

care and dying where the resident chooses

palliative care and disability

fact sheet series

October 2018

Updated January 2024

southern metropolitan region palliative care consortium

Information for disability services staff working in group homes

overview

When given a choice, most people want to die at home. Many people who have a terminal illness, including a deteriorating chronic illness (like Huntington's, Dementia, etc) and live in a group home also want to be cared for and die at home. This is possible and community palliative care services can help. They can:

- prepare staff
- talk to the family
- assist in preparing other residents
- arrange for equipment and medication
- provide specialist care, which may include frequent visits

See the **what is palliative care?** fact sheet for further information.

considerations

Some group home staff, management or organisations are reluctant to care for somebody who is dying. This might be because they have little experience of providing care for someone with a terminal illness or don't know about organisations that can assist.

Advantages

- The resident is in a familiar place amongst residents and staff who know them.
- Hospital routines may not benefit the resident's needs and a home environment could make them feel more comfortable.
- Better access for staff, other residents/friends and family allowing good-byes to occur in the resident's own time.
- The resident is not alone; being cared for at the residence may be a good way for the resident not to be alone.

Challenges

- There may be a need to increase staff at the group home residence, either in caring for the resident or the other residents (consider increased NDIS support).
- Seeing someone at the end of their lives may have an impact on the other residents and staff. If people experience the death of someone who they care for, they may be apprehensive and require support. It can be difficult to predict resident and staff reactions to the end-of-life care of a resident. Palliative care services will be able to advise on support strategies.

Most disability providers will want to offer the best possible care for their residents - they may just need to consider the implications and receive information and support.

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policy background

The Victorian Government has developed the Victorian End-of-Life and Palliative Care Framework, which makes the following points:

- All Victorians deserve the best possible end of life and palliative care, which relieves pain and suffering and provides empowering support to people and their family, friends and carers.
- Focus on person-centred care, valuing and respecting people's preferences and values for end-of-life care.
- Diverse communities and groups should have improved information and access to engage more fully with end-of-life services.
- It is everyone's responsibility in the healthcare, human service, social and community sectors to provide high-quality end of life care for their clients.

The [Disability Residential Services Palliative Care Guide](#) states that the resident's right to choose their place of care and death should be respected and supported as much as possible.

advocacy

Palliative care consultancies in hospitals and community palliative care services can help to:

- talk to stakeholders, including family, staff and management
- officially approach management of the facility
- inform staff about palliative care and provide information and support.

references

- [Disability Discrimination Act 1992](#)