Submission to the VAD Inquiry
Heads of Department – Alice Springs Hospital

Thank you for the opportunity to contribute to the discussion of proposed Voluntary Assisted Dying legislation for the Northern Territory. We provide these comments in relation to the likely implementation of Voluntary Assisted Dying in the NT, from our perspective as senior clinicians committed to the safe and culturally appropriate delivery of health care services across the whole of Central Australia.

Summary of our recommendations and comments

1. While we neither support nor oppose the introduction of VAD legislation, we wish to express our concerns about the likely impact in our community, and our responses are intended to make the Inquiry aware of specific aspects of the Central Australian cultural context that should be taken into account if VAD is being legislated and implemented in the Northern Territory
2. We draw attention to the irony of potentially allocating resources to ending people's lives, when for many in our Central Australian community there are gaps in the delivery both of basic health services and the social infrastructure to enable a reasonable quality of life
3. We support an estimated 12 month prognosis for all diagnoses as an eligibility criterion
4. We do not support a gag clause, however patients should be informed of their options for palliative care at the same time that VAD is discussed with them. We recommend that a code of conduct should be developed to guide clinical practice.
5. We support a centralised, stand-alone model of service delivery, outside the hospital system. Physician administered VAD should not occur in NT Health facilities, and specifically not in palliative care. Telehealth is not an appropriate modality for assessing patients for VAD eligibility.
6. A number of suggestions are made about doctors' roles in providing VAD. The key suggestion is that only doctors employed by the VAD service should be able to undertake VAD.
7. We support the role of VAD Navigator.
8. We believe senior pharmacist involvement will be required as part of the VAD service, and that specifically Central Australian local knowledge will be needed.
9. No doctor should be obliged to be involved in providing VAD, but all should be required to make a referral to the VAD service if requested.
10. The VAD service should be funded by NTG, and during the implementation period it should be resourced adequately to develop a safe service model that includes support for staff. Given that it is not possible to estimate the demand for VAD in advance for Central Australia, consideration should be given to planning in the capacity to downscale in future, if appropriate.

Context and overall comments

We are aware of the progress of voluntary assisted dying legislation in other jurisdictions in Australia, as well as the history of the original euthanasia legislation in the Northern Territory. We recognise and acknowledge that there is, from many parts of the Australian community, a demand that voluntary assisted dying should be made available.

As individual clinicians some of us have ethical concerns about the legalisation of voluntary assisted dying, and the profound social change that this represents. VAD results in:

- A changed understanding about what is permissible for doctors - who have never previously been allowed to act with the intention of ending a person's life
- An enormous shift in cultural and moral views within the Australian community, where the understanding of death is changed radically by access to the ability to legally end one's own life, under conditions defined in legislation. This creates a significant shift in understandings of suicide and suicidality.

The cultural context

We practice in a setting of great cultural complexity. Approximately 85% of our patients in Alice Springs Hospital are First Nations people, many of them from quite traditional remote communities with English as their second, third or even fourth language. Some are first contact people, or just one or two generations on from first contact.

Trust in health care services

Many barriers face Aboriginal people using our health services, but in particular we recognise that trust in clinicians and in health care services is critical to enable high quality health care to be provided. It is therefore essential that our hospital and its associated services are regarded as a safe place for care. With regard to approaches to implementing VAD, we need to be able to ensure that patients know that they will not "be killed" if they come to hospital, and that if people do die in hospital, or under our care, that it is not as a result of intentional harm.

For people who identify as part of the dominant culture, the concept of VAD may be seen as an aspect of autonomy, and a right. It is something that is understood and accepted, and is therefore not threatening or difficult to explain. This is not so straightforward for people from Aboriginal communities, however, who may have very different health beliefs and attributions of blame for sickness and death. As clinicians we are very aware of the impact of these differences between Aboriginal and dominant cultural understandings in our daily work, and their ongoing significance in people's interactions with the health system. We would therefore expect that in any communications about VAD, and in any planning for delivery of VAD, a high level of cultural understanding and engagement will be required, even if Aboriginal people are not likely to be the main users of such services.

Conflicting messages

Suicide and suicidality are significant concerns within Aboriginal communities. The messaging of programs intended to reduce the rate of suicide - a tragically common problem in remote Central Australia - may collide with that of a program by which ending one's own life is enabled and regarded as ok, and may even be supported by doctors and health workers.

Health care priorities

From our own clinical experience, requests for hastened death are infrequent in the Central Australian health care setting, although they do sometimes occur. The health priorities and experiences in our community are very different from those elsewhere.[1] The social determinants of health play out in our hospital daily, revealing continuing deficits in social infrastructure related to housing, nutrition and education, the social disenfranchisement of young people, and the extent of domestic violence and substance misuse. In this setting, it does seem counter-intuitive (or worse) to be envisioning the establishment of a service that will end people's lives, when those people do not have the basics needed for their health and safety in the community, or equitable access to life-maintaining services such as, for example, breast cancer screening, or a reasonable level of home support services to ensure quality of life for people with progressive health problems, or high quality aged care services.

Response to discussion paper on the key clinical issues

On the assumption that Voluntary Assisted Dying is very likely to be implemented, we offer the following comments in response to the issues raised by the discussion paper. If a service is being established *de novo*, notwithstanding our overall concerns, it is important that it be done in a way that provides safety for both patients and staff, and minimises the risk of unintended consequences.

1. **Prognosis**

   Our population has high rates of non-malignant disease, and patients' prognoses may be less predictable as a result. There are also delays that relate to scarcity of health resources, and these should be considered. It may be reasonable to opt for a 12 month prognostic time frame for all conditions.

2. **Initiation of VAD discussions**

   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. VAD should always be discussed in conjunction with the options for palliative care, for fully informed awareness of the person's options. Inclusion of topics related to requests for VAD and how to best respond to these should be included in general communication training for medical practitioners in future. Initiation of discussions about VAD with patients should only be done by senior clinicians, or nurse practitioners. Ideally this should be a clinician who has an ongoing relationship with the patient – eg their regular consultant or nurse practitioner or GP. Completion of cultural training should be a pre-requisite for clinicians having discussions about VAD with Aboriginal patients.

3. **Models of care**

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[1] Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW. *Integrating the social determinants of health into health workforce education and training*. Geneva: World Health Organization; 2023. Licence: CC BY-NC-SA 3.0 IGO.

We strongly believe that VAD should not occur within any NT Health setting, in order to ensure clear differentiation between the intentions of routine clinical care and those of Voluntary Assisted Dying. Nor should physician-administered VAD be offered in the palliative care unit, or collocated with palliative care services, for the same reason. That said, there should nonetheless be easy pathways of referral to VAD and no exclusion from palliative care support for patients who request VAD but who have palliative care needs, and their families. Telehealth should not be used in the context of VAD.

4. Workforce

Medical staffing

4.1 We believe that provision of VAD should only be by doctors employed by the VAD service, a standalone service that should be funded by NT Government. VAD should not be made available under any other arrangement.

4.2 No doctor should work full time in a role as a VAD provider, and we acknowledge that there may be specific professional risks to clinicians working in VAD, so the VAD service will also need to be resourced to provide adequate support to their staff.

4.3 VMOs may need to be recruited to contribute to this role if there are not enough local clinicians to participate, but all will need some local knowledge and experience.

4.4 Doctors working in VAD should have attained the status of a Fellow within their specialty, or the equivalent, in order that they are senior enough to practice unsupervised.

4.5 We believe that the administration of VAD is a role that is as skilled as the role of assessing eligibility, because of the potential clinical and psychosocial complexity involved in the administration of VAD, and therefore a similar level of experience is required for both roles.

Other staffing

4.6 We support the employment of a **VAD Navigator** to provide support to patients, families and also clinicians.

4.7 Senior **pharmacy** input will be required in developing the VAD services. It will be important that there be a Central Australian pharmacist as part of the program, in order to ensure that there is local knowledge regarding the supply and safe management of VAD substances in our setting.

4.8 There should be consideration of creating roles for **nurse practitioners** within VAD. With an appropriate scope of practice a nurse practitioner could act as one of the two clinicians involved in assessment and potentially administration of VAD. There should always be a doctor as the other assessor.

5. Conscientious objection

It is essential that in any model of VAD that is implemented, there is allowance for conscientious objection. This must extend to any and all clinicians, particularly including interpreters, Aboriginal Health Practitioners and Aboriginal Liaison Officers. There should be no obligation to raise or discuss VAD with a patient, however all patients requesting it should be offered information about how to contact the VAD service. In addition, promotional resources need to be carefully developed and widely distributed to assist people to locate and contact the VAD service themselves.

The proposal that only doctors employed by the VAD service are able to undertake VAD makes sense for a range of reasons, but it particularly means that many of the issues that have been addressed in other jurisdictions about conscientious objection are no longer a problem, and the legislative complexity and moral distress for doctors associated with the introduction of VAD is greatly reduced. We note that lack of staffing can create a barrier to accessing VAD, and that unfilled positions are common across the NT, particularly in Central Australia. Backup arrangements (eg between Central Australia and Top End, or possibly by accessing providers from interstate) and rostering will need to be considered to ensure that VAD is in fact accessible as and when needed.

6. **Funding**

We support the provision of specific funding for a VAD service. The roles of assessment, case management and support of people seeking VAD cannot be added on to the current role of any other service or clinician, without potentially impacting their ability to provide the services which are their primary responsibility.
In other jurisdictions in which a fee-for-service approach has been implemented, there is a much more strongly developed private sector to absorb this work. That approach will not work in Central Australia.

We note that it is impossible at this point to estimate the demand for VAD, or the likely uptake in Central Australia, particularly once the service stabilises. Whatever model is introduced may require a significant initial outlay during the establishment period to develop its operational approach, but utilisation should be carefully monitored. We believe the service should have the flexibility to downscale, and/or operate as a “popup” model in future if that is all that is needed, in order not to commit excessive resources to this activity in the long-term.