

Information for disability services staff working in group homes

overview

When residents are diagnosed with a terminal illness, it is a difficult situation for all involved - the resident, their family, other residents and staff. Providing everyone involved with the opportunity to talk about their fears and feelings can help to make the situation easier. Although conversations about dying can be painful it is helpful to allow the person to have input into what matters most to them and to ensure their wishes are heard and carried out as much as possible. An Advance Care Plan may go a long way to reassuring a resident that their needs will be met at the end of life. This also helps to provide information about the next stages and address any fears that the resident may have.

how to care

1. People are different and will want different things - be prepared to ask what would be helpful.
2. Be aware of your own preferences and that they may be different from someone else's. Don't assume that what you would find helpful someone else will.
3. People want to be treated as normal. They are still the whole person they have always been, with the same interests, sense of humour, etc.
4. People want their feelings to be taken seriously and their variety of feelings recognized. Don't try to minimise grief or cheer the person up, there is no 'right way' to feel.
5. Be interested:
 - Listen without trying to give answers – often there are no answers. People generally want to be able to explore for themselves or simply to be heard.
 - Don't interrupt
6. Ask what matters to the resident:
 - Recognise/sit with where they are coming from – *e.g.* religious or not, spiritual or not.
 - Be interested in what's important for them – *e.g.* their connections to family, community, to places and things.
7. Be careful about giving ideas/advice. If you need to, begin with *e.g.* "Have you thought about doing..." rather than "You should do ..."
8. Recognise when you need to seek help – either for yourself to clarify, to debrief or for support, or for the resident when you need to refer on.

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what to say/how to listen/end of life conversations

1. Be prepared to acknowledge the other person's experience *i.e.* to talk about dying and death. Otherwise they might feel isolated and scared.
2. Open up the possibility of talking about end of life issues saying, for example:
 - "What is important to you now?"
 - "How do you feel about what is happening to you?"
3. Follow their lead about where they want the conversation to go. Sometimes they may want to talk about serious matters and at other times they may want to talk about routine things. Go with the content of their conversation.
4. Listen to the words and *what* they are saying *i.e.* feeling underneath the words.
5. Listen without judgement.
6. You don't need to have answers. If you do feel you need to say something, acknowledge them by saying *e.g.* "What can I say, that just sounds very hard."
7. Be yourself.

resources

- Griefline: www.griefline.org.au
Phone: 9935 7400
- Australian Centre for Grief and Bereavement: www.grief.org.au

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