VOLUNTARY ASSISTED DYING

A Guide to the Debate in the NT

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Go Gentle Australia

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Go Gentle Australia is an expert advisory and health promotion charity founded by Andrew Denton to advocate for better end-of-life choices, including the legal option of voluntary assisted dying. The information we produce is backed by evidence and peer-reviewed research.

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Introduction

Territorians have been waiting decades for the return of their democratic right to decide the issue of voluntary assisted dying (VAD), ever since the power to do so was controversially taken away by Canberra in 1997.

Territorians overwhelmingly support VAD. We applaud the Government for its diligence in drafting and introducing VAD legislation, as promised.

As the last jurisdiction to debate a law, the Northern Territory parliament is now in a unique position: it not only has access to two NT reviews about VAD to provide clear expert advice, it has the advantage of being able to choose the best of other jurisdictions' processes in order to give Territorians the best law possible.

This Guide is a straightforward summary of the issues most likely to be raised in the upcoming parliamentary debate. It aims to assist MLAs to come to an informed position on key aspects of the bill and to put forward or support amendments where needed.

The Guide provides explanations of three areas where we believe amendments to the bill are required to best benefit terminally ill Territorians.

These amendments focus on:

1. **prognosis timeframes to death;**
2. **conversations between health practitioners and patients;**
3. **obligations for non-participating health individuals and entities.**

There is also additional information about why MLAs should resist attempts to include VAD as the cause of death on the death certificate.

Wide public consultation

The Guide relies on the two comprehensive reports on VAD in the NT: **The Expert Advisory Panel's 2024 Final Report**[1] (The Expert Panel) and the **Legislative Assembly's Legal and Constitutional Affairs Committee Final Report 2025**[2] (The Committee). Both stemmed from wide public consultations on VAD and provide a strong basis for the legislation now before parliament.

They recommend a law that:

1. **allows doctors and other appropriately trained health practitioners to initiate discussions** about VAD with patients as part of a broader discussion of treatment and end-of-life options, as is the case in other states;
2. **is flexible about prognosis requirements,** provided the person has an advanced and progressive condition expected to cause death and meets all other eligibility criteria;
3. **spells out the obligations of objecting practitioners and health institutions;**
4. **records the person's underlying disease, illness or medical condition as the cause of death o**n the death certificate, rather than VAD.

The Guide also draws on Go Gentle's own research, based on evidence collected from around Australia over the past seven years.

These positions support informed patient choice while maintaining safeguards against coercion, inappropriate access, and obstruction that have proven to be effective across Australia.

Why the fixed prognosis timeframe should be removed

The Expert Panel recognised several problems with restrictive timeframes, particularly the risk that people in remote areas would be unable to complete the process before becoming too unwell to continue.

Nevertheless, the Panel considered that omitting a timeframe would represent a significant departure from existing Australian laws. Their report was written before the ACT's law was passed in June 2024, with no prognosis timeframe. Unable to draw on the ACT's decision – itself based on the experience of other jurisdictions – it recommended a single 12-month prognosis requirement, irrespective of diagnosis, partly to allow sufficient time for people to access services in the NT.

Informed by new evidence, the Committee reconsidered the issue and recommended that eligibility should not depend upon a fixed prognosis period.

It found, as the ACT parliament had, that **medical practitioners can have difficulty reliably predicting a person's remaining life outside a narrow period of days or weeks**, and that evidence from other jurisdictions showed arbitrary timeframes can unreasonably exclude many dying and suffering people, simply on the basis of this unreliable prediction.

Equitable care

Two patients with the same illness, comparable suffering and the same decision-making capacity could be treated differently because one doctor estimates a remaining life expectancy of 11 months while another estimates 13 months.

Such a distinction would not be based on the seriousness of the disease, the intolerability of the suffering, the voluntariness of the request, or the person's capacity. It would rest on a prediction that clinicians themselves regard as uncertain.

Prognostic timeframes can be more readily estimated for some advanced cancers than for neurological disease, chronic organ failure, respiratory disease, and other conditions characterised by variable or prolonged deterioration.

This creates the possibility of a deeply unfair outcome, where a person may initially be considered too far from death to qualify, but later become too cognitively or physically impaired to access the process.

The Bill already includes substantial protections limiting eligibility to genuinely terminal circumstances. A person must be an adult with an advanced and progressive condition expected to cause death and must experience suffering they consider intolerable.

The person must also: undergo two independent medical assessments which includes an assessment that the person is acting voluntarily and without coercion; make a formal, witnessed, request; complete a final review; and retain capacity throughout the process.

The prognosis rule is not a reliable safeguard. Removing the fixed 12-month period would not remove the requirement that the person's condition be terminal. It would simply remove a requirement that doctors give an uncertain prediction and prevent this from becoming an absolute legal barrier for otherwise eligible people.

> "It can be difficult for medical practitioners to reliably estimate a person's prognosis outside of a narrow window of days or weeks... the requirement that a person's condition be 'advanced, progressive and expected to cause death' constitutes sufficient safeguards."
>
> – the Committee Final Report

It shouldn't be about the timeframe

Gavin Perry, cancer

Long-time advocate of VAD, Darwin resident Gavin Perry, 75, has a rare and aggressive form of eye cancer. He wants the option of VAD.

Gavin's oncologist has warned that if his melanoma spreads, he will suffer and there is a risk of going blind.

"If there was VAD, I wouldn't have to worry about any of this. I wouldn't have to sit here listening to doctors talking about a horrible death. It's so bloody simple really.

Now that a second cancer has metastasised, Gavin is saddened that it may be too late for him to access VAD by the time the law is passed and implemented.

Gavin told ABC Radio that the 12-month timeframe to death made little sense. "No doctor can give me an accurate prognosis. They just don't know...

"It shouldn't be about the prognosis; it should be about the intolerable suffering. That is what we all fear."

SUMMARY

Why the 12-month timeframe should be removed

Prognosis is inherently uncertain. A 12-month threshold creates the appearance of precision but frequently clinical prognostication cannot be that precise.

It can lead to arbitrary exclusion. A person may clearly have an advanced, progressive and fatal condition and be experiencing intolerable suffering, yet remain ineligible because their doctor believes their death may not occur within the exact window.

It disproportionately affects some diagnoses. Conditions with unpredictable trajectories, including some neurological, respiratory and chronic organ diseases, do not always follow a linear decline. It is much harder to reliably predict time to death for these conditions.

Other eligibility requirements provide the relevant safeguards. Removing the timeframe does not mean permitting VAD for people who are not dying.

Recommended position

Go Gentle recommends that MLAs adopt the ACT approach which was also preferred by the Committee: that no fixed timeframe be included.

Instead, eligibility should require that the person:

- has an advanced and progressive disease, illness or medical condition;
- is expected to die from that condition;
- is experiencing intolerable and enduring suffering caused by the condition or its treatment;
- has decision-making capacity in relation to VAD; and
- is acting voluntarily and without coercion.

With additional clarification that a person's condition or illness is 'advanced' if the individual's functioning and quality of life:

- have declined or are declining; and
- are not expected to improve; and
- any treatments for the conditions that are reasonably available and acceptable to the individual have lost any beneficial impact; and
- the individual is approaching the end of their life.

This maintains VAD as an end-of-life option without making access dependent upon an arbitrary – and often unreliable – numerical prediction.

The impact of a timeframe on some dying people

Tony Mims, Huntington's disease

Tony Mims has been diagnosed with Huntington's Disease, an inherited illness that causes the degeneration of nerve cells in the brain. It has a similar incidence to motor neurone disease (MND) and affects around 2000 Australians at any one time, with around 9000 Australians at risk of developing the condition.[3]

Like many other terminal neurological conditions, it results in psychiatric and cognitive symptoms as well as physical decline. Physical symptoms can include uncontrollable muscle spasms affecting speech, movement and swallowing. The rate of progression of the disease varies but is normally 10-20 years between first symptoms and death.

'My only option is the dark web. It's a terrible thing to consider.'

Under current laws around Australia, Tony will likely be unable to access VAD. While each case is individual, by the time he reaches the window to apply (12-months to death as proposed in the NT Bill) the cognitive impairment caused by the disease and his inability to consent to VAD would probably rule him out.

"I can't access VAD in its current form, because I don't meet the criteria. Particularly the need to be able to make a decision about VAD and communicate it to a doctor within 6 or 12 months of my expected death. By this stage I will be unable to express my wishes."

'I meet all the criteria but one.'

Tony believes, when the time comes, he will be forced to take matters into his own hands – with all the associated risks.

"My only option at the moment is the dark web. It's a terrible thing to consider and quite impossible to conceptualise the details, like how late should I wait to think about it, what if I go too early, or if I miss my chance?

"Although my own circumstances are unique, there must be many diseases and illnesses whose sufferers are in the same position as me."

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The case against a 'gag clause' that restricts doctor conversations

The Expert Panel considered the different legislative approaches taken across Australia. Only Victoria and South Australia restrict health practitioners from initiating a conversation with patients about VAD, with the Victorian parliament voting to amend their law and remove the restriction in November 2025. All other states and the ACT permit practitioners to raise the topic of VAD provided they also discuss other options such as continued treatment and palliative care.

The AMA, the peak body for Australia's doctors, says gag clauses are contrary to good medical practice and are "not in keeping with the wider and long-established relationship between doctor and patient, where the doctor is responsible for providing an expert and balanced analysis to provide the patient with all of their treatment options."[6]

The NT AMA endorses the approach of jurisdictions which permit health practitioners to initiate VAD discussions when they also provide information about palliative and end-of-life care.

AMA

AMA NT's primary concern with the existing Bill is the inclusion of a gag clause that prevents doctors from raising the topic of VAD with patients.

"That means the onus will rest entirely on the patient to be aware of the VAD option and to be able to proactively raise it with their doctor....

"That is not in keeping with the wider and long-established relationship between doctor and patient, where the doctor is responsible for providing an expert and balanced analysis to provide the patient with all of their treatment options."

Other evidence warns that restrictions on conversations particularly disadvantage people with poor health literacy, people from non-English-speaking backgrounds and people who already have trouble accessing health care. In the NT, this restriction is likely to particularly impact the Indigenous population.

The Expert Panel concluded that legislation should not prohibit practitioners from initiating VAD discussions, provided the practitioner informs the patient about all treatment options, including the availability and scope of palliative care. Its Recommendation 12 stated:

> *Medical practitioners should be allowed to introduce the subject of VAD services to patients during discussion about treatment options.*[5]

The Committee reached the same broad conclusions.

Informed health care

The concerns around possible undue pressure from health practitioners is understandable. However, there is an important difference between:

- **Informing a patient neutrally that voluntary assisted dying is a lawful option;**
- **Recommending, or placing pressure on the patient to choose it.**

The first is a fundamental component of informed healthcare communication.

As it stands, the Bill walks away from the fundamental concept of informed consent. A patient cannot exercise genuine autonomy if the law prohibits healthcare professionals from explaining all lawful treatment and end of life options available to the patient.

Healthcare practitioners routinely initiate discussions about some of the most difficult aspects of end-of-life care, including prognosis, palliative care, advance care planning, do-not-resuscitate orders, withdrawal of life-sustaining treatment, refusal of treatment, and palliative sedation.

It is wrong to equate highly trained health professionals giving balanced health information with exerting harmful influence.

The Bill provides no guidance as to what words would constitute a VAD request. This places an additional burden on professionals to make that determination themselves, a task particularly difficult when the patient communicates indirectly because of illness, disability, language or cultural practice.

Clinicians fearful of repercussions, may well choose silence rather than giving their patient all the information they need to make choices about their life.

The gag clause is intended to protect vulnerable Territorians. But it's likely to disadvantage precisely those people they are designed to protect.

The Bill already requires that the patient personally make the request. It requires two independent practitioners to assess capacity, voluntariness and possible coercion. It requires a witnessed request, a final review and continuing capacity. It also permits withdrawal at any point and establishes serious penalties for coercive and unauthorised conduct.

Allowing a practitioner to provide full and balanced information would not bypass any of these safeguards.

Cultural safety concerns

Concerns have been raised about the impact of end-of-life conversations in Indigenous communities. Any NT VAD law needs to consider the unique needs of Aboriginal people. However, it must also balance these needs with ensuring safe and equitable access for all Territorians.

NT doctors are working with Indigenous and remote communities every day. They already understand that, when it comes to talking about the end of life, communities differ. Some talk of 'death'. Some 'finishing up'. Others simply don't. It is not a one-size-fits all situation.

What is undeniably true, however, is that, by the time any conversation about VAD might start, end-of-life has already been discussed, be that a terminal diagnosis, palliative care, or discontinuation of treatment.

A VAD conversation is no different from any of these. They are all about the end, and the options a person has when facing it.

To deny remote communities – which may be without phone or internet – information about VAD when they have no other way to get that information, is to discriminate against people on the basis of their geography.

Rather than creating a barrier for the entire NT population (including those Indigenous Territorians who may want to access VAD) an appropriate response is the inclusion of cultural sensitivity awareness as part of the compulsory VAD training.

Additional evidence and experience

As in all other areas of medicine, genuine choice at the end of life depends on people having information about the full range of available options, including palliative care and VAD.

The 2025 National VAD Survey[7] provides an example of the practical effect of restricting conversations. A family member of a terminally ill Victorian reported:

> *Nobody mentioned [VAD] during years of hospital visits and consultations, even when all medication was withdrawn and hospice care proposed. I am sure they care but they are gagged and this disadvantages people.* – M.S, family member of a terminally ill Victorian (response to Go Gentle's National VAD Survey 2025)[8]

A doctor responding to the same survey described how a patient's knowledge and confidence affect access:

> *Patients don't know how to bring it [VAD] up. So they don't know where to begin. Delays and misunderstandings undermine the care and wishes of dying patients. Doctors need to be able to speak clearly to their patients.*[9]

If the NT insists on a gag clause, it will quickly become the only Australian jurisdiction to do so. Victoria's prohibition will be lifted in April 2027. South Australia is likely to do the same when its legislative review is completed next year. A gag clause in the Territory would be a rejection of evidence from the rest of the country that it acts as a barrier, not a safeguard.

It does not act as a safeguard for patients

AHPRA and other regulatory bodies already impose the highest standards of care on health practitioners including ethical boundaries and respectful, non-exploitative interactions.

Existing VAD safeguards would all continue, including:

- professional and ethical obligations imposed on health practitioners including their responsibility to understand and consider cultural safety issues;
- mandatory VAD training;
- requirements to provide balanced information;
- two independent eligibility assessments;
- express assessment of voluntariness and coercion;
- enduring decision-making capacity requirements; and
- the person's right to withdraw at any time.

A separate statutory gag clause is therefore a blunt and unnecessary response to risks already addressed by professional regulation, codes of professional conduct and the VAD assessment framework.

It stigmatises VAD by treating it differently from other health services

A restriction of this type does not apply to any other lawful medical service.[11] Singling out VAD reinforces the idea, encouraged by some, that it is illegitimate or unsafe to discuss, despite it being a highly regulated end-of-life option. This can increase stigma for the person choosing VAD and for their family. It can also complicate grief and bereavement.

"We believe that clinicians should not be gagged from introducing the topic of VAD with their patients, however neither should there be an expectation that they do so at a particular point in the trajectory of a life-limiting illness. A code of conduct rather than a legislative gag seems most appropriate to support good clinical practice regarding VAD."

- Alice Springs Hospital Heads of Department, Legal and Constitutional Affairs Committee Final Report

SUMMARY

Why a restriction on doctor conversations should not be included in the NT bill

It undermines informed decision-making

Informed consent depends upon the person being aware of their treatment options A person cannot make a fully informed end-of-life decision if a lawful option is withheld until they know enough to ask about it.

It reinforces existing health inequities

Relying on a patient to initiate a conversation about VAD assumes that the person: knows VAD is lawful; understands that they may be eligible; knows that they must raise it themselves; can communicate effectively with their doctor; and feels sufficiently confident to begin a sensitive conversation.

It interferes with the doctor-patient relationship

The doctor-patient relationship depends on openness, trust and the provision of clinically relevant information. Dr Anita Muñoz, Chair of the Victorian Royal Australian College of General Practitioners, told News GP not allowing GPs to speak about all medical options with their patients has been disadvantaging those with 'less health literacy, less education and less access to information'.

> 'What it really means is patients who are not as health literate as others, or do not have access to accurate health information, can now receive information from their GPs to make informed choices, which is what we do with every other part of medicine,' she said.
>
> 'Patients are entitled to be aware of what their treatment options are, and deliberately gagging a doctor from laying out those options to patients means you're effectively taking that right away from people who don't otherwise have that information at hand.
>
> 'Without GPs being able to do this, many people would miss out on this option just because they don't know that they have access to it, and that creates an inequality in the health system.'[10]

Recommended position

Go Gentle recommends that MLAs adopt the approach of other Australian jurisdictions which allow health practitioners to initiate VAD discussions when they also provide information about palliative and other end-of-life care. Including a gag clause in the NT law would be regressive and place the Territory outside the Australian legislative model.

‘I’d just like the choice... It’s about mercy. Get it done.’

Steve O’Grady, cancer

‘Stevo’ from Darwin knew that a VAD law in the Northern Territory would come too late for him. His terminal cancer was end-stage and progressing quickly. But he didn’t stop campaigning.

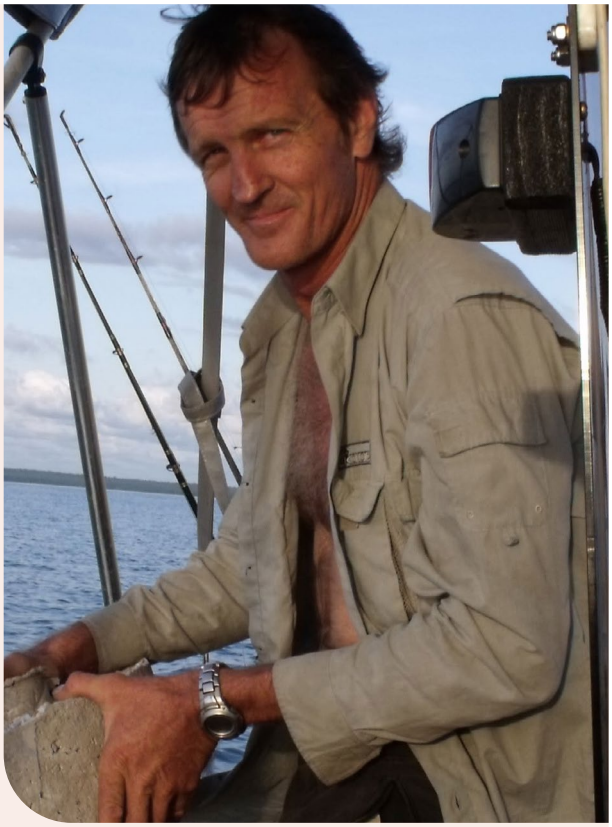
The Weddell local was receiving good palliative care in a hospice but said he would have applied for VAD months before, had it been available.

Stevo was afraid of a painful and undignified ending, because the cancerous tumour, “this monster growing in my body,” had broken through the skin and was bleeding.

Stevo called into ABC Radio regularly to speak about his plight on behalf of other terminally ill Territorians who wanted end-of-life choice.

“I’d just like the choice... I don’t want to leave a mess; I don’t want to make a fuss. I just want a clean end,’’ he said.

“VAD is about easing people’s suffering and giving them a choice beyond suicide or being bedridden. It’s about mercy.”



The legislative progress came too late for Stevo who died in November 2025. But his message to the MLAs remains. “Get it done.”

“VAD is about easing people’s suffering and giving them a choice. It’s about mercy. Get it done.”

Why the bill must contain minimum obligations not to obstruct

The Rights of the Terminally Ill Bill protects a relevant health worker's choice to decline involvement in VAD because of conscientious objection. It similarly allows entities, such as hospitals and aged care homes, to decline to participate in VAD.

However, there is a critical distinction between conscientious objection to VAD and obstruction of what is a legal end-of-life choice.

Currently, the Bill stipulates only that the relevant health worker or entity 'must give the person the information prescribed by regulation'.

Go Gentle believes strongly that minimum requirements for individuals and entities must be included in the legislation to provide clear direction for health workers and ensure the core intent of this requirement is unambiguous.

Information obligations for individuals

While the Bill honours an individual's right to conscientiously object, it does not contain any protections to prevent obstruction of an individual's VAD choice.

Sometimes this obstruction is overt, mostly it is covert – it manifests in a health professional's refusal to acknowledge a VAD request, provide information or direct people to services where they can learn more.

This casual obstruction may seem inconsequential to the doctor, but it can have an enormous impact on a dying patient who does not have the luxury of time, or the confidence to seek a second opinion.

Insisting that a health professional pass on minimum information is consistent with the Australian Medical Association's updated position statement on VAD. It says that conscientiously objecting doctors must inform the patient of their right to seek care from another doctor and ensure the patient has sufficient information to exercise that right.[12]

It is never OK for a health professional to impede access to a legal medical treatment.

The Medical Board of Australia's Code of Conduct[13] for doctors says:

> **2.4.6** Being aware of your right to not provide or directly participate in treatments to which you conscientiously object, informing your patients and, if relevant, colleagues, of your objection, and not using your objection to impede access to treatments that are legal.
>
> **2.4.7** Not allowing your moral or religious views to deny patients access to medical care, recognising that you are free to decline to personally provide or participate in that care.

This is echoed in Palliative Care Australia's guiding principles for the provision of VAD in Australia[14]:

> Ensure people living with a life-limiting illness do not have undue delays in accessing VAD when health professionals/providers/services exercise the right to conscientious objection.

Where a person asks for information or assistance, objecting health workers should be required to:

- promptly disclose that they will not participate;
- advise that another practitioner or service may be able to help; and
- as a bare minimum, provide the contact details of the official VAD Care Navigator service.
- provide any other information prescribed by regulation.

The core responsibilities should be set out *in legislation* rather than left to regulation or institutional policy. A legislative framework provides greater certainty and consistency.

Obligations of institutions

The draft legislation permits a hospital, hospice or aged care provider to *not participate* in VAD. Yet it says nothing about responsibilities *not to obstruct* access to VAD care.

This is a serious deficiency, particularly considering the power imbalance between an entity and the dying person in their care.

Why institutional objection is different from individual objection

The Committee described institutional objections as objections operating at an organisational level. It found that institutional objection can create a much wider access barrier than an individual practitioner's objection.

This distinction is important. A person may be able to consult another doctor when an individual practitioner objects. It may be much harder to overcome an objection imposed by the hospital in which the person is receiving treatment or the aged care home in which they permanently live.

The Expert Panel was particularly concerned about permanent residents of aged care facilities. It found that facilities' values and beliefs should not impede a resident's access to lawful treatment or undermine their dignity and right to choose – **rights which are enforced by the federal Aged Care Act (2024)**. The Act's guidelines are unequivocable: residential facilities must not hinder permanent residents from requesting, being assessed for, or accessing VAD in their own homes. The NT's VAD law should be consistent with these Commonwealth directives.

The Committee broadened the issue beyond permanent aged care residents. It found that the Expert Panel report had not fully addressed people who were temporary residents or patients in hospitals and described this as "a major omission".

The impact of institutional obstruction

The Committee received evidence that institutional objection can result in patients being unable to obtain VAD assessments, VAD practitioners and substances being barred from the premises, and staff being prevented from supporting patients. These experiences are reported in other Australian jurisdictions.

Reported consequences include[15]:

- delays for people with rapidly progressing illnesses;
- forced transfers from a person's home or preferred place of death;
- loss of control over the timing and place of death;
- anger, fear, stress and uncertainty;
- increased suffering; and
- loss of trust in the institution.

Institutional obstruction would be particularly significant for the NT, where there are often few alternative hospitals or aged care facilities, and transfers may involve long distances. A patient or resident may have no realistic choice of institution. Along with the proposed gag clause, the legislation as it is drafted will restrict access for people who are already suffering and for whom every hour is precious.

Minimum requirements for institutions

1. Aged care homes. Aged care is governed by Commonwealth legislation and regulation, both of which are unequivocable that aged care providers must not obstruct a resident's access to medical services. These include VAD services.

Aged care facilities should:

- publish information about their policy not to participate in VAD that is accessible and easy to understand,
- give residents asking about VAD the contact details of the official VAD Care Navigator Service;
- not hinder the person from obtaining VAD information while at the facility; and
- Allow external VAD practitioners onto the premises to conduct VAD assessments and other processes

Aged care homes must allow VAD access

The federal regulator, **the Australian Aged Care Quality and Safety Commission**, says residents have the right to access VAD, even where the aged care provider has decided not to participate, Providers are obliged to support older people's access to medical services, and this includes VAD. No one receiving aged care should be disadvantaged.[16]

2. Hospitals and other health services, similarly, must not obstruct access to VAD information, and must facilitate a person's transfer to another facility that can assist with VAD care. Transfer can only happen if it is reasonable and will not cause harm to the person.

Where a person asks for information or assistance, non-participating hospitals and other health services should be required to:

- provide the person with the contact information for the official VAD Care Navigator service;
- allow access to independent information by permitting reasonable onsite, telephone or other lawful contact between the person and the navigator service;
- not silence willing staff by preventing employees or visiting practitioners from providing information or initiating conversations, where permitted by law;
- facilitate transfers to other facilities that can assist with VAD care if that transfer is reasonable and will not harm the person;
- when transfer is not feasible, or in the best interests of the person, allow external VAD practitioners onto the premises to conduct VAD assessments and other services up to and including the administration of the VAD substance.

Judy's story – Told to move to another facility to access VAD

Judy lives in a Catholic aged care home in Sydney and suffers from cholangiocarcinoma, a rare cancer of the bile ducts. She wants VAD but has been told that even though she can have her assessments at the aged care home, she will have to go somewhere else to take the VAD medication. Judy is aged 87, a frail 32kg, and suffers from painful rheumatoid arthritis and bedsores.

Her daughter Carie said: "She's in so much pain. Any movement is excruciating. It's unreasonable to move someone in that situation."

SUMMARY

Why entity obligations should be spelt out in the legislation

Like obligations for individuals, the Committee found that the rights and responsibilities of entities should be set out in legislation rather than left to regulation or institutional policy. A legislative framework provides greater certainty and consistency, while policy-only arrangements in other jurisdictions have caused practical difficulties.

Clear statutory obligations are needed because:

Patients must be able to know an institution's position before admission. Public disclosure allows people and families to take an institution's VAD policy into account when choosing a hospital or aged care home.

A person should not discover institutional restrictions only after becoming seriously ill. Institutions must promptly disclose any restrictions on access to VAD care when a patient or resident asks about VAD.

Refusal must not become obstruction. An entity may decline to provide its own information, but should not block access to independent, accurate VAD information and care.

People in institutions are dependent on those institutions. Hospitals and aged care homes can control physical access to patients, visitors and practitioners. Without express obligations, an entity's objection may prevent a person from contacting or meeting with an independent VAD service.

Aged care homes are residents' homes. The new rights-based Aged Care Act is explicit: A permanent resident should not be forced to choose between remaining in their home and accessing a lawful end-of-life option.

The NT has limited alternative services. Institutional obstruction is likely to have a more severe effect where the nearest alternative facility or participating practitioner is a considerable distance away.

Recommended position

The legislation should distinguish between:

- **participation**, which an individual or entity may decline; and
- **obstruction**, which must not be permitted.

Neither an individual's conscientious objection nor an entity's institutional position should leave a person without basic information or access to lawful end-of-life care.

Aged care facilities that are people's permanent homes are governed by Commonwealth law and regulation and must not obstruct access to VAD. NT law should be consistent with the rights-based Aged Care Act and federal guidelines.

Non-residential facilities such as hospitals, hospices and other health services who do not participate in VAD must facilitate transfers to an alternative facility but only if that transfer is reasonable and will not harm the person. When transfer is not feasible, these facilities must allow the Care Navigator service and external VAD practitioners onto the premises to meet patients, conduct assessments and administer the VAD substance.

None of these provisions require an individual or entity to provide VAD, endorse it or require its staff to participate against their conscience.

Institutional obstruction
'Don't let this happen to anyone else'

Robbi Flynn, 33, terminally ill with cancer, hadn't chosen the faith-based hospital for treatment for religious reasons; it was simply her local public hospital. She trusted the oncology team and had built strong relationships with them.

Early in her diagnosis, Robbi made it clear to her family and care team that if recovery was no longer possible, she wanted VAD.

When Robbi's cancer was confirmed as terminal adenocarcinoma, Robbi saw VAD as a way to maintain agency over the time and manner of her own death.

However, the public hospital told Robbi they did not support VAD and she would need to transfer elsewhere to pursue it. She was told she couldn't even phone the VAD Care Navigator team. Although this was later corrected, the hospital continued to refuse to allow any aspect of the VAD process on site. Robbi would need to be transferred three times to pursue her VAD choice.

For Robbi, transfers were traumatic. She was autistic, had ADHD, was in pain, reliant on machines, and physically difficult to move.

Her mother Gina describes the transfers as "inhumane"; Robbi needed to be moved on a hospital trolley, ramps were missing, doors too narrow. On one occasion ambulance staff who were not equipped for Robbi's complex needs pulled out and dropped her TPN bag, a form of liquid nourishment administered directly into a vein, putting Robbi at risk of sepsis or falling into a coma.

Robbi eventually achieved her goal, dying peacefully at home using VAD and surrounded by loved ones. But the barriers the hospital put in her way overshadowed her final weeks and caused her anguish and stress right up to her last day.

Before she died, Robbi told her mother: "Don't let this happen to anyone else."

"It was the most grievous example of obstruction I've seen and the pain inflicted on that family was unforgivable."

– a doctor familiar with Robbi's case.

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Why VAD must not be recorded on death certificates

Go Gentle has been made aware of efforts to introduce amendments to the Rights of the Terminally Ill Bill that would force VAD to be listed as the cause of death on official death certificates.

This is a practice rejected – for good reasons – by every other Australian jurisdiction, and by both the Expert Panel and the Committee.

Having considered arguments in favour of identifying VAD on the death certificate in the interests of transparency, the Committee recommended that recording the underlying terminal condition as the cause of death protects the privacy and interests of the deceased person and their family.

It accepted evidence from The Australian Lawyers Alliance that recording the underlying condition as the cause of death recognises that VAD is not suicide (as stated in the bill) and prevents adverse consequences for insurance and other death benefits. It ensures that life insurance claims and superannuation death benefits remain unaffected.

The Committee also heard that recording VAD as the cause of death also potentially exposes bereaved families to stigma, guilt, judgment and isolation.

Health workers in remote communities could face blame or "payback" for participating in a VAD death. Not recording VAD on the public-facing death certificate would help protect people involved in the process.

The Committee nevertheless supported comprehensive notification to the statutory Review Board. Oversight information about VAD deaths and wider statistical analysis would therefore be captured through the VAD reporting system rather than through the death certificate.

Recommended position

The Bill must maintain its stipulation that a person who lawfully dies following administration of a VAD substance:

- **is taken to have died from the disease, illness or medical condition that made them eligible for VAD;**
- **is not taken to have died by suicide.**

Only the underlying condition should be recorded on the death certificate. The person's use of VAD is a private matter and should instead be reported confidentially to the Review Board for monitoring, compliance and statistical reporting.

SUMMARY

Why VAD should not be listed on the death certificate

The underlying disease remains the relevant cause. The person is eligible for VAD because they have an advanced and progressive condition expected to cause death. VAD changes the timing and manner of death; it does not remove the underlying fatal condition. When somebody chooses, for example, to discontinue dialysis for end-stage kidney disease, the death certificate records the disease, not the decision to end dialysis, as the cause of death.

Recording VAD may create financial consequences or uncertainty. Identifying VAD as the cause of death could prompt disputes or delays involving life, health or funeral insurance and superannuation death benefits, even where legislation ultimately protects those entitlements.

It may unnecessarily disclose private medical information. Death certificates can be seen by family members and used for a range of administrative purposes. A person's choice to access VAD should remain private, not automatically become information disclosed through the certificate.

It may expose families and practitioners to stigma or harm. This is particularly relevant in small or remote communities where the identity of those involved may be readily inferred.

Transparency can be achieved through statutory reporting. Coordinating practitioners and other responsible parties notify the Review Board of deaths involving people who have made a formal VAD request. This allows compliance, safety and public reporting without making the death certificate the primary oversight mechanism. This has worked effectively in all other jurisdictions.

Conclusion

As the last Australian jurisdiction to debate voluntary assisted dying (VAD), the Northern Territory has a golden opportunity to learn, not just from the expert advice of two committees, but from more than seven years' experience of VAD in other states and territories.

We urge MLAs to make three simple changes to the Bill to pass a legislative framework that best promotes informed choice and allows access while maintaining proven safeguards. These are:

- **Remove the gag clause:** A prohibition on practitioners discussing VAD would restrict information rather than prevent coercion;
- **Remove the 12-month prognosis timeframe:** a fixed prognosis timeframe creates arbitrary exclusion based on uncertain clinical predictions;
- **Add minimum information requirements and obligations not to obstruct:** including them in the legislative framework provides greater certainty and consistency.

In addition, we urge MLAs to resist attempts to deviate from the national standard and record VAD on death certificates. This risks compromising insurance cover, exposing private information and creates the potential for financial uncertainty and stigma – all without improving regulatory oversight.

The Rights of the Terminally Ill Bill 2026 is a well-drafted piece of legislation but, in a handful of key areas, it falls short of best practise legislated in other jurisdictions. These changes would not weaken the Bill or diminish protections for vulnerable Territorians, but the opposite. We urge MLAs to ensure Territorians have the best VAD law possible, one with strong safeguards and which enables fair access for those who are terminally ill and suffering.

'It's about hope, the alternative is horrendous'

Lori Martin, lung disease

Katherine local Lori Martin has lived a life filled with adventure and contribution to her community. Now, diagnosed with a progressive and incurable lung condition, she wants the option of VAD, should her illness become too much for her to bear.

Lori says, when the time comes, she wants to be able to consider all her options. For her it is to be allowed to die with grace and dignity

"Be compassionate and help us end suffering if we choose it. It's about hope. It's about choice. For most, the alternative is horrendous."

About Go Gentle Australia

Go Gentle Australia is a national charity established by Andrew Denton in 2016 to promote choice at the end of life. We empower people to choose the end-of-life care that is right for them, including the option of voluntary assisted dying (VAD). Our evidence-based approach supports high-quality VAD practice and systems to best serve the needs of dying people, their families and the health professionals providing care. Go Gentle is the only organisation of its kind working at a national level

Notes

1 Report into Voluntary Assisted Dying in the Northern Territory: Final Report 2024
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https://parliament.nt.gov.au/__data/assets/pdf_file/0005/1563314/Voluntary-Assisted-Dying-in-the-Northern-Territory-Final-Report.pdf

3 Monash University/ 'Huntington's Community Connect' Gap analysis report

4 Go Gentle Australia VAD Conference Report 2023
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