



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL

Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),

Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 029

Date Authorised for Publication: 07 December 2023

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.

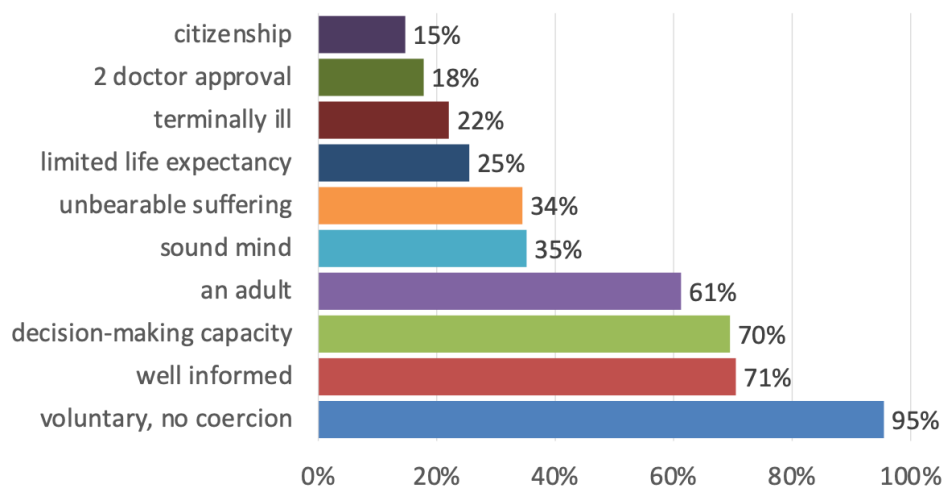
74. We can make a case that there should just be a few eligibility criteria, consistent with Mill's philosophy. People must have VAD decision-making capacity, be well-informed and make a voluntary decision to access VAD. To have VAD decision-making capacity, a person does need to be well informed and 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.

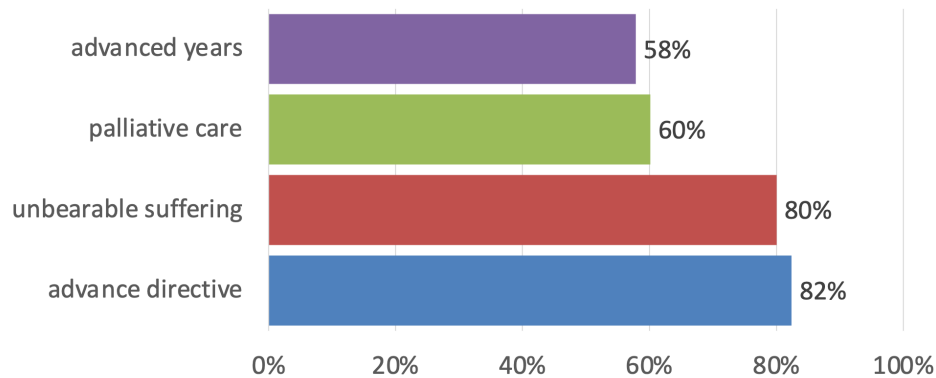
77. Children and infants,¹² non-residents, or persons who are not terminally ill, or who have a disability, mental disorder or mental illness do not lose their VAD decision-making by virtue of being so categorised. No rational Canberran can justify excluding them from eligibility and requiring them to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

Exit International ACT Branch

Submission to the ACT Government on

Voluntary Assisted Dying in the ACT

3 April 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	4
2.	Introduction	7
3.	Arguments for the best VAD regulatory system	10
3.1.	Background	10
3.2.	Criteria for good VAD regulation	11
3.2.1	Ethical regulation	11
3.2.2	Human rights principles	12
3.2.3	Best practice regulation	12
4.	VAD Legislative Options and Policy Objectives	14
4.1.	The Medical Model	14
4.1.1	Definition	14
4.1.2	Problems with state VAD regulatory systems	15
4.1.3	VAD legislation should not unjustly discriminate	16
4.2.	The Human Rights Model	17
4.2.1	Definition	17
4.2.2	The Human Rights Model is justifiable	18
5.	Comparing the Human Rights Model and Medical Model	19
5.1.	Eligibility criteria support and rationale	19
5.2.	Fallacious arguments against VAD and the Human Rights Model	19
5.3.	VAD scenarios	20
5.4.	Type or degree of suffering and life expectancy	27
5.5.	Age	29
5.6.	Doctor involvement	30
5.7.	Residency status	32
5.8.	Palliative care and advanced age	33
5.9.	Advance directives	35
5.10.	Suicide	36
5.11.	Regulatory considerations	37
5.12.	Conclusion	37
6.	Responses to consultation questions	38
	Appendices	47
	Appendix 1. About the author	48
	Appendix 2. VAD Survey Summary Report	49
	Appendix 3. VAD Survey Results	58

LIST OF TABLES

Table 1.	VAD scenarios that should be covered by comprehensive VAD legislation based on a Human Rights Model.	22
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.	24
Table 3.	A comparison of international VAD regulatory systems.	28
Table 4.	Responses to ACT Discussion Paper consultation questions. Responses, where appropriate, are based on a Human Rights Model.	39

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.¹

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:

¹ 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*.'²

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

² 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)¹ is jointly from Exit International ACT branch (Exit ACT) and Ethical Rights and prepared by Dr David Swanton.³

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.

³ 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.⁴

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.⁴

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.⁵

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

⁴ See <https://wfrtds.org>.

⁵ 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.⁶

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.

⁶ Australian organisations such as Lifeline (www.lifeline.org.au) and Beyond Blue (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.¹

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'.⁷

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-

⁷ 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.⁸ 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.

⁸ 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.^{9,10}

53. The Australian states, and some jurisdictions overseas (see Discussion Paper, Appendix 3), have legislated forms of this Medical Model,¹¹ 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*.¹²

54. Legislation based on the Medical Model has problems.

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

¹⁰ The ACT Discussion Paper uses the terms coordinating and consulting health professionals.

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

¹² 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.’¹³

57. In New South Wales, VAD means ‘an eligible person can ask for medical help to end their life.’¹⁴ 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,

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

¹⁴ 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?¹⁵ 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.¹⁶ 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.¹⁷ 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.¹⁸ 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:

¹⁵ 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.

¹⁶ 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>.

¹⁷ 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>.

¹⁸ 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.’¹⁹ 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.

¹⁹ 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),¹⁸ have 2 doctors approve a request for VAD, be terminally ill, and have limited life expectancy. These were the least supported eligibility criteria (all $\leq 25\%$ 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)²⁰
Criteria: unbearable suffering, palliative care, advanced age, not ill, burden, depression, advance directive	
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)). ²¹	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%)
Criteria: doctor involvement, minimum age, role of parents, mental condition	
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%)

²⁰ 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.

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

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)²⁰
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%)
Criteria: pregnancy, prisoners, residency status, VAD telehealth	
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
VAD eligibility criteria				
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
Request to access VAD				
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
														
Eligibility Requirements	'Healthy' - not ill	X	X	X	X	X	✓	X	X	X	X	X	✓	X
	Terminal Illness required	✓	X	X	X	X	X	✓	X	X	✓	X	X	✓
	Unbearable suffering	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	X
	Psychiatric illness	X	X	✓	✓ ³	X	✓	X	✓	✓	X	X	✓	X
 Must be resident  Must be 18+  Cooling off Period  Request in writing  Request can be included in AHD  Single Doctor sign-off  Multiple Doctors sign-off	Must be resident	✓	✓	✓ ^a	✓	✓	?	✓	✓ ^a	✓ ^a	✓	✓	X	✓
	Must be 18+	✓	✓	X	✓	X	?	✓	✓	X	✓	✓	✓	✓
	Cooling off Period	✓	✓	✓	✓	✓	X	✓	X	X	X	✓	X	✓
	Request in writing	✓	✓	✓	✓	X	X	✓	✓	✓	✓	✓	X	X
	Request can be included in AHD	X	X	✓	X	X	X	✓	✓	✓	X	X	X	X
	Single Doctor sign-off	X	X	X	X	✓	X	X	X	X	X	X	✓	X
	Multiple Doctors sign-off	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	X	✓
Means of Administration	Drink	✓	✓	✓	✓	X	✓	X	✓	✓	✓	✓	✓	✓
	Lethal Injection	✓ ¹	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	X
	Self-activated infusion	X	X	X	X	X	✓	✓	X	X	X	X	✓	X
	Rectal	X	X	✓	✓	X	✓	✓	✓	✓	X	✓	X	✓
 Affordable  Expensive	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. N tschke and F. Stewart, The Peacefu P Handbook. The on y correct on (as of 1 March 2023) to th s tab e s that Note 3 shou d be amended: '3 Psych atr c ness perm tted 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.’²² 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

²² 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>.

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.⁹ 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.²³ 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'.²⁴ They further argue that²⁴:

'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.

²³ 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.

²⁴ 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 time²⁵:

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.

²⁵ See 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"'.²⁶

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

²⁶ 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).²⁷ This would add weight, if more were ever needed, to the person's conviction and desire for VAD.

²⁷ 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,²⁸ 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.

²⁸ 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.¹ 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
Eligibility criteria	
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.²⁴ 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.</p> <p>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>
5. Should voluntary assisted dying be restricted to people above a certain age (for example, people 18 and over)?	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.
6. Should a person be an Australian citizen or a long-term resident of Australia to access voluntary assisted dying in the ACT?	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.
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?	No, see point 6.
The process for request and assessment	
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?	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).

Consultation question	Response
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>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.</p> <p>2 If doctors do not want to be involved, they should refer the person to supportive doctors.</p> <p>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>
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?	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.
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?	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.
12. Should a person have a choice between self-administration and administration by an administering health professional of a voluntary assisted dying substance?	<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.</p> <p>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>
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?	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.
14. Are additional safeguards required when an	Self-administration ought to be the first option. Health professionals should only be engaged if self-

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.
The role of health professionals	
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
The role of health services	
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>This will not be a problem with an Elective Death Unit.</p> <p>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.</p> <p>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>
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>Not a problem with an Elective Death Unit. All health facilities should be acting consistent with a person's best interests.</p> <p>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>
Death certification and notification	
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>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>
28. What should be recorded as the cause and manner of death for a person who has died by accessing voluntary assisted dying?	<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.²⁹ 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>
Oversight, reporting and compliance	
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>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>
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>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>
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>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>

²⁹ 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.</p> <p>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>
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?	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.
33.Should there be specific offences for those who fail to comply with these requirements?	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.
Other issues	
34.What other laws might need to change in the ACT to enable effective access to voluntary assisted dying?	<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.</p> <p>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>
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?	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.
36.Are there any other matters you think should be considered in implementing voluntary assisted dying in the ACT?	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.

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>.

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

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)



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



[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

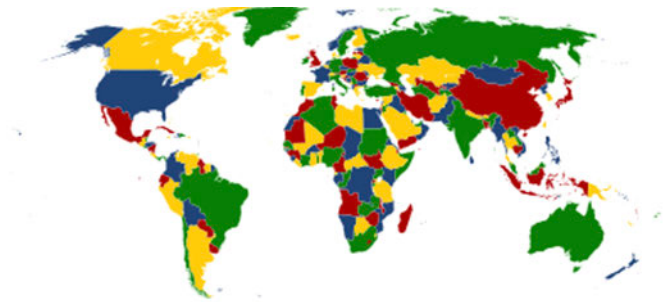
13/10/23

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



ETHICAL RIGHTS VOLUNTARY ASSISTED DYING SURVEY 2021

SUMMARY REPORT (WORLD RESPONSES)



DR DAVID SWANTON
1 AUGUST 2021

This survey can be cited as:

Swanton, D. Voluntary Assisted Dying Survey 2021. Ethical Rights. Published 1 August 2021. <https://www.ethicalrights.com> .

1 INTRODUCTION

The Ethical Rights Voluntary Assisted Dying (VAD) Survey 2021 aims to provide data and to remove subjectivity from the euthanasia debate. Its objectives are to:

- seek views of VAD advocates on a range of VAD issues
- provide data which can be used to inform VAD organisations so that they can make cogent cases to politicians, media and detractors
- help VAD advocates and others to think more about VAD issues
- broaden the VAD debate as appropriate, and
- provide a basis for a longitudinal VAD study.

VAD is commonly used to refer to ‘the assistance provided to a person by a health practitioner to end their life. “Voluntary” indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access VAD’.¹ Other terms such as medical aid in dying, physician-assisted suicide and voluntary euthanasia are also commonly used to describe the practice of VAD or variations of it.

The survey was not intended to determine whether people agreed that VAD should be legally available. That question has been tested regularly in many polls—with responses dependent on the jurisdiction²—but generally 70%–80% or more of people are supportive of VAD.³ The survey instead sought the views of VAD advocates and supporters on the many ethical and regulatory issues, and individual choices, that make up the VAD debate. The views of these stakeholders are critical to the development of any VAD regulatory systems.

Sections 2 and 3 of this *Summary Report* contain the key messages and summary of survey responses respectively. The survey’s background and demographic data for respondents are summarised in sections 4 and 5. This *Summary Report*, the *Results* document (which underpins this document), *Supplementary Material* (containing some analysis of issues) and the *Survey Questions* are available at www.ethicalrights.com.

2 KEY MESSAGES

There were 1640 VAD advocates and supporters worldwide who responded to the survey during 2020 and 2021.⁴ The following key messages can be inferred from trends in survey responses.

¹ Euthanasia and Assisted Dying. Queensland University of Technology. Accessed July 20, 2021. <https://end-of-life.qut.edu.au/euthanasia>.

² A jurisdiction is the country, state or region where particular laws must be obeyed.

³ See, for example, Key Questions. Dying with Dignity. Published March 2, 2017. Accessed July 22, 2021. <https://dwdnsw.org.au/faqs/>

⁴ While 1640 people around the world responded to the survey, not all questions were answered by all respondents.

2.1 Key message 1: VAD should be legalised or better regulated in jurisdictions.

Most respondents (VAD advocates and supporters) do not have legalised VAD in their jurisdiction. Respondents consider that:

- (a) they have the right to implement plans to end their lives and want to do so in their own jurisdictions
- (b) VAD regulatory systems should focus on giving effect to the VAD choice of well-informed adults with decision-making capacity
- (c) having limited life expectancy, being terminally ill, having 2 doctors approve drugs or residency/citizenship criteria are unnecessary VAD eligibility criteria.

2.2 Key message 2: VAD regulatory models should be expanded in scope to meet the needs of people who want to access VAD.

Respondents' major concerns were a person's right to bodily autonomy, a desire to avoid suffering, and to have a good quality of life. VAD regulatory models should be improved and expanded in scope to allow people to:

- (a) specify their choice for VAD in an advance directive⁵
- (b) access VAD if they are suffering unbearably, whether or not they are terminally ill
- (c) have ready access to VAD if they are in the final stages of palliative care or are of advanced years
- (d) request that a doctor prescribe a single dose of a lethal drug for their personal use, noting regulation would be needed to prevent ineligible people obtaining lethal drugs
- (e) self-administer a lethal drug and that non-doctors, such as family members or designated persons, should be allowed to assist them
- (f) access VAD if they are suffering from mental illness, dementia or clinical depression (especially if specified in an advance directive)
- (g) access VAD for children and infants who may have unbearable suffering (guardian/doctor support necessary).

⁵ An advance directive is a written instruction that a person makes about their future medical treatment in the event that they lose their decision-making capacity. With respect to VAD, it might list the medical and other circumstances that, if a person were to be so afflicted in the future, would result in their advance request for VAD being granted.

2.3 Key message 3: If VAD is not legislated or better regulated, then the end-of-life needs of people will not be met and their quality of life will be adversely affected.

Respondents considered that, in the absence of legislation that meets their end-of-life needs, many people who are suffering:

- (a) will continue to suffer knowing that they cannot draft advance directives with the practical option of VAD
- (b) will either suicide prematurely if they obtain legal or illegal lethal substances (the latter being more likely the older a person is) or they will continue to suffer (if they cannot access lethal drugs)
- (c) will find it burdensome or stressful to comply with unnecessary regulatory hurdles, such as meeting citizenship/residency conditions or having the details of a terminal illness or limited life expectancy confirmed by multiple doctors
- (d) would rather die at home with some palliative care support than die in hospital with palliative care or even leave their country or region to die—in which case in-home palliative care services will require greater support where they are deficient.

2.4 Key message 4: VAD regulation that effectively meets the end-of-life needs of people can give them peace of mind and a better quality of life.

Regulation that meets the needs of people who choose VAD means that they will:

- (a) have reduced suffering, even if not terminally ill
- (b) have peace of mind knowing that illegal options will be unnecessary
- (c) not have to travel to find VAD-friendly regulatory systems in other jurisdictions
- (d) have, with VAD-relevant advance directives, peace of mind knowing that they won't suffer even if their decision-making capacity deteriorates
- (e) not require doctors for drug administration
- (f) be able to legally have a partner, or family or other support with them, or assisting them, at their death.

3 RESPONSES SUMMARY

3.1 World responses

With few exceptions, trends in responses did not vary greatly with respondents' gender, age, religion, education level, disability or country of residence. This was not unexpected, given that the survey's target population were mostly VAD 'true believers'. The VAD true believers are people who, as VAD advocates and supporters, have given appreciable time and thought to VAD issues, have joined voluntary assisted dying organisations and would contemplate choosing VAD. Their views on ethical and regulatory aspects of VAD are highly relevant; indeed they are necessary to achieving a good regulatory solution.

These following outcomes have been drawn from survey responses.

3.1.1 Ethical issues (Q1, Q2)⁶

The first two survey questions concerned the ethics of voluntary assisted dying.

- 1633 of 1640 respondents agreed that:
 'it should be legal for a doctor to assist a terminally ill adult of sound mind in ending their life, if that is the person's wish'.

The 7 people who did not agree were exited from the survey.

- 99%⁷ of respondents then agreed that:
 'every adult of sound mind has the right to implement plans for the end of their life'.

These respondents effectively consider VAD as a right. It does not necessarily require that a person be terminally ill or that doctors be involved.

3.1.2 Regulatory eligibility (Q4, Q5)

With respect to VAD eligibility, respondents expressed views that:

- the 3 most important VAD eligibility criteria were deciding voluntarily (95%), being well-informed (71%) and having decision-making capacity (70%)
- common eligibility criteria in existing regulations were the least supported: having limited life expectancy (25%), being terminally ill (22%), having 2-doctor approval and citizenship (each <20%)

⁶ Q numbers refer to the questions in the survey from which the outcomes have been inferred.

⁷ All percentages are rounded to the nearest whole number.

- being of sound mind was somewhat important (35%), but of those people who did not think it important, most respondents offered other options, such as immediate VAD eligibility for people with unbearable suffering or advance directives
- people with advance directives or unbearable suffering (both $\geq 80\%$), being of advanced years or in palliative care (both $\geq 58\%$) should be immediately eligible.

3.1.3 Regulatory access and means (Q3, Q6)

Most respondents (72%) did not have access to regulated VAD. Respondents indicated they should be able to:

- obtain a single dose of a lethal drug and administer the drug themselves (both $\geq 88\%$)
- have a lethal drug prescribed by a doctor (81%)
- have a spouse or other person assist (78%).

3.1.4 Regulatory ineligibility and ethical issues (Q7)

With respect to VAD ineligibility:

- 52% of respondents said untreated clinical depression, 48% said pregnancy and 35% said being a child should make a person ineligible
- 16% said a convicted criminal should be ineligible, while 33% said a person who was the subject of ongoing police investigations should be ineligible
- 17% said that people with dementia should be ineligible for VAD even if specified in an advanced directive, but this increased to 44% if dementia was not specified in an advance directive
- a quarter (26%) ruled out newborn infants being able to access assisted dying, even if it were a decision of the guardian/doctor.

3.1.5 Individual preferences (Q8)

With respect to individual VAD preferences:

- 63% of respondents indicated they would not want to leave their country to die and 48% would not want to leave their region to die
- Respondents indicated that dying at home with palliative care (not wanted by 23%) was preferred over dying in hospital with palliative care (not wanted by 45%).

3.1.6 Other (inc. Q9)

Other survey outcomes include:

- 85% of respondents said that their quality of life would be improved by ready access to an end-of-life substance
- 61% said that their quality of life could be improved by ready access to an illegal (or legal) drug; indeed older people are more likely to want to use an illegal lethal drug (36% in the 40–49 years age group increased to 75% for people ≥ 90 years old).

3.2 Regulate VAD and continue debating VAD issues

There are issues arising from survey responses that require and deserve further analysis. In most areas of public policy, stakeholders express a range of views on how various objectives can be achieved. It is no different with VAD.

Specific VAD issues can be complex, but they are not sufficient to postpone any regulatory or other measures that will allow people to access VAD.

Some of these issues are discussed in this survey's *Supplementary Material*. That document challenges people to think better to understand VAD's underlying ethical principles and develop rational solutions to address VAD issues. Ultimately however, law reform and democratic processes will determine whether the needs and wishes of many people seeking access to VAD can be met.

Some statements can be made about how the survey responses align with what is happening around the world on VAD. The current situations in many jurisdictions show that:

- VAD advocates are working hard to achieve regulated VAD for terminally ill people, noting that regulation is lacking in most jurisdictions
- having to be terminally ill and being required to comply with many VAD eligibility conditions does not meet the end-of-life needs of many people
- from a rights perspective, people (perhaps any person who can make sound, well-informed decisions) should have the right to implement plans for the end of their life
- from a public policy perspective, regulators must ensure that eligible people who want to access VAD can obtain the requisite lethal drugs.

It is imperative that the VAD debate continues to explore issues such as the freedoms people should have regarding the end of their lives, how much suffering governments might require people to endure contrary to their expressed wishes and what role governments should play in ensuring that VAD eligible persons can access VAD drugs and/or other assistance, as required.

The VAD debate must continue, promptly and helpfully. This *Summary Report* seeks to provide an objective contribution to that debate. People's well-being is at stake.

4 SURVEY BACKGROUND

The online survey opened 27 July 2020 and closed 27 February 2021.

- The survey was emailed to the World Federation of Right to Die Societies, as well as Exit International, Dying with Dignity Organisations (DWDs) and Voluntary Euthanasia Societies (VESs). Many of these organisations then forwarded the survey to their members.
- 1640 responses were received from around the world by the closing date. This is roughly estimated as $\approx 1.5\%$ response rate, with an error $< 3\%$ (95% confidence). This means that given a 50% response rate to a particular question, we can be 95% sure that the true percentage of the population who would choose a response lies within the margin of error, that is between 47% and 53%.

5 DEMOGRAPHICS

5.1 Demographics: world responses

Survey respondents are VAD advocates and supporters. The 1640 survey respondents can be characterised as follows.

- Respondents lived in 31 countries. 95% of responses came from 6 regions (Australia, other Europe (mostly France), USA, UK, Netherlands, Canada), each with > 40 responses.
- 61% of respondents identified as female, 84% were > 50 years, and 34% were 70–79 years old.
- Respondents were mostly non-religious (75%) and well-educated (72% have at least one degree, 40% have a higher degree).
- Over 70% of respondents did not have a disability. 27% of those who did have a disability indicated that they had needs or concerns. A typical survey comment was ‘When I am suffering too much, I want to be killed when I ask’.
- There was no evidence of VAD specific cultural needs for First Nations peoples (4% of respondents).
- About 45% of respondents belonged to Exit, 43% to DWDs, 16% to VESs, and 25% to other organisations (or no organisation). Most people joined their organisations to obtain information, practical advice and support their organisation.

6 FURTHER INFORMATION

6.1 Future steps

Follow-up work on the survey analysis and distribution will occur and will include the following steps.

- Relevant information will be sent to respondents' jurisdictions (countries) and organisations, who will be asked to alert individual respondents of the survey results.
- Analysis, data and survey questions will be made available on the Ethical Rights website (www.ethicalrights.com). Further survey details and updates will also be made available on this site.
- Work will continue on data analysis. The possibilities of conducting a longitudinal study on perspectives of voluntary assisted dying advocates, to assess responses over time, will be explored.
- A further report or future book using the survey data as an evidence base may be produced. Contributors would ideally include leaders and experts in the VAD/voluntary euthanasia movement.

6.2 Acknowledgements

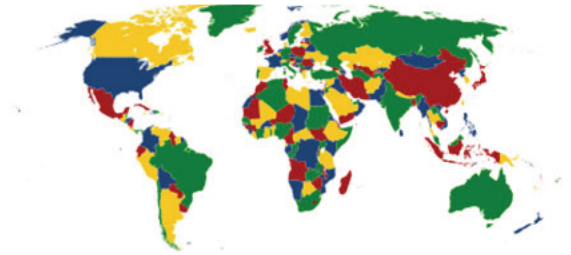
Ethical Rights thanks the following organisations and individuals:

- the World Federation of Right to Die Societies, Exit International and the other DWDs and VESs that passed the survey onto their members
- all the VAD supporters who responded to the survey; this survey reflects their perspectives
- Dr Philip Nitschke for supporting the survey
- Dr Wendy Gunthorpe for her valuable comments on survey design (see www.straighttalkconsulting.org).

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



Ethical Rights Voluntary Assisted Dying Survey 2021 Results (World responses)



Dr David Swanton
1 August 2021

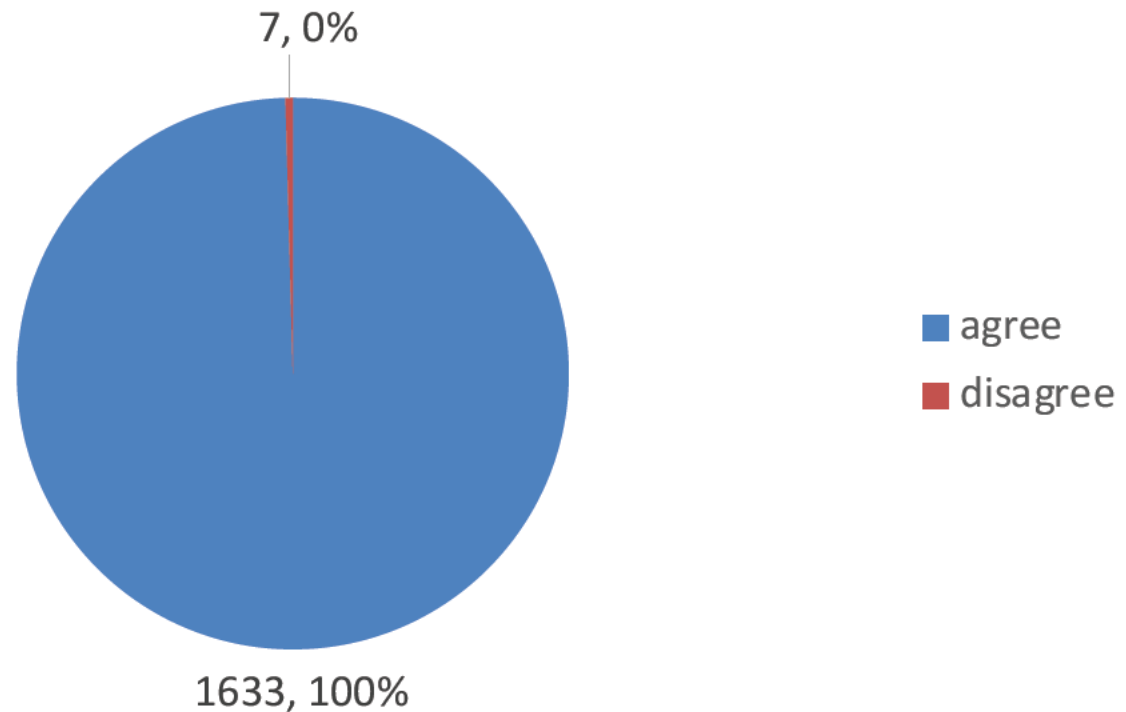
(This Results document should be read in conjunction with the relevant Summary Report available at www.ethicalrights.com)



Note.

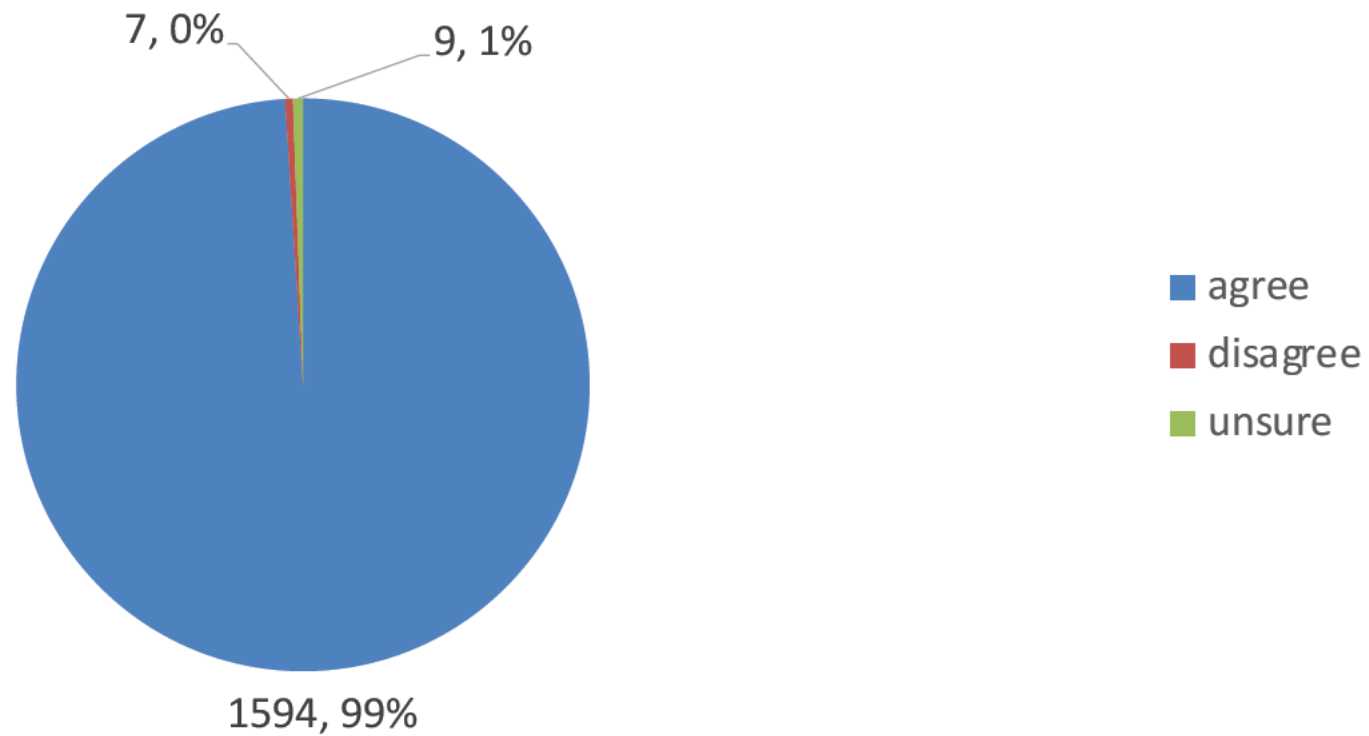
Pie chart sectors are described by 2 numbers. The first is the number of respondents, the second is the percentage of respondents, that gave a particular response to the question. On bar charts, the horizontal axis refers to the percentage of respondents.

Q1. Do you agree that it should be legal for a doctor to assist a terminally ill adult of sound mind in ending their life, if that is the person's wish?



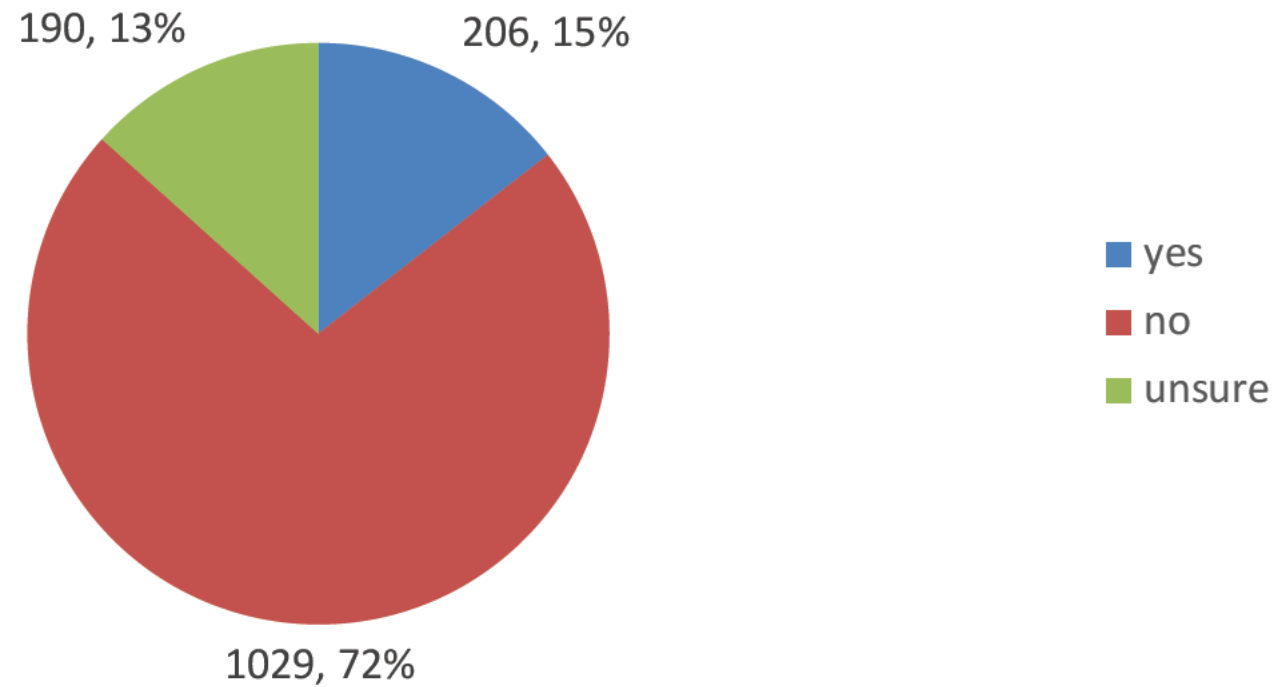


Q2. Do you agree that every adult of sound mind has the right to implement plans for the end of their life?



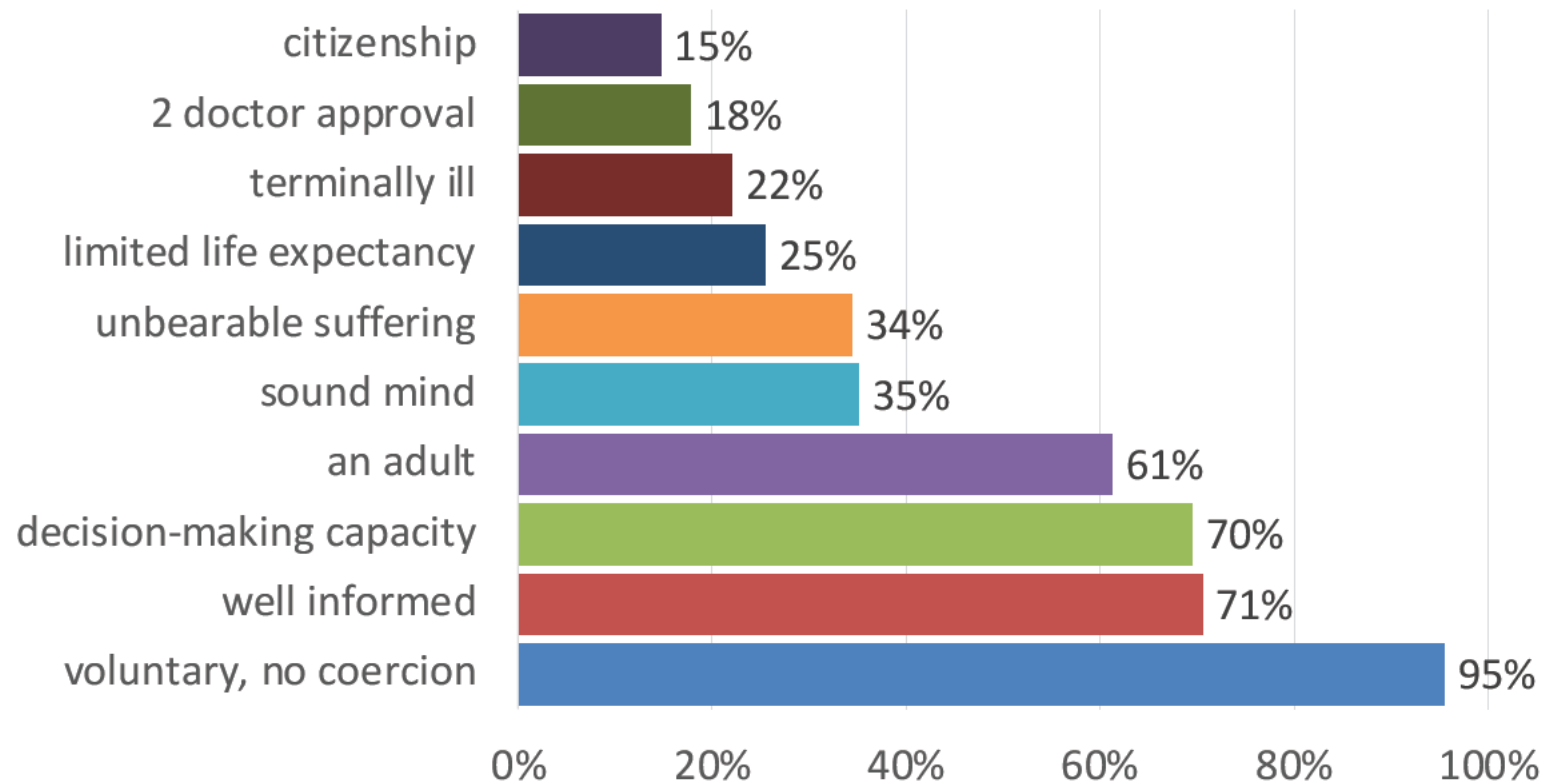


Q3. Do you have access to a legal form of voluntary assisted dying in your region?



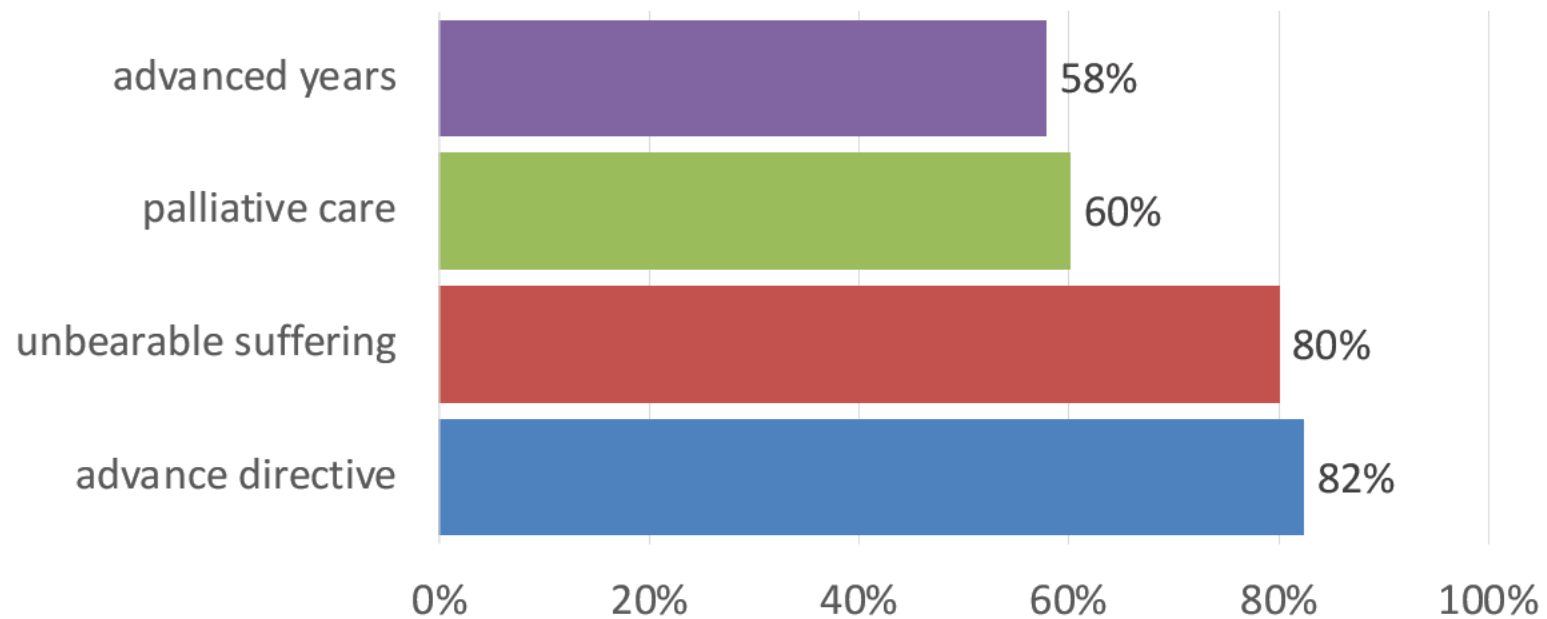


Q4. Which of the following would you consider **NECESSARY** for a person to be **ELIGIBLE** for voluntary assisted dying?





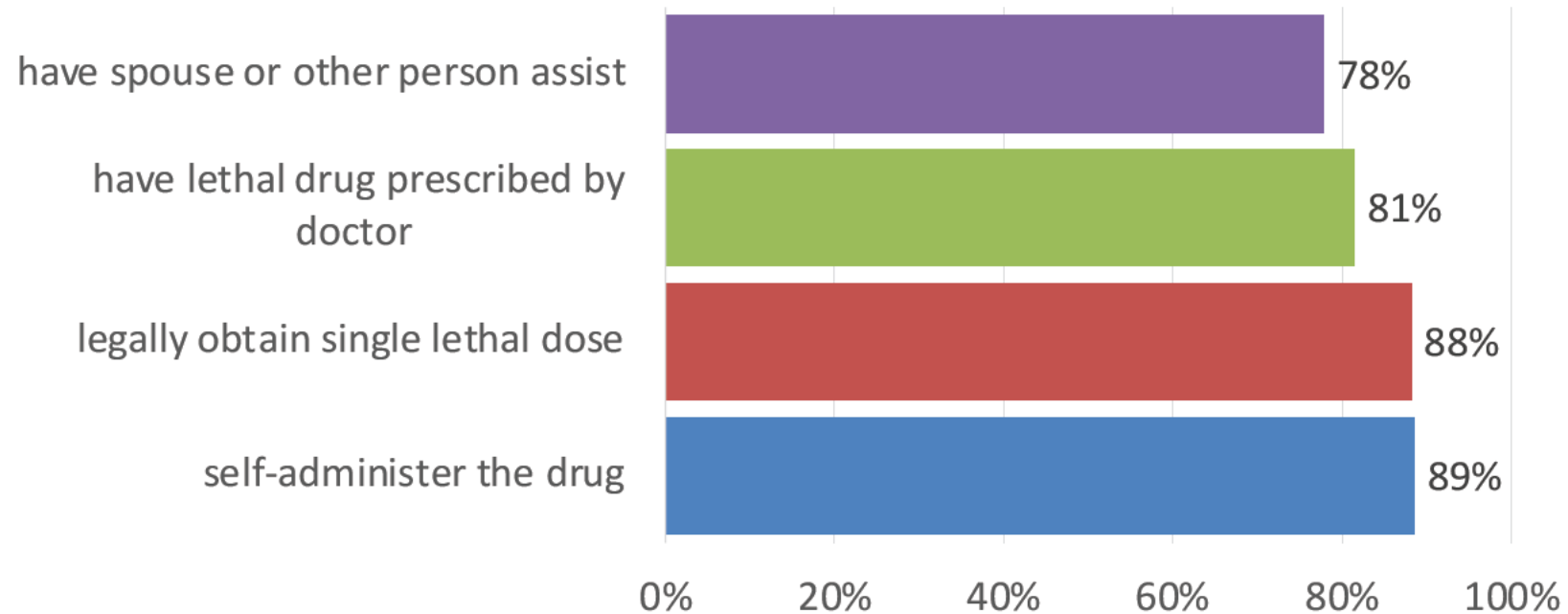
Q5. Assuming that a person has decision making capacity and requests voluntary assisted dying, which of the following should make someone immediately eligible?



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

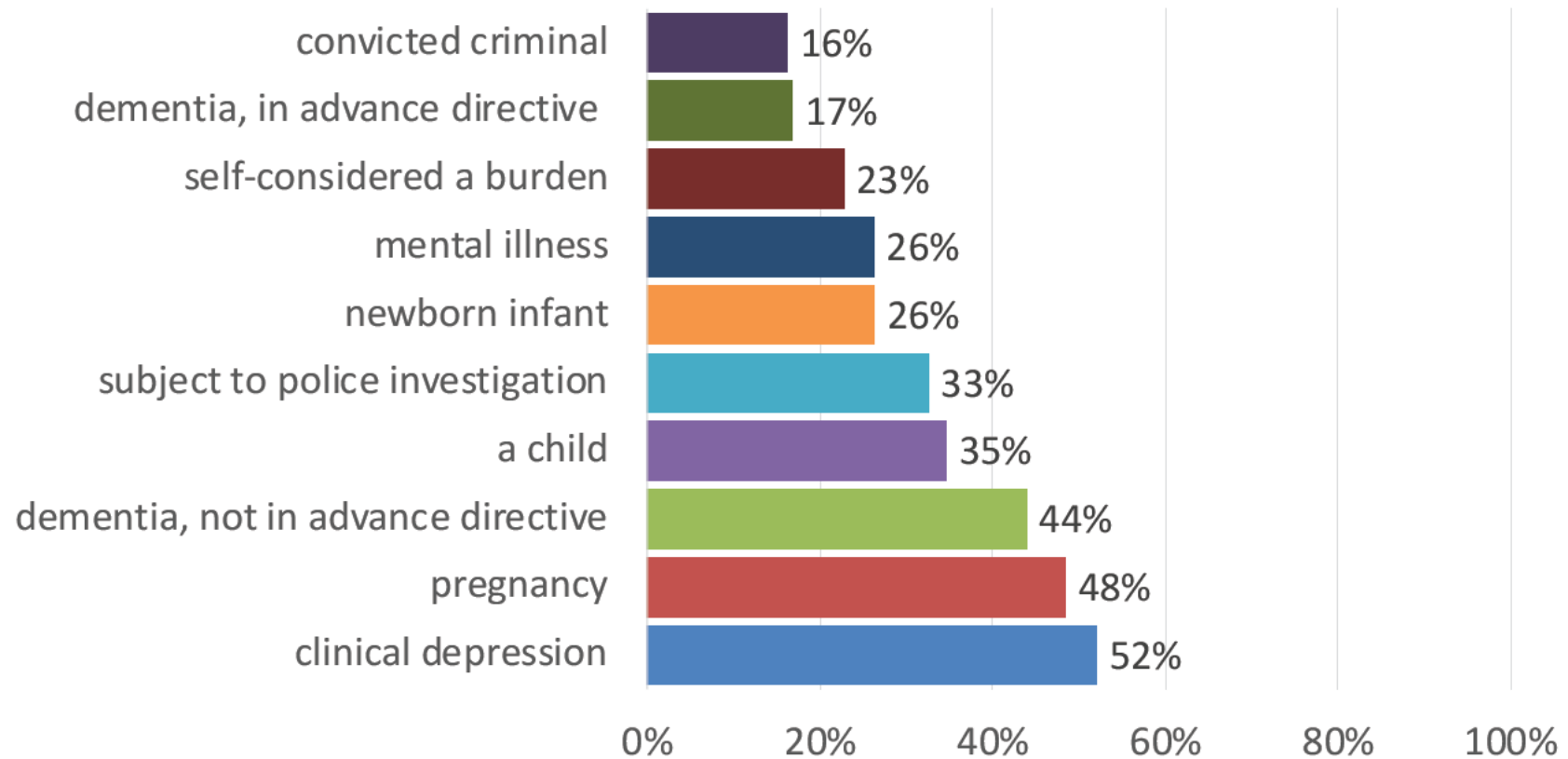


Q6. If a person is eligible, they can do the following...



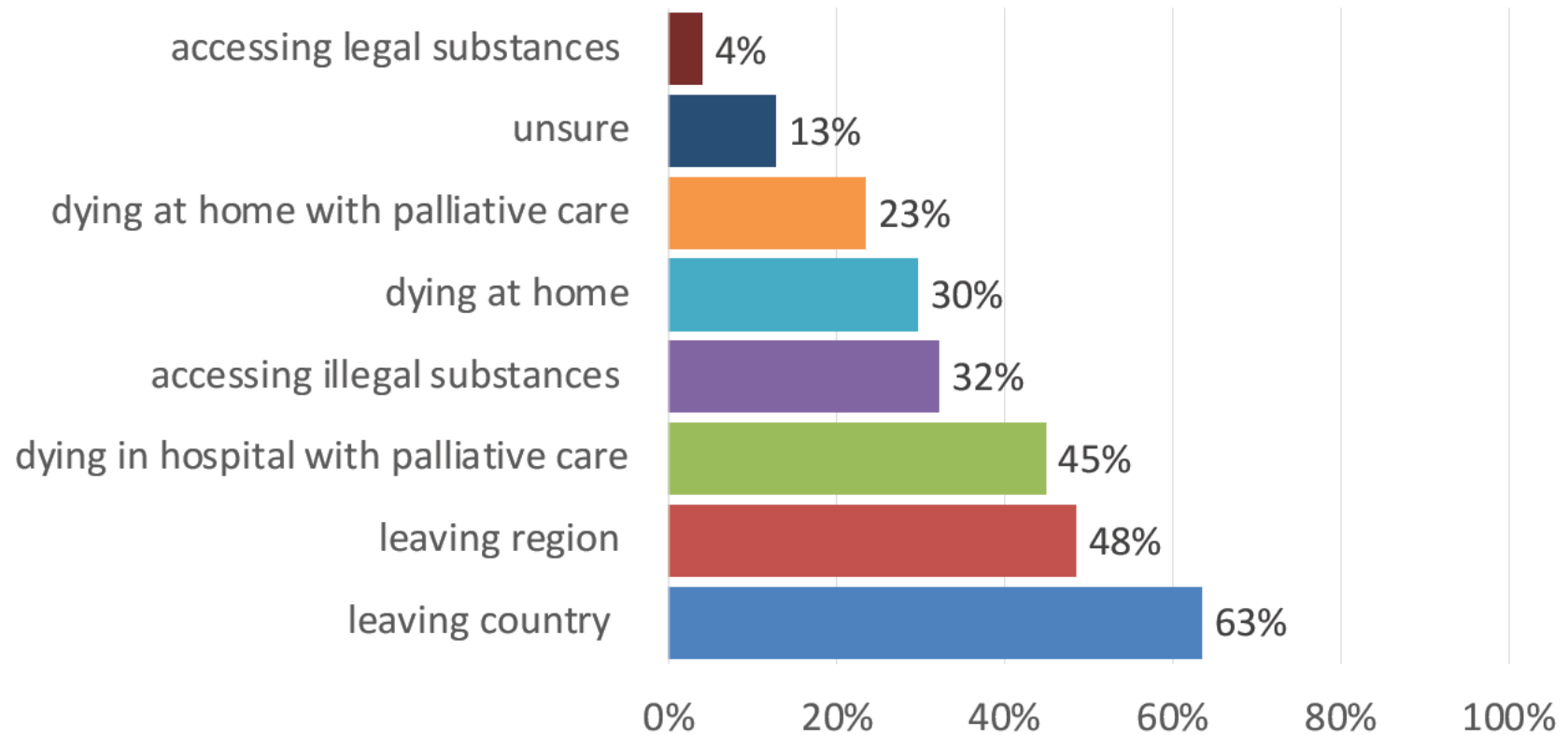


Q7. Which of the following conditions should make a person automatically INELIGIBLE for voluntary assisted dying?



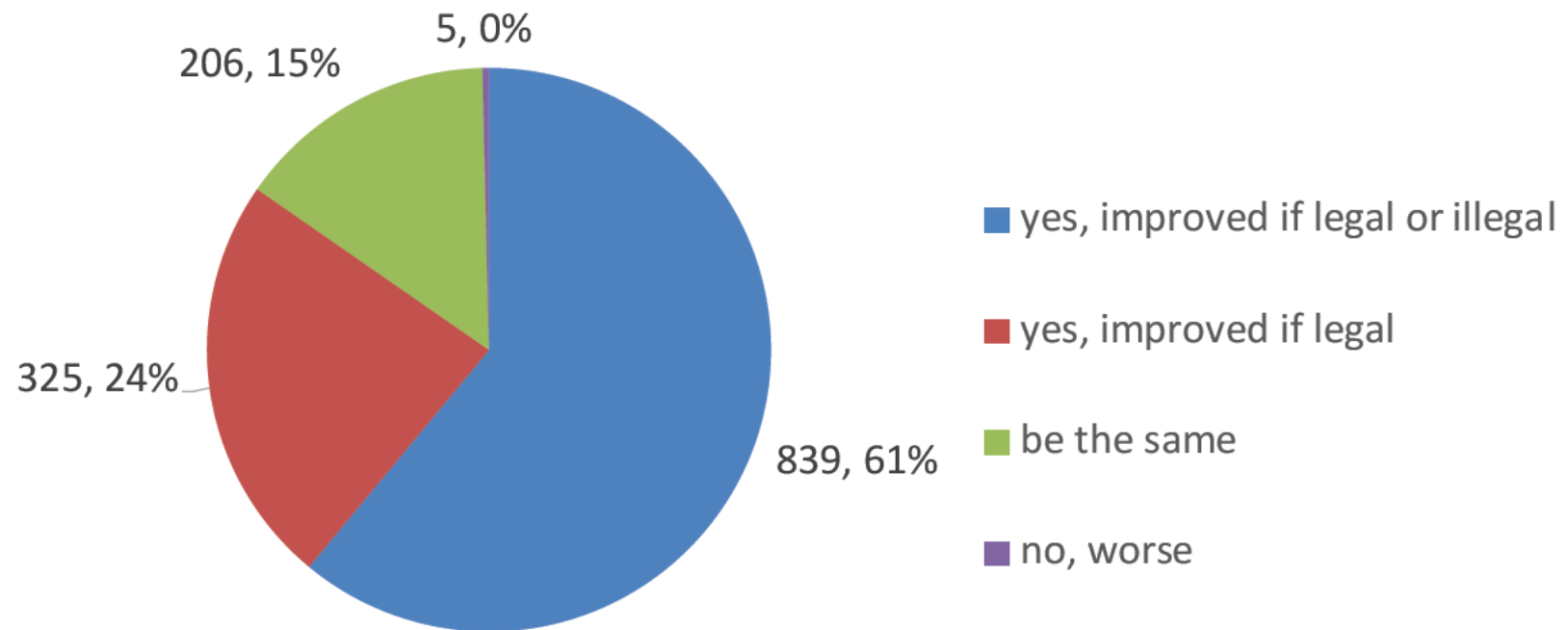


Q8. Which of the following would you NOT WANT as an option for yourself?



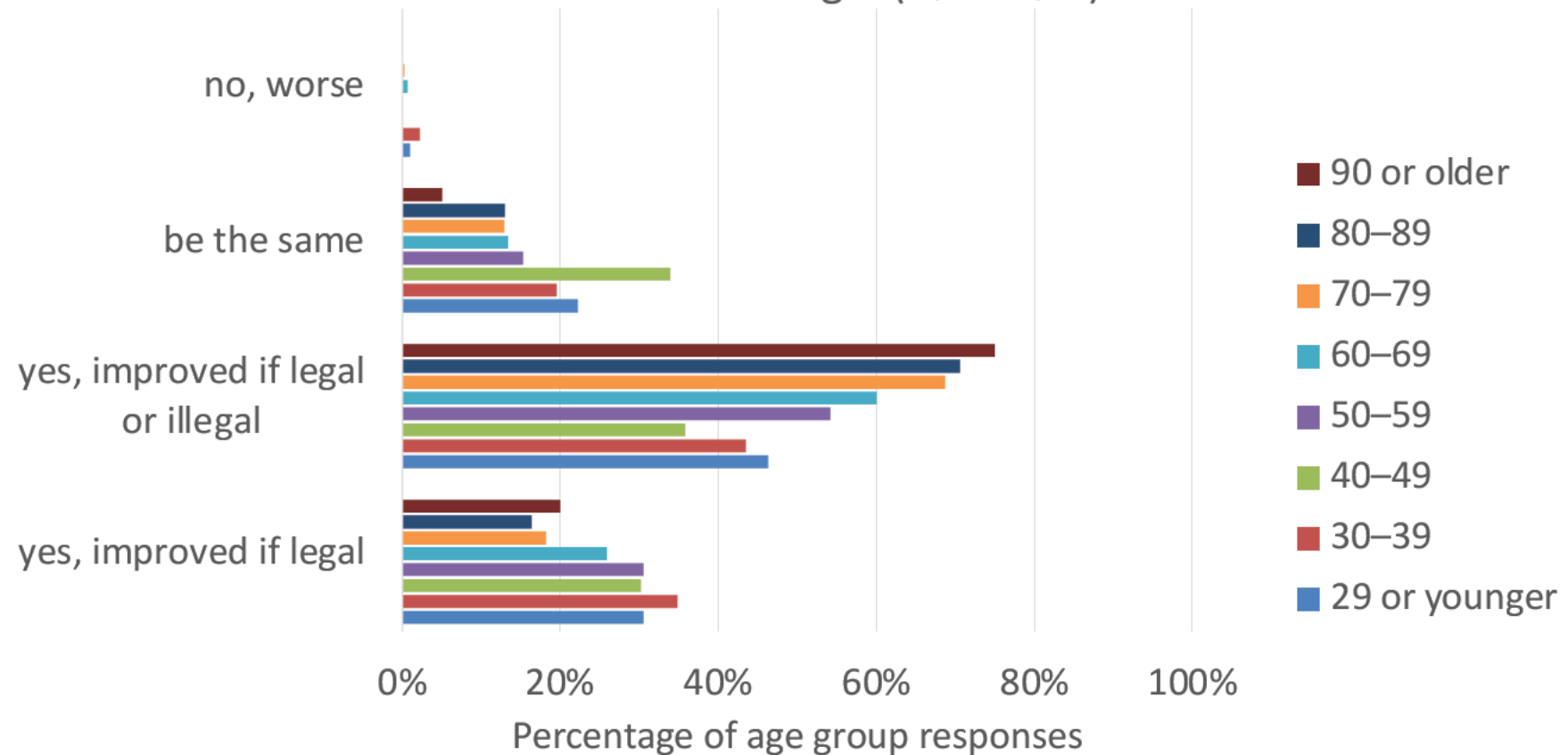


Q9. Would your quality of life be improved if you had ready access to an end-of-life substance?





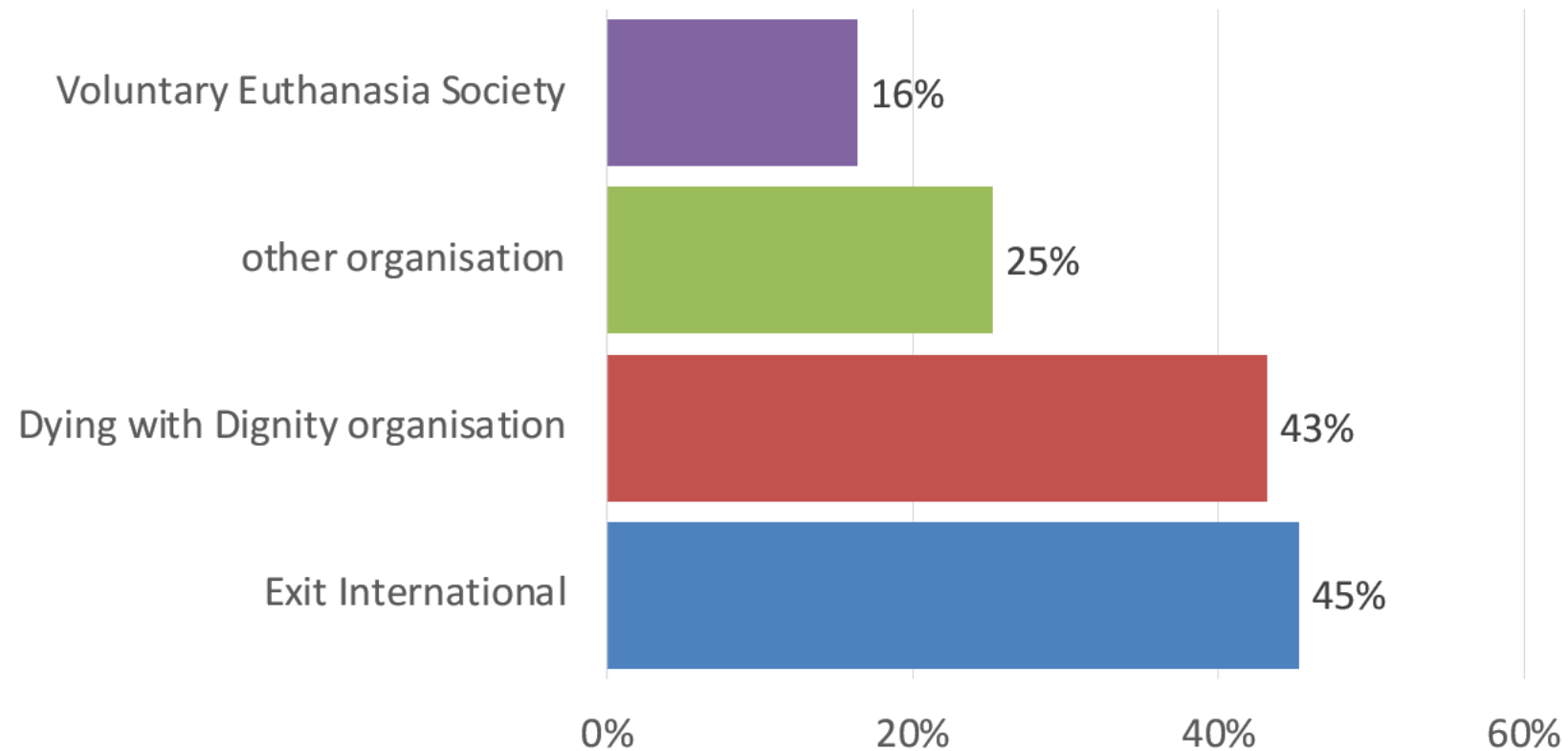
Responses to the question 'Would your quality of life be improved if you had ready access to an end-of-life substance?' as a function of age. (Q9 v Q14)



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

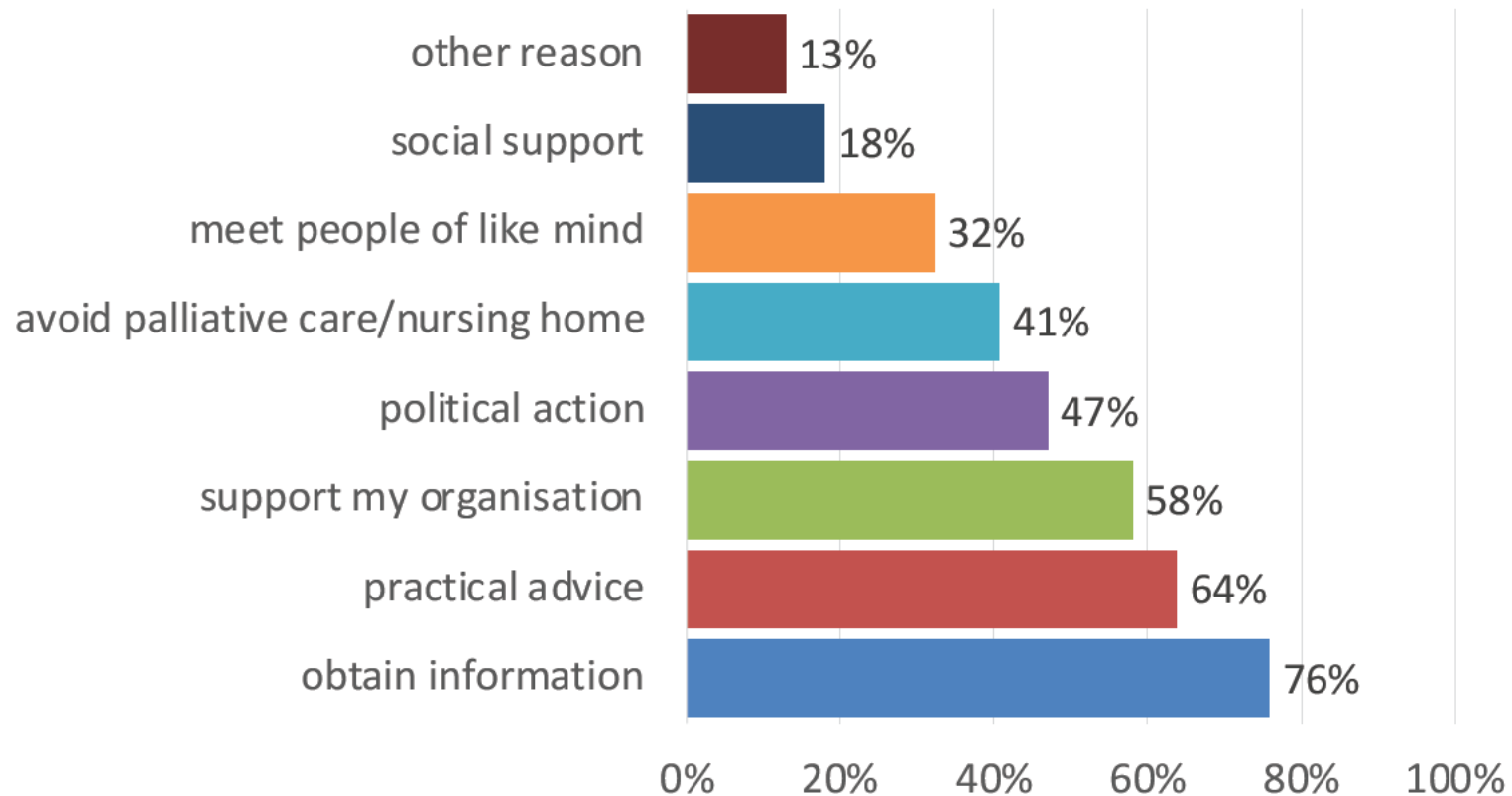


Q10. Of which organisations are you a member?



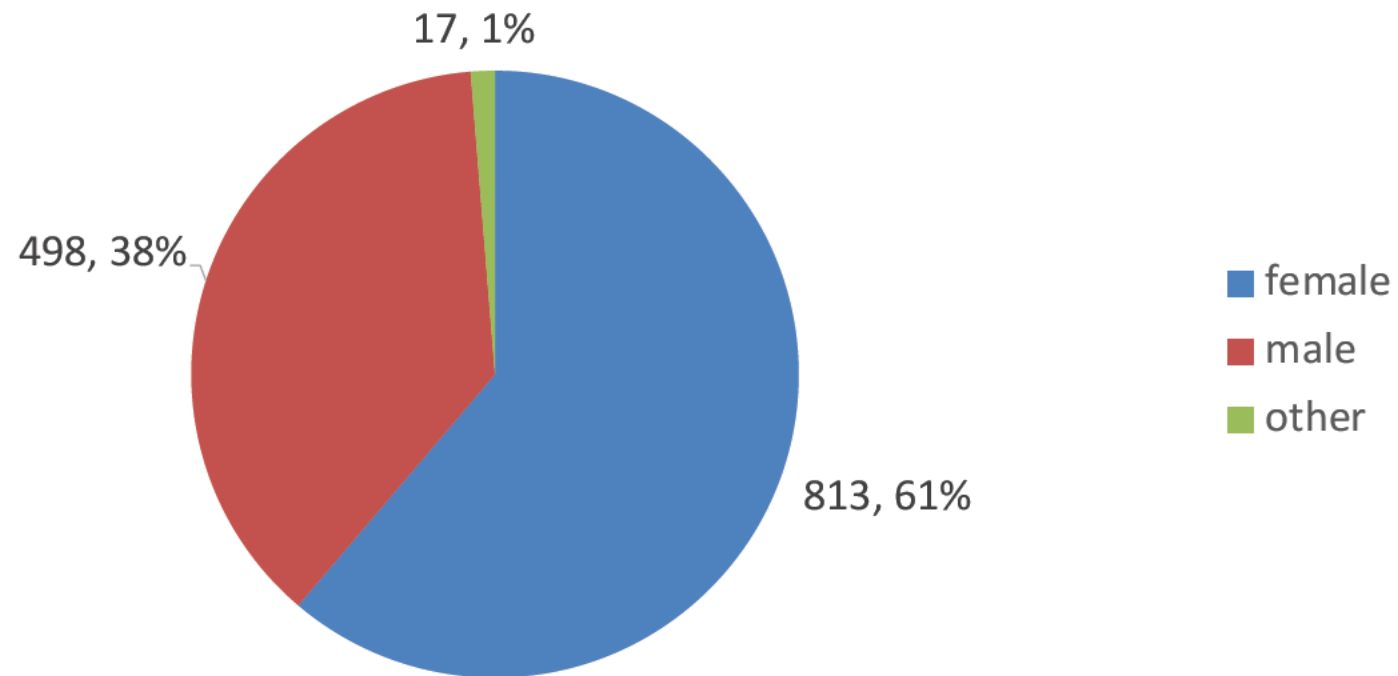


Q11. Why did you join your organisation(s)?



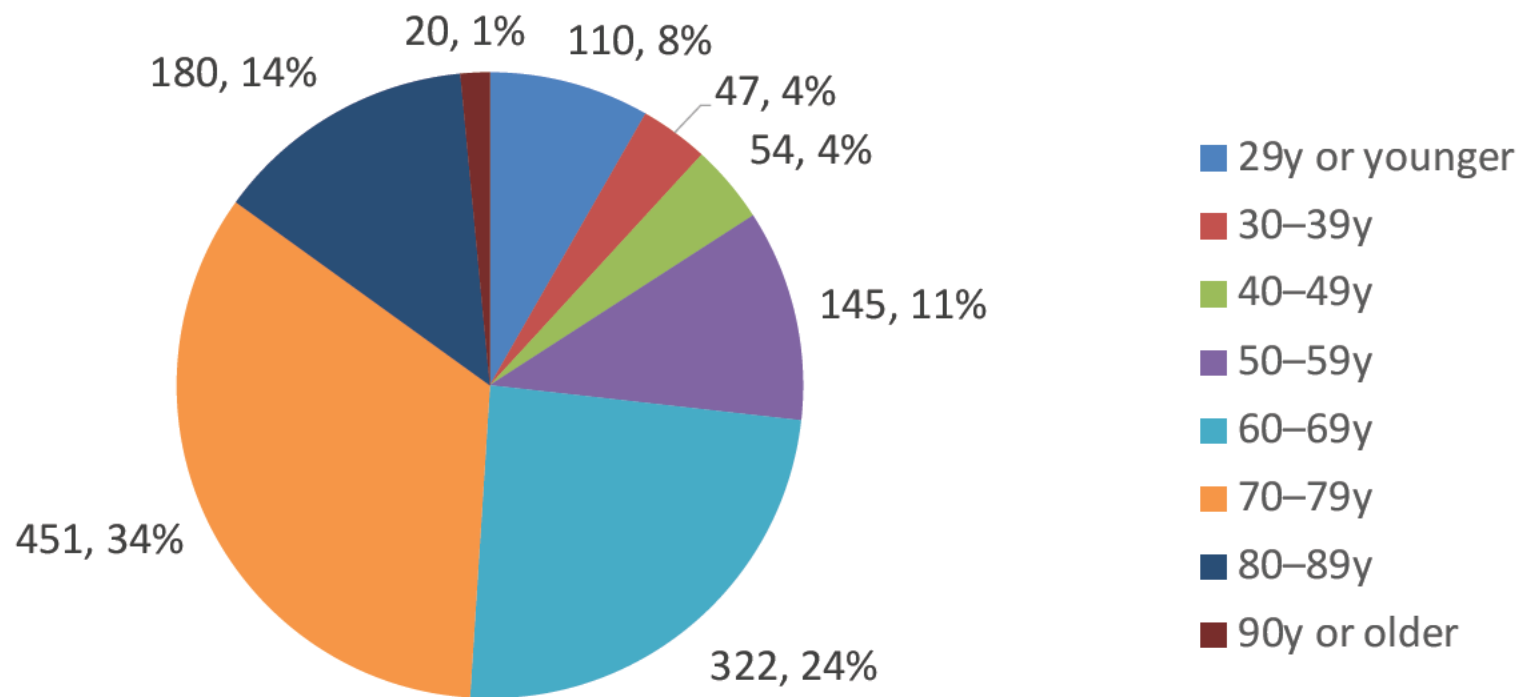


Q13. What is your gender?



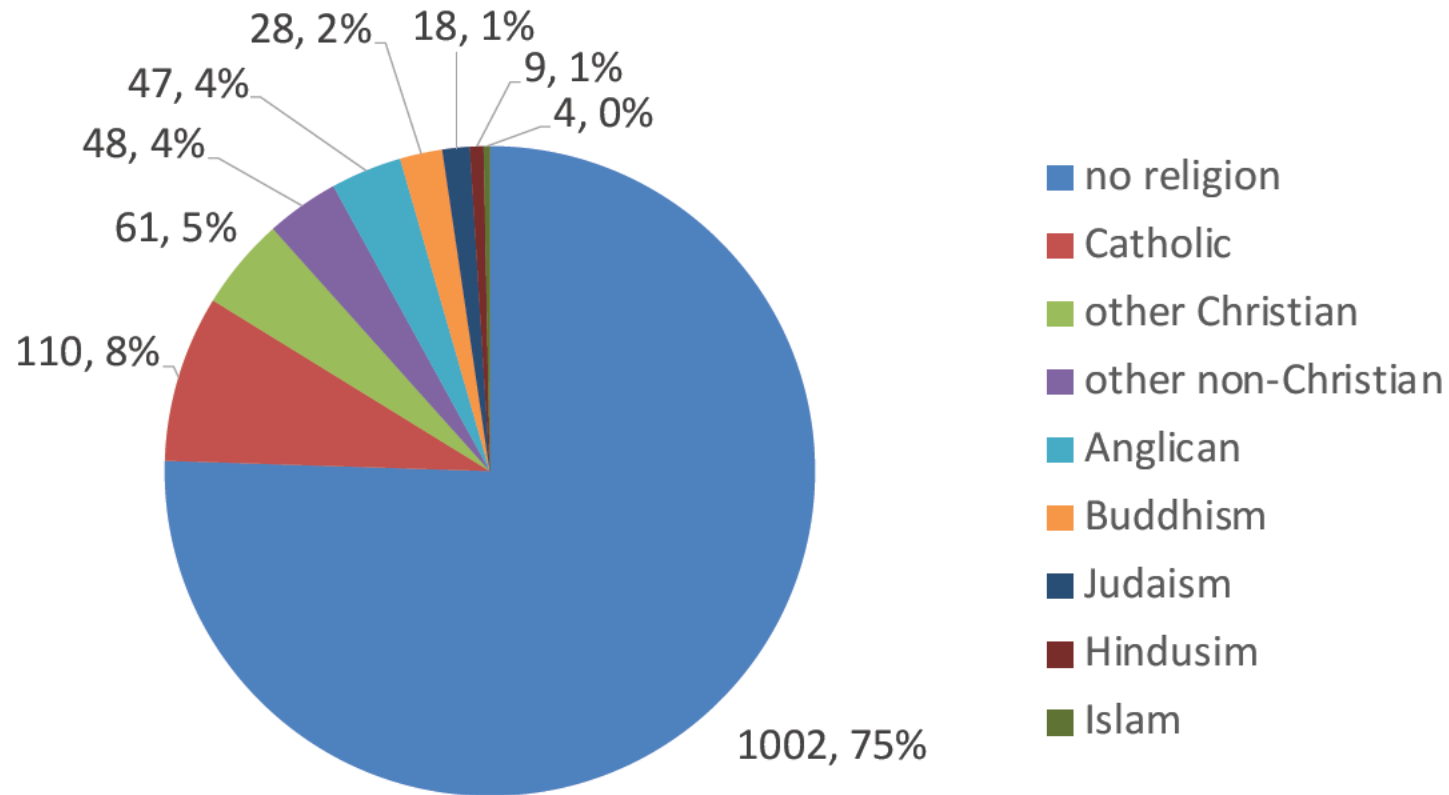


Q14. What is your age group?



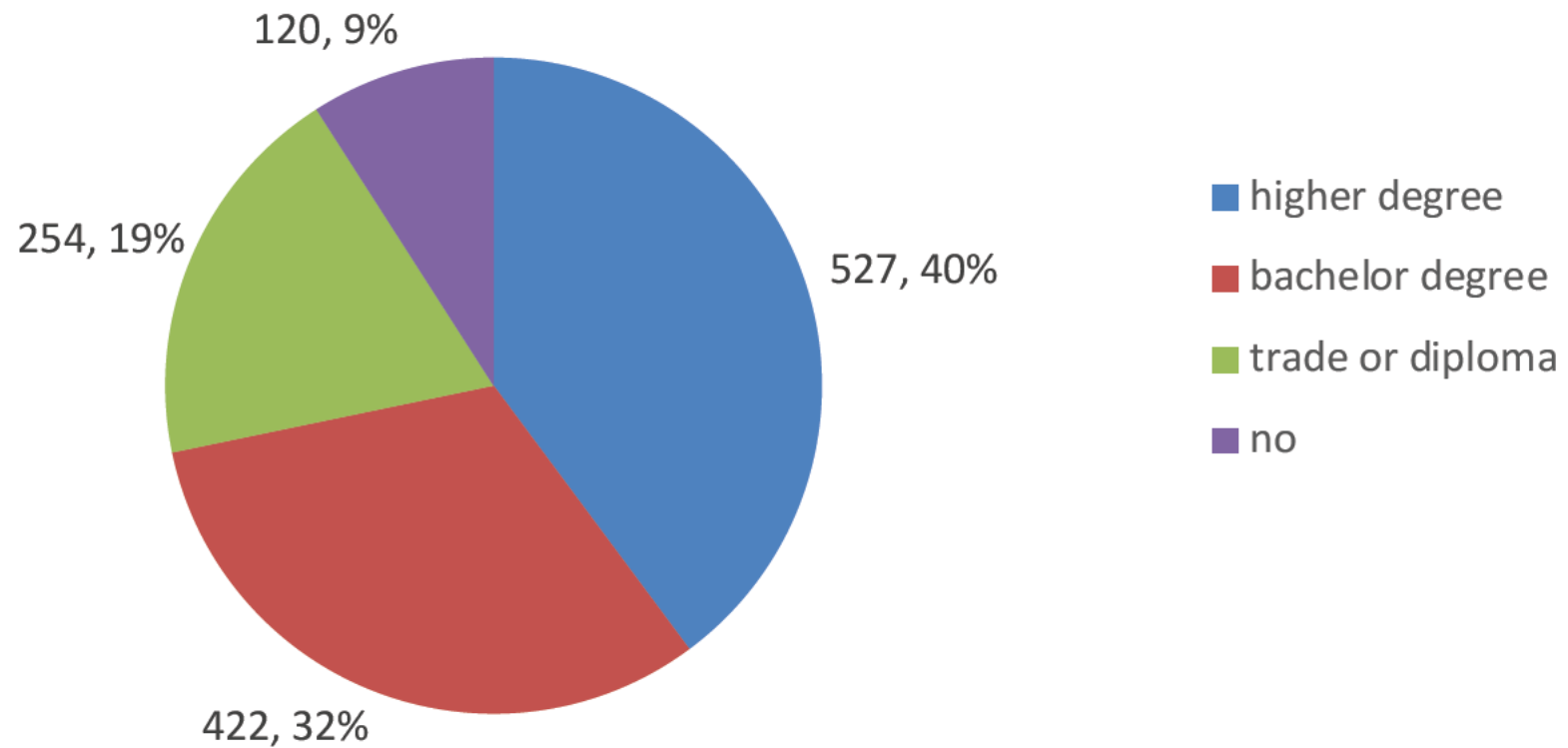


Q15. What is your religion?



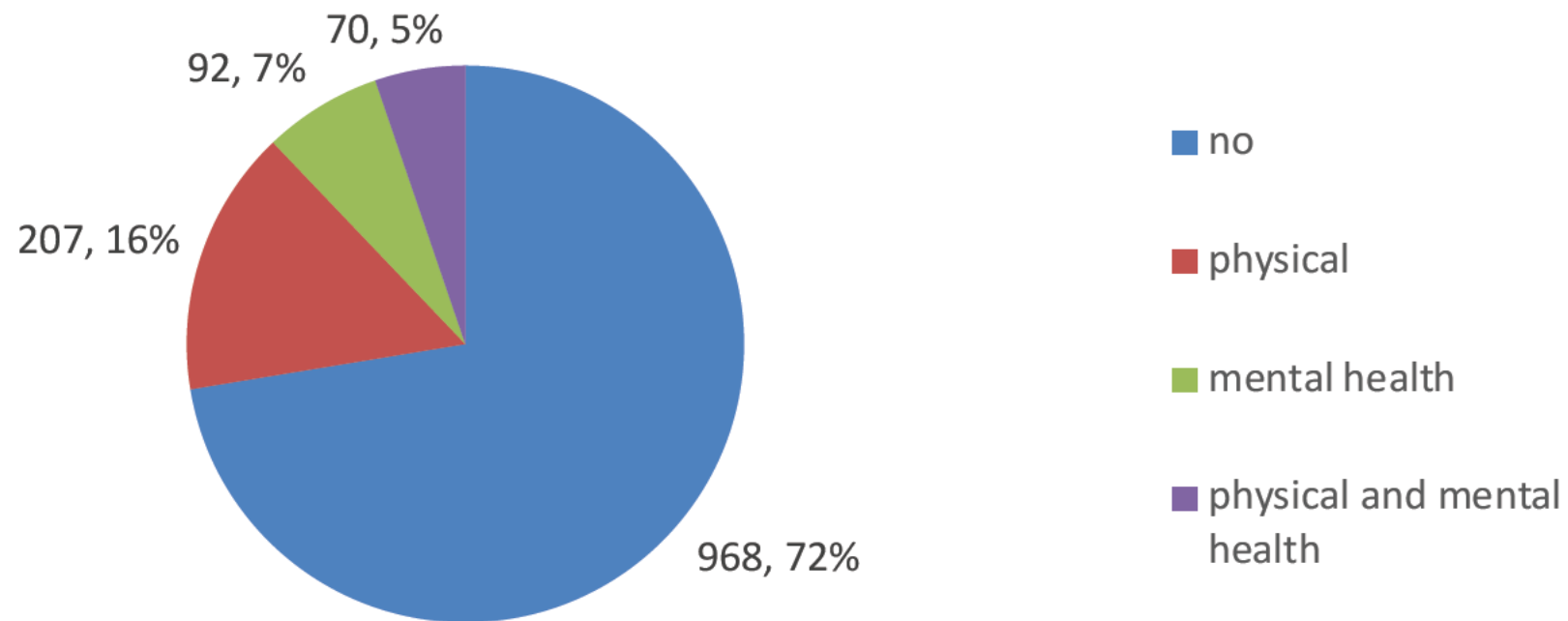


Q16. Did you undertake education beyond high school?



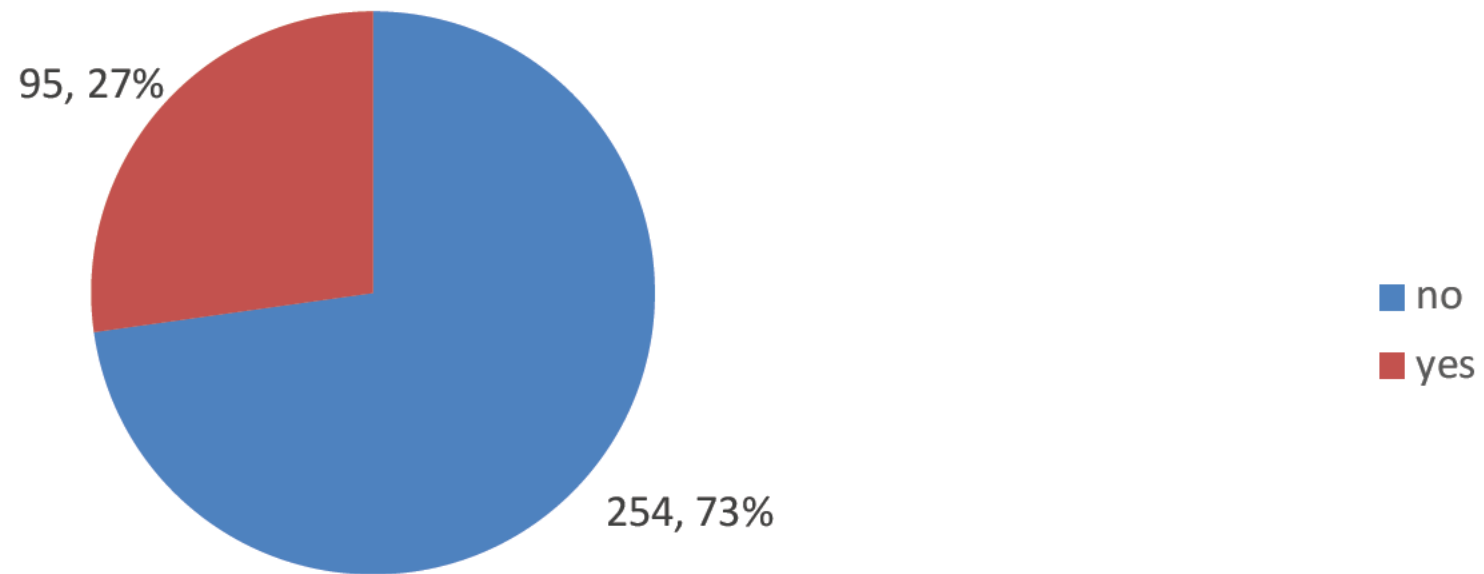


Q17. Do you have a disability?



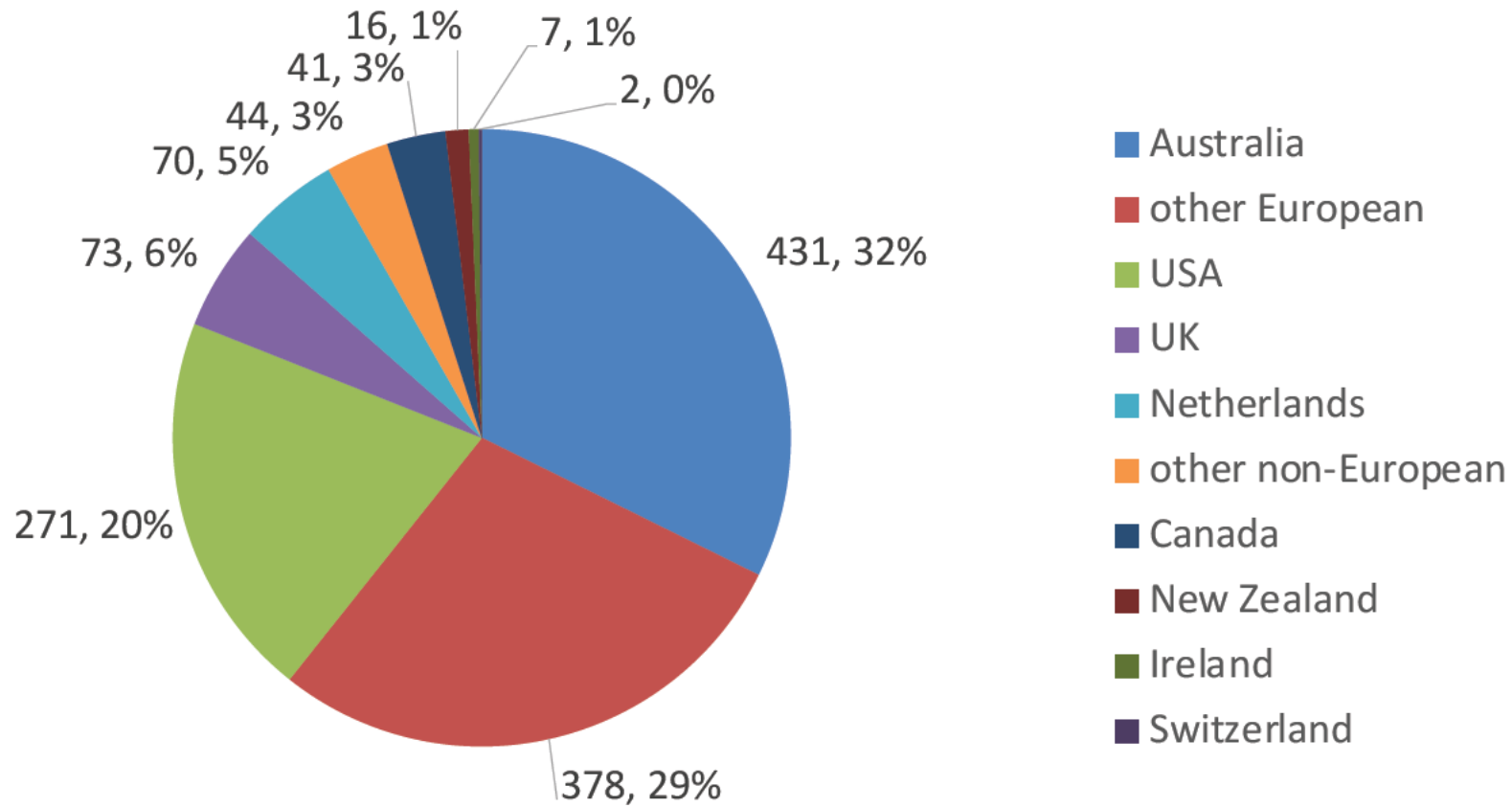


Q18. As a person with a disability, do you have particular needs about voluntary assisted dying?



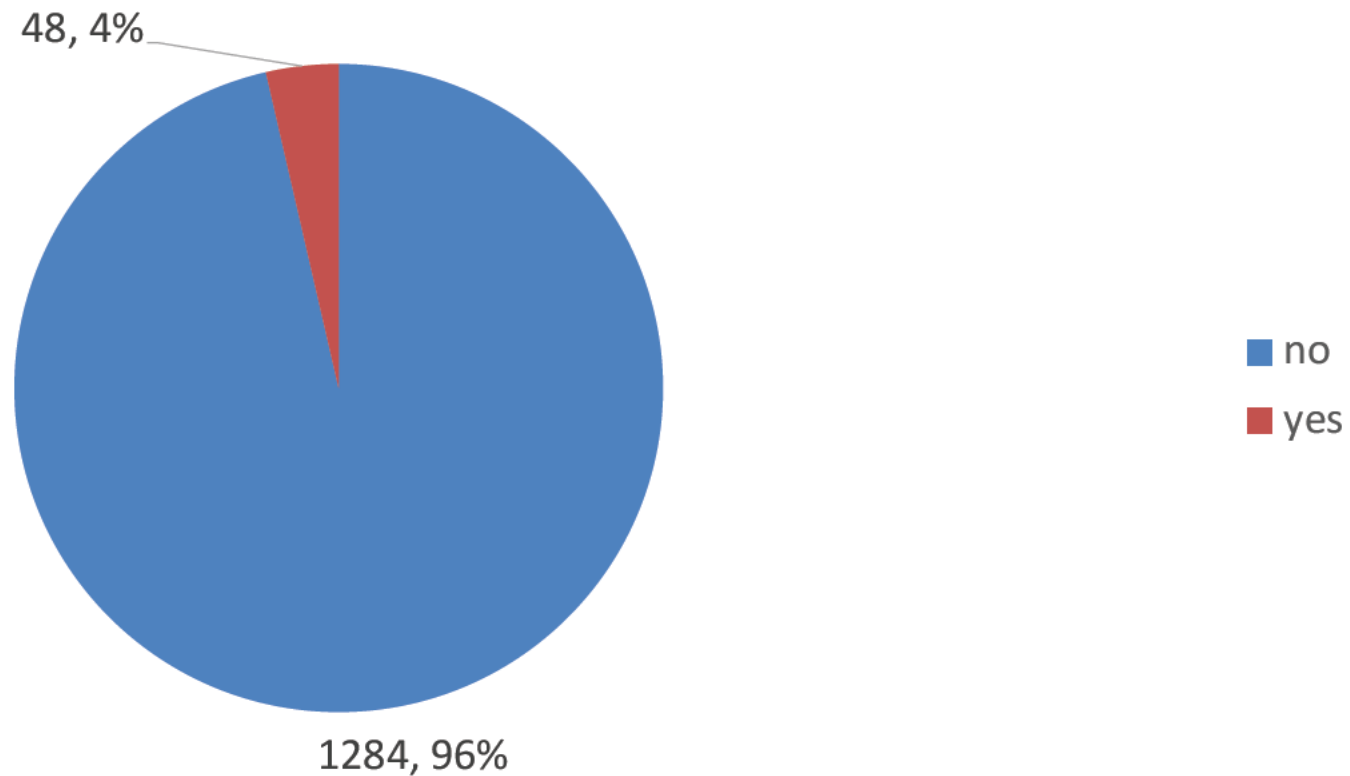


Q19. In which country do you live?





Q23. Are you a member of a First Nations people, i.e. an indigenous or Aboriginal person in your country?





Acknowledgements and further information

Ethical Rights thanks the following organisations and individuals:

- the World Federation of Right to Die Societies, Exit International and the other DWDs and VESs that passed the survey onto their members
- all the VAD supporters who responded to the survey; this survey reflects their perspectives
- Dr Philip Nitschke for supporting the survey
- Dr Wendy Gunthorpe for her valuable comments on survey design (see www.straighttalkconsulting.org).

Further survey details are available at www.ethicalrights.com.