



## If you're a caregiver

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We use the term caregiver to describe someone who provides physical and emotional care to someone with cancer – but not in a professional or vocational role. Today, people with cancer often receive most of their care as an outpatient and are able to spend more time at home. A caregiver is often responsible for providing care at home. A caregiver may be a partner, parent, adult child or close friend of the person with cancer.

Being a caregiver often involves taking on many new, important responsibilities. If you're a caregiver, you already know that while this can be overwhelming and stressful, it can also be very rewarding. Some caregivers have reported feeling a closer bond with their loved one, finding added meaning in their lives, finding new strengths and developing a new appreciation for family and friendships.

### Your role as a caregiver

As a caregiver, you are an important part of the healthcare team. It's a big job. It's important to know what you're getting into. You may be involved with:

- visits to the doctor
- reporting or managing side effects
- keeping family and friends informed
- coordinating care of your loved one
- giving medicines
- keeping track of medicines, test results and papers
- physical care of your loved one including feeding, dressing and bathing

Being a caregiver also includes giving emotional support, such as helping your loved one deal with their feelings and make difficult decisions.

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If you're feeling pressured into becoming a caregiver, it's best to be honest about how you feel. Respect and speak up for your own feelings, needs and desires, as well as those of your loved one. Decide your limits and let others know so that both you and your loved one get the help you need. It's normal to be uncomfortable with the idea of giving medicines, giving physical care (such as helping your loved one to the bathroom) or maybe you're worried about juggling the responsibilities you already have at home or work with this new role. If you talk about it, you can usually work something out. The healthcare team can provide lots of guidance on medicine, or maybe someone else can act as the main caregiver or share the responsibilities with you.

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## Telling a loved one they have cancer

Sometimes you, as the caregiver, are the first to learn about a loved one's cancer diagnosis. In some cases, you may wonder how much to tell the person who is diagnosed or whether to tell them at all. For example, if the person with cancer is very young, very old or has a problem with understanding, it's normal to want to plan their treatment and make decisions for them. Your culture can also influence how cancer is discussed and dealt with. In some cultures, talking about a serious illness or death is considered disrespectful to the person with the illness. Some people may believe that telling the loved one about the cancer diagnosis may bring about unnecessary worry or stress or that it may take away all hope.

It's important for the healthcare team to know about your family's values and beliefs. Don't hesitate to tell them about any cultural beliefs that affect how you and your family approach the cancer journey. Your team may be able to suggest important topics to consider as you make your decisions.

As you're thinking about what to do and considering the individual needs of each person and factors that are important to your family, it might be helpful to know that the person with cancer usually learns about their diagnosis sooner or later. Most cancer patients agree that hiding the diagnosis from them denies them the chance to make important decisions about their treatment and their future.

There are advantages to being open and honest. When there are no secrets, it's easier on everyone concerned to approach the cancer diagnosis as a fact of life. It's also easier to discuss the experience and offer support when nothing is being hidden. Talking about cancer and sharing feelings is hard for many people, but it can be even harder to hide your thoughts and feelings about a cancer diagnosis.

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## Good communication is key

Good communication between the healthcare team, your loved one and you can greatly improve your loved one's care. You may be responsible for communicating your loved one's wants and needs to the healthcare team. You may also be responsible for updating family and friends about your loved one.

Holding regular **family meetings** can be a good way to keep family and friends up to date and to plan for the weeks ahead. Talk openly with friends and family and be clear with what you need and how they can help,

whether it's preparing meals, looking after children or going to an appointment. At family meetings you can:

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- share information, questions or concerns
- discuss the weeks ahead and plan for tests, treatments and appointments
- spend time together just to support and comfort each other
- give people jobs to do in the weeks ahead to share in the care of your loved one

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## Doctor's appointments

You may attend doctor's appointments with your loved one. Your loved one may ask you to be the one to talk to the healthcare team and make important decisions.

- Write down any questions you have or things you would like to say before the appointment.
- Keep a folder of your loved one's health information, including a list of all medicines and take it with you.
- Share information with the healthcare team about any pain or side effects your loved one is experiencing.

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## Giving comfort and emotional support

Caregivers are usually the main source of comfort and emotional support for their loved one. Good communication with and understanding of your loved one is important. You can have a very positive effect on how your loved one copes with cancer if you:

- Involve them as much as possible. Allow them to continue with day-to-day care and activities if they feel up to it. Let them know that you're there to help, but let them decide when they need help.
- Help them to live as normally as possible. Help them to prioritize which activities they can do and enjoy most.
- Share your feelings with them and encourage them to share theirs.
- Listen and allow them to express fears and concerns about what is going to happen. Listen when they want to talk, and respect their need for privacy when they don't feel like talking. Make sure they know you'll be there when they're ready.
- Keep the person company. Talking with them, watching movies together, listening to music, playing cards or just being with the person can be comforting. Sometimes when you can't find words, a squeeze of the hand or a gentle hug can say just as much. Touch is a powerful way to communicate and can show how much you care.
- Respect their need to be alone sometimes.
- Look after your own emotional needs, too. If you're having problems sharing your feelings and communicating with each other, talk to your healthcare team or join a support group. It may be helpful to

talk to others who are experiencing the same thing. There are support groups that include both caregivers

and people living with cancer and those that provide support individually for either caregivers or people

living with cancer.

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## Giving physical care

You may provide physical care for your loved one. Ask your healthcare team for information and ideas on caring for your loved one. Assistive devices are tools that can help your loved one be more independent and make your job easier. These tools may be a walker, lift, wheelchair, shower chair, grab bars, portable commodes or urinals. A home care nurse, physiotherapist or occupational therapist may be able to provide support and give you ideas to help your loved one.

You may need to learn how to help with:

- bathing – helping them get in and out of the tub or shower or giving sponge baths in bed
- lifting and moving – helping them get into or out of a bed or chair, moving cushions or helping them turn or roll over in bed
- bathroom – getting onto and off the toilet, using bedpans, incontinence pads or catheters
- mouth care – brushing teeth, keeping lips moist or rinsing the mouth
- hair, skin and nail care – washing and drying their hair, moisturizing skin and trimming nails
- giving medicine – keeping track of timing, dosages and storage of medicines

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## Looking after yourself

Caring for a loved one who is ill can be physically and emotionally demanding. As a caregiver you may be so focused on the person you're caring for that you forget to take care of yourself. Keeping your strength and spirits up will help you cope with the challenges of being a caregiver.

## Staying healthy

To care for someone with cancer and cope with so many responsibilities you first need to take good care of yourself.

- Make healthy meals and try to eat on a regular basis, even if you feel too tired or too busy.
- Be physically active on a regular basis.
- Have regular physical examinations and dental checkups.
- Get enough rest. Sleep when the person you are taking care of is resting or sleeping.
- Take time to relax and do the things you enjoy.

## Dealing with emotions

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It's normal to feel stressed, angry, afraid, helpless, sad or guilty – and also normal to feel you must ignore your own feelings in order to stay strong for your loved one. You may worry about your loved one and feel frustrated that you can't just make everything better. You may try to do everything and find it difficult to take the time to look after your own needs. As you learn to adjust and cope during this difficult time you can:

- Use relaxation techniques, such as deep breathing.
- Exercise.
- Pray or meditate.
- Talk to someone about your feelings. This might be your spouse, a close friend, a family member, a counsellor or a clergy member.
- Join a support group. There are many kinds of support programs, including one-on-one or group support. It sometimes helps to talk to others who have been through the same experience.
- Ask the healthcare team for support.
- Write down your feelings in a journal.
- Make time for things you enjoy.
- Ask people for help.
- Let yourself cry. It's a normal reaction and can help relieve tension. Don't be afraid to laugh, either.

## Asking for help

You can't do everything. Be honest with yourself about what you can do. Remember what's most important and leave what is not. Accept help from others. Caregivers who take care of their own needs and get the information, help and support they need are better able to take care of their loved one.

Get help from family members, friends or people in the community when needed. People are often happy to babysit, clean the house, help out with meals or stay with the person who is ill. Ask about home care or other community services to help with house or yard work or with physical care.

Caregivers who are more confident are better able to care for their loved ones. Ask your healthcare team for ideas and information and help on how to care for your loved one. The healthcare team can assess the home and may suggest changes or equipment that can make caring for a loved one easier. They can provide information on what to watch for, how to manage side effects and preparing for the future. Be prepared for your role as a caregiver.

## Job, insurance and money concerns

Being a caregiver can lead to issues at work including missed days, low productivity and work interruptions. Talk to your supervisor or benefits office about your caregiving responsibilities and what options are available. You may consider a change in job-related duties, job-sharing or part-time work or you may need to take a leave from work. Some places also offer counselling services.

There are many costs in caring for someone with cancer. You may have to pay insurance deductibles or pay for home care or transportation services. If your loved one is your spouse, they may have been the primary provider in the home and if they are unable to work, that can reduce the family income. In addition, you may have to reduce your work or give up your job to care for your loved one, making it even harder to pay for everything.

As a caregiver you may be eligible for various forms of assistance from the Government of Canada.

## Coping tips

Being a caregiver can affect your quality of life physically, socially, financially, spiritually and emotionally. Some tips to help cope include:

- Find out information from your healthcare team or caregiver groups on caring for your loved one. Being prepared for your role as caregiver will make you more confident and better able to care for your loved one.
- Break big problems or tasks into smaller ones to make them easier to manage. For example, don't try to clean the whole house at one time, do a room a day or divide the work among family members.
- Set aside time for other loved ones and friends.
- Take a break. Go for a walk, have a massage, see a movie or meet up with a friend – whatever activities you enjoy doing. If you're worried about leaving your loved one alone, ask someone you trust to come by while you're away and leave a contact number so you can be reached.
- Pamper yourself in little ways. This could be a favourite magazine or TV show, a hot bath, an early night with a good book.
- Join a caregivers group or another support group. You may find it helpful to talk with other families.

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