Submission No 76

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Human Rights Law Alliance

Date Received: 22 November 2021

HRLA
HUMAN RIGHTS • LAW ALLIANCE

Our ref: 20-0020

SUBMISSION
STANDING COMMITTEE ON LAW AND JUSTICE

DATE: 22 November 2021

TO: Standing Committee on Law and Justice
Upper House Committees, Legislative Council
Parliament House
Macquarie Street
Sydney NSW 2000
By email: law@parliament.nsw.gov.au

FROM: Human Rights Law Alliance Limited

RE: **VOLUNTARY ASSISTED DYING BILL 2021 (NSW)**

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1. This is the submission of Human Rights Law Alliance (**HRLA**) to the Standing Committee on Law and Justice on the *Voluntary Assisted Dying Bill 2021 (NSW)*.

2. We would welcome an opportunity to speak in support of this submission.

ABOUT HRLA

3. HRLA is a not-for-profit law practice based in Canberra, ACT that specialises in matters involving freedom of religion, thought, speech and conscience.

4. HRLA's objectives are to see strong protection of religious freedom and expression in Australia. A core part of HRLA's work is to defend and protect Australians who face legal action aimed at silencing their freedom of speech and expression, and to be a voice advocating for good laws which preserve and protect fundamental freedoms, religious liberty, and viewpoint diversity in Australia.

EXECUTIVE SUMMARY

5. HRLA strongly opposes the *Voluntary Assisted Dying Bill 2021 (NSW)*. The Bill is unethical and harmful to individuals, especially vulnerable people, and society. It should be rejected in its entirety.

6. The Bill is fundamentally flawed and would require significant amendment to provide adequate protections and safeguards to ensure that it is less flawed. In particular, the Bill fails in the following ways:

    6.1 **It fails to recognise that every human life has value**, that every member of society is necessary, valued and equal;

6.2 **It fails to provide a right to palliative care**, to good quality end-of-life care that allows a person to die naturally, instead providing a right to intentionally bring about a person's own death;

6.3 **It fails to adequately provide for a person to exercise a conscientious objection**, and does not provide this right to all those who may have a role in the voluntary assisted dying process;

6.4 **It fails to allow residential facilities and health care establishments to deliver care to patients in ways that accord with their mission and values**, instead requiring them to participate in the voluntary assisted dying process contrary to their ideals;

6.5 **It fails to provide a robust process for making voluntary assisted dying decisions**. It does not ensure that a decision to seek assisted dying will always be made freely and without subtle coercion. It fails to protect against a right to die becoming a duty to die and against elder abuse;

6.6 **It fails to provide a mandatory cooling-off period** before a person may self-administer, or be administered with, a prescribed substance to end their life. This is inconsistent with laws in Victoria and Western Australia, in several states in the USA and in Canada; and

6.7 **It fails to require a person's mental competence to be assessed at the time of death**, that is, at the time a person self-administers, or is administered with, a prescribed substance to end their life. This is inconsistent with laws in Victoria and Canada.

7. The Bill is extremely poorly drafted and provisions of a similar nature that it would make sense to group together are scattered among Parts. This makes the law difficult to follow, increasing the chances of non-compliance. This is unacceptable.

8. We set out below our submissions and recommendations for addressing these flaws.

SUBMISSION

Dignity of the human person

9. The Bill fails to recognise that every human life has value, that every member of society is necessary, valued and equal.

10. HRLA strongly supports high-quality palliative care (see our second submission below), respect for patient autonomy, preservation of personal dignity and a peaceful end to life. Nobody is morally compelled to suffer unbearable pain, nobody should feel like a burden, and nobody should feel that their life is worthless.

11. People need assistance, not to end their lives but **at the end of their lives**, in ways that fully recognise their autonomy and dignity.

Recommendation

It is recommended that the Bill be amended to require a "care-first" approach that allows people at their end of their life to end their life with all the skill and compassion of palliative medicine and palliative care providers.

Right to palliative care

12. The Bill fails to provide a right to palliative care, to good quality end-of-life care that allows a person to die naturally, instead providing a right to intentionally bring about a person's own death.

13. In 2017, 70% of Australia's palliative medicine specialists wrote an open letter to Victorian and NSW MPs saying that euthanasia advocates "actively and deliberately undermine" public confidence in palliative care.[i]

14. Australian palliative care services are ranked second-best in the world. The United Kingdom ranks first, and they rejected euthanasia and assisted suicide legislation in 2006.[ii]

15. Recent Australian data indicates that no more than 2 in every 100 palliative care patients would be in moderate or severe pain at the end of life. In these unusual cases where all other methods of palliation for pain and other symptoms is inadequate, with the patient's agreement, palliative sedation therapy is available to provide adequate relief of suffering.[iii]

16. In view of this, a person should be ineligible for access to voluntary assisted dying if the person has not first been informed of and tried palliative care, or other medical treatments intended to relieve pain and distress.

Recommendation

17. It is recommended that the Bill be amended to provide a person with a right to palliative care.

18. It is also recommended that the Bill be amended so that a person is ineligible for access to voluntary assisted dying if the person has not first been informed of, and tried, palliative care, or other medical treatments intended to relieve pain and distress.

Right to exercise a conscientious objection

19. The Bill fails to adequately provide for a person to exercise a conscientious objection and does not provide this right to all those who may have a role in the voluntary assisted dying process.

20. Clause 9 provides a limited right to allow a registered health practitioner to refuse to do various things related to the voluntary assisted dying process. Significantly, it does not give a registered health practitioner the right to refuse to provide information to a person about voluntary assisted dying, to refuse to participate in an administration decision, or to refuse to prepare or dispose of a voluntary assisted dying substance.

21. Similar rights are not provided to others who may have a role in the voluntary assisted dying process, such as interpreters or employees. These persons should have the same right to exercise a conscientious objection as a registered health practitioner.

22. Any person with a conscientious objection to voluntary assisted dying, whether a registered health practitioner or otherwise, should not be required to assist another person in relation to the voluntary assisted process at all. Further, it should be unlawful for a person who exercises their conscientious objection to face any discriminatory or adverse actions for doing so.

Recommendation

23. It is recommended that clause 9 of the Bill be amended to expand the things a registered health practitioner may rightly refuse to do, specifically:
    23.1 the right to refuse to provide information to a person about voluntary assisted dying, and
    23.2 the right to refuse to participate in an administration decision, and
    23.3 the right to refuse to prepare or dispose of a voluntary assisted dying substance.

24. It is also recommended that the Bill be amended to allow any person who has a conscientious objection to refuse to take part in any step in the voluntary assisted dying process. It should also be amended to ensure that it is unlawful for any discriminatory or adverse action to be taken against a person who exercises a conscientious objection.

Protection for faith-based residential facilities, health entities and health care establishments

25. The Bill fails to allow faith-based residential facilities, health entities and health care establishments (***faith-based bodies***) to deliver care to patients in ways that accord with their mission and values, instead requiring them to participate in the voluntary assisted dying process contrary to their ideals.

26. Clause 89 allows a residential facility or health care establishment to decide not to provide services relating to voluntary assisted dying at the facility or establishment. However, Divisions 2 and 3 of Part 5 require these facilities and establishments:

    26.1 to allow reasonable access to persons involved in the voluntary assisted dying process, and

    26.2 to require residents to be transferred for such purposes.

27. Faith-based bodies should not be compelled to act, actively or passively, to facilitate any step of the voluntary assisted dying process. Nor should faith-based bodies be required to have a voluntary assisted dying substance on their premises.

28. If a resident of a faith-based body wishes to access or carry out a step in the voluntary assisted dying process, the resident can arrange to do so elsewhere.

Recommendation

29. It is recommended that the Bill be amended so that faith-based bodies and their employees are not required to act, actively or passively, to facilitate any step of the voluntary assisted dying process, including allowing reasonable access to anyone involved in the voluntary assisted dying process or requiring residents to be transferred for such purposes.

30. It is also recommended that the Bill include a new offence for anyone who brings a voluntary assisted dying substance onto the premises of a faith-based body, whether the substance is for use, or used, on the premises or not.

Process for making assisted dying decisions

31. The Bill fails to provide a robust process for making voluntary assisted dying decisions. It does not ensure that a decision to seek assisted dying will always be made freely and without subtle coercion. It fails to protect against a right to die becoming a duty to die and elder abuse.

32. The Bill does not contain adequate safeguards to ensure that all practitioner decisions are made exercising independent professional judgement and are subject to judicial oversight, and that patient decisions are made freely, voluntarily and after due consideration.

33. At the practitioner level, there is a need to ensure:

    33.1 a doctor/patient relationship between the coordinating practitioner and the patient seeking access to assisted dying (unless the practitioner has a conscientious objection), and

    33.2 a coordinating practitioner, consulting practitioner or person to whom a matter is referred under clause 26 or 37 to have specialist expertise in a disease, illness or medical condition for which the patient has been diagnosed, and

    33.3 greater independence between all involved in the voluntary dying process, including a coordinating practitioner, consulting practitioner, a person to whom a matter is referred under clause 26, 27, 37 or 38, and an interpreter, and

33.4 all decisions made relating to the eligibility criteria are reviewable by the Supreme Court, including on referral.

34. At the patient level, there is need to ensure:

    34.1 that patients are acting freely, voluntarily and without coercion, and not merely to be relieved of "substandard care and abuse [that] pervades the Australian aged care system[iv]" or of pressure from family members who might otherwise get an inheritance sooner, and

    34.2 face to face communications between practitioners and patients and, if an interpreter is required, between interpreters and patients, so that patients are fully and adequately informed about the process, their rights and the significance of their decisions, and

    34.3 that patients are mentally competent immediately before the time of their death (see our final submission below), and

    34.4 that patient decisions are made and recorded in clear and unambiguous ways.

Recommendation

35. It is recommended that the Bill be amended to address each of the matters identified in paragraphs 33 and 34 above.

Mandatory cooling-off period

36. The Bill fails to provide a mandatory cooling-off period before a person may self-administer, or be administered with, a prescribed substance to end their life.

37. By contrast, assisted dying laws elsewhere provide for a cooling-off period:

    37.1 20 days in Hawaii, USA;

    37.2 17 days in Maine, New Jersey and Washington, USA;

    37.3 15 days in California, Colorado and District of Columbia, USA;

    37.4 15 days (with limited exceptions) in Oregon, USA;

    37.5 10 days in Canada;

    37.6 9 days in Victoria and Western Australia.

38. A mandatory cooling-off period prevents a hasty or emotional decision, or a reactive (subconscious) decision, such as one made when a person is in shock after receiving a terminal diagnosis. Given the irreversible nature of the decision, it is responsible to require a cooling-off period to ensure that the person is 100% sure about their decision. Even decisions of far less import, such as taking out insurance, allow a cooling-off period.

Recommendation

39. It is recommended that the Bill be amended to include a 14 day cooling-off period before a person may self-administer, or be administered with, a prescribed substance to end their life.

Mental competence at the time of death

40. The Bill fails to require a person's mental competence to be assessed at the time of death, that is, at the time a person self-administers, or is administered with, a prescribed substance to end their life. This is inconsistent with the law in Canada.

41. A person seeking voluntary assisted dying should have the capacity to make health decisions for him or herself and to be able to give informed consent at the following times:

    41.1 at the time of making a first request or final request, and

    41.2 immediately before self-administering, or being given, a prescribed substance.

42. This recognises that a person's cognitive impairment may change over time; having mental capacity at the time of making a first request does not guarantee mental capacity at the time of death. To safeguard against this, the Bill should ensure requisite mental capacity at the time of death.

Recommendation

43. It is recommended that the Bill be amended to require a person's mental competence to be assessed at the time of death, that is, at the time a person self-administers, or is administered with, a prescribed substance to end their life.

CONCLUSION

44. HRLA thanks the Committee for the opportunity to make this submission.

45. HRLA commends to the Committee the proposed recommendations for amendments to the Bill outlined in this submission. HRLA is happy to appear before the Committee to speak on, and answer any questions about, the submission.

Yours faithfully,

John Steenhof
Principal Lawyer
Human Rights Law Alliance

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[i] See https://www.noeuthanasia.org.au/letter_members_parliament_australian_palliative_professionals

[ii] "How We Die: A View From Palliative Care" by Michael Ashby in QUT Law Review, Volume 16, Issue 1, pp 5-21.

[iii] See note i above.

[iv] Summary of the Final Report of the Royal Commission into Aged Care Quality and Safety, p 68.