



Canadian
Cancer
Society

Life After Cancer Treatment



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Life After Cancer Treatment

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

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

We're here to support you.

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.



We have short, easy-to-understand videos on common cancer topics. Visit cancer.ca/cancerbasics.

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Introduction

As your cancer treatment ends, you and your loved ones may wonder what the future holds. You may be happy and relieved that treatment is over, but it's also normal to have questions or worries about the future. This booklet will help you prepare for life after treatment – what some people call “the new normal.”

“Everybody thinks that they can just go through this and then they’re done and they’re back to normal. But it doesn’t work that way. I’m not done with it. I’m still dealing with it.” – John



What happens now?

For many people, finishing treatment for cancer is a time of change. While you're getting used to everyday life again, you're probably still facing challenges. You may be very tired and surprised to find that you still feel worried, scared, angry or alone. Some emotions may be as strong as they were during your treatment. Or you may have different feelings. There may be changes to your body as well as in your relationships and sexuality, work and finances, or spirituality. Being aware of and understanding these challenges can help you cope and live well after cancer.

We hope you find it helpful to read this booklet as you near the end of treatment. Many people say that it's helpful to think about and plan for what life might be like after treatment has ended. Your family and friends may also find this booklet useful. Reading it will help them understand what you're still going through, which can help everyone adjust to life after cancer.

Throughout this booklet, you'll hear from John, Ebe, Allan and Julie. Their experience may not be the same as yours, but their words are shared here to remind you that:

- You're not alone.
- You can get help if you need it.
- You can still discover new meaning and joy in life.

What to expect

“I just kept asking myself, ‘Am I really done?’ It’s kind of like a doubt if you’re really done or not. Then the days and the weeks go by and your doctors’ appointments get further and further apart. Yeah, OK, I made it. Did I make it? Let me see. Yeah. I think I made it. Yeah, I made it. It’s like I crossed a very turbulent river or something to the other shore. I don’t believe I did it.” – Ebe

A big part of life after treatment is learning how to manage expectations – both your own and others’ – of what life will be like. It can be hard to know what to expect and how to prepare for this new experience.

During treatment, it’s normal to look forward to being done and expect that life will be easier, more pleasant and less stressful. Many people aren’t prepared for the fact that it takes time to recover – it may even take longer than your actual treatment did. They expect life to go back to the way it was within a few weeks and become frustrated or upset when things don’t work out the way they expected them to. Many people still feel very tired or weak right after cancer treatment. They may not have much emotional energy, either.

“You wonder, ‘Am I always going to feel this way?’” – Allan

Family and friends may also have unrealistic expectations. Many people say that their family, co-workers or friends expect them to be back to normal soon after treatment ends and don’t really understand how much time or help they still need to heal.

You may also feel as though you’re expected to be positive and not complain because you’ve made it through treatment, especially when others have not. But staying positive is really about dealing with things in the best way that you can at the time. “There’s that feeling that if you’re not positive you must be negative,” says Julie. “Well, you can be positive and you can be angry.”

It often takes time and patience to adjust to new roles in the family when treatment is done. The way your family works and each person's jobs within the household may have changed. For example, if you used to do the cooking or yardwork before your treatment, you may find that these jobs are still too much for you. And yet, the family members who took over for you may want life to go back to the way it was.



Tips on managing expectations after cancer treatment

- Give yourself and the people close to you time to get used to things and to sort through feelings and expectations.
- Be honest about how you feel and what you need. You might find it helpful to let people know that you still have a lot to deal with and that you still feel very tired, weak, sore or scared. Having them read this booklet may help them understand.
- Let others know what you're able to do as you heal – and what *not* to expect. For example, don't feel you have to keep the house or yard in perfect shape because you always did those things in the past.
- Connect with other people who've had cancer. There are many ways to do this, such as face-to-face support groups or online communities. Your family members may also find connections like these useful.
- Consider going to counselling, on your own or with your family, if you find it hard to talk about your feelings and your needs. Your doctor or social worker should be able to refer you to someone.



MANAGING EXPECTATIONS: JOHN'S STORY

John was diagnosed with non-Hodgkin lymphoma the day after his daughter was born. What should have been a year of parental leave and enjoying being a new dad was instead taken up with months of intensive chemotherapy followed by 2 years of maintenance therapy.

"It's like you're pushed into the deep end of a swimming pool," says John. "You're falling into the water and everyone important in your life is stuck watching from the sidelines as you try to get yourself to the other end of the pool and out. But it's a long haul to get out of the water, and then, well – you're on the other side of the pool now, and you can't go back to how things used to be. But those people on the sidelines don't always know that."

And so, John found himself with a new and unexpected issue to deal with when treatment was over. His family didn't understand that his struggles hadn't ended just because his treatment had. "People didn't understand that I wasn't back to normal yet, that I might not be able to call them back the minute they phoned or that I didn't have the emotional capacity to deal with too many things."

In particular, John felt as though his mother was in denial about just how sick he'd been and the toll that cancer had taken on his body and his emotions. "I think that she expected it to be like a light switch that we could just turn off and be back to normal," he says. "But it wasn't that way. It was kind of difficult to be with her. I had to straighten her out a few times – let her know that, 'No. I'm not done with it. I'm still dealing with this.'"

Over time, things have gotten easier. John's energy levels are good. He's gone back to work. His daughter is beautiful – and he and his wife are expecting another baby. But, he says, there's definitely a lasting effect. "Having had cancer is something that's always with me, that I haven't let go of. Some days I can take the attitude that the grass is greener now, that I should live each day to the fullest. But I'm still finding it difficult to get back to normal every day. And that's one of the hardest parts." Even so, just knowing that some days are going to be better than others helps with managing expectations – for John and for everyone around him.

Your new normal

“I think normal shifts. And it doesn’t just apply to cancer. I mean, my father passed away years ago, and after that was a new normal. If you have a baby, it’s your new normal. Any life-changing situation sets you into a new normal.” – Julie

In the months after cancer treatment ends, people often gain a new understanding of what their life might be. It’s a time when you need to adjust to new schedules, changes in your body and energy levels, and new ideas about what’s important to you. Although many people talk about getting back to normal, most people find that this transition period is about finding out what’s normal for you now.

How you feel physically and emotionally will depend on many things:

- the type of cancer and the treatment you had
- how these things affected your body
- how you feel about and cope with these changes

It can be scary not knowing what to expect or what you’ll be able to do. You may still feel quite tired and sick and you may be unhappy with the physical or mental changes that cancer treatment has caused. Things that used to be easy – remembering a name, walking around the block, eating at a restaurant – may now seem nearly impossible.

You might find yourself wondering if you’ll ever be able to do things you once took for granted. “I used to run,” says Ebe, “and I went for a walk with my kids and I couldn’t even walk up a small hill. I felt like I was 90 years old. I kept telling myself what the doctors had said – it will not be like this forever.”



SLOW AND STEADY: ALLAN'S STORY

Allan, who was diagnosed with tongue cancer, has a new mantra: “‘Slow and steady’ works for me. I do all the same things I did before I had cancer, but I do them a little slower now.” He explains that chemotherapy and radiation treatments to his head and neck left him weak and exhausted, 30 pounds lighter, with a scarred, painful mouth and throat – and no salivary glands. He had to eat through a feeding tube for 5 long months. The former military man and police constable, an athlete used to cycling 100 km in a day and going on vigorous walks, couldn’t walk around his own block without stopping many times to rest. On his first bike ride after treatment, he passed out from exhaustion. “I overdid it,” he says wryly. “My friends had to carry me out of the woods.”

For Allan, adjusting to his new normal meant learning to accept his new energy levels – and to trust that they would eventually improve. “The healing process is so slow you think you’re never going to get better,” he says. “You really do have to give it time, and that’s the hardest thing for people to do.”

Learning how to eat again, for example, “was a long, slow process,” recalls Allan. “And it was frustrating – I’d be able to eat something one day and a few days later the same food wouldn’t go down. I remember ordering a hamburger in a restaurant and choking on it. That was extremely embarrassing. I learned very quickly there that I am never going to be the first one to finish eating. It’s going to be very small mouthfuls. I’m going to chew 20 times before I even attempt to swallow.” Still, he says, eating is a pleasure again – “It’s just very slow.”

He eventually went back to work, but to a desk job rather than the more physically demanding work he’d done before. He’s back to cycling 100 km at a stretch, “but at a slower pace than I used to go.”

He’s made peace with this new approach to life: “When I work around the house, well, before, everything had to be done that day. That’s not the case anymore. If I don’t get it done today, it’ll be done tomorrow.”

Doing things in your own time

“‘Slow and steady’ works for me. I do all the same things I did before I had cancer, but I do them a little slower now.” – Allan

People are often given overly hopeful information about how long it will take to feel better. You may be told that you'll feel back to normal in a matter of weeks or months, when in fact recovery can take much longer. Some people never feel exactly the same as they did before treatment. Or you may be told nothing at all – which still leaves you wondering if how you're feeling is normal. You may worry that you'll never feel better.

It's important to give yourself time to adjust to life after treatment – especially if there are major changes in the way you look or feel, how easily you can move around or your ability to communicate with others. Take things at your own pace. Remember that everyone is different and that nobody can predict exactly how your recovery will progress. Your healthcare team and other people who've had cancer can provide you with information and suggestions for coping with and understanding your recovery. But in the end, the experience is your own.

Over time, you might notice that things start to improve. Sometimes, change is so gradual that you don't notice it's happening. “One day, I caught myself dancing along to music as I cleaned my apartment,” says Julie. “I was so surprised that I stopped what I was doing. I couldn't remember the last time I'd had the energy to dance. It was so weird to rediscover things that were so normal to me before. But it's getting less and less weird.”

How to cope with stress

“I learned to relax. I learned to breathe deeply. I learned to just take myself away from everything, not necessarily physically, but to take my mind away. If I’m waiting for the subway and the subway is late, for example, I can just sit and meditate and breathe deeply. I learned how to handle stress much better than I did before.” – Ebe

Everyone copes with stress and tension in different ways. You may have to try a few things before you figure out the best way to help yourself feel better after cancer treatment.

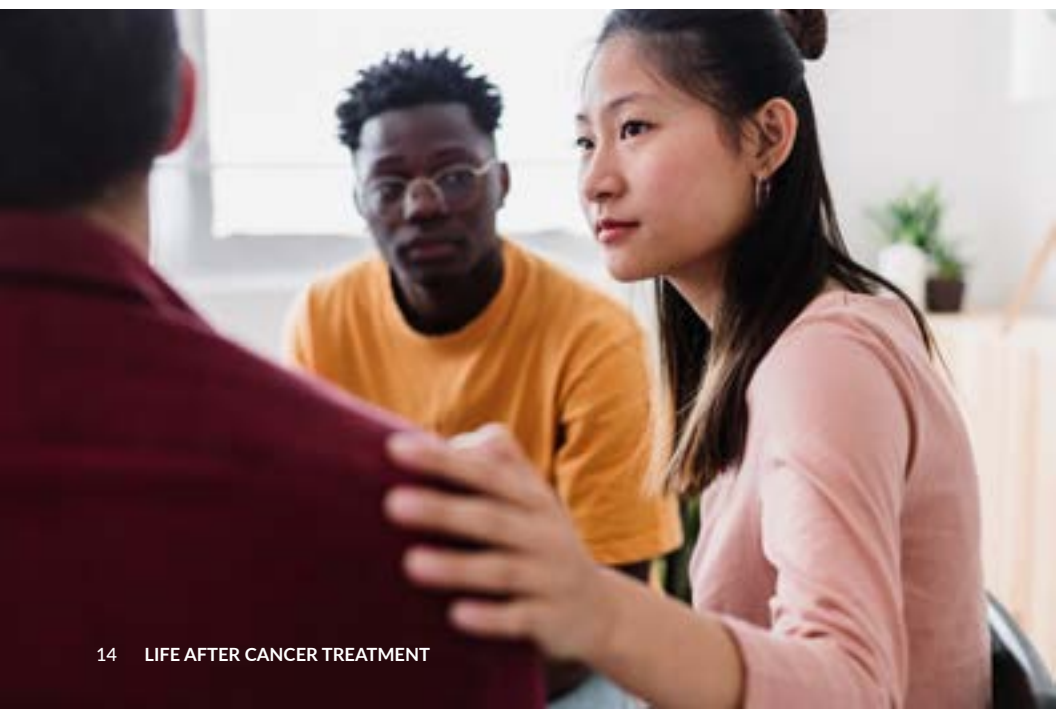
Julie, for example, spent the few weeks between the end of her treatment and going back to work resting, seeing friends and going to the gym for short workouts. She also took a meditation course and visited a dietitian and a social worker at the hospital where she’d been treated for breast cancer.

“I wanted to make good use of that time,” she says. “And I’d have to say those weeks before I started working again were lovely. I was done, I was feeling better, my hair was growing. I was starting to feel normal. I was starting to recognize that normal could be a thing I could enjoy again.”



Tips on coping with stress

- Talk to others about your feelings. For example, joining a support group can connect you with others who have had cancer and understand how you feel.
- Write about how you feel in a journal or blog. Writing can help you express your feelings, set new goals and prepare for follow-up visits with your healthcare team – you may even gain a new outlook on your experience.
- Regular physical activity – even very gentle or moderate movement – can make you feel calmer and more in control.
- Accept that recovery takes time. Even if you don't feel well today, you may find that in time you start to feel better.
- Relax and breathe. Meditation and relaxation exercises can help focus your mind and change your view on things.
- Consider trying complementary therapies, like acupuncture, yoga, massage or music therapy. Some people find that these supportive therapies can help reduce stress and anxiety. They may also help relieve symptoms like pain or chronic fatigue.
- Write out a list of the things that have helped reduce your stress or anxiety levels in the past.





USING MEDITATION TO MANAGE STRESS: JULIE'S STORY

Julie was diagnosed with breast cancer at the age of 44. But her cancer journey started at least a year before that, when her mother was diagnosed with Alzheimer's disease.

"After my mom got her diagnosis, I remember thinking, 'What if somebody told me I had a disease?'" says Julie. "What kinds of things would I want to change in my life? Well, I needed to be a little braver about dating again. I was spending too much time at work. I wanted to be in better shape. So before I knew I had cancer I'd already started to think about my priorities, about the importance of balance."

And so she started to make changes to her life. One of the things Julie did to create that sense of balance was learning how to meditate. "I approached a dear friend of mine who teaches mindfulness meditation and asked her to teach me. It was like the universe was providing me this opportunity at a time that I needed it and, more importantly, was open to it. I knew I was going to need something like this after I was diagnosed with cancer."

Meditation made her better able to focus, in her words, "on what's really important, on what's really happening." She adds, "I realized worrying about stuff that may never happen was just a real waste of my energy. I could worry that, 'Oh my God, what if people look at my hair funny?' Then it doesn't happen. So, I'm a little bit more protective over where I spend my energy. Of course, I still worry. I still get mad at myself. But I get over it quicker and move on."

Meditation has helped Julie deal with many of the challenges of life after treatment – body-image issues, work stress, her fears about cancer returning. "In the waiting room at my first follow-up appointment," she remembers, "I was so nervous. I tried every meditation mantra I knew."

Now that she's back at work, Julie makes regular time to practise. "When I'm at work, 3 or 4 times a week I will just close my door, put on some music, put on my earphones and just meditate to the music." And, in the spirit of a balanced life, she adds, "I make sure that when I'm not at work I don't look at my email. I just enjoy each moment."

Your feelings after cancer treatment

“It was such a relief to know that it was over. It’s like this big elephant was taken off my back. All of a sudden, I was back in control of my life. I could do what I wanted to do – even though I couldn’t do anything. Just the fact that I didn’t have to go to the hospital every day. I didn’t have to have that mask snapped on my face and I didn’t have to listen to that machine doing its banging and clunking. That was a great, great relief.” – Allan

The end of treatment is a big event for most people. You may start to feel better and get back to doing the things you like to do. The weeks and months of going to the hospital are over. Some people think they should celebrate this milestone, but you may not feel like celebrating.

At the end of treatment, you may be very weak and you may still have side effects. And now that you aren’t busy with treatments, you may find that you struggle with mixed emotions. Many people say that of course they feel relieved and happy – but they also feel lonely, angry, worried, sad or depressed. If you’re having a hard time after treatment, you may find it helpful to know that these strong feelings often fade as your strength and energy come back.

“It’s the whole emotional rollercoaster,” says John. “I remember once, after treatment, going out to a baseball game with my buddies, having a beer. I thought everything was great. I felt good. And then when I was driving home, I just lost it, uncontrollably crying. I had to pull the car over and wait to get my composure. I had no clue what was going on, but I was having a rough time. There are times when I still break down and cry for no reason. You’re overcome with emotion, wondering why this happened to you.”

The best thing you can do if you have strong feelings as your treatment ends is talk about them. Sometimes sharing how you feel with family, friends or other people who’ve had cancer is just what you need. Or you may need to talk to someone from your healthcare team or ask your doctor about seeing a counsellor. It isn’t easy, but keeping these feelings inside only makes you feel worse.



Feeling lonely

It's very common to feel lonely or have a sense of being on your own after treatment ends. There can be many reasons for this. You may actually be spending a lot more time on your own now, especially if you took time off work and haven't gone back. Even if you're surrounded by family and friends, you may still feel lonely if it seems like the people around you don't understand what you've been through.

Coping with changes to how your body looks can make you feel lonely because you may find that you now feel different from other people – even if the changes aren't obvious to everyone.

You may be surprised to find that you miss the support and the company of other people with cancer and members of your healthcare team at the hospital or cancer centre. It's normal to become very attached to these people. After treatment ends, you may feel lost or nervous without their support.

Being angry

“I definitely went through an angry phase after all my treatments. Once it was all done and I could breathe, I got angry for a couple of weeks. And my sister asked, ‘Why? You should be so positive.’ I told her, ‘You know what? I recognize that I am very lucky. I’m very grateful, and I always have been, but I’m also angry. I’m allowed to be both.’” – Julie

Many people are angry, an emotion that can be mild or strong. You may be a little bit frustrated about things that happened during diagnosis or treatment or hurt and angry if your family and friends weren’t helpful or supportive. Julie’s anger, which is normal, stemmed from her grief about losing her “whole life.” When she was diagnosed with breast cancer at the age of 44, it felt as though her life had screeched to a halt and then changed greatly: “I was in the best shape of my life, strong, in my sexual prime. I had just started dating again. And now I’m scarred. My lymph nodes have been removed and I’m constantly worried about lymphedema. I have chronic pain. I’m in menopause. My libido went into the toilet. I have to take medication. So, I’m just mad.”

A certain amount of anger is normal – it can even motivate you to make changes in your life. But hanging on to it can stop you from moving on. People have found that when they share their strong feelings like fear, anger or sadness, they’re more able to let go of them. It’s OK to talk about your feelings and OK to ask for help.

Feeling sad or depressed

“I allow myself to have sadness because sadness is part of life. It’s part of being. I don’t push myself to get out of it, but I don’t let it control me.” – Ebe

As strange as it seems, it’s normal to feel sad at the end of cancer treatment. This is a time when you might grieve for what you’ve lost or think about the hard times during treatment. You may be sad about the changes to your body or your energy levels.

But sometimes people find that their sadness never goes away or that it gets worse over time. When a sad, despairing mood won’t go away and gets in the way of your day-to-day life, you may have depression. It’s an illness, sometimes called clinical depression, and it’s not a sign that you failed or can’t cope. It’s easy to miss the signs of depression – but recognizing it is the first step to feeling better. Possible signs of depression include:

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

Talk to your doctor if you have any of these signs of depression. Depression can and should be treated. A person who is depressed can’t “snap out of it” or “cheer up” through willpower alone.

You may need to see a specialist such as a psychiatrist or psychologist for medicine or therapy. Treating your depression can improve your sleep, appetite, energy and self-esteem.

Grieving

Grief is the sense of loss that you feel when you lose something valuable in your life. Grief isn't only about death. Most people connect grief with the death of a loved one, but you can grieve for other reasons. Grief is an emotion that many people feel as they adjust to life after cancer. You may feel grief over the loss of your sense of health and security, a lost body part, infertility, disruptions to future plans, or money problems from taking time off work. Feelings of grief may come on suddenly, especially if treatment kept you very busy – you may have been so focused on making decisions and having treatments that it's only when you start to slow down that the feelings come.

Everyone experiences grief in their own way and in their own time. To cope with grief, you need to recognize, accept and release the feelings.

Being honest about how you feel is the best way to get through your grief. Family and friends may want to help but not know how to. Let them know that all they really need to do is listen and support you – that you don't expect them to make everything better for you.



Worrying that cancer will come back

“For a while after the treatment had finished, if I had headaches or something, I'd say, ‘Why this headache? Could the cancer be in my brain, in my head?’ I said, ‘No, no. You can’t live this life with a sword over your head and you don’t know when it’s going to come down. If the doctor did everything and they didn’t tell you anything, then it’s good.’” – Ebe

Many people worry that their cancer will come back (recur), especially during the first year or so after treatment. During treatment, you know that something is being done to stop or slow the cancer. But after, it can seem as though nothing’s happening and the cancer could return. Certain events can also trigger this fear and anxiety such as:

- your follow-up visits
- hearing about someone else being diagnosed with cancer or dying from cancer
- visiting or going by the hospital where you had your treatment
- feeling sick or having symptoms similar to the ones you had when you were first diagnosed with cancer
- significant life moments such as weddings, birthdays and anniversaries

Fear of the cancer coming back should become easier to manage with time. But you may never stop worrying completely. For some people, the fear stays or is so strong that they no longer enjoy life, sleep or eat well, or keep their doctors’ appointments.

To help cope with the fear of cancer coming back, you can ask your doctor in follow-up visits about the chances of cancer coming back and the symptoms to watch for so that you don’t have to worry about every ache or pain. Being informed and understanding what you can do for your health now can also give you a greater sense of control. Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible. Eating well, exercising regularly and getting enough sleep can all help you feel better physically and emotionally.

How you feel about your body

“If you’d asked me how I felt about my body a year ago, I would’ve told you I felt sexy. Now, well, I have this dented boob. I’ve gained weight. My hair is growing back – but it’s growing back very differently than it was before. My libido is returning, but really slowly. So, I look at pictures of myself from before the diagnosis and I think, ‘Wow, I looked good’ – but I also had cancer in my body. Now, I’ve got some work to do, but I don’t have cancer in my body.” – Julie

Many people are upset or angry at the way that cancer treatment has changed their bodies. Any change can be hard to accept and can affect how you feel about yourself and your body. For example:

- You may have scars from surgery.
- You may have lost a body part, such as a breast or limb.
- You may have to live with a stoma.
- Your hair may have fallen out or grown back differently.
- You may have gained or lost weight.
- Your skin may have changed because of treatment.

Some of these changes may be for just a short time, while others may last a long time or be permanent. People may be able to see the changes to your body, or they may not. Even if you don’t have any physical changes from cancer, you still might feel that others see you differently. You may think that others don’t understand you now.

Be patient with yourself. Over time, as you learn to cope with and accept them, the changes may just become part of everyday life. Some people even come to see some of the changes such as scars as signs of strength and survival.

“I feel I’m more in touch with my body now and that I have to take care of it by exercising and eating better. I value myself, I value my body, I value all the organs that tolerated that toxic chemotherapy. Thank you to my liver, thank you to my kidneys. It’s an appreciation.” – Ebe

Some people may need more time or struggle harder to accept changes to their body. Sometimes, negative feelings about these changes can affect your quality of life. Signs that you might need some help coping include:

- You don’t want to leave your house because you don’t want people to see you.
- You don’t want to date or meet new people.
- You avoid intimacy or sex with your partner.
- You’re afraid to undress in front of your partner.
- You won’t let your partner see your scars.
- You’re embarrassed because you lost or gained weight.
- You feel ashamed for having cancer.
- You’re unable to accept yourself for who you are now.

It can be hard to talk about these personal changes, or you might worry that people will think you’re vain because you care about how you look. But these are very common, very real concerns. Keeping your feelings to yourself can stop you from doing the things you enjoy or getting help.

Getting help

“I hated the idea of seeing a counsellor at first. But then I made a connection with the social worker at my treatment centre. She’s very down to earth and always seems to say the right thing – even if it’s something you sometimes don’t want to hear at first. She really helped me deal with some of the feelings of negativity and sadness, even some of the physical things. I still have that connection with her, even after treatment.” – John

One-on-one support

You may be uncomfortable with the idea of going to a therapist or counsellor. But most people find that talking to an expert really helps, and they soon get over feeling awkward.

Many different professionals – including psychologists, psychiatrists, social workers and spiritual care workers – can provide counselling. They are trained to listen and to help you deal with your situation. They can help you:

- cope with feelings like fear, anger, guilt, depression and anxiety
- work through issues with identity, self-esteem and body image
- deal with family and relationship problems
- find meaning and purpose in life

Don’t worry if you’re not clear about how counselling might help or even exactly what it is you want help with – the counsellor will help you figure that out. Counselling for people who have had cancer usually involves:

- talking to the counsellor about your cancer and treatment and how it’s affecting you
- sorting out what issues or concerns you want help with
- coming up with a plan to deal with your concerns

Support from people like you

“There’s an immediate kinship between cancer survivors. I can’t describe it other than the people that haven’t been through it don’t really understand it. They give you words and maybe talk about it and say they’ve been through something similar, but it’s just different.” – John

Many people find that it really helps to talk with other people who’ve been through the same thing. It can help to know that you’re not alone and to get the outlook and experience of people who’ve “been there.”

Support groups are places where several people can meet to safely talk about feelings and experiences. These groups often meet at a cancer centre or hospital. John, for example, went to a lifestyle change program put on by his local hospice. “You’re kind of thrown into this group of people and you get to hear their stories, share your experiences and what you’re going through, which really, really helps,” he says.

If you think meeting with a group of people isn’t for you, you may find support through an online community. Or try one-on-one support by phone, in person or online.





WE CAN HELP YOU FIND SUPPORT

The Canadian Cancer Society can help. We can offer support, answer questions you might have and help you find other support services.

- Call our Cancer Information Helpline at 1-888-939-3333 (TTY 1-866-786-3934) or visit us at cancer.ca.
- Search our Community Services Locator at csl.cancer.ca. You'll find information about support groups and more in your community.
- Join our online community, CancerConnection.ca. It helps people with cancer, as well as loved ones and caregivers, connect with others who know what they are going through.

Follow-up care

“It’s very comforting to know that people want to keep seeing you. I have great respect for everybody where I was treated, from the hall cleaners to the nursing staff to the doctors. Everybody in that hospital, their whole focus is on the patients. I know some people never want to see the place again. But to me, that hospital is a lifeline.” – Allan

After cancer treatment, you’ll likely have regular visits with your doctor to keep track of how you’re doing and to make sure that any problems are found early. This is known as follow-up care. At first, you may see one of the specialists from your healthcare team for follow-up care. Later on, you may see your family doctor.

Going to follow-up visits may help you feel in control as you get back into everyday life. Or you might not be happy about the idea of still going to doctors’ appointments. You may find them scary, or you may be frustrated by the idea of more tests and exams.

If you have any doubts about your follow-up care, talk to someone on your healthcare team. Don’t avoid a visit or a test. Follow-up care is meant to help you stay healthy. And know that as time goes on, these checkups should become less frequent.

BEING ON MAINTENANCE THERAPY

After active cancer treatment ends, some people are put on maintenance therapies that last for months or even years. The goal of these therapies, which are usually drugs or hormones, is to keep the cancer under control or prevent it from coming back or spreading.

Being on maintenance therapy can make you feel as if you're stuck somewhere between being a patient and finishing your treatment. For some people, maintenance therapy is reassuring – they're happy to keep doing something to help make sure the cancer doesn't come back. For others, it's a constant reminder of the illness.

If you're having maintenance therapy, it may help to think of cancer as a health condition that has to be managed, like asthma, diabetes or heart disease. So continuing treatment is just part of your plan to look after your overall health.

Keeping track of your health

People often need information on the treatment they had in the past and the kind of follow-up care they will need in the future. You may find it helpful to collect these details for your own personal health record and follow-up care plan.

Your hospital or treatment centre usually has this information, and you can ask your healthcare team to help you gather or create these documents for you. You may need to pay for it. You might want to keep paper copies of these documents in a binder or file folder at home, or you can create electronic or online versions of them.

Many people find that having information about their past and future healthcare is very useful. It can be reassuring to have all this information in one place and to have a clear plan for your healthcare in the years to come.



What to include in your personal health record

As time passes, it can be hard to remember each and every detail of your cancer diagnosis and treatment. Your personal health record keeps track of this important information. It can be very valuable to the doctors who care for you throughout your lifetime. Personal health records usually contain information on:

- the date of your diagnosis and test results
- the type of cancer you had, including tissue or cell type, stage and grade
- the types of treatment you had and when, including drug names and doses
- other medical issues during treatment, such as side effects
- support services you used during your treatment
- contact information for your healthcare team

Creating your follow-up care plan

Gathering together information about the follow-up care you will need in the future can also be useful to you and your healthcare team. Details in a follow-up care plan may include:

- your schedule for follow-up visits
- your schedule for any follow-up tests needed – for example, blood tests, x-rays, CT scans, MRIs and other tests
- information about the risk of cancer coming back and what signs or symptoms to watch for
- information about the late and long-term side effects of your treatment
- tips for healthy living and your wellness plan, such as eating well and being active

What to expect during checkups

During your follow-up visits, your doctor will examine you and ask how you've been feeling. Be honest. Talk about any symptoms that are bothering you, even if your doctor doesn't ask about them. Tell your doctor how you feel mentally as well as physically. Depending on the type of cancer you had, you may need to have blood tests, x-rays, scans or other medical tests.

It can help to bring a family member or friend to your checkups to take notes and offer support.

Coping with anxiety before your checkups

The first thing that many people want to know is which symptoms might mean that cancer has come back. The answer will depend on the type of cancer and the treatments you had, as well as your overall health. You may be told to watch for certain symptoms, but it's also important to just know your body and what's normal for you.

Going to your follow-up visits can make you feel anxious, especially at first. It's very common to worry that your doctor is going to tell you that the cancer has come back. You may also feel anxious if your follow-up is with a doctor at the hospital because going back there brings back bad memories of your treatment, tests and side effects.

It can help to make a plan for coping with anxiety before your checkups. Think about activities that you know make you feel calmer or can distract you from worry, like meditation, yoga, walking or spending time with friends. These can help you get through the day of the appointment and maybe the days leading up to it too. Once you've had a few checkups and all is OK, you should begin to feel less anxious about these visits.



Questions to ask at follow-up visits

- Who is in charge of my follow-up care? Where will these checkups take place?
- How often, and for how long, will I have follow-up visits?
- What signs or symptoms should I report right away? Which ones can I wait to report at my regular follow-up visits?
- What follow-up or screening tests will I need? How often will I need these tests and for how long?
- How long will I have to take the medicines I'm on? Do they have any side effects and how do I manage them?
- Are there any lasting effects I should watch for? What should I do if I notice them?
- Who will manage any late or long-term effects, like pain or fatigue?
- Can I get a written summary of my personal health record and my follow-up care plan?
- What can I do to lower the chances of cancer coming back?
- What type of physical activity would be best for me?

Healthy living

Your wellness plan

Now that treatment is over, you may be thinking about some healthy goals to work toward. Being active, eating well, keeping a healthy body weight, limiting alcohol, living smoke-free and protecting yourself from the sun can help you:

- regain or build strength
- ease side effects like fatigue and anxiety
- lower the risk of second cancers
- lower the risk of other health problems like type 2 diabetes and heart disease
- manage stress
- feel more energetic
- enjoy life more

If you'd like to make some lifestyle changes but don't know where to begin, your healthcare team can help. After all, a wellness plan is an important part of your follow-up care. Your wellness plan will be made just for you and your own needs, preferences, health and fitness level – it may look very different from another person's plan. One person might need to focus on quitting smoking while another needs to start exercising and eating more vegetables and fruit. What's important is that you understand your plan and can start to follow it.

It can be hard to make lifestyle changes and even harder to stick with the changes in the long term. Having the support of your family, friends and healthcare team can make it much easier to follow your wellness plan. For example, you might ask your partner or a friend to keep you company as you walk, or ask a dietitian for tips on healthier snacking.

It can take time to discover what you're capable of and to get used to changes in how your body works. You may be quite tired, especially at first. Don't get discouraged by setting goals that are too big. Start with small goals you can reach and work toward them bit by bit. Even someone who used to run marathons needs to start with a short walk.

Be active

"I'm a big walker. But, at first, walking down the street I felt like I had cement on my feet." – Julie

If you were physically active before or during cancer treatment, you may be able to get back to your regular routines without too much trouble. But most people find that it takes time. You may have to accept that your body has new limits, especially at first. You may not be able to move as far or as fast. Work with your healthcare team as you decide to increase your activity level. "Now, I do virtually everything today that I did before," says Allan. "I walk. I go for long bicycle rides. But I just don't do anything as fast or as hard."



If you've never been physically active before, you can start slow and try to gradually increase the amount you move. Even gentle, regular exercise like brisk walking is good for you and can help you feel better and stay healthy after treatment. Research also shows that staying active after cancer treatment can help lower the risk of cancer returning. Plus, it's a great way to relieve stress.

Getting started

Almost any sport or activity can be adjusted to your fitness level, so the important thing is to choose something you enjoy. You might try walking at first to build up some strength and stamina. If you need to stay in bed during your recovery, even stretching or moving your arms and legs can help you stay flexible, relieve muscle tension and feel better. Eventually, try getting out of bed and walking around the house.

TALK TO YOUR HEALTHCARE TEAM BEFORE GETTING STARTED

Gentle exercise such as short, slow walks, stretching and swimming are often OK to start with. But if you're planning something more energetic like running, lifting weights or playing a contact sport, your doctor needs to know. They can help you come up with a plan that's best for you.

A good goal to work toward is to be active for about 30 minutes a day or almost every day. Try brisk walking, tai chi or water aerobics. Or try raking leaves, vacuuming or doing the laundry. You can also reach your overall goal of 30 minutes a day by splitting your activity into 3 sessions of 10 minutes each.

When you're ready, you may consider vigorous activities such as hiking uphill, digging in the garden, doing martial arts, swimming laps or playing a sport like soccer or hockey.

If you're not sure what kind of physical activity is right for you or you'd like help adjusting what you did in the past, talk to your healthcare team. You may also be able to join a special class or exercise program that is just for people who've had cancer – these places often have personal trainers, physiotherapists or other healthcare experts you can work with.



Tips

- Try to exercise when your energy level is highest.
- Always warm up and cool down. Try stretching or taking a short walk before and after other physical activities.
- Set goals for yourself that you can reach. Start with small steps and then add a little bit tomorrow to what you did today.
- Find simple ways to get active. Take the stairs, park farther away or get off the bus or train a few stops early.
- Walk indoors, such as in the mall, when the weather is bad.
- If you find physical activity dull or are bored with your usual routine, combine it with something you like to do. For example, do arm curls, squats, stretches or sit-ups while you watch TV.
- Find an exercise partner or group. Exercising with others can keep you motivated and provide some friendly support. Someone who went through treatment with you or someone from a local support group might be interested in walking together.
- Try line dancing, belly dancing or Zumba if you enjoy music.
- Find activities you can do as a family, such as bowling or playing active video games that encourage you to get up and move around.
- Avoid overdoing it. If you feel tired, listen to your body and lower your intensity. Wear light, breathable clothing and drink plenty of water to stay comfortable throughout your activity.

Eat well

Eating a healthy diet is an important part of your wellness plan. Eating well will help you get your strength back and stay at a healthy body weight, which is good for your overall health.

It's also important for you to eat well because eating well can lower your risk for other health conditions, such as heart disease, type 2 diabetes and osteoporosis (weakening of the bones). Healthy eating can also help reduce your risk of developing some types of cancer.

It can be hard to change the way you eat, and even harder to stick with those changes in the longer term. Many cancer centres have dietitians who can discuss your food choices with you and help you create a food plan that works. In time, and with support and practice, these new habits should become easier.



WANT MORE INFORMATION ABOUT EATING WELL?

Our booklet *Eating Well When You Have Cancer* has detailed information on eating well during cancer treatment and recovery. It's written for people with cancer and for caregivers helping with menus, food shopping and preparing meals.

Get to and stay at a healthy body weight

The very fact that you had cancer treatment may make it harder to get to and stay at a healthy body weight. For example, certain kinds of chemotherapy, steroids and hormone therapies can lead to weight gain. Sometimes the weight stays on even when treatment ends and you go back to eating the way you once did. And if you're very tired, you may find it hard to exercise, which can also make it harder to keep or get to a healthy weight.

Some people have the opposite problem – they have no desire to eat and they lose weight. Some people say that weight loss or loss of muscle tone makes them feel weaker or less capable.

You may find that the usual ways to gain or lose weight don't work. That's what Julie found when she tried to get back to the shape she was in before she was diagnosed with breast cancer. As she began to ease back into her workout routine, she noticed it was harder to lose fat or gain muscle after surgery. "I'd gained about 15 pounds. I'm angry or frustrated at times about it," she says, "but I keep telling myself, 'You know what? You're doing the best you can.'"

Keeping a healthy body weight is an important part of healthy living after treatment – it can make you feel better and stronger and help prevent other health problems. But you're not alone if your weight changes after cancer treatment. Be patient with yourself and focus on what you can control, such as eating a healthy diet and being active if and when you can. A dietitian can help you create a food plan that works for you.

Limit alcohol

To reduce your cancer risk, it's best not to drink alcohol. *Canada's Guidance on Alcohol and Health* outlines the health risks of alcohol and can help you make an informed decision on whether you drink and how much. If you choose to drink alcohol, keep your cancer risk as low as possible by having no more than 2 standard drinks a week. The less alcohol you drink, the lower your cancer risk.

One standard drink is:

- a 341 mL (12 oz) bottle of beer (5% alcohol)
- a 142 mL (5 oz) glass of wine (12% alcohol)
- a 43 mL (1.5 oz) shot of spirits (40% alcohol)

Live smoke-free

There are many reasons for people who've had cancer to not smoke:

- Research shows that smoking tobacco can increase the chances of getting cancer in the same area or developing a new, different cancer somewhere else in the body.
- Quitting can help you recover more quickly from surgery and feel better in the short and long term.
- If cancer treatment has put you into menopause, quitting can help relieve hot flashes.

If you smoke and have tried to quit, you know it isn't easy. The nicotine in tobacco is very addictive. For many people who smoke, using cigarettes and other tobacco products is part of their routine to relax and relieve stress. Although you might not have been able to quit during the stress of cancer treatment, maybe it's time to think about it again now that treatment is over.



READY TO QUIT?

It's OK if you need help to quit smoking – most people do. You don't have to do it alone. To find a free, confidential quitline service in your area, contact 1-866-366-3667 or visit cancer.ca/quitlines.

Protect yourself from the sun

Some cancer treatments, including radiation and chemotherapy, can make your skin more sensitive to the sun. This increased sensitivity can last for years.

To protect your skin:

- Try not to be in the sun between 11 a.m. and 3 p.m. (when the sun's rays are strongest) or any time of the day when the UV Index is 3 or more.
- Seek shade, and cover up with clothes that are tightly woven or have labels that say they are UV-protective. Also wear a wide-brimmed hat, and remember your sunglasses.
- Use a broad-spectrum sunscreen with a sun protection factor (SPF) of 30 or higher. Sunscreen should be used along with shade, clothing and hats – not instead of them.



Dealing with side effects

Most people have at least some side effects – such as nausea, fatigue or hair loss – during cancer treatment. But many people are surprised when they still have side effects after treatment has ended. These are called long-term effects. Other side effects can start after treatment finishes and are called late effects.

Whether you'll experience late or long-term side effects will depend on the type and stage of cancer you had, as well as the treatment you received and how your body responded to it.

Visit cancer.ca/sideeffects for a complete list of side effects and symptoms and how to prevent or manage them.

Bladder and bowel incontinence

Cancer and its treatments can sometimes lead to incontinence – the loss of control over your bladder or bowel. These problems can last for a short time during and after treatment, or they may never completely go away.

While you were in treatment, it may have been easier to accept these problems as something you just had to put up with. Now that you're done, you may be more worried about your control because you're returning to work or want to get back to your usual activities like eating out, shopping and travelling. These problems can be very upsetting and may make you feel ashamed or embarrassed.

Fortunately, most people who are suffering from incontinence can find ways to improve their symptoms. Incontinence pads, found at any drugstore, can help. Some people find it helpful to empty their bladder on a schedule or change what they eat and how much they drink.

Ask your doctor what you can do if you're having issues – including coping emotionally – with bladder or bowel control. If it's still not getting better, your doctor may suggest medicine or surgery. A physiotherapist may also be able to help you manage incontinence.

“I had to get up sometimes 4 or 5 times a night to go to the washroom. You know, I'm 65, so you get older and you get up more often. But never like that. For a couple of years it was that way, but now it's gone back to once a night.” – Allan

Changes in weight and eating habits

Weight gain or weight loss are common late and long-term side effects. You may have lost weight because chewing and swallowing were very difficult or you may have gained weight because you weren't able to be active. Feeling as though you weigh too much or too little can affect your self-esteem. Coping with weight gain or loss after cancer treatment means accepting and understanding the different way your body might work now.

Your doctor may be able to refer you to other healthcare professionals who can help with these kinds of side effects. You may want to talk to a dietitian about a food plan that can help you get to a healthy weight or to a physiotherapist about how to rebuild strength and muscle tissue. These types of services are different across the country, but there should be something available to you.



Fatigue

“For a year after treatment I didn’t feel I was back to normal energy-wise. I felt like I had maybe 30% of the energy I had before. And then as time went by I gained a little bit more energy, maybe 75%. Now I would say I’m 95% normal energy-wise, according to my age and the things I used to do.” – Ebe

Fatigue – or feeling extremely tired – is something that many people experience, especially during the first year after treatment. This fatigue is different from normal tiredness. It doesn’t go away with rest or sleep and can affect your quality of life. You may find it hard to find the energy to get through even the most basic tasks of daily life, like bathing, dressing, shopping, cooking or eating. You might even feel that you can’t return to work because you’re simply too exhausted.

Feeling this tired, all the time, is very distressing. Fatigue can make you grumpy, especially if you find yourself too tired to eat after making lunch or needing a nap right after a good night’s sleep. Sometimes even having a conversation or making a decision can seem overwhelming.

The good news is that this side effect gets better over time for most people. Try not to be discouraged if you keep feeling tired for some time. Tell yourself, and others around you, that fatigue is a sign that your body is still healing. Listen to your body and don’t overdo it. It’s OK to have lots of breaks or naps in your day as you continue to recover.

In Allan’s case, his fatigue is much better than it was at first, but he still gets tired. He says, “Before, I could work an 8-hour day and go out and work some more at night.” Now, he manages by making sure that he has a break and takes a rest. “Now if I work around the house for 3 hours straight then I have to sit down and rest for a minute. If I’m on the bike for 3 hours, after that I have a shower, sit in my lazy chair and have a nap.”

Be sure to talk to your healthcare team if your fatigue isn’t getting better or if it gets worse over time. Sometimes it means that another condition that adds to fatigue, such as depression, chronic pain or infection, needs to be treated.



Tips

- Get some regular exercise. Many studies show that exercise helps with cancer-related fatigue. And so, as odd as it may sound, the best strategy if you're feeling tired is regular activity.
- Start slowly. Even trying a 10-minute walk at first and working up to half an hour a few times a week can make a difference.
- Use less energy for household tasks. For example, sit on a stool to chop vegetables or wash dishes.
- Pace yourself. If a task is too tiring, divide it up into smaller steps and spread the work over several days.
- Let others know that you still need help. Ask for what you need, whether it's help with meals, errands or household chores. Friends and family are often still willing to help but may not know that you need it or what to do.
- Think about joining a support group or online community. Talking about your fatigue with others who've had the same problem may help you find new ways to cope.
- Ask about a flexible work schedule or reduced hours. Gradually resume a normal work schedule or duties as you feel up to it.
- Ask yourself if you might be depressed. Being very tired on its own can be depressing, but the symptoms of depression can also be mistaken for fatigue. Treating depression may help the fatigue go away.

Fertility problems

Sometimes treating cancer can lead to infertility. If you are infertile, it means you can't get or stay pregnant or you can't get someone else pregnant. Infertility can last a short time or be forever.

If you wanted to have children after cancer treatment, this can be devastating. Even if you weren't planning to have children, it may still make you feel strange to be told that you can't. For some people, loss of fertility is as emotionally painful as getting their original cancer diagnosis. It can feel like the end of normal life – as though they won't be able to achieve the goals they had before cancer. If you're finding it hard to come to terms with infertility, it may help to speak with a counsellor.

Lymphedema

Lymphedema is swelling caused when your lymph fluids – the clear, yellowish fluid made of nutrients, white blood cells and antibodies – can't flow normally and build up in the body. It often happens in the arm, leg, face or neck.

You may be at risk for lymphedema if you had lymph nodes removed by surgery or if they've been damaged by radiation therapy or the cancer itself.

Lymphedema can happen soon after treatment or months or even years later. It can be short term or last a long time. Common symptoms of lymphedema include:

- swelling of the arm, leg or trunk on the affected side of the body
- feeling of heaviness or discomfort in an arm or leg
- less flexibility in a hand, wrist, arm or ankle
- problems fitting into your clothes, such as a sleeve or pant leg
- tightness of rings, a watch or bracelets (even though your weight hasn't changed)
- redness or increased warmth in the swollen area, which may mean you have an infection
- infections that won't go away or keep coming back in the same area
- feeling of tightness in the skin (even before there is noticeable swelling)

Check your body regularly for changes, and tell your doctor right away if you notice any of these symptoms. Ask for a referral to a lymphedema specialist who can assess and treat the condition. It's easier to manage lymphedema when it is found and treated early.



Tips

- Wear a compression sleeve if a doctor or specialist recommends it.
- Be careful using saunas, steam baths and hot tubs. Some people find that heat can make lymphedema worse.
- Keep your skin moisturized. This helps keep the skin supple and prevents it from becoming dry and cracked, especially in winter.
- Wash the area well with soap and water if you get a cut or burn on your arm or hand.
- Keep the area clean. Your doctor or pharmacist may suggest an antibacterial cream or ointment.
- Don't be afraid to do physical activities. For example, research shows that lifting weights does not make swelling worse. Listen to your body. Start slowly and build gradually.

Memory and concentration changes

Many people notice changes in their abilities to think clearly, get or stay organized, concentrate, or remember words or things. These symptoms are often called chemo brain or chemo fog, although they can also show up in people who've had radiation therapy and other types of treatment. Admitting to and accepting these kinds of changes can be upsetting and challenging.

These changes are real. They can appear at any point during cancer treatment, shortly after treatment ends or even much later. They may get better over time, but they don't always go away. Sometimes, other health issues, such as depression, anxiety or menopause, can also affect attention, concentration and memory.

It can be annoying and embarrassing to struggle with tasks that used to be simple. You may no longer enjoy reading a long book or you may find social situations like parties can be a challenge if you can't follow conversations. If you're working, changes to concentration and memory can make it harder to do your job.

Often, just knowing that the changes are due to cancer or its treatment can make dealing with them a bit easier. Learning about your symptoms and what you can do to cope can be helpful. It might be useful to talk to others who have gone or are going through the same thing. Talk to your doctor if you think that a medicine you're taking is causing memory or concentration problems, or ask about seeing a specialist to help you with them.



Tips

- Write everything down. Keep lists and carry them with you or saved in your phone.
- Record dates, times and reminders in a journal, in your phone or on a whiteboard in the kitchen.
- Don't try to do too much at one time. Try to recognize and accept your abilities as they are right now.
- Do things that need more focus when you are most alert. For example, set aside time in the mornings to read and reply to email.
- Put small signs around the house to remind you of things to do, like taking out the trash or locking the door.
- Keep things (such as your keys, wallet and phone) in the same place all the time so you can find them when you need to.
- Develop good sleep habits that will help you get at least 7.5 to 8 hours of sleep every night.
- Tell people about your symptoms instead of hiding them. Laugh or use humour to help ease tension about your situation.
- Do crosswords or play games to keep your brain active.
- Lower your stress with activities to restore your attention and sense of hope, like meditating, walking in nature or playing with a pet.

Treatment-induced menopause

Menopause is when the ovaries stop making estrogen and you have not had a menstrual period for at least 12 months. It usually happens around 50 years of age. If your ovaries are removed because of cancer or are affected by chemotherapy or radiation to the pelvis, menopause can happen earlier. This is called treatment-induced menopause. You may have symptoms like hot flashes, weight gain, moodiness, sweating, vaginal tightness and dryness, changes in sleep patterns or a loss of interest in sex.

If your menopause symptoms are severe, consider talking to your doctor about the risks and benefits of using hormone replacement therapy (HRT) or other medicines to help control them. You can also talk to your doctor about ways to reduce your chance of getting osteoporosis (loss of bone mass) and heart disease. Menopause can increase your risk for both of these conditions.

Nerve damage (neuropathy)

Some cancer treatments can cause nerve damage. This nerve damage is called neuropathy. Most people first notice symptoms as tingling, burning or numbness in the hands and feet. Nerve damage can also cause pain or muscle weakness and can affect your sense of touch, your balance and your ability to walk. Neuropathy can also make you more or less sensitive to heat and cold.

Neuropathy symptoms can range from mild to severe – at their worst, they can greatly affect your daily activities and quality of life. For example, neuropathy in your feet or hands might make it dangerous for you to drive a car. These kinds of changes can be frustrating or upsetting, especially if you feel that you're losing some of your independence.

In some cases, neuropathy can be completely cured, although the recovery often takes a long time. Sometimes, the symptoms improve but never go away completely. Even if the condition is permanent, you may still benefit from treatments to relieve your symptoms. Treatments include medicines, topical creams and pain patches. Acupuncture, guided imagery, meditation, occupational therapy, physiotherapy and exercise can also help.

You can also ask your healthcare team about exercises and lifestyle changes to manage and improve the symptoms of nerve damage.



Tips

- Install safety equipment such as grab rails and night lights in your home.
- Take extra care when handling knives, scissors and other sharp objects.
- Remove area rugs and loose wires you could trip over.
- Put non-slip bath mats in your tub or shower. You may need to install a bar or shower chair.
- Get up slowly from sitting. Walk slowly, and steady yourself by using a cane or walker.
- Wear footwear with rubber soles so that the grip surface is firm. Avoid heels.
- Avoid extreme temperatures. To avoid burns, use a thermometer and gloves instead of your bare hands to check the temperature of bathwater. If possible, lower the temperature setting on your hot water heater.
- If you're having trouble with your shoes and clothes, your local pharmacy may be able to help. There are tools to make it easier to get your shoes on and off and to help with buttoning buttons.
- Don't let nerve damage stop you from the benefits of being active. If you feel weak or have lost your sense of balance, there are safer exercise options such as riding a stationary reclining bicycle.

Osteoporosis

Some people may experience osteoporosis – a condition where there is a loss of bone mass. This makes the bones weak, and they can break (fracture) more easily. Osteoporosis can exist for years without symptoms – you may not realize that you have it until you break a bone.

Certain cancer treatments can raise your risk of osteoporosis. Ask your doctor about:

- your risk for osteoporosis
- having a bone mineral density (BMD) test
- what you can do to prevent or treat osteoporosis

Your doctor may suggest that you stay physically active and take extra calcium and vitamin D every day.

Pain

Some people continue to have pain after treatment has ended. But over time, as your body heals, you may find that your pain eases. While some types of pain are chronic, or long-lasting, there are usually ways to manage them. If you're in pain, it's important to tell your healthcare team right away, even if they don't ask about it. Tell them where and exactly how bad the pain is, and how it affects your day-to-day life. Even if your doctors can't get rid of the pain entirely, they can almost always find ways to reduce it. They may prescribe medicines or suggest options like physiotherapy, hot and cold packs, massage and relaxation techniques.



WANT MORE INFORMATION ABOUT PAIN?

Our booklet *Pain Relief: A guide for people with cancer* has detailed information on cancer-related pain and how to manage it. It was written for people who are in treatment, but you may find it helpful as well.

Second (new) cancers

Unfortunately, having had one type of cancer doesn't prevent you from developing another, different type of cancer at some other point in your life. It isn't common, but it can happen. People who've had cancer still have the same general risk that everyone has for developing a new cancer – and in some cases, having had and been treated for certain types of cancer means you have a higher risk for another type.

Talk to your doctor about your risk factors, based on your lifestyle and your personal and family medical history. It's also very important to ask about screening programs for certain types of cancer and whether you should have screening tests earlier or more often than the general population.

Sexuality

“For a while there, George Clooney could have stripped naked for me and I would've said, 'You know, thanks, but not now. I've got some things to do around the house.' I just wouldn't have been interested. But now, I'm noticing that my desire is starting to come back, which is nice, because I thought it was gone forever.” – Julie

Cancer and its treatment can affect your ability or desire to have sex. This can be caused by many things, such as changes in how your body functions, pain, stress or side effects. Some people are simply too tired to think about having sex, while others may be upset or embarrassed by changes to the way their body looks or works. These kinds of concerns about body image, and their effect on sexuality, are very common.

Hormone therapies, pelvic surgery or radiation therapy – as well as treatment-induced menopause – can change the size of the vagina or cause vaginal dryness. This can make it hard or painful to have sex. These treatments can also decrease sexual desire.



Surgery to treat certain cancers, such as prostate or colorectal, may cause problems with getting an erection or ejaculating. Some of these side effects may go away over time, while others may be permanent.

It can be very hard to deal with changes to your sex life. The changes can upset you or make you angry, but they can also be a chance to learn new ways of giving and receiving sexual pleasure. Surviving cancer doesn't mean that you can no longer have a satisfying sex life – but you may need to change how you have sex.

It helps to talk openly and honestly with your partner about your feelings and tell them what does and doesn't feel good. If these conversations feel awkward, you can also talk to a counsellor, psychologist or sex therapist. These professionals can help you talk openly about your problems, work through your concerns and come up with new ways to help you and your partner be intimate and find pleasure together.



WANT MORE INFORMATION ABOUT SEXUALITY?

Our booklet *Sex, Intimacy and Cancer* has detailed information that can help you cope with changes that cancer treatment brings to your sex life.

Speech problems

Some types of cancers – particularly head and neck cancers – and cancer treatments can affect your ability to speak. You may have trouble with certain sounds or you might slur some words. Sometimes, speech changes can be more severe, so that people can't easily understand what you're trying to say. These changes can be short term or last forever.

Losing the ability to speak clearly or at all, even for a short time, can be scary and frustrating, especially if you feel as though you can't make yourself understood. It may make you feel like you can't or don't want to be part of social situations where you might have to talk to other people. It can help if you explain to people that you've had medical treatment that has made it hard for you to talk. You might want to write this information on a card that you can hand out when you're having trouble getting the words out.

Speech therapy can help you learn to cope with these changes and to talk as clearly and effectively as possible. Speech therapy often involves exercises to improve the range and strength of your mouth and tongue movements, or it helps you find new ways to make speech sounds. If a speech therapist is not part of your healthcare team, ask your doctor for a referral. If you find that speech problems are making you withdrawn or depressed, it can help to talk to a social worker or counsellor.

Dealing with everyday issues

After cancer treatment is over, you may find that your focus turns to practical, day-to-day issues. You may worry about your job or wonder how you will pay for help around the house or the changes you need to make to your home so that it meets your new physical needs. You may need to think about things like travel and holidays in a whole new way.

Money concerns

Cancer can affect your finances even after treatment is finished. Extra expenses, loss of income and mounting debt can leave you feeling worried about money and how you'll pay for everything.

If your income has been affected by cancer, a social worker at your hospital or cancer centre should be able to tell you about financial assistance programs, income tax credits and government benefits. Account managers at your bank and financial planners can help with budgeting. They can also offer advice about whether to use equity from your home, RRSPs or other investments.

It can also be useful to understand more about your health insurance, if you haven't already done so. If you have private disability insurance or insurance through your employer, get familiar with the terms and conditions of your coverage. Make sure you understand:

- what your insurance will continue to pay for and what you will need to pay for
- if your policy has a waiting period before disability coverage starts
- if your policy has a yearly or lifetime cap (the maximum amount they will pay out) on benefits



GOVERNMENT SERVICES AND BENEFITS

The Canadian government has services and programs for people with disabilities, their families and caregivers. To find out about employment, health, income support, tax benefits and housing programs and how to apply for them, contact Employment and Social Development Canada at 1-800-O-Canada (1-800-622-6232) or visit canada.ca.

To find benefits that you may be eligible for, use the benefits finder at www.canadabenefits.gc.ca.

Going back to work

Most people who are able to work do go back to their jobs. Many say it helps them get back to normal. Give yourself time to adjust to being back at work again. In the beginning you might feel awkward or out of place. It may seem hard to reconnect with your team, which may include new co-workers or a new boss. It may take you a while to get used to the stress of work again, especially as you may still have other worries after treatment. Some people feel guilty for having left their co-workers with a greater workload – it's normal to then worry about how these co-workers will now feel or act. You may think that co-workers are treating you differently when you really just want to be treated the same as before.

It's possible that some parts of your job may need to change when you go back to work. Some people find that it works well to go part time at first and gradually increase working hours. Employers have to make such reasonable changes in your hours or duties to help you do your job after cancer treatment. But they don't have to make changes that would be overly costly, unsafe or disruptive.

In Allan's case, reasonable change was possible. He was working as a constable with the city police before his diagnosis – a job that required a lot of physical power. After treatment, he'd lost 30 pounds and much of his strength. "Going back to my old job was out of the question," he says. "So, I was assigned to an office job. That was disappointing. But the alternative was worse."

People can sometimes have problems if they want to work and they need some changes to be made to their role. They may find themselves demoted or passed over for promotions. Or they may feel that they're being denied benefits or have problems taking time off for medical appointments. They may be let go from their jobs.



DISCRIMINATION IS AGAINST THE LAW

Protect yourself from employment discrimination by learning about your rights in the workplace. For example, an employer cannot treat you differently from other workers in job-related activities because of a cancer history, as long as you are qualified for the job.

If you feel that you've been discriminated against, you can contact the Canadian Human Rights Commission in your province or territory by calling 1-888-214-1090 or visiting chrc-ccdp.gc.ca.

Deciding if you are able to go back to work

You and your healthcare team will talk about when and if you can go back to work. It will depend on your job and the type of cancer and treatment you have had. If you're not sure if you're ready, you may need to see a specialist to help you with the physical and emotional parts of going back to your job.

Try doing tasks that have similar physical, mental and emotional demands as your job. Keep track of how long you can work before you need a break. This can help you decide if you should go back part time until you build up more strength.

There are also online tools to help decide what's right for you. For example, at cancerandwork.ca, you can download assessment tools to track your physical and mental abilities to find out if you're ready to go back. You can also learn how side effects can affect your work and find ways to modify your workspace.

What if you can no longer work?

Some people find that they can't return to their job even if they want to. If you can no longer work, this can be very stressful. You will most likely still need a regular income to pay bills, the mortgage or rent and other living expenses.

It's important that you get the support and advice that you need to deal with financial issues. You can ask a social worker at your hospital about financial assistance programs and government benefits. You may qualify for Canada Pension Plan (CPP) disability benefits if you have a disability that prevents you from working at any job on a regular basis.

You may also find it useful to see a financial advisor or planner to discuss financial concerns. Your bank may have a financial advisor you can talk to. FP Canada has helpful information on finding a certified financial planner.

Making changes to where you live

You might find that your home doesn't work as well for you now that you've been through cancer treatment. It could be that:

- You find it tiring to go up and down the stairs.
- You'd like it to be easier to get in and out of the tub or shower.
- You feel you live too far away from a hospital or from family or friends who could help you.
- You're tired of keeping up with chores like yard work and shovelling snow.
- You don't earn as much and your rent or mortgage is now too expensive.

These kinds of issues may make you consider renovating or moving. If you think you need to change your living arrangements, your family and friends may have ideas or suggestions that can help you decide where to live or what changes to make to your home.

You may be able to get some financial help from the federal and provincial governments or other agencies for housing costs or for renovations you're making because of the effects of cancer treatment. A social worker can also tell you about grants or programs in your province or community.

Personal care

Especially at first, you may find that you need some help with personal care, like eating, dressing, bathing or taking care of your body as it heals. Some people are most comfortable when their partner or a close friend or family member helps them with these tasks. Others would rather get help from a nurse or home care worker. The same is true for caregivers. Some will be comfortable and others will prefer to have some professional help to assist them.

Many programs and services can provide you with access to personal care at home. Ask the social worker at your hospital or another member of your healthcare team about getting personal home care, as well as about the costs of this care.

Travel

For many people, taking a trip or going on a holiday is a way to celebrate the end of cancer treatment and to mark a new phase of life. Travel can be a great way to unwind and relax.

When Julie took her first trip – a weekend away – after finishing treatment, it felt like she was crossing an emotional border, not just a geographic one. “As we crossed the border into the United States, I got this feeling in my gut: ‘I’m leaving Toronto. I’m leaving Ontario. I’ve never been away since being sick. My God.’ But that feeling went away. I had energy and felt normal. It was like, I’m just normal, doing what normal people do on normal vacations. It was great.”

Although you might want to leave town the moment your treatment is finished, it's a good idea to plan ahead and give yourself a few weeks or more to recover your strength and energy. Start small – maybe with a night or a weekend away, somewhere fairly close to home. And slow down if you need to. You might want to break up a long drive into shorter segments, see one museum instead of 3, or build some rest time into your plans. This can be frustrating, especially if you're used to vacation days packed full of sightseeing and activities. In time, your energy levels may increase and you may be able to do more.

When travelling, take your detailed personal health record with you, including information on the type of cancer and treatments you had, any medicines you're on, your doctor's name and contact information, and your insurance information.

Travel after cancer treatment may come with different or new concerns, especially if your body has changed. For example:

- It may be harder or cost more to get travel health or trip cancellation insurance. Check to see what your healthcare plan covers and read the fine print on your policy to make sure you understand its terms. When you're applying, ask lots of questions and be open about the fact that you've had cancer and any other health conditions you have. If you don't tell the insurance company about an illness or health concern, your coverage may not be valid.
- Some cancer treatments, including radiation and some types of chemotherapy, make your skin more sensitive to damage from the sun. If you're going on vacation somewhere sunny, take extra care to protect your skin.
- If you have a stoma to remove stool or urine from your body, it won't stop you from travelling, but you will have to bring supplies and think through your first few trips more carefully than you used to.
- If you've had lymph nodes removed, air travel can put you at increased risk for lymphedema. This is thought to be due to low cabin pressure, poor air quality and keeping still for long flights. Talk to your doctor about this before getting on a plane.

- You may need to bring medicines or extra supplies. For example, if you have a weak immune system due to recent cancer treatment, you may need to take a supply of antibiotics with you. Ask your doctor about this possibility. Make sure you have enough medicine to last the whole time you're away, even if you're delayed by a few days. If you're flying, pack all medicines in their original, labelled containers in your carry-on baggage.
- Some cancer treatments interfere with the types of vaccines you need to travel to some parts of the world. This may affect your choice of holiday location. Ask your doctor before having any vaccines and follow the guidelines for any travel vaccines you get. You may also need to be vaccinated again for diseases you were already vaccinated against before your cancer treatment.



Finding meaning after cancer treatment

“When I hear the word survivor I feel as if I won something. Not exactly the lottery. But I’m a winner and I’m different somehow, as if I had accomplished something that not everybody was lucky enough to accomplish.” – Ebe

Some people with cancer describe their experience as a journey. While it’s not a journey they would have chosen for themselves, it can sometimes present the opportunity to look at things in a different way. Whether good or bad, many people say that the life-changing experience of cancer gave them the chance to grow, learn and appreciate what’s important to them.

A new outlook

Surviving cancer can change your outlook on life. Many people say they feel lucky or blessed to have survived cancer and take new joy in each day.

“I know that I was never a big hug person. But now when someone wants to give me a hug, I greatly accept it and give it back as well.” – Allan

Other people find this outlook frustrating or too simple – they may be relieved to have survived but certainly aren’t grateful to have had the disease. In fact, life after cancer for many people is the same or worse than life before, especially if they’re dealing with late or long-term side effects, or if they can no longer work or do activities they enjoyed. If this is how you feel, you’re not alone.

After cancer, people often make changes in their lives to reflect what matters most to them now. You might spend more time with your family and friends, focus less on your job or enjoy the pleasures of nature. Ebe describes this process as “tailoring your life to fit, like you tailor a dress to fit you: a little bit by a little bit.”

Spirituality

Spirituality is a person’s sense of peace, purpose and connection to others as well as their beliefs about the meaning of life. Finding meaning in life is a deeply personal process. For some people it means quiet, solitary reflection – others may find it helpful to have guidance from a spiritual advisor from their faith. People who’ve had cancer often say that they look at spirituality or faith in new ways.

Wherever you make your spiritual home, surviving cancer can affect your outlook on it. After treatment, you and your family may struggle to understand why you got cancer or why you survived when others do not. People who didn’t have strong religious or spiritual beliefs before may feel no different. Or they may have new questions or be confused about what these issues mean to them now. There’s no one way or right way to connect with your spiritual side – and in fact, you may not feel any spiritual connection before or after cancer treatment.

Some people pursue spirituality through organized religion and find this to be a source of comfort and strength. Allan, for example, says that having had cancer “made me appreciate my faith more and made it grow a bit deeper.” Organized religion often provides a community of people who share similar experiences and can provide support. This framework can begin to address spiritual questions that have come up during treatment.

For others, spirituality is something separate from organized religion. They may find it in nature or in the goodness of others or in the connections between us all. They may practise meditation or rituals from different cultures. They find spiritual value in activities such as journalling, making or viewing art, yoga, music, or time spent in nature or with loved ones.



A CRASH COURSE WITH MY SOUL: EBE'S STORY

"Having cancer was like a crash that put me in better touch with my body, with my soul," says Ebe, who was diagnosed with breast cancer at the age of 49. "You don't know if you're going to live or die. It's a mystery. It made me realize that I'm alone in this: I have to take care of me to survive."

Taking care of herself meant setting new limits with her family, friends and co-workers: "Now, if I'm tired, I'm going to sleep. Or I'm going to tell people to back off. I couldn't say that before. If somebody wanted my help I gave my help. It didn't matter if I was tired or not. But now, I say, 'I'm sorry, I can't help you today. Can we do it later? Can I help you in another way? Can I find somebody else to help?' This is how it transformed me."

Taking care of herself also meant that Ebe decided to focus on the things that made her happy: beading, painting, photography and gardening. Through these kinds of activities – in particular, out in nature, in her garden – she found spiritual nourishment: "I became a much better gardener. My goodness, I mean, when I started I didn't know half the things I know now. It's a pleasure to garden because there is no talking. There is no verbal communication. It's just water and green and you're nourishing. I just look at the flowers. I like the feeling of nourishing something or talking to somebody to lift their spirits, things like that."

Years after her diagnosis, Ebe says that, physically, she feels the way she did before cancer. But spiritually, she says, "I'm much better. Every day I feel it's a different day. It's a present for me. The trees are greener, the sky is more blue. More things that I probably never appreciated that much before. Every day, every month, every year, as the days go by it's a thank you gift for me."

Giving back

Many people express a strong desire to give something back in thanks for the good care and kindness they received while they were in cancer treatment. You may find a sense of personal fulfillment and accomplishment through some of these activities:

- Volunteer at a cancer centre.
- Join a patient advocacy group.
- Become a trained volunteer to share your cancer story and listen to others as they go through treatment.
- Enrol in a cancer research study.
- Volunteer to drive patients to treatment.
- Raise funds for research.
- Donate money.

Getting involved can help ease fears about cancer, make you feel like you have more control over your life and develop bonds with other people who've had similar experiences. Other people prefer to keep their volunteer or charitable work separate from their cancer experiences. Whether and when to get involved with cancer-related volunteer activities – or any volunteer activities at all – is a personal decision. Some people are ready to volunteer right now, while others choose to devote their energy to giving back later on.

While volunteering is a great way to help you deal with your own experience of cancer, you also need to make sure that you have taken enough time to heal, physically and emotionally. This is why many programs require that you be out of treatment for at least a year before you volunteer with them. If you'd like to participate in cancer-related volunteer activities, ask yourself if now is the right time to get involved. You may not be ready yet if you:

- are focused more on your own needs than the needs of others
- want to talk a lot about your problems with other people
- feel lonely and want to be with others who understand what you're going through
- wonder if taking part will be a constant reminder of your cancer experience



WANT TO VOLUNTEER?

Volunteering with the Canadian Cancer Society is a great chance to make a difference in someone's life, be part of a team, share your experience, learn new skills and develop lasting friendships. Visit cancer.ca/volunteer for more information on giving your time.

Going forward

The challenge is to celebrate the joys of the present and get on with living. Just as your experiences during cancer treatment were your own, the way you adjust to life after treatment will be unique to you as well. There's no map to follow and no right or wrong way to feel about the effect this disease has had on your life.

Life after cancer is a time of adjustment and change – you may move between the highs and the lows, between relief and fear, joy and grief. During times of doubt, it can help to remember that life after cancer is a process, not an event. It can take time to come to terms with all that has happened to you and with the uncertainties of the future. Recognize when you still need help and ask for it.

“I see changes in myself in that I'm more aware of things. There's a little bit more equilibrium. I think that's fantastic. I learned that I'm a strong person, and I am really proud of myself that I was open to the growing that I did while I was going through hell.” – Julie

“I think when you come to grips with your own mortality, that makes changes in you. You don't notice them at the time ... I always was sort of a laidback person and let other people do the talking. I don't do that anymore. I speak my mind a lot more than I used to. For me, that has been a big step forward. I think when you've battled cancer you gain a new confidence in yourself.” – Allan

WE'RE HERE TO HELP



Find information you can trust

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

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Get answers to your questions

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

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Connect with someone who's been there

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

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Find services in your community

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

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

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



Canadian
Cancer
Society

IT TAKES A
SOCIETY

1-888-939-3333
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