



This factsheet covers some basic information about caring for someone who is very sick and may not get better. We answer some of the common questions that families have when they are looking after someone who is very sick.



Am I a carer?

You probably don't feel like a 'carer' but it is helpful to know that you are called a 'carer' if you are the main person involved in helping your sick friend or family member. A 'carer' also has rights and privileges, such as financial payments, so it is useful to identify yourself as a carer.

Often the health workers will ask 'who is the main carer?' so they can speak with just one person in the family to:

- Provide information on your family member or friend.
- Ask for help with decisions about the person's care.
- Offer support.

What do carers do when someone is very sick?

It can be difficult at times to care for someone who is very sick, and you will need to do more for them over time. You may need to help the person with washing themselves, toileting, preparing food and feeding, and managing their medicines and appointments. There may be more forms to complete and paperwork to help them organise their affairs. The person you are caring for may also develop symptoms like being confused, very tired, or agitated, that can be hard to manage.

It is important that you have support and share the caring duties with others if possible.

How might I feel about being a carer?

Caring for someone who is very sick can often be a positive and rewarding experience but also can be a difficult one. Each person will have their own feelings about this.

There is no right or wrong way to feel. However it is very important that you have people to talk to about how you are feeling. It is okay to ask for help and there are many services available to help with the caring role and also to support you emotionally. It is okay to share the caring role with others, often it is too much for just one person.



Where is the best place for my family member or friend to be?

Most people want to be cared for at home. This is not always possible. In order to stay at home your family member or friend will need someone to live with them and provide care. It can be very hard to decide whether you can or should care for the person at home.

To assist you to make this decision you may want to talk to the person's doctor and consider the below.

Sometimes, the health worker will recommend that the person have a short stay in hospital to give you a break or to make changes to medicines. Sometimes you may plan to care for the person at home and it doesn't work out. Remember that this is no one's fault but may be necessary for them to receive the best care and stay comfortable. If this happens, you will still be able to visit them and be involved in their care.

There are social workers at all hospitals who can help link you to home care services and also assist you to complete forms to access services or financial payments.



How do I navigate the health system?

1. Be open and honest about what you want and need from the health care team.
2. It is okay to ask questions and let people know if you do not understand.
3. You can ask your Aboriginal health worker to attend appointments with you and ask them to explain the information to you if you are unsure.
4. You can ask for an Aboriginal liaison officer to assist you navigate the hospital.
5. You can bring up any concerns or questions you have about the illness, care, and finishing up. Their job is to provide you with information and support.
6. You can let the health workers know if you have any cultural needs. They are required to provide care in a culturally safe way. If you feel they are not being sensitive to your needs then you can ask for an Aboriginal health worker or liaison officer to support you.

7. It is up to you and the person you are caring for to decide how much information is right for you. Usually the health worker will want to talk about whether the person you are caring for prefers more treatment or whether they want to focus on comfort and managing symptoms only.

Consider if you want to know about whether the person is finishing up soon. While it can be uncomfortable to talk about, it can be helpful to have a clear understanding of what is likely to happen so that you can make plans and focus on helping the person live their best.



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Marrawuy Journeys artist Sarah Richards