

Caring for a family member or friend?



A Commonwealth
Government Initiative

Support for Carers in their Caring Role

Family members or friends who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged are referred to as carers. Carers can be parents, partners, grandparents, sisters, brothers, friends or children.

Many carers talk about the need to be supported in their role. Caring for someone can be rewarding but also demanding and exhausting. Sometimes carers may feel that others don't understand what they need.

Some carers may experience feelings of grief and loss. There may be times when they feel the person they are caring for has changed so much that they have lost the person they once knew. Carers can also grieve for the loss of their own identity, independence, privacy and time for themselves.

If you are close to someone who is a carer you may find this information helpful in knowing how to support them and understand their role.

To the best of our knowledge, this information was correct at the time of printing

? Why is it hard for carers to accept help?

You may find it particularly difficult to understand why, when carers seem to need so much help, they are unwilling or unable to accept it.

For most people it is much easier to give help than to receive help. It is for this reason that many carers find it is so difficult to accept help when it is offered.

Other reasons for this may also include:

- A sense of duty to the person they are caring for
- Not wanting to trouble people
- Not wanting to seem demanding
- Feeling uncomfortable about other people helping
- Feeling that another person may not do it as well or that it's quicker and easier to do it themselves

Some other reasons may be:

- Feeling that it is a sign of not coping
- Fear of being blamed or criticised by their family, friends and their own community
- Feeling that they couldn't return the favour
- Feeling guilty about needing help
- The person being cared for not wanting others to know how much support they need
- The person being cared for not wanting another person to help

? What do carers need?

Some of the things carers tell us they need are:

- To be treated with respect and dignity. To be listened to
- To be appreciated
- To know that information about them is treated confidentially
- To know that there is support when they need it
- To be able to express and share their worries, feelings and experiences without feeling guilt
- To be informed. To be involved in making decisions about the care they provide
- To have social contact and companionship. Isolation is one of the problems most often mentioned by carers
- Breaks from caring
- To be able to balance their needs with the needs of the person they are caring for
- To know that they are not alone and that their needs are important

? What can you do?

It may not always be easy to know how to support a carer in their role. You may find the following suggestions made by other carers helpful:

- Listen to the carer
- Try not to judge them
- Respect the carer's experiences and knowledge
- Support them to take steps to improve their health and wellbeing
- Provide the help they need. This may include allowing the carer to take a break
- Recognise the carer as an individual with their own needs, hopes and concerns

'It was a great comfort knowing I could talk to my friend about how I felt. We had been friends for years and it didn't matter whether I wanted to laugh or cry. Sometimes she cried with me.'

? What can you do as a professional or service provider?

In addition to the suggestions listed for family and friends, professionals and service providers can:

- Provide support in a way that acknowledges that a carer has first-hand knowledge of the person being cared for
- Consider the needs of the carer as well as those of the person being cared for
- Consider cultural and language differences especially in relation to assessment, treatment and information. Use professional interpreters
- Try to maintain clear and honest communication, but break unpleasant news gently, as the carer may be feeling extremely vulnerable
- Don't assume a person may automatically provide care without any back-up support or resources
- Consider the impact of the disability or illness on all family members and their relationship with each other
- Keep well-informed of appropriate services and other helpful resources that may be of benefit to the carer
- Respect the privacy of a carer's home
- Try to let the carer and their family know in advance about changes in your service, such as staff leaving or roster changes

Supporting carers in the workplace

In addition to being a carer, a person may be employed in paid work or unpaid work. Unpaid work within the community is referred to as volunteering. Carers work for many different reasons. Even a small income from paid work can make a big difference financially to carers. Work may also help by providing opportunities for friendship, confidence, a sense of identity and a break from caring. Support within the workplace or where the carer is volunteering can make a crucial difference to how much stress a carer may experience from the demands of work and caring. Supports that have helped other carers in their work role include:

- Flexible work hours
- Access to a telephone at work so that they can be contacted in an emergency
- Opportunities to work from home
- Access to training when entering or returning to the workplace
- Reduced pay in return for extra paid leave
- Carers leave

Even in the most ideal workplaces conflicting demands between work and caring can be stressful. As an employer, you can make a real difference by trying a few of the following:

- Create an environment for carers to talk to you about their needs
- Try to look for creative solutions to accommodate the needs of carers
- Understand that carers don't always know in advance when they are going to need time off
- Try to give advance notice of changes to rosters so the carer can change their care arrangements

Carers with children

Caring can involve several roles at the same time. For example, a carer may be caring for their own parent while also being a parent. It can be difficult to balance the demanding roles.

You may be able to support the carer by taking time to:

- Help the family to maintain their routine whenever possible
- Provide support for the children in an emergency
- Help provide ways for the children to keep in contact with their friends or peers

Peer support programs are available for children when someone close to them is seriously ill. These can be provided through schools, community, health or welfare organisations.

Your **Commonwealth Carer Resource Centre** can put you in touch with programs in your area. They can be contacted on **1800 242 636** (freecall*).

How can I support someone who is caring for a family member or friend who has a terminal illness?

The needs of carers are very important when caring for someone whose illness is life threatening (terminal) and there is no cure. Caring for someone who is terminally ill can be emotionally and physically demanding. In addition, there are:

- Additional visitors and phone calls that, although welcome, can mean less time for other tasks
- Extra work, such as washing and cleaning
- The emotional stress of dealing with other people's advice
- Trying to support others who are also grieving
- Coping with feelings about loss

At this time you could:

- Offer to help in practical ways, respecting the routines the carer has in place
- Listen to the carer, and take time to find out how things are going

Practical ways to help

Your friend or relative may be finding it difficult to cope with their caring responsibilities and may not have thought about ways you could help them. Perhaps you could offer to help them in the following ways:

- Write a list of things others could do to help. Have your relative or friend keep the list handy for when others offer to help
- Home deliveries: Check with the local pharmacy and supermarket if they can home deliver
- Use the internet to obtain information or do their shopping
- Offer comfort in a way that supports the carer
- Encourage the carer to use an answering machine to return calls at a convenient time. They could re-record their message to provide regular updates when friends or family phone
- Encourage the carer to talk to you or someone else about their day. Reassure the carer that you think their work is important and deserves recognition
- Encourage your friend or relative to regularly give themselves a treat. Reading a magazine, watching a video, taking a bath, reading the paper, or going for a walk are all good ways to relax – suggest ways you could help them to plan those sorts of breaks

* Free call except from mobile phones. Calls from mobiles are charged at mobile phone rates



Where can I get more information and assistance?

You can get more information and assistance from your **Commonwealth Carer Resource Centre** on **1800 242 636** (freecall*). They can provide you with referral to services and practical written information to support you in your caring role.

You can contact the **Translating and Interpreting Service (TIS)** on **13 14 50** (for the cost of a local call) if you need assistance in a language other than English. They will connect you to the Commonwealth Carer Resource Centre and will interpret for you.

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COMMONWEALTH CARER RESOURCE CENTRE 1800 242 636