



Australian Government

Loss and Grief

Carers are usually family members or friends who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers may be parents, partners, brothers, sisters, friends or children of any age.

Carers may care for a few hours a week or all day every day. Some carers are eligible for government benefits, while others are employed or have private income.

Everyone experiences loss during life. However, for carers many of the changes and losses experienced come quickly and often. These losses can lead to feelings of grief.

? What is grief?

Grief is a natural reaction to a painful loss. It is not an illness. It is as much a part of your emotions as joy. Grief can occur not only through death (bereavement) but also from major changes and losses in our lives, such as:

- moving or migrating;
- changing or losing your job;
- separation or divorce;
- children leaving home; and
- death of a loved pet.

Everyone experiences loss sometime during their life. Losses such as the death of a family member may be very obvious to other people. Personal or private losses may be less obvious and not always recognised by other people yet still very painful. Some of the losses that carers talk about include:

- being a carer and losing your sense of being an individual. You may also lose your independence, privacy and time for yourself;
- missing out on employment and career opportunities and your financial security being affected;
- not seeing friends or family as often as you'd like;

- missing the relationship you used to have or might have had with the person you care for; and
- the person you care for going into residential care so you feel you are no longer valued or needed.

These kinds of losses may affect your self esteem and confidence and your hopes and dreams about the future. You may also experience grief before an actual loss occurs. This may happen when someone you care for has a terminal illness and you know you will have to face a loss.

? What does grief feel like?

Everyone responds to grief in their own way. If you are grieving you may sometimes feel physically unwell as well as emotionally upset. Physical symptoms can include shortness of breath, dryness of mouth, loss of appetite, crying, tiredness and sleep problems. Grief can also cause deep feelings of loneliness, anger, fear, guilt, rage and resentment, confusion, ongoing sadness, not wanting to go out or do the things you used to do. These symptoms can be frightening but are normal reactions to grief.

Recognising your grief and talking about how you're feeling can help. Making some time for yourself each day and having some plans in place for those bad times may make it easier to cope.

Some of the signs described above may also be symptoms of other problems so it's a good idea to talk about them with your doctor. Make sure your doctor knows about your caring role and how it affects you. If you are feeling very anxious or fearful, have trouble looking after yourself or think about hurting yourself, it is very important to get professional help from your doctor, a counsellor or a psychologist.



? Ongoing grief

There may be no clear beginning or end to your feelings of grief. You may continue to feel losses for years and sometimes for a lifetime. The constant reminders may make it difficult or impossible to resolve your feelings of grief.

Carer support groups can help you get through times when your grief seems overwhelming. They can also be a safe place to talk about feelings such as anger and resentment. Walking or any form of exercise, deep breathing or writing in a journal are other safe ways to release angry feelings, blame or resentment. For some people crying can be a great release.

✓ Relationships

Caring for a partner

Caring for a partner can mean changes to your relationship. It can be hard to feel romantic when it seems that you've become more like a nurse, parent, driver or therapist and less like a spouse, lover or friend. You might have to learn new skills such as organising the finances or running the household. These changes can be difficult to adjust to and it may take a long time for some carers to feel comfortable in these new roles.

Caring for a parent

For some people caring for a parent is an opportunity to repay the care they received as a child. For others, finding themselves in the role of caring for a parent can be very upsetting. You may miss having someone you can turn to for support or feel uncomfortable about tasks such as bathing and toileting.

'My diary saved me. I really let my feelings out. It helps a lot. There are a lot of tears in that book'.



Caring for a child

Caring for a child can be very confronting. Parents expect that their children will grow up to become adults and start their own lives. Parents may grieve for the hopes they had for their child for the future. Carers may feel frustrated if they can't stop what is happening to the child or solve the problem. They may feel guilty about having less time and energy to spend with other members of the family. They may worry there are not enough services to support their child.

Support groups

Whatever your situation there is a support group you can join to meet other carers with similar experiences. Support groups can be a safe place to talk about your worries and to hear how other carers have coped with difficult situations. Carer support groups offer different types of support and if you find that one particular group doesn't suit you then ask about others in your area.

Your **Commonwealth Respite and Carelink Centre** can help put you in touch with carer support groups in your area. Contact them on **1800 052 222***.

'I always call one of the others in the carers group when I need a shoulder to lean on'.



Stages of caring

When you first become a carer

Becoming a carer may be a slow and gradual transition or it may happen suddenly. If you have gradually taken on a caring role by doing a few extra tasks it may have taken a long time for you to become aware of the changes in your life.

If you became a carer as the result of an accident,

the birth of a child with a disability or a sudden illness the immediate changes in your life and your relationship with the person you care for may be very frightening and stressful. You may have mixed feelings about being a carer and feel resentful about the changes in your life. These are normal feelings and reactions.

After you've been caring for a long time

If you have been a carer for a long time you may have stopped thinking about the things you would like to do and instead spend all of your time thinking about the things you have to do. You may have forgotten what your life was like before you were a carer or you may think about it all the time. Other people might expect that you are used to being a carer and you don't need their help and support anymore. You might not remember the last time anyone asked about you.

Trying to maintain your interests and activities is an important part of looking after yourself. It's not selfish to be healthy and happy. In fact it can make it easier to continue caring.

When your situation changes or you stop being a carer

In the future your role as a carer may change. The transition of moving someone into residential care or adjusting to the death of the person you cared for is not easy. There will be changes in your routine and lifestyle. You may miss the companionship and at the same time be relieved to have more time for yourself. You might feel guilty or worried about what to do next.

If you are considering residential care you might wonder if you are making the right decision:

- Will the person I care for be looked after properly?
- What will other people think of me?
- Have I done everything I could?

- Am I a failure because I can't care for them at home anymore?
- What will I do with my life when I am not so busy?

It can be hard to think about your own needs but it's important to be realistic and try to decide what's best for everyone including you. Only you can decide if the responsibility of caring is too much for you. Remember there are still many ways to help care for your relative or friend even if they are living in an aged care home.

If the person you cared for dies your whole life can change. Other people may understand that you feel grief for the person who has died but they may not realise that you can also feel the loss of not being a carer anymore.

Good days and bad days may come and go. It may take a long time for you to get used to a new routine. You may miss all the things you used to do and the workers you used to see and life may seem very lonely.

If you feel it's been a long time since you had the energy to do things you'd like to do, or if you feel you're not really interested in anything, then a bereavement counsellor may be able to help.

Talking to them about your loss and what it was like being a carer may help you start to feel like trying to get out and about again.

'My family has been great and I try to surround myself with them'.



Where can I get more information?

There is a lot more information for carers available on a range of topics. Commonwealth Respite and Carelink Centres in each state and territory provide carers with referral to services and practical written information to support them in their caring role. Contact your **Commonwealth Respite and Carelink Centre** on **1800 052 222***. Alternatively, carers can use the services provided by the carer association in each state or territory. More information on these services can be found by contacting **1800 242 636**.

The **Translating and Interpreting Service (TIS)** can help you if you need assistance with a language other than English. TIS can be contacted on **13 14 50***

COMMONWEALTH RESPITE AND CARELINK CENTRE
1800 052 222*

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