

Coping When You Have Cancer



The Canadian Cancer Society would like to thank the people who shared their personal stories with us. To protect their privacy, and with their permission, we have changed their names unless asked not to.
We would also like to thank Rosana Faria who shared her professional experience working with cancer patients. Rosana is a clinical psychologist at St Mary's Hospital Center, McGill University Teaching Hospital, CIUSSS West Island Montreal.

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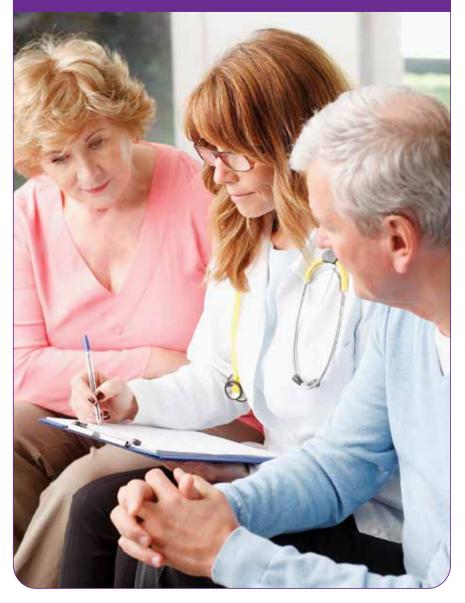
Introduction

When you have cancer, the focus is often on the physical side of your illness – on symptoms, treatment choices, side effects and what the test results show. But your emotional health – your feelings and how you cope with them over time – is also important. It deserves as much care as your physical health.

There really is no right or wrong way to feel when you have cancer. Everyone will react to their diagnosis in their own way. This booklet will give you ideas on what you can do to get through the hard times, to keep your relationships strong and to feel like you have some control while you face the challenges of cancer.

The booklet is for people who are newly diagnosed or in active treatment for cancer. Throughout it, you'll hear from Canadians who have been where you are now and from a psychologist who helps people just like you. They speak honestly about their experiences with cancer and share the wisdom they have gained along the way.

Coping when you are first diagnosed



Everyone reacts in their own way when first diagnosed. For many people, the days and weeks right after a diagnosis are very stressful. Sometimes they're overwhelming.



You're thinking about everything but you can't concentrate on anything. You're just trying to find a way to deal with it and you don't know what to expect. My emotions and thoughts were all over the place. My mind was racing: What's going to happen, do I start planning for the worst? – David

There is a lot to learn and many decisions to make at first. It's easy to feel like you can't cope. You might feel like you have to act as quickly as possible, like it's an emergency. In other ways, time might seem to stand still. You may find it hard to believe what the doctor tells you, and it may take you some time to adjust to the news. Many people wonder why this is happening to them, or they wonder what they could have done in the past so that they wouldn't have cancer now.

Waiting for treatment to start

Every cancer is unique, so everyone's treatment plan will be different. Before your doctors can get you the treatments you need, in the order you need them, they need to find out as much as they can about the cancer. That means you'll have tests and have to wait for the results.

Most people with cancer find that this time right after diagnosis and before starting treatment is very hard. Some even say it was the worst period they went through.

Mei-Ying was diagnosed with cancer at the age of 45. The weeks after were extremely stressful. Learning she had cancer was hard enough, but this was followed by many tests before doctors figured out that she had metastatic breast cancer. This means that the cancer that started in her breast had already spread to another organ. Then she had to wait 6 weeks before starting

chemotherapy. "Those were the longest 6 weeks of my life," Mei-Ying recalls. "I felt powerless. It was probably my lowest point psychologically." For the first time in her life, she couldn't sleep at night. In the darkness, her thoughts would race. "I would be lying in bed and I absolutely had the impression that I could feel the cancer cells growing inside me. It became extremely difficult for me to calm my thoughts."

If you're struggling with waiting, it may help to find out more about how the test results will be used to plan your treatment. Your doctor can also reassure you that the time spent on having tests, making a plan and scheduling your treatment should not affect how well the treatment works.

What you can do

Getting involved in your own care can help you manage your fears and get back some control. There are several ways you can do this as you prepare for and go through treatment.

Get organized

In the early days after your diagnosis, there will be a lot that you don't know about the future. What you probably do know is that you suddenly have a lot of appointments, tests and paperwork to deal with. Make this as easy to manage as possible. You can:

- Start a filing system for medical records and test results. Some hospitals give out binders you can use, or you can create your system using folders or an accordion file.
- Use a diary, an online or paper calendar or an app to track appointments, tests, symptoms and side effects.
- Ask someone you trust to help you maintain your schedule and review it with you regularly.

Get to know your healthcare team



The doctors were good at explaining what my treatment would be. They explained everything in detail and what would happen day to day. They kept me informed of the progress of my treatment. It was an amazing team of healthcare providers. – David

Treating cancer is about teamwork – the team is you and the many healthcare professionals who are focused on your physical and emotional health. Team members may include your family doctor, oncologists, surgeons, nurses, social workers, psychologists and many others. As they become part of your team, take some time to get to know them, understand their roles and find out how they might be able to help you.



Cast your net as wide as possible – get access to as many people and resources as you can, use them all at first and then when you see what doesn't work for you, get rid of it. – Mei-Ying

Knowing who does what on your team can help you know where to direct your questions. Or you may find it easier to ask if there can be one person on the team as your main contact for answering questions and sharing information.

Don't forget that **you** are the most important person on this team. Help your team get to know you, for example, by telling them about your cultural customs, preferences and beliefs. Make sure you understand your own responsibilities. For example, you can:

- Show up on time for appointments.
- Complete blood work and other tests.
- · Report symptoms and side effects.

It's OK to speak up

Many of us think that Canada's healthcare system does a good job of looking after Canadians. Even so, you can and should say something if you're not sure that you're getting the care you need. Speaking up for what you think you need or asking someone else to speak up for you is often called advocating. You may not know exactly what you need, but your healthcare team cannot help you if you stay silent.

Advocating for yourself may mean asking for a second opinion from another doctor. You can do this even if you've already started treatment. Final decisions about treatment are yours to make, with information provided by the healthcare team.

"If you feel the system is letting you down, you need to be vocal. You need to speak up, you need to ask for somebody else or for more help." – Mei-Ying

Gather information

Information about cancer is everywhere. It's easy to feel overwhelmed or confused. Friends and family who mean well can weigh in with opinions. When you're struggling with a diagnosis, it can feel like there are too many voices. But there are ways you can try to make things easier.

Decide how much information you want. When Eleanor was diagnosed with colon cancer at 81, she chose to rely on her doctor's advice and not do any of her own research. "I didn't have a lot of questions," she recalls. When Sylvain was diagnosed with melanoma at 27, he wanted as much information as possible. It helped him feel in better control and reduced his stress. It's up to you to decide how much information you want to have about your illness and treatment.

Rely on your healthcare team. It can be hard to know what information is accurate or reliable. Your healthcare team is your best place to start. Ask them where you can find good information about the type of cancer you have and about your treatment plan. Then ask them questions about what you read. Your healthcare team is the bridge between general information about cancer and your personal situation.

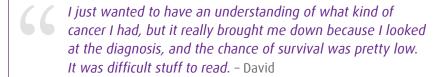
Make a list of questions to ask at your appointments. If you don't understand an answer, ask the doctor to use simpler words and explain things again. To be sure you have it right, you can repeat back what the doctor has told you.

Help with asking questions

Our booklet Questions to Ask When You Have Cancer can help you keep track of important information. It also suggests questions you can ask your team.

Keep a record of what is said at appointments. Take notes or ask if you can record answers so that you can review them again later. You can also ask if it's OK to contact team members between appointments with any follow-up questions.

Be careful of online sources of medical information. The Internet and social media offer an endless supply of information and stories about cancer. Some of it is accurate and reliable, but a lot of it isn't. And even if what you find is accurate, it doesn't mean that the information will be relevant to your personal situation.



If you do search the Internet, go to websites by nationally known cancer centres, medical schools, government agencies or non-profits. While you will find general information on these sites, you may find that it helps you talk to your doctor about your treatment.

When I come home from an appointment I read up on the Internet but I always validate with the doctor. When they ask if I want to try a treatment protocol, I say 'OK, give me one week.' I come home, I look on the Internet, I get involved and informed. Then I go back to the team and say 'I read this and that – Is it good? Is it correct? What do you think?' It helps me feel like I'm part of the solution by doing that. – Sylvain

The Canadian Cancer Society as a source for information

The Canadian Cancer Society offers you information in print, online at cancer.ca and by phone at 1-888-939-3333. Our information is updated regularly and it's reviewed by Canadian experts before we share it with you.

The information we offer can help you, but it is never meant to replace your relationship with your doctor or another expert on your team. Only your doctor can tell you whether it's right for your situation.

Be patient with yourself



Give yourself time to adjust to everything that is happening. Learn about the treatment, how you react to it and how you can cope. Be patient with yourself. Everything that's new takes time. – Rosana Faria, psychologist

When your world is turned upside down, it's human nature to want to fix it – and fix it fast. That's how Mei-Ying reacted: "I'm a person who likes to get things done. So to find myself in a situation where I had to wait was very difficult for me. The system is overwhelmed. Tests take such a long time before you can get the results and then the results need to be interpreted. It was very, very difficult for me to be patient."

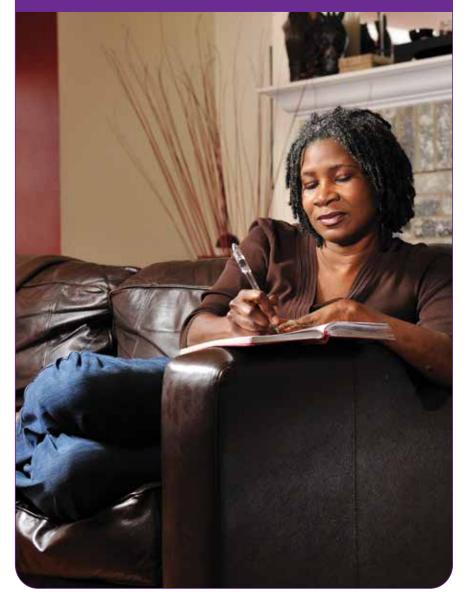
Mei-Ying remembers pacing in hospital waiting rooms before appointments. She remembers urging her oncologist to start chemo immediately. Now, she looks back and sees how unhelpful that was. If she could go back in time, she would tell herself: The pacing isn't going to do you any good. The answers will come in due time and in order to get the right answers you need to let people do their work.

Try to focus your energy on taking care of yourself. What each person needs might be different and it may take some time to figure out. Rosana Faria, a psychologist at a large hospital-based cancer care program in Montreal, says that sometimes people realize, "I was not thinking much about myself. It was all other

priorities, never myself." Rosana encourages people to think of this as a time for self-care, a time to tell themselves, "Yes, I'm allowed to think about myself and I'm going to take this as my time."

Give yourself time and be patient as you adjust. Rosana explains: "Our lives are like a puzzle, and we put its many pieces together over time. With a cancer diagnosis, it's like someone has come along and put all the puzzle pieces out of place – your profession, your family, your relationships, how you relate to yourself. And it takes time to start to put the pieces together again."

Coping with emotions



Going through many emotions is a normal part of having cancer. Strong feelings of all kinds may come and go, or feelings may be constant. For some people, it's like being on an emotional roller coaster. Everyone reacts to a cancer diagnosis in their own way.

People cope with strong emotions in different ways. But you don't have to suffer alone. Ask for help from others. Help yourself by trying different coping strategies to see what works for you.



We are human beings and we feel things. If you feel sad or worried, you have the right to feel that way. It's a big change in your life. - Rosana Faria, psychologist

Shock

Shock is often the first reaction to a diagnosis. It can make you feel confused and numb, unable to know what to think or feel. Shock can make it very hard for you to take in information or complete simple tasks. You may even forget where you are or feel like time has stopped.



The doctor showed us a picture of the tumour. I don't remember seeing the picture. It was shock. It was something I couldn't believe. Healthy all my life and all of a sudden I have cancer - Fleanor

Denial

It can take time to accept that you have cancer, especially if you don't feel sick. Denial is the mind's way of coping with painful facts. No one chooses to be in denial. Often, it fades with time.



The first thing that went through my mind was I was convinced that they were looking at the wrong file and that this could not be me. I was 45 years old and had never had any major health issues in my life. I didn't look like what I thought somebody with cancer looked like, so I assumed that there was an error somewhere. - Mei-Ying

Fear and uncertainty

A cancer diagnosis is scary. It's normal to worry about being in pain or dying. You may feel at times as if your life is out of control and you don't know what the future holds. This is especially true soon after diagnosis, but these feelings can come and go at times during your treatment. For many people, fear and uncertainty fade as they learn more about cancer and what to expect from treatment. You may also feel more in control once you are into a treatment routine.

Anger

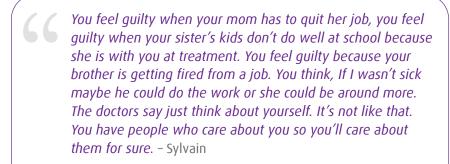
Anger is a common response to something that feels very unfair. You may feel anger toward the cancer itself, healthcare professionals, or friends and family who are healthy or who don't understand what you're going through. You may also feel angry with your god or even yourself.

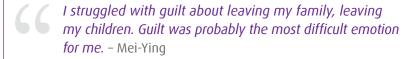
Sometimes people get angry instead of expressing other emotions like fear or sadness. Lots of us grow up with the idea that it's not OK to express our anger. But anger is a normal response to cancer. You don't have to pretend that everything is fine if it's not. You might want to reassure friends and family that if you seem angry or moody sometimes, it's not because of them.

Guilt

People sometimes blame themselves for their cancer. You may wonder if you could have done something to prevent it or to discover it sooner. You may also feel guilty about how your illness is affecting your loved ones.

Sylvain and Mei-Ying are at very different stages of life, but both describe strong feelings of guilt. Sylvain was living with his parents when he was diagnosed at 27. He felt guilty about the toll on his family. Mei-Ying was married with children when she was diagnosed with metastatic breast cancer. She was uncertain if she would survive.

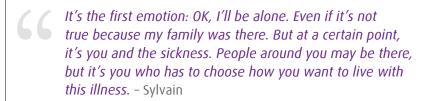




Guilt is sometimes described as a useless emotion. This may be true, but it's an emotion many people feel. It's real, even if it's not helping you. It's also true that cancer is not your fault. No one deserves to be sick.

Loneliness

Cancer can make you feel very alone. Friends and family may not phone or visit as often as you'd like. You may feel too sick to work or enjoy social activities. Even when you're with people, you may feel that no one understands what you're going through.



Sadness

Many people feel sad after a cancer diagnosis or while being treated for cancer. Maybe you feel sad about the loss of your good health or unhappy because you can't spend time with your family as you used to. Some people feel sad because they have to give up something they enjoy, like travel or playing a certain sport, for a while. It's normal to feel sad or to be tearful, frustrated or discouraged when dealing with stressful or upsetting events.

Depression

Many people feel unhappy, tearful, hopeless or discouraged at times when they have cancer. These feelings are normal. But if they don't go away or last a long time, get worse or get in the way of day-to-day life, they could be a sign of depression. This is also called clinical depression. Other signs of depression are:

- · changes in appetite, weight or sleep
- · feeling worthless or guilty
- · finding it hard to think clearly
- · thinking regularly about death or suicide

Depression can and should be treated. It is not a sign of weakness. A person who is depressed can't "snap out of it" or "cheer up" through willpower alone.

Talk to someone on your healthcare team if you think you may be depressed. They may refer you to a specialist such as a psychologist or psychiatrist for medicine or therapy.

Anxiety

It's normal to feel anxious when you have cancer. It's a stressful time and there are many things that can make you feel very worried. For example, you may feel anxious about test results or about how your illness is affecting your job, family or finances.

Many people find it hard to cope with strong feelings of anxiety. Anxiety can be diagnosed as a medical condition that needs treatment. It may be that you can't concentrate, are irritable and easily distracted, sleep badly and get tired easily. Some people notice physical changes such as being out of breath, feeling dizzy or sweaty or having chest pain.

Your healthcare team may be able to help by teaching you ways to cope, suggesting a stress management class or referring you to a counsellor or support program. Sometimes, anxiety is treated with medicine.

Depression and anxiety – finding it hard to live in the present

As a clinical psychologist who works with cancer patients, Rosana Faria has helped many people cope with depression and anxiety. "What I usually say to patients when they go through strong emotions is that the problem is not the emotions themselves. The problem is when the emotions freeze you, when you cannot function because you can't deal with what's happening to you."

Rosana emphasizes that when you start to feel like you can't function, it's time to discuss your feelings with a healthcare professional. They can help you develop strategies to move forward.

Both depression and anxiety can be overwhelming, but there are important differences.

"Depression, in general, has a lot to do with the past, which we all see in our own way," she explains. "People feel they are being punished, they feel regret, they blame themselves for what happened. Looking to what happened in the past provokes a sense of discouragement. They lose energy and motivation. They are completely frozen in their idea of their past."

Anxiety has more to do with the future. "People feel really concerned, they feel they've lost control, they are frightened. Everything is about the future. In both situations – either depression or anxiety – the person is losing the present moment. And this can be because the present moment is too hard to deal with. They can't stay there."

Getting help

People's emotions vary, and so does the path to getting help. What works for you may not work for someone else. And over time your needs may change. The key thing to remember is that help is available when you need it.

Your healthcare team

If you need support coping with emotions, ask your healthcare team where to start. They can refer you to services and specialists near you. If asking for help makes you feel uncomfortable, remember that emotional supports are an important part of your healthcare. Treating cancer is about treating more than just the body.



There were so many services that were offered as well. A psychologist and a counselling service were available and a whole bunch of other things. I was always asked by the doctors, 'How are you feeling this week?' and 'Do you need this or that?' I didn't make use of the services but they were there if I needed them. – David

Some psychologists, psychiatrists and social workers specialize in the mental health of people living with cancer. They are trained to listen, identify problems and explore ways to help you feel better. Some nurses, family doctors and spiritual care workers at treatment centres also provide counselling. They may offer one-on-one or group therapy. Some also do counselling by phone or online.

There are many different approaches to counselling. Don't worry if you aren't clear on what you want help with – the counsellor will understand. A healthcare professional that is trained to offer support can help you see things that you might not be able to see for yourself.

Oncology social workers

Oncology social workers are licensed professionals who can provide counselling and emotional support. They can refer you to other services like support groups and community programs. And they can help with practical issues like arranging financial support, home care and transportation, and completing paperwork. Most cancer centres have oncology social workers on staff. You can ask to see one.

Support groups

Support groups are a way to meet people who understand what you are going through because they have had a similar experience. In a group setting you can give and receive support. People often say they help you feel less alone. Support groups can also be good sources of information on coping as people share tips and resources.

Support groups can be in person, by phone or online through closed, moderated chat rooms or discussion groups. The structure and approach of groups can vary widely so it's important to find one that feels like a good fit. Try talking to the group leader to see if a group will match your needs.

One-on-one support

If you don't feel comfortable in groups or prefer something less structured, you may want to connect with people you know who have or had cancer for one-on-one support. Even people you've just met or have not known very well can support and encourage you based on your shared experience. If you do not know someone who has had cancer, a friend or family member may be able to connect you to someone they know.



Since my recovery, there are 2 other individuals in the community that went through the same type of cancer. I was talking to them every second or third day, telling them what to expect. I try to pass that on from my own experiences. I told them the good things and also the bad things. – David

Social networking

Many people turn to online communities for support and information on coping. These include private Facebook groups and online message boards for people with cancer. They provide a place to share your experiences and build relationships without leaving your home.



The wisdom and comfort I have found from various online communities has meant so much to me. Knowing there are other people who have the same diagnosis, the same treatments and even the same fears has helped me feel less alone. It also provides me with a group of people with whom I can openly discuss things that my non-cancer friends and family can't truly relate to, try as they may. – Mei-Ying

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with someone online?

If you'd like to join our online community, visit **CancerConnection.ca**. You can read news, join discussion groups that may interest you, get support and help others at the same time. You'll find caring, supportive people there.

Positive thinking



There were days during my treatment that were rough on me, and even days that I just wanted to give up a little bit. But I always found something within me to keep positive. We all have rough days, but you have to be able to pick yourself up. – David

People with cancer sometimes talk about positive thinking. Or you may have people in your life who encourage you to think this way. Some people find it helpful, but others find it an added pressure. It's impossible to be positive all the time. And trying to always be positive can drain your energy. It can also stop you from talking about fears and feelings that are real and that deserve to be talked about.

"Sometimes when something very bad happens in life, you cannot just keep positive," says Rosana Faria. "Some people can feel very bad because they cannot be positive. It's not always controllable. The nature of our minds is to have thoughts and they are not always positive. You need to allow those thoughts to come the way they are."

Rosana encourages people to focus on their attitude rather than trying to force positive thoughts. She explains that attitude is about how you are going to deal with the situation in front of you or how you are going to deal with the thoughts that you have. It's about making things better by focusing on what you can control. For example, maybe you are upset that friends aren't calling you while you're having treatment. Rosana says this is quite common. "But it may be that friends don't know what to do or say. So you can ask them what's happening in their lives, you can give them a sign that it's OK to not talk only about your disease." By focusing on what you can do to try to change what is happening, you can improve your situation.

Biting into life – Mei-Ying's story

Mei-Ying had a busy career and 3 children when she was diagnosed with breast cancer that had already spread throughout her body. At 45, she had always exercised and eaten healthily and had an endless supply of energy. So the diagnosis was a shock, and at first she struggled to accept it. "The hardest part for me was when I began to see parts of my life slip away and I began to feel like I had no control. I think the hardest thing to lose was my career." Mei-Ying was a human resources manager at a research institute, a position she'd worked for years to achieve. "I felt like the carpet had been pulled out from under my feet."

Over 5 years of multiple rounds of chemotherapy and radiation, Mei-Ying found her own ways of coping.

She told herself she would do whatever she could to keep the cancer from taking over her life. "I was always a person who enjoyed life. So my way of fighting back was just by biting into life and enjoying every second I could. I tried to make sure that the parts of my life that I enjoyed most, or that allowed me to feel normal, were not affected. Silly things like when I was going for chemo, I made sure I did my makeup and chose a nice outfit as if I was going downtown for a good day."

Mei-Ying made sure to walk in smiling, even if she didn't feel well. "I became very attached to some of the nurses. Because I was going over and saying hi, they would always make a point of giving me a hug." She also spoiled herself with little things. "There was a coffee shop nearby that made a great coffee and Danish. My husband would go there and buy them for me. So I could say, 'Today's chemo day – I'm going to have that cheese Danish that I love."

At home with her husband and children, Mei-Ying tried to keep life as normal as possible. "I identified what I needed to do to make myself feel as though my life was not being turned upside down. I would really squeeze every second of joy and energy out of the days that I was feeling well. We would do things outside as much as possible, even if it was just things where they could run around and I was quiet. Even things like a Saturday night popcorn-and-movie night, we made sure it was a big thing."

Exercise was a great stress reliever. She swam and cycled when she could and took short walks to get out of the house when that was all she could manage.

And always, she made sure to find joy wherever she could. "About a week after a chemo treatment we went to the Dominican Republic and ziplined through the rain forest." Her doctor had told her she could give it a try if she felt up to it. And she did. "My middle son, who was 18 or 19 at the time, said, 'Mummy, I'm so proud of you. I can't believe you're doing this." She laughs now, remembering.

Relieving stress

Most people who live with cancer will experience some stress. How you coped with it in the past may not work now. But there are many things you can do to relieve stress and cope better. It is worth taking some time to figure out what works for you. Lowering your stress levels can help your mood and give you emotional strength to get through the tough times.

Some of the ideas below involve going out into the community. Other approaches are quiet, calming activities you can do at home. Even just a few minutes at a time can help.

Mind-body practices



When I feel tired, I do 20 minutes a day of meditation. I close out everything in my house. I breathe. After 20 minutes, I feel the energy coming back and after that, I'm good for the day. – Sylvain

There are several types of mind-body practices that can help calm your mind, restore your body and reduce stress, anxiety and fatigue. Many hospitals and cancer centres run classes where you can try them out. Or you can practise at home using books, CDs or websites. The idea behind these techniques is to focus on the present moment rather than sadness about the past or fears about the future.

Relaxation exercises usually involve slow breathing and loosening your muscles.

Meditation involves focusing the mind on a single thing, like your breathing. There are many forms of meditation, which can be done sitting, lying down or walking.

Guided imagery combines deep breathing and meditating as you imagine a peaceful scene or setting. Some people like to play gentle music or nature sounds while practising. Others prefer silence.

Mindfulness meditation is a more structured type of meditation that therapists and doctors sometimes teach as a way of coping with emotions. It involves bringing awareness to each particular moment without judgment or the need to change it.



The use of mindfulness to help you cope with a difficult situation and learn to focus more on the present moment can be a good strategy. It can be used as self-support or as therapy that's more specific to control particular symptoms. It helps a lot. – Rosana Faria, psychologist

If you are interested in trying one of these techniques, ask your healthcare team for information and referrals.

Mind-body physical activities

Some gentle types of exercise connect the mind and body through movement. Yoga is probably the most well known. Some types of yoga are slower and more meditative while others are more athletic. Tai chi is an ancient Chinese form of "moving meditation" that involves slow, continuous movements that help relax the mind.

Be sure to talk to your doctor before starting any physical activity. It's also important to practise with a trained practitioner at first so that you learn proper techniques. Hospitals and cancer centres sometimes offer classes for people with cancer. Once you've learned the basics, you can practise at home with a book, CD or online support.

Writing and other creative outlets

Many people find it helpful to keep track of feelings by writing them down. The writing process can get your emotions out and help you process your feelings. This, in turn, reduces your stress levels. Some people find it easier to write about their emotions than to talk about them.

You can write as much or as little as you want, depending on how you are feeling. Your words can be written in a private journal or

diary, just for you. Or they can be shared with select friends and family through letters, group emails and Facebook posts. You can also share your thoughts with the world through a blog, a personal website and social media channels.



Writing about living with cancer and sharing my story with other people who were newly diagnosed, I felt a sense of satisfaction. I realized that what I had gone through was not for nothing. – Mei-Ying

If writing isn't for you, or if you find it's making you tired or upset, try another creative outlet. Photography, drawing or painting, and music are also great ways to express your emotions.

Need more info about relieving stress?

Visit cancer.ca/complementarytherapies.

Hobbies and interests

Many cancer survivors emphasize how much it helped them to spend time on hobbies and interests. Doing something enjoyable and relaxing each day, or something physically challenging that you enjoy, helps balance out the stresses of daily life. It also helps time pass, and many people feel better when they stay busy.



Waiting for test results is always stressful. They say, 'I will call you in 2 weeks with the results.' That's why I always have projects. I make sure those 2 weeks go by as fast as they can. So I'm not sitting on my couch and waiting. I make life go by. – Sylvain

You can stick with something you've always enjoyed and can still do. Sylvain kept as active as he could, and he also started organizing sporting events with his friends as cancer fundraisers. "When I'm doing this, I'm not thinking about my illness," he says.

Or you can try something new. Mei-Ying learned to crochet. "It was incredible the sense of serenity that I found in being able to lose myself in this very rote task," she remembers.

Even if you have to change your activities from what you would normally do, try to focus on what you can do instead of what you can't.



I went for walks outdoors when I could even though I was very ill. I couldn't go fishing, I couldn't go hunting. I was away from home just waiting for my next appointment. So the biggest thing I did was walk. – David

David's life had always revolved around the outdoors. In his small community in Labrador, he hunted, trapped and fished. During his 7 weeks of cancer treatment in St John's, he couldn't do those things. So he did the closest thing he could think of - he walked outdoors.

Time with friends and family

Spending time with people whose company you enjoy can ease your stress levels. Sometimes you might talk about your feelings with people close to you. Other times you might share a laugh or do things you've always loved to do together – and try to forget about cancer for a bit.



I was very lucky that I had family. I couldn't skidoo but I went for car rides with them. I lost my appetite but they took me out to dinner for whatever I could eat. That was a huge support for me. – David

Sylvain's friends helped him forget about his illness and treatments just by doing things with him as they always had. "If we had to go have a few beers, then we did that. If we had to laugh, we did that. It wasn't always about how's your shoulder, how's the treatment? They understood that I didn't always want to be Sylvain the Cancer Patient."

Eleanor made new friends while at a cancer lodge away from home. Everyone was having treatment, but they didn't always talk about it. "We did a lot of laughing and talking and drinking coffee on the patio. It was all good."

Mei-Ying enjoyed having more time to spend with her children when she became too ill to work. "I became much more involved in their activities. I would go to the hockey games and the swim meets, which in my career life I didn't really have time for." She made sure to only spend time with people who made her feel better: "I used to say that cancer helps you clear the crap out of your life. I kept at bay people who tended to be more negative and more draining of my energy."

For some of us, friends and family might include a pet. Research shows that spending time with a dog or other animal can ease stress and anxiety and improve your sense of well-being.

Spirituality

Many people find comfort in religious faith and spiritual practices. Some research shows that feeling spiritually connected can reduce anxiety and depression for people with cancer. It can bring a sense of calm and purpose.



It's always a comfort for me to pray anyway. I always feel that I'm not alone. I don't pray to be cured. I don't ask for miracles. I always pray for strength or courage or not to have too much pain. I pray to get through it. – Eleanor

Some people, like Eleanor, strengthen their spirit through prayer, worship or reading spiritual writings and faith-based texts.

Others may find spiritual meaning by being in nature or other spiritual spaces such as retreats.

Talking to spiritual leaders can also help you find peace of mind. Don't worry if you haven't been going to religious services regularly or if you aren't sure what you believe. Spiritual care workers, especially those at hospitals, are often trained to support people of different faiths.

Coping with physical changes



Cancer or cancer treatment can affect your body. These changes to your body can affect your mood, your quality of life and how you feel about yourself. But there are things you can do to cope.

Talk to your healthcare team

Physical changes aren't always obvious. Your healthcare team might not know that you find it hard to sleep or that you're having trouble remembering things. Tell them about physical changes and how you feel about them. Sometimes a healthcare professional, such as an occupational therapist, can help you find practical ways to cope with symptoms and side effects. This can in turn help with your emotions.

Changes in energy levels

Many people with cancer tire easily and feel weak at times. It's different than normal tiredness because it doesn't always go away with sleep or rest. This kind of exhaustion can really affect your daily life. And it can be hard on your mood and sense of self. When you're tired, everything seems worse and it can be even harder to manage your emotions.

During cancer treatment, you may find you have good days with more energy and bad days when your energy is low. Try these ways to cope:

- Keep track of your energy levels in a journal or calendar. You may notice that there is a pattern that goes along with your treatment schedule. You can then try to plan the activity level of your days around this pattern.
- Let yourself rest on days when you're tired. Do something that you find relaxing perhaps having a bath or listening to music.
- Do something special on days when you have more energy. Use that energy on things that matter most to you.
- Rearrange your house as much as you can so you're not using so much energy - or getting frustrated - by having to go from floor to floor in your house.

Ask your healthcare team to suggest exercises or activities you
can try. Moderate activity can actually give you more energy.
 When thinking about an activity plan, you may want to have
one for good days and one for days that aren't as good.

Changes to how you look

Cancer can change the way you look. Some people gain weight while others lose it. Cancer treatment might make your hair fall out. Surgery may leave scars or change how your body looks as well as how it works. These changes may last a short time or they may be permanent.

A physical change can affect how you feel about yourself. Changes to your appearance can make you feel self-conscious and less confident. You may feel unattractive or negative about your body or worry that your partner will reject you. These feelings are normal, but there are ways to start feeling better:

If cancer has affected your weight, ask to talk to a dietitian who can help you manage your appetite and maintain a well-balanced diet. Many hospitals and treatment centres have dietitians on staff. Talk to your doctor about an exercise routine that is safe for you. Staying active and doing activities you enjoy can help you feel better about yourself even if your weight isn't what you would like it to be. It's also important to wear clothes that make you feel good and spend time with people who appreciate you as you are.

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. Reconstructive surgery helps some people feel better about themselves. Even if you have to wait to have it, you may find it helpful to know that it's an option.

If chemotherapy or radiation therapy has made you lose your hair, you may want to wear a wig. If you want to match your usual colour and style, get the wig before you start treatment. You can also try wearing a hat or scarf.

Keeping busy while everything changes - David's story

When David was diagnosed with a rare, aggressive cancer of the nasal passages, doctors recommended a gruelling treatment plan. First, he went through 7 weeks of radiation combined with 2 rounds of chemotherapy. He was told it was "probably one of the strongest doses of chemo they can give anyone." More chemotherapy on its own came after the combined radiation and chemotherapy.

The side effects were severe. "I lost an extreme amount of weight. I couldn't eat. I lost all my taste. One hundred and twenty pounds fell off me in 2 weeks." David had always been a self-described "big boy," weighing about 300 pounds before his cancer treatment. But he'd always been very active and spent a lot of time outdoors. "I was a strong, husky guy. And I led a very active life even though I was a big quy."

Now he watched his body breaking down and could do little to stop it. The drastic physical changes seemed to go to the core of who he was. "I absolutely had no muscle strength," he recalls.

After David's second round of chemo, doctors began to question if he should have a third dose that they had planned. The chemo affected his hearing, and there was a risk this side effect could become permanent. "That was the most troubling time I had during my treatment. I had a lot of questions about the chances of surviving on 2 versus 3 batches of chemo. The doctors laid it all out for me and left it up to me to decide. I asked all kinds of questions. And I decided on my own: If I survive I want to be able at least to hear. So I elected not to take the third batch of chemo combined with the radiation."

David lives in the small Inuit community of Nain in northern Labrador. He had to fly to Goose Bay then on to St John's for treatments. "One of the biggest things during my treatment was missing home and missing the things I did on a daily basis. I couldn't go fishing, I couldn't go hunting. I'm out there just waiting for my next appointment." David made a point of getting outdoors as often as he could. "I couldn't practise the things I normally did at home so the biggest thing I did was walk. I did a lot of walking until the point when my body just couldn't do it."

Back at home, David focused on staying busy. Normally, he worked full time running his own freight-handling business. Now, his staff did most of the work but he did what he could. "The first thing was to keep busy and do the things that I normally did. You just try to get back into your day's routine. For me that was working. After losing 120 pounds, there was no way I could do the things I did before at work. All my work was outdoors and physical, very demanding on the body. But I had to find ways to keep myself sane instead of thinking about cancer. So I got into it as much as I could." He did smaller amounts of work, for shorter periods – and trusted his staff to do the rest.

Four years after completing treatment, David is healthy again and back to his active outdoor lifestyle. It was a gradual process. "It took me a long time to regain my muscle mass and the only way I got there was by eating the right foods. Even though I couldn't taste my food yet, or didn't like food, I kind of forced myself to rebuild my body. I'm nowhere near the 300 pounds I used to be, but I put some weight back on. It's a comfortable weight for me. And I feel good. My body feels good."

Mental changes

Cancer and its treatments can sometimes affect mental functions like memory and concentration. You may be easily distracted or have trouble multitasking (for example, following a recipe while someone is chatting with you). These tips may help you cope:

- Plan activities that need you to concentrate for times of day when you feel most rested.
- Keep track of things by making lists of medicines, appointments or things to do. You can also use a smartphone app or clock alarm to keep you on schedule.
- Ask friends or family members to help you remember by listening, taking notes and asking questions at appointments.

Changes in sleep

Sleep is important for your mind and your body during cancer treatment. But physical symptoms like pain or nausea along with worry, sadness and other emotions make it hard to sleep well.



It was usually when I settled back for the night and thought things over that reality kind of kicked in. I did think about, Am I going to pull through? It's going to cross everybody's minds when they're going through treatment: Will I make it? And those were the tough times. Some nights it was quite difficult. – David

Try these tips for a better night's sleep:

- Go to bed and get up at the same time every day.
- Put electronic devices away an hour before bedtime. It's almost impossible to fall asleep soon after staring at a screen.
- Avoid caffeine (coffee, tea, chocolate, cola drinks) close to bedtime.
- Relax before bedtime with a bath, some soft music and a glass of warm milk.
- Have someone give you a gentle massage.
- Limit daytime naps to 30 minutes so you feel more tired at bedtime.
- Be as physically active as you can during the day.
- · Keep your room cool and quiet.

Changes to fertility

Cancer and its treatment may affect your fertility, which is your physical ability to have a child. A woman who is infertile either can't become pregnant or can't carry a baby to full term. A man who is infertile can't get a woman pregnant.

If you think or know that you'd like to have children in the future, talk to your healthcare team before you start treatment. Ask them how cancer and treatment can affect your fertility. You might want to talk to a fertility specialist about having your sperm or eggs preserved for use after treatment.

Learning that you may become infertile can be devastating. Even if you weren't planning on having children (or having more children), you may still be upset. It may make you feel differently about yourself as a man or a woman. Sometimes it's hard to be sure about whether treatment will make you infertile for just a period of time or whether it will be permanent. Not knowing this may make it even harder to adjust and adapt. It's natural to feel a great sense of loss and to worry about how your relationship or future relationships will be affected.

Talk to your partner and share your feelings. If you don't have a partner right now, talk to a friend. If you're struggling to cope, ask your doctor about talking to a counsellor.

Being active and eating well can help

Being active and eating well can help you feel better during treatment.

Being active

Physical activity during treatment helps both mind and body. It can improve your sleep and appetite, lower your blood pressure and reduce stress. Exercise helped Mei-Ying through the many changes that treatment brought to her life. "I found great solace and the ability to reduce my stress through swimming and cycling. I just emotionally felt so much better."

If you have always been active, try to keep exercising once your healthcare team says it's OK. You may not be able to do as much as you did before diagnosis, but even a little bit of daily activity can help. If you don't usually exercise and want to start, talk to your team first.

Many people fear that exercising will make them more tired. But regular daily activity – such as a brisk walk – actually is a good way to reduce fatigue. Try to build up to at least 30 minutes of activity every day. If you can't do that, some activity is better than none. You can push your body to do more as long as you don't get dizzy or have chest pain or feel like your heart is racing.



With time, as the chemo began to affect me, I had to recognize what I could do physically. I had to really make sure that I made the right choices as far as how I was going to be physically active. Maybe it was a short walk instead of a run. Maybe it was just sitting outside in the sun and getting out of the house. I did have some of those days. But I also had days where I could do a lot more. It's about doing what your body allows you to do but actually getting up and doing it. – Mei-Ying

Eating well

A healthy diet gives your body the nutrition it needs during cancer treatment. It can give you energy, help you feel better and keep your body strong. It can also help you feel like you have some control over your own health.

But eating well can be a challenge when you have cancer. Symptoms and side effects can affect your appetite and eating habits. Emotions like sadness and anxiety can change the way you feel about food.

In general, eating well means eating a variety of healthy foods like vegetables, fruit and whole grains. But everyone's nutritional needs are different. Talk to your healthcare team. A registered dietitian can help you find ways to get the nutrition you need.

You can find more information and recipes in our booklet *Eating Well When You Have Cancer.*

For more information about physical symptoms and side effects, refer to our other booklets, including *Chemotherapy and Other Drug Therapies* and *Radiation Therapy*.

Cancer taught him to care for himself - Sylvain's story

Sylvain was working as a high school coach and phys ed teacher when he was diagnosed with melanoma at age 27. He'd always loved sports and had a degree in kinesiology. But he hadn't always taken the best care of himself in every way he could. "When you're 27, things like cancer happen to other people. You go outside and you don't really protect yourself from the sun. You don't check everything you eat. You don't take care of those things because you just don't expect to get sick."

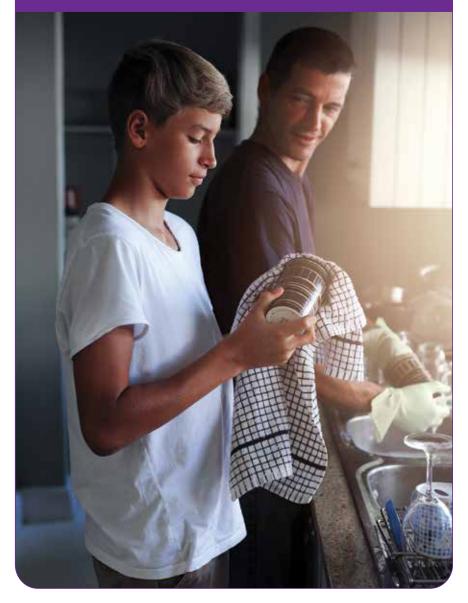
But now he was sick. Doctors weren't sure how well the treatment would work. "But they always gave me hope. This was enough for me to change a lot in my life: about eating, about physical activity, about mindset."

Sylvain had been a regular fast-food eater before his diagnosis. Now he began to include a lot more vegetables and lean protein. "When I was an in-patient, the cafeteria was open 24 hours and had healthy food. At home, it was always small portions that included some protein. My parents helped with making the food. It was a lot of vegetables, a bit of meat. And I cut out all fast food. When I was younger, I didn't have a lot of time because I was running around, refereeing hockey and coaching. I was using a lot of fast food. Then for the first 3 years of my illness I think I ate fast food maybe twice. Eating vegetables, you get a lot of energy. For sure it helped."

During his lengthy treatment, Sylvain stayed as physically active as he could. But having cancer meant he had to adapt the way he worked out. He had always loved pushing himself, but now he felt weaker if he did too much. "At one point I said, OK, I've got to put aside being the best athlete possible. I had to modulate everything. I still hike and I run, but I limit how much I do. And if I need to rest, I rest."

Physical activity had many emotional benefits as well. Staying active, he says, helps him feel alive. Today, he skis, swims, plays baseball and plays badminton with his girlfriend when he can. He also makes a point of planning ahead to do the things he loves, especially travel. Planning the next trip – like the tour he took of baseball stadiums in California – helped him through the tough times. "When you're in a hospital bed you say, What do I want to do with my life to make it worth it to be there. And for me it was travel. So the next time I'm in a hospital bed, the images in my head will be good images – of the projects I do and the travel I've done."

Coping with relationships



Cancer can strain your relationships. Family, friends, neighbours and people you work with can be good sources of support – but they are also trying to find their own ways to cope with the fact that you have cancer. Getting the support you need doesn't always happen as smoothly as you might like, but there are ways you can make it better.

Telling people you have cancer

Talking about a cancer diagnosis can be hard. You may worry about what to say or how family and friends will react. But telling people about your illness is the first step to getting support. Many people will want to help once they know what you are going through.

Prepare and plan first. Decide who you want to tell in person or by phone. Think about what you want to say and how much detail you will give. Try to think of the questions people might ask and then come up with some simple answers. You don't have to answer every question. It's up to you how much or how little you choose to share. When you are ready to talk, find a quiet time and place so that you won't be interrupted.

Be as honest as you can about how you feel. You don't have to pretend that you're fine.

Let other people help. It can be exhausting to keep talking about your diagnosis. You don't have to tell everyone yourself. You can ask a friend or family member to share the news with as many people as you would like. If you are telling people yourself, it sometimes helps to have someone with you who already knows about the diagnosis for support and to help answer questions.

Use email and social media. Telling people by email or on social media allows you time to choose your words carefully. It can also be less emotionally draining.

Mei-Ying used email to share her diagnosis with many people outside her close family. She remembers: "I could not bring myself to do it in person sometimes. I know my strengths and weaknesses. I understood that if I was to be doing it in person I might break down. And I did not want to break down. So I chose to put a little distance between me and the person with whom I was having the conversation."

She found that the most supportive responses she received came after she'd sent emails. People had time to think about how they wanted to respond.



They actually had the chance to absorb the information a little bit within their own time frame. I think pretty much everyone who responded by email or sent a card, note or letter, I saved all of those. I would go back in my times of darkness and read them. These are emails I still have now, almost 8 years later. – Mei-Ying

Dealing with how people react

You will probably get a range of reactions when you talk about your cancer. Some people will be easy to talk to and will know just what to say and how to support you. Others may react in ways that surprise or confuse you. They may get so upset that you end up having to comfort them. They may say the wrong things, sound overly positive or say nothing at all.

It didn't go smoothly when Mei-Ying shared her news: "My friends who I told over the phone were left pretty much speechless. And when they did say something, they often uttered your typical words of comfort that you think you should be saying. Things like 'You're going to get through this' or 'I know somebody else who went through this and they're fine.'" Mei-Ying was disappointed but accepting. "The person saying it might think it's comforting, but what you really want to hear is something that recognizes your fear and your anxiety. But people are just so shocked and dismayed and concerned about saying the wrong thing."

How people respond doesn't always have a lot to do with you and your situation. It can have more to do with their own personalities, experiences and knowledge of cancer. If people don't react as you'd like, try not to assume that it means they don't care. Give them time to adjust to the news and deal with their own feelings. Often, family and friends become more supportive over time.



Interestingly enough, most of my friends within a couple of months actually called me back and apologized for their initial reaction. - Mei-Ying

Sharing your feelings

It's not always easy to talk about feelings. You may worry that you'll start to cry or lose control. You may think that talking about your feelings is a sign of weakness. Or you may feel you need to be strong so people won't worry about you.



I wasn't the type of person to share my burdens with other people. I didn't want to tell my friends and family, 'This is how my day was,' when it was bad. When people asked, I'd just say that I was doing OK. – David

See the value in talking. It's good to talk. It can make your relationships stronger and help people understand what you're going through. It can help you understand your own emotions and feel more in control. And simply having someone listen can provide much-needed support.

Be honest about how you feel. You're allowed to have all of your emotions. You don't need to protect people by hiding your fears. It's healthy to express them. If you aren't sure how you feel, say so. Once you start talking, you may find it's easier than you expected.

Don't force it. Most people find there are times when they want to share and times when they don't. Be honest if there are times when you don't want to talk.

Keeping people informed

Cancer treatment can last for months or even years. Over time, it's up to you to decide what information you're comfortable sharing and who you want to share it with. Even though you know people mean well, answering endless questions about your health may start to feel like a burden.

If people ask how you are, it's OK to give a short, simple answer. It's also OK to tell them you are glad to have their support but you can't talk right now or you don't feel like talking right now.

Some people find it helpful to ask someone they trust to act as a point person. Your point person can monitor and return calls and emails and arrange visits at times that work for you. You might also want to direct people who contact you to that person by recording a message on your phone or using an automatic reply on your email. Your point person might send out group emails or post updates on your situation on a web page, blog or social media channel.

Building your support network

Building a support network can help you cope and feel less alone. Help comes in many forms. Some people are good at practical help such as child care, preparing meals, housework or looking after pets or plants. Others can help you organize calendars and to-do lists. Some friends or family members will be best at listening and sympathizing, providing comfort when you're upset.

Many people find it hard to ask for or accept help from others. Do not worry that you're being selfish or burdening other people. Many people really do want to help and to feel useful. If you are open to it, you may be amazed at how much support is out there.



What I have realized is that sometimes the people who can be your best supporters are the ones you least expected it from. So don't close your doors. Leave your doors open because you'd be surprised who is going to walk through. – Mei-Ying

Accepting help

People often make a general offer to help – there's a good chance they won't be clear about what they can do for you. It's OK to tell someone what you need. Be specific. If you need a ride to a doctor's appointment on Tuesday, ask for it. If you need someone to mow the lawn or shovel your walkway, say so. Family and friends may find it easier to be told rather than trying to guess.

You may even be overwhelmed by many offers. A point person can organize help on your behalf. They can help decide what needs to be done, who can do it and when. They can also use an app, online calendar or Facebook page to set up a plan or schedule so that people can sign up for whatever they feel best able to provide.

Asking for help

Not everyone is flooded with offers of help. Try not to assume the worst if people don't step forward. Sometimes they just can't find the words or don't know how to offer their support. You may find that more help will come your way if you make it obvious that you need it. Asking for help when you need it is a sign of strength, not weakness, so don't be afraid to reach out for help.



Sometimes just sharing information is the catalyst for a person to say 'I'm glad you mentioned that because I was wondering how to help.' In some instances we're the ones who need to step forward and say 'I need help' or 'I wanted to let you know that this is what's going on.' Because people feel uncomfortable. They don't know how to offer without fearing that they're insulting you in some way. – Mei-Ying

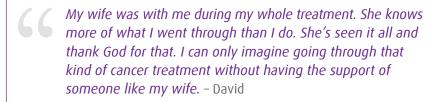
Family matters

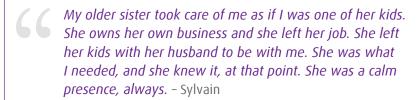


It changed all of our lives and the way we were together – my parents, my sister and my brother. – Sylvain

Your family members will all react to your cancer and cope with it in their own way. They can struggle with strong feelings, such as fear or even anger or guilt. They too are dealing with change and upset, even though they're not the person with cancer.

Cancer and its treatment can take a toll on family relationships. Some relationships suffer, especially ones that were already troubled. But many people say that family relationships become stronger and more meaningful. Family can be your safe place, your greatest source of comfort and strength.





Changing roles and responsibilities

Cancer can change the roles and responsibilities in your family. You may have to give up or cut back on some of the things you've always done – whether you are the main wage earner or homemaker, the parent who drives the kids to swim lessons or the adult child who helps elderly parents look after their yard. And when your role changes, the roles of others in your family

often do as well. The changes that you all need to adjust to often depend on the stage of life you are at. For example:

- You may reverse roles with your adult children who start taking care of you, the parent.
- If your parents are in good health and able to help you, cancer may make them more involved in your life than they have been in years.
- If you are taking care of your elderly parents, someone else may need to help them while you focus on your own health.
- Your children who are still living at home may be expected to help more around the house or take on jobs that a parent would have done before.

Change takes time to adjust to, and it can be stressful. Sylvain was a young adult still living with his parents when he was first diagnosed. He relied on them a lot. They drove him to the hospital for appointments and even slept beside him when he was having experimental treatments in Washington. But it wasn't always easy. Sylvain says, "When you're sick, I think as parents they want to take over. Over the 10 years we've had our ups and downs in communication. Now they understand that they have their role and it's OK. But at the beginning, as a parent when your kid is sick I think you want to do everything."

Helping your family cope

The way your family copes with all this change and the feelings that go along with it will depend in part on how you've coped with hard times in the past. To help you and your family get through this time, try to:

Make the most of your time together. Talk about how much you mean to each other and express your feelings – love, anxiety, sadness or anger. Don't worry so much about saying the wrong thing. It's better to share your feelings than to hide them. And it can help others do the same.

Give feedback when family members try to help you. Let them know that you appreciate their help, but be honest about what you need and don't need. No one in your family – not your partner, parent or child – can read your mind.

Keep family members informed about your health. Being informed can help people cope. Answer any questions people have. Respect the right of family members to agree or disagree with your decisions, but make it clear that they are your decisions to make.

Have regular family meetings to talk about the week ahead.

Together you can create a schedule that includes your upcoming medical appointments and treatments, as well as family members' activities that week. You can make lists of tasks that need to be done and agree on who does what. These meetings can be a good way to spend time together while checking on how everyone is coping. During the meeting, talk about anything – good or bad – affecting family life. Out-of-town family members who want to be involved can be on the phone or can join through video or online chat tools.

Keeping partnerships strong

Your relationship with your partner or spouse may face some new challenges. Each of you may cope with the situation very differently. One person may be more hopeful than the other. One may want lots of information about cancer while the other doesn't want to know much. And one of you may be more comfortable asking for help or talking about how you feel.

Try these strategies to help keep your relationship strong:

Talk to your partner about what they are thinking and feeling. Be as open and honest as you can be. Mei-Ying emphasizes that communicating well saved her marriage. "Without it, I might have ended up divorcing him," she says with a laugh. "My husband tends to be more stoic than me. I mistook that to mean he was disinterested or disengaged. Luckily we have very open conversations. He explained to me, 'I'm not disengaged. I just can't let myself fall apart in front of you. But I cry every day in my car on my way to work.' He was always making sure that nobody saw anything but his strongest self. He didn't feel he could allow his emotions to show because he felt I would interpret that as weakness."

Remember how you've coped together in the past. Think about what strategies worked and what didn't. You might want to write a list of things you both can do to keep your relationship strong.

Give yourselves a break from focusing on cancer. Talk about and do other things together. It can also help to take short breaks from each other. You may need time alone to not feel like "the cancer patient." Your spouse may need a rest and time away from worrying about you.

Be sensitive. It's OK to keep difficult or emotional discussions for another day if one of you is having a bad day or is in a bad mood.

Get help if you need it. You and your partner may need to see a family therapist, either together or separately. Support groups can also be helpful for spouses.

Sex and intimacy

Cancer and its treatments can affect sexual relationships. Some people with cancer lose interest in sex or lose the ability to become aroused. Many of these changes won't last forever. But they can affect your relationship in the meantime.

Even though your sex life may not stay the same, it doesn't have to stop completely. Some people say that hugging, cuddling, kissing and caressing become more important. Even quiet time alone together, holding hands, can be healing for both of you.

Talking openly is also important. Together, you can decide what gives you both pleasure and comfort.

If you find it hard to talk about sex, a counsellor can help. Whether you are single or in a relationship, you can also talk to your team. They should be able to give you information, suggestions and support.

Our booklet Sex, Intimacy and Cancer has lots of information on dealing with sexual issues.

Helping your children at home cope

You may worry a lot about children who are still at home and how cancer affects them. They also have to cope with changing family roles and with their own feelings about a parent being ill. They may feel angry, sad or guilty. They may worry about how their own lives will change or feel abandoned when the family focuses on your illness. To help your children cope you can:

Comfort and reassure your children. Tell them they will be loved and looked after. Encourage them to talk about how they're feeling. And try to be patient. Children of all ages will need time to adjust.

Provide information about your illness that is right for the age of your children. Let them know that you're available to talk and answer questions. Tell younger children over and over that they didn't cause your illness.

Maintain routines as much as possible. Encourage them to see their friends and do things they enjoy. Let them know in advance if a routine may change. If possible, let them help plan changes.

Continue to do things with them. Even if it's just watching TV or helping with homework, it's important. Talk to them about what's going on in their lives.

Ask a friend, relative or other trusted adult to spend extra time with them. Teenagers may find it easier to open up to someone other than their parents. Younger children may need to be looked after when you're not feeling well. You can ask people to pick them up from school, drive them to lessons or have play dates and sleepovers.

Tell teachers, school principals, guidance counsellors and other caregivers such as daycare staff, babysitters or coaches what's going on. They can help your children cope and may notice changes in behaviour that you aren't aware of.

Stay consistent with rules. Your children need to know that you are still the parent - and in charge - even if you are unwell.

Get them involved. Encourage them to help with small tasks at home. Even young children can feel good by drawing a picture for your room, for example.

If you're concerned about big changes in your child's behaviour, talk to your healthcare team. But all of these behaviours are normal:

• Younger children may act out to get your attention. They may misbehave or become clingy or insecure, refusing to leave your side. Some children start acting younger than their age. They can also lose interest in some of their favourite activities or have trouble sleeping or with schoolwork. Sometimes younger children worry that they caused the cancer or that they might "catch" it.

• Teenagers are able to understand more about your illness but may still struggle to cope. Some teenagers can seem indifferent, showing little emotion or withdrawing from you. Others may react with anger, act out or get into trouble. Teens may resent extra responsibilities or respond with offers of help and assurances of love – sometimes both in the same day.

How much should you tell your child or teen?

You might be tempted to avoid talking about your cancer, especially with younger children. But children often sense something is wrong and may imagine the worst if they're not told the truth. They may be angry if they hear the news or updates from someone else. By talking honestly and helping them share how they feel, you make it easier for them to feel safe and secure. These strategies can help:

Prepare in advance. Think about what you want to say and practise saying it or write it down. Simple, direct words are best. Choose a time to talk when you're feeling calm.

Ask what they know about cancer. You can then talk about any information that's incorrect. Don't overload them with information. Provide the basics such as the name of the cancer, where it is in your body and the treatment and side effects you might have. You can ask what else they want to know.

Give children plenty of time for questions and to share their feelings. Try to answer questions honestly. If you don't know the answer to a question, that's OK. Tell them you'll look for answers and then share what you find.

Having careful conversations with your children - Mei-Ying's story

When Mei-Ying was diagnosed with breast cancer, she had a 5-year-old daughter and 2 teenage sons at home. She and her husband put a lot of thought into how to talk about her cancer.

"With my 19-year-old, I decided he was able to be spoken to as an adult. I used similar terms with him that I used with my parents. Both my sons were

absolute pillars. They hugged me and they shed tears and did everything you would expect in that situation. But after that they more or less took their signals from me and my husband. So after the initial shock, they both became very strong as far as wanting to participate and looking to see what they could do in their own way to feel that they were helpful."

Over many years of chemotherapy, her survival was uncertain. They only had the conversation with their daughter after Mei-Ying had been in chemo for about a year. "She knew that I was sick but we never really discussed it in greater terms than that until I lost my hair. And we never discussed the gravity of the situation with her until she was about 8 years old and I was admitted into the intensive care ward at the hospital. And then we did have to have a serious conversation with her."

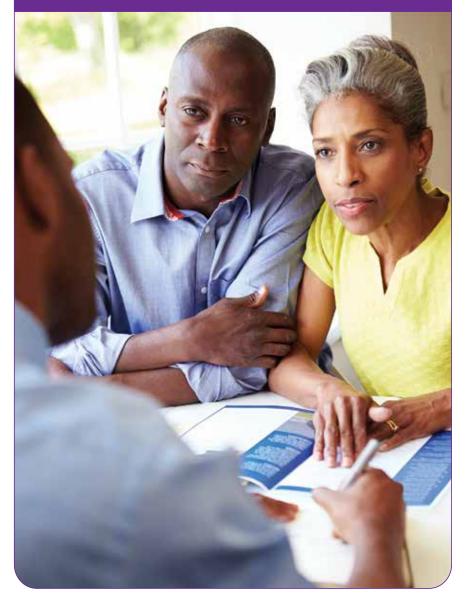
Mei-Ying put just as much thought into this conversation. "I know that children always take their cues from us. So I made sure that I spoke to her about it at a time where I was emotionally prepared. I used terms that she could understand. I didn't use medical jargon and I didn't use words that were complicated. And I said to her, 'What I have is really quite serious but I want you to know that for as long as possible, life the way you've known it will not change. I will always love you and Daddy will always love you and our family will always be here.' I talked about the illness but also about how it was not going to change the loving, comforting environment in which she had grown up."

At first, there were tears. But afterwards, she basically did the same thing as her brothers and supported her mother in her own way. Mei-Ying recalls that her daughter would always tell her how beautiful she was. "She would say 'Mummy, it doesn't matter that you have no hair. You're beautiful." Mei-Ying believes that her daughter saw that they were all managing and were still enjoying every day and still doing family things and so that was what she did, too.

Mei-Ying kept her daughter's school informed and was impressed with the level of support. The school librarian ordered books about having a parent with cancer. A teacher read the books to her daughter's class. There were group discussions in which all students were encouraged to talk about family members with cancer. Mei-Ying's daughter shared her family's situation. That prompted emails from parents offering sympathy, support and play dates.

"We were very fortunate. You know the expression 'It takes a village to raise a child'? In my case, I had a village supporting my children."

Coping with life changes



Having cancer can affect many of the practical details of your life – work, finances, where you live and how you travel. It can lead you to think about a will or who will make decisions for you if you can't make them yourself. Your emotional health can suffer when practical matters that used to be more straightforward become stressful.

Work

It's possible that your way of working will change during cancer treatment. Some people can keep working during treatment, but others may need to stop. How much time you need to take away from work will depend on your treatment plan, side effects and the type of work you do. Working or not working can affect your emotions in ways that you might not expect.

Do you have to tell people at work?

The short answer is no. If you need to take time off, reduce your hours or change how you work during treatment or afterwards, you can ask your doctor for a note that says there are medical reasons for your request. That is all that your boss or supervisor needs to know. You don't have to tell co-workers anything at all if you don't want to.

If you don't tell anyone at work, it protects your privacy, but there are some downsides. People you work with will likely wonder what is going on if you're away a lot or if cancer changes how you look. This can lead to gossip, which may add to your worries. Also, if you don't tell people, they can't help and support you.

The decision is yours, based on what you know about your workplace and the people you work with. Many people do share the diagnosis at work. If you do, think about who you will tell and how much detail you would like to share.

Taking time away from work

Some people with cancer try to keep working while being treated for cancer. 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. It may reassure you to at least know what your options are for taking time away from work. Talk to your employer or human resources department about sick leave, vacation leave or leave without pay. Your union or employee association may also be able to help.

If you are able to continue working, it can help you feel good about yourself. For many of us, our jobs are closely tied to how we see ourselves and our place in the world. Working reminds some people that there is more to their life than cancer. You may find that work can help keep your mind off your illness. Being around other people at work and having their support may also make you feel better.

If you want to continue working as much as you can, tell your healthcare team. It may be possible to arrange treatment times to lessen any impact on work. You can also discuss ways to manage side effects during work hours.

For some people, taking time away from work may feel like a relief. But it can also be stressful if it leads to money problems. If you enjoy your job, it can be hard to give it up. Mei-Ying spent years building up a career she loved and found it very hard to stop working. "It wasn't just a question of no longer working. It was also losing my routine, losing all the people who I had begun to look at as more than just colleagues."

Giving up work, even for a short time, makes some people feel like they've given in to the cancer. If you feel this way, try instead to think of your time off as a chance to focus on your health.

Try to stay in contact with people at work while you are away. People at work may be very supportive while you are going through treatment, and staying in contact with them can also make it easier to return to work.

Returning to work

Most cancer survivors who are able to do so go back to their jobs. Many say it helps them get back to normal. But it can take time to recover fully from treatment. Some people find that it works well to go part time at first and gradually increase working hours. Talk to your doctor about when you might be ready to go back to work and what to expect. Discuss any challenges you might face and try to plan how to make your return to work both safe and successful.

Once you're back, give yourself time to adjust. It may seem hard at first to reconnect with your team. There could be new people or a new boss to get to know.

Some people end up changing jobs and careers. David, for example, gave up his business and returned to a previous career in politics. "I was a mayor for 9 years and a councillor for many years. So politics was in my blood."

Discrimination is against the law

Some people with cancer can face problems in their workplace when they try to continue working while in treatment or when they return to work. As long as you are qualified for the job, employers cannot treat you differently from other workers in job-related activities because of a cancer history. By law, employers have to make reasonable changes, such as changes in work hours or duties, to help you do your job during or after cancer treatment. They just don't have to make changes that would cost too much or create risks to health or safety.

If you feel that you have been discriminated against, you can contact the Canadian Human Rights Commission in your province or territory at 1-888-214-1090 or visit **chrc-ccdp.ca**.

Finances



We're so financially strapped, but I had a lot of financial support from a couple of friends that helped me with gas to go back and forth to Moncton for treatment. – Eleanor

Cancer can affect your finances. Time off work can overlap with extra healthcare and travel costs. You may have to pay for help around the house, help with your children or your elderly parents, or medicines and therapies not covered by health insurance plans. Losing income at the same time as having expenses that you haven't planned for can add to your stress.

These people can help by answering questions about money and helping you budget and plan:

Your human resources department or your private insurance broker. You may have private insurance through your employer or a private insurance company. Ask about the terms and conditions of your coverage – what it will pay for and when – and how to access it.

Your bank manager or personal financial planner or advisor can help you budget your money and suggest solutions to money problems.

An accountant can tell you about expenses you can claim on your income tax return. Some of your medical costs (such as drugs, equipment and supplies) may be claimed. You may be able to claim other costs such as travelling to treatments or child care.

A social worker at your treatment centre can help you access financial assistance programs and government benefits. They can also help you fill in and submit forms.

Government financial support

The Government of Canada provides benefit programs (financial support) to people who are sick or who are caring for family members who are sick. Talk to a social worker at your hospital about federal benefit programs, visit the Government of Canada's website at **Canada.ca** or call 1-800-0-Canada to see what you're eligible to receive.

Being away from home

If you don't live in a major city, you might need to travel for at least some of your treatment. In order to get the care you need, you might even need to live somewhere else during treatment.

Even if it's what you need to get the best possible care, spending long periods of time away from home is hard. David had to move to St John's for 7 weeks of treatment. "I had to be away for an extended period of time. It can really take a toll on you." He found it to be one of the most stressful things he had to deal with. "I was lucky that my son was renting a home in St John's while he was in school so my wife and I stayed with him. I'm so grateful for family. At least I had a place to stay."

Sylvain had 5 years of long hospital stays for experimental treatment in Washington, DC. In between treatments, he returned to his family home in Montreal. "I actually learned a lot from going to the United States for treatment. When I was home, I was Sylvain and when I was in Washington, I was Sylvain the Sick Man. So I was able to separate that. The sickness was in Washington. It was a good way for me to learn to separate. You're a person with cancer. It's not your whole life."

If you need to change your living arrangements, for either a short time or a long time, talk about it with friends and family. They may have ideas or suggestions that can help you decide where to live. Someone on your healthcare team, such as a social worker, may be able to help you find a temporary place to live during treatment. Your treatment centre may have a patient lodge nearby.

If you must be away from home for treatment, take some comforting items with you, like family photographs, your preferred pillow or your favourite music and headphones. This way, you will have something familiar even in a strange place. You can also ask staff if it's OK to decorate your room. You might want to put your children's or grandchildren's drawings on the wall, for example, or a treasured piece of art.

Leaving home – Eleanor's story

Eleanor was 81 years old when she was diagnosed with colon cancer. She had surgery to remove the tumour and less than a year later doctors discovered a cancerous lymph node. Travel was a big challenge. Eleanor lives in a small town in New Brunswick and the closest cancer centre is a 4-hour drive away in Moncton. "I had a whole lot of things done, including a PET scan and biopsy, all of it in Moncton. So I had to travel back and forth." Family members would do the driving and go with her to appointments. She would break up the trip by staying overnight with her niece, who lived in Moncton. "My family were very helpful."

When her cancer returned, Eleanor needed radiation and chemotherapy. For this, she moved to a cancer lodge in Moncton. She spent 2 months there.

"The lodge wasn't home but it was fine. I had a private room with a nice bathroom. They came and cleaned every couple of days. And I had towels, face cloths, soap – everything I needed. The rooms had no TV or Internet but I had my iPad so I could play on that. They had great staff, great people. Everything was just perfect. If you have to have a place to stay to get treatment, you're lucky to have that."

Eleanor also enjoyed the company of other residents. "I made really good friends who are still friends with me. Everybody was going through the same thing so we didn't have to explain ourselves. We were just like, 'Well, how are you this morning?' We were all counting the days, marking off the calendar till we could go home."

Every weekend, she stayed with her niece. "She would come and get me on Friday and take me back Sunday night. She took good care of me." When Eleanor felt up for it, she'd take advantage of being in a larger city and go on outings with her niece. "She did all kinds of things for me. She'd take me shopping. We'd go to Swiss Chalet, which I love and we don't have back home."

It was hard being away from home for so long. But Eleanor is now cancerfree and matter of fact about her experience. "It is what it is. Just take it one day at a time. Go through your treatment. It's not all bad. I always look for the positive side."

Cancer on vacation – travel tips

Planning a vacation or a trip to visit friends and family can give you something to look forward to and provide some much-needed fun. It's possible to go on holiday when you have cancer, but you might need to plan ahead more than usual. These tips will help you be as prepared as you can be when you're away.

Talk to your doctor

Ask if you are able to travel or when you can travel. Ask for backup copies of your prescriptions and when you should take your medicines if you cross time zones. Talk to your healthcare team about where you are going and where you could get care if needed. Take along contact information for members of your healthcare team so you can get in touch if you have questions.

Write down key information about your cancer

Before you leave, make a list of basic medical information and keep it in a safe place. You may even want to think about getting it translated if you're going to a country where English isn't the first language. 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 medicines you're taking (for cancer and anything else)
- · notes about any other illnesses or health problems

Buy travel insurance if you are leaving Canada

This is very important to do before you leave, even for a one-day trip to the United States. Be honest with the insurance company about your health history when you're setting up the policy, and confirm that you are still covered. Ask lots of questions. Read your policy carefully and make sure you understand it.

Pack well

Make sure you take all the medicines you need with you, as well as your health card and any insurance information. Pack medicines and any paperwork in carry-on luggage rather than in your checked bags. Keep your medicines in their original containers in case you have to show them at customs. It's a good idea to have extra medicine, just in case.

Advance care planning

All adults should think about the type of healthcare and personal care they would like to have in their future. It's important for everyone – not just people with cancer – to plan for this and tell their loved ones what they would want. This process is called advance care planning.

It's normal to want to avoid subjects like how you feel about breathing tubes or when you would no longer want a treatment that is keeping you alive. Making plans might make you feel like you're giving up on your treatment or yourself. You're not. You're just doing your best to think ahead for yourself and for your loved ones.

As long as you can speak for yourself, healthcare professionals will speak directly with you about what you want in terms of your care. But there may be a time in your life when you can't speak for yourself. At that time – which may have nothing to do with cancer – having an advance care plan will make sure that your wishes are followed. By thinking about these topics and telling your loved ones what you would want in different situations, you will make things easier for them if they ever have to make decisions for you. Knowing that your wishes are understood can make you feel relieved and less stressed. And it can relieve some of the stress and uncertainty for caregivers and family.

Many hospitals have a policy of asking people if they want CPR (cardiopulmonary resuscitation) to try to revive them if their heart or breathing stops. If they don't want CPR, the person can agree to a DNR (do not resuscitate) order or No CPR order, which is written in their medical chart by their doctor. It may be called different things in different hospitals, so it's best to ask.

Write it down

Decisions that you make about your care should be written down, and the originals need to be kept somewhere safe. You can also give copies of any legal documents related to medical care to your doctor or other members of the healthcare team. Many people worry that once things are written down, they can't change their minds. But even once things are written down, advance care planning can still be talked about and you can make changes to the plan.

Along with making sure that your loved ones and the healthcare team understand your wishes, it's a good idea to choose someone to be your substitute decision-maker. This person needs to be someone you trust and who understands your values. Your substitute decision-maker needs to understand what you want because doctors and nurses will ask this person to make decisions about your healthcare if you can't. This person can also be known as your power of attorney, which means they have legal authority to act for you on your behalf. (You can also choose a power of attorney to make financial decisions for you.)

Organizing important papers

- Make sure your family knows where they can find your important documents.
- Give copies of the documents to family members or healthcare professionals.
- Keep your originals in a fireproof box, a safety deposit box or with your lawyer. Make sure someone knows how to get them.

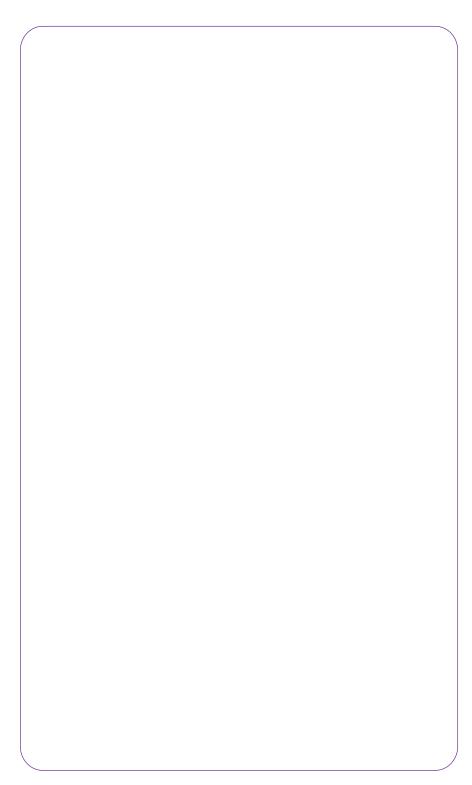
Wills

All adults – even those who don't have cancer – should have a will and keep it up to date. A will gives legal instructions about how you want your money, property and other assets to be handled after your death. It can also include information about who might look after your children (under age 18) if you die. 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.

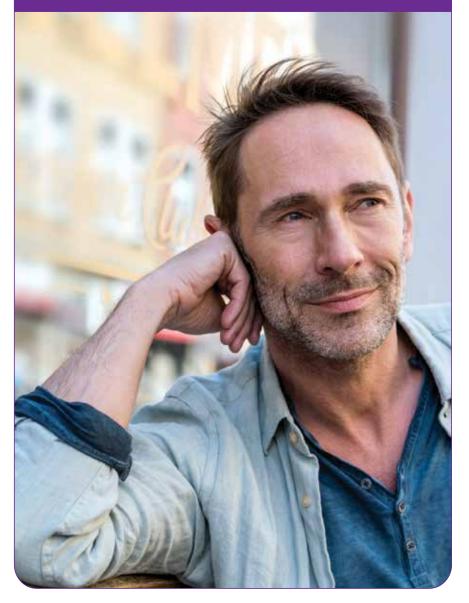
You may want to change an existing will or create a new one. Once it's done you may feel relieved to have taken care of an important task. You can always update or change it later by talking to your lawyer.



I had to prepare myself in case I did not make it through my treatment. We had to get certain things straightened away, like a will. All that plays on your mind. But it was only preparation. Coming from an Inuit family, we have strong customs of how things are divided up when the head family member passes away. So I went in that direction. – David



Coping with life after treatment





When treatment is finished sometimes people have in mind, OK, now it's done, I've turned the page. But that's not true. You still have a way to go. The end of treatment is a big step. – Rosana Faria, psychologist

The end of cancer treatment can be a time of mixed emotions. This may surprise you. Yes, there is happiness and relief – but it's also normal to feel stressed and worried about the future. Moving from being a cancer patient to a cancer survivor means change – and as you've probably learned by now, change can be hard.

People sometimes feel pressure to get back to normal right away. But your body and mind need time to adjust and recover. Many people say that family, friends and co-workers do not understand how much time or help you still need. Knowing that this can be a challenging time may help you cope as you start to rebuild your life.

Emotions after treatment

It's normal to experience a wide range of emotions after cancer treatment. As the focus shifts away from hospital visits and medical issues, you may start to think about your emotions and understand them in a way you hadn't before.

Many people struggle with feelings of sadness, anger, loneliness and even guilt about surviving when others have not. It's easy to become frustrated and upset. Many people continue to struggle with weakness and fatigue. This can drain your emotional energy as well. Try to be patient with yourself and take things at a pace that's right for you. It took time to adjust to cancer and treatment. You now have to give yourself time to adjust all over again.

Not everyone will struggle with emotions after treatment is finished. But if you do, know that the strong feelings often fade. Allow yourself to cry and to express your feelings with family and friends. You can also talk to your healthcare team. They may refer you to counselling or to a support program.

Fear of recurrence

Many people worry that their cancer will come back (recur). With time, the anxiety often lessens. But the worrying can come back with certain events such as birthdays and holidays, follow-up appointments and when you hear about someone else having cancer.

David has had regular testing and checkups with his doctor since completing his cancer treatment. He's in remission, which means there are no signs of cancer in his body. But he says, "It's always in the back of your mind that it can come back." Recently he had nasal congestion that was like what he'd had just before his diagnosis. Of course he worried. "Through testing, x-rays and everything else, I know my condition is not cancer-related. It's actually sinuses this time for sure," he says with a chuckle.

Eleanor has trouble accepting that the cancer is really gone and worries that it will come back. She finds it hard to plan ahead and focuses on living "just for one day at a time."

Talk to your team about regular follow-up care and about your risk of recurrence. Many cancer survivors say it helps to talk with others who can relate to what they're feeling. Counselling can help if your fear of recurrence doesn't go away or becomes overwhelming.

For more information on life after treatment

Our booklet *Life after Cancer Treatment* provides more information and can help you prepare for life after treatment.

Finding your new normal

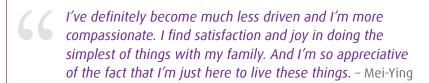


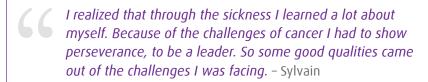
I can't say I'm back to my normal life from before because there have been a lot of changes in my life. You learn from what you went through. And I certainly do appreciate life more. – David

In the months after cancer treatment ends, people often gain a new understanding of what their life might be. You may find you're not getting back to the old normal but discovering a new one. It can be exciting but also scary when you don't know what to expect.

"In my practice, we talk a lot about the new normal," says Rosana Faria. "It's the integration of all your experiences. After you finish treatment, you have a new piece – cancer experience – to fit in to your personal life puzzle. You might need to put some strategies in place to help you function. You need to look at how to live your life with this new piece, and that will be the new normal. The new normal can also be about your lifestyle – how you take care of yourself now, your diet, your level of exercise. Managing stress can be part of it. All this is the new normal."

Many people find that what's important to them has changed. It's a process of self-discovery – one that they are happy to be able to make. They find themselves reflecting on relationships or professional goals or just life in general.





Resources



Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.



Ask a trained cancer information specialist your questions about cancer.

Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others.

Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer.

Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.



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 and our services or to make a donation.



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