



Factsheet 1: Making use of services

There are many services and resources that can help you provide care for someone with a life limiting illness. This can make a difference to your well-being and to the comfort and support of the person needing care.

However, carers often don't make use of these services because they don't know they exist, they have no time to ask, or they don't want to feel a failure.

These services and resources exist because the community and the government realises that the contribution of carers needs to be valued and supported.

Below are a range of services that can help. Please make use of these services.

Palliative care services

Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social. GPs, aged care, and community services as well as specialist palliative care services may all provide care to people coming to the end of their life.

You should talk to your health care provider about palliative care as an option. Palliative Care Australia: www.palliativecare.org.au has information on palliative care and also has a directory of palliative care services you can search.

There are palliative care organisations in each state or territory: www.palliativecare.org.au/members who can provide you with local information.

Carer services

Carer Gateway provides an extensive range of services and resources for carers. They include:

Counselling

The Carer Gateway Counselling Service is a free service for carers available from 8am to 6pm weekdays. www.carergateway.gov.au/counselling

Rural and remote services

If you are a carer in a rural or remote area, there are many online and phone services available to help you: www.carergateway.gov.au/tips/rural-and-remote

Respite care

Respite helps you take a break by providing someone to look after the person needing care: www.carergateway.gov.au/respice

Home changes

As a carer, you help the person you care for with many activities in and around the home. Small changes can make your environment safer: www.carergateway.gov.au/help-advice/home

Financial help

You may be able to get payments and other financial support to help with your costs: www.carergateway.gov.au/financial-help

Carer Gateway also provides resources in different languages: www.carergateway.gov.au/resources-language

Equipment services

Equipment can be important in enabling people to remain at home. Talk to the health care team about what is needed. Each state and territory has an equipment scheme.

Equipment is usually loaned to you free or at low cost. These schemes are often means-tested (to see if you can pay for the service yourself or will need help), and some states have waiting lists for equipment.

The schemes are:

- Australian Capital Territory – Oxygen and Equipment Services
- New South Wales – Aids and Equipment Program
- Northern Territory – National Disability Insurance Scheme (NDIS)
- Queensland – Medical Aids Subsidy Scheme
- South Australia – Domiciliary Equipment Service
- Tasmania – TasEquip
- Victoria – Aids and Equipment Program
- Western Australia – Community Aids and Equipment Program

Grief and loss services

When you are caring, you may feel grief not only about the expected loss of the person you are caring for but also losses associated with taking on the carer role. You may have given up or reduced your paid work, you may feel a loss of independence, and you may have less time for friends and a social life. You may also feel anxious with new responsibilities and the uncertainty of the future.

Carer Gateway offers a phone counselling service: www.carergateway.gov.au/counselling

GriefLine provides an online support service from midday to 3am: www.griefline.org.au





Eat healthy, nutritious meals

- Try eating fresh fruit or cut up vegetables as a quick and easy snack.
- Use ready-made meals or frozen meals if you don't have time to cook. Look at the ingredients list on the packet and try to choose options that have more vegetables and protein and are not high in fat or sugar.
- Say 'yes' when people offer to drop off a meal for you. They feel good when they can help, and this takes some of the burden off you.
- Avoid having too much caffeine, alcohol or nicotine. Don't use substances to try to manage your feelings – always talk to a health professional if you are struggling to cope.
- Order your groceries online and arrange to have them delivered if you don't have time to go shopping in person.

Get enough sleep

- Take naps during the day if you are not getting enough sleep at night. Sleep when the person you are caring for sleeps.
- Sleep in a different bed or room than the person you are caring for.
- Let friends or family take over caring duties for a night so you can sleep.
- Consider using respite services if you are not getting enough sleep.
- Don't make big decisions when you are tired.
- If you are having difficulty sleeping because you are worried or upset, talk to your doctor about this.

Have health checks

- Make regular visits to your own doctor for health checks, immunisations and to manage your own illnesses and health conditions so you are as well as possible.
- Keep up regular visits to the dentist.



- Consider asking your doctor to assess your mental health or ask if you can have a mental health care plan put in place so you can speak to a mental health professional if you need to.
- Talk to your doctor or a counsellor or psychologist if you are distressed or overwhelmed. People who are caring for someone at the end of their life often feel stressed, anxious or depressed and may feel grief even before the person has died. This is very normal, but there may be things that can be done to help you feel better.

Do physical exercise

- Go for a walk or bike ride.
- Attend an exercise class.
- Try some in-home exercises such as yoga, stretching or pilates.

Maintain social activities and activities you enjoy

- Set up regular times to see your family and friends.
- Attend local clubs, activities or social events.
- Do relaxing activities at home. This could include reading, playing card or board games, listening to audio books or podcasts, watching your favourite TV shows or movies, sewing, gardening, baking or taking a bath.



Factsheet 2: Tips for staying well

- Get a massage. You could go to a massage service, or there are some services that will come to your home.

Share the load

- Ask friends, family, or neighbours to sit with the person you are caring for while you go out.
- If it is hard to go out, ask friends or family if they would be willing to cook a meal and come to your home to eat together.
- Talk to your friends and family about how you are, your concerns and what you need.
- When people offer to help, say 'yes'. Make a list of things that people could do to help you so that when someone asks, you have an idea to give them. Suggestions for things they could help with include gardening, cooking, sitting with the person while you go out and doing the shopping.



Factsheet 2: Tips for staying well



Say 'no' and change your expectations

- Say no to things that you can't or don't want to do. Now is not the time to take on extra things.
- Be kind to yourself. You may need to change your expectations of yourself. For example, cleaning the house weekly can be reduced to fortnightly. Don't worry if the front lawn is a bit overgrown. It is okay if some household chores are not priority, as long as the environment is sanitary and safe.

Put your health and wellbeing first

- Acknowledge to yourself and others that your own health and wellbeing is important.
- Speak to the health care team if you are struggling, need help or are not comfortable with any aspect of the caring role.
- If caring at home is affecting your health and wellbeing, talk to the health care team about other options for where the person can be cared for. If home care doesn't work out, that doesn't mean you have done anything wrong.





Factsheet 3: Tips from carers

The team behind CarerHelp spoke with people who are currently caring for, or used to care for, a partner, relative or friend at the end of their life. Below are tips on what they thought was useful. If you need additional help, contact Carers Australia (1800 242 636) or the local state or territory Carer Association.

- Look after yourself and take some time out. Your mental and physical health is important. You can't support others if you are unwell.
- Don't feel guilty. You are doing the best you can.
- Plan ahead. Although the demands of caring for someone with advanced disease can be hard and time-consuming, try to find time to stay connected with work, friends and family. Staying connected will make the future easier for you.
- Think about where the best place is for the person you are caring for to be looked after. Consider the person's needs, and your own health and ability to provide care. It is okay to change your mind.
- Look at what financial supports may be available and speak to Centrelink early because applications for assistance can take a long time to process.
- Think ahead about the types of services or supports you might need later on and identify those services or people who can help you early.
- Register for My Aged Care even if you do not need it now. It can be a slow process.
- Take steps to change names on mortgages, bank accounts, etc
- Ensure you have a GP (or other health professional) that you are comfortable talking with.

Factsheet 3: Tips from carers



- If you feel like you need some additional emotional support, ask your GP about a Mental Health Care Plan. These plans give you access to a limited number of sessions with a psychologist or other mental health professional that are subsidised by Medicare. They can even be free if that professional bulk bills.
- Ask your GP or health care team if there is respite available to give you a short break from caring. Use respite, if available.
- Ask for help and accept help when it is offered.
- Ask about equipment, such as a hospital bed or wheelchair, which may be helpful if you are caring at home.
- Write any questions down that you might have prior to going to appointments (it's hard to remember everything you want to ask!)
- Don't be afraid to call a helpline. The people on the other end of the phone have a lot of knowledge and suggestions about caring and also provide emotional support and reassurance.
- If there is something you don't understand, don't be afraid to ask questions.





Factsheet 4: Common emotions at the end of their life

Caring for someone at the end of their life can be a very demanding and distressing experience. We know that approximately half of people caring for someone with an advanced disease report high levels of distress and that it impacts on their overall level of functioning.

This fact sheet describes the common ways that distress can be experienced and gives some tips for managing distress. However, it is important that you talk with your GP or other health professional if you are experiencing high levels of distress.

Stress

Many carers experience stress. You may feel overwhelmed, exhausted, frustrated or angry, or guilty. You may feel like you lack choice over your caring responsibilities.

Stress can come in many forms but feeling stressed for long periods of time is also called 'chronic stress'. Stress can result in physical changes in the body which if prolonged can result in stress related illnesses.

High demands, lack of support and being isolated due to the caring role can all contribute to chronic stress.

What to do about feeling stressed

If you are experiencing chronic stress then you should see if you can reduce the demands on yourself by asking others (friends, family and the health care team) to do more.

If you are caring at home, try and organise a break from caring by organising some 'respite' (this is where the person you are caring for has a short stay in hospital or an aged care facility).

Alternatively, you may want to consider moving the person you are caring for permanently to an aged care facility, hospital or hospice/palliative care unit.

Also, try some self-management strategies such as:

- Make healthy changes to your lifestyle (improve your diet, increase your sleep, attempt some gentle daily exercise, and try and socialise with friends and family)



- Identify the signs of stress (physical tension, increased heartbeat, a short fuse) and monitor your own stress levels. Identify if there are any situations that increase your stress and try to minimise those situations.
- Take a break for 5 minutes when you feel like your stress levels are increasing. Try some deep breathing before you return to the situation.
- Accept things or situations that are out of your control. Try not to expend energy on things you cannot change. Focus on things that you do have control over and can change.
- Plan ahead. Seek information about what is likely to happen in the coming weeks and try and plan ahead to reduce the burden on yourself.

Anxiety

When you are caring for someone who is seriously ill, it makes sense that you would feel worried about them, panicky about all the things you need to do, and anxious about whether you would be able to cope if there was an emergency situation related to their illness. It is normal to feel some level of anxiety as a result of your situation.

However, it is not helpful or healthy to be feeling high levels of anxiety for long periods of time. Anxiety is associated with lower quality of life, poor functioning, poor sleep and diet, and even poor physical health.

The signs of anxiety can include physical symptoms such as panic attacks, hot and cold flushes, racing heart, tightening in the chest, rapid breathing, restlessness, and feeling tense, wound-up, and edgy.

Psychological symptoms of anxiety include excessive fear, worry, thinking the worst, and obsessive thinking. Behaviour changes such as avoiding people or situations can also be a sign of anxiety.

Factsheet 4: Common emotions at the end of their life

What to do about feeling anxious

Firstly it can be helpful to seek support from your GP or other health care professionals. In addition, you can try some simple self-management strategies such as:

- Slow your breathing and concentrate on your in and out breaths
- Make health changes to your lifestyle (improve your diet, increasing your sleep, attempt some gentle daily exercise, and try and socialise with friend and family)
- Try and focus on the present moment
- Try meditation or progressive muscle relaxation (relaxing each of your muscle groups by tensing it, holding for 3 seconds, and then letting it go)
- Write all your worries down in a journal.

Depression

Many people feel sad when they are caring for someone at the end of their life. However, depression is a term for when these sad feelings are more intense and last longer than usual.

Depression means that you are sad, miserable, or down most of the time and are not feeling interested in things or experiencing pleasure the way you usually would.

You may have even lost your appetite, may be sleeping more or less than usual, and may have withdrawn from friends and family. You may be experiencing lots of negative thoughts about yourself and your situation and may feel like things will never get better.

What to do about feeling depressed

Taking time for relaxation, planning activities that you enjoy, socialising with friends and family, and looking after your health are all helpful ways to manage depression.



However, it is important that you seek help if you are depressed. Talk to your GP or other health professional about proven effective treatments for depression including talking therapies and medication.

If you are having thoughts of harming yourself or others, then call Lifeline on 13 11 14.

Grief

If you are caring for someone at the end of their life, then you are probably already experiencing grief. Grief is the natural response to loss. You may be grieving for the loss of the life you once had, or grieving for the loss of a shared future, or grieving for the loss of the person as they were before they were ill, or grieving in advance for the loss that you know is coming when the person you are caring for dies.

Grief can be exhausting, both emotionally and physically. It can affect any aspect of your life and be expressed in many ways. Grief can leave you feeling sad, angry, anxious, shocked, regretful, relieved, overwhelmed, isolated, irritable, or numb.

What to do about grief?

- Share your grief with others.
Talk to friends and family
- Look after yourself physically (eat well, sleep, regular gentle exercise)
- Give yourself time and space to grieve
- Seek help through your GP, a grief counsellor, support group etc.

For more information on anxiety, depression and grief, please visit www.beyondblue.org.au.

