to be (it might have been missed in our reading) any provision to allow anybody to act for people who do not have VAD decision-making capacity, such as intellectually disabled persons, persons with dementia, or children. Decisions should be able to be made by a person's guardians, as happens for many medical conditions. Without such arrangements, or advance care directives—and cl 12 sets the framework for advance care directives—the ACT will be condemning many people to suffer before they die.

ATTACHMENT 1. The Exit ACT and Ethical Rights submission to the ACT Government during the Bill's consultation phase.

ATTACHMENT 2. A letter from Exit ACT to Tara Cheyne MLA and all ACT MLAS.

Dr David Swanton
Exit ACT Chapter Leader
Email: xxxxxxxxxxxxxxxxxxxx
Phone: xxxxxxxxxxxxxxxxxxxx
18 September 2023

Ms Tara Cheyne MLA
Member for Ginninderra
cheyne@act.gov.au

Dear Ms Cheyne

I am writing as ACT Chapter Leader of Exit International, the voluntary assisted dying (VAD) and euthanasia advocacy organisation headed by Dr Philip Nitschke. Exit has thousands of Australian members and over 200 in the ACT. We argue that VAD should be legalised because individual choice and autonomy should be prioritised.

Together with Dying with Dignity ACT, we advocate that all people¹ should be able to choose VAD. Both groups made substantial submissions to the ACT consultation process on VAD. We represent people who would use ethical VAD legislation, rather than stakeholders who oppose it or want to administer it. Unfortunately, we were not invited to attend any roundtables, workshops, or meetings in the development of the ACT Government's Listening Report. Hence this letter to all ACT MLAs.

This letter and the comprehensive Exit ACT submission² make the case for an ethical ACT VAD regulatory system based on a VAD human rights model. However, the ACT Government's consultation process and feedback in the media indicates that the ACT could be leaning towards adopting a form of the VAD medical model. That would be a mistake.

The Australian states' discriminatory VAD medical model

In the British Medical Journal's definition of a VAD medical model,³ and as legislated in the Australian states, doctors are used to counsel, refer, assess, and prescribe but also, ultimately, to judge whether a person's life is worth living or not. No person should be answerable to a doctor for their own life. Under the states' VAD laws, doctors are required to determine VAD eligibility by discriminating on a person's degree and type of suffering and their life expectancy. States' VAD laws also discriminate on age and residency or citizenship status.

¹ Individuals must have decision-making capacity with respect to VAD, which includes being well-informed and making a voluntary decision.

² Further details and arguments can be found in the Exit ACT submission at <https://www.ethicalrights.com/images/stories/pdf/ERVADsubmission2023.pdf>.

³ See British Medical Journal 2021;374:n2128 <https://www.bmj.com/content/374/bmj.n2128/rr-9>.

Individual autonomy is the capacity of each person to determine and act on what is right for each of their lives. We can choose to have an abortion, or live in LGBTIQ+ relationships, and nobody can overrule our decisions. Yet, if a few years later, we are suffering and choose VAD, medical model legislation allows doctors to overrule us: doctors might assess that we are 'not sick enough' or 'going to live too long'.

It is abhorrent that the states' VAD medical models legalise unjust discrimination. Why should people who could suffer more be required to suffer more? At what age does a person lose the right to determine what is right for their own body? Why should anybody be required to suffer against their will? Individuals should have the right to determine how they live their lives and how they die.

The ethical VAD human rights model

Exit ACT recommends that the ACT Government legislate for VAD based on the human rights model, with a policy objective 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'.

Legislation based on the human rights model is humane, compassionate, and allows dignity in death. The only necessary eligibility criteria under the human rights model should be that a person (or their guardian) has decision-making capacity with respect to VAD, including that any person's choice for VAD is voluntary and well-informed.

In this model, there is no discrimination on the degree or type of suffering, life expectancy, age, residency, pregnancy status, race, sexual orientation, gender identity, criminal record, disability, etc. Compassionate outcomes can even be obtained for an infant who might, for example, be born with inoperable multiple intestinal atresia and will vomit and suffer for two weeks until death, or a child with terminal cancer.

For many people, it is undignified to suffer unbearably, suffer in old age, wait for death in a palliative care facility, or die with dementia. We consider unbearable suffering as only a sufficient, but not necessary, criterion to access VAD. People who are of advanced age, or in palliative care, should be able to choose and be granted immediate access to VAD. Under the states' medical models, they are required to suffer against their will. In addition, we would not want to see more cases where elderly Canberrans suicide or are assisting partners to die because any ACT VAD legislation does not support VAD advance directives.⁴ Without ethical VAD legislation, such cases are likely. Unwanted suffering is not humane, dignified, or civilised.

⁴ See the recent case of Donald Morley, a 92-year-old Canberran who has been charged with killing his wife.

ACT VAD legislation should respect individual autonomy

Just as the Federal Parliament should not be interfering in the ACT's drug decriminalisation policy or takeover of Calvary hospital, the ACT Government should not be interfering with individuals' autonomy.

Concerning autonomy, the responsible minister, Tara Cheyne MLA, has condemned the Senate inquiry into the Calvary public hospital takeover as legitimising the idea of the Federal Parliament again overruling territory rights. She said, 'I find it particularly egregious this level of interference in our ability to decide our own laws and make our own decisions for ourselves doesn't occur anywhere else'.⁵

If the Government were to legislate the VAD medical model, then Canberrans could use the same logic to say, 'we find it particularly egregious this level of interference in our ability to make our own decisions for ourselves'.

The Government can do better than copying other jurisdictions' mistakes.

ACT MLAs should think critically

The ACT is fortunate that Ms Cheyne has long been a very strong supporter of VAD. There should be no pressure on her to propose a form of the discriminatory and unacceptable medical model.

Members of the ACT Legislative Assembly should think critically and develop rational arguments in support of a just and non-discriminatory VAD legislative system. It should be an ethical and humane system that allows people to mitigate their suffering far more broadly than has been suggested in the Government's VAD Discussion Paper.

Exit ACT recommends that VAD legislation be based on a human rights model that:

- has an ethical, compassionate, non-discriminatory VAD policy objective
- respects individual autonomy by specifying decision-making capacity for VAD, being well-informed, and making a voluntary decision, as the only necessary VAD eligibility criteria
- does not give doctors the right to overturn the choice of individuals with VAD decision-making capacity.

Unfortunately, media reports include unsound arguments that should be refuted. Jeremy Hanson CSC MLA has written 'Why I won't vote to euthanise children'.⁶ He questions whether the Government will allow children to access euthanasia without parental

⁵ 'Calvary takeover inquiry 'legitimises' efforts to limit territory rights, Human Rights Minister Tara Cheyne says', Canberra Times, 26 July 2023.

⁶ 'Why I won't vote to euthanise children, City News, 8 August 2013, <https://citynews.com.au/2023/why-i-wont-vote-to-euthanise-children/>.

consent. Such fallacious arguments can and should be rejected. Voting 'to euthanise children' is clearly different from voting 'to allow choice so that all suffering people can access VAD'. No person, whether adult or child, is immune from suffering. VAD is too important for misleading and untrue claims to be propagated.

Most people choose quality of life over quantity of life. They do not want other people, such as Mr Hanson, taking away their individual freedom to make choices about their own lives. Nobody, including doctors, should be judges of whether somebody else's life is worth living. For VAD, just as with LGBTIQ+ relationships and abortion, individual autonomy is of paramount importance.

In summary, VAD legislation based on the human rights model is humane and allows people to choose what is right for their own lives, maintaining their dignity and autonomy. The medical model rejects individual autonomy and causes discriminatory outcomes that result in suffering. We know this is wrong, since civilised democratic societies should not egregiously interfere with individual choices about individual lives: 'the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others'.⁷

We urge MLAs to legislate for VAD based on the human rights model. It would be undesirable for the Assembly to legalise unjust discrimination and prevent people from choosing VAD to mitigate their suffering.

Other matters

Appendix 1 to this letter highlights other issues of concern.

- 1. Advance directives.** The ACT Government should legislate to allow VAD compatible advance directives.
- 2. Unwanted police activities.** Police should not be used to check on people just because they are alleged to have legal lethal drugs.

I am available to discuss any aspect of VAD.

Yours sincerely

Dr David Swanton
Exit ACT Chapter Leader and
Director, Ethical Rights

⁷ John Stuart Mill, 'On Liberty', Penguin, London, 1974.

Appendix 1

VAD advance directives

Exit and an overwhelming majority of VAD advocates want to be able to develop VAD compatible advance directives. One reason is that most people dread an existence that ends with dementia, causing them and their loved ones enormous distress.

The ACT has advance directives, but they do not allow for a person to choose VAD. Belgium, Italy, Luxembourg, and the Netherlands have legislated for VAD advance directives. VAD advance directives are not difficult to legislate, but it requires a government with a keen desire to allow people to choose what is right for their lives so that they can avoid suffering.

VAD advance directives would result in a decrease in elderly suicides. In Canberra, and around the world, people seek and take legal lethal drugs to suicide because they want to avoid being unable to take these drugs when, in later years, they might suffer from dementia.

Unwanted police activities

Police should not be used to monitor people accessing legal lethal drugs. People access such these drugs because VAD regulatory systems are inadequate and do not allow for VAD advance directives.

Some months ago, police awakened some Canberrans very late at night under the guise of undertaking 'welfare checks'. The elderly women were alleged to be in possession of legal lethal drugs. Suicide is legal, but these police visits were counterproductive as the women were quite stressed by these visits.

In addition, when a person uses lethal substances to suicide, eyewitnesses have reported many police in attendance at the person's house as if the most horrendous homicide has been committed.⁸

Police are well respected in the ACT and have a difficult job to do. But such involvement following legal actions seems excessive. Police resources can surely be better allocated.

However, if the ACT does not legislate for VAD based on an ethical human rights model and allow VAD advance directives, the police and Government should not be surprised if more people choose to access legal lethal drugs.

⁸ I have been informed of 10–12 police being at a house for most of the day after a person's suicide, presumably caused by a legal lethal drug.

ATTACHMENT 3. The response from Tara Cheyne MLA to Exit ACT'S letter.



Tara Cheyne MLA

Assistant Minister for Economic Development
Minister for the Arts
Minister for Business and Better Regulation
Minister for Human Rights
Minister for Multicultural Affairs

Member for Ginninderra

Our ref: PRO23/3302

Mr David Swanton
EXIT ACT Chapter Leader

canberrachapter@exitinternational.net

Dear Mr Swanton

David

Thank you for your email attaching the letter you intended to circulate, and have now sent, to ACT MLAs. I appreciated the advance notice and apologise that I did not respond before you circulated your letter.

As you would have seen in our listening report *Voluntary Assisted Dying in the ACT: report on what we heard*, during our eight weeks of extensive community consultation we heard strong support for incorporating voluntary assisted dying as part of advanced care planning in order that it might be available once a person has lost capacity. We also heard support for access for under 18-year-olds. Our consultation with the advocacy, clinical and broader communities also revealed, however, the significant complexities around these issues.

This is especially so regarding under 18s, particularly in relation to a young person's emerging capacity and autonomy, and in assessing their decision-making capacity. While the concept of Gillick competency is known and recognised, its application in this context is untested. This presents a significant risk to both the support of the clinical care community and the potential impact on implementation timeframes.

Further, there would be limited demand for this in the ACT due to the very small numbers of young people that would be eligible. Initial modelling and clinical experience indicate that for a small population like the ACT, uptake of VAD by mature minors would be expected to be extremely infrequent.

ACT Legislative Assembly London Circuit, GPO Box 1020, Canberra ACT 2601

+61 2 6205 0100

cheyne@act.gov.au

[@In_The_Taratory](https://twitter.com/In_The_Taratory)

[taaraforginninderra](https://www.facebook.com/taaraforginninderra)

[in_the_taratory](https://www.instagram.com/in_the_taratory)

Rather than delay the implementation of voluntary assisted dying in the ACT while these complexities are researched and resolved, the government has committed to considering these issues further once voluntary assisted dying has been in operation in the ACT for several years. The extensive community consultation undertaken by the government is also outlined in the listening report. The roundtables, workshops and meetings mentioned in your proposed letter were composed of specific targeted groups to ensure inclusive and accessible consultation as well as the inclusion of consumers with lived experience and health workers and advocates responsible for the delivery of health services to the ACT community. The listening report was also based on extensive community feedback through the YourSay Panel, as well as hundreds of community submissions and over one hundred formal submissions from individuals and organisations, including yours.

As you know, the discussion paper that provided the basis for community consultation was informed by advance consultation with yourself and a small number of trusted expert external stakeholders. This group was also generous enough to review the proposed paper. I would like to take this opportunity to thank Exit International and Dying with Dignity ACT for your substantial contribution to the issue.

During public consultation we heard strong support for some aspects of the Australian model, and for some adjustments to this model to build on the experiences of other jurisdictions and to meet the unique needs of the ACT. The Government is currently working through the issues and is on track to introduce legislation in late 2023.

As you may have heard, our preference is firming that a person with an advanced, progressive and terminal condition may access voluntary assisted dying without the coordinating or consulting practitioner having to estimate whether they fit into a specific time until death category.

Additionally, a preference is emerging that Nurse Practitioners be able to act as a coordinating or consulting practitioner as long as the other coordinating or consulting practitioner is a medical practitioner.

On the final issue you raise, ACT Policing have advised that this matter is before the court. I am unable to comment on individual matters before the court.

Thank you for writing to me on this matter. As you know, I continue to be committed to working to enhance compassionate end of life choices and outcomes for people in our community.

Sincerely



Tara Cheyne MLA
Minister for Human Rights

13/10/23

ATTACHMENT 4. The Summary Report of the Ethical Rights Voluntary Assisted Dying Survey 2021.

ATTACHMENT 5. The Results of the Ethical Rights Voluntary Assisted Dying Survey 2021.