

Getting started – Caring for someone who is seriously ill and may not get better

This factsheet covers some basic information to help you get started including:

- What does it mean to be a carer?
- How might I feel about being a carer?
- Where is the best place for my family members to live?
- What services are available to help?
- Talking to health professionals

Am I a carer?

It is helpful to know that in Australia you are called a 'Carer' if you are the main person involved in helping your ill 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 doctors and nurses 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

In Australia, there are many services to help you care for your family member or friend. There is also some financial assistance you may be able to access.

What do carers do when someone is seriously ill?

It can be difficult to care for someone as their health gets worse, and you will need to do more for them. Often the person you are caring for will require a lot of help with washing themselves, toileting, preparing food and feeding, and managing their medicines and appointments. There can also be more forms to complete and administrative tasks to take on to organise their affairs. The person you are caring for may also

have other symptoms like being confused, very tired, or agitated, that can be difficult to manage.

It can be difficult to care for someone who is seriously ill and it is important that you have support and share the caring duties with others if possible.

How might I feel about being a carer?

Many people find it rewarding to provide care to their family member and some feel they develop a closer bond with them. However, caring for someone at the end of life can also be very demanding and distressing at times. Each person will have their own unique emotional response.

- You may feel overwhelmed with the responsibility of caring for your family member or friend.
- You may feel like you lack choice over your caring responsibilities and feel that you are obligated to care for the person.
- You may feel sadness or intense grief as you realise they may die from their illness. But also grief about other losses that are the result of the person being ill such as loss of a future together or loss of a relationship.
- You may feel anxiety about whether you can cope or about what will happen in the future.
- You may feel frustrated, angry or even guilty.

There is no right or wrong way to feel as you move through this very difficult experience. 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 other family members. 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:

- your own health and wellbeing
- if there are people or services that can assist you care at home
- whether your home is set up in a way that the person can still get around (such as walk to the toilet easily from their bed, no stairs, room for any equipment the person may need)
- if the person has any symptoms that are difficult to manage at home
- the preferences of the person you are caring for as well as your own preferences

Sometimes, the health care team will recommend that the person have a short stay in hospital to give you a break or to make changes to medications. 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.

What services might be able to help?

There are a lot of services to help you care for the person who is seriously ill. Firstly there is your family doctor (your General Practitioner) who

should be able to help you find support.

There also are the health professionals involved in treating the specific illness, usually at the hospital. At this time the person you are caring for might also be offered Palliative Care. Palliative care is holistic and focuses on improving symptoms, quality of life, and ensuring the person is as comfortable as possible. Palliative care also supports the family.

Sometimes the person you are caring for will be able to access support in the home. This might be through the Palliative Care home service, through local community nurses, or the person might be eligible for home support through the My Aged Care system (Ph: 1800 200 422).

Carer Gateway (Ph: 1800 422 737) is another National service that can provide support options for carers.

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.

You can ask for an interpreter for any meetings at the hospital or use the National Translating and Interpreting Service (Ph: 131 450) for any phone calls.

Talking to health professionals

In Australia, patients and families are encouraged to be very open and honest about what they want and need from the health care team. You are encouraged to ask questions and let people know if you do not understand. Doctors and nurses are comfortable talking about any topics related to



illness and care. They are there to provide you with information and support.

Australia is made up of people from many cultures and countries and you are encouraged to tell the health care team about any cultural needs you may have related to the person's care.

It is up to you and the person you are caring for to decide how much information is right for you. In Australia, most people want to know whether they are dying and how long they have to live. They want to talk about whether they prefer more treatment or whether they want to focus on comfort and managing symptoms only. 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. You and the person you are caring for will have to decide how much information you are comfortable with.