

Voluntary Assisted Dying in the Northern Territory

Legislative Assembly of the Northern Territory

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Contact:

Dr Jennifer O'Connor

General Manager, Policy, Advocacy and Government Relations

policy@speechpathologyaustralia.org.au

About Speech Pathology Australia

Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 16,000 members. Speech pathologists are university trained allied health professionals with expertise in diagnosis, assessment, and treatment of communication and swallowing difficulties. The Association supports and regulates the ethical, clinical and professional standards of its members, as well as lobbying and advocating for access to services that benefit people with communication and swallowing difficulties.

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Key recommendations

Recommendations

1. Ensure wording in the VAD Bill supports communication accessibility of the scheme such that a variety of communication methods are supported and acknowledged throughout the VAD process
2. Include 'communicating with people with complex communication needs' as a mandatory topic within training for VAD practitioners
3. Ensure pathways for equitable access to speech pathology supports are built into the Scheme
4. Map the availability of speech pathology services with relevant expertise across the NT
5. Develop protocols and guidance for the integration of service delivery between the stand-alone VAD service practitioners and speech pathology services
6. Continue to advocate for the explicit removal of VAD from the Commonwealth Criminal Code Amendment Bill, to enable the use of telehealth services
7. Establish hardship provisions to ensure access to speech pathology for those seeking to access VAD
8. Enable a range of treating health professionals, including speech pathologists to initiate a discussion about VAD alongside provision of onward referral to a medical practitioner
9. Ensure the Bill explicitly recognises '*Certified Practising Speech Pathologists*' as having the same legal protections including immunity from criminal and civil liability and the right to conscientiously object to participation in the VAD process
10. Ensure the Bill recognises the importance of a swallowing assessment by an appropriately qualified health professional prior to the administration of the VAD substance, to determine the most suitable route of administration

Speech Pathology and Voluntary Assisted Dying

Speech Pathology Australia welcomes the opportunity to provide comment on the consultation on the recommendations arising from the *2024 Expert Panel Report: Report into Voluntary Assisted Dying in the Northern Territory*, following our previous submissions.

Speech pathologists play a pivotal role in ensuring equitable access to Voluntary Assisted Dying (VAD) for people living with communication and / or swallowing difficulties. Many of the populations accessing VAD experience difficulties with their communication and swallowing skills, which impact the VAD access process in a significant way for these individuals. This may include but is not limited to people with progressive neurological conditions such as Motor Neuron Disease, or cancers of the head and neck / brain. People with communication and swallowing difficulties must have access to essential speech pathology supports to ensure they can:

- make their needs and decisions known to initiate and confirm VAD requests
- have decision-making capacity appropriately assessed to confirm eligibility
- be communicated with in a way that respects their autonomy, decision making skills and need for information
- Have the most safe and effective medication administration route chosen, where swallowing difficulties may otherwise lead to aspiration into the lungs rather than ingestion of the substance

Speech pathologists actively support people who have complex communication needs (e.g. little or no speech) or swallowing difficulties and seek to access VAD by:

- assessing communication skills and identifying relevant communication aids and strategies that enable the person to demonstrate their decision-making capacity, express their wishes and ask questions to gain information,
- educating their treating medical team on how best to support two-way communication during VAD conversations, and
- assessing swallowing and risks of aspiration to inform medical decision making of the most appropriate and safe route for medication administration.

The involvement of speech pathologists is therefore a vital part of the VAD process, which must be appropriately reflected and accommodated within VAD legislation.

Speech Pathology Australia provides recommendations to ensure access to speech pathology supports for equitable access to the VAD scheme for all.

1. People with communication difficulties must be ensured equitable access to VAD

Recommendations

1. Ensure wording in the VAD Bill supports communication accessibility of the scheme such that a variety of communication methods are supported and acknowledged throughout the VAD process
2. Include 'communicating with people with complex communication needs' as a mandatory topic within training for VAD practitioners
3. Ensure pathways for equitable access to speech pathology supports are built into the Scheme

Key consultation questions:

3. How could the NT make sure that an eligible person can access VAD in a safe and effective way, including people living in remote areas, and Aboriginal and Torres Strait Islander people?

5. What aspects of VAD legislation in other States or Territories do you think should or should not be adopted in the NT?

6. Given the NT's unique cultural and geographic circumstances, what additional or different safeguards should be included?

9. How can we ensure that people with progressive diseases are protected but treated fairly as part of a VAD framework?

11. What topics should be covered in the mandatory training for VAD practitioners?

12. Should one request for VAD be required in writing? How should flexibility be built in for people who cannot physically write a formal request?

13. Should witnesses be required for a person's formal requests for VAD? If so, who should be permitted?

People experiencing communication difficulties face potential difficulties accessing VAD, including when making access requests, confirming decision making capacity or gaining appropriate information to support decisions. This includes people with 'complex communication needs' – such as those with little or no speech or speech that others find difficult to understand, or difficulties understanding written or verbal information. People with progressive neurological conditions are a key cohort who seek VAD and likely to experience such difficulties due to their conditions (e.g. Motor Neuron Disease, Multisystem Atrophy). People with communication difficulties need specific supports and accommodations to ensure they have equitable access to the VAD scheme.

Speech Pathology Australia (SPA) strongly advocates for the NT VAD Bill to include provisions that ensure the 'communication accessibility' of the Scheme. This should include specific inclusions as within other State-based VAD legislation that appropriately address this need.

This includes:

- Explicit wording that a request for VAD access can be communicated in a variety of ways: “in writing or orally or by communicating in any other way the individual can” (e.g. Vic VAD Act 2017ⁱⁱ)
- Wording referring to ‘Capacity’ assessment specifically should outline a requirement to ensure relevant supports such as ‘*relevant communication aids or strategies*’ are provided as needed during any assessment of capacity. (see SA VAD Act 2021ⁱⁱⁱ).
- Where a need to sign a written declaration is in place, there is wording that removes this requirement in the case of both physical and *communication* difficulties (i.e. where someone has acquired reading comprehension or spelling difficulties).

It is often mistakenly believed, even by some medical professionals, that individuals who cannot speak lack legal capacity. In reality, there are many ways that many people with communication difficulties can demonstrate their decision-making capacity if they are properly supported. To ensure fair access for those with progressive conditions or other communication support needs, it is essential that legislation includes explicit requirements to address these needs.

Furthermore, how to communicate with people with little or no speech or using communication aids should be included as a mandatory topic in training for VAD practitioners.

It is within the scope of practice and expertise of speech pathologists to provide this support to individuals with communication difficulties – identifying and prescribing the appropriate communication supports and aids that would enable this communication to occur. Additionally, speech pathologists provide education and training to the support networks and health professional team around the person to enable them to know how to successfully communicate with the person. It is imperative that the NT VAD scheme work with relevant stakeholders including NT Health to ensure equitable access to required speech pathology support.

2. Speech pathologists must be recognised as playing an essential role in VAD

Key consultation questions:

7. What are the benefits or challenges you see with a stand-alone VAD service operating separately from existing NT health services?

8. How can we make sure people in remote or regional communities can access VAD fairly and safely if they wish.

10. What support is needed to assess a person’s capacity to make decisions about VAD?

Recommendations

4. Map the availability of speech pathology services with relevant expertise across the NT
5. Develop protocols and guidance for the integration of service delivery between the stand-alone VAD service practitioners and speech pathology services
6. Continue to advocate for the explicit removal of VAD from the Commonwealth Criminal Code Amendment Bill, to enable the use of telehealth services
7. Establish hardship provisions to ensure access to speech pathology for those seeking to access VAD

Despite being an essential component of ensuring access to and successful engagement with the VAD scheme, speech pathology supports are not consistently available. This includes gaps in funding (e.g. for those living in residential aged care), workforce resource limitations and geographic distribution within the NT. This has implications for successful roll out of the VAD scheme.

Successful roll out of the VAD scheme will need to target how speech pathology services will be integrated into the operations of the stand-alone VAD service which has been slated as only incorporating VAD practitioners, VAD Care Navigators and Pharmacists. Speech pathologists are also essential to the VAD scheme – the work of the VAD service depends on their input. It is not sufficient to assume that this will be automatically available through other means such as NT health services. Speech Pathology Australia recommends the following actions as a starting point in considering speech pathology access and support:

- Mapping of the availability of all local speech pathology services with appropriate levels of expertise and experience in supporting complex communication needs in adults should be undertaken across both public and private services.
- Development of protocols and guidance around integration of service delivery from the stand-alone VAD service and external speech pathology services
- Advocacy for being able to use telehealth as a service delivery option. Being able to conduct conversations that allude to the VAD scheme via telehealth services will be a critically needed component of service delivery in NT across all professions including speech pathology. Speech Pathology Australia supports the continued efforts by State and Territory governments to call for revision of the current commonwealth legislation prohibiting this from occurring (Commonwealth Criminal Code Act 1995 e.g. section 474.29A and 474.29B)^{iv}
- Hardship provisions are established to ensure funding subsidies are available as a last resort where an existing funding gap does not enable someone to access the scheme. For example, someone living with Motor Neuron Disease in a residential aged care setting may typically not have speech pathology funded to support their communication needs. Without a viable means of communication set up (such as through an electronic speech generating device), they may be deemed unable to request VAD – creating inequitable access.

3. Initiation of discussion of VAD must be allowed across treating health professionals, including speech pathologists

Key consultation questions:

14. Should health practitioners be free to initiate a discussion about VAD, providing information alongside other treatment and management options such as palliative care?

Recommendations

8. Enable a range of treating health professionals, including speech pathologists to initiate a discussion about VAD alongside provision of onward referral to a medical practitioner

Speech pathologists, by the nature of their professional role, may be involved in sensitive conversations with individuals considering Voluntary Assisted Dying (VAD), often prior to a formal access request being made. However, current legislative frameworks—such as the *Voluntary Assisted Dying Act 2017 (Vic)*—do not consistently provide explicit protections for speech pathologists engaging in these preliminary discussions. This legislative gap has led to significant concern and uncertainty within the profession, potentially impacting the ability of speech pathologists to provide appropriate support while remaining compliant with the law.

The NT VAD Bill should explicitly recognise that a range of treating health professionals including speech pathologists can initiate a conversation about VAD, in line with the NSW VAD Act 2022.^v

Given speech pathologists' role and expertise in supporting communication with people with complex needs, these individuals often identify their wishes to a speech pathologist in the course of providing this supported communication. For them to be able to make themselves understood to make an access request a speech pathologist may have to program the vocabulary for that request. For example, "I want to request VAD" may need to be programmed into a speech generating device or communication board that they will then use with a medical practitioner to make an access request. This incorrectly places the speech pathologist at risk due to the incorrect perception that the speech pathologist has initiated the topic by providing such vocabulary. Speech pathologists must be able to support equitable access to VAD to people with complex needs with full protection from criminal and civil liability. Some jurisdictions only afford this protection to registered health professionals, however speech pathology is a self-regulated profession.

Speech pathologists must have legal protections to initiate discussions about VAD in association with an onward referral to a medical practitioner. These measures are essential to ensure equitable access to VAD for people with complex communication needs and to protect the professionals who support them.

4. Speech pathologists must be protected by the legislation for both participating in or conscientiously objecting to VAD

Key consultation questions:

15. If a health practitioner declines to be involved in a person's request for VAD, should they be required to take any particular actions?

16. What categories of persons or professionals should be permitted to conscientiously object to VAD?

Recommendations

9. Ensure the Bill explicitly recognises 'Certified Practising Speech Pathologists' as having the same legal protections including immunity from criminal and civil liability and the right to conscientiously object to participation in the VAD process

Speech pathologists must be formally recognised as part of the health professional workforce supporting access to VAD, with equivalent rights, responsibilities and protections under the Bill. This includes protection from criminal prosecution for actions taken in good faith within the scope of the VAD legislation. It also includes the right to conscientiously object to being involved in supporting someone undertaking the VAD process (e.g. see QLD VAD Act 2021^{vi}). As per other jurisdictions, it is appropriate for speech pathologists to have obligations to ensure that the person's request is appropriately passed on to further supports. (e.g. see ACT VAD Bill 2023)^{vii}

VAD legislation must also define the appropriate eligibility of health professionals to provide necessary support in the VAD process. As a self-regulating profession, Speech Pathology Australia oversees the standards and auditing of the credential of 'Certified Practising Speech Pathologist' which denotes a speech pathologist who has met requirements that are similar to those health professionals registered under the National Registration and Accreditation Scheme. The Bill must provide clear protections for all relevant registered and self-regulating health professionals, including Certified Practising Speech Pathologists. These protections should explicitly include immunity from criminal prosecution when engaging in lawful professional conduct related to Voluntary Assisted Dying (VAD), as well as the right to conscientiously object to participation in any aspect of the VAD process.

5. Safeguards for people with dysphagia must be built into administration responsibilities

Key consultation questions:

21. Are additional safeguards required when an eligible health professional administers the VAD substance (compared with self-administration) and if so, what safeguards would be appropriate?

25. What safeguards should be put in place to ensure the supply of a VAD substance by a pharmacist is safe and accessible?

Recommendations

10. Ensure the Bill recognises the importance of a swallowing assessment by an appropriately qualified health professional prior to the administration of the VAD substance, to determine the most suitable route of administration

People living with swallowing difficulties, such as those with progressive neurological diseases or cancer of the head/neck/ brain, may be at risk of aspirating the VAD substance into the lungs, where it will not necessarily be effective.

The Bill should indicate the need to ensure appropriate assessment of swallowing from the relevant health professional prior to medication administration, to ensure the appropriate administration route is chosen. Speech pathologists can assess swallowing and provide advice on likely aspiration risks, to enable the medical practitioner to determine an appropriate medication route. This cannot be done via a pharmacist medication review – a swallowing assessment by a speech pathologist is essential.

11. References

- ⁱ Report into Voluntary Assisted Dying in the Northern Territory 2024. Northern Territory Government.
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- ⁱⁱ Voluntary Assisted Dying Act 2017 (Victoria) , Victorian Government
<https://content.legislation.vic.gov.au/sites/default/files/2021-06/17-61aa005%20authorised.pdf>
- ⁱⁱⁱ Voluntary Assisted Dying Act 2021 (SA) . South Australian Government
https://www.legislation.sa.gov.au/_legislation/lz/c/a/voluntary%20assisted%20dying%20act%202021/current/2021.29.auth.pdf
- ^{iv} Commonwealth Criminal Code Act 1995 (Suicide Related Material Offences). Parliament of Australia
<https://www.legislation.gov.au/C2004A04868/latest/text>
- ^v Voluntary Assisted Dying Act (NSW) 2022. Parliament of NSW.
<https://legislation.nsw.gov.au/view/html/inforce/current/act-2022-017>
- ^{vi} Voluntary Assisted Dying Act (QLD) 2021. Parliament of QLD.
<https://www.legislation.qld.gov.au/view/pdf/asmade/act-2021-017>
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