Care plan for the dying person

Family and carer distress in the last days of life

Symptom assessment and management fact sheet

Caring for a person in the last days of life is both physically and emotionally challenging. Supporting the family and carer(s) is a highly important aspect of routine care; this includes explaining what to expect and how they can help.

How family and carer(s) perceive and experience the care provided towards their special person, can have a significant impact on how they will process their grief in bereavement. Pay attention to the details, as little acts of kindness and responsiveness will be remembered, replayed and appreciated by family and carer(s). Consider the way the family are coping and adapting to the situation and recognise that family members will have different coping styles. Acknowledge that there may be tension or conflict within a family at such a tense and stressful time.

Gently support family and carer(s) to know that all will be done to keep their special person as comfortable as possible, but that it can be very challenging to witness them going through the physiological changes (sights, noises, smells) of their last days of life. Listen and respond to family requests as best as possible, whilst normalising the expected physiological changes. Encourage family and carer(s) to stay with the person as much as they wish, providing and assisting with care at the bedside can help them feel involved if they choose. They may also need 'permission' to take a break and have some rest themselves. Be honest about the uncertainty of any prognosis estimate and regularly update them with changes, encouraging them to discuss their feelings and concerns, and offering support.

How to help

- Consider a referral to the ward social worker with their consent, for psychosocial, emotional support and assessment for bereavement risk.
- Consider a referral for pastoral, spiritual or cultural care support.
- Explain the dying process to the family and carer(s) as well as how symptoms will be managed in the last days of life, offer written brochures and resources.
- Family and carer(s) are often reassured when they are told that the person may be able to hear, understand and appreciate familiar voices, or respond to touch.
- Acknowledge the feelings about their loved ones impending death and any concerns they may have.
- Some families express concerns that medications may accelerate the dying process, carefully explain that deterioration is due to the dying process and that medications are required to manage symptoms and promote comfort rather than to hasten death.
- Consider engaging the ward social worker to coordinate a family meeting to provide information, discuss any concerns and needs of both the patient and family.

Key message

'Family' should be interpreted in the broadest manner – it includes whoever the patient says is important to them.

References

Therapeutic Guidelines. (2024). *Family Support in palliative care*. https://app.tg.org.au/guidelines/Palliative_Care

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