

CAREGIVERS, FAMILY AND FRIENDS



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Being a caregiver has been described as one of the toughest, but also the most rewarding, challenges. The thought of caring for someone with cancer can be frightening. You may worry that you don't have the skills or emotional strength. But many people who have done it say it can be rewarding and satisfying to help someone when they need it the most.

Caregivers, family and friends can make a huge difference to the quality of life, or even to the survival of the person with cancer.

BEING A CAREGIVER

- A caregiver is anyone who provides unpaid personal care and support to a person who needs help because of a disability or illness, like cancer.
- Becoming a caregiver can be sudden, or it can happen gradually over time.
- Caregivers can be connected to a person with cancer in many ways, such as family, marriage, friendship, or other types of relationships.
- When supporting someone with cancer, you can be as involved as you are prepared to be; it may be a weekly cup of coffee, a chat and just listening or it could involve a whole lot more.
- For many people, being a caregiver is a full-time responsibility, usually on top of work, looking after children, or other roles. There are about 3 million caregivers in Australia. To learn more about what it means to be a caregiver, visit [Carers Australia](#).
- There are no rules about what is involved in caring for someone with cancer. It depends on each person's needs and limitations and what other help and support you may have.
- For Aboriginal and Torres Strait Islander families, or for those living rural, remote or very remote, caregiving may involve unique challenges. ATSI services and Telehealth can provide extra support.

WHAT IS INVOLVED IN BEING A CAREGIVER?

If you know someone with head and neck cancer you may be wondering what you can do to support them. There are many things you can do to help. They may need ongoing personal and medical care for a long time or help while they are having treatment.

Caring for someone with cancer may involve the following:

- **Practical help:** In forms such as shopping, cleaning, picking children up from school, or driving to and from medical appointments.
- **Helping them follow health advice:** Such as taking their medicines and looking out for side effects or signs that they are having trouble sticking to health advice, for example smoking or drinking a lot of alcohol. They may also need help with treatments that assist with treatment side effects such as application of creams for [skin](#) reactions or medications for chemotherapy related nausea.
- **Eating well:** Support the person with cancer meet their diet and nutrition needs, for example choosing foods which are easier to swallow and helping them to maintain their weight. They may receive information from a dietitian, and you can find out more about this on the [Head and Neck Cancer Australia website](#).
- **Organisation:** This may include helping coordinate appointments, dealing with medical forms and bills, or getting information about, and applying for financial support.
- **Counselling:** This may be in the form of listening, providing emotional support or looking for signs the person with cancer may not be coping or be depressed and may need professional help. The [Head and Neck Cancer Australia Help Line](#) is available for both patients and carers to access.
- **Making decisions:** Sometimes getting a second opinion or further information about treatment is necessary. It is also helpful to talk early about the person's wishes for their future care and document these in an Advance Care Directive. This ensures that if they become very ill and are unable to express their wishes, their values and preferences are respected and can guide decision making. If you need more information on Advance Care Directives, speak to your GP.
- **Being an advocate:** Help make sure the needs of the person with cancer are met, their wishes are being heard and they get the support they are eligible for.
- **Finding a 'new normal':** By supporting and encouraging them to cope with changes, reconnect to family and friends and possibly go back to work or activities they enjoy.

Treatment for head and neck cancer can be tough for the person physically and can often lead to weight loss and problems swallowing and/or speaking. The patient may also struggle emotionally as they struggle with their own fear and discomfort. The patient may get very ill for a time and may need to totally rely on you. It can be a distressing experience to observe suffering in someone you love and care for, and it is important to take time for your own wellbeing and helps you to stay strong and continue to provide care and support.

You may be able to cope better if you have someone outside the family to talk to, like a counsellor or psychologist. Your GP or the cancer care team may be able to help you find someone to talk with or identify a person who you can call on for advice on practical care issues.

LOOKING AFTER YOURSELF

Being a caregiver can be hard, both physically and emotionally. It's normal to feel satisfied some days and frustrated, angry or resentful on others. Caregivers can also feel lonely and isolated. The stress of caring for someone with cancer can affect the caregiver's health, so it's important to look after yourself too.

TIPS FOR LOOKING AFTER YOURSELF

- Eat regularly and try to eat three meals during the day, including vegetables, fruit, lean proteins and wholegrains.
- Try to get enough sleep.
- If you take any regular medicines remember to take them and see your doctor if you feel unwell.
- If there are activities you usually do without the person you are caring for, try to keep this up. Even if it means organising someone else to stay with them while you are out. Try to keep doing the things you enjoy, like playing a sport or going to your club or a local group.
- Ask for help from family and friends. Don't try to do everything yourself.
- Talk to others about how you're feeling. You may want to talk to your family and friends or a health professional, such as your doctor or a counsellor.
- Make time to relax. Go for a walk or make a cup of tea and sit outside. Find a place or activity that is not related to your role as a caregiver, so that you have a sanctuary to go to for a set period of time every day. This might be something like going to the gym or swimming pool every day or gardening or perhaps doing a course – just for you.

- It's important to know the signs that you're not coping and talk to someone who can help. Many cancer support groups and education programs are open to caregivers as well and can be a good way to meet other caregivers and share ways of coping.

About Head and Neck Cancer Australia

Head and Neck Cancer Australia is the only national charity dedicated to providing free, trusted and easy to understand information, education and support to people affected by Head and Neck Cancer.

We represent over 5,300 people who are newly diagnosed each year and more than 17,000 people who are living with Head and Neck Cancer across Australia.

We also lead the national effort to advocate for government support to encourage prevention, increase early diagnosis and improve the quality of life of people living with Head and Neck Cancer in Australia.

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