

Cancer: A guide for caregivers

We've developed this guide to support you on your care journey and share practical ways you can live life to the fullest while caring for a loved one with cancer.



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Caring for someone with cancer

Caring for a family member or friend with a life-threatening disease like cancer often means being very involved, and extending a lot of support and encouragement.

Every care situation is different and can change over time. One day, you may be providing emotional support and hands-on care. The next day, you may be helping with medication or coordinating appointments. You may also find yourself doing more everyday tasks like cooking and cleaning. Caregiving is rarely just one thing, which is what can make it so challenging.

These new responsibilities can be demanding and sometimes stressful. But there are ways to make the care journey less stressful. You'll need to make sure to plan tasks, take care of yourself and take advantage of the help that's available. Also, remember that you need as much information and support as the person in your care.

Caring for a loved one with cancer can also be very rewarding: you may develop a closer bond with your loved one, and you may discover new skills and inner strength and resilience, as well as a new appreciation of supportive family and friends.



Caregivers are an important part of the healthcare team.



Getting a diagnosis

Being a caregiver is a big job, so you'll need to know what to expect.

You may be involved with:

- Coordinating and attending doctor visits
- Giving medicines, monitoring and managing side effects
- Physical care of your loved one, including feeding, dressing and bathing
- Keeping family and friends informed of developments
- Coordinating the care of your family member
- Keeping track of medicines, test results and other paperwork
- Managing legal and financial issues
- Giving emotional support to the person in your care and being a supportive ally
- Helping your loved one make decisions about the future

As the disease progresses, changes may take place in the person with cancer. These can be side effects of treatment or changes caused by the cancer.

They may include changes in:

- Appearance
- Personality or mood
- Memory
- Sleep
- Appetite or nutrition needs

The person you are caring for may or may not experience any of these. But it will be helpful if you ask the doctor whether any of these might happen and what you can do about them when they arise.

For a list of apps to help you stay organized, and other resources you may find helpful in your caregiving experience, please visit [TevaCanada.com/Caregivers](https://www.tevacanada.com/caregivers).





The impact of caregiving

Many caregivers often prioritize their loved one's need ahead of their own. But self-neglect can have a serious impact on a person's health and wellbeing. If you neglect yourself, it will make it hard to provide quality care to your loved one.

If the demands of caregiving go beyond your ability to cope, you may start to feel burned out. Burnout can also be caused by the mental stress of seeing a loved one undergo cancer treatment and being concerned about the outcome. Burnout often shows up as fatigue, stress and an overall lack of energy.

Compassion fatigue, another kind of burnout, can happen when someone is very active and involved in the care of a person who is suffering. The caregiver can become overwhelmed by feelings of being helpless, and with few reserves or resources to replenish their own well of energy.

As the cancer advances, the person will need different health and social care.



Caregiver stress symptom checklist

If you recognize these symptoms of caregiver stress in yourself, talk with a healthcare provider about ways you can improve your health and wellbeing.

- 1 Feeling tired (**fatigue**)
- 2 Lower ability to fight off illness; slower healing of wounds (**weaker immune** system)
- 3 **Problems sleeping**
- 4 **Higher blood pressure**
- 5 **Changes** in appetite or weight
- 6 **Headaches**
- 7 Anxiety, depression or other **mood changes**
- 8 Not making time for social activities or friends (**social withdrawal**)
- 9 **Less interest** in activities or hobbies

Feeling stressed and overwhelmed is very common among caregivers. You'll feel better and be better able to care for your loved one if you find ways to manage stress and take care of your own health.

Remember that you're allowed to ask for support—including professional help—before you feel overwhelmed.



Talk to your
healthcare provider
about strategies to
help you manage.



Take care of yourself

The person with cancer needs and wants you to be a healthy care partner. Follow these suggestions so you can be at your best to help yourself and your loved one



Accept your reality

It can be hard to admit that your loved one has a life-threatening disease. But when you accept this, it will be easier to manage your expectations and adapt to this new reality.



Acknowledge your limits

Caring for someone with cancer takes time and energy. There will probably be limits to what you can do, and you will have to prioritize. It may be difficult to admit that you cannot do everything, and you will need to get comfortable with saying "no" to some things.



Accept your feelings

Caregivers experience a lot of different feelings. At different times, you may feel contented, angry, frustrated, guilty, happy, sad, loving, afraid, resentful, hopeful and hopeless. Be kind and patient with yourself and try to find positive ways to cope with these changing feelings. This could include talking with supportive friends, exercising or keeping a journal.



Share your feelings

Try not to keep your emotions to yourself. Sharing your feelings with someone you trust can make your concerns seem more manageable. Caregiver support groups are also available both in-person and online. These can give you an opportunity to meet and learn from others in similar situations.



Look for the positive

Looking for the good things in life and showing gratitude may make you feel better, even when you're busy. Remember, it's okay to keep your sense of humour and to laugh, even when your loved one is in treatment—laughter releases tension and makes you feel better.



Take care of yourself

Be sure to make time to exercise, eat healthy foods, stay hydrated and get enough sleep. Make your emotional and mental health a priority. Don't hesitate to seek professional help—speak with your doctor or a counsellor if you need to.



Take time for yourself

You need time for yourself, to get back to your interests outside of caregiving. You deserve a much-needed break. Take the time to keep up with things and relationships that are important to you—before you become exhausted. This will help you keep your energy and mood up over a longer period of care.



Communication with healthcare providers

Good communication with healthcare providers can positively impact your and your loved one's wellbeing.

Here are some tips to help you communicate effectively with healthcare providers.

- ✓ Keep a journal or a checklist, which you can bring to an appointment.
- ✓ Communicate your concerns clearly.
- ✓ Educate yourself about your loved one's cancer diagnosis—including how it's treated and what resources are available to you.
- ✓ Keep a log of new or changing symptoms, and outcomes of medical visits.
- ✓ Be prepared to advocate for your loved one to access needed assessments, services and therapies. You are allowed to have a voice and participate in decisions.
- ✓ Be clear about your boundaries—let others know what you can and cannot do.



Be sure that you understand and are involved in treatment plans.



After treatment

Even after the treatment is over, cancer survivors often deal with side effects from treatment. They also need to adjust to other changes they've experienced. The following tips can help you manage your expectations after treatment has ended.

Be aware of your feelings

It's normal to have mixed feelings after the treatment ends. You may feel:

- Relieved that your loved one has finished treatment
- Anxious because you're no longer actively fighting the cancer
- Guilty that you feel you may have not done enough despite your helpfulness
- Lonely and isolated

Take time to reflect on your experience with cancer. And remember that you and your loved one, and other family and friends, will need different amounts of time to work through their emotions.

Make time for yourself

Caregivers often put their own needs aside during treatment. After your loved one's treatment is over, think about how to best care for yourself. Consider:

- Getting back to the activities that you enjoy
- Finding ways that others can help you
- Finding new ways to connect with your friends

Let others help you

Asking for help is a sign of strength. While you may be tempted to tell everyone that you and your loved one are doing fine, consider that friends, neighbours, co-workers and others who stayed away during treatment may now be able to support you. Think about what types of help would be welcome. The clearer you are about your needs, the easier it will be to get the help you need.

Talking with family

After treatment, communication is still as important as it was during treatment. This can be an unpredictable time, and your family may need time to adjust. Be sure to listen to each other, and be patient and supportive.



"Getting back to normal" may take longer than anyone expects.



Advanced cancer

If your loved one's cancer progresses, caregiving can get more difficult. It's more important than ever—for you as well as for the loved one with cancer—to take care of yourself and reach out for help.

Your feelings

You may experience the following feelings; these are normal and common.

- **Denial:** You may find it hard to accept that your loved one may not recover. While there's nothing wrong with staying hopeful, try to listen to your loved one and the doctor to really hear what they're saying. Denying the facts may make the person in your care feel that you don't understand what's happening.
- **Grief:** You may begin to feel the loss of your loved one, even while they're alive. This is called anticipatory grief. It's normal to feel sad about future losses and the changes you're experiencing in your environment, and in your thoughts and feelings.

Your loved one's feelings

You'll also need to consider how the person with cancer feels. They may fear:

- Becoming dependent
- Being seen as weak or a burden to others
- Moving to a healthcare or other type of assisted living facility

Talking to your loved one with advanced cancer

When someone you love has advanced cancer, it's common to struggle with what to say, worrying that you will say the wrong thing. But remember, showing that you care is more than the words you choose. Both you and your loved one likely share the same thoughts and fears about the end of life. While it's difficult, you should try to talk to your loved one about the stage of the cancer, preparing for the future, your feelings about death and their end-of-life wishes. It's important to prepare a living and end-of-life will, which will allow you to fulfill their wishes while easing decision-making during a stressful period.

Living arrangements

You may need to decide whether the person with advanced cancer should live at home or be moved to a care facility or hospice. When making these decisions, consider:

- What kind of help does your loved one need?
- Are you capable of taking care of them at home?
- If they live alone, is it risky for them to keep doing so?
- What are the options for home care?
- How often will they need help?



End of life

Signs that death is near

Certain signs can indicate that death is near. However, not every person has all of these signs, and even if these signs are present, it doesn't always mean that the person is close to death. A member of your loved one's healthcare team can give you more guidance about what to expect near end of life. Common signs include.

- Drowsiness and sleeping more
- Confusion about time, place, or identity of friends and family members
- Being more withdrawn and unresponsive
- Less need for food and liquids
- Loss of appetite
- Loss of bladder or bowel control
- Dark urine or decreased amount of urine
- Skin becomes cool to the touch or bluish in color
- Rattling or gurgling sounds while breathing
- Turning the head toward a light source
- Pain that is hard to control

The grieving process

Once your loved one dies, your grief may become more intense. Everyone grieves differently:

- Some may show less emotion than others.
- Some stay busy, showing their feelings by doing things, rather than talking about them.
- Some get angry.

These feelings are normal. Although it may vary in intensity, grief can come and go for many months and can occur when you least expect it. If you feel you need support through the grieving process, seek help from hospice staff, a mental health expert or a bereavement group.



Ask for help

You may be a spouse, partner, child, family member or friend providing care on a regular basis to someone diagnosed with cancer. Your role as a caregiver is an important one.

Accept that you may need help with everyday household and caregiving tasks. Family and friends can be vital members of your circle of care. Tell your friends and family that you need their help. Most people want to help, but they don't know what you need. Friends often worry that offering help might seem intrusive, so let them know their help is welcome. Don't hesitate to be specific with your support needs.

Keep a list of projects, errands and services that others can do. Then, the next time someone offers to help in some way, you can guide them on how to best support you.

People with cancer often need significant help with daily care. In many cases, family and friends may not be able to do it alone, and additional help may be needed. Talk with your medical team or your local Canadian Cancer Society to determine what additional professional care is available. This additional help may be covered by the government or private insurance.



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Additional resources

Canadian Cancer Society–Cancer types
cancer.ca/en/cancer-information/cancer-type/see-all/

Canadian Cancer Society–Caregiving
cancer.ca/en/cancer-information/living-with-cancer/caregiving/

Canadian Cancer Society–Peer Match from Canadian Cancer Society
cancerconnection.ca/reviews/item/24/201

Cancer Chat Canada at de Souza Institute–Online support group
cancerchat.desouzainstitute.com/

Cancer.Net–Caring for a Loved One
cancer.net/coping-with-cancer/caring-loved-one

Dying with Dignity Canada
dyingwithdignity.ca/

Huddol–Online caregiver support community
huddol.com/CaregiverSupport

National Cancer Institute–Advanced Cancer and Caregivers
cancer.gov/about-cancer/advanced-cancer/caregivers

National Comprehensive Cancer Network (NCCN)–Patient and Caregiver Resources
nccn.org/patients/resources/

Wellspring–Community-based resources for people with cancer
wellspring.ca/

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We're committed to caring for caregivers.

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