

Caring for Someone with Life-limiting Illness

Carers may be a friend, neighbour, extended family member, spouse, sibling, child or parent. You may not think of yourself as a 'carer'.

Caring may not be something that you thought you would ever have to take on. You may take it on willingly, or it may be more of an obligation. Some people just cannot do it at all. It is ok to say no. It can be helpful to find and use support services to help you continue as a carer.



Family carer role: Caring for someone at home at the end of life is complicated and you may find it challenging. The intensity of the caring situation can be hard to deal with.

Benefits may include:

- Being in familiar surroundings
- Being able to follow usual routines
- Freedom in decision making
- Fewer visits to hospital.

The challenges to caring at home may include:

- Dealing with people coming to the house
- Taking on unfamiliar tasks
- Having to take on personal tasks for another, such as toileting
- The unexpected, such as coping with someone who has fallen or who is in pain
- Equipment needed at home.

Managing daily life: Caring for someone who is seriously ill can be satisfying or you may find it challenging. Sometimes it can be both. Ask health professionals for advice. This could be about how to:

- Physically care for someone who is very ill
- Balance your carer role with other responsibilities
- Maintain a social life
- Keep yourself physically and emotionally well.

Help at home: If you are caring for someone at home there can be many other people involved. There may be a community nurse, a GP, an Occupational Therapist or a Physiotherapist. You may also have other care workers to help you. You may also have family and friends visiting.

Having so many people around can be reassuring or it can sometimes feel intrusive.

Family conflict in caring: Sometimes family members disagree with care directives or decisions. This can be hard if they are not directly involved but want to give advice.

Families are not always close and this may lead to general communication problems. If this happens to you, talk to a health professional such as your community nurse about a family meeting. This can help to get everyone together to talk about what is happening.

If you cannot continue in the caring role:

Being a carer is a demanding role to take on. There may come a time though when you are not able to continue to do this. You may feel distress or guilt at having to say that you cannot cope. You may find it hard to hand over to someone else. Even though you may have promised the person who is ill that you would always look after them, it may not be possible.

You may also feel a sense of relief. This is ok as well. There is no right or wrong way to feel about giving up this role.

It is important to look after your health while caregiving. This will help now, as well as in the future.

The palliative care support team are there to help make things easier for you. But when you are able, try to set aside some private, quiet time for the family.

Respite: Respite is a chance for a break for you and the person you are caring for.

There are a range of respite support services available (see www.carergateway.gov.au):

In-home respite - a care worker provides care in the home or may organise to take the person you care for on an outing.

Centre-based respite - held at a centre or club that organises group activities for the person you care for, allowing them to meet other people.

Community access respite - provides activities and social interaction.

Residential respite care - a short stay in a residential care home can be organised for the person you care for.

Consumer-Directed Respite Care (CDRC) - a CDRC package gives you more choice about the type and delivery of respite care.

Some respite services are free; others are not. The cost of respite care depends on the care provider, the length of time involved, and the type of care. A health professional may be able to give you advice about respite.

The Carer Gateway can help with advice on the types of respite and support available in your area.

CareSearch is a website that has been developed to provide trustworthy information about palliative care. For more information on this topic visit www.caresearch.com.au