Who Gets a Say at the End? LGBTQ+ Voices in Community End-of-Life Care

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This document explains how to prepare a case study for submission to the Palliative Care NSW 2026 State Conference. The headings outlined on this template are the headings to be used in your submission (Keywords, Executive Summary, Introduction, Year Case Study was Implemented, Case Study Detail)

KEYWORDS

Please list a minimum of three (3) keywords

- LGBTQ+
- Community
- Conversations
- Trauma-informed
- Preventative

EXECUTIVE SUMMARY (100 words maximum)

If submission is successful, the 100 words will be used in pre-Conference promotion.

The LGBTQ+ community face barriers to accessing equitable palliative care often due to a mistrust of institutional systems. Mainstream knowledge gaps around LGBTQ+ cultural specificities, or widespread lived experiences of discrimination inform perspectives that identifying as LGBTQ+ may worsen care or endanger them when accessing palliative care.

LGBTQ+ specific 'Death Cafes' positively engage community members to share concerns, ideas, and preferences; while offering an opportunity to share regionally specific palliative care information in a LGBTQ+ autonomous space. By taking these 'Death Conversations' across NSW, ACON reports positive experiences from attendees and increased comfortability in engaging with end-of-life decision making.

INTRODUCTION

YEAR CASE STUDY WAS IMPLEMENTED

2025 to 2027

CASE STUDY DETAIL

Maximum of 700 words providing an overview of the activity addressing the points below.

- **The specific issue** being addressed.
- **Approach** developed to address this issue.
- **Summary of activities and their implementation.**
- **Summary of outcomes and measurable impacts** of the activities.
- **The extent to which the activity is scalable** and ease of adoption by other services / organisations.
- **Important lessons learnt and critical success factors.**
- **Other comments/information**

Specific Issue:

Community care is a crucial factor in LGBTQ+ culture, which extends to understandings of accessing health care. The HIV/AIDS epidemic particularly saw LGBTQ+ communities forced to reckon with unfathomable numbers of loss within a homophobic landscape that greatly affected ability to access palliative care. LGBTQ+ communities stepped up to assist those dying, and provide palliative care outside of mainstream systems, ultimately creating a unique community understanding of navigating personal preferences and support in death, dying, and bereavement.

Despite the LGBTQ+ community's unique relationship to community-led palliative and after-death care, barriers to accessing services and supports are increasing. Discrimination, heteronormativity, and religious prevalence in end-of-life settings create mistrust and avoidance of mainstream services. Older LGBTQ+ adults are more likely to have non-traditional or smaller family supports, greater isolation, and heightened anxiety about care. Those without legal documents like a Will, an appointed enduring guardian, or an Advance Care Directive face increased risk of discrimination and loss of autonomy and rights after a partner's death. There is a critical need for safe, LGBTQ+ affirming spaces where informative conversations about death can occur proactively.

Approach:

ACON's Community Health Promotion approach is a multi-diciplinary practice that includes practice based frameworks for co-designing and delivering trauma-informed community led workshops across NSW that strengthen the capacity for person-centred agency in end-of-life decision making. Our program partners with community and health services across NSW, and our workshops engage LGBTQ+ communities in discussions covering legal planning, Advance Care Directives, accessing palliative care, and grief and bereavement, delivered across online and in-person formats. This work explicitly responds to systemic barriers that prevent LGBTQ+ people having genuine choice in how they live and die. By embracing community-led models, culturally specific themes like chosen family and navigating heteronormative systems are explored with the depth and authenticity required.

Summary of Activities and Scalability

After conducting community consultations, the LGBTQ+ Death Conversation program was co-designed and implemented in 2025 and has hosted 4 events across NSW with over 60 attendees, both in regional NSW and metropolitan Sydney. The unique workshop receives enormously positive feedback from attendees, with 83% positive feedback, most of whom have never attended a Death Cafe or similar palliative care education initiative. The program works in partnership with local stakeholders and community experts, as well as representatives from state-wide organisations, such as Palliative Care NSW, and Dying with Dignity.

Critically, Death Conversations respond to the local needs of communities and attendees, which means information is both tailored specifically for a certain region, and simultaneously flexible enough to allow for genuine engagement about topics that community members identify as being important. Furthermore, situating the activities through specific cultural and queer lenses, from facilitators to scenarios has meant the activities resonate and outcomes are achieved such as reported increase in attendees starting or updating legal documents and an increase in community-initiated conversations.

This program creates real impact for LGBTQ+ individuals hoping to take control of their end-of-life choices by providing culturally informed community-led conversations. This approach is scalable with investment and interest from LHDs and PHNs to also create these LGBTQ+ safe spaces. By

appreciating the power community conversations have when drawing on specific cultural experiences of navigating death, dying, and palliative care will increase LGBTQ+ community death literacy and understanding of end-of-life care options within NSW.

Outcomes/Lessons:

Drawing on multidisciplinary approaches, these workshops build participant capacity and translate complex systems into practical action to improve pallative care outcomes for LGBTQ+ people in NSW. Critically, the program centres lived experience, so death and after-death planning reflect the realities of LGBTQ+ lives, not assumptions embedded in mainstream institutions and systems.

The impact is tangible. Over 50% of participants discussed feeling increased confidence to initiate future conversations and feel empowered to advocate for themselves and others with documentation that reflects their identity and their wishes. Services engaging with this work gain greater insight into inclusive practice, reducing the risk of delayed decision-making, conflict, and care that does not align with a person's expressed preferences.

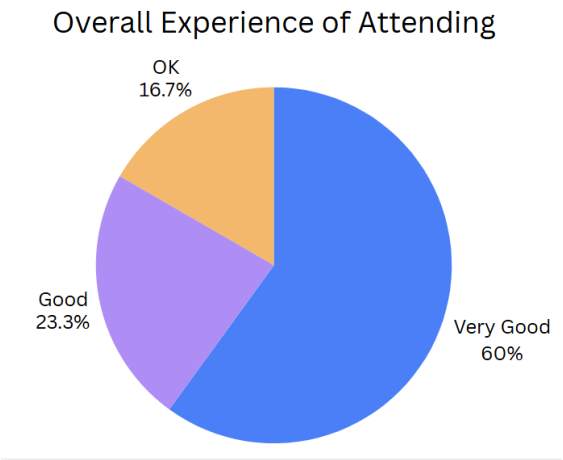

Figure 1: Overall Experience of Attending ACON Death Conversations

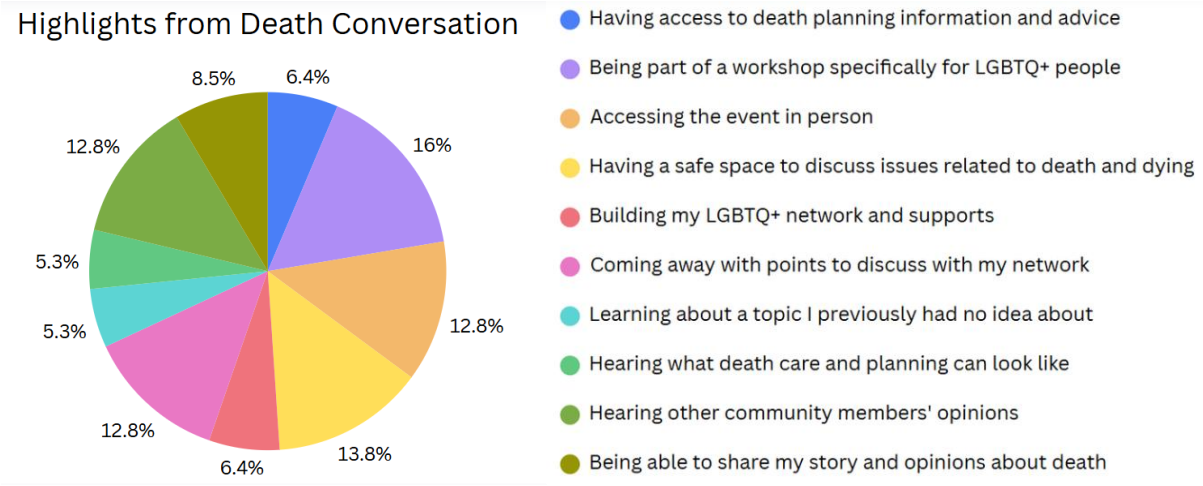

Figure 2: Attendees' Highlights from ACON Death Conversations