

Submission: Independent Review of the End-of-Life Choices (Voluntary Assisted Dying) Act 2021

1. Overview

COTA Tasmania supports a voluntary assisted dying (VAD) framework that respects the autonomy and dignity of eligible Tasmanians while retaining strong safeguards against coercion, abuse and decisions driven by inadequate care, poverty, isolation or lack of support.

For older Tasmanians, the central issue is not a choice between safeguards and access. A sound system must deliver both: clear information, timely and equitable access for people who meet the law's requirements, and rigorous protection of voluntariness and decision-making capacity.

This submission distinguishes between matters requiring legislative amendment and matters requiring better resourcing, administration, public information and clarity about existing legal protections.

COTA's principal priorities for legislative reform and government action are::

- reviewing the six- and twelve-month prognosis requirements, particularly their effect on people with progressive neurodegenerative conditions, while retaining contemporaneous decision-making capacity and all other core safeguards;
- clarifying the responsibilities of institutions, including residential aged care facilities, so that residents are not denied information, assessment or lawful access simply because their home does not participate in VAD;
- repealing the 12-month continuous Tasmanian residency requirement, which is no longer justified now that VAD is available in every Australian state; and
- addressing the limits on electronic communication that create avoidable barriers for rural, regional and frail Tasmanians.

COTA also urges sustained investment in care navigation, participating-practitioner capacity, palliative care, advance care planning, bereavement support and transparent public reporting.

2. About COTA Tasmania

COTA Tasmania is the peak body representing the interests of older Tasmanians. We work to ensure that Tasmanians can age with dignity, security, opportunity and choice, and that public policy, services and communities recognise the diversity, experience and contribution of older people.

COTA Tasmania brings the perspectives of older Tasmanians to government, service providers and the wider community. Our work includes advocacy on health, aged care, housing, transport, digital inclusion, safety, participation and the rights of older people to make informed decisions about their own lives.

3. Why this matters

End-of-life decisions are among the most personal and consequential choices a person can face. For many older Tasmanians, they arise alongside serious illness, disability, bereavement, changing care needs, dependence on family or services, and concern about loss of control. The legal and service framework must therefore protect people from coercion and neglect while respecting their right to make informed choices about their own care and dying.

This review matters because a right that exists in legislation may not be meaningful in practice if people cannot obtain reliable information, find a participating practitioner, travel for assessments, access palliative care, or remain in the place they call home. These barriers are particularly acute for people living in rural and regional Tasmania, people with limited mobility, residents of aged care facilities, people living alone and people who are digitally excluded.

Older Tasmanians are not a single or uniformly vulnerable group. Some will prioritise access and autonomy; others will be concerned about safeguards, family pressure or the adequacy of care and support. A mature VAD framework must make room for both perspectives. It must ensure that no person is driven towards VAD by remediable suffering or inadequate services, while also ensuring that eligible people are not denied a lawful choice through avoidable procedural, geographic or institutional barriers.

4. Detailed Comments

4.1 Principles for the review

Older people have the same right as all other adults to make decisions about their health care and dying. Age, disability, dependence on care, cognitive impairment or residence in an aged care facility must not be treated as proof that a person lacks capacity or cannot make an autonomous choice.

VAD should remain one lawful option within a broader system of high-quality end-of-life care. It should not be promoted as a preferred option, but neither should it be made practically inaccessible through avoidable delay, lack of information or institutional barriers.

Recommendation 1: The review should reaffirm autonomy, dignity, informed choice, voluntariness and equal access as the governing principles of Tasmania's VAD framework.

4.2 Clear public information and respectful language

Many Tasmanians still do not understand what VAD is, who may be eligible, how to begin the process, or how VAD differs from suicide, advance care planning, and decisions to withhold or withdraw treatment. People should not have to discover a lawful end-of-life option by chance, or only when they are already very unwell.

Public communication should use accurate, respectful language. Terms such as “euthanasia” can be imprecise and polarising, and should not be used as a substitute for the statutory term “voluntary assisted dying”. Information should be available in plain English, community languages and accessible non-digital formats.

Recommendation 2: The Tasmanian Government should fund an ongoing public education program about VAD, its safeguards, palliative care, advance care planning and other lawful end-of-life decisions, using accurate and respectful language.

4.3 Legislative amendments: access without weakening core safeguards

4.3.1 Prognosis and dementia

The current requirement that a condition be expected to cause death within six months, or 12 months for a neurodegenerative condition, may operate as an arbitrary barrier where prognosis is inherently uncertain. This is especially relevant for people with dementia and other progressive neurological diseases, who may retain decision-making capacity while experiencing profound concern about a future they regard as intolerable, but be unable to satisfy a fixed prognosis test.

COTA does not support VAD on the basis of an advance directive or substitute decision-making after a person has lost capacity. Contemporaneous, decision-specific capacity must remain essential. However, the review should examine whether removal or substantial reform of the prognosis restriction could provide a lawful pathway for people with advanced, progressive conditions who retain capacity, without compromising voluntariness or other safeguards.

Recommendation 3: The review should examine removal or substantial reform of the six- and twelve-month prognosis requirements, with particular attention to people with dementia and other neurodegenerative conditions who retain decision-making capacity.

Recommendation 4: The Act should continue to require contemporaneous, decision-specific capacity and should not permit substitute decision-making or activation of VAD through an advance care directive.

4.3.2 Institutional responsibility and aged care

Residential aged care is a person's home. Residents should not lose access to lawful information, assessment or services because a provider has a conscientious objection or non-participation policy.

Individual practitioners should retain the right not to participate; however, institutions should not obstruct a resident's pathway to an external practitioner, the statewide service or a care navigator.

A resident should not be required to leave their home unless this is clinically necessary or genuinely chosen by the person. Policies should be transparent before admission and readily available to residents, families and staff.

Recommendation 5: The Act should clarify the obligations of institutions, including aged care facilities, to provide information and enable practical access to an external VAD practitioner or care navigation service where the institution does not participate.

Recommendation 6: Aged care providers should be required to disclose their VAD policies clearly before admission and should not require residents to leave their usual home solely because of institutional non-participation.

4.3.3 Information by health practitioners: clarity in existing law

Section 17 of the Act is intended to protect people from being encouraged or pressured to pursue voluntary assisted dying. However, its structure begins with a general prohibition and then sets out exceptions for medical practitioners and other registered health practitioners.

While those exceptions permit appropriately balanced discussion, the provision may be misunderstood by practitioners as preventing them from raising VAD even where this forms part of a broader conversation about treatment, palliative care and end-of-life choices. That uncertainty may discourage timely, neutral information-sharing.

COTA Tasmania does not support any change that would permit pressure, suggestion or promotion of VAD. However, the review should consider whether section 17 could be more clearly drafted so that practitioners understand when they may provide balanced information about all lawful end-of-life options.

Recommendation 7: The review should consider clarifying section 17 of the Act, and supporting it with professional guidance and training, so that health practitioners can confidently provide neutral, balanced information about VAD, treatment and palliative-care options without encouraging or pressuring a person to seek VAD.

4.3.4 Residency

The 12-month continuous Tasmanian residency requirement was introduced when voluntary assisted dying was not available in most Australian jurisdictions and was intended to discourage “forum shopping”. That context has changed. VAD is now available in every Australian state, and the requirement can exclude people with an enduring connection to Tasmania who have spent time interstate for treatment, work, caring responsibilities or travel. It may also prevent people from being close to family, community and usual supports at the end of life. COTA considers the requirement an unnecessary and disproportionate barrier and supports its repeal.

Recommendation 8: The Act should repeal the 12-month continuous Tasmanian residency requirement.

4.4 Rural, regional and digital equity

Tasmania’s dispersed population, limited specialist workforce and transport barriers create particular risks for people outside the major centres. A person who is seriously ill may be unable to manage repeated long-distance travel; carers may face substantial financial and practical burdens.

Commonwealth restrictions on electronic communication about VAD continue to create uncertainty and can require sensitive information to be provided face to face even where video or telephone communication would be safer, less distressing and more equitable. Tasmania cannot resolve this alone, but it can document the effect and advocate for change.

Recommendation 9: The Government should publish de-identified geographic data on practitioner availability, travel requirements, timeframes and outcomes, and ensure care navigation is sustainably funded statewide.

Recommendation 10: The Tasmanian Government should work with other jurisdictions to seek Commonwealth reform so that lawful, clinically appropriate VAD information may be communicated electronically with proper safeguards; pending reform, clear guidance should be issued to patients, families and practitioners.

Recommendation 11: Where face-to-face attendance is required, assistance should be available to meet reasonable travel and accommodation costs for an eligible person and, where necessary, a support person.

4.5 Capacity, coercion and elder abuse

Decision-making capacity must remain central to the integrity of VAD. It should be assessed fairly and in relation to the particular decision.

Dementia, disability, mental illness, communication difficulty or dependence on others must not automatically be treated as incapacity. At the same time, older people may be vulnerable to elder abuse, coercive control, financial abuse, family pressure, loneliness, fear of inadequate care or concern about being a burden.

Practitioners need training and clear referral pathways to identify and respond to these issues. The purpose is to ensure that a request is genuinely voluntary and that remediable causes of distress are addressed, not to apply paternalistic assumptions about older people.

Recommendation 12: Mandatory training should include decision-specific and fluctuating capacity, communication support, elder abuse, coercive control, family violence, financial abuse, ageism and the distinction between dependence and lack of autonomy.

Recommendation 13: Specialist capacity and safeguarding assessments should be available promptly and without prohibitive cost where reasonably required.

4.6 Palliative care, advance care planning and support

VAD and palliative care should not be portrayed as mutually exclusive. People considering VAD should receive timely information about palliative care and symptom management, but should not be required to undergo unwanted treatment or prove that every intervention has failed.

No person should seek VAD because they cannot access pain relief, personal care, housing, disability support, mental health care or relief for an exhausted carer. Equitable access to high-quality palliative care, including community-based and after-hours services, remains essential.

Advance care planning is especially important following a diagnosis of dementia or another condition likely to affect future capacity. It cannot authorise VAD after capacity is lost, but it can help people communicate their values and preferences for treatment and care.

Recommendation 14: The Government should guarantee equitable access to high-quality palliative care and strengthen practical support for early advance care planning, particularly after a diagnosis likely to affect future capacity.

Recommendation 15: The review should examine whether people and families receive adequate VAD-specific information, counselling and bereavement support before, during and after the process, including independent support for people who are socially isolated or at risk of coercion.

4.7 Workforce, navigation and transparency

A workable VAD system cannot rely on the goodwill of a small number of committed practitioners. Participating doctors, pharmacists, nurses, care navigators and administrative staff need remuneration that reflects the work involved, legal and clinical advice, peer support, wellbeing support and succession planning.

The statewide care navigation service is critical. It should be widely known, adequately funded and readily accessible to people before they encounter unnecessary barriers in the health system.

Public reporting should enable the community to assess access, equity and safeguards in practice. Privacy must be protected, but annual reporting should include information on inquiries, applications, eligibility outcomes, withdrawals, deaths or loss of capacity before completion, timeframes, regional distribution, diagnoses, methods of administration, palliative-care involvement, complaints and practitioner coverage.

Recommendation 16: The Government should maintain an adequately resourced statewide practitioner and care-navigation network, with training, professional support, workforce planning and public awareness of how to access the service.

Recommendation 17: The Commission's reporting framework should be expanded to provide sufficient de-identified data to assess equity, timeliness, safeguards, institutional barriers and practical access.

5. Conclusion

Voluntary assisted dying involves profound questions of autonomy, dignity, vulnerability, suffering and the role of the state. These questions have particular significance for older Tasmanians, but older people should never be treated as a single or uniformly vulnerable group.

The legislative framework must guard against coercion, elder abuse and decisions arising from inadequate care or support. It must also guard against paternalism, ageism and the denial of autonomy simply because a person is older, disabled, dependent on care or approaching the end of life.

COTA Tasmania considers that the essential foundations of the current framework - voluntariness, informed decision-making, decision-making capacity, clinical eligibility and independent oversight - should be retained.

The review should focus on whether those protections are operating effectively and whether eligible Tasmanians can navigate the system in a timely, equitable and humane manner.

In particular, action is needed to improve public information, rural access, practitioner availability, advance care planning, aged care arrangements, workforce sustainability, data transparency and the interaction between voluntary assisted dying and palliative care.

The effectiveness of the legislation should ultimately be judged not only by whether its formal processes have been followed, but by whether Tasmanians approaching the end of life are treated with compassion, dignity and respect; are protected from abuse and coercion; have access to appropriate care and support; and are able to make genuinely informed choices within the law.