

**Submission
No 23**

**INQUIRY INTO PROVISIONS OF THE VOLUNTARY
ASSISTED DYING BILL 2021**

Organisation: NSW Council for Civil Liberties

Date Received: 18 November 2021



NSW Council for Civil Liberties Inc.
PO Box A1386, Sydney South,
NSW 1235, Australia

e: office@nswccl.org.au
t: 02 8090 2952
www.nswccl.org.au

@nswccl
@nswccl

NSW Council for Civil Liberties Submission

NSW Legislative Council Standing Committee on Law and Justice

Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021

18 November 2021

NSWCCCL

About NSW Council for Civil Liberties

NSWCCL is one of Australia's leading human rights and civil liberties organisations, founded in 1963. We are a non-political, non-religious and non-sectarian organisation that champions the rights of all to express their views and beliefs without suppression. We also listen to individual complaints and, through volunteer efforts, attempt to help members of the public with civil liberties problems. We prepare submissions to government, conduct court cases defending infringements of civil liberties, engage regularly in public debates, produce publications, and conduct many other activities.

NSWCCL is a Non-Government Organisation in Special Consultative Status with the Economic and Social Council of the United Nations, by resolution 2006/221 (21 July 2006).

Contact NSW Council for Civil Liberties

<http://www.nswccl.org.au>

office@nswccl.org.au

Correspondence to: PO Box A1386, Sydney South, NSW 1235

Phone: 02 8090 2952

Fax: 02 8580 4633

The New South Wales Council for Civil Liberties (NSWCCL) welcomes the opportunity to make a submission to the Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021.

NSWCCL's position on the Voluntary Assisted Dying Bill 2021

- 1 NSWCCCL strongly supports the Voluntary Assisted Dying Bill 2021 (Bill). The Bill has very strong public support in New South Wales and its passage into law is long overdue.
- 2 Death is inevitable, but it need not be cruel. The Bill will allow NSW adult patients, with terminal illnesses who are near death and suffering intolerably, the informed and voluntary choice to die painlessly and with dignity.
- 3 The Bill incorporates strong safeguards to ensure that patients are making a truly voluntary and considered choice, and that they are fully informed of the treatments available to them.
- 4 The Bill recognises that terminally ill patients have the right to live with dignity and respect, and to be provided with high quality palliative care. But for some patients, even the best end of life care available cannot prevent intolerable suffering. The Bill will allow these patients to end their suffering on their own terms.
- 5 Having the choice to access voluntary assisted dying will also give comfort to patients who are receiving palliative care and wish to continue doing so. They can receive treatment and care without having to live with the fear that they will have no options available to them to prevent further suffering if their treatments become less effective at alleviating their pain and suffering over time.
- 6 Whilst there is strong public support for the Bill, NSWCCCL recognises that some in the community have deeply held convictions against voluntary assisted dying. The Bill adequately and appropriately respects those convictions and espouses the principle that all persons, including health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.
- 7 Below, we set out an outline of the Bill and its safeguards, note the strong public support for the Bill, and describe the Australian precedents for the Bill. We also set out our responses to some of the common concerns raised about voluntary assisted dying.

Outline of the Bill and its Safeguards

- 8 The Bill provides for a person (referred to in this section as the patient) to access voluntary assisted dying (VAD), provided they satisfy its clearly prescribed eligibility criteria.
- 9 In order to become eligible a patient must undertake a rigorous process of assessment which involves several stages:
 - (a) a first request by the patient;
 - (b) two rounds of assessment to determine whether a patient is eligible to access VAD, each by a qualified and trained medical practitioner, with the assistance of specialists where required. As described below, in each round of assessment, the practitioner must be satisfied that the patient's condition meets eligibility criteria set out in the Bill and that the patient is acting voluntarily;
 - (c) a written declaration by the patient;
 - (d) a final request made by the patient more than five days after their first request; and
 - (e) after the final request, a patient choosing to have a medical practitioner administer a substance, or to administer it themselves, causing death.
- 10 The assessment process is structured so that only patients with terminal illnesses causing intolerable suffering, who have made a free and fully-informed choice, may access VAD. Patients must be given access to information about alternatives, including the range of palliative care options available to them.

Eligibility criteria

- 11 The eligibility criteria to access VAD are strict, and ensure that a patient makes a free and voluntary choice.
- 12 A patient must be an adult and have a terminal illness that will, on the balance of probabilities, cause death within 6 months (or 12 months for neurodegenerative conditions). The illness must be causing suffering to the patient that cannot be relieved in a way they consider tolerable.
- 13 Accessing VAD is a choice for the patient, and the patient alone. For a patient to be eligible, each medical practitioner making their assessment must be satisfied that the patient:
 - (a) has decision-making capacity;
 - (b) is acting voluntarily; and
 - (c) is not acting because of pressure or duress.
- 14 Where either of the medical practitioners assessing the patient cannot decide that the patient has capacity, is acting voluntarily, and/or is not acting because of pressure or duress, they must refer the patient to a psychiatrist or another registered practitioner with appropriate skills and training.

Access to information

- 15 Not only must a patient's choice to access VAD be voluntary, it must be well-informed. The Bill is structured to achieve that aim, and requires a detailed suite of information to be provided to a patient before they can access VAD.¹
- 16 Among other matters, a patient must be given the following information each time the practitioner is satisfied during the assessment process that a patient is eligible to access VAD:
 - (a) the patient's diagnosis and prognosis;
 - (b) the palliative care and treatment options available to the patient and the likely outcomes;
 - (c) a description of the steps involved in the VAD process;
 - (d) that where a patient is receiving ongoing health services from a medical practitioner other than the assessing practitioner, it is unlawful for that medical practitioner to withdraw their services because of the patient's request for VAD; and
 - (e) crucially, that the patient may decide, at any time during the assessment or implementation process, not to continue the assessment process or to access VAD.

Safeguards

- 17 The Bill contains safeguards to protect the rights of patients, to ensure the integrity of the VAD system, and to empower the free exercise of conscience by practitioners opposed to VAD.
- 18 In addition to the rigorous assessment process outlined above, NSWCCCL considers that the Bill contains strong and sensible safeguards to ensure that a patient's decision to access VAD is a voluntary and informed choice:
 - (a) A patient may discontinue the assessment process or decide not to access VAD at any time before death.
 - (b) The Bill ensures that patients are not dissuaded from accessing the quality end of life care that they have a right to receive. If a patient has not raised VAD, then a health care worker cannot initiate a discussion with the patient that is in substance about VAD, or in substance suggest VAD, unless they also describe the palliative care and treatment options that are available to the patient.
 - (c) All medical practitioners and interpreters involved in a patient accessing VAD, and a witness to a patient's written declaration, must not:

¹ See Bill s 28 for the full list of information.

- (i) be a family member of the patient;
- (ii) know or believe they are a beneficiary under a will of the patient; or
- (iii) know or believe that they will otherwise benefit financially or in any other material way from the death of the patient (other than, in the case of medical practitioners, by receiving reasonable fees for their services).

19 Those safeguards are bolstered by strict oversight of the VAD process:

- (a) The Bill provides for judicial review to the NSW Supreme Court for decisions made throughout the VAD process.
- (b) The Bill provides for the creation of the Voluntary Assisted Dying Board, which will monitor the Bill's operation if enacted.
- (c) The Minister must review the operation and effectiveness of the Bill, and prepare a report within two years after it comes into effect, with further reports at least every five years thereafter.

20 The provisions of the Bill (if enacted) will come into effect 18 months after assent, which will allow time for its regulatory framework and implementation procedures to be established.

21 The Bill also safeguards the free exercise of religion, and ensures that health practitioners are not disadvantaged for following their conscience. A registered health practitioner may refuse to participate in the VAD assessment process, to provide or administer a substance to be used for VAD, or to be present when VAD occurs. The Bill similarly allows residential facilities, private health facilities and public hospitals to opt-out of VAD. In our view, these safeguards achieve the right balance between the rights of patients seeking to avail themselves of VAD and those of health practitioners who may hold principled objections.

Public support for VAD

22 There is very strong and sustained public support in Australia, and New South Wales specifically, for access to VAD.

23 In April 2021, the Australia Institute surveyed a representative sample of approximately 1,400 Australians about their attitudes to VAD.² From the results of that survey, 76% of Australians agree with the principle that a person experiencing unrelievable suffering who asks to die should be allowed to receive the assistance of a doctor to do so. 12% of Australians disagree, whilst 12% do not know or are unsure.

24 Those results are consistent with public opinion in New South Wales. In December 2020, approximately 1,000 NSW residents were surveyed by the Australia Institute on the same question, with 72% in favour, 13% opposed and 15% replying "do not know / not sure".³ That level of support is largely stable amongst voters for each party – by voting intention, 74% of Coalition voters, 71% Labor, 77% Greens, 70% One Nation and 64% 'other' were in favour of VAD being legal.

25 This polling should be considered in a context where the public has been exposed to significant public debate about this policy issue for decades. Such debate has been informed by political, legal and medical commentators. Ian Cohen MLC first introduced a motion to introduce voluntary euthanasia on 27 February 2001 which was defeated. In 2013 Cate Faerhmann MLC introduced the Rights of the Terminally Ill Bill, which was defeated by ten votes in the Legislative Council. Most recently, Trevor Khan MLC introduced a bill to similar effect to the present one in 2017 which was defeated in the Legislative Council by one vote. There was much public discussion and debate about the issues at those times. Thus the views of the public should be considered well informed.

Comparison with Legislation in Australia

26 New South Wales is the only state in Australia that has not yet passed legislation to access VAD.

² The study is available at <https://australiainstitute.org.au/report/polling-voluntary-assisted-dying-and-the-territories/>.

³ See <https://australiainstitute.org.au/report/3-in-4-nsw-voters-back-victorian-style-euthanasia-laws-including-76-of-coalition-voters/>.

- 27 There is now precedent for New South Wales to follow. VAD has been in effect in Victoria for over two years, and in Western Australia since July 2021. Tasmania's legislation will commence in late 2022 and Queensland and South Australia in early 2023.

The Bill is substantially similar to the legislation in other states

- 28 The Bill as proposed contains substantially similar eligibility requirements to the legislation in other states, notably that in Western Australia:
- (a) all states, consistent with the New South Wales Bill, provide for access to VAD only for terminally ill adult resident patients with decision-making capacity, who will die within six months, or 12 months for neurodegenerative conditions.
 - (b) all states require a patient's decision to be voluntary and 'without coercion'. The New South Wales Bill requires that a patient act voluntarily but goes further than legislation in other states and adopts a broader expression than coercion, requiring that a patient is '*not acting because of pressure or duress*' which the Bill defines as including '*abuse, coercion, intimidation, threats and undue influence*'.
- 29 All states rely on a similar assessment process involving two medical practitioners, as provided for in the Bill.

The Bill adopts and refines other state models

- 30 The New South Wales Bill is modelled on Western Australia's legislation which, whilst very similar to the Victorian legislation (and the legislation in all other states), has practical advantages:
- (a) **Discussions about VAD:** under the Victorian legislation, practitioners are prohibited from referring to VAD unless a patient broaches the topic. The Western Australian legislation and the New South Wales Bill allow a practitioner to raise the subject of VAD, but only if they also provide information about treatment and palliative care options. The approach adopted in the Bill is preferable – it recognises that discussions about death are natural and complex, but protects against a patient being steered towards choosing it over other treatment and care to which they are entitled and may otherwise prefer.
 - (b) **Conscientious objection and provision of information:** the Victorian legislation allows a practitioner who conscientiously objects to refuse to provide any information about VAD. The Western Australian legislation and the Bill require a practitioner to inform a patient of their refusal, and provide a standardised set of approved information (which in Western Australia describes the process of accessing VAD).⁴ This requirement strikes a better balance between conscientious objection by the practitioner and the rights of a patient to access VAD.
 - (c) **Permits:** the Victorian legislation requires permits to be issued by the government where a patient accesses VAD, whilst the WA legislation and New South Wales Bill do not. The Victorian legislation imposes an unnecessary administrative burden on patients, and the Western Australian approach reflected in the Bill is appropriate.
 - (d) **Choice to have a practitioner administer a VAD substance:** the Victorian legislation requires patients to self-administer their VAD substance, unless they do not have the physical capacity to do so. The Western Australian legislation requires self-administration unless a patient's practitioner is satisfied it is inappropriate. The New South Wales Bill gives patients the choice as to whether they will access VAD by self-administration or practitioner administration. This approach is preferable, and allows patients to access VAD in the manner most comfortable to them.
 - (e) **Administering professionals:** in Western Australia, nurse practitioners may administer VAD substances, whereas only doctors can do so in Victoria. The New South Wales Bill provides for administration by nurse practitioners, and nurses who have practised in the profession for at least

⁴ The Western Australian approved information can be accessed at <https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Approved-information-for-a-person-making-First-Request.pdf>.

five years. Allowing appropriately qualified nurses to administer a VAD substance will help ensure equitable access to VAD across all communities in New South Wales.

NSWCCL's Response to Common Arguments Against VAD

31 In this section, NSWCCL responds to some of the common arguments raised against VAD.

Access to palliative care

32 Opponents have suggested that greater resources should be devoted to palliative care, rather than enacting the Bill. NSWCCL rejects the argument. Effectively pitting VAD and palliative care as opposed paths to treating terminal illness misapprehends the intentions of the Bill. We believe that VAD does not diminish but supplements the care a patient is given. Necessarily, funding VAD should not be to the detriment of funding palliative care.

33 It should be kept in mind that to be eligible to access VAD under the Bill, a patient's illness must be terminal and must cause them suffering that cannot be relieved in a way they consider tolerable. The Bill proceeds on the footing that a patient is receiving treatment and care, but that their condition is *still* unbearable. Even the best palliative care in the world cannot prevent intolerable suffering for all patients.

34 A related argument raised against VAD is that it "pushes" patients towards death, rather than encouraging them to seek palliative care. On the contrary, and as outlined above, the Bill requires that patients who elect to commence the VAD assessment process are given information regarding the palliative care treatments available, and the rigorous assessment process ensures that VAD is only accessed by patients making a free and voluntary decision through a staged and controlled process.

35 VAD gives patients choice to determine for themselves that palliative care is no longer alleviating their pain and suffering. Simply knowing that the option of VAD is available can provide a patient with great comfort as they receive palliative care and cope with the approaching end to their life. It is a compassionate addition to the options available to patients suffering with terminal illnesses.

Respect for dignity

36 Well-meaning concerns over VAD have been founded upon a respect for the dignity of patients. It is that same dignity, however, that supporters of the Bill respect when allowing a person suffering intolerably from a terminal illness to choose when and how they die. We respect the dignity of the person when we respect their choices about their lives, not when we force our own view of their dignity upon them.

Religious objections

37 Some object to VAD because of their religious convictions.

38 It is not the place of government to enforce any particular religious outlook. Legislation should be passed democratically and respect the views of a diverse constituency. As we have referred to above, VAD benefits from broad and strong support among the voting public of New South Wales that their elected representatives should reflect.

39 However, NSWCCL recognises and supports the right of health practitioners to conscientiously object to participating in VAD on religious or other grounds. The Bill protects that right, and requires only that a standard set of information be provided to a patient who requests access, which is necessary to allow equitable access to VAD.

40 Further, the rights of a professional who voluntarily enters a care profession like medicine (and other allied fields) should never outweigh the rights of a patient to access reliable advice and information about healthcare options and to exercise free choice. To do so would undermine the countervailing right of access to healthcare and services.

Moral shift and the "slippery slope"

41 It has been argued that if the Bill is passed, there will be a moral shift; the protections the Bill contains will be legislated away, and as a society we will permit more people to die.

- 42 There is no historical precedent or evidence to support this notion in Australia. Moreover, the experience in New South Wales indicates there has been and will be no moral shift. Majority support for VAD has persisted in Australia for decades. The Bill represents the values that the overwhelming majority of voters in this state have consistently held.
- 43 The requirements for review of the legislation, if passed, and for any parliamentary amendment of the Act ensure that the VAD scheme will be sustained into the future in line with community expectations.

Conclusion

- 44 NSWCCCL strongly supports the passage of the Voluntary Assisted Dying Bill 2021. It follows the precedent seen in all other Australian states and contains strong safeguards. It balances the autonomy and dignity of the person with the right to free religious expression. And it will give terminally ill patients comfort as they receive treatment and care, confident in the knowledge that if their pain becomes unrelievable and too much for them to bear, they will not have to suffer.

We hope our submission is of assistance and would be pleased to assist further, if required.

Yours sincerely,

Michelle Falstein
Secretary
NSW Council for Civil Liberties