

advocating for a resident with a terminal illness

palliative care
and disability

fact sheet series

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southern metropolitan region palliative care consortium

Information for disability services staff working in group homes

what is advocacy?

Advocacy involves representing and working with a person who may need support to exercise their rights. Advocating for a resident with a terminal illness can include:

- educating health professionals about the resident's needs
- speaking up when you feel something is not right
- representing the resident's wishes

the role of the disability support worker in the palliative care context

Specialist palliative care services, either in the home or in a hospital consider the whole 'family' as defined by the resident with a terminal illness. This may include other residents and staff in the group home. However, many specialist palliative care staff do not have much experience in working with people with disabilities and may not understand the close bonds that can exist between residents and staff.

The role of the disability support worker in the context of palliative care is very important because the worker is likely to know the resident better than the health professionals and have a higher level of knowledge in the area of disability. Advocacy for the resident needs to take into account any areas of policy and confidentiality and may include:

Before any diagnosis

- assisting with developing Advance Care Plans (see Advance Care Plan fact sheet)
- **For the resident with the terminal illness**
 - if the resident wants to be cared for at the group home, arranging for this to be possible though receiving all necessary assistance
 - giving relevant information to palliative care and other health professionals
 - assisting with communication
 - letting the palliative care staff know if you feel uncomfortable about anything
 - letting the palliative care staff know about any issues with the other residents and family
- **For other residents**
 - ensuring that other residents' needs are not neglected in the process (information, grief, participation in the care, funeral, etc.)

resources

- VALID Position Statement on advocacy: www.valid.org.au/sites/default/files/advocacy_role.pdf
- Disability Justice Australia: <https://dja.org.au/>