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Society

# Being a Caregiver to Someone with Cancer



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# Being a Caregiver to Someone with Cancer

We provide a support system for people affected by cancer. Our services help answer your questions about cancer, manage life with cancer, find community and connection, and build wellness and resilience. Many of our programs are available in different languages.

From diagnosis to treatment to life after cancer, you can trust our publications for reliable information that's easy to understand.

We're here to support you.



We have short, easy-to-understand videos on common cancer topics. Visit [cancer.ca/cancerbasics](https://cancer.ca/cancerbasics).

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## About this booklet

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If you're a caregiver to someone who has cancer, this booklet is for you.

People who have cancer have a team of healthcare professionals involved in their care. These healthcare professionals plan and carry out treatment plans, help manage side effects and support people in their cancer experience. The team often includes cancer doctors (oncologists), surgeons, radiation therapists, nurses, social workers, psychologists and many others.

But as well as having this professional team, people who have cancer often rely on a caregiver or group of caregivers for physical and emotional care and support. Caregivers are usually a family member (for example, the partner or spouse, parent or adult child of the person who has cancer) or they are someone who is like family to the person with cancer.

Being a caregiver to someone who has cancer isn't easy. There can be a lot to learn and adjust to. With the right information and support, you can be there for your loved one. But it's just as important to look after yourself. The feelings, needs and concerns that you have when caregiving – which can be different from those of the person with cancer – still need to be taken care of.



# All about caregiving

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You probably never expected to be a caregiver to someone with cancer. You're not alone if you find the idea of it scary. Caregiving can involve taking on many new and important responsibilities, often for months and sometimes for years. Today, people with cancer often receive most of their care as outpatients, which means they do not stay in the cancer centre or hospital. They are able to and want to spend more time at home.

The responsibility of caregiving can be overwhelming and stressful, but it can also be very rewarding. Most caregivers agree that the experience changes their lives. Some of the rewards that caregivers have reported include:

- feeling a closer bond with the person with cancer
- finding added meaning in life
- finding new strength
- appreciating family and friendships in new ways

## What is helpful to know when becoming a caregiver?

Caregiving is a big job. Thinking through and getting answers to questions like the ones below can help you understand what you're getting into.

*Will you be the only caregiver?* It's important to know if you are caring for someone on your own or as part of a group of people who make a caregiving team. The person with cancer might prefer that you are the main caregiver, but there may be other people who can also help.

*What tasks will be part of caregiving?* Make a list of what caregiving tasks need to be done. A lot will depend on the treatment plan, so you will likely need input from the healthcare team. Be aware that the need for caregiving and the tasks that have to be done may change over time.

*What is your role?* It's important that you, the person with cancer and the healthcare team know what you will be doing as a caregiver. You also need to let people know what you aren't comfortable doing as a caregiver and where other help will be needed.

*What are your limits?* It's normal to be uncomfortable with the idea of giving medicines or giving physical care (such as bathing the person with cancer or helping them use the toilet). Maybe you're worried about juggling this new role with the responsibilities you already have at home or work. Be honest with yourself about what you can do and what you are most comfortable doing.

*Is there help through home care services?* Home care services such as having a nurse or personal support worker come to your home to help with medicines and bathing may be available where you live. Home care staff can also teach you caregiving tasks like how to turn someone in bed. It can be reassuring to know that there are services that can help if you need it.

## Is caregiving right for you?

As much as you may want to help, you may realize that you aren't able to take on too much in caregiving. It may be that you have your own health challenges to manage, you live a long distance away from the person who has cancer or you have other responsibilities like being the main source of income for your family. And that's OK. You may still be able to help out in some way.

In some cases, it may be best for both you and the person who has cancer if you are not the caregiver. Sometimes changes in roles negatively affect relationships. For example, it may be hard for a couple to still feel like partners in life if their relationship becomes one of patient and caregiver. Family members, especially spouses, can find cancer just as hard to cope with as the person with cancer, and they often need support of their own. In that case, they are not in a good position to be a caregiver.

If you're feeling pressured to become a caregiver, it's best to be honest about how you feel. Focus on your positive feelings toward the person with cancer, and how you and others can help. If you talk about it, you can usually work something out. You also don't need to have everything settled at the beginning. It's OK to try different things and adjust as you go along.

### **Managing your job and money concerns**

When you're caregiving, you may find it hard to focus on your work or you may even miss all or part of your workday sometimes. And you may be tired from trying to do as much as possible at work and home.

Talk to your boss or human resources manager about your caregiving responsibilities and what your options are. There may be solutions such as changing what you do at work, job-sharing, working part time or flexible hours or taking some time away from work. Some workplaces also offer counselling services that may help you or your family.

Many caregivers worry about their household finances. Sometimes keeping up with your usual bills on your usual income is hard enough. It can be even harder if you have to work less because you're a caregiver or if your partner with cancer can't work for a period of time. And having to pay insurance deductibles or pay for home care, transportation services or meals and somewhere to stay close to a cancer centre can be very stressful at a time when family income is less than it was.

As a caregiver you may be eligible for different types of government tax credits and benefits. Depending on where you live, there may be other financial support programs that you can apply for. Ask the social worker at the cancer centre about what programs may be available to you. The social worker may also be able to help you fill in and submit forms.



### **Shared caregiving**

You may find that being the only caregiver is too much for you, especially if you have other responsibilities like working or taking care of your own family. Caregiving shared with other family members or close friends can help make it easier. Each person can focus on the responsibilities that they are most comfortable doing or that they have time to do. You may have a flexible schedule so you can drive to treatment and other appointments. Another family member may be able to take over bathing and other personal care after being trained to help with physical care. Others may find they can help by cleaning the house, doing laundry, going grocery shopping or cooking meals.

## Long-distance caregiving

Even if you don't live very close to the person who needs care, you can still help out. Long-distance caregiving is more common than it used to be because families are more spread out than they used to be.

Think about what you can do from a distance. A common long-distance caregiving task is to make sure that bills get paid or to sort out other financial matters. You can make regular phone calls to your loved one to talk and share. When you visit, you can give the full-time caregivers a rest by taking over some of their caregiving tasks.

Thanks to technology, such as video calls with the healthcare team and other caregivers, you can still be involved in discussions about care and treatment. Some healthcare visits are offered virtually, making it possible for you to take part from anywhere. Social media can also help you keep in touch with the other caregivers and the person who has cancer.

It's hard when you can't be there to help every day. You may feel guilty about it or feel pressure to move closer so that you are there more often. With a little creative thinking and effort, you can find ways to contribute and be involved in caregiving even from far away.

## What caregivers do

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What you do as a caregiver often changes over time, depending on what the person you're caring for needs. As they recover from treatment and get back to health, your caregiving role may get smaller. Or you may slowly take on new caregiving responsibilities if the person you're caring for has advanced cancer and starts to need more help.

### Talking with the healthcare team

One of the key roles you may have as a caregiver is being the main contact for the healthcare team. The person you are giving care to may ask that you talk to the healthcare team and help make important decisions about treatment and care. Make sure you understand what the person who has cancer wants and how involved they want you to be in this role.

You may be responsible for keeping track of any appointments for tests and treatment sessions, and making sure the person gets to them. During visits, you may be asked to make notes and keep track of any changes or decisions that were made. You may want to keep a file of test results, a list of medicines and other important information from the healthcare team.

It's important that you share information with the healthcare team about any pain or side effects your loved one is having. Let them know how you're both coping, and let them know about any concerns you have.



## Giving physical care

Helping with physical care is a common part of being a caregiver. The amount of physical care you have to help with will depend on how well the person with cancer is and how much they can do alone. You may be asked to help someone:

- walk or move around with a walker or wheelchair
- get in and out of the tub or shower, or by giving sponge baths in bed
- get into or out of a bed or chair
- turn or roll over in bed
- use the toilet or bedpan
- change incontinence pads or catheters
- brush their teeth, keep their lips moist or rinse their mouth
- wash their hair, moisturize their skin or trim their nails
- with eating, including making meals

You may also be responsible for giving and storing medicines. This includes giving the correct amount (dose) of medicine and keeping track of when they were given.

With physical care, there's a lot that is probably new to you. That's OK. You can learn how to safely care for someone with cancer. If you have to turn or lift the person you are caring for, you need proper training. You don't want to hurt yourself or anyone else. A home care nurse, physiotherapist or occupational therapist can teach you how to do this and can suggest how best to care for your loved one.

Ask the healthcare team about getting assistive devices to help with care at home. Assistive devices are tools that help people be more independent and make your job easier and safer – for example, a walker, lift, wheelchair, shower chair, grab bar, portable commode or urinal.

You may not be comfortable helping with some personal care, like bathing or changing catheters. Or the person you are caring for may not want you to do some things. Many people feel this way. Talk to the healthcare team about home care services that can come and support you and the person you are caring for with the tasks you'd both be more comfortable having someone else do.

## Offering emotional support

Caregivers are often the main source of comfort and emotional support for the person who has cancer. You may have to help them deal with their emotions and talk through difficult decisions that have to be made about care and treatment.

Here are some ways you can have a positive effect on how someone copes with cancer:

*Help them live as normally as possible.* Allow them to continue with their usual day-to-day life as much as they can. Let them know that you're there to help – but let them decide when they need it. Encourage them to decide which activities they can do and think about what they enjoy the most. Help them make those activities their priority.

*Encourage them to share their feelings with you.* And it's just as important to share your feelings with them.

*Listen when they want to talk.* Let them know it's OK to express fears and concerns about what is going to happen. And it's not always easy, but listening without judging is often more helpful than giving advice or offering solutions. If they don't feel like talking, let them know that you'll be there when they want to.

*Keep them company.* Just being there can be comforting. Talk, watch movies together or listen to music. Use this time to take a break from the worries and concerns that you have about cancer.

*Use touch when you can't find the words.* Touch is a powerful way to communicate and can show how much you care. A squeeze of the hand or a gentle hug can say a lot.

*Respect the need for privacy and to be alone.* Coping with cancer sometimes means that you and your loved one have to take some time alone to think or reflect or just take a break from each other.



### MORE INFORMATION ON EMOTIONS

Understanding emotions and offering this kind of emotional support may be new to you. Supporting someone through cancer can be very hard, and you may wonder about the need for more help for you or for the person with cancer. You can find information about emotions and cancer, how to cope and when help from the healthcare team might be needed at [cancer.ca/emotions](https://cancer.ca/emotions).



## Handling practical matters

Part of caregiving means that you may have to handle tasks that are part of day-to-day life, such as cleaning, doing laundry, shopping for food, making sure bills get paid, looking after children or sorting out childcare. While these aren't directly a part of caregiving, they are still things that have to be done to keep a household going. It can be hard for anyone in the family to adjust to role reversals in terms of who does what at home.

You may also have to be in charge of coordinating care for the person with cancer. This involves a lot of organizing and scheduling. You may have to arrange home care and nursing visits or transportation to appointments. If you have other family members sharing responsibilities such as driving to the treatment centre, you may have to make a schedule and let everyone know what they have to do to help.

Another practical task is making sure that important papers are organized and kept in a safe place. This can include medical records, insurance documents, wills, advance directives and other legal or financial papers.

Caregivers often become the main contact for letting family and friends know how the person with cancer is doing. Social media and email allow you to share messages and photos and update many people at once. You may also want to start a call list of people that you want to call or who need to be called with important news. If tasks like these take up too much of your time or you find them hard to do, ask someone you trust to help out. Keep this person updated and then they can update others.

## Taking care of yourself

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Caregiving can be a very intense and tiring job. While you're caregiving, you may be so busy that you forget to take care of yourself. But it's very important to do so. Caregivers who get the information, help and support they need to take care of their own needs can better take care of their loved one with cancer. And for your own sake, you'll want to avoid what healthcare professionals call caregiver burnout or caregiver fatigue.

### Stay healthy

To have the strength and energy to care for someone else, you need to be healthy yourself. Here are some things that you can do to stay healthy:

*Eat well.* It's not easy, but try to eat a balanced diet that has a variety of foods each day to get the nutrients you need for good health. Just do your best – and accept help from others with meals.

*Be active.* You may feel exhausted, but a little bit of movement can go a long way to help you feel better. Go for a walk, a swim or a bike ride. Being active can help you cope with stress and improve your sleep – and it just generally makes you feel better.

*Get enough rest.* When you're well rested, it's easier to cope with the demands of caregiving. Do what you can to get enough sleep. If you need to, try to nap when the person you are taking care of is resting or sleeping.

*Don't ignore your own health.* Go for regular checkups with your doctor and dentist. Be sure to report any concerns you have about your health.



*Find ways to cope with stress.* There are many different ways to cope with stress. Because everyone feels and handles stress differently, everyone will also have their own way of managing it. One person may like to play or listen to music, while another person may choose to spend time in nature. Some people learn to meditate and practise mindfulness, while others sweat it out at the gym or by playing a sport. Keep trying until you find ways to cope with stress that work best for you. Talk to your healthcare team if you're having trouble handling stress on your own. They may suggest taking a class that teaches different ways to manage stress or refer you to a self-help group, support program or counsellor.

## Ask for help, and accept help from others

You can't do everything. Be honest with yourself about what you can do. Decide what's most important to you, and don't worry about the other stuff.

Get help from family members, friends or people in the community when you need it. People are often happy to babysit, clean the house, help out with meals or stay with the person who is ill.

Talk to the healthcare team about home care or other community services to help with house or yard work or with physical care.

Don't hesitate to tell others exactly what sort of help you need from them.

## Share your feelings

It's normal to feel stressed, angry, afraid, helpless, frustrated, sad or guilty. It's also normal to feel you must ignore your own feelings in order to stay strong for the person with cancer. Even though it can be hard, it's a good idea to talk about your feelings instead of keeping them inside. Hiding your feelings can use up energy that you need to cope with caregiving.

Talk to someone, like a trusted friend, a family member, a counsellor or a clergy member, about how you feel. A caregivers' support group is a good place to talk to others who have been or are going through the same experience.

### **There is no right way to feel**

Every caregiver is different. You probably have many feelings about what you're going through right now. Some common feelings that come and go for caregivers include the following:

*Sadness* – Many people feel sad while caring for someone with cancer. But if the feeling lasts a long time, gets worse or gets in the way of day-to-day life, talk to your doctor.

*Anger* – Anger is a common response to something that feels very unfair. You may be angry at yourself or family members. You may be angry at the person you're caring for. Know that anger often comes from fear, panic or stress. Try to look at what is beneath the anger.

*Grief* – You can grieve for anything that is important to you. This may be your loved one's health or changes to future plans. It could be the loss of the life you had before the cancer was found. Let yourself grieve these losses.

*Guilt* – Feeling guilty is common, too. You may feel guilty when you take time away from caregiving or think you aren't helping enough. Or you may feel guilty that you are healthy.

*Loneliness* – You may be spending less time with others or you may feel that no one understands what you're going through. You can feel lonely, even with lots of people around you.

## Take a break

Taking time to rest and recharge does not mean you're weak or selfish. It's a key part of taking care of yourself.

Go for a walk, have a massage, see a movie or meet up with a friend – whatever you enjoy doing. If you're worried about leaving the person you're caring for alone, ask someone you trust to come by while you're out and leave a contact number so you can be reached.

If you can't get out, you can still pamper yourself in little ways at home. Take a break with a favourite magazine or TV show, a hot bath or an early night with a good book.

If the person with cancer needs a lot of physical caregiving, talk to the healthcare team about respite care. It can give you short-term relief from your caregiving responsibilities, while making sure that the person you're caring for is still getting care. Respite care can be given at home, at an adult day care centre or at a healthcare facility. You might want it on a regular schedule, such as a certain day or afternoon every week. Or you might need to arrange respite care for a longer period of time. The healthcare team can help arrange care and explain any costs involved.





## HOW WE CAN HELP CAREGIVERS

The Canadian Cancer Society is here to help you in your caregiving experience.

- Call our Cancer Information Helpline at 1-888-939-3333 or visit [cancer.ca](https://cancer.ca). We provide reliable, up-to-date information about cancer. Ask about our transportation and accommodation programs that may be available to you.
- Connect with other caregivers on [CancerConnection.ca](https://CancerConnection.ca). In this online community for caregivers and people with cancer, you can share your experience, find comfort and support and get practical caregiving tips.
- Use our Community Services Locator at [csl.cancer.ca](https://csl.cancer.ca) to search a database of over 4,500 cancer-related services and resources nationwide, including respite care, support groups in your community and counsellors for emotional support. If you can't find what you need, contact us and we'll help you with your search.

## Life after caregiving

Just as you had to adjust to being a caregiver, at some point you will need to adjust to not being a caregiver. This can take some time.

*Your loved one recovers from cancer treatment.* Getting used to life after treatment can be challenging in surprising ways for both the caregiver and the person with cancer. Both of you may be anxious and worried that the cancer will come back. You may also have to cope with changes in your relationship. It can be hard to move on from being a caregiver and back to being a partner. And now that your loved one is healthier, you will find that you are slowly doing less and less as a caregiver. You may have been looking forward to this day, but when it comes you may find that you've lost a sense of purpose.

*Your loved one has died.* Even if you were expecting it, caregiving ends suddenly when your loved one dies. This can leave you feeling lost and unsure, especially if you were a caregiver for a long time. You may also feel a great sense of relief now that the caregiving is done – but this relief may also make you feel guilty.

### Moving forward

It can take time for life to get back to normal after caregiving has finished. For some people, it can be hard to move forward now that they are no longer caregivers. These ideas might help:

*Make yourself a priority for a while.* You may not have been taking time to live a healthy life or do the things that you enjoy. Now that caregiving is done, it's time to put some time into your health and life.

*Get ready to go back to work.* If you had been taking time away from work in order to care for your loved one, getting back into a routine at work can help you get used to life after caregiving.

*Reconnect with people.* Often the demands of being a caregiver mean that you lose touch with some family members and friends. It can take a bit of effort to get back on track. People may not contact you because they aren't sure how sociable you're feeling or they don't want to burden you. But if there is someone that you would like to see, contact them and make plans.

*Get out and do things.* While you were being a caregiver, you may not have had a chance to go out to a movie or for a meal or to celebrate a friend's birthday. Now that your caregiver role is over, you can get out and enjoy some activities that you may not have had the time or energy to do before.

*Take part in hobbies.* Start doing something new that interests you or get back to hobbies that you had before you were busy caregiving.

*Remember that you did the best you could at the time.* Don't feel guilty about things that you could have done differently or mistakes that you made. No one's perfect.



# Notes

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## WE'RE HERE TO HELP



### **Find information you can trust**

Visit cancer.ca for information on more than 100 cancer types. You'll find topics ranging from diagnosis and treatment to managing side effects, living with cancer and reducing your risk. We also have publications, videos and webinars.

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### **Get answers to your questions**

When you have questions about diagnosis, treatment, prevention, emotional support and other services, our trained cancer information specialists can help you find answers. Call us at 1-888-939-3333. Our Cancer Information Helpline is available in English and French with an interpreter service for other languages.

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### **Connect with someone who's been there**

Visit CancerConnection.ca to join our moderated online community. You can join discussion groups, get support and help others at the same time. It's a safe place to connect, learn and share your experience with cancer.

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### **Find services in your community**

Our Community Services Locator (CSL) helps you find the cancer-related services you need. You can search over 4,500 listings across Canada for emotional support programs, home care, help getting to your cancer treatment, where to find a wig or prosthesis and much more. Start your search at [cancer.ca/csl](http://cancer.ca/csl).

The Canadian Cancer Society works tirelessly to save and improve lives. We raise funds to fuel the brightest minds in cancer research. We provide a compassionate support system for all those affected by cancer, across Canada and for all types of cancer. Together with patients, supporters, donors and volunteers, we work to create a healthier future for everyone.

Because to take on cancer, it takes all of us. It takes a society.



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IT TAKES A  
SOCIETY

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