

Support Workers

Tips for supporting someone who is seriously ill and may be dying

This factsheet provides information on who to call and some basic tips for anyone who is supporting a seriously ill person as part of their work role. You may be a paid carer, support worker, disability worker, aged care worker, aboriginal health worker, prison officer, religious leader, health professional, or a volunteer.



# What do I do if someone that I support seems to be very unwell and not getting better?

When a person is reaching the end of their life you may notice that they are much more tired than usual, are complaining about pain or nausea, or their behaviour has significantly changed.

If you are concerned about someone's health, you can:

- 1. Write down all the changes that you have noticed.
- 2. Share your concerns with them or their family, if possible.
- 3. Contact their regular General Practitioner or other health professional, with their permission, or your manager and discuss your concerns.





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- 4. If they are seriously ill, you may want to call the local community palliative care service to organise a visit and assessment. Alternatively, you can call their local hospital to discuss options, to ensure they are 'in the system'. Often hospitals have a service that will come out to the home or a social worker that you can talk to about your concerns.
- 5. If it is an emergency, such as their breathing is very shallow, they have high levels of pain, are very dehydrated or are unconscious, please call an ambulance.
- 6. If you are worried about them being on their own after you finish your shift/visit, then you should:
  - Contact a family member or next of kin (if possible).
  - If there is no family to contact, then speak with your manager.
  - If you have their General Practitioner details, call, and see if you can organise a home visit for the same day.
  - If they are funded by NDIA or My Aged Care (in home supports), contact them and see if you can talk to someone about providing emergency in-home care.
  - Call the community palliative care team or local hospital.
  - If there is no-one else available or no other service which can assist you, then call an ambulance.
  - Always, leave your name and number with whichever person/service you contact in case they need more information or want to keep you up to date.

### Useful Contact Numbers/Online directories

View the Palliative Care Australia <u>National</u> <u>Palliative Care Services Directory</u>.

Visit the <u>MyAged Care website</u> or phone 1800 200 422.

Visit the <u>NDIA website</u> or phone 1800 800 110.

Visit the <u>Health Direct website</u>.

### Providing ongoing support to a person who is seriously ill and may be dying

CarerHelp has a lot of useful resources that provide basic care information to anyone caring for someone at the end of life. Check out the <u>CarerHelp library</u> for factsheets on a variety of topics which might be useful for you:

- · Common emotions at the end of their life.
- · How to recognise if someone is dying.
- Caring for the dying person.
- After the death.

There are also <u>videos from health</u> <u>professionals</u> talking about specific topics and many links to other trustworthy resources.



# Tips for supporting someone who is seriously ill and may be dying



#### Personal care and responsibilities

As part of your role, you may be responsible for personal care, feeding, giving medicines, taking the person to appointments, talking to them about concerns and providing emotional support. As people get closer to dying, they require 24-hour care. It may be that you continue to support them at home as part of a team, or they get moved into an aged care facility, palliative care unit or hospital.

If at any time you feel that the person is not getting enough support or is very uncomfortable due to symptoms, it is okay to let the palliative care service, general practitioner, or hospital team know so that they can review the person's care.

### What do I say to the person I am caring for?

Sometimes people are unsure what to say to the person they are caring for about their prognosis. If the person is going to die from their illness, they may have already had a discussion with a health practitioner.



The following questions/comments may be useful in starting a conversation:

- What is your understanding of your illness and what is going to happen? If you have any questions, I could try and help you find the right person to ask.
- I understand this might be a difficult time for you. Would you like to talk about what is going on for you?
- Sometimes people have a bucket list. Is there anything that you really want to do or anyone you want to see?
- I'd love to hear a bit more about your life and your most important memories.
- I'm here to help care for you and so are the rest of the team. Is there anything that I can do to help you feel more comfortable?
- Thinking about the practical side of things, is there anything that you need to get organised? Would you like help finding any important documents or making any phone calls?

People who are coming to terms that they are dying are likely to express a lot of emotion. It can be useful to allow them to express that emotion without trying to 'fix' anything. Sitting with the emotion in silence, reflecting to them what they said, or responding with empathy, for example, 'that sounds really difficult', can all be useful strategies.

You may find it helpful to read the CarerHelp factsheet on <u>Emotional care of the seriously ill</u> <u>person</u>.



#### Caring for someone who is dying

Caring for someone who is dying can have both a positive and negative impact on you. It can be very rewarding to feel that you are assisting someone at such an important time. You can also really get to know them on a deeper level and gain an understanding of death and dying. However, it may cause additional stress and bring up a sense of your own mortality, which can be unsettling.

It is important to recognise the additional emotional load and seek support through your team, manager, possibly friends and family, or formally through your general practitioner or a mental health practitioner. Some workplaces have supports in place, such as an Employee Assistance Program, that you can access for support.

It is also okay to let people know, such as your manager, if there are aspects of your role that make you feel uncomfortable. You may feel that you cannot continue to do the role without more support. If this is the case, it may be a good time to consider whether the person's care would be better managed within a palliative care unit, residential care environment or hospital, rather than the community.

