

Supporting bereavement for families navigating voluntary assisted dying (VAD): learnings from an Australian-first pilot program

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Abstract

While the impact of Voluntary Assisted Dying (VAD) on grief and bereavement outcomes remains largely unknown, there is growing recognition that VAD can introduce unique grief and bereavement challenges for families, friends, and caregivers. Recognising this, Dying with Dignity Victoria (DWDV) and Griefline collaborated to design and pilot a pioneering support group program tailored to the specific needs of bereaved family members, friends and caregivers of people who used VAD.

The pilot engaged 17 participants across Australia and revealed key insights into the transformative role of peer-based support in addressing VAD-specific grief. Notably, over 66% of participants reported reduced feelings of isolation and improved mental health outcomes.

Based on these findings, the program will expand nationwide in the upcoming fiscal year to include pre- and post-VAD support services.

Introduction

Background

With VAD now available to most Australians, an increasing number of families, friends and caregivers are experiencing VAD-related grief. VAD was first legislated in

Victoria in 2017, and is now legal in every Australian state (and soon in the ACT) as well as New Zealand. This provides eligible individuals the legal right to access VAD as an end-of-life choice. While this choice brings relief for people seeking VAD, the process often involves challenges for their loved ones in navigating its complexities.

Recognising these needs, DWDV and Griefline joined forces, leveraging over 80 years of combined experience in community support, to deliver an Australian-first program offering tailored post-VAD bereavement support groups.

Program development

Collaborative approach

The program draws on the strengths of both organisations. DWDV's expertise in providing VAD-related peer support and advocacy in Victoria, and Griefline's national reputation for evidence-based bereavement support and group facilitation, created a partnership that deeply resonated with participants' needs.

Objectives

The pilot aimed to:

1. Provide a safe and stigma-free space for individuals to process VAD-related grief.
2. Offer psychoeducation on grief and VAD-specific themes to support participants in making meaning of their unique experience.
3. Equip participants with emotional tools and a support network to mitigate the impact of VAD-related grief.

Pilot program details

Funding and duration

Funded by DWDV, the pilot ran from September 2023 to August 2024, serving 17 participants across Australia.

Program design

Informed by lived experience and overseas research, the program was structured as follows:

- **Co-facilitation model:** Each session was led by a peer with lived experience of supporting a loved one to access VAD and a trained bereavement facilitator, ensuring both understanding and expertise.
- **Closed groups:** Groups of up to six participants met weekly for six weeks for two-hour sessions.
- **Accessibility:** Sessions were hosted via Zoom to maximise reach across both metro and regional/rural areas.

Content structure

The program featured a combination of grief psychoeducation and VAD-specific themes, including:

- The uniqueness of VAD as a mode of death.
- Challenges in navigating the VAD process, such as procedural delays.
- Experiences of stigma from community members and healthcare providers.
- Mixed feelings surrounding the VAD decision and its impact on bereaved participants.

Demographics

- **Participants:** 13 women, 4 men.
- **Age demographics:** ranged from 30's to 70+

- **Relationship to VAD participant:** 41.2% were parents, 47.1% were partners, and 11.8% other relationships.
- **Geographical reach:** Participants spanned multiple states, with the majority (70.6%) based in Victoria, where the program originated; 53% of the participants were in metro areas and 47% were in regional and rural areas.
- **Time since death:** For just over 50% of group participants, the death of their loved one was less than 12 months. For just over 20% of group participants the death of their loved one was greater than 12 months and for the other 20% the death was longer than 2 years.

Findings

Impact of VAD on grief

The program revealed that specific aspects of VAD, such as procedural delays and societal stigma, significantly influenced participants' grieving processes. For many, the VAD experience intensified their grief, creating a need for peer-based support that was both validating and emotionally safe.

The role of connection and shared experience

A sense of deep connection and bonding was formed between group members, who shared the unique experience of supporting loved ones through VAD. These connections helped alleviate feelings of isolation and provided participants with a comforting space to share their grief and complex emotions with others who truly understood.

Navigating complex emotions and stigma

Participants expressed that VAD involves a unique and complex emotional journey, often combining relief, guilt, and trauma. Additionally, as previously highlighted, there continues to be stigma and negative judgement surrounding VAD, with many participants noting they were cautious about sharing their experience openly.

Participants reported experiences of stigma from health professionals as well as community members.

Duality in their experience

For some, the VAD experience was traumatic but peaceful at the same time. There was tension between what the mind understood about the choice their loved one made and what their heart felt. After the death there was a lot to be said, however limited opportunities to be heard. We were told stories of advocating for choice and control, yet feeling unprepared for how the death would unfold.

Openness, flexibility, and space for expression

The program's structure allowed for open expression, balancing guided exercises with opportunities to share personal stories. Participants appreciated both the therapeutic exercises and the chance to discuss their loved ones and VAD experiences in-depth.

Healing and mental health benefits

Many participants mentioned how the group significantly impacted their mental health, relieving isolation and feeling more understood. This support group acted as a vital emotional lifeline, particularly in navigating the unique challenges of the VAD experience.

Meaning making

Many participants expressed a need to make meaning of the VAD process, a journey uniquely addressed in this program. Participants reflected to the group that meaning came from connecting with each other, sharing their beliefs and values regarding VAD, and forging continuing bonds with their loved ones.

Need for greater accessibility and awareness of support services

Several respondents emphasised the importance of making VAD support groups more accessible and widely known. They felt that navigating the VAD journey would

have been far more challenging without such support and suggested linking this service more effectively to those who might benefit.

Feedback

Participant feedback underscored the program's positive impact. Participants expressed feeling a greater sense of connection and understanding in their grief. In the words of one of our participants, making connections with others and hearing their own unique experiences has instilled a sense of direction and purpose to their own VAD involvement.

Despite participants communicating their gratitude for support, there was a sense that there was a missing link throughout the VAD process. Participants wondered about support pre-VAD and immediately after the death of their loved one.

Participants have expressed a willingness to contribute their time and provide ongoing feedback to improve the process for those who come after them.

Conclusion and next steps

Program expansion

Due to positive outcomes and high demand, DWDV and Griefline will expand the program in FY 24/25 to include:

- **Eight post-VAD support groups**
- **Ten pre-VAD drop-in sessions** for families and friends during the VAD decision-making process.

Future goals

To meet increasing demand and deepen support, Griefline also aims to develop a meaning-centred therapy program specifically for those considering VAD. This offering, along with ongoing one-on-one peer support from DWDV, will continue to provide much-needed resources for families impacted by VAD decisions.

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We extend our sincere thanks to the program facilitators and participants, whose courage and openness have allowed us to develop and refine this essential service.