

Response to the ACT's Discussion Paper on Voluntary Assisted Dying

April 2023



Contents

Executive Summary	3
Our recommendations	5
Consultation questions	6
The process for request and assessment	18
The role of health professionals	24
The role of health services	29
Death certification and notification	32
Oversight, reporting and compliance	33
Other issues.....	35

Executive Summary

Go Gentle Australia (GGA) is a national charity established in 2016 to promote choice at the end of life. We empower people to choose end-of-life care that is right for them, including the option of voluntary assisted dying (VAD). We believe the voices of dying people should be heard and their decisions respected. We work to ensure high quality VAD practice and systems for dying people, their families and the health professionals caring for them.

We have played a critical role in the introduction of VAD legislation in Australia, where all six states have now passed laws, as well as advocating for the recent **Restoring Territory Rights Act 2022 (Cth)**.

We recommend approaching VAD law reform in Australia in line with four principles:

Centre the dying person

VAD legislation must prioritise the needs of the dying person. Strong safeguards ensure the law's safe operation, but should not make the law too onerous for those who need it.

Practise continuous improvement

Our work is evidence-based and our insights draw on the experiences of how individuals, health professionals and care providers navigate VAD in Australia. We expect any change to Australian VAD laws to be incremental and based on examination of the evidence. We do, however, encourage improvements in VAD systems, where necessary, to allow VAD practice to develop, evolve, and best serve the needs of dying people and the health professionals caring for them.

Aim for consistency

Workable laws need to be clear and consistent in their content and application. We support harmonisation of VAD laws across Australian jurisdictions so there is greater consistency, making the system easier to understand and navigate for health professionals and patients.

Take a holistic view

VAD laws must be viewed holistically. As detailed in our submission, some safeguards may seem reasonable in isolation but, in concert with other provisions, present considerable barriers to access – and may on occasion block access altogether. An example is the interaction between time frames and residency requirements, which may force a person to wait so long to make a VAD request that they miss their window of decision-making capacity altogether.

We support compassionate, safeguarded VAD laws and encourage their introduction in the ACT.

We appreciate that the ACT has its own unique characteristics and circumstances and that parliament will design legislation that best reflects the interests and concerns of its citizens. That said, we recommend the ACT's law broadly follows the 'Australian model', in line with the six states, and that where differences occur the best elements of each jurisdiction's law – based on experience and evidence – be adopted. Broadly speaking, we believe a combination of Tasmania and Queensland's legislation strikes the best balance between accessibility for the individual and the safe, workable provision of VAD in Australia.

In our responses below, we have addressed the consultation questions in detail only where we believe the ACT could depart from – and improve upon – this broad Australian model.

The Australian model is working for the majority of cases. We counsel against significant changes to eligibility criteria. Instead, we suggest exploring if compassionate exceptions may be made where compelling cases fall just beyond the eligibility criteria, as contained in Tasmania's law. This allows VAD laws to stay true to their intention – to provide choice and reduce the suffering of people who are dying – while promoting consistency across Australia.

Our recommendations

Our key recommendations are:

- A 12-month timeframe for all conditions, with provision for compassionate exemption
- Residency requirements that allow VAD access for Australian citizens, long-term residents and those who have been ordinarily resident in Australia for three years
- No territory-specific residency requirements mandated in the ACT
- A duty for health professionals to provide information to a patient if they cannot accept a VAD first request
- The coordinating practitioner and a single adult – rather than two – witness the final written request
- Patients can choose between practitioner or self administration, and provision is made for alternative self-administration methods e.g. intravenous self-administration
- Clear guidance for institutions detailing their obligations to patients, and financial penalties for any institution or individual who blocks, harasses or attempts to coerce people away from their legal choice of VAD

We urge the ACT government to support the reform of two further issues impeding access to VAD in Australia:

- Amend the *Criminal Code Act 1995* (Cth) to ensure telecommunications such as email and messaging services can be used to discuss VAD and – crucially – telehealth can be used for VAD assessments
- Ensure VAD services are funded at a territory level so health professionals are properly remunerated for their time. Currently, the Medicare Benefits Schedule (MBS) general explanatory notes (GN.13.33) state that “euthanasia and any service directly related to the procedure” will not attract Medicare benefits

Consultation questions

Eligibility criteria

1. What should the eligibility criteria be for a person to access voluntary assisted dying?

GGA recommends the ACT adopts the following eligibility criteria for access to VAD, broadly in line with the Australian model. That is, that a person be:

- Diagnosed with an incurable disease, illness, medical condition that:
 - is advanced, progressive and will cause death within 12 months
 - is causing suffering that cannot be relieved in a manner the person finds tolerable
- Capable of making decisions about their medical treatment and communicate those decisions throughout the assessment process
- Acting freely and without coercion
- Aged 18+
- Ordinarily resident in Australia for three years.

2. What kind of suffering should a person be experiencing or anticipating in order to be eligible to access voluntary assisted dying?

GGA believes a broad conception of suffering, in line with Tasmania's approach, is best. We agree with the proposition in the ACT's discussion paper that the Tasmanian legislation gives greater flexibility for a person and their registered medical practitioner to access end of life options in order to relieve many kinds of suffering.

3. Should a person be expected to have a specified amount of time left to live in order to be eligible to access voluntary assisted dying? If so, what timeframe should this be? Should there be a different timeframe for different conditions, for example for neurodegenerative disorders? If there is no timeframe required, what should a prognosis be instead?

GGA recommends a 12-month timeframe for all conditions, with provision for compassionate exemption.

Most Australian VAD laws require that, to be eligible, a person must have six months or less to live – or 12 months in the case of neurological conditions. The exception is Queensland, where a single 12-month timeframe is in place.

The rationale for timeframes is clear. Although prognostication is not an exact science, timeframes offer a clear eligibility threshold and limit VAD access to people who are at the end of life. They give guidance to medical practitioners, ensure consistency and provide confidence to the public and parliament. However, it can be argued that timeframes are inherently discriminatory because they unfairly limit the number of, otherwise eligible, people who can access VAD.

First, a six-month timeframe demands that the rigorous VAD application and assessment process is completed in the final few months of a person's life. Although someone can begin to get their documentation in order earlier, there is no option to start the formal assessment until they have met the timeframe threshold. This exacerbates the logistical, physical and emotional challenges experienced by dying people when applying for VAD. Sometimes these challenges are insurmountable; in Victoria, almost a third of people found eligible for VAD die before the process can be completed.¹

Second, even the wider 12-month timeframe for neurodegenerative illnesses can be a barrier to access for some people who would otherwise be eligible. Although designed to allow greater flexibility for the unpredictable disease progression of degenerative neurological conditions, people with these conditions often decline suddenly and rapidly, despite initial assessments that death is not imminent. Some neurological conditions can also reduce or remove a person's decision-making capacity early in their trajectory, rendering them ineligible for VAD well before they approach their final year of life.

If the intention of compassionate VAD laws is to give those facing unbearable suffering a choice about the timing and circumstances of their death, it is problematic and devastating that many people with conditions such as Huntington's disease, for example, are unable to meet the eligibility criteria; especially when this condemns them to greater suffering over a longer time period.

In Victoria and WA, parliamentary committees did not initially recommend timeframes for the assessment of terminal illness (although expert panels did later recommend 12 months). WA's committee considered a time limit as 'too prescriptive'². Tasmania's law was introduced to the Upper House without a specific timeframe to death; they considered doctors well equipped to decide when a person had reached a point of unbearable suffering making them eligible for an assisted death.

¹ Voluntary Assisted Dying Review Board, Report of operations: July 2021 – June 2022 (Safer Care Victoria, June 2022) p5.

² WA Joint Select Committee on End of Life Choices Report (2018) [7.43].

Tasmania's Act allows the VAD Commission to exempt a person from the requirements of a 'relevant medical condition', which means they would not have to meet the timeframe criteria, if they are 'satisfied that the prognosis of the person's relevant medical condition is such that the [timeframe] should not apply'. They must obtain a person's medical records and the opinion of a specialist in the condition in question to apply this exemption.³

GGA recommends the ACT include a single 12-month timeframe to echo Queensland's legislation, offering maximum palliative value to a majority of applicants and staying broadly consistent with the Australian model.

We also recommend the ACT add an 'exemption by discretion', echoing the Tasmanian approach. This ensures the law remains accessible to those people it is clearly intended to help. It should be noted that a person would still need to meet all the eligibility criteria, including retaining decision-making capacity throughout the process, but would allow for exceptional cases to prepare for and access VAD beyond a 12-month timeframe if their disease or condition's likely trajectory would otherwise preclude their eligibility.

3 End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas) s 6(3).

“In our experience of patients requesting voluntary assisted dying, we’ve seen improved patient-related symptom control of previously difficult to manage symptoms such as fatigue and anxiety. And this has happened almost as soon as the first assessment has been completed.

My advice to patients is to start early... The shorter the timeline you’re working to, the more fraught it gets.”

Fiona Jane

Clinical Hospice Manager, Albany Community Hospice, WA



Case Study

“My only option at the moment is the dark web. It’s a terrible thing to consider.”

Tony Mims

Huntington’s disease.



"I meet all the criteria but one"

Tony 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 condition¹.

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.

Under the current law in Victoria (and laws elsewhere in 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) the cognitive impairment caused by the disease and his inability to consent to VAD will 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.”

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.”

1 Monash University/ 'Huntington's Community Connect' Gap analysis report <https://huntingtonsvic.org.au/wp-content/uploads/2021/11/HCC-Gap-Analysis-Report-FINAL-210211-1.pdf>



**“I am just grateful to sail away
in peace and without suffering,
on my terms. No one should
lose control over their own self.”**

**Sue Parker,
Motor Neurone Disease.**

Sue, pictured with her daughter, chose VAD in Victoria November, 2022.

Case Study

Sue Parker, 75, took six months to navigate access to VAD in Victoria

By mid-2022, six months after Sue Parker began her VAD application, the paperwork was complete.

Because hers was a neurological condition (motor neurone disease), Sue had to be examined by her GP and two specialist neurologists, to confirm her diagnosis and agree on how long she was expected to live. "I naively thought it would be an easy process," she said.

It was the middle of a Covid lockdown, securing appointments was difficult, and very few neurologists had completed the VAD training, especially in regional Victoria. "I think at the time there were about two-and-a-half who had done the training," Sue said.

There was also the requirement that all the consultations be in person, and not via Telehealth, which was prohibited under a Commonwealth prohibition on using a carriage service to discuss or incite 'suicide'.

Sue wrote of her relief on being finally deemed eligible. "Now I can really relax. The burden of MND has been lifted. Life is wonderful. I can now live and enjoy my life knowing when I feel the quality has gone... so too can I go."

Sue achieved her wish of an assisted death on the 28th of November 2022 with her family at her side.

Nicole Lee, who was with her mother until the end, said the death was "unbelievably peaceful".

Nicole said the family was relieved Sue achieved the death she had fought so hard for, but they are angry the assessment process was so difficult.

"It was too long and the hoops you have to jump through ... she wasted six months of the only 12 months that she had left, getting it done."

"If you only have 12 months to live, and you're wasting six months on applying for this, that's the best six months."

Nicole said right until she had the medications in her hand her mother was worried that something would drastically go wrong with her health and she would be denied her wishes.

"That she would lose the ability to swallow and therefore she wouldn't be able to take the medication. Or she would have some sort of MND brain haemorrhage, and therefore wouldn't be able to speak and give consent. It was the biggest fear."

4. How should a person's decision-making capacity be defined or determined in relation to voluntary assisted dying?

GGA recommends the approach taken by all six states to assessing capacity i.e that health professionals who are conducting the VAD assessments are responsible for assessing whether a person has decision-making capacity in health care, and that capacity is assumed until indicated otherwise, is the best approach. It maintains the presumption of capacity in a positive sense and also gives maximum discretion to healthcare professionals directly involved with VAD care to investigate further if any doubts arise.

5. Should voluntary assisted dying be restricted to people above a certain age (for example, people 18 and over)?

GGA recommends the ACT adopt the age restriction of 18+ years, as included in other Australian legislation.

GGA appreciates that, in the ACT, a human rights framework recognises that 'mature minors' can and should have decision-making power in relation to their medical care.

However, we counsel against removing the 18-years age threshold that currently exists in all other states. The question of allowing minors – even those recognised as 'mature minors' – access to VAD is, in many quarters, a highly controversial and emotive one, that is yet to be tested in Australia.

If eligibility for mature minors is to be considered it must be based on evidence and demonstrated need and include input and guidance from relevant medical groups, including paediatric medical oncologists. As yet, we do not believe any case for change has been established.

6. Should a person be an Australian citizen or a long-term resident of Australia to access voluntary assisted dying in the ACT?

GGA believes the approach that a person has been resident in Australia for three years to meet the VAD eligibility criteria is correct. If limited to citizens and permanent residents, we risk excluding significant sections of the population who consider Australia their home.

Most Australian state VAD laws limit access to citizens and permanent residents to prevent people travelling to Australia only to access VAD laws. However, we have seen instances where this has become a barrier to access for people whose immigration status falls outside these categories but who otherwise would be considered to live in Australia permanently. As such, laws in Tasmania, Queensland and New South Wales have made exceptions so that residency for three continuous years (or 'ordinarily resident' for three years in the case of Queensland) is also sufficient.

GGA recommends the latter position as this allows access to a small but significant group of people who have not required a permanent residency visa or citizenship to remain in the country – as is the case for a range of Working and Skilled Visa holders; people from New Zealand; and British citizens who made Australia their home before current visa requirements were implemented in 1984.

Case Study

Julian Bareuther, terminal pancreatic cancer, denied access to VAD in Victoria

Julian Bareuther was among the first people to apply for VAD in Victoria after the law came into effect in June 2019.

Suffering intolerably with multiple medical conditions, including inoperable pancreatic cancer, Mr Bareuther wanted to end his life on his own terms through VAD with the assistance of GP Dr Nick Carr.

After an initial assessment, Dr Carr believed Mr Bareuther satisfied all the criteria under the law, except one: the UK-born man had never taken Australian citizenship, despite having lived here for 40 years.

Under the Victorian legislation, applicants for VAD must be an Australian citizen and have lived in Victoria for at least 12 months. Dr Carr had no choice but to deem Mr Bareuther ineligible.

Three months later, Mr Bareuther was found dead in his apartment, having asphyxiated himself using plastic bags and nitrous gas. Dr Carr had spoken to him just three days before.

"I am not a person who cries easily," Dr Carr told Australian Doctor. "But I sat at my desk sobbing when I got that report. It was one of the most awful days of my life."

Mr Bareuther's case was widely reported when Victorian Coroner Philip Byrne handed down findings into his death in June 2020.

Coroner Byrne wrote it was difficult not to feel sympathy for Mr Bareuther's plight. He suggested a level of discretion should be built into Victoria's VAD scheme, although he stopped short of making a formal recommendation, saying he wanted to avoid sailing "into a maelstrom".

Dr Carr, however, is less circumspect. He believes the Victorian VAD legislation failed Mr Bareuther – and himself as a VAD practitioner.

"[The law] was framed for people like Julian ... so they have a better, legitimate, safer and more peaceful option. That option was denied to him in a way that I'm sure law-makers never, ever intended."

Dr Carr wrote to the Victorian Coroner:

I first met Julian Bareuther on July 1, 2019. He came to see me as he had seen me in the media talking about Voluntary Assisted Dying. He had inoperable pancreatic cancer and was seeking my help. We met on several occasions.

The focus was almost entirely about his desire for control about the end of his life, and his request for voluntary assisted dying. He had full control of his faculties and while at times was despondent about the process, he was never at any time overtly depressed. Julian told me he had a history of agoraphobia and anxiety, treated by his regular doctor, but that this was well controlled and stable. He once asked me for scripts to save him having to go back to his own doctor for these, but otherwise I was not involved in managing his anxiety. I did not make any referrals for his anxiety.

I knew Julian for a short time. He was hugely relieved when I told him I could act as his coordinating doctor for voluntary assisted dying, and it was as if an enormous burden had been lifted from him.

When I discovered that he had never taken out Australian citizenship, we went to great lengths to see if he might still be eligible.

When I finally had to tell him that there was nothing more we could do, that he was not eligible, he was very upset and stopped seeing me. When I last rang him on September 21, 2019, he seemed resigned to the situation.

I personally was immensely distressed when I heard that Julian had killed himself.

Here was a lonely man, dying of a horrible cancer, who sought my legitimate help.

He was an Australian in every sense but a technical one, a previous taxpayer, a current Centrelink recipient and on the Electoral Roll.

Because of this technicality, he was denied the opportunity to access Victoria's Voluntary Assisted Dying scheme.

I had to tell him that I was unable to help him in the only way he wanted and as a result he ended up committing suicide.

I do not believe that this was what any of those who framed the law would have wanted to happen.

7. Given every Australian state now has voluntary assisted dying laws, is there any need for voluntary assisted dying in the ACT to be restricted to people who live in or have a close connection to the ACT?

GGA recommends the ACT does not enact local residency requirements as a first step in harmonising Australia's VAD legislation in this area.

The rationale behind state residency requirements was to ensure people did not travel to a particular state to access VAD, and overburden that state's system. It made sense when only Victoria offered VAD. However, it is GGA's view that local residency requirements are unnecessary now all jurisdictions but the Territories have passed VAD laws and simply impose an added layer of bureaucracy to an already complex process.

Australians with terminal illness who need support should be able to freely move to other parts of the country to be closer to friends, family or carers, or simply to spend their final days in the place of their choosing.

There is a small risk that people may travel to the territory to access VAD if they are deemed ineligible elsewhere, and that consideration needs to be given to possible stress being placed on local health systems. However, moving to another part of the country is a big undertaking, especially if you have a terminal diagnosis. Our view is that the number of people this is likely to involve will be small, and that restrictive residency requirements cannot be justified on these grounds.

If a residency requirement is to be included, GGA recommends an exemption, as Queensland and New South Wales have done, if the person has substantial connection to the ACT.

Trish Walker relocated following a motor neurone disease diagnosis

When first diagnosed with motor neurone disease (MND) in 2020, Trish Walker relocated to Melbourne from Adelaide to be closer to her daughter and to have access to an assisted dying law (South Australia's VAD law was yet to pass).

Another reason was the excellent quality of care available in Victoria for people with MND. "Victoria has got, probably, the best MND care in Australia," her daughter, Miki, said.

However, because of the residency requirements in the VAD legislation (a person must have lived in Victoria for 12 months to be eligible) Trish wasn't able to immediately begin the application process. This meant by the time she could apply, her MND had progressed to the point where she had trouble speaking and moving.

"When she got here, she could write, she could speak; she would have been able to make the request easily. With MND, you know, you can lose so many functions very quickly. Allowing that request to be made straight away would have taken away a lot of stress," Miki said.

"Instead she had to wait 12 months before she was eligible. I understand why that is. But I think we have to look at the practicalities. Terminally ill people don't really work to deadlines well, or timeframes. "

Despite the barriers faced, including finding neurologists and care facilities willing to participate in VAD, Miki said her mother's VAD death was a blessing.

"For someone who was unable to speak and to move and to have that, to have control over that and to know that she could choose when she had had enough, that's a really huge thing to be able to give to someone.

"So, I fully support VAD. I just hope that when my time comes it's a little bit less bureaucratic, and there are fewer hurdles."

The process for request and assessment

8. What process should be in place in the ACT to ensure that an eligible person's access to voluntary assisted dying is safe and effective?

Provided current issues that are impacting access to VAD can be addressed (i.e. a lack of VAD-trained doctors, inflexible residency requirements and obstruction because of a medical practitioner or institution's objection to participation) GGA believes the VAD request and assessment process and safeguards mandated in Victoria, WA, SA and QLD are working well and offer a clear and workable pathway through the process (excepting the requirement that the coordinating or consulting practitioner must also be a specialist in the patient's disease, per Victoria's law, which we do not support).

9. If a coordinating health professional or consulting health professional declines to be involved in a person's request for voluntary assisted dying, should they be required to take any particular action?

GGA recommends the ACT include a duty for health professionals to provide information to a patient if they cannot accept a VAD first request; at a minimum, contact details for VAD Care Navigators (or equivalent service).

A health professional may decline to be involved with VAD, a right enshrined in all states' VAD laws. This may be because they have a conscientious objection. More commonly, however, doctors tell us they decline requests on other grounds; for example, lack of time or because they are unable to take on the emotional load.

Dr James Hurley, VAD practitioner and consultant physician in Western Victoria, said:

"Not many medical practitioners are conscientious objectors. In my experience, many more practitioners do not feel 'comfortable' in the unfamiliar space of VAD. They would certainly not be able to invest the time required to complete the VAD training and the minimum five hours required for each patient. Indeed, all three palliative care practitioners in my region are [non-participants] on the basis of personal reasons rather than religious reasons."

Whatever reason a medical practitioner gives for declining a VAD request, referral is a standard practice in other areas of health care, including abortion. Providing relevant contact details or up-to-date information costs health professionals little in time or effort but ensures terminally ill people do not hit brick walls when trying to access information in a timely fashion.

10. Should witnesses be required for a person's formal requests for voluntary assisted dying? If so, who should be permitted to be a witness?

GGA recommends the ACT follow the approach of the majority of VAD laws, which requires a person's final written request for VAD to be witnessed. (Tasmania is the exception, requiring no witnesses at this step in the process). However, we suggest the presence of the coordinating practitioner and a single adult witness is sufficient – rather than two – to make the process as simple as possible while also ensuring a safeguarded process. The witness should not be a family member or a beneficiary of the person's will, and should be chosen by the individual.

We support the Victorian approach that the coordinating practitioner must also attend because we feel it is important for the witnesses to be able to ask questions of the coordinating practitioner to ensure they are comfortable with providing their signature. While this attendance would ideally be in person, there may be circumstances when telehealth is a necessary compromise and this option should not be excluded.

"I make it very clear to the witnesses that your role is not just to witness the signature, it's to witness the person does have the mental capacity, that's their own free will. They know exactly what will happen when they take the medication and so on. And once they get the medication, they don't have to take it. So the witness needs to be reassured that all that's the case before they can sign."

- Dr John Stanton, GP, West Brunswick

Regarding the signing process, GGA supports the provision contained in other states' legislation of alternative options for applicants who are unable to write or sign their formal request, including the use of alternative communication such as gestures or disability aids. These forms of communication are valid and witnesses should have no problems assessing them as a true and proper request for VAD.

11. Should the process for seeking access to voluntary assisted dying require that a person take time to reflect (a 'cooling off' period) before accessing voluntary assisted dying?

GGA supports the inclusion of a minimum timeframe between first and last request to enable reflection by the person about the decision to access VAD. However, this time period should be as short as reasonably possible; for a person who is terminally ill and experiencing enduring and unbearable suffering, even 24 hours is a very long time to wait to end that suffering.

Katie Harley, whose father, Phil, died of multiple metastatic cancers applied successfully to have the nine-day cooling off period contained in the Victorian legislation shortened. Nonetheless, it was a stressful time for Phil and his family.

"10 days for someone who is in agony with every breath that they take is, you know, it's a long time... I could see Dad was very deflated about that... so, we had to see another doctor. She had to then come in and ascertain that Dad was in his right mind again, ask him the same set of questions."

Katie Harley and father Phil Ferrarotto

Phil, who had metastatic bowel cancer, chose VAD in Victoria in 2019



All states have specified that the waiting period can be shortened if the person is at risk of dying before the time has elapsed. WA, Queensland, and NSW also allow an application to be expedited if the person is at risk of imminently losing capacity. We support this provision for the ACT.

12. Should a person have a choice between self-administration and administration by an administering health professional of a voluntary assisted dying substance?

GGA supports as much choice for the dying person as possible. This includes who administers the VAD medication.

13. Should one method of administration be prescribed as the default option, or should methods differ depending on the circumstances? Does this need to be prescribed in legislation, or is it a matter best determined between the registered medical practitioner and patient?

GGA supports the right of a patient to choose between self and practitioner administration. No one method should be prescribed as a default option.

If a patient chooses practitioner administration, medical professionals should be allowed to opt out of providing it. In that case, they should be required to hand-over their role to a practitioner who does not have an objection. However, this practitioner then must also independently form the view that this patient meets all eligibility criteria. To avoid delays that may extend the suffering of a person who is dying, it is important that the regulations / implementation establish a protocol that can expedite the transfer of authority from one qualified medical professional to another with minimal delay, in order to provide practitioner administration.

It should be noted that experience from WA shows that increased patient choice around the method of administration has resulted in a far greater number of practitioner administrations compared to self-administrations; in WA, 70-80% of administrations are doctor administrations, compared to 20% in Victoria. This is likely the result of wording in the WA legislation that precludes the person receiving any assistance in the preparation or handling of the VAD substance prior to self-administration. GGA recommends the ACT pay special attention to the wording of its legislation in regard to administration methods. Self-administration should not be made so onerous that practitioner-administration becomes the default method by proxy.

GGA also urges the ACT parliament to consider wording that allows (or at the very least does not preclude) an alternative form of self administration, namely self-administered IV delivery. This would allow patients who can no longer swallow or ingest the VAD substance the option of this alternative form of self-administration if that is their wish. It would also go some way to lift the burden of administration from practitioners, many of whom support VAD but hesitate to be involved in administering the substance.

Victoria and South Australia's laws both require a person to be able to 'self administer and digest' medication, which precludes IV self-administration. All other states' wording could technically accommodate IV administration, but it has not yet been practised in Australia.

14. Are additional safeguards required when an administering health professional administers the voluntary assisted dying substance (as compared with self-administration) and, if so, what safeguards would be appropriate?

Yes, see next question.

15. Should administration of the voluntary assisted dying substance to an eligible person be witnessed by another person? If so, who should be permitted to be a witness?

GGA recommends a witness, ideally a supportive friend or family member of the patient, be present when practitioner administration occurs. This can be reassuring for the person accessing VAD, their family and the administering health professional.

16. What safeguards are necessary to determine whether or not a person has taken the voluntary assisted dying substance, and to return the voluntary assisted dying substance if it has not been taken?

GGA recommends the ACT adopt the provisions contained in other states' VAD legislation regarding the confirmation of use and the safe return of any unused VAD substances – namely that the coordinating or administering practitioner be required to notify the VAD Board of the use of the medication and the disposal of any unused substances (in the case of practitioner administration) and that a contact person be appointed who is responsible for notifying the coordinating practitioner of the VAD death and returning any unused substances (in the case of self-administration) to the designated authority (eg; a central pharmacy).

**“It gives me comfort
just knowing I have it
there. When the time
comes, will I do it?
I don’t know.”**

**Phil O’Keefe,
motor neurone disease.**

Bacchus Marsh, Victoria.
Pictured here with his partner Triss.



The role of health professionals

17. Who should be permitted to be a person's coordinating health professional or consulting health professional? For example, a registered medical practitioner, a nurse practitioner, or someone else?

GGA recommends the ACT adheres to the existing Australian model regarding who should be permitted to conduct VAD assessments. Only registered medical practitioners (doctors) should be able to act as a coordinating practitioner or consulting practitioner to assess the person's eligibility. Before assessing a patient, both doctors must be required to complete approved training in assessing the eligibility criteria; assessing decision-making capacity of the patient; and identifying risk factors for abuse.

18. What minimum qualification and training requirements should there be for health professionals engaged in the voluntary assisted dying process?

GGA recommends that registered medical practitioners who act as coordinating or consulting practitioners should either have a specialist qualification with five years' experience post-qualification, or a minimum of ten years' postgraduate experience if they are not a specialist.

Given the limited number of medical specialists in the ACT, and to ensure there is appropriate access to VAD, GGA does not recommend mandating that the coordinating or consulting practitioner must also be a specialist in the patient's disease.

19. Which health professionals should be able to administer the voluntary assisted dying substance? For example, a registered medical practitioner, a nurse practitioner, registered nurse, or someone else?

GGA recommends that only medical practitioners (doctors) or a suitably qualified nurse practitioner be authorised to administer the VAD substance, and to be in attendance, if requested, at self-administration. We believe administration should not be undertaken by registered nurses, unless they are under the direct supervision of a suitably qualified medical practitioner.

20. Should registered health practitioners or other health professionals be free to initiate a discussion about voluntary assisted dying, providing information alongside other treatment and management options such as palliative care, where appropriate?

GGA believes health professionals must be able to raise VAD with their patients. VAD is a legitimate, legal end-of-life choice and patients have a right to know about all the available options. We support the safeguard that all other appropriate treatment options should be discussed in the same consultation, including palliative care.

We recommend every effort is made to ensure health professionals can have open conversations about VAD with their patients, without fear of legal repercussions.

Limiting health professionals' ability to discuss all treatment options with their patients has the potential to discriminate against certain members of the community. Those people who are poorly informed, or those who do not speak English as a first language, are likely to be less aware of their options as a result, particularly given there have not been official public information campaigns about VAD in Australia.

On this basis, it is our view that medical practitioners should not be censored on the conversations they can have with their patients, and they need to be able to raise the option of VAD with patients without fear of being reported for disciplinary action. As noted by the WA Committee, Victoria – and now South Australia – are the only jurisdictions in the world with assisted dying that prohibit health practitioners from starting such a conversation.

GGA supports the integration of VAD choice into Australian care provision. VAD is now a legal medical treatment, available to those who meet strict criteria, and should not be treated differently or exceptionally within health care. It should also not carry stigma for the people who seek to use it. VAD will work best, and the highest quality care will be offered, when it is given equal footing with other end-of-life care options.

“One of the most important things that I think should be changed in the legislation that doctors are not allowed to bring it up in a consultation. You can talk about palliative care, but you’re not allowed to tell them about the VAD option, which is a bit mad to me”

Dr Andrea Bendrups

GP and Rheumatologist,
Royal Melbourne Hospital



“I think the other thing that’s had an effect on is not only the doctor-patient interaction but the nurse-patient interaction on the ward, other health care professionals and the patient because no one is really sure about whether that means every time that this needs to be raised they need to talk, they need to wait for the patient to raise it or not.”

Dr Cam McLaren

Oncologist, Melbourne



“It’s like saying to someone with heart disease, I can give you pills but not tell them about the option of surgery. And voluntary assisted dying is one of their legal rights of medical care and for a doctor not to be able to inform some of that is ridiculous. The idea that any doctor is going to foist voluntary assisted dying on people is just an insult.. It’s not gonna happen.”

Dr Nick Carr

GP, Melbourne



21. Should health professionals be required to provide certain information to a person who asks about voluntary assisted dying, in addition to providing information about other treatment and management options such as palliative care?

To assist medical practitioners with this and to ensure that balanced, patient focused information, consistent with good end-of-life care, is given to each person who enters into such a conversation, GGA recommends that printed /electronic literature – or perhaps a link to an explanatory video – be created by the Department of Health, in relevant languages and accessible formats, outlining; the process of VAD, what to expect, how to prepare for a VAD death and, importantly, advice for loved ones on navigating VAD grief and bereavement, a unique form of loss that brings its own issues and challenges.

22. What categories of persons or professions should be permitted to conscientiously object to being involved in voluntary assisted dying? Should this be limited to registered health practitioners?

GGA considers the right of any medical professional to object conscientiously to VAD to be a bedrock of the law. Legislation must specifically permit medical professionals to 'opt out' without sanction or criticism. This may be on the grounds of religion, or for practical reasons such as lack of time, emotional capacity or an unwillingness to participate in an unfamiliar process. Whatever their reason, a doctor or other medical professional has a right not to participate.

However, this right is not absolute. While health professionals' rights must be protected, so must the rights of a dying person to access a legal medical treatment. This means certain levels of participation, such as the duty to refer a patient in the event that they cannot accept a first request for VAD, can and should be imposed.

Equally, the right to conscientiously object is not a right to conscientiously obstruct. Any effort to do so should be punishable within the Act by financial penalty.

23. Should health professionals who conscientiously object or who choose to not participate in the voluntary assisted dying process be required to declare their objection or non-participation to a person who is or may be interested in accessing voluntary assisted dying?

Yes, and at the outset of the application process, but they should not be obliged to provide reasons.

24. Should health professionals who conscientiously object to voluntary assisted dying be required to refer a person to other health professionals? Is there anything else that health professionals should be required to do if they conscientiously object, such as provide certain information about voluntary assisted dying?

GGA recommends there be a duty to disclose if a health professional – or someone connected to the process of VAD in some other way, for example someone working in aged care – is unable to support a person with their request for information about VAD. They should do this during the conversation when VAD is raised, in a timely manner, to avoid causing any delays for the person seeking VAD.

However, we do not support a requirement that they declare the nature of their objection or non-participation; the only pertinent detail is that they are unable to assist. In this instance, GGA strongly recommends a duty to refer the person on to someone who can help, for example the local Care Navigator Service (or equivalent). This is vital to the safe and effective operation of VAD and we have detailed our view on this in Q9.

GGA recommends the ACT implement guidance to the effect that an objecting health professional must not attempt to influence or change that person's mind in any way. This is likely to cause distress and could constitute coercion or harassment.

"Our only request of any of our staff who objects to the process is that if a patient does bring it up, they explain to them where they can access information about the program or how to explore it. And that they're also welcome to explain why they don't particularly participate. That's what the law requires. I think that's important."

- Dr David Speakman, Chief Medical Officer, Peter MacCallum Cancer Centre

The role of health services

25. Should a health service be permitted to not facilitate voluntary assisted dying at its facilities, for example at a residential aged care facility, a hospital, or accommodation for people with a disability?

GGA argues that an institution does not have a conscience and, as such, should not be able to conscientiously object to VAD, though individuals within the institution may.

In particular, we hold that any hospital or health facility which receives public funds should be denied the right to refuse to participate in the provision of VAD on their premises, regardless of their philosophical underpinnings.

In support of this view, we cite recent research released by the Australian Centre for Health Law Research, entitled '[Harms To Patients Caused By Institutions Objecting To Voluntary Assisted Dying](#)'.¹

26. If a health service wishes to not facilitate voluntary assisted dying at its facilities, what is the minimum the provider should be required to do so that a person's access to voluntary assisted dying is not hindered?

Should the ACT not wish to go down the path of rejecting, in entirety, institutional objection, GGA recommends that any institution that prefers VAD not to take place on its premises must inform potential patients/residents of this policy prior to admission of the person. Their position should also be part of any published literature (print, digital, or other) where they advertise, or inform people about, their services. This avoids potentially harmful situations if patients wish to apply for VAD in the future.

A hospital that is religiously or philosophically opposed to VAD, if requested by a person in their care to provide VAD, must immediately respond, informing them they cannot support that request. They must then facilitate transfer to a suitable facility in a timely and professional manner. Until such transfer can be arranged, no institution should be allowed to block access to the person making the request of: either the co-ordinating or consulting practitioner; the care navigators; the pharmacist; or anyone else involved in that person's legal right to access VAD. Any efforts to do so should be punishable by a significant fine.

If transferring the patient is impossible, or if it is likely to cause increased suffering to the patient, or if the patient is at risk of losing decision-making capacity as a result, the hospital must allow external VAD practitioners and personnel onto the premises to fulfil the person's VAD wishes. This includes assessors, care navigators, witnesses and pharmacists. This must be non-negotiable.

¹ White, Ben, Jeanneret, Ruthie Emma Hart, Close, Eliana, & Willmott, Lindy (2023) Harms to patients caused by institutions objecting to voluntary assisted dying: Research briefing. <https://eprints.qut.edu.au/238638/> Accessed April 2023.

Health services, such as aged care facilities and retirement homes, however, are in a different category, as they have legal status as people's permanent homes. No person should be blocked from accessing legal medical treatments in the privacy of their own home. While individual employees may invoke their right to opt out of participating, these facilities must not block access to VAD services in any way.

There should be significant financial penalties built into the Act for institutions, or individuals, who block, harass, or attempt to coerce people from their legal choice of VAD.

GGA strongly recommends the health department prepare guidelines and education materials for health facilities during the implementation period that outline these expectations and obligations to avoid unnecessary confusion and suffering once VAD begins operation.

We also urge the establishment of clear pathways for complaints to be made against institutions and/or individuals who attempt to coerce or harass people out of their VAD choice. As well, that there is capacity for the Review Board and/or the Department of Health to receive such complaints, and to enforce appropriate penalties.

“Lying in bed with
a bucket each side
draining my kidneys.
Where’s the dignity?”

It will be a load off
my mind just knowing
VAD is an option.”

**Peter Bailey,
acute kidney failure.**

Narre Warren, Victoria.

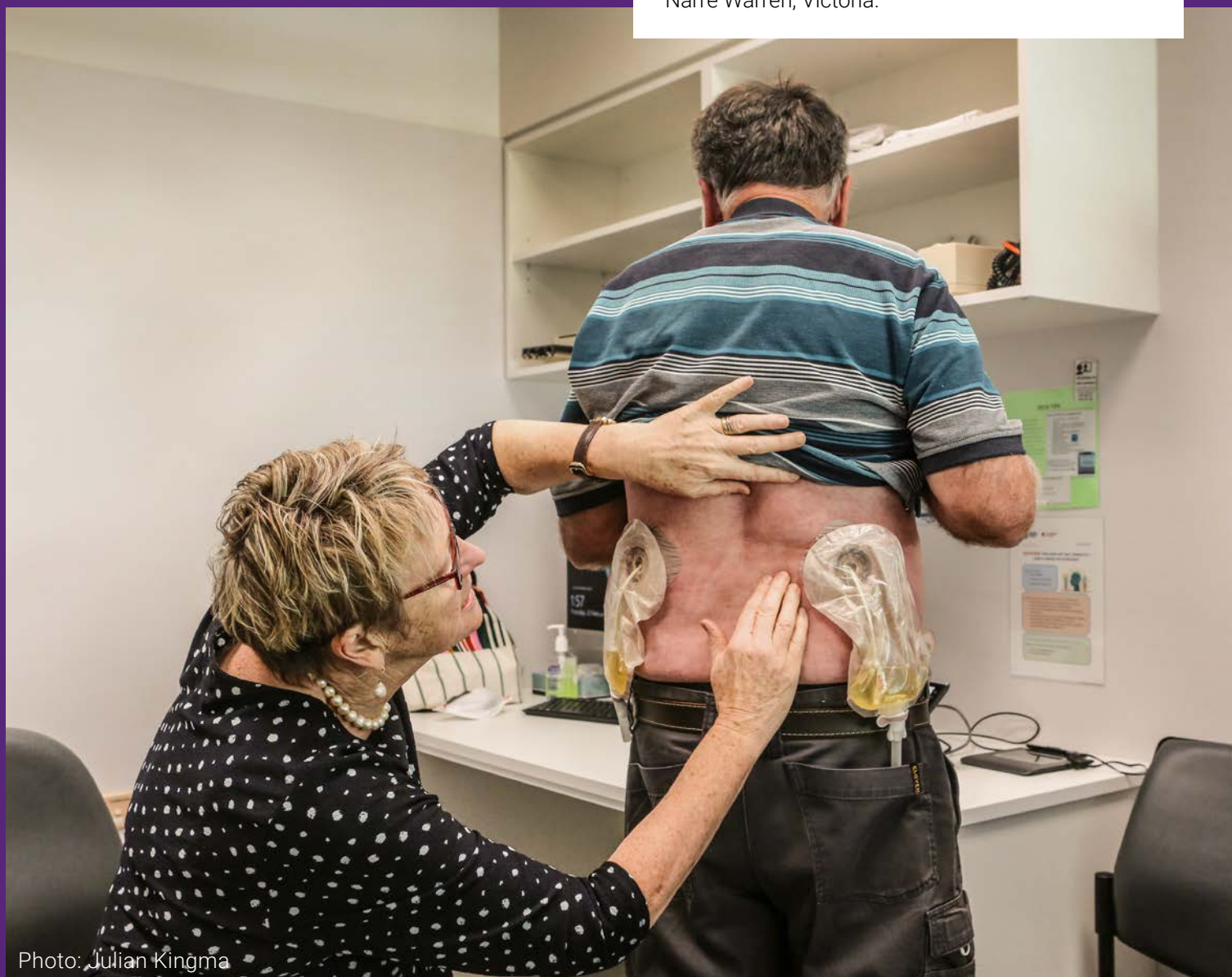


Photo: Julian Kingma

Death certification and notification

27. Should information about the Registrar-General's discretion for death certificates under section 44 of the *Births Deaths and Marriages Registration Act 1997* (ACT) be made available to families who may require support after a person dies by accessing voluntary assisted dying?

See next question

28. What should be recorded as the cause and manner of death for a person who has died by accessing voluntary assisted dying?

GGA supports the requirement that VAD be listed as a contributing cause of death only on the Medical Certificate Cause of Death, and only if this information remains publicly unavailable. GGA counsels against providing this information to family members or others not directly involved in the person's end-of-life care.

Death certificates are used for a range of purposes, and there is no reason to include information about VAD on such a public document. This is to preserve the privacy of the person, their family, and health practitioners. While we have not seen a draft of the proposed ACT legislation, we assume it will provide access to voluntary assisted dying under limited circumstances for terminally ill people at the end of their life. They would die from that condition even if they did not choose VAD. Other medical treatments or actions taken that may hasten death such as stopping dialysis or withdrawing other life sustaining treatments, are not included on death certificates.

In our view, it is sufficient to list VAD as a contributing cause of death on the Medical Certificate of Death. This allows information to be collected on VAD, but also protects the privacy and confidentiality of the person involved and avoids conflicts with extended families or cultural groups.

Oversight, reporting and compliance

29. What sort of oversight mechanisms are needed to ensure voluntary assisted dying is safe and effective? In particular, should oversight focus more on retrospective compliance or prospective approval? Should oversight mechanisms be independent from government?

GGA strongly supports and recommends the creation of a review board, independent of government.

We believe a board or commission is best served by members with a wide range of experience in public health, consumer advocacy, palliative care, and legal services.

For example, Victoria's Voluntary Assisted Dying Review Board was chaired through its first two years by a retired Supreme Court judge and included amongst its members: a neurologist, an oncologist, a palliative care specialist, a professor of nursing, and a consumer representative. Other states' review boards have similar varied expertise.

GGA recommends a culturally diverse mix of members and inclusion of a representative from the disability communities, in recognition of their particular concerns about how they are regarded by the medical community.

Any review board or commission should focus on retrospective compliance. Real-time compliance is the responsibility of the VAD Secretariat or similar body tasked with facilitating the step-by-step application process.

There should be provision for review of certain administrative decisions, such as residency status or exemption by discretion before an independent tribunal; however, we do not support any move to include reviews of decisions relating to whether a person has capacity or is or is not acting voluntarily and without coercion. There will have already been assessments by two independent doctors (and provision for them to seek further medical opinion if in doubt). We feel that allowing prospective appeals on these issues leaves the door open to people who may disagree with the option of VAD, such as family members, or even health professionals, to unduly frustrate the process.

30. If an oversight body is established, should this body review or approve compliance with key stages in the voluntary assisted dying process as a person is progressing through the process? If so, what should these key stages be?

While there should be a comprehensive system of checks throughout the process, there needs to be a balance between the desire for transparency and oversight and the need to avoid unnecessary administrative burden for those delivering VAD and to ensure any oversight does not lead to delays in people accessing VAD.

For consistency and to allow data insights to be shared across jurisdictions it would be preferable to align the ACT reporting metrics with those already in place for other established VAD processes.

A separate Secretariat can provide a comprehensive system of reporting and identify any breaches. The review board has the power to refer breaches to the police, to AHPRA, to the coroner or to the medical board. Medical practitioners, and others involved in the process, must report in real time. This has the twin effect of reminding them of all their responsibilities under the law and of the high likelihood that any breaches will be detected and may be investigated.

31. Should mechanisms be available to review the decisions of a coordinating health professional or consulting health professional in relation to a person's eligibility to access voluntary assisted dying? If so, what kind of mechanisms, and what aspects of health professionals' decisions should be reviewable?

GGA believes the role of the oversight body should focus on retrospective compliance with the law and not the contemporaneous approvals process. The coordinating and consulting doctors are best-placed – and best-qualified – to decide the eligibility of the patients in their care. Similarly, the health department secretariat is best placed to deal with compliance issues related to paperwork and the 'machinery' of application, such as the practitioner portal.

32. What protections might be necessary for health professionals, and potentially others, who act in accordance with voluntary assisted dying legislation in good faith and without negligence?

Please refer to the provisions contained in other Australian VAD laws, specifically Section 10 (Protection from Liability) in the Queensland Voluntary Assisted Dying Act 2021.

33. Should there be specific offences for those who fail to comply with these requirements?

Yes, GGA supports the inclusion of offences such as "Falsifying a form or record required to be made under the operation of the legislation" as outlined in other Australian VAD laws. Please refer to the provisions contained in Section 9 (Offences) in the Queensland Voluntary Assisted Dying Act 2021.

Other issues

34. What other laws might need to change in the ACT to enable effective access to voluntary assisted dying?

We have no specific recommendations here.

35. Are there experiences elsewhere in Australia or internationally that the ACT might usefully learn from in the development of its own approach to voluntary assisted dying?

We urge the ACT to look closely at the experience and evidence from Victoria and Western Australia, where VAD laws have been operating for several years, and more recently the experiences emerging from Tasmania, Queensland and South Australia.

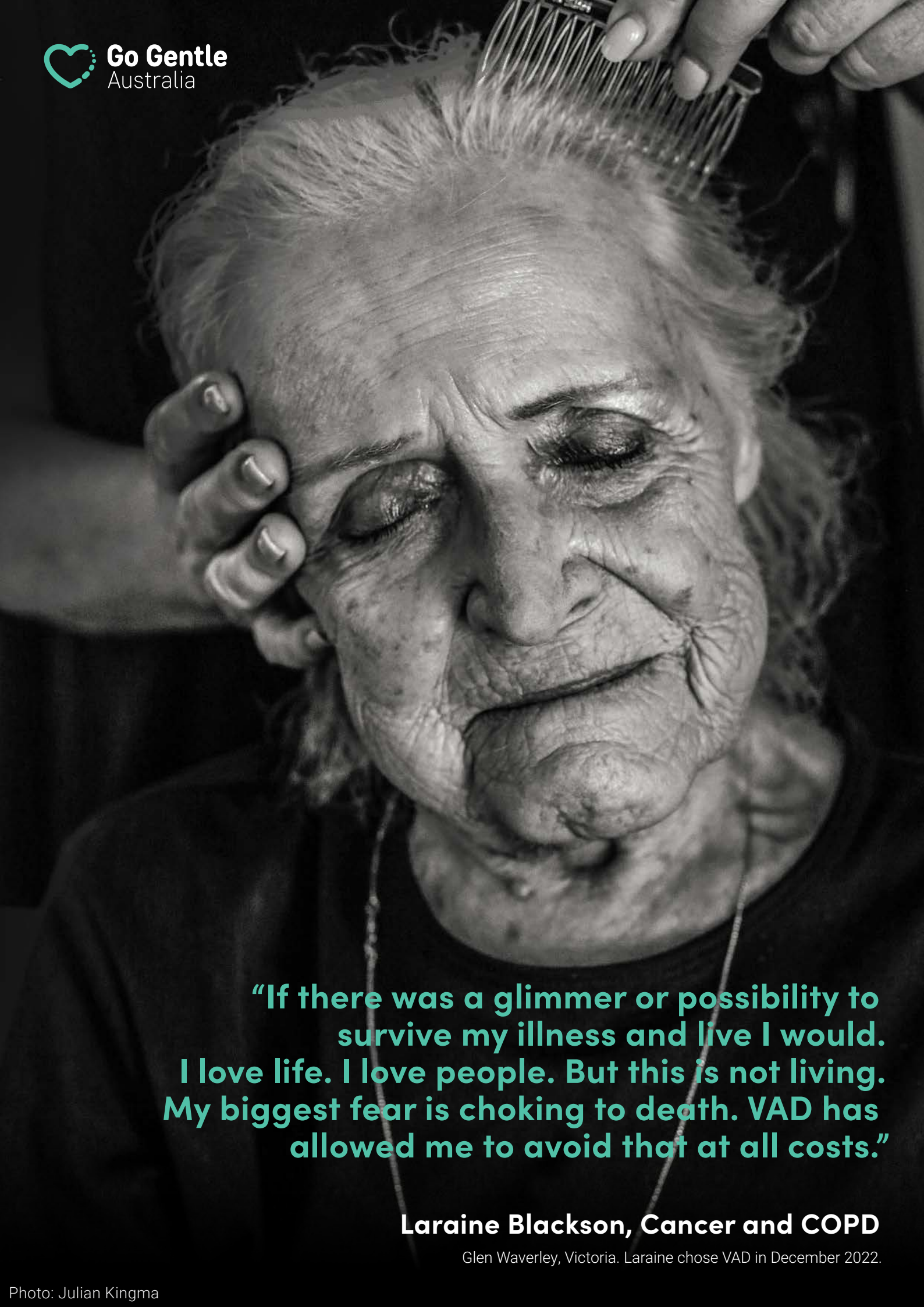
Some of these Victorian and WA experiences are detailed in the GGA publication [VAD in Action: What we've learnt from Victoria and Western Australia](#) (July 2022).

36. Are there any other matters you think should be considered in implementing voluntary assisted dying in the ACT?

First, part of the Cth Criminal Code is negatively impacting VAD practice as there is ambiguity as to whether telecommunications such as Telehealth can be used in the VAD process. The Standing Council of Attorneys General is soon to look at this issue in detail and we would greatly appreciate the support of the ACT Attorney General to urge the issue's swift resolution.

Second, VAD services should be properly funded at a territory level, including provision to ensure doctors can be properly remunerated for their VAD workload. At present, the Medicare Benefits Schedule (MBS) general explanatory notes (GN.13.33) state that "euthanasia and any service directly related to the procedure" will not attract Medicare benefits. The only exception is "services rendered for counselling/assessment about euthanasia". In other jurisdictions, this means the time spent by many health professionals on VAD goes unpaid, which is unfair and unsustainable.

GGA can provide full briefings on both these issues.



"If there was a glimmer or possibility to survive my illness and live I would. I love life. I love people. But this is not living. My biggest fear is choking to death. VAD has allowed me to avoid that at all costs."

Laraine Blackson, Cancer and COPD

Glen Waverley, Victoria. Laraine chose VAD in December 2022.