

**Submission
No 16**

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Council on the Ageing (COTA) NSW

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Submission: Provisions of Voluntary Assisted Dying Bill 2021

Council of the Ageing (COTA) NSW

COTA NSW is the peak body representing people over 50 in NSW. We're an independent, non-partisan, consumer-based, non-government organisation. We work with politicians, policy makers, service and product providers, as well as the media to ensure the views and voices of older people are heard and acted on.

Our work is to:

- inform
- educate
- engage
- advocate

We work with:

- the community
- service & product providers
- government
- the media

COTA NSW has launched some of the State's most important initiatives for older people, including NSW Meals on Wheels, Carers NSW, and the Retirement Village Residents Association.

Currently COTA NSW delivers a range of services to older people in NSW, including an Aged Care Navigation service, the Legal Pathways program and Strength for Life.

Acknowledgement of Country

COTA NSW acknowledges the unique status of Australia's First Peoples as the original people of this land. We recognise their cultures, histories and ongoing relationship and obligations to the land, sky and waterways.

In the spirit of reconciliation, COTA NSW acknowledges all traditional custodians of the lands we today know as New South Wales.

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Introduction

Council on the Ageing (COTA) NSW welcomes the opportunity to respond to the Terms of Reference of the *Provisions of the Voluntary Assisted Dying Bill 2021*.

COTA NSW supports this Bill and the legalisation of Voluntary Assisted Dying (VAD) in New South Wales. The question of voluntary assisted dying is fundamentally a question of autonomy and agency. Every person deserves the right to make informed choices about their end-of-life care.

This position is based upon the strong support for VAD that has been expressed by older people in New South Wales. The Council on the Ageing Federation (comprised of eight state and territory organisations) has twice commissioned SEC Newgate Australia to undertake research to explore the views, life experiences and needs of Australians aged 50+.

This online survey was conducted in 2018 and 2021 and was a nationally representative sample of 2,830 Australians aged 50 and over, with quotas set for state and territory, metropolitan and regional areas, gender, and age.

Questions on Voluntary Assisted Dying were asked in both years of the research and published in the State of the (Older) Nation report.¹ The results are provided in the table below. *Please note that the small decrease in overall support for VAD in the years 2018 to 2021 was due to the addition in the 2021 survey of the option to select 'neither support nor oppose'.*

| | State of the (Older) Nation 2018 Results | State of the (Older) Nation 2021 Results |
|--|--|--|
| “Assisted dying” is the practice whereby a person suffering from a terminal illness or incurable condition has the right to request a lethal drug from a doctor to end their life. Assuming there are sufficient protections and legislation in place, do you support or oppose this for your state/territory? | 84% | Net 76% |
| If you were in this situation, how likely do you think you would be to personally look into assisted dying as an option? | Net 54% | Net 55% |

When analysed by state, support in NSW was broadly consistent with the national result with 72% of people aged 50+ responding in the affirmative (2021).

¹ COTA Federation (2021). *State of the (Older) Nation, 2021*. Retrieved from: www.stateoftheoldernation.org.au

This strong support has been reinforced in research undertaken by other peak bodies that represent older Australians, including National Seniors Australia. Their report *'The Quality of Death? Senior Australians' Views on Voluntary Assisted Dying'* found that 86% of respondents supported the option of voluntary assisted dying for those with a terminal illness.²

In research conducted by COTA NSW in 2019, and published in the 2020 50+ report, *'Dignity, Respect, Choice: Planning for the final Chapter'* attitudes around death and dying were explored. The survey found, that approximately 3 out of 4 respondents believed that as a community we don't discuss death and dying enough. However, conflicting results arose when asked about personal confidence in discussing death, with half of participants felt comfortable in personally talking about death. Encouragingly, approximately 75% of respondents had discussed their end of life wishes with someone else – indicating an increased imperative amongst many older people to express their needs and desires in this stage of life. These results indicate that a large majority of older people asserted that the the taboo around death and dying needs to be challenged and this fundamental aspect to life normalised.³

It is our belief that older people in the last stages of a terminal or incurable illness have the right to make informed decisions on their end-of-life medical care, including the choice to receive medical assistance to end their life peacefully, at a time of their choosing.

Provisions of Bill

COTA NSW supports the provisions within the Bill in its current form. The Bill builds on previous work in other jurisdictions and contains robust safeguards to ensure that people seeking voluntary assisted dying are protected from any coercion or malpractice. The current Bill balances the rights and choices of the terminally ill person, with the necessary protections for healthcare workers and those institutions seeking exemptions.

Much of the discourse from those opposed to the bill has been highly emotive and unconstructive. Listed below are commonly raised arguments that have been prosecuted by opponents of this Bill and accompanying refutations.

- Older people will become the victims of coercion from unscrupulous relatives for financial gain.

As outlined the NSW Parliamentary Research Service Issues Backgrounder, the Bill contains robust safeguards to protect an adult wishing to participate in VAD. To be eligible for VAD, a person must be an adult, have a terminal illness, be suffering unbearably and facing

² Orthia L., Hosking D., Ee N., McCallum J. (2021) *The Quality of Death? Senior Australians' Views on Voluntary Assisted Dying*. National Seniors Australia. Retrieved from: <https://nationalseniors.com.au/research/voluntary-assisted-dying/the-quality-of-deathquestion-senior-australians-views-on-voluntary-assisted-dying>

³ COTA NSW (2020). *50+ Report: Dignity, Respect, Choice: Planning for the final Chapter*. Retrieved from: <https://www.cotansw.com.au/publication/50-report-dignity-respect-choice-planning-for-the-final-chapter/>

imminent death (within 6 months, or 12 months for a neurodegenerative disease). Advanced age, disability, or mental illness on their own do not qualify a person for VAD. The request for VAD can only be made by the person, who must have decision making capacity and be acting voluntarily. Multiple safeguards ensure no-one is coerced or pressured into a premature death. Two independent doctors must assess the person and agree all eligibility requirements have been met and that the person is mentally competent and free from coercion. All decisions are reviewed by an independent statutory body and strong penalties apply for noncompliance, including professional de-registration and jail.⁴

Furthermore, there has been no evidence that coercion has been employed by relatives of terminally ill people to end their lives in jurisdictions such as Victoria. In the first 6 months under the Victorian legislation, 52 terminally ill people ended their lives. Betty King, Chair of the Voluntary Assisted Dying Review Board stated that despite being alert to the possibility she had seen no pressure on individuals to end their lives.⁵ That assertion has been recently reiterated by Dr Charlie Corke, the current acting chair of the Victorian Voluntary Assisted Dying Review Board, who has stated that coercion had not emerged as an issue in Victoria.⁶

- That there will be an assumption made, that the older person will have the appropriate level of cognition to have decision making capacity.

The Bill defines several measures on which to determine decision making capacity before an application to access VAD may proceed. A key component of the Bill is that if the coordinating practitioner cannot determine if a person has sufficient cognition to be deemed as having satisfactory decision-making capacity, the practitioner must:

27 (2) The coordinating practitioner must refer the patient to— (a) if the coordinating practitioner is unable to decide whether the patient has decision-making capacity in relation to voluntary assisted dying—a psychiatrist or another registered health practitioner who has appropriate skills and training to make a decision about the matter.

During the final review of the process, the coordinating practitioner must sign:

52 (f) a statement certifying whether or not the coordinating practitioner is satisfied that— (i) the patient has decision-making capacity in relation to voluntary assisted dying.

⁴ NSW Parliamentary Research Service (2021). *Issues Backgrounder – Voluntary Assisted Dying Bill 2021 (NSW): a comparison with legislation in other States.*

⁵ Hendrie, D. (2020). *More than 50 Victorians have utilised new assisted dying laws.* RACGP, 19/02/2020.

⁶ Ward, M. & Carroll, L. (2021). *Assisted dying bill prompts calls for new focus on palliative care.* Sydney Morning Herald. Retrieved from: <https://www.smh.com.au/national/nsw/assisted-dying-bill-prompts-calls-for-new-focus-on-palliative-care-20211110-p597pr.html>

In the discussion around decision making capacity, it is important to be alert to the assumption that older people by definition are vulnerable and may be impacted by reduced cognition. All applications to utilise VAD and subsequent eligibility should be determined by each individual's unique circumstances, including their level of cognition and decision-making capacity and not be influenced by age-related biases and conjecture.

- That the provision of adequate and readily available palliative care support negates the need for Voluntary Assisted Dying legislation.

COTA NSW supports a well resourced and accessible palliative care system in New South Wales. A report commissioned by Palliative Care Australia in 2018, found palliative care sector had benefitted in overseas jurisdictions where assisted dying legislation had been passed. There was greater awareness of the importance of palliative care and the need to adequately fund and train health care services in those places.⁷

There have been many medical advances in providing support to those experiencing terminal illnesses. Unfortunately, there are exceptions where no medication will adequately address pain levels or suffering. Again, this legislation is about choice, when a person has exhausted treatment options, when their pain cannot be tolerably relieved – that they will have the authority and autonomy to make an informed choice about their end-of-life care.

- The Bill must include additional processes to provide adequate safeguards.

The Bill has been largely based on the Western Australian model and has been designed to provide robust safeguards whilst ensuring that dying people can reasonably follow a systematic and accessible process not limited by location or unrealistic requirements. COTA NSW is opposed to the inclusion of any amendments to the Bill that would result in the process becoming too difficult for dying people to access, such as requiring one of the doctors to be a specialist in the persons disease, such as a neurologist for MND. This would discriminate against those living in regional and remote NSW, where access to specialists is limited at best.

The provisions within the Bill have addressed the concerns of individual choice and beliefs of healthcare workers and other institutions and facilities, whilst ensuring that the dying person will not be disadvantaged by these exemptions. The Bill allows for any healthcare worker to conscientiously object to involvement in the provision of voluntary assisted dying services. This objection extends to faith-based institutions and facilities, such as Residential Aged Care Facilities (RACF) or hospitals. It is important to note that whilst a RACF may refuse to implement VAD processes they will not be able to prevent a resident from accessing VAD services within the facility. This is an important recognition that for many older people in

⁷ Apex Consulting (2018). *Experience internationally of the legalisation of assisted dying on the palliative care sector FINAL REPORT*. Palliative Care Australia. Retrieved from: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

the last stages of a terminal illness and living in a RACF, this is their home and should have the same human rights for personal autonomy and access to VAD if they so choose.

COTA NSW argues that the Bill must not be amended to include any further restrictions of medical practitioners to discuss the option of VAD with a terminally ill person within the broader context of palliative care and other treatment options. For a dying person to be able to provide informed consent and demonstrate effective decision-making capacity – it is critical that they have a full understanding of all the options that are available to them.

Conclusion

The *Voluntary Assisted Dying* Bill 2021 (NSW) provides a balanced process, that allows for individual choice for the terminally ill person, but also for those healthcare workers and institutions that may have conscientious objections. It also includes robust safeguards to protect against coercion for those accessing VAD services but also contains protections for healthcare practitioners involved in the VAD process.

This Bill has benefitted from other states experiences in formulating and enacting VAD legislation, including numerous inquiries and reports that have examined in detail all aspects of processes, safeguards and eligibility that enables an effective equitable process to access voluntary assisted dying.

New South Wales is the last state jurisdiction in Australia to enact Voluntary Assisted Dying laws. The introduction of VAD legislation is supported by a significant majority of people in NSW, including large numbers of people aged 50+. It is incumbent upon the NSW parliament to ensure that this support is finally translated into action by enacting the *Voluntary Assisted Dying* Bill 2021 (NSW).

Thank you for opportunity to provide comment.