Grief
Australia

Submission to the Northern Territory Legislative Assembly, Legal and Constitutional Affairs Committee Inquiry into Voluntary Assisted Dying (VAD).

Grief Australia (www.grief.org.au) welcomes the opportunity to provide a submission to the NorthernTerritory Legislative Assembly, Legal and Constitutional Affairs Committee Inquiry into Voluntary Assisted Dying (VAD).

Our submission aims to provide the Norther Territory Government with an understanding of the bereavement and grief-related implications of Voluntary Assisted Dying (VAD). While debates frequently focus on patient autonomy and clinical practice, bereavement outcomes for families, carers and healthcare professionals are equally important.

1. Executive Summary

Grief Australia welcomes the opportunity to provide evidence to the Northern Territory Legislative Assembly Inquiry into Voluntary Assisted Dying (VAD). While public debate often focuses on patient autonomy and clinical practice, the grief and bereavement consequences for families, carers and healthcare professionals remain under-examined.

VAD offers unique opportunities for anticipatory grief, relational closure and personalised rituals, which can assist the bereaved to adapt in healthy ways. However, it also brings distinctive risks. Families may experience complicated or disenfranchised grief, particularly where stigma, secrecy or cultural and spiritual conflict is present. Evidence shows that guilt, judgment and isolation are common among families bereaved through VAD. Children and adolescents bereaved by VAD deaths face additional challenges, yet there are few appropriate resources to support them.

Healthcare professionals involved in VAD are also vulnerable to moral distress, cumulative grief and burnout. Protective factors such as debriefing, supervision and wellbeing programs must be embedded into service design to safeguard staff.

Despite these needs, current VAD legislation and practice frameworks in Australia largely end at the point of death, with little structured bereavement care. Grief Australia recommends the routine provision of bereavement information, referral pathways, culturally appropriate supports, resources for children and families and dedicated services for health professionals.

Integrating bereavement care into VAD frameworks will ensure compassionate, ethical and sustainable policy that honours both the autonomy of the dying person and the needs of those who grieve.

2. Background and Recommendations

Voluntary Assisted Dying is a profound shift in end-of-life care. It not only affects the dying person but also fundamentally shapes the grief experiences of those left behind. The way death occurs influences bereavement trajectories, with implications for mental health, family functioning and community wellbeing. Legislative frameworks must therefore incorporate provisions for bereavement care alongside patient rights and clinical safeguards.

Since the introduction of Voluntary Assisted Dying (VAD) in Victoria on June 19, 2019, Grief Australia, as the Victorian Government funded Statewide Specilist Bereavement Service, has received referrals from many Victorians who have been bereaved as a result of VAD.

VAD encompasses many emotional, psychological and social factors that can impact individuals and families experiencing this form of end-of-life decision-making. These implications can vary widely among the bereaved, depending on their relationship with the deceased, their personal beliefs and values, the nature of the illness, the degree of social support and the circumstances surrounding the decision to pursue VAD.

Under current State legislation VAD frameworks, family members have no formal role in the VAD process. Most literature concentrates on clinical aspects and the person electing VAD. The experience of the bereaved remains largely ignored in both policy and practice. Many protocols finish at the time of death and policies have no inbuilt bereavement support mechanisms in place.

Several studies (Gamondi et al., 2015; Frolic et al., 2020; Huhn et al., 2018 and Srinivasan, 2019) have concluded that VAD bereavement has unique and challenging features, including anticipatory grieving, navigating policy requirements, scheduling the date, interacting with clinicians, experiencing stigma from opposers (e.g., relatives, friends and professionals), witnessing the death and disclosing the cause of death to others. These studies have identified guilt, burden, discomfort and blame as common features within this cohort. Clearly, for some individuals, their grief following a death by VAD is complex.

Those who experience discordance or family conflict over the VAD decision report more significant challenges with grief and bereavement (Gamondi et al., 2015; Srinivasan, 2019 and Starks et al., 2007).

Family members' prolonged guilt and trauma tend to be under-recognised by professionals and VAD programs because their involvement with relatives often ends at death (Crumley et al., 2023). Healthcare professionals may also not know that VAD is kept secret and unintentionally overlook relatives' unique needs, which may undermine family-centric care.

Support and bereavement options may be limited if relatives do not feel comfortable discussing VAD, and what they need could differ depending on how involved they were in the process.

Previous studies find that a lack of social support and experiences of stigma may compound mental health challenges following an assisted death. Individuals may be judicious with whom they choose to disclose that their relative died from VAD, which can lead to secrecy and social isolation. Hales and colleagues (2019) found that the burden of maintaining secrecy surrounding VAD may lead to stress and anxiety, complicating the grieving process.

Our experience in supporting those bereaved as a result of a VAD confirms these findings in the literature. We can best summarise our experience under three themes:

1. **Absence of bereavement information and referral guidance**. Those bereaved following VAD

report that they received no direction or support with their current or future bereavement needs. Information was not routinely provided either in terms of psychoeducational information about grief, and in particular grief in the context of VAD, nor were referral options provided. Many talked about navigating a complex service system in order to find the support that they desired.

The availability and quality of bereavement support for those who have experienced a loss through VAD can significantly affect their healing process. Access to supportive counselling, bereavement groups and educational resources tailored to the unique aspects of grief after assisted dying are crucial. Many of our clients have stated that they did engage with mental health services, but that these services "did not get it". For others, they have a strong desire to meet with other people who have also experienced a death as a result of VAD.

Recommendations

A. **The development of bereavement care guidance and resources related to bereavement and VAD for health providers**. Routine bereavement care is an integral component of palliative care. Bereavement Support Standards have been developed, which outline best practice bereavement care for palliative care services (see Bereavement support standards for palliative care services). Similar practice guidance should be developed to assist healthcare professionals in the Northern Territory with evidence-informed bereavement support which is designed to meet the needs of this cohort.

B. **Providing information on bereavement impacts and referral options for those bereaved as a result of VAD**. Bereaved carers and family members need to routinely be provided with bereavement information that both normalises their bereavement experience as well as information on referral options. Given the desire to meet with others who have had a similar experience, these service options need to include individual and group support, available in both face-to-face and telehealth variants.

2. **Clients experience high levels of social stigma, self-stigmatisation and isolation:** A frequent experience of the bereaved clients that we have seen is the social stigma attached to VAD due to varying personal, cultural and religious beliefs about the sanctity of life and the ethics of assisted dying. Bereaved individuals may encounter judgment or lack of understanding from others, leading to feelings of isolation or alienation. We also see high levels of self-stigmatisation where clients are reluctant to seek social support because of a fear of adverse judgement.

Recommendations

C. **The development of resources for the bereaved which specifically addresses guilt, judgment and secrecy**.

Family members may benefit from having information or support for managing guilt, judgment and secrecy. Testing different educational and support initiatives to help relatives manage their experiences (e.g., arts-based initiatives, counselling and support groups) is needed. VAD programs could include information about guilt, judgment and secrecy in family resources and provide or refer relatives to VAD-specific grief and bereavement supports.

3. **Absence of support for children and adolescents bereaved as a result of VAD**

Although the precise number of children and adolescents who will be bereaved following a death due to VAD is unknown, we know that many children and grandchildren will experience bereavement following VAD. Many parents and caregivers wonder how best to talk to their children about death and dying. It can be especially challenging when someone in their life chooses Voluntary Assisted Dying. There is also an absence of Australian literature that is written specifically for children.

Recommendations

D. **That resources be developed to assist parents and carers in supporting children bereaved following a VAD**.

Providing practical assistance to parents and carers in managing conversations with children and adolescents about VAD is a weakness in State health services. There is a need to develop written resources for parents and carers that can help guide these often complex and challenging conversations.

Although there are examples of resources developed for children in other jurisdictions, such as the MAID Activity Book for children (see https://www.kidsgrief.ca/local/staticpage/pdf/ACTIVITIYBOOK.pdf) we require localised and culturally appropriate resources for children and adolescents.

4. **Research be undertaken to better appreciate the needs of those bereaved following VAD**

During the development of the Victorian legislation great emphasis was placed on North American research which indicated that there was no greater level of bereavement distress following VAD when compared to individuals who died in a palliative care setting (see for example Ganzini, et.al., 2009). The practice of generalising the findings from other jurisdictions to an unknown Australian setting was ill-advised. What has become clear is that for some individuals who are bereaved following a VAD death, there are unique challenges that are different from other contexts of death.

In order to establish a clearer picture of the needs of those bereaved following VAD, good quality qualitative and quantitative research needs to be undertaken. This will allow for the development of client-led services and resources which will most effectively meet the needs of Territorians.

Assumptions are often made about the potential risks to bereaved individuals of participating in research on grief, however participants view the experience as positive and beneficial to themselves and to others (Cook & Bosley, 1995).

Recommendations

E. That research be undertaken to better appreciate the needs of those bereaved following VAD.

5. Health Professional Grief and Moral Distress

Healthcare professionals engaged in VAD may face moral distress, cumulative grief, and burnout. Evidence from paediatric and critical care settings shows that while work may be meaningful, exposure to death carries risks of psychological distress. Protective factors include humour, peer belonging, debriefing, and structured wellbeing programs. Recommended supports for clinicians involved in VAD include:

- Regular debriefing and supervision.
- Access to counselling and wellbeing initiatives.
- Education on grief, coping, and moral distress.

Recommendations

F. That support for Healthcare Professional be provided, including structured wellbeing interventions: debriefing, counselling, and Compassionate Conversations for staff engaged in the provision of VAD.

3. About Grief Australia

Grief Australia is Australia's leading voice on grief and provides evidence-informed grief therapy and education services. Grief Australia is the largest national provider of bereavement counselling services and education in Australia and operates on three distinct policy foundations:

- Education and health promotion.
- Clinical and support services.
- Advocacy, research and consultancy services.

Grief Australia has a long-term history of partnering with different governments to support populations following numerous adverse events. This is inclusive of:

- Successfully delivering a federally funded $5m national grief and bereavement program for aged care facilities, staff, family, and residents impacted by COVID-19.

- Worked in partnership with clinicians and governments to provide specialist bereavement support services following the 1997 Thredbo landslide, the 2002 Bali bombings, the 2004 Indian Ocean tsunami and deaths as a result of the disappearance of Malaysian Airlines Flight 370 in March 2014 and the destruction of Malaysia Airlines Flight 17 in July 2014.

- In partnership with the Victorian Government, we delivered a five-year support program following the February 2009 Black Sunday Bushfires and the deaths of 173 people.

- We have worked with numerous state governments across Australia in relation to the introduction of Voluntary Assisted Dying legislation and the unique bereavement needs of adults and children impacted by these deaths.

4. Conclusion

Voluntary Assisted Dying reshapes not only the dying process but also the landscape of bereavement. To safeguard the wellbeing of families, communities, and healthcare professionals, policy must integrate grief support and cultural sensitivity as central features of VAD implementation. By doing so, VAD can be enacted in a way that honours both the autonomy of the dying person and the needs of the living who grieve.

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