

# YOU'RE IMPORTANT TOO: LOOKING AFTER YOURSELF AS A CARER

## FACT SHEET

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This fact sheet was produced by Breast Cancer Network Australia

This fact sheet will provide information to help support you in your role as carer. It will also provide some tips on looking after yourself.

### The carer role

Many Australians diagnosed with breast cancer will have carers in their lives – people who provide regular support, personal care or assistance to them, both during and after treatment. Carers can be anyone – a spouse or partner, a parent, daughters and sons, sisters and brothers, friends, colleagues, or neighbours. You don't have to see yourself as a 'carer' to be in a caring role.

For some, the carer role is a new experience. For others, the carer role may already be established. This could be because the person diagnosed has a disability, low literacy or language barriers. In this instance, you may find your carer role will change. You may need to take on additional responsibilities to ensure they feel supported during and after treatment for breast cancer.

It is important to be aware of the level of support and care required, so that you can put strategies in place to help you manage these extra responsibilities.

### Looking after yourself

We know that a diagnosis of breast cancer can significantly affect carers, and carers can experience feelings similar to those of the person who has been diagnosed. It is normal for carers to feel overwhelmed and to experience a whole range of emotions including shock, numbness, uncertainty, fear, helplessness, sadness, anger, depression and anxiety.

If you are the main carer for someone with breast cancer (also known as a primary carer), or you have a very close relationship, you may need practical or emotional support to help you take on caring responsibilities.



You may have put your own wellbeing on hold to give all your attention to caring for the person diagnosed. Looking after yourself will help you better support them.

### Social and emotional support

Some carers believe that they should ignore their feelings and focus on the needs of the person with breast cancer. Doing this for a little while is okay, but by putting your own needs on hold for too long, you may 'burn out' and no longer be able to care for the person well. Paying attention to your own needs and taking care of yourself is an important part of supporting the person close to you.

*It was very lonely. It was exhausting. I realised I needed emotional support myself because I was doing my best to give emotional support to my partner. – Greg*

Sometimes caring can be isolating. You may find that you are not as involved in social activities and events outside the home as you used to be. It is also normal to want to pull away sometimes when times are difficult. It is important to reach out if you are feeling isolated or alone.

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Talking to someone other than the person you're caring for about how you're feeling can help you come to terms with the situation and may give you a sense of control. It may also provide you with reassurance that your feelings are normal and that you are not alone.

You might also find it useful to talk to a professional about how you're feeling. A general practitioner (GP) can refer you to a counsellor, social worker, psychologist or psychiatrist with expertise in counselling people with cancer and their carers.

### **Help with stress, anxiety and depression**

Some carers may feel overwhelmed or find it difficult to cope. Signs of stress can include things like poor sleep, fatigue, unhealthy changes in eating habits and problems with anxiety and depression.

If you think you are experiencing depression or anxiety or would like to speak to a professional about what you are feeling, you can talk to your GP, who can refer you to someone who can help.

In the same way that you can get a Medicare rebate when you see a GP, you may also be able to get part or all of the consultation fee subsidised when you see certain mental health professionals. You will need your GP to draw up a treatment plan for you.

Cancer Council provides free, confidential information and support from trained staff. Call 13 11 20.

For information about depression, anxiety and other mental health concerns, call beyondblue on 1300 224 636.

For immediate, confidential telephone counselling, call Lifeline on 13 11 14.

### **Support for partners**

Taking on a carer role can sometimes change your relationships. While being there for each other during a difficult time can strengthen relationships, it can also present challenges.

You may find that the person you are caring for worries about losing their independence.

Partners may feel they have lost the intimacy they once had.

If a relationship was difficult before becoming a carer, these difficulties can make the carer role more challenging. There are many resources and supports available that can help.

As a partner, talking through any issues with a counsellor may help. Your GP can refer you to a psychologist or psychiatrist and you may be eligible for a Medicare rebate for counselling sessions if you've been referred by a GP.

Counselling may be available through hospitals and community health centres. Some general cancer support groups welcome partners and families.

BCNA's booklet *'I wish I could fix it': supporting your partner through breast cancer* has information for partners of people diagnosed with breast cancer in the last 12 months.

Cancer Council's *Caring for Someone with Cancer* booklet has tips to help partners cope.

### **Support for lesbian, gay, bisexual and transgender (LGBT) partners**

LGBT partners have unique needs and concerns in addition to the common concerns that all partners experience. You may worry about how members of the treatment team respond to LGBT couples. You may also be concerned about being excluded from important decisions involving your partner or not being recognised as a partner or carer by health professionals.

Some partners feel that the process of regularly 'coming out' to health professionals is almost as stressful as dealing with their partner's breast cancer diagnosis.

It is helpful to seek care from a medical team who is sensitive to your needs, respects your privacy and encourages you to be involved. The Australian Lesbian Medical Association (ALMA) has a list of health professionals who are recommended by lesbian and bisexual women. Visit [almas.org.au](http://almas.org.au) for more information.

You might want to talk to other LGBT partners in a carer role. Your local cancer support group or LGBT support services may be able to point you in the right direction.



The National LGBTI Health Alliance provides information on organisations and individuals that provide health-related programs and services focused on lesbian, gay, bisexual, transgender and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities. Call (02) 8568 1123 or visit [lgbtihealth.org.au](http://lgbtihealth.org.au).

You can also find information for same-sex couples through BCNA by visiting [bcna.org.au](http://bcna.org.au) or by calling 1800 500 258.

### Support for family members in a carer role

Other than partners, family members can also take on a caring role, either as a sole carer or someone who shares caring responsibilities with others. You might find it helpful to get access to practical support, counselling and peer support. The Carer Advisory Service provides information and advice to carers and their families about carer supports and services. Call 1800 242 636.

Adolescents and young adults can also be carers for a parent or sibling with breast cancer. For young people in a carer role, there are additional challenges such as disruption to schooling. It is important to have opportunities to share the caregiving role with others, or to be cared for by other family members. As a young carer you may need additional supports to help you. There are services available specifically for young carers, including respite care, financial support, educational support and counselling.

Young Carers Australia provides information and support for young carers, including confidential counselling by telephone. Call 1800 242 636 or visit [youngcarers.net.au](http://youngcarers.net.au).

### Support for friends, colleagues and neighbours providing regular care

Sometimes friends, work colleagues or neighbours may provide care and support to a person with breast cancer. This may mean needing to take on a carer role in different ways, such as making home visits that you need to work into your schedule, or coordinating care with a person's family members.

The Carer Advisory Service provides information and advice to carers and their families about carer supports and services, which you may find helpful. Call 1800 242 636.

BCNA's booklet *Helping a friend or colleague with breast cancer* has useful tips to help friends and colleagues support someone with breast cancer. For more information, visit [bcna.org.au](http://bcna.org.au) or call 1800 500 258.

### Getting financial and practical support

As a carer, getting financial and practical support may be one of your main priorities.

Treatment and care can be costly. General day-to-day expenses continue, as well as additional expenses such as specialist appointments, medications, treatment and tests, counselling, adjustments to the home, travel and other costs related to treatment and care.

If you are the main carer, it can also be difficult trying to balance work demands with your commitments as a carer. Sometimes you may need practical support, such as help around the home. There are a number of government and community support services available that provide practical assistance.

Cancer Council offers a range of services for people and their families that are financially affected by cancer, although they are different in each state and territory. Contact Cancer Council on 13 11 20 for information about:

- financial assistance schemes
- accommodation if you have to travel with the person getting treatment
- travel assistance
- practical assistance, such as home help
- grants or subsidies that may be on offer in your state or region.

You might also qualify for home help services through your local council. It's worth checking, though you may need a health care card or pension card to qualify. The council may also be able to provide practical help such as child care or transport, or a disability parking permit.

If the person you are caring for can no longer work in the same capacity and you are required to take time off work to care for and support them, the loss of income can place a great deal of financial pressure on you and the person with breast cancer.



It is a good idea to speak with your employer about your situation. Discuss what options there may be, for example flexibility around leave arrangements and work hours, and what support programs are available. Some companies have employee assistance programs with work-life counsellors for you to talk to.

If you are having difficulties remaining at work because of the demands of your caregiving and other responsibilities, carer payments and other forms of financial assistance are available.

The Department of Human Services (Centrelink) supports primary carers financially through various schemes. Contact the Carers Line on 13 27 17 or visit [humanservices.gov.au](http://humanservices.gov.au).

If the person you are caring for has a disability you may both qualify for the National Disability Insurance Scheme (NDIS). For more information contact the National Disability Insurance Agency (NDIA) on 1800 800 110 or visit [ndis.gov.au](http://ndis.gov.au).

You can also find more information through BCNA by visiting [bcna.org.au](http://bcna.org.au) or calling 1800 500 258.

### **Ways you can look after yourself**

It is difficult to care for someone else if you are unwell or neglecting your own wellbeing. If you aren't looking after yourself, you might find it more difficult to deal with the ups and downs of caring for someone. Every carer is different in terms of their needs for support, as well as the types of support they prefer.

The following are some practical strategies you may like to explore to help look after yourself.

#### **Exercise and eat healthy**

Regular exercise along with eating a healthy balanced diet can help reduce stress, increase energy and improve mood.

Going for a walk with a friend or joining a club or class is a great way to get out and have time for yourself.

Find something you enjoy so exercising doesn't become a chore to maintain.

Eat a diet that includes a variety of healthy foods, cut back on not-so-healthy foods and continue to enjoy the treats you love in moderation.

#### **Ask for help**

Many people don't want support when they need it most. It is okay for you to ask for things that will help you and the person you are supporting. Remember that getting help for yourself can also help the person you are supporting.

#### **Make time for yourself**

Give yourself time each day to do something for you. Think about this as beneficial, not as an indulgence. This may be seeing a movie, keeping up with a hobby or catching up with a friend.

A great way to switch off is through exercise – go for a walk or run, or try yoga or Pilates.

#### **Access respite care**

If you find it difficult to find time for yourself when you are caring for someone close to you, you may want to access respite care. Respite care allows carers to have a break. It can be given at home, in a respite centre or sometimes in a hospital. Respite care can be accessed for any reason and for any amount of time, from a few hours to a few days.

Commonwealth Respite and Carelink Centres provide free and confidential information on local carer support services and respite options. Call 1800 052 222 or visit [dss.gov.au](http://dss.gov.au) to find out more.

#### **More information and support**

There are many organisations that can provide resources and support for carers of a person with breast cancer.

Visit [bcna.org.au](http://bcna.org.au) for a list of resources, or call BCNA's Helpline on 1800 500 258 for free and confidential information, support and referral.