Lawyers for the People
AUSTRALIAN LAWYERS ALLIANCE

Consultation: Voluntary Assisted Dying

Submission to the ACT Government

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Who we are

The Australian Lawyers Alliance (ALA) is a national association of lawyers, academics and other professionals dedicated to protecting and promoting justice, freedom, and the rights of the individual.

We estimate that our 1,500 members represent up to 200,000 people each year in Australia. We promote access to justice and equality before the law for all individuals regardless of their wealth, position, gender, age, race, or religious belief.

The ALA is represented in every state and territory in Australia. More information about us is available on our website.[1]

The ALA office is located on the land of the Gadigal of the Eora Nation.

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[1] www.lawyersalliance.com.au.

Introduction

1. The ALA welcomes the opportunity to have input into the ACT Government's YourSay Community Conversations consultation on voluntary assisted dying.

2. In 2022, the ALA advocated in support of – and welcomed the eventual passage of – the Restoring Territory Rights Bill 2022 (Cth), which we believe resolves an historical injustice and unjustifiable imbalance for both the ACT and the Northern Territory in relation to the ability to legislate on voluntary assisted dying.[2]

3. The ALA contends that the current legal framework in the ACT prevents a significant number of persons who are suffering and dying from choosing the manner and timing of their death and, as such, voluntary assisted dying legislation should be introduced by the ACT Government as soon as possible. Passage of such legislation and the establishment of a voluntary assisted dying scheme in the ACT would allow eligible people in the ACT to access voluntary assisted dying in certain circumstances as part of their end-of-life decisions.

4. The ALA also submits it is imperative the ACT's voluntary assisted dying framework is transparent, to ensure that the activity being regulated is clear, that the eligibility criteria are unambiguous, and that the process is not burdensome on those accessing or administering voluntary assisted dying. Further, the ACT's scheme must be closely monitored, regularly reviewed, and reported on transparently.

5. In this submission, the ALA will respond thematically to the questions detailed in the discussion paper issued in February 2023 by the Justice and Community Safety Directorate in conjunction with ACT Health Directorate and Canberra Health Services ('the Discussion Paper').

6. At the beginning of each section in this submission, we have indicated to which questions from the Discussion Paper the ALA has provided responses.

[2] See: Australian Lawyers Alliance, 'Passing of Restoring Territory Rights Bill welcome: an injustice resolved' (Media Release, 2 December 2022) <https://www.lawyersalliance.com.au/news/passing-of-restoring-territory-rights-bill-welcome-an-injustice-resolved>.

7. In our submission, the ALA reflects on the implementation of voluntary assisted dying schemes in the six state jurisdictions, especially Victoria (accessible since 19 June 2019), Western Australia (accessible since 1 July 2021) and Tasmania (accessible since 23 October 2022); as well as the legislation underpinning the voluntary assisted dying schemes in place for Queensland (which has only been accessible since 1 January 2023), South Australia (which has only been accessible since 31 January 2023) and NSW (which will only be accessible from 28 November 2023).

Eligibility criteria

This section answers the following questions from the Discussion Paper:

1) What should the eligibility criteria be for a person to access voluntary assisted dying?

2) What kind of suffering should a person be experiencing or anticipating in order to be eligible to access voluntary assisted dying?

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?

4) How should a person's decision-making capacity be defined or determined in relation to voluntary assisted dying?

5) Should voluntary assisted dying be restricted to people above a certain age (for example, people 18 and over)?

6) Should a person be an Australian citizen or a long-term resident of Australia to access voluntary assisted dying in the ACT?

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?

8. The ALA considers that eligibility requirements must be met before a person is able to access voluntary assisted dying, as outlined in this section.

Temporal connection to expected death

9. The ALA notes the following eligibility requirements within the six state jurisdictions' respective legislation on voluntary assisted dying:

    - In Victoria, a person must be diagnosed with a disease, illness or medical condition that "is expected to cause death within a period not exceeding 6 months".[3] However, if the person suffers from a neurodegenerative condition, that period of time is extended to 12 months.[4] In Victoria, prior to the passing of that state's legislation, there was concern that persons suffering from neurodegenerative conditions could lose capacity before the application process was complete if their passing was expected to occur within a 6 month period;[5]

    - In Western Australia, one of the eligibility requirements is that the disease, illness or medical condition "will, on the balance of probabilities, cause death within a period of 6 months" <u>or</u> "in the case of a disease, illness or medical condition that is neurodegenerative, within a period of 12 months";[6]

    - In Tasmania, section 6(1)(c) of that state's legislation requires a disease, illness, injury, or medical condition that is expected to cause the death of the person within six months,[7] <u>or</u>, if the disease is neurodegenerative, within 12 months.[8] However, section 6(5) allows for the Voluntary Assisted Dying Commission, established by section 110 of the legislation, to find on the application of a person that they are exempt from this requirement. Tasmania's legislation includes the term "injury" and provides a possible avenue for exemption;

    - In Queensland, the Heath, Communities, Disability Services and Domestic and Family Violence Prevention Committee recommended in its March 2020 report

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[3] *Voluntary Assisted Dying Act 2017* (Vic) s 9(1)(d)(iii).

[4] Ibid s 9(4).

[5] Victoria, *Parliamentary Debates*, Legislative Council, 16 November 2017, 6098.

[6] *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(ii).

[7] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 6(1)(c)(i).

[8] Ibid s 6(1)(c)(ii).

arising from an inquiry into aged care, end-of-life and palliative care and voluntary assisted dying that the Queensland scheme should not impose any precise timeframes for anticipated death due to the "complex, subjective and unpredictable nature of the prognosis of terminal illness".[9] However, the legislative scheme ultimately included a timeframe of 12 months in all cases and did not distinguish between neurodegenerative diseases and other conditions.[10] The provision does overall enable greater access to voluntary assisted dying;

- South Australia's legislative scheme requires that "the person must be diagnosed with a disease, illness or medical condition" that "is incurable" and "is advanced, progressive and will cause death" and "is expected to cause death within weeks or months, not exceeding 6 months" and is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable";[11]

- In NSW, section 16 of the *Voluntary Assisted Dying Act 2022* (NSW) requires a person is diagnosed with at least one disease, illness or medical condition that "is advanced, progressive and will cause death", and "will, on the balance of probabilities, cause death" either within 12 months "for a disease, illness or medical condition that is neurodegenerative", or within six months for other conditions, and "is causing suffering to the person that cannot be relieved in a way the person considers tolerable".[12]

10. The ALA is of the view that a specific timeframe should not be specified in which a person's death is likely to occur. The ALA considers that there is little utility in prognosticating whether a condition will cause death in six or 12 months, when one of the primary purposes of voluntary assisted dying is to ameliorate extended or

[9] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary Assisted Dying* (Report No 34, March 2020) 120, Recommendation 5.
[10] *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(ii).
[11] *Voluntary Assisted Dying Act 2021* (SA) s 26(1)(d)(i)-(iv).
[12] *Voluntary Assisted Dying Act 2022* (NSW) s 16(d)(i)-(iii).

unnecessary suffering prior to death. In addition, many illnesses and medical conditions are likely to result in a person losing capacity as their illness and/or medical condition progresses, which may have the effect of limiting their access to a voluntary assisted dying scheme.

11. Analysis has been undertaken on whether patients with cancer, motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease, anorexia, frailty, spinal cord injury and Huntington's disease would be eligible to access voluntary assisted dying under the Victorian, Western Australian, Oregon and Canadian schemes, as well as a model bill that was recommended by the Queensland Parliamentary Inquiry.[13] That analysis has suggested that access to voluntary assisted dying would be very unlikely under the schemes in most of those jurisdictions for patients suffering from Alzheimer's Disease and Huntington's Disease because they would be unlikely to have decision-making capacity at the end-of-life.[14]

12. **Rather than prescribing any temporal requirement, the ALA considers that an individual should be able to access voluntary assisted dying if they are experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative disease, illness or condition that cannot be relieved in a manner tolerable to the person**. This definition of medical condition emphasises the degree of suffering, the advanced or progressive nature of the condition, and the inability of suffering being ameliorated.

13. **If a condition will cause death, the ALA considers that there should be no temporal requirement to when the person is expected to die from the disease, illness or medical condition in question**. The ALA considers that including such a requirement complicates the process for the coordinating and consulting practitioner, given the "complex, subjective and unpredictable nature of the prognosis of terminal illness".[15]

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[13] Ben P. White, et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed Against Five Legal Frameworks', 45(2) *UNSW Law Journal* 401.
[14] Ibid.
[15] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary Assisted Dying* (Report No 34, March 2020) 120, Recommendation 5.

14. The ALA submits that a person should not be excluded from a voluntary assisted dying scheme because their death is expected to occur over a more protracted timeframe, even though their disease, illness or medical condition is causing them intolerable suffering. This restricts those experiencing long-term pain and suffering from accessing voluntary assisted dying.

15. **If the ACT Government determines that one of the eligibility requirements for the ACT's future voluntary assisted dying scheme should include a temporal connection to the time of death, the ALA is of the view that there should be no differentiation between neurodegenerative diseases and other illnesses, diseases, and medical conditions**. The ALA is unaware of any evidence-based research, which confirms that persons with a neurodegenerative disease, illness or medical condition are more likely to lose decision-making capacity more than six months prior to their expected death compared to those persons suffering from other illnesses, diseases, and medical conditions. In addition, there is no justification for patients to potentially suffer for longer periods of time because they have an illness or medical condition that is not neurodegenerative.

16. **Without a clear justification for the application of different timeframes for different conditions, the ALA considers that persons should be able to access the scheme if they suffer from a disease, illness or medical condition that will cause death within a period of 12 months**.

Decision-making capacity

17. The ALA considers it is vital to any voluntary assisted dying scheme that the person has decision-making capacity, namely that the person has decision-making capacity in relation to understanding, communicating about and evaluating voluntary assisted dying, as well as that the person is acting voluntarily.

18. **The ALA refers the ACT Government to the criteria in the legislation underpinning the voluntary assisted dying schemes in NSW and Queensland as two examples of models which include appropriate criteria regarding decision-making capacity**.[16]

19. Additionally, the ALA submits that the definition of 'decision-making capacity' included in any future ACT legislation should be consistent with the definition of 'decision-making capacity' or 'capacity' in other ACT legislation.

20. The ALA also submits that a person should be ineligible from accessing voluntary assisted dying if they have a mental health impairment, as defined by the relevant legislation.[17]

Minimum age

21. **The ALA considers that it would be appropriate to limit eligibility to voluntary assisted dying to persons who are 18 years of age and older**.

Citizenship and residency requirements

22. **The ALA considers that citizenship and residency requirements are appropriate as part of a state- or territory-based voluntary assisted dying scheme**.

23. This can prevent international and domestic voluntary assisted dying 'tourism', and importantly would ensure in the ACT that the resources provided for and funded by the ACT Government are available first and foremost to ACT residents.

24. However, the ALA considers that there can be an exemption for Australian citizenship and/or long-term residency in appropriate circumstances.[18]

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[16] *Voluntary Assisted Dying Act 2021* (Qld) s 11; *Voluntary Assisted Dying Act 2022* (NSW) s 6.

[17] See, eg, *Voluntary Assisted Dying Act 2021* (Qld) s 13, as defined in the *Mental Health Act 2016* (Qld) s 10.

[18] See, eg, *Voluntary Assisted Dying Act 2021* (Qld) s 12.

The process for request and assessment

This section answers the following questions from the Discussion Paper:

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?

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?

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?

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?

12) Should a person have a choice between self-administration and administration by an administering health professional of a voluntary assisted dying substance?

25. The ALA supports a request and assessment process for accessing voluntary assisted dying that is consistent with the processes in the states' schemes.

Core recommended processes

26. The ALA supports the following core processes as part of a functional and accessible voluntary assisted dying scheme:

    - A person must undergo two eligibility assessments provided by separate and independent health professionals who themselves meet specific eligibility requirements (the ALA addresses this later in our submission);
    - A person seeking access to voluntary assisted dying must formally initiate a request to a health professional;
    - The health professional then assesses the person's eligibility to access the voluntary assisted dying scheme;

- If a health professional cannot determine whether the person meets the eligibility criteria, they must refer that person for further assessment;

- If eligibility is confirmed, the person seeking access to voluntary assisted dying is then referred to another health professional for a second assessment;

- Once the person is deemed eligible to access voluntary assisted dying by two independent health professionals, that person must then make a second request in writing in front of two independent witnesses;

- Before access is granted a third request must be made, with a required period (for example, five days) between the first and third request;

- At any time during this process, a person may decide not to take further action to access voluntary assisted dying; and

- In relation to the administration of a voluntary assisted dying substance, a person may decide to self-administer or decide to be assisted by an administering practitioner.

27. **The ALA recommends that the above processes are included and enshrined in the ACT's future legislative scheme.**

Counselling services

28. **The ALA supports the availability of counselling services on a case-by-case basis and undertaken voluntarily for persons wishing to access voluntary assisted dying.**

29. The ALA does not consider that it should be a mandatory requirement for health professionals to offer access to counselling services or to compel a person's participation in counselling before they can access voluntary assisted dying. This is consistent with the approach in other jurisdictions, including Queensland and NSW.

30. Overall, the ALA contends that a requirement for counselling could also delay the voluntary assisted dying process and cause additional distress and suffering to the person seeking to access voluntary assisted dying.

31. Another reason underlying the ALA's position is that it is anticipated that there would be a component of counselling provided during the assessment by the two health professionals involved in the aforementioned voluntary assisted dying process anyway.

32. Further, the requirement to participate in counselling sessions could also prevent persons living in rural and remote areas from accessing voluntary assisted dying entirely due to the difficulty of accessing counselling services. Those approaching the end of their life may also be too unwell to travel to and participate in counselling services.

The role of health professionals

This section answers the following questions from the Discussion Paper:

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?

18) What minimum qualification and training requirements should there be for health professionals engaged in the voluntary assisted dying process?

19) Which health professionals should be able to administer the voluntary assisted dying substance? For example, a registered medical practitioner, a nurse practitioner, registered nurse, or someone else?

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?

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?

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?

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?

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?

Minimum qualifications

33. Participation by health professionals in any voluntary assisted dying scheme should be limited to those who are appropriately qualified and experienced, in addition to having also completed a minimum level of training regarding the voluntary assisted dying scheme. This latter criterion regarding training will be addressed in the next subsection of our submission.

34. In addition to not being a family member of the person requesting to access voluntary assisted dying, the ALA notes that the varied minimum qualifications in the states' schemes include the following:

    - South Australian legislation requires that the coordinating and consulting practitioners have held a fellowship with a specialist medical college for at least five years or have been a vocationally registered general practitioner for at least five years,[19] as well as that one of the practitioners has "relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed".[20]

[19] *Voluntary Assisted Dying Act 2021* (SA) s 27(1) and (2).

[20] Ibid s 27(3).

- In Queensland, it is sufficient for a coordinating and consulting practitioner to have general registration with five years' experience;[21]

- Legislation in NSW and Western Australia requires coordinating and consulting practitioners with general registration to have had at least 10 years' experience;[22]

- In Tasmania and Victoria, at least one of the doctors involved must be a specialist with at least five years' experience, and one must specialise in the person's disease, illness or medical condition.[23]

35. **The ALA recommends that health professionals, especially those who would be coordinating health professionals or consulting health professionals in the ACT's voluntary assisted dying scheme, should be required to have general registration with five years' experience**.

36. While eligibility requirements for health professionals may be to ensure they have the necessary skill and expertise to participate in a voluntary assisted dying scheme, in practice requirements that are too specific or narrow jeopardise equitable access to the scheme, especially for persons living in smaller jurisdictions and/or remote and regional communities where access to a range of doctors with specific qualifications can be very limited.[24]

37. **The ALA notes our support of the involvement of suitably qualified nurse practitioners to participate in the ACT's voluntary assisted dying scheme**, if they otherwise meet any training or other requirements and especially if that would enable access to the scheme for persons living in rural and remote areas.

[21] *Voluntary Assisted Dying Act 2021* (Qld) s 82(1)(a)(ii).

[22] *Voluntary Assisted Dying Act 2022* (NSW) s 18(a)(ii); *Voluntary Assisted Dying Act 2019* (WA) s 17(2)(a)(ii).

[23] *Voluntary Assisted Dying Act 2017* (Vic) s 10; *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 9.

[24] This has been noted by the Queensland Law Reform Commission: *A Legal Framework for Voluntary Assisted Dying* (Report No. 79, May 2021) 403 at 13.114.

Training requirements and resourcing

38. The ALA believes it is appropriate that ACT health professionals undertake specific training about voluntary assisted dying and the processes governing the ACT's scheme, once established by future legislation proposed by the ACT Government.

39. Other jurisdictions have utilised the time between passing the legislation establishing a voluntary assisted dying scheme and voluntary assisted dying becoming accessible (usually 18 months) to offer that training to practitioners.

40. The ALA notes the importance of training a large enough group of health practitioners to meet demand when voluntary assisted dying becomes accessible, especially in smaller jurisdictions and/or rural areas. The ALA refers the ACT Government to issues that arose in Tasmania where only a small group of practitioners had completed the training by the time voluntary assisted dying became accessible in Tasmania.[25] That resulted in longer wait times and accessibility issues for Tasmanians seeking to access Tasmania's voluntary assisted dying scheme.[26]

41. There have been calls, for example in Western Australia, for incentives and greater support offered to health practitioners to undertake voluntary assisted dying training, especially health practitioners in rural areas who are overworked and overstretched as is.[27]

42. **The ALA recommends that the ACT Government ensure ample training resources and structures are available to health practitioners, and that undertaking that training is incentivised to ensure there are an adequate supply of appropriately-trained health professionals ready when the ACT's voluntary assisted dying scheme officially begins**.

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[25] Meg Whitfield, 'Voluntary assisted dying is now legal in Tasmania but for some, the wait remains', *ABC News* (online, 28 November 2022) <https://www.abc.net.au/news/2022-11-28/voluntary-assisted-dying-legal-in-tasmania-but-wait-remains/101703358>.

[26] Ibid.

[27] Katie Hampson, 'Perth doctor reveals how WA's voluntary assisted dying laws are making an impact', *The West Australian* (online, 27 October 2021) <https://thewest.com.au/lifestyle/health-wellbeing/dying-with-dignity-ng-b881982971z>.

Remuneration for health professionals

43. Voluntary assisted dying schemes in the six states – those five schemes that have commenced and the NSW scheme which is set to commence later this year – are tightly regulated and involve significant input from health professionals, particularly coordinating practitioners, who are responsible for co-ordinating the care of people seeking to access voluntary assisted dying. That care includes:

    - completing the aforementioned mandatory training;
    - travelling to see patients in person, especially if audio-visual communication is not permissible and/or the patient is unable to travel to the practitioner;
    - assessing the patients;
    - liaising with the patient's family members and/or friends;
    - liaising with other practitioners about the patient's condition; and
    - completing a substantial amount of documentation.

44. As described by Casey M. Haining et al,[28] medical practitioners perceive that they are largely unremunerated despite the significant time commitment involved in providing voluntary assisted dying services. The ALA notes there are no dedicated Medicare Benefits Schedule (MBS) items for voluntary assisted dying, although some MBS items can be used for services rendered for counselling/assessment about voluntary assisted dying.

45. Western Australia and Victoria have provided some funding to support practitioners involved in the scheme; however, if appropriate funding is not provided, practitioners have expressed that they would be reluctant to privately bill their patients for

[28] Casey M Haining, Lindy Willmott, Simon Towler and Ben P White, 'Access to voluntary assisted dying in Australia requires fair remuneration for medical practitioners', (2023) 218(1) *Medical Journal of Australia* 8.

voluntary assisted dying services.[29] This affects the ability of health professionals to remain involved in the voluntary assisted dying scheme.

46. Without health professionals willing to be involved in the provision of voluntary assisted dying services, any voluntary assisted dying scheme is unlikely to succeed in meeting its intentions of providing a lawful medical service to the relatively small number of patients that would be eligible to access the scheme.

47. **As such, the ALA considers that there should be careful consideration as to how health professionals are to be remunerated under the ACT's future scheme, as well as whether local funding will be made available with consideration given to what extent of MBS items are not expanded to cover voluntary assisted dying services**.

Initiating discussions

48. The ALA contends that it is important that in any voluntary assisted dying scheme, appropriately-qualified health professionals are permitted to initiate conversations about voluntary assisted dying.

49. Providing patients with information about all lawful end-of-life options, including voluntary assisted dying, is part of good clinical practice and should lead to optimal end-of-life care.

50. **The ALA notes that there are no prohibitions on health professionals from initiating discussions about any other lawful treatment options for other diseases, illnesses, or medical conditions in Australia**.

51. A person seeking to access voluntary assisted dying would still need to meet all eligibility criteria to access voluntary assisted dying, make at least two formal requests to access voluntary assisted dying and fulfil all other processes for accessing the ACT's voluntary assisted dying scheme, as discussed earlier in this submission.

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[29] See: Marcus Sellars, et al, 'Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: a qualitative interview study among participating doctors' (2022) *Social Science & Medicine* 292.

52. **The ALA recommends that the ACT's legislation concerning voluntary assisted dying permits health professionals to initiate conversations about voluntary assisted dying before a person makes formal requests to access voluntary assisted dying.**

Conscientious objections to voluntary assisted dying

53. The ALA considers that health professionals should be allowed to conscientiously object to voluntary assisted dying and should not be forced to participate in any voluntary assisted dying scheme.

54. The ALA recognises that there is a wide range of personal views and beliefs that will determine whether individuals support the introduction of a voluntary assisted dying scheme in the ACT, including individuals within the health profession.

55. The ALA strongly believes that the personal beliefs and values held by medical and health practitioners should not be devalued by their forced participation in a voluntary assisted dying scheme.

56. Inclusion of clauses regarding conscientious objections in the ACT's legislative scheme would also ensure consistency with the legislative voluntary assisted dying schemes in all six states,[30] as well as with codes of conduct for medical and health professionals.[31]

57. **Regarding the process of a health professional communicating their conscientious objection to voluntary assisted dying, the ALA supports the following processes for inclusion in the ACT's legislative scheme**:

    - A requirement for health professionals to immediately advise a person of their conscientious objection; and

    - A requirement that health professionals who, following a person's request to access voluntary assisted dying, refuse to act as a coordinating practitioner must provide that person with information that assists the

[30] See, eg, *Voluntary Assisted Dying Act 2021* (Qld) ss 16(2)(a), 26(3)(a), 84–5.

[31] See, eg, Medical Board of Australia, *Good medical practice: A code of conduct for doctors in Australia* (2009) rr 2.4.6-2.4.7.

person to navigate referral services that are available to assist with voluntary assisted dying.

58. The ALA believes that the above processes will promote the autonomy of persons seeking to access voluntary assisted dying to make their own decisions about their end of life options and to ensure that health professionals' personal views about voluntary assisted dying do not adversely impact on the care of their patients and prevent patient access to a lawful end of life option.

59. A requirement for health professionals to refer a person to another practitioner in these circumstances is consistent with concepts of good medical practice in codes of conduct and medical ethics.

60. **The ALA supports legislation that ensures a person is not prevented from accessing information about voluntary assisted dying or that prevents access to the ACT's future scheme**.

The role of health services

This section answers the following questions from the Discussion Paper:

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?

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?

Objections by health services or other related institutions to voluntary assisted dying

61. Health services and related institutions play an important role in voluntary assisted dying schemes, including public and private hospitals, residential aged care facilities, and accommodation for people with a disability.

62. **The ALA submits that a health service or related institution should not be able to prevent the provision of voluntary assisted dying services at their facility**.

63. In a paper by Ben P. White et al,[32] the authors interviewed 32 family caregivers and one patient about the experience of 28 patients who had sought voluntary assisted dying in Victoria. Participants reported institutional objection affecting eligibility assessments, medication access, and taking the medication or having it administered. Institutional objections occurred across all health settings and institutions often did not clearly communicate their objections to patients and family members.[33] It was concluded that institutional objections created additional barriers in a system that was already procedurally challenging, and the policy approach appeared to preference institutional positions over patient choice.[34]

64. In another paper by White et al,[35] the following three possible models of legal regulation were discussed:

    - permitting institutional objections without limit;
    - permitting institutional objections but imposing limits on them; and
    - not permitting institutional objections.

65. The authors considered that a model permitting institutional objections without limit would have adverse outcomes for some individuals, who may be deprived from accessing voluntary assisted dying if they were unable to transfer to another facility. They considered the second model worthy of consideration but considered that such a model should be subject to regulation rather than left to policymakers.

66. **The ALA is of the view that not permitting institutional objections is the most appropriate way to ensure access for the small cohort of patients seeking voluntary assisted dying at the end stages of their life.**

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[32] Ben P. White, et al, 'The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions' (2023) 24(1) *BMC Medical Ethics* 22, 24.
[33] Ibid.
[34] Ibid.
[35] Ben White, et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' [2021] 3 *University of New South Wales Law Journal Forum* 1, 13.

67. If institutional objections are permitted to some extent, the ALA considers that regulations should be introduced which promote transparency of objections and impose positive obligations on those health services or institutions to connect and facilitate transfers to other health services or institutions that do not hold such objections to ensure patients are not prevented from accessing lawful end-of-life options.

Death certification and notification

This section answers the following question from the Discussion Paper:

28) What should be recorded as the cause and manner of death for a person who has died by accessing voluntary assisted dying?

68. **The ALA contends that the ACT should require that a person who dies through their participation in the ACT's voluntary assisted dying scheme is taken to have died from the disease, illness or medical condition from which the person suffered and which made them eligible for accessing voluntary assisted dying**.

69. Legislation should require that this is reflected on that person's death certificate.

70. This also acknowledges that voluntary assisted dying is not suicide, as is explicitly noted in voluntary assisted dying legislation in other jurisdictions in Australia.[36]

71. The ALA supports the inclusion of such a provision in the legislation underpinning the ACT's voluntary assisted dying scheme itself, as it will ensure that access to a person's death insurance is not impacted.

[36] See, egs, *Voluntary Assisted Dying Act 2019* (WA) s 12; *Voluntary Assisted Dying Act 2021* (Qld) s 8; *Voluntary Assisted Dying Act 2021* (SA) s 6.

Oversight, reporting and compliance

This section answers the following questions from the Discussion Paper:

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?

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?

72. The ALA regards oversight, review and compliance as essential components of any safe and accessible voluntary assisted dying scheme.

Establishing an ACT Voluntary Assisted Dying Review Board

73. Oversight over and reviewing voluntary assisted dying legislation have been identified as "critical" in order to ensure schemes are improved, where needed.[37]

74. **The ALA contends that ongoing oversight and review of the ACT's voluntary assisted dying scheme is crucial for ensuring ongoing safety and accessibility**.

75. The ALA refers the ACT Government to all six state jurisdictions, which have established statutory bodies for these purposes. While some functions differ between jurisdictions, all six statutory bodies:

    - monitor the operation of their respective pieces of voluntary assisted dying legislation;
    - refer any identified issues to government or other relevant public entities for legislative amendment, investigation or further action; and
    - review and report on the functions, powers and implementation of the voluntary assisted dying scheme in their jurisdiction.

[37] Ben White, et al (2022) 'Who is eligible for voluntary assisted dying? Nine medical conditions assessed against five legal frameworks' 45(1) *University of New South Wales Law Journal* 401, 444.

76. **The ALA recommends that the ACT Government establishes the ACT Voluntary Assisted Dying Review Board as an independent, statutory body to oversee, monitor, review and report on the operation of voluntary assisted dying in the ACT.**

Other issues

This section answers the following questions from the Discussion Paper:

34) What other laws might need to change in the ACT to enable effective access to voluntary assisted dying?

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?

36) Are there any other matters you think should be considered in implementing voluntary assisted dying in the ACT?

77. In this section, the ALA will share further reflections on the implementation of voluntary assisted dying schemes in the state jurisdictions, namely Victoria, Western Australia and Tasmania.

78. Deeper reflections on the more recently-accessible schemes in Queensland and South Australia, as well as the yet-to-be-accessible NSW scheme, will emerge in time but will likely share many or even all of the issues and areas for improvement identified regarding the other states' voluntary assisted dying schemes.

Reform needed to allow for Telehealth consultations

79. **The ALA is of the view that for an effective voluntary assisted dying scheme to be implemented in the ACT, the *Criminal Code Act 1995* (Cth) – which contains The Criminal Code ('the Code') – requires amendment**.

80. The impact of the Code's carriage service provisions on the operation of voluntary assisted dying schemes in state jurisdictions (especially access for individuals who

are housebound and/or those who live in rural, regional or remote areas) and the urgent need for legislative change have been publicly and widely identified.[38]

81. Currently, health professionals and others who are involved in providing voluntary assisted dying services and who communicate with patients through a ‘carriage service’ risk contravening provisions of the Code, which prohibit the use of ‘carriage services’ for ‘suicide related material’.[39] Broadly speaking, the Code sets out a range of offences for the following situations:

    - Counselling or incitement of suicide or attempts at suicide.
    - Using carriage services to access, transmit or cause to be transmitted, make available or publish or otherwise distribute suicide related material.
    - Promotion of methods of suicide or providing instruction on a particular method of suicide.

82. The ALA is not aware of any prosecutions for offences under sections 474.29A and 474.29B of the Code. “Suicide” is not defined in the Code, and it has been a source of debate among authors as to whether voluntary assisted dying would meet the legal definition of “suicide”.[40] However, if voluntary assisted dying falls within the meaning of “suicide”, there needs to be careful consideration as to how the ACT’s voluntary assisted dying scheme could interact with the Code offences.

83. In their article, ‘Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth ‘Carriage Service’ Offences’, Del Villar et al interpreted the provisions of the Code against the voluntary assisted dying

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[38] See, egs: Voluntary Assisted Dying Review Board, Safer Care Victoria, *Report of operations: July 2021 to June 2022* (Report, June 2022) 2 <https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-2021-to-june-2022>; Comments from Queensland Attorney-General Shannon Fentiman about the impact of Commonwealth laws on the Queensland scheme, see: Sean Parnell, ‘Labor would review laws that clash with assisted-dying schemes’, *Brisbane Times* (online, 25 April 2022) <https://www.brisbanetimes.com.au/national/queensland/labor-would-review-laws-that-clash-with-assisted-dying-schemes-20220425-p5afut.html>.

[39] *Criminal Code Act 1995* (Cth) ss 474.29A–474.29B.

[40] See: Katrine Del Villar, et al, ‘Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth ‘Carriage Service’ Offences’ (2021) 47(1) *Monash University Law Review* 125; Cf: Cameron Stewart, et al, ‘Suicide-Related Materials and Voluntary Assisted Dying’ (2020) 27 *Journal of Law and Medicine* 839.

schemes in Victoria and Western Australia.[41] The authors noted that the interpretation of the Code was not settled and as such, its interaction with the schemes in Victoria and Western Australia were unclear.[42] If the meaning of "suicide" captured the use of self-administered medication authorised under a State scheme, they were of the view that the likelihood of breaching the Code provisions depended on whether the communication involved the patient directly, the level of specificity of the information provided and whether the communication occurred towards the beginning or end of the voluntary assisted dying process.[43] They concluded that providing information about specific methods of voluntary assisted dying may constitute an offence, and providing the detailed information required when prescribing or dispensing a voluntary assisted dying substance was highly likely to contravene the Code if performed electronically.[44] They considered the risk to practitioners to increase towards the end of the voluntary assisted dying process because the level of detail concerning the method of voluntary assisted dying would likewise increase.[45]

84. The Victorian Government's response to the above inconsistencies between their voluntary assisted dying scheme and the Code was to issue a Guidance requiring all discussions, consultations and assessments concerning voluntary assisted dying to occur in person rather than by telephone, email, or telehealth.[46]

85. Health professionals and Victoria's Voluntary Assisted Dying Review Board alike have continuously identified the barriers this poses to the operation of Victoria's voluntary assisted dying scheme since mid-2019.[47] **The ALA notes that these**

[41] Katrine Del Villar, et al, 'Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth 'Carriage Service' Offences" (2021) 47(1) *Monash University Law Review* 125.
[42] Ibid 166.
[43] Ibid 167.
[44] Ibid.
[45] Ibid 168.
[46] Department of Health and Human Services, Victorian Government, *Voluntary Assisted Dying: Guidance for Health Practitioners* (Policy Document, July 2019) 4, 74.
[47] See, egs: Every report from Victoria's Voluntary Assisted Dying Review Board since 2019 has identified the concerns of practitioners and the Voluntary Assisted Dying Review Board and the need for reform of the Commonwealth's Criminal Code: <www.safercare.vic.gov.au>.

concerns were raised before the COVID-19 pandemic and, as such, these issues will continue after the pandemic until federal legislative reform is enacted.

86. The Western Australia voluntary assisted dying scheme specifically allows the use of audio-visual communication for a patient's verbal requests for voluntary assisted dying and the final administration decision if an in-person assessment is not practicable.[48] However, the Western Australian Voluntary Assisted Dying Guidelines caution practitioners about the provision of information via a carriage service and state that "as a general rule, any information that relates specifically to the act of administering a voluntary assisted dying substance or provides details or instructions about the act of administering a voluntary assisted dying substance must not be discussed or shared by phone, fax, email, videoconference, internet and the like".[49] They go on to state that some discussions must occur in person and some information must be provided in hard copy.[50]

87. Western Australia's Voluntary Assisted Dying Board has affirmed that the Code's provisions regarding the use of a carriage service has placed limitations on voluntary assisted dying consultations.[51] Western Australia's Voluntary Assisted Dying Board has recommended that the Code be amended.[52]

88. If voluntary assisted dying falls within the definition of "suicide", the provisions of the Code are likely to prevent some conversations and assessments and the distribution of material relating to self-administration occurring via Telehealth. This will undoubtedly further restrict access to voluntary assisted dying due to patient's being unable to travel for in person assessments due to geographical limitations, poor health, and socioeconomic reasons.

89. Similarly, given the low numbers of medical and health practitioners participating in existing state voluntary assisted dying schemes, there are likely to be time

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[48] *Voluntary Assisted Dying Act* (WA) ss 18(2)(c), 47(2)(b), 56(3)(b), 158(2).

[49] Department of Health, Government of Western Australia, *Western Australian Voluntary Assisted Dying Guidelines* (Policy Document, 2022) 26.

[50] Ibid.

[51] Voluntary Assisted Dying Board Western Australia, *Annual Report 2021–22* (16 November 2022) 3.

[52] Ibid.

constraints and financial constraints on practitioners travelling to see patients in person when those patients are unable to travel.

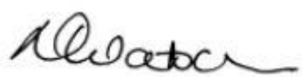
90. **The ALA considers the potential inconsistencies between the state or territory voluntary assisted dying schemes and the Code to be undesirable**. It puts health professionals and other persons who are involved in the voluntary assisted dying schemes at risk of prosecution and has had significant impacts on the accessibility and efficiency of voluntary assisted dying schemes in Victoria and Western Australia.

91. The ALA considers that Commonwealth Government action is required and that the Code should be amended so that "suicide" does not include voluntary assisted dying carried out lawfully pursuant to a state or territory law. **The ALA invites the ACT Government to urge the Commonwealth Government to amend the Code to allow Telehealth consultations for voluntary assisted dying, for at least one of the two consultations a person is required to undertake with a medical professional in order to access voluntary assisted dying**.

Conclusion

92. The Australian Lawyers Alliance (ALA) welcomes the opportunity to have input into the ACT Government's consultation on voluntary assisted dying.

93. The ALA is available to provide further assistance to the ACT Government on the issues raised in this submission.



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