



Cancer survivorship information for survivors and carers



Caring for a cancer survivor: tips for coping

Being a carer for someone with cancer can be a rewarding and special experience. However, it may also be tiring and challenging. There may be times when you wonder how you are going to keep on going. You don't want to 'break down'; you feel you need to stay strong for the person you are caring for.

It is only natural that you might look forward to when treatment is over and you can return to a more 'normal' day-to-day life.

Does the caring role end once treatment is over?

For most carers it is unlikely their caring role will end as soon as treatment has finished.

Recovery period

The recovery period for some people who have had cancer treatment can take weeks, months or even longer. So you may need to continue caring for the person for some time after their initial cancer treatment.

This often depends on whether or not the person you are caring for has:

- health issues related to their cancer and its treatment (e.g. immobility, eating problems and fatigue)
- health issues they may have had before they were diagnosed with cancer (e.g. diabetes or heart problems).

How the person who has been treated for cancer is feeling can also play a part. Fear, anxiety and depression are not uncommon in people with cancer. These feelings can linger even once treatment is over.

Getting back to 'normal'

You may be surprised by how you feel without the regular support and contact from the health care team at the hospital. You may be left feeling lost, upset and at times even lonely. You may not have realised how much you were depending on them for support and information. You may start to question how you are going to resume a 'normal' life again.

Common feelings

Your feelings and reactions to all that has happened so far, as well as fear of the future, can have a powerful effect on you. You are likely to have gone through a range of emotions over the diagnosis when you first became a carer such as shock, anger, fear and sadness.





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You may have wished it could have been you who had the cancer instead. You didn't like to see the other person suffer so much.

During your caring role you may also have felt:

- guilt about wishing you had more time to yourself again
- taken for granted
- resentment towards the person you were caring for
- frustration towards yourself and the person you were caring for
- intolerant and irritated by the situation
- helplessness
- loss and grief.

Some of these feelings can remain once your caring role is over. This is very natural and they will usually go in time. But some feelings can linger and turn into depression.

Depression is different from sadness. It is a much more intense feeling than sadness. It can be serious and may need medical treatment. It is important you see your GP if you feel you may be suffering from depression.

Learning to cope with your feelings

We are all unique and have our own ways of coping during good and bad times. There is no wrong or right way to feel when you have cared for someone with cancer.

If you are struggling to cope, try not to feel alone. What you are feeling is likely to be perfectly normal. You just need time to adjust to the situation as well as trying to get your life moving forward again.

Knowing your feelings are normal and working out how to manage them is an important part of being a carer.

If you are unsure about how to best deal with your emotions, ask yourself:

- What helps me keep anxious, angry or sad feelings away?
- What helps me relax?
- What helps me feel at peace?
- What helps me feel happy?

Try to think about your own responses rather than what might make others happy. Work out what helps you best manage your emotions. What may have helped you feel better before you became a carer may not be the same now. Other people's suggestions may not work for you either but try keeping an open mind. You may find trying something you wouldn't normally do does actually help you feel better.

Tips to help you cope

The following few tips won't work miracles but they may help you find the best way to cope with your feelings as your caring role changes after treatment finishes.

- Acknowledge your feelings and allow yourself the time to feel and work through your emotions. There is no time limit on

how long you may need to do this.

- Try to read the signs of stress and do something before it gets too serious. You may find it helps to talk about feelings with a close friend or relative or seek help from a professional counsellor.
- It is okay to feel angry, to cry and to let people see how you are feeling. You can't be cheerful all the time.
- If you are having trouble with intimacy talk to your partner about your sexual needs and concerns and about how they're feeling. This can be difficult but it is likely to be worthwhile.
- Acknowledge the losses and the changes that cancer has brought into your life and the person who went through treatment. If it was your partner let each other know that you may need time to adapt but you do want to make the relationship work.
- Know that you are doing the best job you can and there may be some things you cannot change.
- Don't be afraid to ask for help. Those close to you are likely to want to help you but they may not realise you are struggling so, as hard as it can be at times, you may need to ask and guide them as to exactly what help you need.

Fear of the cancer coming back

Like most cancer survivors, carers also worry about the cancer coming back.

If you are very close to the survivor your fears may be quite strong. For some people the fear of the cancer returning is so strong that day-to-day life can become a big struggle. If the cancer comes back you may worry how you would cope being a carer again. It took a lot out of you the first time. How would you ever find the energy to do it again?

The thought that you may have to put your life on hold again may be overwhelming. Such fears can cause similar feelings to those of the cancer survivor.

You may feel:

- caught in a 'no-man's land' or 'in limbo'
- full of confusion and uncertainty
- fearful of planning ahead





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- that life has 'stalled' or been 'put on hold' with no way of knowing how to 'get started' or 'move forward' in life again.

However, with time and the right support it is likely that your fears will lessen. By acknowledging fears and taking control of them, most carers and survivors find they can enjoy life again.

If you are unsure about where to go for help you can call the Cancer Council Helpline on 13 11 20 and speak with a cancer nurse. They can give you further information about coping with your fears, counselling or joining a support group.

Coping with practical issues (work, finances and home)

Depending on your relationship with the person you cared for, your practical issues will vary. For example, caring for your partner will bring up different issues than those you would face if you were caring for one of your children or your mum or dad.

Whatever your situation, you may face challenges with sorting out money matters such as:

- earning and managing income to provide for yourself or your family
- life insurance
- superannuation funds.

You may also have the added worry of coping with going back to work or study. Or you may find yourself in the situation where you need to work more hours to cover your family costs now. Everyone's situation will be different.

Whatever your situation, sorting out work and money matters takes time and energy. Many people say they find it very stressful. However, knowing where to get help and who to ask for help about practical issues may lessen your stress. See 'Further information'.

Caring for yourself

Most carers find this a hard thing to do. Some carers do not have anyone to talk to about their feelings and needs. Often carers don't ask for help or think their needs are not as important as the person with cancer.



Caring for yourself while you are a carer is extremely important. But it is just as important that you continue to do this once your caring role is lessened or over. Most carers know this but still find it hard to do.

Try to ask yourself what it is you need or what you are struggling with most:

- Is going back to work worrying you?
- Do you feel overwhelmed by sorting out finances that have been let go a bit during your caring role?
- Do you seem to be constantly worrying about the cancer coming back or maybe about whether or not you will get cancer?

You may have health issues that you have been trying to cope with during your caring role. You may not have taken as good a care of yourself as you usually do: forgotten to take your regular medications, missed check-ups with your GP or ignored 'new' health problems you might have.

It is very natural to begin to have worries about your own health when you have been caring for someone who is ill. Whatever it is you need help with, try to ask for it.

Asking for help

This doesn't come easily to everyone. For some, giving help comes more naturally than receiving it.

You may feel you should be able to cope alone now you no longer have the stress of

caring for the person with cancer. Asking for help may seem like a sign of failure. This simply isn't true. It is very hard to do everything alone. Most carers benefit from some help even when treatment is over. People might not offer help because you appear to be coping so well alone. However, this doesn't mean that they don't want to help. Many people will be very happy to help if asked.

Getting some help may allow you to feel more in control. It may reduce your stress, give you more time to yourself and allow you to see a way forward again. You may want to lean on close family and friends for help or you might find it easier to get outside help. Do what suits you and will help you most.

Staying fit and healthy

With the added stress of caring for someone with cancer you may have easily become run down. It is very important to stay aware and listen to your body's needs.

If you have medical problems, be extra careful that you don't neglect your own health. During your caring role you may have been tempted to do this. But now you may have more time to focus on your own health.

You may find it helps to:

- Find a GP who you trust and can maintain good contact with if you need help.



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- Have a check-up of your own health and any illnesses.
- Build in a proper health check program for yourself. For example, you may need regular blood pressure checks or blood sugar checks. Also, don't forget to have your regular screening tests such as Pap test, mammogram and bowel checks.
- Eat a regular well-balanced diet with lots of fresh fruit and vegetables. Don't forget to treat yourself every now and then as well.
- If you can, take regular exercise: whatever appeals to you and is possible. Walking, running and swimming are good. But if these don't appeal you may like to try an exercise class or watch a DVD at home (yoga, tai chi or Pilates). Even just 30 minutes of exercise a day can help you feel more relaxed.
- Try to get enough sleep. If you are having trouble sleeping, take a warm bath, or read or listen to some relaxing music before bedtime.
- Limit the amount of alcohol you drink and avoid drugs that are not prescribed

by your doctor. Although they may help you sleep or feel better at the time, long term, too much alcohol and recreational drugs can affect your health.

See your doctor if you notice any changes in your health. Weight changes, aches and pains, bowel and urinary problems, sleep changes and feeling tired and low in mood all the time are all possible when you have been using up a lot of energy caring for another person.

Preparing for the days ahead

If you can do even a few of the things discussed above it might help with getting your life back on track.

There may still be some bad days ahead. No matter how hard you try, you may still feel a bit down on some days. You have had to deal with so much and probably not had much time to think things through.

Give yourself a pat on the back now and then for all you have done. If you have bad days try not to let it worry you too much. It is likely there will be more good ones ahead.

Further information

-  Beyond Blue (1300 22 4636) has information about depression.
-  Cancer Council (13 11 20) booklets include: 'Talking to kids about cancer', 'Sexuality, intimacy and cancer', 'Caring for someone with cancer', 'Living well after cancer'.
-  Carers Australia (1800 242 636) provides a carer advisory and counselling service.
-  Through the Cancer Council (13 11 20) you can speak with a cancer nurse: ask about Family Cancer Connect and support groups and other support services that may help you. Cancer Connect is a free phone peer support service that puts people in touch with others who've had a similar cancer experience.
-  The DoHA (1300 650 172) can help with financial and practical matters. For information on disability, sickness and carers payments, call Centrelink (13 27 17). You may be eligible for help with childcare costs: call the Family Assistance Office (13 61 50).
-  FIDO (Australian Securities and Investments Commission) (1300 300 630) provides a range of financial advice services.
-  Moneyhelp (1800 007 007) is a government service that offers free, confidential and independent financial information for Victorians experiencing job loss or reduced working hours.

All of these services may be accessed through their websites.

We thank Cancer Council Victoria for permission to adapt information from its booklet 'Caring for someone with cancer'.



Australian Cancer Survivorship Centre

A Richard Pratt Legacy



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