1. **Do you support making VAD legal in the NT?**

I strongly support making VAD legal in the NT. I believe this will provide NT residents with access to expanded end-of-life care choices, in line with what is available across other states and territories in Australia, and in accordance with contemporary community expectations for patient-centred choice in medical treatment.

In my opinion, there is no downside to enacting VAD legislation if adequate safeguards are included in the legislation. The experience of VAD elsewhere in Australia and overseas, show that legalization can empower individuals to make choices about their lives and the terms of their deaths, preserving personal autonomy and granting a sense of control. It can provide relief for patients who are suffering from terminal illnesses and intolerable pain or other suffering, allowing them to die at a time and place of their choosing.

While I am in support of VAD, I do not dismiss concerns about abuse or slippery slope arguments around the potential risks to vulnerable people. Vulnerable populations include patients with disabilities, intellectual impairment, elderly people, patients with severe psychiatric conditions or children, if the capacity exists to pressure or coerce a person into accepting an early death against their will. However, I believe with stringent safeguards and robust evaluations by multiple medical professionals, with clear eligibility criteria and ongoing monitoring of the practice, that risks of abuse can be minimised. The critical argument is in the use of the word "voluntary". If coercion is not possible and decision-making capacity is mandatory, then the risks are minimal.

Most arguments against VAD appear to come from (a) religious groups that posit deeply held beliefs around ideas that people should not play god, or (b) doctors who believe that VAD is fundamentally at odds with their professional demands to preserve life at all costs. To the religious groups, I say that their members can choose to abstain from accessing VAD if they do not believe in it, in the same way that religious groups can abstain from eating the meat of particular animals or consuming alcohol. The beliefs of churches should form no part in the decisions of a secular state, and public opinion overwhelmingly supports the introduction of VAD legislation. To doctors who do not wish to participate, I say that these professionals are able to exercise their right to conscientious objection, without preventing other people from exercising their right to die with dignity. All views can be encompassed, when coercion is not possible and participation is voluntary.

Where VAD has been available for some time, it is noted that some patients who seek access to this treatment option, do not go through with the process. Rather, for some of these patients, knowing that they have an option to end their life with dignity and control is sufficient to relieve the extreme anxiety of knowing they are otherwise likely to die with significant suffering. Providing a level of control over the degree of pain or lack of bodily control that a person must experience before dying can be enough, and we should not discount this very real psychological fear and suffering as part of the process of dying.

Since VAD was introduced in Victoria in 2019, thousands of people have accessed this process without negative consequences. The process is increasingly accepted as integral to ethical and appropriate end-of-life care. Having watched a family member die a prolonged death from emphysema, and as a patient with a chronic illness that causes severe muscle weakness including, at times, life threatening respiratory weakness, I know that I would not choose to die from respiratory failure if (a) I had a terminal diagnosis, and (b) I had a choice to die on my own terms. Restricting oxygen from a person or animal is a terrifying experience; being in relentless pain is also horrifying. If an animal is suffering in this way, we expect that veterinarians will provide access to euthanasia, or a "good death". Humans should also be able to access the kindness and compassion of a peaceful death, when the suffering of life becomes unbearable.

Finally, at present, palliative care options include terminal sedation, the use of narcotics to the point of oblivion, and withholding food and water from a dying person. All of these medically sanctioned processes are done in the full knowledge that they will hasten the death of the patient. The only difference is (a) the intention of the medical practitioner overseeing care, and (b) the time it takes to die. All palliative care options can be drawn out and horrific to witness. VAD would give dying people the option to end their lives quickly and painlessly, and should be supported.

2. What eligibility criteria should a person need to meet before they can access VAD?

I support providing access to VAD for patients with a terminal illness, or a chronic condition that will cause progressive debilitation, loss of personal autonomy and bodily control and eventual death. While I believe there should be guidelines around a terminal diagnosis being likely to result in death within 12 months, I also feel there should be some flexibility around the timing of access. It can be very hard to predict when someone is likely to die. For some eligible conditions, people may wish to proceed to end their lives while they still have physical control over their bodies – for example, patients with a confirmed diagnosis of motor neurone disease may not wish to wait to access VAD because they may lose control of swallowing. I support the concept of having two medical practitioners being consulted, but also feel there should be access to a "third umpire" in the form of a psychologist, who could be called on to assist with decisions in complex cases. Another option for additional decision making could be the reinstatement of and referral to an NT Health ethics committee (currently non existent), which would be consumer led. This committee was disbanded for no discernible reason, but referral for VAD cases that lack clear reasons could be helpful.

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

People living in remote areas and people from any cultural background ought to be able to access VAD by utilising modern communication methods. To begin with, aboriginal communities should be consulted to find out if there is likely to be any demand for this service. Traditional owners, local authorities and ACCHOs need to be involved in policy design so that:

- Aboriginal Health Workers or nurse practitioners can explain VAD in local language, using culturally appropriate concepts and metaphors.
- Resources are available in plain English and in language, including visual/graphic formats to reach people with low literacy.

The NT could provide access to remote areas by:

- providing secure access to telehealth for VAD. We are already able to access high quality telehealth services for most medical specialties including psychiatry; end-of-life care should not be any different.

- amending or seeking an exemption from the federal criminal code that currently prevents using telehealth to discuss VAD; this should be considered a form of discrimination in this context, and needs to be revisited.

- consider removing barriers, by organising combined visits (two practitioners at the same time, with electronic records). Remote community health services could provide access, with an AHP, nurse or nurse practitioner present in the room during the consultation.

- adequately resourcing the training of remote area GPs, nurses and AHPs in the groundwork associated with accessing VAD, such as eligibility assessments.

- including VAD in palliative care, and providing outreach services.

- evaluating existing controlled medication supply chains, so that we can be sure that VAD medication can be safely and reliably delivered and administered in remote locations.

Given the historical mistrust of government health interventions in aboriginal communities (e.g.: the 2007 emergency intervention in the NT), it would be important to provide very clear, culturally appropriate information campaigns to explain eligibility, what the safeguards are, and how to access the process. I am not personally convinced that current NT government processes are up to this task, given recent lacklustre efforts to embrace community expectations around important issues such as the Territory Coordinator legislation. Rushing through legislation without listening to consumers and without incorporating their feedback in decision making, causes harm, engenders mistrust and lacks transparency and accountability.

4. **How could the NT monitor the process to ensure VAD is delivered safely and effectively?**

Robust safeguards in the legislation should include that:

- Medical practitioners who do not support VAD on religious or other grounds, are permitted to be conscientious objectors and abstain from participating, but must provide and not obstruct access to an alternative pathway for their patients (referral to another practitioner).
- Medical services who do not support VAD (e.g.: hospitals, aged care or disability services owned by religious organisations) do not obstruct the capacity of medical practitioners to provide all options for end-of-life care to their patients.
- People making a request to access VAD medication must be assessed as making an autonomous choice via a voluntary and informed request to more than one medical practitioner, to avoid the possibility of coercion, convenience death or elder abuse.
- For each request, there should be:

    - Two independent assessments — with one assessor being familiar with the person's cultural and social context.
    - Protection against coercion — private consultations, without family present where appropriate, &/or with an unrelated interpreter.

- Ongoing monitoring and safety should be conducted by:

    - Clinical oversight and reporting — there must be a VAD Review Board ensuring compliance and transparency, which the government of the day and department executives cannot override and dismiss. Examples of this include the recent decision of the NT Health CE to dismiss the NT-wide Health Advisory Committee, and an earlier decision to disband the NT Health Ethics committee. These consumer groups previously provided community oversight across a range of health-related issues, but have been removed with ease and without explanation. Embedding a review board, which must include consumer representatives, should be included in the legislation to ensure there is adequate oversight over the monitoring. The services providing access to VAD should not be monitoring themselves.
    - Opt-in provider model — so that practitioners are not forced to participate, but the system ensures that patients are referred promptly to willing providers.

- The NT should adopt VAD laws in line with those of other states: with rigorous eligibility and approval processes—including requiring two independent doctors, a terminal prognosis, multiple patient requests, and criminal penalties for misconduct, so that coercion or abuse are exceedingly unlikely.