



Canadian Cancer Society  
Société canadienne du cancer

# Living with Cancer

*A guide for people with cancer  
and their caregivers*



Let's Make Cancer History

1 888 939-3333 | [cancer.ca](http://cancer.ca)

The Canadian Cancer Society would like to thank the people who shared their personal experiences with us. In some cases, their names have been changed – these names are marked with an asterisk (\*).

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## Introduction

When you or someone you love is diagnosed with cancer, your main focus may be on understanding treatment options and getting the best care possible. But medical issues are only one part of a cancer diagnosis. Cancer also affects emotions, self-image, family, work, relationships and plans for the future. This booklet was written to provide information and support to help you understand and cope with the impact of cancer on your life.

Everyone's cancer experience is different. But whether you're newly diagnosed, are in treatment or are caring for someone with cancer, you'll probably need to deal with practical issues, make tough decisions and cope with many emotions. The information in this booklet can help you along the way.

### Definitions for some terms used in this booklet

- A **person with cancer** refers to the person diagnosed with cancer.
- **Caregivers** provide physical and emotional care to people with cancer. In many cases, caregivers are family members, partners, parents, children or close friends.
- **Partner** refers to a spouse, girlfriend or boyfriend. You may be married to your partner, live common-law or live separately. You may be in a heterosexual or same-sex relationship.
- **Family** can be defined in whatever way that is most meaningful to you. It may be you and your partner, with or without children. You might be a step-parent, single parent or foster parent. Your family may include grandparents, siblings, close friends, neighbours or other adults and children.
- Your **healthcare team** includes the doctors, nurses and other healthcare professionals who give you care throughout your cancer experience.

## How to use this booklet

Because each person has a different cancer experience, some topics in this booklet may have more meaning for you or may seem more useful than others. You may want to read some sections right away and come back to others later or not at all. If certain topics upset you, you may want to read about them when you're alone or with someone you trust – it's up to you.

Some information in this booklet is meant for people with cancer, while other information is for caregivers – and some information is for both. Both people with cancer and those caring for them can worry about many of the same things – but they can also have different concerns. You may find that it helps to understand more about how the other person sees things.

## Reacting to the diagnosis



“ *There’s just so much going through your mind. It’s a very tumultuous time because you are trying to digest, ‘I have cancer, I have treatment options, I have a family to deal with.’ There’re just so many different things that impact at the same time. ~ Dan*

### Common first reactions

“ *It was really a period of complete disbelief. I felt, ‘It can’t be. That’s not what it is.’ It seemed surreal, like it wasn’t really happening. ~ Andrew\* (caregiver)*

A cancer diagnosis – yours or someone else’s – can be shocking. You may feel overwhelmed, devastated, numb, frightened, angry, or you may not believe it. Your emotions can be very strong and upsetting. They may come and go quickly, and they may change often.

“ *To be totally honest, my first reaction when they found the tumour was a sense of relief. We’d finally figured out what was going on. And then I was just really scared. My aunt had died of the same cancer, so it was pretty overwhelming. ~ Lydia\**

The diagnosis can cause many fears – of death, changes to your body, painful treatments or feeling sick. You may worry about how your family and friends will react and how to cope with day-to-day tasks, work or finances.

Some people feel all alone, even if friends and family are with them. Others feel like they’re watching things happen to someone else, from the outside. Some people find it hard to understand what the doctor is telling them – they need to be told the same information many times.

“ I felt like I was in a cloud. I don't know what happened to me, but I felt like I wasn't myself. All I could think about was cancer. I couldn't remember or hear anything the doctor had told me, and I was angry with myself because I didn't bring anybody with me. That's all that kept running through my mind. ~ Lillian

All of these responses are normal. It's also normal for these feelings and fears to come back again and again throughout your cancer experience.

### Why has this happened?

“ It was awful, very painful. It was like, 'Why is this happening?' I am a very positive person, always have been a very positive type of person and enjoy everything. And now, why this? Why my husband? He is the only thing that I have. ~ Sarife (caregiver)

Many people with cancer look for a reason behind the illness. People sometimes think they could somehow change the situation, if only they knew why it happened.

But cancer is not a simple disease. It's not always possible to know why things happen the way they do. Not knowing why this happened can be hard, and you may struggle with it throughout your cancer experience. But knowing why cancer has occurred won't change the course of the illness. And worrying about *why* can use the energy you need to help you and your family move forward.

Some people may feel guilty and blame themselves. They think that something they did in the past caused them to get cancer. It's important to know that no one deserves to get cancer. If you're having a hard time coping with these feelings, talk to a counsellor or someone on your healthcare team.

### Will there be pain?

Almost everyone worries that cancer or cancer treatment will hurt. And it's true that some people do have pain. But others have pain only once in a while, and some don't have any at all. Everyone is different.

Living with cancer doesn't have to mean living with pain. There are many ways to control and even prevent pain. If you're worried about it, tell someone on your healthcare team so that they can help you. You don't have to face pain alone.

Emotions such as anxiety and sadness can sometimes make you more sensitive to pain. Learning to cope with these emotions may also help reduce pain and improve your mood.

#### For more information on managing cancer pain

Our booklet *Pain Relief: A guide for people with cancer* provides information and support on understanding and managing pain.

### Thoughts about dying

“ That question, 'Is this the end?' – it's huge. My thinking automatically went to the worst place – what it would mean in terms of life and death and understanding that this could be a terminal cancer. The logistics for any of the other things really had to come later. ~ Andrew\* (caregiver)

Finding out that you or someone you love has cancer often leads to thoughts of death. This is a common reaction. These kinds of thoughts can be painful and overwhelming, especially at first.

“ Nights were incredibly difficult. I was okay during the day when the kids were up, but then it would start to get dark and I would get a bit nervous. My mind was going 100 miles an hour – 'What should I be doing? Would I make it? Would my kids be okay? What about my parents?' ~ Lydia\*

When first diagnosed, many people with cancer and their families think about the possibility of *dying of* cancer. But after getting used to day-to-day life with cancer, many people start to focus instead on *living with* cancer. This can mean finding the strength and resources to cope with cancer, getting used to uncertainty and finding new ways to appreciate life. This change of focus can take time and is different for everyone.

## What should I expect?

“ *Once the initial shock had worn off, it really came to a practical set of questions – ‘What are we going to do with the kids? What are we going to do with my work? What’s it going to mean in terms of treatment and how are we going to coordinate this? How do we make travel plans?’ And we were trying to do that in a rational, realistic way but without all the information.* ~ Andrew\* (caregiver)

A cancer diagnosis can mean many changes – big and small – to your daily routines, work and family life, finances, self-image and well-being. All of these changes can be hard. It can be just as hard when you don’t know what changes to expect or how you and your family will react to them. Your healthcare team should be your first source of information.



## Talking to your healthcare team

Your healthcare team is there to answer your questions and give you information throughout your treatment. They may not be able to answer all your questions in full or right away, but you can still ask.

### > **TIPS** during your visits

It’s not easy to understand everything your healthcare team tells you, especially if you’re scared or confused. Make sure you get the information you need from your healthcare team:

- Write down your questions before your appointments and bring them with you. If you have a lot of questions, you and your doctor may want to plan extra time to talk about them.
- Ask questions and also share your concerns. Don’t worry if your questions seem silly – your questions are important and deserve an answer. It’s also okay to ask your doctor to use easier words and explain things that are new to you. To make sure you understand, use your own words to repeat back what you heard the doctor say.
- Take someone with you to appointments. This person can help by listening, taking notes, asking questions and talking with you later about the appointment.
- Make notes of your conversations with your doctor. Many people have trouble remembering conversations with their doctor or members of the healthcare team. Ask if you can contact them between appointments if you have other questions.

Your healthcare team works together to set up a treatment plan for you. Treatment may include surgery, radiation, chemotherapy or other drug therapies. Your team can give you information on each treatment and its potential side effects. Sometimes they can give you a timetable for your treatments. Having this kind of information may comfort you and help you plan the weeks ahead. But it’s important to remember that treatment plans can change as your healthcare team finds out more about the cancer or they can depend on how you respond to treatment.

> **TIPS** for coping

You may find it useful to:

- Talk to people who've had similar experiences.

“ *I had a colleague who went through the same thing. As I went through it, she was really good ... telling me what to expect at that time frame. I found that really helpful, and it kind of gave me a sense of control.* ~ Brenda

- Learn more about the type of cancer you have and treatments for it.

“ *I spent hours and hours on the Internet preparing myself, reading blogs of people who have been through it, talking to people that I knew had been through it.* ~ Brenda

- Talk to a counsellor if it's hard to deal with the uncertainties ahead.

“ *I started going for therapy, for counselling. That helped me and it felt better. I felt safe.* ~ Lillian

- Do things that help you relax, like reading or listening to music.

## Talking about the diagnosis



“ Good friends of ours were supposed to come over for dinner. And when someone walks into your house for dinner, you can't just say, 'Hi! Guess what? I have cancer!' My friend started talking and I couldn't get a word in edgewise, and it started to get really funny. I finally said, 'Can you shut up for a second? I have to tell you something.' Oddly, it was exactly what we needed at that moment. It just felt really normal and good, and I remember things hadn't felt very normal until then. ~ Lydia\*

One of the hardest parts of a cancer diagnosis is telling other people. You're not alone if you don't know how to start.

### Telling family members and friends

It can be hard to tell your close friends and family members about your cancer diagnosis. You may worry about how they will react, what you will say or how to start the conversation.

#### > TIPS

- Make it easy to have a private conversation. Turn off the TV, close the door and try to make sure there are no interruptions. It might be helpful to have someone who already knows about the diagnosis with you.

“ My parents were watching the kids while I had my tests, and then we were supposed to go to their place for dinner. So we put on a video for the kids to keep them occupied, and then we told my parents in another room. ~ Lydia\*

- Ease into the conversation by saying something like, “I think it would be good to tell you what's going on. Is that okay?” or “I have something serious to talk to you about.” If the person already knows a little about the situation, you might start with, “I think you probably know some of this already, so why don't you tell me what you know so far. I can take it from there.”
- Give information in small amounts, a few sentences at a time. Check regularly to make sure the person understands. You can ask, “Is this making sense?” or “Do you see what I mean?”

- Don't worry about silences. You may find that holding hands or sitting together quietly says more than any words. If silence makes you uncomfortable, you might want to ask a simple question such as, "What are you thinking about?"
- Be as honest as possible about the situation and your feelings. You don't need to act positive if that's not how you're feeling.

### Telling people online

For some people, it may be easier to tell others about a cancer diagnosis by e-mail or on a social networking site. Sending out this kind of group message can be useful when you have many people to tell or feel overwhelmed by telling the same news over and over.

Lydia\*, for example, knew the news that she had cancer would travel quickly in her small community. "I wanted to be able to control the information," she says, "and I didn't want to have somebody else share that information for me, and I couldn't call everyone who I thought I wanted to know. So we told our immediate family and a few close friends in person, and then I sent an e-mail. That allowed me to have control over what was said and how it was said. It was a really hard e-mail to write."

### Telling children

“ We sat on it for about 24 hours without telling the kids, which was incredibly difficult. And then we had a family meeting. The four of us sat on the couch and we cuddled together under a blanket and I told them. I explained that I had a tumour and that they had finally figured out what was wrong with me. ~ Lydia\* ”

It can be hard to know how and what to tell your children about a cancer diagnosis. But it's important to be honest with children because:

- They probably already know something is wrong.
- They can imagine the worst if they're not told otherwise.
- Children can feel betrayed or stop trusting you if they hear the news from someone else.

- By talking with your children honestly and helping them show their emotions, you make it easier for them to feel safe and secure.
- If you pretend to them that everything is fine, children may feel that they have to keep their worries to themselves, and they may not be able to tell you how they're feeling.

“ I was really worried about my sons. My 10-year-old was lying on the bottom bunk bed watching TV. I went and laid with him and just held him so tight because I knew my life was going to be different and I didn't know the outcome. ~ Lillian ”

### > TIPS on telling children about cancer

Here are some tips on *how* to tell children about a cancer diagnosis:

- Think about what you'd like to say ahead of time. Many parents find it helpful to practise or write down the things they want to talk about.
- Remember that children, especially young ones, have short attention spans. Only talk as long as they can listen.
- Choose a time to talk when you're feeling calm. Let your kids know that you may get sad or upset during your talk. That way, they will be prepared for your emotions.
- Don't be afraid to tell your children about your feelings. It may help them to be able to show theirs.
- If your children know somebody who's survived cancer, you might find it helpful to talk about that person.

“ We had a close family friend who had had breast cancer and so we could use the word "cancer", and our children understood that you can have cancer and that you can be really, really sick, and yet you can continue on again and live a very full, active life. ~ Lydia\* ”

Here are some tips on *what* to tell children:

- Give some basic information, such as the name of the cancer, the body part it affects, the treatment and its possible side effects. Use words children can understand. For example, say “doctor” instead of “oncologist” or “medicine” instead of “chemotherapy”.
- Prepare your children for possible side effects from treatment. Let them know if you might lose your hair or be tired all the time.
- Reassure children that they can’t catch cancer from you. It may also help to reassure them that it would be very unlikely for their other parent to get sick as well.
- Tell children that nothing they did caused the cancer. Children may worry that the cancer is their fault, and they must have done something wrong for this to happen.
- Tell children how their lives might change. Since cancer treatment can affect children’s routines, it’s important to prepare them for possible changes to school, lessons, meals, chores and so on.
- Give children time and other chances to ask questions and share their feelings. If they ask questions that you can’t answer, tell them you’ll find out the answers for them. Don’t be afraid to say, “I don’t know.”

“ *It was important to try and give enough information that they could understand ... what was going on, but without overwhelming them with information that wasn’t going to really help them and could confuse them. I think it was probably more frightening for me, as an adult, than for kids who don’t really have an understanding of the implications.*  
~ Andrew\* (caregiver)

As well as telling your children, try to tell other adults in your children’s lives (teachers, neighbours, coaches, relatives) about what’s going on. These other adults may be able to take your children to their activities, as well as listen to their feelings and concerns. Members of your healthcare team may also help by talking to your children and answering their questions.

### ***What if your child asks if you’re going to die?***

“ *My oldest son, who was 14, was the one that asked, ‘Is it going to kill you? Is cancer that bad?’ I told him, ‘I don’t know if it’s going to kill me.’ I told him, ‘Granny lived and she had breast cancer. They just need to get this cancer out as soon as possible, so that’s what we’re waiting for.’ ~ Lillian*

Just as it’s scary for you to think about death, it’s scary for children to ask this question. Many children think about it but don’t ask.

You may want to prepare an answer to this question in case your child asks. Your response will depend on many things – the type of cancer and how easy it is to treat, the stage of the cancer and what the doctor has told you.

“ *I didn’t make any promises that I couldn’t keep, which was incredibly hard because you just want to give them a big hug and say, ‘Of course, everything’s going to be fine.’ ~ Lydia\**



## Telling people at work

Whether you are the person with cancer or a caregiver, telling people at work about a cancer diagnosis is a very personal decision. It might be hard to keep cancer a secret in the workplace, especially if you're gone for a while or if your appearance changes.

### Who to tell at work

“ *I told my boss first, and then I asked her to share the news with my colleagues.* ~ Lydia\*

If cancer and treatment are likely to interfere with how you do your job, then you probably need to tell your boss and possibly some people who work closely with you. They'll need to know if you have to take time off, if you won't be able to work as much or if you need to change how you do your work. If you're the boss, you may need to explain the situation to at least some, if not all, employees.

If you don't know where to begin or if you're concerned about how your employer will react, try starting with your human resources department or personnel manager. You can use their experience and support to guide you through the process.

### When to tell people at work

It may be a good idea to wait until you know about your treatment schedule before telling co-workers. That way, you can let people at work know if and when you'll be away and for how long. The sooner you tell people, the more they can plan for your absence.

## What to tell people at work

Many people are nervous about sharing details of a cancer diagnosis at work. It's hard to predict how people will react. Some of your co-workers may know very little about cancer. Or they may think that you'll be less productive, competent or reliable.

Try to be prepared for different reactions, and plan your response. To start, you might want to tell people:

- your diagnosis and the plan for your treatment
- how much you expect to be away, if at all
- how you plan to do your work during this time

If you have close relationships with co-workers, you may find it comforting to share some of your feelings, worries and concerns. Let them know that sometimes your mood or your ability to work will be affected and that you may need their help. You can also tell them that your appearance might change.

Don't be afraid to ask for the kind of support you need. For example, you may not want to talk about having cancer while at work. You can always ask a trusted co-worker to let others know you'd prefer to focus on the tasks of the day rather than talk about cancer.

“ *The president of my company came to visit us in the hospital. She brought flowers. She talked with us for an hour. I am not her assistant either, and she came. I thought, 'Wow. They have a heart. They have feelings.'* ~ Sarife (caregiver)

## Responding to people's reactions

“ There was a lot of shock. A lot of, ‘Oh my gosh, what are you going to do?’ Overall, there was this huge outpouring of support, which was exactly what I needed. ~ Lydia\*

People will probably react to the news in different ways, whether they're family, friends or co-workers. Some people will know exactly what to say and do, and they will be easy to talk to. They'll know how to support you throughout the treatment.

Others may react in ways you don't understand. They might withdraw from you. Lillian remembers that many people in her community stopped talking to her. “They'd say, ‘Hi’ and suddenly there was no more ‘Hi.’” I felt that. I think it was ... fear. They didn't know how to relate or what to say to a person who had cancer.”

People can react in surprising ways for different reasons. They may be scared to see you looking sick or in pain, or they may be afraid that seeing you will be upsetting. They may be threatened by illness, or they may worry that they'll say the wrong thing or not be able to help. These kinds of reactions are not your fault, but you may find that they hurt.

If you feel up to it, try phoning those friends or relatives, or sending them an e-mail or letter. Let people know what's happening and that you'd like to see them. You can ask them to do practical favours for you, like cooking a meal or walking the dog. This makes people feel useful. Next time they may feel able to call you or just drop in. People sometimes need to be told how they can help. But in some cases, you may have to accept that someone might not be able to deal with cancer.

“ I would have people come up and the look on their face would be like someone died. And I'm going, ‘It's okay.’ I felt I had to help those people deal with something that I had accepted. That was hard. Like, ‘Don't look at me like that,’ you know? I'm past that point. You need to get there or don't come around me until you get there because I need to deal with what's coming up next. ~ Andrew\* (caregiver)

## Understanding and sharing your feelings about cancer



“ *When I was preparing for surgery, quitting smoking, I had a week of what I called a “pity party”. There was the anger. There was the pity ... From anger to crying to whatever, all in that week. And then it was done. Now I just experience maybe little emotions here and there, but not like it was. That was probably the worst. I would never want to go there again.* ~ Brenda

Living with cancer can mean living with a lot of different emotions. Learning about the emotional effects of cancer can help you cope, as well as understand and support others through these hard times.

### Common emotions

All of the feelings explained below are a normal part of a cancer experience. You're not alone if you feel any or all of them at some time or another. Emotions don't follow a schedule. It's also normal to sometimes feel numb, as if you can't feel anything at all. Everyone's experience is different.

“ *Seeing my wife's frustration or sadness or anger, or seeing her feeling down or depressed, really emphasized for me the need to be there and available for her. It was hard to watch, but I think it also highlighted that I needed to be an advocate for her and to be on her side and simply listen.* ~ Andrew\* (caregiver)

### Anger

You may feel angry at different points throughout your cancer experience. Anger is a common response to what feels like a very unfair situation. You may be angry at:

- the cancer
- your healthcare team
- friends and family who are in good health
- your body
- yourself
- your god

Sarife's husband and her brother-in-law were both diagnosed with cancer at the same time, and her husband's brother later died. "I didn't think I was angry until the day of my brother-in-law's funeral," she remembers. "I started hitting the coffin – they had to take me out of there. And that's not like me. I realized I was very angry that this had happened to both of them. They were both so young."

People sometimes get angry instead of expressing difficult emotions, like fear, sadness or frustration. People might seem angry at others – their healthcare team, or family and friends – when what they're really angry about is cancer or the situation. Many people have grown up with the idea that it's not okay to be angry. They hide anger instead of accepting it as a normal response to cancer.

“ *I was a little bit angry at the whole thing. Coming home from the hospital, I had this whole new system to figure out, and all of a sudden homecare nurses were coming in and they didn't know what the system was, and they didn't listen to me, and it was incredibly difficult. I probably wasted a fair bit of my energy being mad at them when, really, I was just mad at the situation.* ~ Lydia\*

If you feel angry, you don't have to pretend that everything is okay. Talk to your family and friends about your anger. Explain that you may seem angry or moody at times and that really you're angry at having cancer, not at them.

If you feel that someone is taking out their anger on you, it can help to remember that they're probably angry at the situation. Still, no one should have to deal with extreme anger, mood swings or violence. If you're worried about someone else's anger, you can try to talk to them about it, take a break from each other or ask a friend, family member or a counsellor for help.

## Denial

“ *The tumours are there. I know they are going to grow again one day. The doctors say, 'No. He is never going to be cured.' I think sometimes that I'm in denial because I'm still waiting for the moment when the doctors tell me he is cured.*

~ Sarife (caregiver)

Some people with cancer and their caregivers at first refuse to believe or accept the cancer diagnosis – this feeling is known as denial. Denial is the mind's way of coping with difficult information by refusing to accept or believe it.

A short period of denial can be helpful because it gives you time to get used to the diagnosis and feel less overwhelmed by the news. But it can be a problem if it lasts too long (several weeks or months) and prevents you from getting treatment or making important decisions.

“ *It's important to recognize the reality of what's happening and accept it. Because it doesn't necessarily limit your life completely, but it can certainly be hurting other people if you use denial.* ~ Mark\*

True denial – when someone never accepts or acknowledges the diagnosis – is very rare. People may choose not to talk a lot about their cancer, or they may stay optimistic when the outlook is actually not very good. But these ways of dealing with the cancer diagnosis don't necessarily mean they're in denial. Everyone copes in their own way.

If you feel that the person with cancer is in denial, give them some time to get used to the news. Many people have accepted the diagnosis by the time treatment begins. If a refusal to accept the cancer diagnosis interferes with making treatment decisions, try to persuade the person to talk to a counsellor.

Denial can also cause problems in relationships if one person is in denial while the other person has accepted the diagnosis and is ready to get on with treatment and making decisions.

“When I sat down and told my mom that I had breast cancer,” Brenda remembers, “she changed the topic. She kind of avoided it.” Talking to a counsellor together can help.

### **Fear and uncertainty**

“ Nobody knew how afraid I was inside. I was really scared that I was going to die. ~ Lillian

It’s normal to be afraid of the unknown. After a cancer diagnosis, life seems less secure and hard to predict. You may feel as if your life is out of control and you don’t know what’s in the future. The time between diagnosis and the start of treatment can be very hard. You may be scared or feel uncertain, and you may:

- wonder if you will die or lose someone you love
- worry about pain
- worry you can’t handle the treatment
- feel like you can’t do things you enjoy or that you have to put plans on hold
- feel helpless

All this uncertainty can make you anxious, irritable, angry or frightened. It may feel like things are out of control.

#### > **TIPS** for coping with uncertainty

- Learn as much as you can about cancer and its treatment, if you’re the kind of person who wants a lot of information. For some people, finding more information and using it to make decisions helps them feel more in control.
- Ask questions. Tell your healthcare team if you don’t understand what they’re saying or when you want more information. Consider making an audio recording of any important meetings with your healthcare team.

- Look beyond the cancer. Many people with cancer feel better when they stay busy. You might still try to work part-time. Hobbies such as listening to music or reading can also help.

“ I relied on walking and running, doing a lot of physical activity, a lot of meditation. I relied a lot on yoga. That was how I coped. ~ Lillian

- Try to focus on what you can do instead of what you can’t do. Remind yourself that you *are* coping, however bad you feel.
- Remember that the uncertainty from a new cancer diagnosis often goes away as you and your family learn more about the diagnosis and treatment.

If fear or uncertainty is interfering with daily activities, talk to your healthcare team. They can help you find counselling or support programs.

### **Guilt**

“ There were times when I wondered what would happen if my wife died and what I would do if she did. And then I would feel guilty about thinking that way, about not thinking positively. ~ Andrew\* (caregiver)

Sometimes people with cancer feel guilty. They may:

- wonder if they could have noticed symptoms earlier and done something to prevent the cancer or make it less serious
- think they caused the cancer because of lifestyle, attitude or work environment
- worry that their children will also get cancer someday
- feel bad for upsetting others or feel guilty because they think they’re being an emotional or financial burden

“ It’s really hard to feel like you’re the one who is responsible for having turned your children’s life upside down. I also felt guilty because my husband is a healthcare professional, and he actually worked with cancer patients all day long, and then he got to deal with it at home, too. ~ Lydia\*

Caregivers, family members or friends may feel guilty for some of these same reasons or because they:

- are healthy while someone they love is ill
- can't help as much as they want to or think they aren't doing a good job of helping
- feel stressed and impatient
- cannot make the person with cancer feel better
- may feel that they've caused the cancer

If you feel guilty, remember cancer is not your fault and no one deserves to be sick.

“ *Over time, my guilty feelings evolved into recognizing that, yes, there was a chance that she would die and that we needed to be prepared for that, just like we needed to be prepared for the surgery, and the time off, and dealing with the kids. But I still remember feeling guilty, feeling like I shouldn't think about negative things, even though I knew that we needed to.* ~ Andrew\* (caregiver)

Counselling and support programs can help with feelings of guilt. Tell your doctor or another member of your healthcare team if you or a family member wants to talk to a counsellor or someone who's been through a similar cancer experience.

### Hope

Once the first shock of the diagnosis has passed, people often feel a sense of hope. Hope allows people to cope with the difficulties of the present and to imagine a positive future. Hope is very personal – you might find it easy to be hopeful, or it may be hard to bring hope to your situation.

Although hope is very important to people with cancer, try to keep a balance between being realistic and having false hope. Cancer is a serious illness, and being realistic about the future will help you and your family make decisions about treatment and care.

People find hope in different ways:

- Your faith may give you hope, or you may find hope in stories about people who've overcome cancer.
- You may find hope by enjoying nature or spending time with your family.
- Many people find hope in the fact that cancer research has made so much progress in recent years or that it's possible to live a long time with cancer, like some people live with heart disease or diabetes.
- For some people, a cancer diagnosis brings a new clarity and purpose to life – and this can bring hope.
- Others find hope in making plans for the future – even the immediate future – such as a trip or projects around the home.

### Loneliness

People with cancer may feel lonely or isolated from others. Sometimes friends have a hard time dealing with cancer and may not visit or even phone. You may feel too sick to take part in activities you used to enjoy. Even when you're with people you care about, you may feel that no one understands what you're going through.

Caregivers can also feel lonely. When her husband was diagnosed with a brain tumour, Sarife wished for the company and support of her family in Mexico. “I spent a full weekend in bed or on the couch watching TV shows, totally depressed, thinking, ‘What am I doing here? We're by ourselves. There is no family.’ I felt so by myself. It was awful.”

If you're a caregiver:

- You may feel as though you've lost your best friend in the person with cancer or that you have no one to talk to about what you're going through.
- You may feel overwhelmed with your new responsibilities and not have time to see friends or do the activities you enjoy.

- You may feel guilty about going out and having fun if the person with cancer can't do similar things.
- You may also feel overlooked by healthcare professionals, family and friends, who often focus most of their attention on the person with cancer.

People with cancer and caregivers may feel less lonely if they can talk to other people going through the same experience. Many people feel better when they join a support group or connect in other ways to people who are facing, or who have faced, the same challenges.

### **Sadness and depression**

“ I was depressed in the hospital. I would cry myself to sleep. I refused to eat. I was really having a hard time dealing with all this stuff that I was going through. ~ Lillian

Many people feel sad after a cancer diagnosis or while being treated for cancer. If you're unhappy at certain points, or even throughout your treatment, this is a normal response to a stressful situation. You may feel sad at the loss of your good health or your ability to enjoy your life as you'd like to. It's natural for caregivers to feel sad too when someone they care about is seriously ill.

But depression is more than feeling sad or down for a few days. When these feelings don't go away, get worse and get in the way of your day-to-day life, they could be a sign of clinical depression.

Many people will experience depression at some point in their lives. It's an illness that can affect anyone at any age. If depression does occur, it can and should be treated. The first step is recognizing it and then getting help as soon as possible. It's not a sign of personal failure or an inability to cope. Depression can also be a side effect of some medicines.

The main symptom of depression is a sad mood that:

- is present most days and lasts most of the day
- lasts for more than two weeks
- affects performance at work, at school or in social relationships

Other symptoms of depression may include:

- loss of interest in work, hobbies, people or sex
- withdrawal from family members and friends
- feeling useless, unworthy, hopeless, excessively guilty or pessimistic
- irritability
- crying easily or feeling like crying but not being able to
- trouble concentrating, remembering and making decisions
- changes in appetite and weight
- fatigue
- sleep problems
- thoughts of suicide (which should always be taken seriously)

Talk to your healthcare team if you have any of these feelings or symptoms for more than two weeks.

### **Getting help**

A person who is clinically depressed can't just “snap out of it” or “cheer up” on their own. Your doctor can diagnose depression and prescribe medication, therapy or a combination of these.

> **TIPS** for coping with sadness or depression

- Talk to family members or friends about how you feel. It may also help to talk to someone who's had a cancer experience similar to yours.
- Look for supportive people to be around – people who make you feel better.
- Play with pets – yours or those of friends and neighbours. Spending time with animals can be calming.

- Eat well and be physically active if you can. Exercise can help your mood naturally.
- Try ways to relieve tension, like yoga, meditation and exercise.
- Look to your spiritual faith for comfort to keep you going in difficult times.
- Talk to your doctor about seeing a mental health professional who treats depression.

### Living with someone who is depressed

“ My husband would take me, and we would go canoeing out on the lake. Way out somewhere. We would just paddle and we would sit on this island and have a picnic. Not one word would be said from either me or from him. That’s how he supported me whenever I was down. ~ Lillian

It can be hard to live with or help someone who is depressed. It may feel as though you’re living with a stranger. A depressed person may not have the energy to do simple activities or household chores. These changes are usually temporary, and nothing you have or haven’t done has caused the depression. When the depression improves, the person’s usual personality generally returns.

Although you can’t solve someone else’s problems or make their depression go away, you can support them.

#### > **TIPS** for supporting someone who is depressed

- Listen and be patient.
- Remind the person that the depression won’t last forever.
- Encourage them to talk about their feelings.
- Encourage them to try different ways to relieve tension.
- Offer to go with them to the doctor or mental health professional.
- Take care of yourself so you can cope better with living with someone who’s depressed.
- Try not to take their irritability personally.

### What to watch for

Depression can become very serious. For example, someone who is depressed may refuse to eat or take medication, or they may have thoughts of hurting themselves. Try to persuade the person to talk to a doctor. If the depressed person refuses, then talk to the healthcare team about getting help.

### Stress and anxiety

“ Live day by day. When I start having my negative feelings or thoughts, I kind of think, ‘Why am I suffering today? I shouldn’t suffer today because I don’t know what’s going to happen, so try to enjoy today and then we will see tomorrow.’ ~ Sarife (caregiver)

The challenges that cancer brings can make people with cancer and their caregivers feel stressed and anxious. These are natural responses to a stressful situation. When you’re stressed, you may feel nervous or be unable to “turn off” your thoughts. Stress and anxiety often have physical symptoms, such as:

- fast heartbeat
- problems swallowing
- pressure or tightness in the throat or chest
- chest pain, muscle pain or headaches
- problems breathing
- upset stomach, nausea or diarrhea
- trouble sleeping or getting too much sleep

#### > **TIPS** for managing stress and anxiety

- Talk to someone who’s had a cancer experience similar to yours – this may help you cope with anxiety.
- Decide how much you’d like to know about your situation. Some people become anxious because they have too little information, while others feel better not knowing everything.
- Keep a journal or diary during treatment. Writing down your thoughts and feelings can help relieve anxiety. A journal is also a good place to write positive thoughts you can return to when you’re feeling low.

- Try meditation or relaxation exercises. Regular physical exercise can also be very helpful.
- Avoid caffeine (coffee, tea, cola drinks, chocolate) – try decaffeinated drinks instead.
- Focus on what you can do to relieve stress, rather than on what you can't.

If you feel stressed or anxious most of the time, talk to your healthcare team. They may be able to help by teaching you ways to cope, suggesting a class to help manage stress, referring you to a counsellor or support program, or prescribing an anti-anxiety medication.

### Want someone to talk to?

We can help you find the support you need close to home. Contact us to find out about professional counselling in your community or to find out what programs and services are available.

If you'd like to talk with someone who understands what you're going through, we can help you connect with a trained volunteer who's had a similar experience. You may meet with your volunteer in person or over the phone. To find out more:

- Call us at 1 888 939-3333.
- Visit the support/services section at cancer.ca.
- Contact your local Canadian Cancer Society office.

### Want to connect with someone online?

If you'd like to connect with someone online, join our online community, CancerConnection.ca. There are discussions, blogs and groups that may interest you, and you'll find caring, supportive people there.

## Sharing your feelings about cancer

### Why it's hard to talk about feelings

Some of us aren't used to talking about personal, private feelings. This can make it hard to talk about feelings about cancer – even if we want to. It can be hard to talk about emotions for many reasons.

You may:

- worry that you'll lose control and cry
- not know what to say and feel awkward
- have grown up with the belief that talking about your worries, sadness, anger, grief or fear is not appropriate or is a sign of weakness
- not want people to worry about you or be upset

### Why it's important to talk

“ *There are times when you're going to have some [bad] days and you're going to need to be sad, and that's okay. And it really helps to be able to talk about those feelings. Talking really helped me put my own feelings in perspective. ~ Lydia\**

Even though it can be hard, it's good to talk about how you feel and share your emotions, instead of keeping them inside. Talking about how you feel can:

- make you feel better and more in control
- help you understand your feelings and make them seem less overwhelming
- make you feel less alone
- strengthen your relationships with other people
- help relieve stress
- make other conversations easier

“ *I kept people informed – it was a way of dealing with your feelings, getting your feelings out. Your feelings can eat you up. ~ Ron*

## **Signs that someone is ready to talk**

Some people need time before they can talk about their feelings. If you're not ready to talk, say so. When you are ready, make sure that your listener is also ready. You can help people feel more comfortable by asking them what they think or how they feel. Sometimes people can't put their feelings into words. Sometimes, they just want to hug each other, hold hands, sit quietly or cry together.

### **Lillian's story: Sharing feelings**

Lillian, who is a member of the Sagkeeng First Nation in Manitoba, talked to her two sons about her cancer and her feelings at a ceremony called a Sharing Circle:

"I went and got some wood, and I brought out my cedar and my [ceremonial] tobacco. I showed them what to do. I prayed in English to them so they could hear what I was saying. I was asking Creator to support them during this time and that I was sick with cancer. I wanted them to feel safe and to tell me exactly how they feel, to give them that strength.

My oldest son was 14 at the time. He did exactly what I did. He told me how I made him feel – how lonely he was and how he wanted me to be home with him and how much he doesn't want me to die and how scared he was.

My little guy, he didn't say very much. All he did was pick up the [ceremonial] tobacco and toss it into the fire.

The Sharing Circle lasted just about every night. Then it was once a week, once a month, once every few months, and then only once a year. It got to the point where I noticed in my home that my sons didn't need that Sharing Circle anymore. We were having conversations in the house where you could actually talk to one another and share with one another without having the Sharing Circles."

### **> TIPS for talking about emotions**

- Respect people's ways of communicating. Some people may be more comfortable than others with personal details or humour.

“ I have a group of friends. We can very openly tease one another. Those types of people were really good for me because they didn't let me pity myself. It was important to have a group of people that allowed me to express myself the way I wanted to. ~ Brenda

- Understand that some people don't want to talk about the illness. Others may want to talk about it one day but not the next.
- Be honest if you don't know how you feel, don't know how you're going to cope or don't know what will happen. It's okay not to know.
- Don't be afraid to say how you feel. You could say, "I think we're both finding this hard," or "I know you're worried about what could happen and so am I."
- Avoid putting pressure on people. If you say, "You're so brave," or "You're so strong," it can put a lot of pressure on them to be strong when they may not feel able.
- Tell a joke and laugh – it can help to relieve tension.

“ We'd often joke about things. My wife would say, 'Well, if the cancer spreads and that's it, then I get to pick a new partner for you before I die. And you can't be with this person, or this person.' It was a bit odd, but in a funny way and in a helpful way, because that would bring up that topic and allow us to talk. ~ Andrew\* (caregiver)

- Don't feel you have to say something all the time. Silence can help people think about what they're going to say.
- Try a hug or a squeeze of the hand if you can't find words.

### **Be honest about how you feel**

If you're trying to protect the people around you by hiding your fears, don't. When you have cancer or are living with someone who does, you have many reasons to be upset. You don't need to pretend to be cheerful when you're not. Spending lots of energy hiding your feelings doesn't leave a lot of energy for dealing with cancer in your day-to-day life.

## If you don't want to talk

“ I rode on the same bus to the clinic with two women from my community. They were in complete silence. I would try to talk a little bit about breast cancer, and I knew I shouldn't talk anymore because their heads would go down. I took that as they don't want to hear it. I thought I'll just be quiet and not say anything. I can't make them talk. I can't make them say, 'Let's talk about this,' as much as I wanted to. ~ Lillian

Some people just don't want to talk about their feelings about cancer. If you feel this way, ask others to respect your wishes. And then if you want to discuss it, you can bring it up.

You may decide that you don't want to share your feelings with every person who asks. With casual friends or co-workers, it may be easier just to say a few words without a lot of detail. When they ask how you are, you can give a short but honest answer like, “I had a bad day yesterday but today is better. Thanks for asking.”

If you find it hard to talk about your feelings with people close to you, talk with people who are not family or friends. For example, find a support program for people with cancer or for caregivers, or talk to a counsellor. Sometimes meeting with a counsellor with your partner or other family members can help you talk more easily about difficult topics.

## Sharing without talking

“ Writing helped me a lot. I found it was therapy. I have a friend who is a psychologist. She told me, 'Whenever you feel like writing, just write. Write everything that you feel like.' I did that a lot. It gave me a lot of relief. ~ Sarife (caregiver)

If it's hard to talk, think about other ways to share your feelings. For example, you may find it helpful to write them down and then share them. Letters, e-mails and blogs can be good ways to share feelings without talking to anyone directly.

## Sharing online

“ I used Facebook ... to let people know how I was doing. I would say, 'Going for surgery on whatever day, will be home.' And then when I got back, I put on there, 'Back, lots of tubes but doing well.' ~ Brenda

Your journal can also be online – blogs are web pages that act like a journal. You can make your blog public, so that anyone can read it, or private, so that only the people you want can read it. You can invite readers to post comments on what you've written.

“ I spent hours and hours on the Internet preparing myself, reading blogs of people who had been through breast cancer, mastectomy, reconstructive surgery. I found the blogs really helpful because they went through so many of the scenarios, and every woman was different. ~ Brenda

Many people turn to social networking sites like Facebook in order to share news with friends, family and community. There are also social networking sites just for people with cancer or other illnesses.

“ One of the tools we ended up using was a social networking site for people with illnesses. This is something I would highly recommend. It has huge privacy controls on it. And so only people who I invited can see my page. It became a really easy way for us to communicate with people, and you can put pictures up and people could post on it or send you private e-mails. ~ Lydia\*

Many people turn to online communities. These sites provide a place where people can share their experiences and build relationships with others going through cancer.

### Want to connect with someone online?

If you'd like to connect with someone online, join our online community, CancerConnection.ca. There are discussions, blogs and groups that may interest you, and you'll find caring, supportive people there.

## Getting help from others



“ *I had huge community support. Lots of people wanted to help, so I just told them to see my neighbour, who set up meals to be provided three times a week to my house for two months. That was a big, huge help.* ~ Brenda

Throughout your cancer journey, you might need help with getting to treatment, doing housework or yardwork, cooking meals, taking care of children, walking the dog and so on. Some people – often family and friends – are very good at this sort of practical help.

Another important kind of help is the kind that comes with listening, offering support or counselling. Some of your family and friends may support you by doing this, or you may also find it helpful to turn to healthcare professionals or other people living with cancer.

Although you may find it hard to ask for and accept help, having help often makes it easier to cope with cancer. Many people with cancer and their caregivers are often surprised – and deeply touched – by just how much people want to help.

### **Asking for or accepting help**

Many people find it hard to ask for help. They may be used to being independent and managing everything on their own. They see needing help as a sign of weakness. Some people are uncomfortable talking about their needs or asking people to do things for them. They may feel like they are being selfish or burdening other people.

“ *As much as people offered help, our first reaction was to decline it. You know, you don't want to be a burden to your friends. But we learned as we went along that people were able to help and that we were able to actually turn to those close friends who said, 'You know, we can do something.'*  
~ Andrew\* (caregiver)

If you're finding it hard to ask for or accept help, remember that many people really want to help. People often don't know what to do when someone is ill, and helping out is one way for them to feel useful. Many people see the opportunity to help as a gift, something that is good for them and you.

“ Our friends are quite thrilled to be able to offer something, in terms of watching the kids or making a meal – sometimes even just to spend a little time with my wife while I went for a run or did something for my mental health. You could see that people appreciated being able to help. ~ Andrew\* (caregiver)

## Building your support system

When you or someone you love has cancer, help comes in many different forms and from many different people and places. You might find help through support groups, family and close friends, co-workers and your larger community, through volunteer agencies or counselling.

It can be comforting to know so many people want to help and there are so many resources available. It can also be overwhelming when people ask what they can do.

Sometimes, it can be helpful to have a “point person” ask for and organize help on your behalf. This person can create charts or lists and give people specific tasks on specific dates. They can update people on your condition, and let them know good times to call or visit (or when you’re not ready for visitors).

### Brenda’s story: Getting help

Brenda, who manages two long-term care facilities, used her skills as a manager to build a support team when she was diagnosed with breast cancer.

“If I didn’t know what I needed, I could say to my friends, ‘You know what, people are asking me what they can do and it’s frustrating me. Can I send them to you?’ And they were like, ‘Yeah.’ They wanted something to do. And I think that worked out really well.

One girlfriend organized meals. Another girlfriend, she came to my procedures. She and my husband both came. Someone else organized driving so that I could visit my mother. A work colleague, a breast cancer survivor, talked to me about what she had gone through and what I would go through next.

It’s not just your spouse. It’s not just your children that are supportive. I think as a cancer survivor, I picked people for certain things that I knew that they were good at because of the experiences I had with them.”

But there may also be times when people with cancer and their caregivers feel they don’t have the support they need or want. People with cancer who are far away from family and friends may feel isolated and overwhelmed. If that’s the case, talk to someone on your healthcare team in order to learn more about support services and support groups in your community.

### Support groups

Support groups help by giving people a chance to talk to others going through similar circumstances.

### Lydia’s story: Online support

Lydia\* was diagnosed with colorectal cancer at the age of 37. She had surgery to remove the tumour and her colon. Today, she has an ostomy – an artificial, permanent opening in her body to allow waste to pass through to be collected in a small bag.

“Adapting to the whole ostomy thing was pretty big. In terms of what helped, I actually found an online group. There were a whole ton of people out there with the same thing. And there were some great people who provided tips and tricks and normalization and all that kind of stuff. So I spent a fair bit of time for a number of weeks, really just lurking and hanging out there because I felt like I knew nobody. I still know nobody, within my social group, who has an ostomy.”

Although your friends and family might be very supportive, it can also be comforting to spend time with people who’ve gone through the same things as you. You can often talk to these people about things you can’t discuss with anyone else. Someone who’s had cancer can:

- understand how you feel
- talk to you about what to expect
- tell you how they coped
- help you learn ways to enjoy each day
- give you hope for the future

You may already know someone you can talk to, or you may meet them through friends, family or co-workers.

“ *I had known that one of my colleagues had gone through breast cancer, but I didn't really know her story. I wasn't really close with her as far as feeling like I could phone her and talk to her, but when she saw my Facebook status, I contacted her and asked if she would be willing to share what happened to her. And she had no problem doing that. That was very helpful.* ~ Brenda

Some people meet others with similar experiences through organized programs offered by hospitals or treatment centres, doctors' offices or not-for-profit organizations. These types of programs come in different formats:

- one-to-one support offered by telephone
- one-to-one support offered in person
- group-based support
- online support on the Internet

### Different types of support groups

Not everyone finds it easy to talk in a group setting or wants to talk about their feelings with strangers. There are many different kinds of groups – some are informal while others are more formal. Try to find a support group that's right for you:

- Some groups are open to everyone. Others are for certain people, like women with breast cancer, men with prostate cancer, teenagers or caregivers.
- Some groups talk about all aspects of cancer. Others focus only on specific topics, such as treatment or self-esteem.
- Therapy groups (often led by mental health professionals) can help you learn specific coping skills, such as managing fears and uncertainty or dealing with communication problems.
- Sometimes, people with cancer meet in one support group and their family members can meet in another. This way, people can talk freely without worrying about hurting someone else's feelings. In other groups, patients and families meet together. These groups can be a good way for each to learn what the other is going through.

- Some support groups take place online – through chat rooms or moderated discussion groups. People in these groups can message each other online. People often like online support groups because they can participate at any time of the day or night. They're also good for people who can't travel to meetings.

### Talking with someone who's been there

If you've been touched by cancer and would like to talk to someone who's had a similar cancer experience, we can help you connect with a trained volunteer – in person, over the phone or in a group setting.

To contact the Canadian Cancer Society:

- Call us toll-free at 1 888 939-3333 (TTY: 1 866 786-3934) Monday to Friday, 9 a.m. to 6 p.m. If you need help in other languages, interpreters are available.
- E-mail us at [info@cis.cancer.ca](mailto:info@cis.cancer.ca).
- Visit our website at [cancer.ca](http://cancer.ca).
- Contact your local Canadian Cancer Society office.

Our services are free and confidential.

### Family, friends, co-workers and community

“ *A friend who had survived cancer said that one of the things she wished she had done with her kids was to make sure they had something new to cuddle while she was in surgery. A different friend organized a gift certificate for a company that lets you design and build your own teddy bears. You can put a sound recording into the bear, so I could record my voice and say goodnight to the kids. My son and daughter each built one, and we had enough money left over to make a bear for me, which I brought with me to the hospital.* ~ Lydia\*

Your family and friends can be very supportive. Some will know exactly what to do and say without being asked. Others might not be sure how to help.

## What family and friends can do to help

- Keep other people informed by making phone calls or sending out regular e-mail or Facebook updates for you.
- Water your plants, bring in your mail or take care of your pets while you're at the hospital or recovering from treatment.
- Go grocery shopping or prepare meals that can be frozen and reheated.

“ *One family gives me vegetables and fruits every two weeks. There were very tough moments financially, so that was very nice. They say they get them for free. That is what they say, but I don't think so.* ~ Sarife (caregiver)

- Clean the house, mow the lawn or shovel the snow.
- Check out or return library books and DVDs.
- Record favourite television shows for you to watch later.
- Provide a distraction – watch movies or TV shows with you, or bring books, magazines or music.

“ *I asked for music recommendations because that's one of the ways that I keep myself calm. So people would make song recommendations or they made playlists for me. It both allowed me to ask for something but also to receive something that I would really use well.* ~ Lydia\*

- Drive you to and from appointments.
- Drive children to school or lessons, or babysit on treatment days or days when you're very tired.

“ *A lot of my friends knew that a huge worry for me would be my children and what was going to happen with them, and so people offered to come and do stuff with them. People gave books ... there were little care packages put together. People would take the kids to swimming lessons. My kids still had a really fun summer – just with other people.* ~ Lydia\*

Sometimes, you may want or need someone from outside your family or friends to help with certain tasks. For help with physical care (such as bathing or dressing) or skilled care (such as giving special feedings or medications), you may find the help you need through your local public health department or community care service.

## Counsellors

### Mental health or psychosocial oncology professionals

Some people living with cancer find it helpful to talk to a mental health professional. Many different professionals, including psychologists, psychiatrists, nurses and social workers, can provide some type of counselling. Spiritual care workers at treatment centres can also provide counselling. These professionals are all trained to listen and help you deal with your situation. They can:

- help you find and understand information about your cancer and then make decisions
- help you cope with emotions such as fear, anger, guilt, depression and anxiety
- help you with identity, self-esteem and body image issues
- help you – individually, as a couple or as a family – talk about communication issues, family issues and relationship problems (including problems with sexuality and intimacy)
- help you find meaning and purpose in life

In most cases, these professionals will see you or your family members at any time during your cancer experience, including after treatment. Don't worry if you aren't clear about how counselling might help or even exactly what it is you want help with – the counsellor will understand.

## Social workers

“ *I did therapy. I received a lot of help from the oncology team. There was a social worker there. That helped me because it's very different when you talk with a friend or with your mom. It was a person that was totally outside of the picture. It was really good to talk freely.* ~ Sarife (caregiver)

In addition to giving support through counselling, social workers can help you with practical needs. They can refer you to support groups, financial assistance and other resources.

## Spiritual care workers

“ *I would meditate in the bush for hours. I would ask for Creator to look after me. From there, I relied on my ceremonies ... I actually felt like my spirit was being nurtured. I felt like people cared. I felt safe.* ~ Lillian

Cancer can affect people's spirituality. Sometimes people find themselves turning to their spiritual side more often to help cope with the situation. Others may begin to question their faith.

If you'd like to talk to someone about spiritual issues, don't worry if you haven't been going to religious services regularly or aren't sure what you believe. Spiritual care workers can help you with your doubts and beliefs and help you find peace of mind.

If you don't have a spiritual care worker to talk to, your hospital or treatment centre likely has spiritual care workers on staff to help you and your family. Although they come from specific faiths, they're trained to provide support to people with traditions different from their own.

## Patient advocates, discharge planners, nurse navigators and volunteers

Your healthcare team is there to help you. In addition to planning your treatment and watching your physical progress, they can help you with other aspects of living with cancer. If you need practical assistance or emotional support, they may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

Many treatment centres and hospitals have people on staff to help make your cancer experience a little easier.

- **Patient advocates** can help when you have a concern that you don't want to discuss with your doctor, nurse or social worker.
- **Discharge planners** work with you and your family as you get ready to leave the hospital. They can help with tasks like making follow-up appointments and making sure you have the things you need at home.
- **Nurse navigators** (also called patient navigators) are new members of many cancer treatment teams. They help you find your way through the healthcare system. Nurse navigators can speak on your behalf, make sure your questions are answered and help you find the resources you need.
- **Volunteers** often visit with patients in the hospital and offer comfort and support. They may bring books, puzzles or other things to do. Many volunteers have had cancer.

## Caring for yourself



A big part of coping with cancer is learning how to take care of yourself. Everyone has their own ways of relieving tension. As you learn to cope with cancer, you can try to find the best ways to make yourself feel better and get a sense of control over the emotions that come with cancer.

### Ways to relieve tension

“ *In terms of cancer, in terms of your health in general, you may not have control over what happens to you, but you do have a choice about how you handle it.* ~ Lydia\*

### Complementary and alternative therapies

#### Complementary therapies

A complementary therapy is any practice, therapy or product that is not considered conventional medicine for cancer care. Complementary therapies are used *together with* conventional cancer treatments. Before using any complementary therapy, talk to your doctor or other members of your healthcare team about all the possible risks and benefits.

Complementary therapies may help you feel more in control over what is happening to you. They can reduce your feelings of helplessness or anxiety and can help to improve your mood. Many complementary therapies build on the body's own strengths and abilities and show the link between mind and body.

#### Alternative therapies

Alternative therapies are those used in place of conventional treatments. They are considered scientifically unproven therapies. While complementary therapies are used *together with* conventional treatment, alternative therapies are used *instead* of conventional treatment.

For example, a complementary therapy might include using herbal medicine together with conventional cancer treatment. An alternative therapy is deciding not to use conventional care and using *only* these therapies.

### For more information on complementary therapies

For more detailed information on complementary therapies, you may find our booklet *Complementary Therapies: A guide for people with cancer* useful.

### Hobbies and pastimes

“ I learned how to knit. I’ve discovered that knitting is incredibly grounding for me. I like the idea of producing things. I am not very good at it. I’m not a very detailed-oriented person. But that kind of works for me. ~ Lydia\*

Many people find that creative activities help them feel better. You may want to try drawing or painting, woodworking, playing a musical instrument or dancing. You don’t have to be formally trained, and you don’t have to have expensive equipment. Try something – and if you feel better, try it again.

### Relaxation methods

Learning to relax your body and your mind, even for a short time each day, can help you feel better, calmer and more in control. Relaxation can also help you cope with difficult emotions, pain and other symptoms. Books, DVDs, podcasts and classes can teach you different self-help relaxation methods.

### Meditation

Meditation is used to relax your body and calm your mind. It can also be referred to as mindfulness-based stress reduction. This means focusing your attention to let go of certain thoughts in your mind. You can focus on your breathing, repeat certain words or phrases (a *mantra*) or focus on an object.

Meditation may help you reduce anxiety, stress, blood pressure, chronic pain and insomnia. It may help improve your quality of life and help you feel more in control.

There are many different types and styles of meditation. Meditation may be done while sitting or lying down. There are also moving forms of meditation such as qui gong or walking meditation. Meditation can be self-directed or guided by trained professionals such as psychologists, psychiatrists or other healthcare professionals.

### Exercise

“ As soon as I got clearance from my physician, I started to exercise again. Now, I prioritize my exercise. If I have an errand to run and something else to get done and my house is a mess, I will still prioritize my exercise. Because to me, that’s just part of my mental health, it’s part of my commitment to my post-cancer self, and yes, it’s just become a really active self-care for me. ~ Lydia\*

Many people with cancer and caregivers find they feel better, have more energy and are less fatigued and stressed when they do physical activities like swimming, walking, stretching or biking.

If you have cancer and have always been active, try to keep exercising – if you’re able and your healthcare team says it’s okay. If you don’t usually exercise and want to start now, first talk to your healthcare team about the activity you want to try.

Many people living with cancer find that yoga or tai chi are gentle but effective forms of exercise that help relieve tension.

### Yoga

Yoga combines exercise for your body with breathing exercises and focus for your mind. There are many different types of yoga. Some are slower and more meditative, while others are faster

and more athletic. Most types of yoga can be done by people at all levels, ages or stages of health, and it can be done anywhere – community centres, yoga studios or at home.

### Tai chi

Tai chi is the ancient Chinese art of “moving meditation”. When you do tai chi, you move slowly and rhythmically with continuous movement. Tai chi can bring physical control to the body and balance to the mind. Many gyms and community centres offer classes. Once you know how to do tai chi, you can also do it at home.

### Be careful if using alcohol or other drugs to relieve tension

Some people relieve tension by using alcohol or other drugs (illegal, prescription, over-the-counter or herbal). This is risky, especially during a cancer experience. While the occasional drink may help you relax or help your appetite, it's important to be careful:

- Combining alcohol or other drugs with cancer treatments can be harmful, and there are other possible negative effects on your health.
- Using alcohol or other drugs to cope may prevent you from learning other, healthier ways to cope during hard times.
- Using alcohol or other drugs to cope may damage relationships with family and friends – relationships that are very important at this time.

If you choose to drink alcohol or use other drugs, talk to your doctor.

## Changes to self-image

Having cancer can change the way people think about their bodies. It can cause both physical and mental changes, and these changes can have a big effect on your self-image. While living with these changes may not be easy, it may help to remember that many of them are temporary.

### Changes in appearance

“ *The ostomy has been a huge adjustment. I have never been concerned about body image, but this is different. I had to change the type of clothes that I wear. My ostomy, or my stoma, continues to stick out more and more, so I have to be quite aware of that.* ~ Lydia\*

Cancer can change the way you look, temporarily or permanently. Some people gain weight while others lose weight. Cancer treatments sometimes make your hair fall out, and surgery can leave scars.

All these changes can affect your self-image. At times, you may feel unattractive and negative about your body. You may worry that your partner will reject you. Or you may not feel like being intimate with your partner. But it can help to remember that some of these changes are only temporary, and you'll probably start to look and feel more like your usual self when treatment is over. Staying active, visiting with friends and doing activities you enjoy can also help you feel better about your body image.

And you do have different options when it comes to changes to your appearance. If you lose your hair because of chemotherapy, you may want to wear a wig. If you want to match your usual colour and style, get the wig before you start treatment. Try to find a wig that fits well and doesn't scratch, since your scalp may be tender and sore. You may be able to claim the cost of a wig on your income taxes, or your health insurance may pay for it. Many cancer centres lend out wigs for free. You can also try wearing a hat, scarf or turban.

If surgery to remove cancer has changed the way you look, you may want to talk to your doctor about plastic (reconstructive) surgery. For example, you may choose to have surgery to reconstruct your breast or improve the look of a surgical scar. Some people feel that reconstructive surgery helps them feel better about themselves.

“ *Before, I tried to cover my body as much as I could. But the minute that I had cancer, there are doctors who are looking at you and doing the biopsies on you. The plastic surgeon has to take pictures of you. After I had the mastectomy, it was an entourage of the doctor’s team that would come and look at my breasts. It got to the point that I was comfortable. In terms of how my body looks [after reconstructive breast surgery], I’m happy with my results.* ~ Lillian

### If your partner has cancer

“ *My husband has had a hard time with it – my body looks different. The physical breast isn’t the same. Right now, I have no nipples. I still have to get those reconstructed. He’s very respectful, but that intimacy is hard for him. As long as we keep an open dialogue and can discuss it together, then we will be fine. But I think it will take a while.* ~ Brenda

It’s natural for you to notice and worry about changes to your partner’s appearance. You may feel less physical desire for your partner during cancer treatment. This may be because of changes in appearance, but it can also be because you’re tired or stressed.

Remind your partner that your love and attraction for them go beyond their outward appearance to their inner qualities – like personality, intelligence, sense of humour or thoughtfulness. These qualities don’t change when the body looks different. Do your best to keep a close, caring relationship between you and your partner.

## Changes in energy levels

“ *We have different types of energy – physical, mental, emotional, spiritual – so when I felt physical fatigue, I tried to go into a different area. I read, I talked to someone.* ~ Ron

People with cancer can get tired very easily and may feel weak at times. They may have good days with lots of energy and bad days when their energy is very low. If you’re very tired and weak, you may have to make some changes. For example, you may not be able to drive or play sports. You may have to reduce your work hours or stop working. You may have to rest more often, walk more slowly or use a cane, walker or wheelchair. It can take time to get used to these changes.

David, for example, found that the major side effect of his radiation therapy was fatigue – he was already very tired and weak from surgery for a brain tumour. His wife, Sarife, remembers that it was hard – “He was used to being the strong one, the one who helps.”

### > **TIPS** for when you have less energy

- Let people know that you have good and bad days. Try to do something special on days when you feel better. Let yourself rest on the days you’re tired. Don’t be afraid to tell others when you’re tired or if you need to change plans.
- Save your energy for the things you really want to do. You can reorganize your daily activities to make sure that you plan enjoyable things for when you’re most likely to have energy. You can also set aside a time to rest every day.
- Try to stay active, even for short periods of time. Exercise can increase your energy levels and mood.

Caregivers can also have fatigue, often from the stress and extra responsibilities of caring for a person with cancer. Sometimes caregivers give care during the night, and so their sleep is interrupted. If you’re caring for someone with cancer, try to

make sure that you get enough rest, and ask for and accept help. Try not to feel that you must do everything for the person you're caring for. People with cancer may tire easily, but they can still do some things as before if they're physically able and willing.

## Mental changes

Cancer and its treatment can sometimes affect a person's memory or ability to concentrate. You may forget a friend's name or where you left your glasses. It could be hard to do a simple math problem in your head. You could be easily distracted or find it hard to concentrate on more than one thing at a time – like following a recipe while someone is talking to you. These changes can be a side effect of chemotherapy or a result of stress, fatigue, anxiety or depression.

### > TIPS for remembering things

- Plan activities that need your concentration for the times of the day when you're most rested.
- Keep track of things by making lists of appointments, things to do, medicines and so on. You could also set an alarm or use a smartphone app to remind you of things.
- Ask a family member or friend to help you to remember by listening, taking notes and asking questions at appointments.

## Changes to fertility

“ I lost my breasts and I lost my uterus. I knew I wasn't going to have any more children. When I was depressed, I was thinking about that. ~ Lillian

Fertility is your ability to have children. Fertility can be affected by cancer and its treatment. This can be an emotional topic for many people. If you think or know that you'd like to have children in the future, talk to your healthcare team about how cancer and treatment can affect your fertility. You might want to consider

having your sperm or eggs preserved to use after treatment. Your healthcare team can refer you to a fertility specialist to talk about these options.

It's important to use birth control while you're being treated for cancer. Drugs used to treat cancer can damage sperm, which may lead to birth defects. And some cancer treatments can cause problems for a developing fetus. Ask your doctor about birth control if you think you or your partner could become pregnant.

Changes to your fertility can affect how you feel about yourself as a man or a woman. Talk to your partner and share your feelings about fertility. If you're having a hard time with your feelings about this during or after your cancer experience, talking to a counsellor may help.

## Changes to independence

Having cancer may make it harder for you to do some of the things you used to do on your own or for yourself. You may need to ask for and accept help with errands or chores because you can't get around as easily. Or you may need help with cooking or yardwork, even though you've always done these yourself. It can be hard to lose some of your independence.

“Not being strong and independent was difficult for him,” says Sarife of her husband, who has a brain tumour. “We had battles over that. I wanted to put a chair in the shower so that he could sit and he didn't want that. He said, ‘No. I am standing up.’ He was very stubborn. He wanted to prove that he was okay and that he could do it. Then of course I was worried all of the time, but I had to give him the chance – and to give me the chance as well – to be back to normal. It was important for him.”

You may have to learn to get help for some things and still do other things yourself. Try to accept help with some tasks, so that you

don't feel too tired or overwhelmed. Be realistic about what you can do. Get help from your partner, family or friends before things become too much for you.

### **Getting help with personal or intimate tasks**

“Immediately after surgery, my wife really needed me and others to help with her basic bodily functions. I think that was a big challenge for her to have that reliance and dependence on me, [for] something that isn't necessarily what partners do. But in some ways it almost seemed like it was a natural thing to say, 'Well, it needs to be done and I'm here. I should be the person to help do it.' ~ Andrew\* (caregiver)

At times, some people with cancer may need help with personal tasks, like eating, dressing, taking a bath or shower, or using the toilet. This can be a challenge, both for people with cancer and their caregivers. Some people with cancer are most comfortable when their partner can help them with these tasks. Others would rather accept help from a professional – someone they don't know as well. The same is true for caregivers. Some are comfortable, while others prefer to have a professional help them.

Talk to each other about what you both are comfortable with, and ask your healthcare team for help in making these decisions. Sometimes, caregivers can feel more relaxed about helping with certain activities – for example, giving a sponge bath – once they have been shown how.

If you need day-to-day care, you can keep some of your independence by explaining how and when you would like things done, and by whom. If you can tell your caregivers what you need and how they can best help you, you will both be happier. They can feel more confident in helping you, and you can feel that your life is still your own.

### **Taking care of yourself as a caregiver**

“The most important things that I found was to remember to eat, remember to exercise, remember to sleep. I felt that I needed to be there for my partner, but in order to be there and be able to help, I needed to have some return to reality time. It didn't need to be a whole bunch of time, but a couple hours a day I'd go for a run and have a quiet lunch or something and just take a little bit of a break. It really allowed me to be in the moment for her when I got back. ~ Andrew\* (caregiver)

To care for someone with cancer and cope with so many responsibilities, you first need to take good care of yourself. You may worry that looking after your own needs seems selfish, but it's not. Remember that caring for yourself is just one part of caring for someone with cancer. Keeping up your strength and spirits will help you cope with the challenges of being a caregiver and prevent you from becoming overwhelmed.

#### **> TIPS**

- Talk about what's happening. Sharing feelings and frustrations with trusted friends and family members can help reduce stress. You can also talk to a counsellor or other people who've been through similar experiences. Find out about support programs for caregivers.
- Don't feel that you have to do everything. Ask for help, and say “yes” to offers of help with cooking, housework, childcare and other tasks.
- Ask friends and family members if they would be willing to be “on call” in times of stress. Plan a regular “check in” time when you can get together or call each other.
- Be easy on yourself. Try not to feel guilty when you're tired, frustrated or overwhelmed. These are normal responses to a stressful situation. Focus on all the positive things you're doing for the person with cancer.

- Take a break. Go for a walk, see a movie or meet up with a friend – whatever activities you enjoy. Taking some time away can make it easier to return to your role as a caregiver.
- Take care of your physical and emotional health. See your doctor if you have any health concerns. Make sure you get enough sleep, exercise regularly and eat well. It's okay to think about your own needs, and tell others if you need help or are having trouble coping.
- Talk to your healthcare team if you want to find out about respite care. With respite care, a trained person usually comes into the home to take care of the person with cancer while the caregiver goes out for a while. It gives you a break from being a caregiver so that you can rest or take care of other things.
- Know your limits. Say “no” when people ask you to do tasks you don't have the time or energy for.

“ *I wasn't sleeping. I was going in all directions. I was putting myself last. I decided, 'This is enough.' I talked with my husband, and I said, 'I need to be okay to take care of you. If I am not okay, if I am not well and I am going crazy, I am not going to be able to take care of you.'* ~ Sarife (caregiver)

## Coping within the family



A cancer diagnosis affects people with cancer and their family and friends. There are many issues that can come up for families living with cancer. And family members of all ages can be affected.

### Cancer is a family affair

After a cancer diagnosis, family can give great comfort and strength, as well as cause stress or anxiety. The way your family deals with the cancer diagnosis and treatment may depend a lot on how you've coped with hard times together in the past. Many relationships may become stronger and more meaningful as people develop a new understanding of each other. Some relationships suffer, especially ones that already had problems.

### Friends can be your family

"My friends are like my family. From the moment we checked into the hospital, I was never alone again. They were with me all of the time. They took turns to sleep at my house before my mother arrived. I told them, 'I am okay. I can do this.' They were like, 'No. We are staying with you. We are taking turns.'" ~ Brenda

Many people have a circle of friends that they consider family. Some people are closer to this group of friends than they are to their relatives. If there are special people in your life that you want included as family, let your healthcare team know.

Close friends may also be able to give you a different perspective on family relationships and give you a break from day-to-day aspects of family life.



## Changing family roles

“ *My kids were active in different sports, and I was the main one that took them to all those sports. So, my husband’s role changed, and I think it was a good change because then he got to see a lot of the stuff he wasn’t seeing before.* ~ Brenda

People with cancer and caregivers may have to give up or reduce some or all of their family roles and responsibilities – as wage earner, homemaker, child caregiver, volunteer or caregiver for an aging parent – while they focus on treatment and recovery.

At the same time, other family members may have to take on new roles and responsibilities. For example, a partner may need to help pay bills, shop or do yardwork, or a child may be asked to do more chores. Sometimes it’s hard for family members to get used to these new roles. Family meetings are one good way of checking in to make sure everyone is coping with these changes.

“ *Maybe it’s just growing up, but I think my older daughter became a lot more motherly. She started cooking more. All of a sudden, she’s really nice to her sister. That changed in her. I don’t know if it was because of her age, but I think my youngest probably helped her out more emotionally and that was her way of repaying that.* ~ Brenda

## Family meetings

Regular family meetings (perhaps once a week) are a good way for families to keep up with what’s going on with everyone. They can be a special time for everyone to talk about anything that is bothering them, to prepare for the coming week, to plan or to spend time with each other, especially when family members live elsewhere.

## > TIPS

- Talk about the schedule for the week. The person with cancer may have treatment, while other family members have different activities. It can be useful to use a big calendar, posted on the fridge or somewhere obvious, to keep track of everyone’s activities.
- Arrange time to be together as a family.
- Prepare the family if you’re expecting a hard week.
- Make lists of jobs that need to be done and decide who can do them.
- Tell family members if anything about the person with cancer’s condition or treatment has changed, or find out if anyone has questions or needs more information.
- Talk about anything that affects family life, not just cancer.

If family members who want to be kept up to date don’t live nearby, they can still be included in meetings by phone, online chats or Skype. They can also be updated by e-mail after the meeting.

## Younger children

“ *My four-year-old had absolutely no questions. And my seven-year-old ended up having a ton of questions, but generally at nighttime. That’s when she would ask if I was going to die or what would happen to them if I died.* ~ Lydia\*

Younger children may find it hard to adjust to a family member having cancer, whether it’s a sibling, a parent or grandparent. It can be especially hard if their routines are interrupted or if the person with cancer looks and acts differently or is in the hospital.

“ *My little one would try and prepare something for me to eat. He would try and cook something, whatever I wanted. He was only 10.* ~ Lillian

You may feel guilty if you constantly ask children to be quiet, help around the house or stay with friends after school. Your children may behave badly or act out in different ways to get your attention – they may misbehave, act younger than they are, become clingy or insecure and refuse to leave your side.

> **TIPS** for helping younger children cope

- Have someone else (such as a friend or relative) look after your children when you're not feeling well or are busy caregiving. People are often happy to pick up children after school, drive them to lessons or appointments or arrange sleepover or play dates so that you can have a break and concentrate on feeling better.
- Try to find ways to let children participate in your day-to-day routines, or give them small jobs that make them feel helpful – they can bring in the mail or draw pictures to put up in your room. Being able to help makes them feel good about themselves.
- Do what you can to make sure that children's routines – school, after-school activities, bedtime and other rituals – stay the same, as much as possible. Tell children ahead of time if a routine may change and let them help plan changes whenever possible.
- Tell children if a family member will be in hospital or will need to rest at home. Or if you or your partner may not be able to do everything you normally do with your children, like go to their hockey games or walk the dog together.
- Tell your children's teachers, principals or guidance counsellors about the situation, and talk to them about any changes in your children's behaviour. They can be partners in helping your children cope with cancer.

## Teenagers

“ My youngest, she asked lots of questions. She's very curious, very open. She bluntly just said, 'Are you going to die?' The oldest is a little more reserved and quiet. She's the kind of child that needs to go away with it and think about it. ~ Brenda

Teenagers are at a time in their lives when they are trying to be independent from their family. When someone in the family has cancer, breaking away can be hard for teens to do. They may react in very different ways – getting angry, acting out, getting into trouble, withdrawing from you, taking on (but possibly resenting) more responsibility or offering help and assurances of love. Some may seem indifferent with no reaction at all. Like everyone else, teenagers may be worried that cancer treatments won't work. Like younger children, they can also feel abandoned as the family focuses on the person with cancer.

> **TIPS** for helping teenagers cope

- Encourage teens to keep doing the things they like to do. Teenagers need to keep as much of their normal routine as possible.
- Make sure your teenager gets a break from the situation at home, perhaps by spending time with friends or having a regular night out for movies or pizza.
- Try to get your teens to talk about their feelings. Answer their questions as honestly as you can. Ask for their opinions and, if possible, let them help you make decisions. Find out if there's a support program in your community for teens whose parents or relatives have cancer.
- Try to be patient if you can't understand or predict teenagers' behaviour or emotions.

## Adult children

Like teenagers, adult children of people with cancer are often in between two worlds – they are still your children, but they may also be parents and have the responsibilities of adulthood. Cancer may reverse your roles – your adult children, who were used to your taking care of them, may now have to take care of you. They may feel troubled by trying to cope with all of the responsibilities in their lives.

People with cancer and caregivers may find that their relationships with their adult children change with the diagnosis of cancer.

For example, you may:

- ask your adult children to take on duties like paying bills or taking care of your house
- ask your adult children to explain some of the information you've received from your doctor or to go with you to doctor's visits
- need your adult children to give you emotional support
- become closer to your adult children and find that your family is closer after the cancer diagnosis
- want your adult children to spend a lot of time with you – this can be hard, especially if they have jobs or families of their own
- find it hard to receive – rather than give – comfort and support from your children
- feel uncomfortable if your adult children help with your physical care, such as feeding or bathing

Even though they're grown up, your children may be scared of cancer and the possibility of losing a parent. They may feel guilty if they haven't been close to you or if they can't spend a lot of time with you because they live far away or have other duties. Some of these feelings may make it harder to talk to your adult children.

## > TIPS on talking to adult children

- Include your adult children when talking about your treatment and let them know your thoughts and wishes about your treatment and care. It's important to talk to them about cancer, even if they get upset or worry.
- Make the most of the time you have with your adult children. Talk about how much you mean to each other. Express all your feelings – not just love but also anxiety, sadness and anger. Don't worry about saying the wrong thing. It's better to share your feelings rather than hide them.
- Let your adult children know they can talk to a doctor about their risk of developing cancer if they're worried, and consider asking your doctor or healthcare team about risk factors for your children.

## Parents

“ *Part of me worries that my parents are heading to an age that I am supposed to be taking care of them, and here they are taking care of me. So I kind of hope that they won't miss out on the opportunity for me to really care for them.* ~ Lydia\*

It can be one of life's most painful experiences to be the parent of a sick child – even if that child is an adult. Although you may have been independent from your parents, the changes in your life throughout your cancer experience may mean you'll turn to your parents more often than you used to.

“ *I worried about my parents. My dad had found it extremely difficult, obviously, when his sister died of cancer, and I look an awful lot like my aunt, and I act a lot like her. I worried about him in terms of how he was going to be able to handle it. My mom, of course, is great. She was pretty matter of fact about the whole thing.* ~ Lydia\*

If your parents are in good health, and they live close by or can spend more time with you and your family, they might be able to support you. They can help you around the house, run errands, look after your children or go to appointments with you. Your biggest challenge may be working with your parents to make them understand how they can be helpful without making you feel helpless or like a child again.

If your parents' health is poor and you've been caring for them, you may need extra help while you're in treatment or caring for someone with cancer. There are no easy answers for planning what's best for your entire family in this situation. While you may feel sad or even guilty that you can't look after your parents as you have in the past or as you would like to, it's important to focus on your own health issues.

#### > TIPS

- Make the most of the time you have with your parents. Talk about how much you mean to each other. Express all your feelings – not just love but also anxiety, sadness and anger. Don't worry about saying the wrong thing. It's better to share your feelings rather than hide them. If you or your parents are having trouble communicating, a counsellor may help.
- Keep your parents informed about your situation. They may be feeling helpless or left out – being informed may help them cope.
- Give feedback to your parents if they try to help. Be as specific as you can about what is most helpful. Most parents want to help but aren't sure how.
- Respect the right of your parents to agree or disagree with decisions you're making at this time, but make it clear that they are your decisions to make.

Turn to other family members and friends for help with looking after your parents (if necessary). Community agencies may also be able to help.

## Partners/spouses

“ *My wife was uncomfortable, and sometimes physical contact became more difficult. We had to have patience because the recovery time was long, longer than anyone ever tells you, so we'd often become short with each other as a couple. But I think that the things that we did well were trying to keep talking about those feelings, and talking about where things were at, and what we were doing, and what our fears were. I definitely believe that communication is hard to maintain but is essential.* ~ Andrew\* (caregiver)

Cancer is a very stressful event that can strengthen a relationship or weaken it – or both. You and your partner may cope differently with cancer. For example:

- One of you may feel more hopeful, while the other is more pessimistic.
- One of you may want to find out all you can about the cancer, while the other feels better not knowing as much.
- One of you may want to choose more aggressive treatment than the other.
- One of you may be more comfortable talking about feelings and emotions, or asking for help, than the other.

“ *The night before the surgery, we went out for this great dinner and really had a good chance to talk and say, 'Listen, this is what I'm really afraid of' and for him to say, 'Yeah, I'm kind of afraid of that too.' I wanted to let him know that if things didn't go well, and if it looked like I was going to die that I would be okay with that because I had a really good life and he was really important in that.* ~ Lydia\*

If both partners can see their strengths and weaknesses, then you can work together better. For example, the person who likes to do research can take on that responsibility and feel useful, while the person who is better at talking about feelings and emotions can make sure that you both talk about what you need and feel.

## > TIPS

- As you deal with cancer, think about how you and your partner have coped with hard times in the past. What strategies worked for you then? What would you do differently? It can help to write down a list of things that you both do to make the relationship strong.
- If you're feeling stressed, it may help to give yourselves short breaks from each other. Caregivers may be so worried about their partners that they forget to look after themselves. The partner with cancer may need time to be alone and not feel like "the patient" while caregivers need to rest.
- Think about what you most need from the other person when times are hard. Then, ask for it.
- Keep communication open and honest. Don't assume or try to guess what your partner is thinking or feeling.
- Be sensitive to signs of a bad day or a bad mood. Keep difficult or emotional discussions for another day.
- Give yourselves some time away from cancer – a time or place where cancer is not the topic of conversation. Talk about and do other things together.
- Even though it isn't easy, both of you should think about the future and make plans for it. Planning for your care in advance – and writing it down – lets you decide for yourself how you want to be cared for in different situations and who will act for you, if necessary. Meet with a lawyer or financial planner, or both, to help you plan for the future.

## Sex and intimacy

“ I think for my husband and me, the intimacy part is slowly coming. And I don't think it's something that happens overnight. I think once my reconstructive surgery is complete and everything is there, it will be easier for him, and he's expressed that. I think if after everything is done and he is still having problems, then we'll go to counselling. ~ Brenda

A physical relationship is very important for some people, and they're sad when it stops or changes. If cancer and treatment are affecting your sex life, talking about it with your partner may help reduce your fears. Or, if you're not interested in sex at the moment, you can explain that it's because of fatigue or stress, not because you don't love or respect your partner. Knowing how the other person feels may help you both feel more secure.

“ I really have been amazed how little the physical changes have really mattered in the scheme of things and how lucky we are to be together. The ostomy bag is, I think sometimes, more of a challenge for her than for me. ~ Andrew\* (caregiver)

You and your partner may find that sex and intimacy change during treatment. Hugging, touching, holding and cuddling may become more important than sexual intercourse and other forms of sexual activity. Even quiet time alone together or holding hands can be healing for both of you. Together, you and your partner can decide what gives you both pleasure and comfort.

If talking to each other about sex is hard, a counsellor may be able to help you talk in a more open way. You can also let a member of your healthcare team know if you're having problems.

### For more information on sexuality

Our booklet *Sexuality and Cancer* has more information on dealing with sexual issues.

## New romantic partners

If you're single, you may feel differently about dating or starting new relationships.

Some people's thoughts about dating change for the better. They may feel that going through cancer treatment has made them stronger and wiser – they may feel that they now have more to offer in a relationship.

For others, dating becomes harder. They may worry about how a date will react or wonder if having had cancer makes it harder to find people to date. They may be uncomfortable or unhappy if their appearance or body has changed and find it difficult to feel attractive or sexual. Cancer may also have made them more uncertain about the future.

### > **TIPS** for dating

If you'd like to date but are finding it hard, it can help to:

- Remember that dating and new relationships often make people insecure – whether or not they've had cancer.
- Get involved in activities where you can meet new people. Join a club, volunteer or take a class.
- Try to meet new people and make new friends, without worrying too much about dating at first. That way, you can get comfortable in new social situations, with less pressure.
- Try not to let cancer be an excuse for not dating or trying to meet people.
- Consider talking with a counsellor or look for a support program where you can talk about dating with other cancer survivors.
- Remember that not every date has to be a success. If someone doesn't want to see you again, you have not failed. After all, not all dates worked out before you had cancer.

## When to tell someone new about your cancer experience

If you're in a new relationship, finding the right moment to tell the other person about your situation is not easy. Deciding when and how to tell someone new about your cancer experience can be very stressful. You may choose to:

- Tell someone right away and see how they react.
- Wait a while to get to know and trust someone a bit better before giving this personal information.
- Take each situation as it comes and do what feels right for you.
- Practise what you'll say and think about how you might respond to a negative reaction.

You'll know best when to tell someone new about your cancer experience. Pick a good time to talk about cancer with the person you're dating, when you can both focus on each other and not be distracted.

## Practical considerations



A cancer diagnosis often means you'll have to think about many practical details in your life. From living arrangements to work and financial issues, you may have to make many important decisions. While no one can predict exactly how cancer will affect day-to-day life, it's important to think about the possibility of change and how you might handle certain situations if they come up.

### Changes to where you live

To get the care they need, people with cancer sometimes need to make changes to where they live. The changes could be permanent or just for while you have treatment. For example, Lydia\* and her husband had to travel to a different city for surgery to remove a tumour in her colon. "We're incredibly lucky that friends of ours had an apartment walking distance from the hospital, which they lent to us," she says. "My husband stayed there while I was in the hospital for two weeks."

You may need to think about changing your living arrangements if:

- You live far away from where you will be treated.
- You live alone or your caregiver doesn't live with you or near you.
- You no longer feel comfortable or safe in your home.

If you need to change your living arrangements, temporarily or permanently, it can help to talk about your options with family and friends. They may have ideas or suggestions that can help you decide where to live. You can also talk to your healthcare team or a social worker, who may be able to help you find a temporary place to live during treatment, for example, a lodge near the hospital.

Moving can be difficult. If you need to move, or if you must travel far from home for treatment, it can help to take a few little things from home with you, like family photographs or your favourite pillow. This way, you will have something familiar even in a strange place.

### **Cancer on the road: Travel tips**

Whether you're travelling for cancer treatment or going on a much-needed vacation, here are some tips to help you be as prepared as possible when you're away.

#### ***Know the basics about your cancer***

Before you leave, make a list of basic medical information and keep it in a safe place. The list should include:

- the type and stage of cancer
- the types of treatment received, including chemotherapy, radiation and surgeries, as well as the date of last treatment
- the doctor's name and contact information, as well as the hospital
- the names of any medications, for both cancer and any other conditions
- notes about any other illnesses or health problems

#### ***Plan ahead***

- Make sure you take all medications with you, as well as your health card and any insurance information.
- Talk to your healthcare team about treatment facilities at your destination that could give care if needed.
- Take along contact information for members of your healthcare team so you can get in touch if you have questions.

#### ***Adjust your activity levels***

Travelling, whether it's a vacation or an emergency trip, can be tiring when you have cancer. You may need to slow your pace or break up a long drive. You can:

- Apply for a permit that allows you to park in designated accessible parking spaces for people with disabilities. Check with your provincial ministry of transportation.
- Ask for accommodations with elevators or rooms on the ground floor.
- Bring along a folding wheelchair or walker just in case.
- Watch for any signs of medical issues, such as fever, chills or shortness of breath.

#### ***Keep it clean***

Airports and popular tourist sites bring together lots of people, which can expose you to germs. To avoid catching colds or other diseases, you can:

- Wash your hands often with soap and water. Use hand sanitizer if soap and water aren't available.
- Stay away from uncooked or undercooked food.
- Avoid drinking water that may not be clean or treated.

### **Work or employment issues**

“ *With the initial diagnosis I took the rest of that day off, and the next day. I don't think I would have been any use at work at that time. We needed time just to step back and say, 'Okay, what does this mean?'* ~ Andrew\* (caregiver)

If you have cancer, it's very possible that your way of working will change. If you work outside the home, you may have to take time off or change your work schedule to allow for treatment and to rest and recover. If your job is running your household and taking care of your children or an elderly parent, you may also need to change the way you do this, perhaps by getting someone to help you.

#### ***Taking time away from work***

“ *I never stopped working. Two things about working – one, it was the money. I was the one providing for the house totally. The second was that work was my therapy. In those hours, I was not thinking about cancer and my husband dying. I was just focused on what I was doing. It helped me a lot not to give up my job.* ~ Sarife (caregiver)

Some people with cancer and their caregivers try to keep working around medical appointments, hospital admissions and caregiving. Others take time off work – because they choose to or because they have to. Some cancer treatments may mean taking only a few days off work, but some may require several weeks or months of recovery.

For some people, taking time away from work may feel like a relief. But it can also be stressful, particularly if you have to live on less money. Sometimes a household loses two incomes when both the person with cancer and the caregiver stop working. Many people enjoy their jobs, and it can be hard to stop going to work. Giving up work, even for a short time, may make some people feel as though they're giving in to the cancer. If you feel this way, try to think of

the time away from work as a chance to focus on your health – and the sooner you do that, the sooner you may be back at work.

If you need to take time off work for treatment or recovery, or to care for someone with cancer, talk to your employer, human resources manager, personnel officer, union or employee association. Even if you don't need to use sick days or take a leave of absence, you may find it helpful to know what your options are.

If you can't or don't want to take time away from work, talk to your friends and family. If they can help out with day-to-day tasks, it may allow you to keep working.

### **Returning to work**

“ I was off for three months. I was really glad to be back at work because I love my job and I was very bored at home. I took the advice of a colleague. She said, 'Open your door for periods of time during the day, and then keep it closed because it's going to be overwhelming. Too many people will come by [just to say hi].' And she was right. It was overwhelming to come back, but I was really happy to be back because it creates normalcy. It's order in my life. ~ Brenda

Many people with cancer and caregivers are happy when they can return to work. They enjoy having their routines again and the company and support of their co-workers. But even if you're looking forward to it, it's okay to be anxious about returning to work.

You will know best when you're well enough to go back to your job. When you're ready, talk to your doctor and your employer. If you can, give yourself time to make the return to work. You could start by working part-time hours and gradually move up to full-time. If you have a very hard job, you may need to change the way you work or try working part-time.

### **Discrimination is against the law**

Some people with cancer can face problems when they try to go back to work or get a new job after treatment. Some employers may not want to hire someone who's had cancer. It's against the law to discriminate against someone who has cancer or any physical disability.

If you feel that you've been discriminated against, you can contact the Canadian Human Rights Commission in your province or territory by calling 1 888 214-1090 or visiting their website at [www.chrc-ccdp.ca](http://www.chrc-ccdp.ca).

### **Financial issues**

Cancer can affect your finances. You may have to spend more money on things like help around the house, transportation, child care or drugs or therapies that aren't covered by your provincial or private health insurance plans. You may need unpaid time away from work, which can affect your income. These extra expenses and loss of income can be stressful and make you worry about how you'll manage financially. If you're a caregiver, you may feel guilty for thinking about these issues while the person with cancer isn't feeling well.

If you're concerned about money, a good first step is to understand more about health insurance. If you have private disability insurance or insurance through your employer, learn the terms and conditions of your coverage. Find out what your insurance will pay for and what you'll need to pay for. Ask about the terms and conditions of coverage – and how to access your coverage. For example, many policies have a waiting period before disability coverage starts.

If your income is affected, talk to the following professionals:

- Account managers at your bank, personal financial planners or advisors can help you budget your money and help you decide whether you should access the equity in your home, RRSPs or other investments.

- Social workers can help you find out more about financial assistance programs in your province or government benefits that you are entitled to. (Most hospitals and treatment centres have a social worker on staff.)

Don't forget about friends and relatives. You may already know a bookkeeper, credit officer or accountant who would be happy to help you with money matters.

## Advanced planning

A cancer experience often pushes people to put their affairs in order. It's a good idea for all adults – whether or not they have cancer – to do things like:

- Have an up-to-date will.
- Decide on guardians for minor children.
- Choose someone to look after your pets.
- Decide how you'd like to be cared for if you become seriously ill and can't make decisions for yourself.
- Give someone you trust power of attorney in case you can't make decisions for yourself.
- Decide how you would like your life to be acknowledged after your death.

Deciding on these important matters – and writing decisions down – doesn't mean you'll die of cancer and it doesn't mean you're giving up. Organizing these matters allows you to live each day to the fullest and think about the future.

## Why it's important to have a will

You may want to change an existing will or create a new one. A will gives legal instructions about how people want their money, property and other assets to be handled when they die. It can also include information about who might look after a person's children (under age 18) after death. You may also want to include who you want to look after your pets. When writing a will, get advice from a lawyer to make sure that the document is legal.

When you have a will, you can make sure that your property or possessions go to the people or charities of your choice. If you don't have a will, your property and finances are decided according to federal and provincial laws and your possessions may not be divided up as you might have chosen. Without a will, it can often take much longer to sort out your affairs after you die, which may put a financial strain on your family. Having a will makes it easier on your family.

It may feel painful or strange to think about making your will. But once it's done, you may also feel relieved to have taken care of an important task. You may feel pleased that you're helping protect your family's future or satisfied that your gift to your favourite charity will help others. Once you have a will, you can always update or change it by talking to your lawyer.

Making a will doesn't have to be hard or expensive. A lawyer experienced in wills can make sure that your will is done properly and that your wishes will be carried out exactly as you want. A lawyer can also help you plan for your care in advance through a power of attorney and other directives.

If you don't have a lawyer, you can ask friends or relatives to suggest one, look in the phone book, search online or contact your province's or territory's law society or bar association.

## Thinking about the future



“ I think much more about the fragility of life. As we get back to the normalcy of regular routines, it’s always just there, still. And so I think about trying not to put off some of those things that are really important to us. You know, when should we go on that trip? Instead of saying, ‘Let’s do it 10 years from now,’ well, ‘let’s try and do it sooner’. ~ Andrew\* (caregiver)

Throughout your cancer experience, you may find yourself thinking more and more about what life holds for you after treatment is finished.

### The end of treatment

“ If I didn’t get sick with cancer, I wonder if I would have gotten well mentally and physically and spiritually. What would it have taken for me to find where I’m at today? ~ Lillian

When treatment ends, you may feel very positive – glad that treatment is over, excited about your future and ready to move forward. Everyone around you probably expects you to be pleased. But you may not feel this way. Some people have mixed feelings about the end of treatment – and you might be surprised to find that you’re still emotional about the experience. Many people find the time after treatment to be a time of transition and adjustment – and harder than they expected.

If your emotions keep changing, you’re not alone. During treatment, people with cancer and their caregivers are often so focused on the medical issues that they don’t experience the full emotional impact of having cancer until it’s over. The end of treatment also means fewer meetings with the healthcare team – this transition can leave some people feeling anxious or alone. They may worry that cancer will return. Give yourself time to adjust to these changes and to think about what you’ve been through and what you learned about yourself.

Caregivers may need time to really think about their own emotions and needs. The support of others who've gone through similar cancer experiences can be very helpful at this time. Your healthcare team is also there to help you, even after treatment is over. You may want to consider a support group for post-treatment cancer survivors and their caregivers.

As you go through and finish treatment, it can help to think about what you want to do when you feel well again. Some people find it fun to do something to celebrate at the end of treatment, like take a vacation or learn a new skill, such as gourmet cooking or ballroom dancing. Other people don't mark the end of treatment in any way – they prefer to get back to their usual routines as best they can. It's important to do whatever feels right to you.

Some people find it helpful to set goals – this gives them something to think about and work towards. If your goal is to travel at the end of treatment, you may want to spend your treatment time researching the places you want to visit or learning a new language. You may even find yourself thinking about a career change or going back to school. Goals can also be related to your health. At the end of treatment, some people make the effort to exercise regularly, eat healthy or quit smoking.

## Late or long-term side effects

“ *With the ostomy, things can be tricky. I have to plan ahead more for different activities. I have to watch what I eat. I have to chew more carefully. I have to adapt to the unpredictability of body sounds and of what it means to live with part of my internal organs on the outside of my body. I would definitely say it's a sense of vulnerability.* ~ Lydia\*

After cancer treatment is over, you may find you still have to deal with side effects from treatment. Some problems disappear quickly. Long-term side effects may take weeks, months or even

years to go away. And other side effects may be permanent. Late side effects are problems that appear a long time after treatment is over. Side effects can be physical, mental or emotional.

“ *My husband's personality changed with the brain tumour. He forgets people's names. Now he talks a lot, with anyone. And he gets upset very easily. We can be at a party and he will get upset at something that someone says to the point where he ruins his whole night, and therefore mine. Last week, I told him that we need to have a code so that when he gets upset, I can tell him and he will stop. It was a very sad moment. We cried together. He said, 'I wasn't like this before.' I told him, 'I know. We have to work at it together.'*  
~ Sarife (caregiver)

Late and long-term effects are different depending on the type and stage of cancer, as well as the type of treatment you had. Everyone is different – someone who had the same type of cancer treatment as you may have a completely different experience. But any change in how your body looks, feels or works can be very hard to deal with.

If you're having trouble coping with or adjusting to late or long-term side effects, it's important to get help. Your healthcare team can help with many of the physical problems. Talking to friends and family, a counsellor or others who've gone through similar experiences can be very helpful.

### For more information on late or long-term side effects

Our booklet *Life after Cancer: A guide for cancer survivors* provides information and support for people who have finished cancer treatment.

## What if cancer comes back?

“ *Every time my wife has a test, every time she has blood work, every time she sees the doctor, the thought can't help but cross through your mind – is it back? It becomes easier over time to dispel those thoughts and those fears and say, 'No, that's not the story.' And it just continues to get easier.*  
~ Andrew\* (caregiver)

It's normal to wonder if cancer will return and to think about how you'll react and cope if it does. Worrying that the cancer will come back is one of the most common fears people have after treatment. Living with this anxiety can be very challenging.

“ *There's always that fear, and to be totally honest, that hasn't completely gone away. And I don't know if it ever will.* ~ Lydia\*

As time goes by, many people find that their fear of cancer coming back becomes less, and they find themselves thinking about cancer less often. Certain events, however, may bring the worries back. These include:

- follow-up medical visits
- critical dates, such as the date of diagnosis or surgery
- illness of a family member
- symptoms similar to the ones that led to a cancer diagnosis
- the death of someone who had cancer
- personal reminders, such as going to a restaurant that you used to go to during treatment

“ *It's always there in the back of my mind, the anxiety. Waiting for an MRI last week, I was still angry that I have to do all of this stuff. I just wish the whole cancer machine would just leave me alone. It's infringing on my life and it still scares me.* ~ Lydia\*

If you're worried and anxious all the time, or if your anxiety is interfering with your daily activities, you may want to talk about your feelings with a counsellor or another member of your healthcare team. It's important to get your worries under control so that you can focus on living, take care of your health and make the most of each day.

## End-of-life care

“ *We have always known that the cancer is terminal. I know that it could be now one year. It could be two, three, four, five, who knows? I try to just enjoy the moment and plan a little bit of the future, just a little bit. Two months ago, we saw a really good deal to Portugal, where my husband was born. We talked about it, and we bought the tickets for October. For me, that was like the big plan for the future.*  
~ Sarife (caregiver)

Sometimes, people diagnosed with cancer don't get better. Finding out that cancer cannot be cured is very upsetting. It can cause many of the same reactions and fears that come when you first learned of the cancer diagnosis.

“ *I don't want to think too much. If I start thinking and analyzing too much, then I start hurting, and then I feel bad. There are times that I am like, 'Oh God, am I going to make it?'*  
~ Sarife (caregiver)

People may live for months or even years with incurable cancer. During this time, they can be helped by palliative care. This is a special type of care that provides physical, emotional, social and spiritual care for people with cancer and their families. The focus of care is on making the person as comfortable as possible, helping to relieve symptoms, focusing on their quality of life and providing support during this time, which may be months or even years.

## For more information on end-of-life care

Our booklet *Living with Advanced Cancer* provides information and support for people with advanced cancer that is unlikely to be cured, and for their caregivers.

## The new “normal”

“ I keep waiting for it to end. It doesn't feel like it's over. And that's the part that I find really tricky. But I'm also trying to make an active decision of not letting it bother me and focus very much on the here and now. And hope for the best and plan for the worst. ~ Lydia\*

What is “normal” after cancer treatment? Just as everyone's cancer experience is unique, life after treatment is unique as well.

For some people, depending on whether they feel their cancer experience has changed them, normal may mean going back to exactly how their life used to be. The best thing about treatment ending will be getting back to their usual routines and ways of doing things.

For others, life has definitely changed. There may be new physical or practical issues that are a permanent part of life – perhaps new health routines or financial situations to deal with on an ongoing basis. Values and priorities may have changed – material things may be less important than spending more time with family or friends, doing volunteer work or enjoying hobbies or sports. If you feel that your cancer experience has changed you, you won't be going back to the way things were. You'll be figuring out what your new “normal” will be.

You may find that you're somewhere in between – in some areas of life, your new normal is very different from your old, and in other areas, things go back to exactly as they used to be. One way isn't better than the other – the most important thing is figuring out what works for you.

“ You have to prioritize your life. There's friends, family, your relationship, there's the intimacy part of your relationships. Because for the most part, you're in the fight of your life. You've got to be focused on the main issue, which initially is survival. Once you know you've got that beaten, or at least closer to where you want to have it, you have to then be able to pull in the other things that need attention. But you need preparation prior to that. You need to know what is going to happen before it happens. ~ Dan

There's no right or wrong way to live with cancer, and no right or wrong way to feel about the disease and its impact on your life. You are the expert on your own life, and you're the person who will recognize the best coping strategies for you. Some days, you may feel that you can deal with anything that comes up. During harder times, it can help to remember that you don't have to go through this alone – you have your healthcare team, community and your friends and family who can all give you support during this journey.

“ I think I have a responsibility to figure out what having cancer has meant for me. I have learned that I need to be gentler with myself. I think I've matured a bit in understanding that I am a person with a vulnerable condition, and I might need to spend a bit more time paying attention to it. But it's not going to define who I am or how I see the world. ~ Lydia\*



### Canadian Cancer Society

The Canadian Cancer Society fights cancer by doing everything we can to prevent cancer, save lives and support people living with cancer.

All of our services are free and confidential.

#### *Helping you cope while living with cancer*

Our trained information specialists take the time you need to answer your questions over the telephone and by e-mail. If you need information in a language other than English, interpreters are available. We have information you need about:

- symptom management
- nutrition
- emotional support
- complementary therapies

Through our Community Services Locator, we can help you find services and programs in your community that are offered by the Canadian Cancer Society and other organizations.

We offer resources on a wide range of cancer-related topics in print and online. You may find these publications useful:

*Pain Relief: A guide for people with cancer*

*Complementary Therapies: A guide for people with cancer*

*Life after Cancer: A guide for cancer survivors*

*Living with Advanced Cancer*

*Sexuality and Cancer*

Note: These titles may change when new versions of the booklets are published.



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## We'd like to hear from you

E-mail us at [publicationsfeedback@cancer.ca](mailto:publicationsfeedback@cancer.ca) if you have comments or suggestions to help us make this booklet more useful for you and other readers.

## What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer, our services or to make a donation.



Canadian Cancer Society  
Société canadienne  
du cancer

Let's Make Cancer History

1 888 939-3333 | [cancer.ca](http://cancer.ca)

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