care planning for palliative care

palliative care and disability

fact sheet series

March 2016
Updated January 2024

southern metropolitan region palliative care consortium

Information for disability services staff working in group homes

what is care planning for palliative care?

Care Planning is the process of determining the resident's goals of care and the resources, supports and services required to assist carers to facilitate these goals.

what needs to be considered for people with an intellectual disability?

Care Planning in group homes is very important. People with disabilities can have very short illness trajectories and symptoms can change rapidly. It is essential that everyone involved understands the goals of care and is working together. For residents with communication challenges, it is helpful if everyone who cares for the person has input and is able to advocate for the resident with accurate information.

Planning can assist with potentially distressing procedures and events such as a hospital admission. For example, a hospital bag can be packed 'just in case' with communication aids, medication and information such as the contact details of the person responsible for consent.

who is involved and what are their roles?

When a resident has been diagnosed with a terminal illness it is critical to discuss and plan for the resident's care needs to explore what supports will be needed. An understanding of what will happen during the illness can give an idea of what services and supports might be needed in the future.

Community Palliative Care Services are a good source of support if a resident has complex needs. Some of the people you may want to include in a care planning meeting include:

- Resident
- Family, friends and significant others
- Unit Supervisor, Key Worker and Group Home Staff
- Day Program staff
- Guardian/Person Responsible or Medical Power of Attorney
- GP and/or specialist
- Home Care Agency
- Community Palliative Care service
- Allied Health and community services
- NDIS care coordinator

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what is the process?

In the early stages of the resident's illness, it may be enough to have an initial meeting to ensure that the roles and responsibilities of everyone are clearly identified. This meeting is also an opportunity to establish the goals of care with the resident and/or person responsible.

If everyone is not able to attend a meeting, the person who is in charge of coordinating the care of the resident should gather as much information and talk to as many people as possible before the meeting. A plan should be documented and copies available for everyone involved.

Regular reviews will need to be planned and the flexibility to both respond to symptom changes as well as anticipate them should be taken into account. Discussions with the treating doctor can be useful in order to better understand the likely trajectory of the resident's condition.

what could be covered?

Areas of Care Planning to be considered for palliative care can include:

- Advance Care Planning (ACP)
- Resident's desires and needs for their care
- Choice of place of care/place of death
- Additional resources and supports required
- Person Responsible or guardian contacts and roles
- Staff training and support
- Supporting other residents
- Not For Resuscitation (NFR) if appropriate
- Anticipating process i.e. Coroner's enquiry
- Family and friends' needs e.g. quiet space to visit
- Aids and supports for hospital admissions

resources

Disability Residential Services Palliative Care Guide

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