



7. THE PEOPLE WHO CARE FOR YOU

Caregivers come in all shapes and sizes and for people with advanced cancer they are often the secret to an optimum quality of life.

Caregivers can be spouses, partners, grown children, other family members, friends or neighbours. They may care for you full-time or they may call in now and then to cook meals, do housework, pay some bills, sit with you or provide emotional support.

Adjusting to being a caregiver can take time and can be fraught with strong and often conflicting emotions. For some, caring for someone close to them makes them feel good about themselves. It allows them to appreciate life and makes them feel useful and needed.^{61, 62} Care giving can also strengthen relationships.

On the other hand providing care can be time consuming and emotionally draining. Long-term carers may also find that their employment, social activities and overall physical and emotional wellbeing suffer.^{58, 63, 64, 65}

Identifying carers' needs is the first step in helping them overcome issues that may be causing much distress and anxiety. The Needs Assessment Tool (Patients & Families) included on pg 116 may help a caregiver identify the areas they may require additional help with. Please pass it on to anybody you think may benefit from it.

Physical health

Shopping, housework, cooking, personal care, medicating, lifting, transporting, calling health care workers, making medical appointments, offering a shoulder to cry on^{63, 66, 67} and more, could be in the job description of someone caring for a person with advanced cancer.

It is little wonder then that many caregivers say they have too much on their plate⁶⁷ and their own health suffers as a result. They may be tired and exhausted, have back, neck and shoulder problems, struggle with weight and fitness or be sick from stress.⁶³ To top it off, they may not be getting enough sleep.⁵⁸

What may help

Looking after themselves

This is easier said than done when someone else is depending on them. Eating regular, balanced meals – even if you do not have the appetite to eat with them – is the key to keeping up their energy and strength.



- You may be able to draw on services such as Meals on Wheels, to free up time for a carer whose duties include cooking.

Both you and your caregiver may be able to look at the list of things to be done and see where time may be freed up for the carer to perhaps get some exercise or sleep. Again, family or friends may be able to take over for a short period of time while your caregiver takes a mini-break.

Safety first

To maintain physical and emotional well being, your carer needs to be aware of safety and hygiene for their sake as well as for yours. Your doctor or hospital may be able to suggest an occupational therapist who can advise on suitable equipment, lifting techniques and other physical matters. A nurse will also be able to advise on hygiene practices.

Help with coping

The Commonwealth Carer Resource Centre can put caregivers in touch with services in their area that may be able to provide some assistance. Go to the [Carers Australia website, www.carersaustralia.com.au](http://www.carersaustralia.com.au) or phone **Freecall 1800 242 636** for state and territory carers associations.

Respite care

Respite care – provided by family, friends, neighbours or a formal service – allows caregivers to take a break.

A formal service may arrange for you to access a day care centre or admit you to a hospital or aged-care facility for a short time. Alternatively, a trained person may take over in your home. The relief care may be for a few hours or a few days, depending on your needs and those of your caregiver.

If your caregiver needs help organising respite care, talk to your doctor or health care team or call the **Commonwealth Carer Respite Centre on Freecall 1800 059 059** or the **Commonwealth Carelink Centres on 1800 052 222**, or go to the **Department of Health and Ageing website, www.health.gov.au**

Mental health

Looking after someone close to them can bring a carer much pride and satisfaction.⁵⁸ It may mean they get to spend more quality time with you at home and this can strengthen your relationship.^{61 68}

The caring role can take a mental toll. They may feel anxious, sad, depressed or even resentful about your illness and the care you need. These feelings in caregivers may also increase as the health of the person they are caring for worsens.^{69 70}

Carers may also experience degrees of grief and the demands on their time may leave them feeling isolated and lonely. Left untreated, these states of mind can affect their long-term health and it can take years for them to recover.

What may help

Take breaks

Carers can try to schedule time each week to do things they enjoy – walking, gardening, having coffee with a friend or spending time with their family.

Family or friends may be able to take over some duties while your carer takes a break. If not, formal respite care (see under “Physical health” in this chapter) may be an option.



Q&A

Q: How can I get my carer to take a much-needed break?

A: They may feel guilty about taking a break, so maybe you need to step in and arrange it (or get a social worker to help you). How about pointing out to them that the break, even a short one, will probably be as good for you as it is for them?

(Source: Australian Government Department of Health and Ageing)

Talk your Doctor

If your carer seems anxious or sad, suggest that their doctor may be able to prescribe some medications that can help them feel better, or refer them to a psychologist or counsellor.

Emotional support

A carer may find it helpful to talk to someone else about how they are feeling, perhaps someone who is going through the same thing. Even if they don't feel comfortable talking with you about things (for fear of worrying you, for instance), they may be willing to talk to trusted friends or family members. At the very least, it may help those close to them understand their situation.



If they don't have that sort of support, or need more than family and friends can provide, there are trained counsellors through the [Cancer Council Helpline \(13 11 20\)](https://www.cancer.org.au/cancer-council-helpline).

These counsellors, or even the carer's own doctor, may also direct them towards local support groups. [Carers Australia \(Freecall 1800 242 636\)](https://www.carersaustralia.org.au) has officers who, among other services can provide emotional support, information and referrals to counsellors for people who are caring for someone with advanced cancer.



- A sense of humour is always a good thing for a caregiver. Even though your illness is serious, sometimes the best way to deal with embarrassment and other awkward moments is to have a laugh.

Social effects

Taking on a caring role can mean hobbies, social outings, work, travel, holidays, shopping and time with family and friends fall by the wayside.

These are sacrifices many caregivers are prepared to make for someone they love, but they may also feel a sense of loss, loneliness or isolation because of these social limitations.

It is important that your carer somehow finds time for social activities, since doing things they enjoy will help sustain a positive approach to their caring role and relieve the stress on their other relationships.

What may help

Talk about it

If your caregiver is generally positive about their role, those around them may not realise how much they are missing in their life. Being open and honest with family and friends may draw out some helpful ideas and offers of help.

Respite care

Family, friends or community members may be able to offer a caregiver some informal respite so they can take part in occasional, or preferably regular, social activities. Formal relief care from agencies may also be available (see "Physical Health" in this chapter pg 94).

Financial effects

A caregiver may well need to reduce work hours, or even give up work. On top of that they may have extra expenses. They may have to travel to be with you and perhaps pay for help (such as child care) to cover their other responsibilities. They may also be reluctant to reclaim the cost of medications, products and other household items that they may pick up for you.

What may help

Government benefits

While they will not cover the full cost of caring for a person with advanced cancer, the payments and allowances available through Centrelink for caregivers are worth investigating. See "Caregiver benefits" in Chapter 5 for the details.

Access to superannuation

With the right documentation (written certification from a specialist and one other doctor) a person who is expected to live for less than a year may apply to their superannuation fund for a lump-sum payout. You may choose to use some of this money to cover your caregiver's costs.

Other assistance

The Cancer Services Directory on your state's Cancer Council website will have information about the financial assistance programs run by charities in your area. Some of these programs may help with the cost of care giving.

For more information

- **The Federal Department of Health and Ageing** has a fact sheet for caregivers on managing money. Go to www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-carerkit.htm
- The Cancer Council has a Welfare Grants Program that can, in cases of extreme hardship, provide financial help to people with cancer. Contact the Cancer Council in your state.

Access to information

A major concern for carers of people with advanced cancer is just how much they don't know. Many become stressed and frustrated by what they see as a lack of adequate information. The more they can find out about your illness, the better they will be able to cope.

What may help

Talk your Doctor

Carers should not hesitate to ask any questions of their doctor, your doctor or other members of your health care team. It may help for them to write down their questions before a consultation or phone call. They can book a longer appointment to give them ample time to talk. The Needs Assessment Tool (Patients & Families) on pg 116 may help identify any questions they may have.

Talk to you

You may not have told your caregiver everything about your illness, possibly for fear of worrying or overwhelming them. Tell them they should not be afraid to ask you anything, and that you will be as honest as you can in reply.

For more information

A wide variety of information is available for caregivers, much of it accessible online:

- Care Search provides reliable information about advanced cancer, palliative care and the types of services in the different states. There are also links to other reliable websites. Go to www.caresearch.com.au
- Carers Australia provides caregivers with information and education resources. Go to www.carersaustralia.com.au or phone **Freecall 1800 242 636**
- The Cancer Council has a range of brochures for people with advanced cancer, their caregivers and families. Call the **Helpline on 13 11 20**, or go to www.cancercouncil.com.au
- **The Department of Health and Ageing** has fact sheets in a caregiver information pack. They cover topics such as managing money, taking a break and loss and grief. Go to www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-carerkit.htm
- The **US Caring Connections** website has detailed information for patients and caregivers. Go to www.caringinfo.org
- The **US National Cancer Institute** has a booklet on support for caregivers. Go to www.cancer.gov



Effect on families

Caregiving often changes the roles and responsibilities of every member of a family, and this can take some getting used to.

The most noticeable impact is usually on young children, particularly if the carer is their mother or father. As a rule, children like routine, and a parent's focus on someone else's needs can throw them. If they are not coping with these changes, they may not sleep well, may wet the bed, or they may play up as a way of reclaiming attention.

Care giving may also put strain on other relationships within the family. Some family members may feel they are carrying the burden of responsibility, while others may feel left out. Some may resent the changes in routine and loss of normality.

What may help

Reassure children

Children need to know they are loved and will be cared for. Communication is the key. Let them know what is happening and who will be taking care of them. If a caregiver can't give their children the time they need they may like to ask another trusted adult to give them some extra attention.

Family talks

It may pay to schedule in regular family meetings (perhaps a weekly meal) where everyone can air their thoughts and feelings without being judged. This may also be a good time to go over routine matters in order to maintain a sense of normality in day-to-day life.

Practical matters

Caring for someone with advanced cancer is a big undertaking and depending on your needs, many of the jobs involved may be new to your caregiver.

What may help

Community nurse

Community nurses can often come to your home and teach carers how to carry out many of the tasks. They may for example help organise medications,

demonstrate how to change dressings or give advice on aids. Your doctor or local hospital should have details about services available in your area, or ask at your nearest community health centre.

For more information

- **The Palliative Care Council of SA** has a resource called Palliative Caring at Home, which provides information for caregivers about the practical aspects of caring for someone at home. Go to the council's website www.pallcare.asn.au or phone **Freecall 1800 660 055**



- The Cancer Council NSW booklet on Caring For Someone with Cancer. Call the **Helpline on 13 11 20** to get a copy sent to you, or go to www.cancercouncil.com.au to download it.

- **Carers Australia** has fact sheets on managing health care and medications and emergency care plans. Go to www.carersaustralia.com.au/index.php?option=com_content&task=view&id=27&Itemid=105 or phone **Freecall 1800 242 636**
- **Care Search** also has information on practical care giving and has contact details for national and state support. Go to www.caresearch.com.au

