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# Life after Cancer Treatment



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The Canadian Cancer Society would like to thank the people who shared their personal stories. To protect their privacy, and with their permission, we have changed their names.

## Table of contents

<b>3</b>	<b>Introduction</b>
3	What happens now?
<b>6</b>	<b>About survivorship</b>
7	What's in a name?
8	Managing expectations
<b>12</b>	<b>Returning to a "normal" life</b>
13	Challenges of creating your new "normal"
15	Doing things in your own time
16	Stress and finding balance
<b>20</b>	<b>Your feelings after cancer treatment</b>
22	What's normal?
22	> <i>Feeling lonely and isolated</i>
23	> <i>Being angry</i>
23	> <i>Grieving for what you've lost</i>
24	> <i>Worrying that cancer will come back</i>
27	Issues with body image
29	Counselling and peer support
29	> <i>Individual counselling</i>
30	> <i>Support from people like you</i>
<b>32</b>	<b>Follow-up care</b>
34	Keeping track of your health
35	> <i>What to include in your personal health record</i>
35	> <i>Creating your follow-up care plan</i>
36	What happens during checkups?
36	> <i>Coping with anxiety before your checkups</i>
37	Questions to ask about follow-up
<b>38</b>	<b>Side effects</b>
39	Changes in weight and eating habits
40	Fatigue
42	Feeling sad or depressed
43	Fertility problems
44	Incontinence

45	Lymphedema
46	Memory and concentration changes
48	Menopausal symptoms
49	Neuropathy
50	Osteoporosis
51	Pain
52	Second (new) cancers
52	Sexuality
53	Speech problems

## 56 Healthy living after cancer treatment

57	Your wellness plan
58	> <i>Be active</i>
61	> <i>Eat well</i>
61	> <i>Get to and stay at a healthy body weight</i>
62	> <i>Live tobacco-free</i>
63	> <i>Protect yourself from the sun</i>

## 64 Dealing with practical issues

65	Financial concerns
66	Returning to work
67	> <i>What if you can no longer work?</i>
68	Changing your living arrangements
69	Home care
69	Travel

## 72 Finding meaning after cancer treatment

73	A change in perspective
74	Spirituality
76	Giving back

## 78 Going forward

## 80 Resources

81	Canadian Cancer Society
82	Suggested websites

## Introduction

As you finish cancer treatment, 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.”

“ 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, okay. All right. I made it. Did I make it? Let me see. Yeah. I think I made it. Yeah. I made it. Yeah. It's like I crossed a very turbulent river or something to the other shore. I don't believe I did it. ~ Ebe

## What happens now?

For many people, moving from cancer patient to cancer survivor is a time of change. It isn't like returning from a holiday and getting back to routine – because while you're getting used to everyday life again you're still facing challenges. You may be very tired and surprised to find that you still feel worried, scared, angry or alone. You're not just adapting to changes to your body – you may also be adjusting to changes in your relationships and sexuality, work and finances, or spirituality. Recognizing and understanding these challenges can help you cope with them and adjust to living well as a survivor.

We hope you find it helpful to read this booklet as you near the end of treatment. Many survivors 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 as a survivor, which can help everyone adjust to life after cancer.

“ 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

Throughout this booklet, you'll hear from Canadians who speak from personal experience. You may not relate to everything they say, but their stories are offered here to help you understand that:

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

## About survivorship



“ 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

Survivorship is the experience of living through or beyond an illness. But the term cancer survivor means different things to different people. For many, being a cancer survivor starts at the moment of diagnosis and continues for as long as a person lives. For others, survivorship begins once active treatment is over and there are no more signs of cancer in the body. For some, the definition of cancer survivor is very broad and also includes family members, friends or caregivers touched by cancer, to reflect that they too have lived through the experience.

In this booklet we use the term survivor to mean anyone who:

- was treated for cancer and now has no signs of cancer in their body
- has finished and is recovering from active cancer treatment
- is on maintenance therapy (such as tamoxifen)
- is having ongoing treatment for a cancer that is stable

### What’s in a name?

“ I do consider myself a survivor. I think the word simply reminds me that the outcome could have been entirely different. ~ Allan

Survivor isn’t a perfect word. For some people, it’s a strong, positive way of describing their situation. Using it helps them as they work through the challenges they face after treatment. But others don’t like it at all.

“ It’s funny – I hate the word survivor. I didn’t want to be Julie with breast cancer and I don’t want to be Julie who had breast cancer. I am Julie who just happened to have this happen in my life. ~ Julie

Whether you like the word or not, it expresses that you've gone through a certain experience. In the end, the word used may not matter. What matters is that many people agree that cancer treatment is an experience that stays with you and can change your outlook on life.

## Managing expectations

“Some days I was just so down, it was just like I never thought I'd ever feel good again. I'd sometimes say to my friends, “Tell me it's going to be okay. Tell me it's all going to be normal again. Tell me my hair is going to grow back. Just tell me it's all going to be okay.” ~ Julie

A big part of being a survivor is learning how to manage expectations – both your own and others' – of what life will be like after treatment. As this is probably a new experience for everyone involved, knowing what to expect and preparing for it isn't easy.

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 recovery takes time – 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 cancer survivors still feel very tired or weak immediately after 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 survivors 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 the 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 survivors. 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 individual or family counselling 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." The only solution to this frustrating situation was to have some tough conversations about how he felt and what he needed. "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.

## Returning to a “normal” life



“ 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

The first few months after cancer treatment ends are often a time of change. It's a time when you need to adjust to new schedules, changes in your body and energy levels, and new understandings of what life might be like. 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.

“ Before cancer I used to work so many hours, 8:00 to 8:00. I didn't really pay attention to the fact that the body is not a machine. It needs its rest. I didn't care. I felt determination – you just go on like a soldier. After the cancer, I felt like my body and mind have a right to rest and relax and enjoy. ~ Ebe

How you feel 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

### Challenges of creating your new “normal”

“ It's a long, slow process to get back to some normality. ~ Allan

The transition to your new normal can be challenging. 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 phone number, 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 in 2004, 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 kilometres 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 kilometres 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 any more. If I don't get it done today, it'll be done tomorrow."

### **Doing things in your own time**

“ My doctor told me, "Four weeks after the last chemo, I promise you, you will feel like you did before."  
And, yes, it's true that I felt much better after a month off the chemo, but not back to normal yet. It took a while.  
And it was a struggle. ~Ebe

Cancer survivors 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 cancer survivors 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.

If you have a timeline in your head and you're not meeting it, it can make you feel frustrated and hopeless or as though you're doing something wrong. You may think, "If I'm not feeling the way my doctor said I would by now, there must be something wrong with me. Maybe I'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 survivors 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 to my iPod 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."

#### > TIPS

- Nap when you need to. Your mind and body still need a lot of rest to recover from all you've been through.
- Let family and friends know that you can still use help with housework, errands and shopping.
- Share your feelings and worries with people who are close to you or with a healthcare professional like a social worker or counsellor. Some people say that this helps a lot.
- Talk to another cancer survivor or join a support group for survivors.
- Recognize that you might need to push yourself a little bit. Go out for a short errand, for coffee or lunch with a friend, or for a very short walk. At first, going out may feel scary. But over the long term, most people say that getting out makes them feel better.
- If you're going back to work, work only a few hours a week to begin with if you can and build up slowly.

### Stress and finding balance

“ 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 difficult emotions, stress and tension in different ways. You may have to experiment as you figure out the best way to help yourself feel more normal after cancer treatment.

Julie, for example, spent the few weeks between the end of her treatment and going back to work resting and seeing friends, and going to the gym for short workouts. She also took a meditation course and made appointments with a nutritionist 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

- Talk to others about your feelings or write about how you feel in a journal or blog.
- Get up and move. Regular physical exercise – even very gentle or moderate movement – can make you feel better, calmer and more in control.
- Recognize 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. You may find that meditation and relaxation exercises focus your mind and give you perspective.
- Talk to someone who's had cancer. Or find a support group.
- Consider trying complementary therapies, like acupuncture, hypnosis, massage and music therapy. Some people find that these therapies can help reduce stress and anxiety, and they may also help relieve symptoms like pain or chronic fatigue.

#### Want more information?

Our booklet *Complementary Therapies: A guide for people with cancer* can help you make the choices that are right for you. It was written for people who are in treatment, but survivors may find it helpful as well.

### **Finding balance: 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," says Julie, "I remember thinking, What if somebody told me I had a disease? 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 as a cancer survivor – 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. "Three to four times a week when I'm at work 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 BlackBerry. 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. Survivors often think they should celebrate this milestone, but you may not feel like celebrating. At the end of treatment, you may be very weak and side effects can still be an issue. And now that you aren’t so busy with medical appointments and connected to your healthcare team, you may find that you struggle with emotions such as moodiness, sadness or depression.

And so even though this is what you’ve been waiting for, it’s important to recognize that you could still have strong feelings and mixed emotions at the end of treatment. Your feelings, as well as how strong they are and how quickly they change, can surprise you. “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.”

Not everyone will have a hard time after treatment is finished. But if you do, you may find it helpful to know that these strong feelings often fade as your strength and energy come back.

## What's normal?

It's normal to experience a wide range of emotions after cancer treatment. Many cancer survivors say of course they feel relieved and happy – but they also feel lonely, angry, sad and worried.

### *Feeling lonely and isolated*

It's very common for survivors to feel lonely or have a sense of being on their 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 you feel that the people around you don't or can't understand what you've been through.

If you're coping with changes to your appearance, this 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 the nurses and other 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.

“ When you're in treatment, you feel as though you're being taken care of, that you don't have anything to worry about, especially with the cancer centre where I was treated – they're pretty phenomenal people. They knew all our names. Afterwards, though, you sometimes feel as though you need to be looked after. You almost *want* to go to a doctor's appointment. ~ John

The best thing you can do if you're feeling lonely or isolated is talk about it with someone you trust. It isn't easy, but keeping these feelings inside only makes them worse.

## 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, very grateful, and I always have been, but I'm also angry. I'm allowed to be both.” ~ Julie

Many cancer survivors are angry, an emotion that can vary in intensity. You may be a little bit frustrated about things that happened during diagnosis or treatment or very angry if your family and friends weren't helpful or supportive. Julie's anger, which is very normal, stemmed from her grief about losing her “whole life.” When she was diagnosed with breast cancer at the age of 44, she says, 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.”

While a certain amount of anger is normal – it can even motivate you to make changes in your life – hanging on to it can stop you from moving on from your cancer experience. It's okay to admit that you need some help. Sometimes talking to family, friends or other survivors 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.

### *Grieving for what you've lost*

Grief is the sense of loss that you feel when you lose something valuable in your life. Most people think of grief together with the death of a loved one, but it's an emotion that many survivors go through as they adjust to life after cancer. It may seem to come



out of nowhere, especially if treatment kept you very busy – you may have been so focused on making decisions and getting to appointments that it’s only when you start to slow down that the feelings come. As a survivor, you may grieve for many things, such as a lost body part, the inability to have a child, financial losses due to time away from work or the loss of your sense of security and health.

Everyone experiences grief in their own way and in their own time. To heal, you need to recognize, accept and release the feelings. People who fully experience grief usually find that they can be happy again and may even find that they feel better – stronger and more capable – than they did before.

Talking about how you feel is the best way to resolve or get through your grief. This may not be easy – either because you find it hard to talk about or because the person you’re confiding in has their own struggles in dealing with intense emotions. 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.

It doesn’t really matter who you talk to, as long as you talk. You may find the support you need from family or friends, your healthcare team, other survivors, counsellors or spiritual care workers.

### ***Worrying that cancer will come back***

“ For a while after the treatment had finished if I have 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. I say, Well if the doctor did everything and they didn’t tell you anything then it’s good. ~ Ebe

It’s very common for cancer survivors to worry about cancer returning, especially during the first year or so after treatment. While you’re in treatment, you know that something is being done to stop or slow the cancer. But when treatment is over, it can seem as though nothing’s happening and the cancer could return. Over time, your worries about cancer coming back may fade, but certain events can bring the fear right back. These could include:

- your follow-up appointments
- hearing about someone else being diagnosed with 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

“ At first, it terrified me – it could come back. Will it come back? What’s going to happen? Am I done? Is this a blip? Am I going to die? Am I going to achieve what I wanted? What if the treatment didn’t work? What if it’s come back already? But the terror has lessened over time, which is a relief, because I didn’t want to live my life in fear of cancer returning. ~ Julie

Fear of the cancer returning should become easier to manage, although it may never go away completely. For some people, though, the fear stays or is so strong that they no longer enjoy life, sleep or eat well, or keep their doctors’ appointments. If your fears about cancer coming back feel overwhelming, the following tips may help.

### > **TIPS** to help cope with the fear of cancer coming back

- Talk to your doctor about regular follow-up care. Your doctor can also give you information about the chances of cancer recurring and the symptoms to watch for. This kind of information can help you stop worrying that every ache or pain means that cancer is back.

- Be informed. Understanding what you can do for your health now and finding out about the services available to you can give you a greater sense of control.
- Accept and talk about your worries. You will probably find, as do other survivors, that it's easier to let the feelings go once you've expressed them. You can talk to friends or family, other cancer survivors or a counsellor.
- Try to use your energy to focus on wellness and what you can do now to stay as healthy as possible. You might try eating a healthy diet, exercising regularly and getting enough sleep. All these activities can help you feel better physically and emotionally.

### How likely is it that the cancer will come back?

Doctors use survival rates (or survival statistics) to help estimate a person's chances of surviving cancer.

Doctors usually refer to 5-year or 10-year survival rates. These rates tell you, on average, the percentages of people who live at least 5 or 10 years after their cancer is diagnosed. For example, if the 5-year survival rate for a type of cancer is 75%, this means that, on average, 75% of people diagnosed with this type of cancer are likely to live 5 years after their diagnosis. Many of these people go on to live much longer, productive lives.

In order to get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Since that time, treatments may have improved for certain kinds of cancer, and the chances of surviving 5 years or more after diagnosis may be better for people who have these improved treatments.

Your doctor is the best person to ask about the average survival rate for the type and stage of cancer you had. But the best doctor in the world cannot say for sure whether cancer will come back or not for any individual patient. They can just make an educated guess.

## Issues with body image

“ 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 cancer survivors are upset or angry at the way that cancer treatment has changed their bodies. Any change can be hard to accept and can affect your body image (the way you feel about your body). For example:

- You may have scars from surgery.
- You may be missing a body part, such as a breast or limb.
- You may have to live with a stoma.
- Your hair may have fallen out and grown back in a different colour or with a different texture.
- You may have gained or lost weight.
- Your skin may have changed because of treatment.
- You may no longer be able to have children.
- You may feel very tired, all the time.
- You may have trouble swallowing and eating.

Some of these changes may be temporary, while others are permanent. Other people may be able to see the changes, 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 or can't relate to 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. You may even come to see the changes 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

Other people may take longer or struggle harder to come to terms with these changes. Sometimes, negative feelings about your changed body can affect your quality of life. Signs that you might need some help in 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.

If you have negative feelings about the changes to your body, it can help to talk about them with someone you trust, like your partner, a close friend or a counsellor. Many people find that talking to other survivors, either one-on-one, in a support group or online, is very helpful. It might be hard to talk about more intimate 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.

## Counselling and peer support

“ 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

### *Individual counselling*

You’re not alone if you’re uncomfortable with the idea of going to a therapist or counsellor. But most survivors find that seeing someone really helps, and they soon get over feeling awkward.

Many different professionals – including psychologists, psychiatrists, nurses, 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 emotions 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 cancer survivors usually involves:

- telling the counsellor about your cancer and survivorship experiences and how they’re 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 cancer survivors 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 in person, at a cancer centre or hospital. John, for example, went to a lifestyle change program put on by his local hospice. “It was really enlightening,” he says. “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. It helped me figure out where I was at and what was going on.”

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

### **The Canadian Cancer Society: Helping you find support**

The Canadian Cancer Society understands that your cancer experience doesn’t end when treatment does – and we want to help. Contact us to find out about support groups and other services for survivors in your community. We can also put you in touch with one of our trained volunteers who understands what you’re going through. To find out more:

- Call us toll-free Monday to Friday at 1-888-939-3333 (TTY 1-866-786-3934).
- Email [info@cis.cancer.ca](mailto:info@cis.cancer.ca).
- Visit [cancer.ca](http://cancer.ca).

### **Want to connect with someone online?**

If you’d like to connect with someone online, join our online community, [CancerConnection.ca](http://CancerConnection.ca). There are discussions and groups that may interest you, and you’ll find caring, supportive people there.

## Follow-up care



“ When I went for the results after my first follow-up appointment, I was so nervous. It was probably the worst I’ve been through the whole process. I was just terrified. When my doctor told me that they didn’t want to see me for another 12 months, I burst into tears. ~ Julie

After cancer treatment, you’ll likely have regular, routine 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. Now that you’re done treatment, you might not be happy about the idea of still going to doctors’ appointments. You may find them frightening, or you may be frustrated by the idea of more tests and exams. Then again, going to follow-up appointments may help you feel in control as you get back into everyday life.

“ 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

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



## Being on maintenance therapy

After active cancer treatment ends, some cancer survivors are put on maintenance therapies that may continue 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 returning or spreading.

Being on maintenance therapy can make you feel conflicted – as if you're stuck somewhere between being a patient and being a survivor. John was on a maintenance drug therapy for 2 years after treatment for non-Hodgkin lymphoma. "It's weird," he says, "because they tell you that you're in remission, but it takes more drugs to make sure that it doesn't come back."

For some people, maintenance therapy is reassuring – they're happy to continue to be doing something to fight the cancer. For others, it's a constant reminder of the illness. "I don't like taking a pill every day," says Julie, who is taking tamoxifen following treatment for breast cancer. "But it is what it is. It's an extra insurance. If the cancer comes back, at least I want to be able to look back and say I did everything I could."

If you have conflicting feelings about 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

Cancer survivors often need information on the medical treatment they received in the past and the kind of follow-up medical care they will need in the future. You may find it helpful to collect these details in a personal health record and follow-up care plan.

The information that goes into your personal health record and follow-up care plan is usually available from your hospital or treatment records. If your treatment centre hasn't offered to create these documents for you, ask them to help you gather this information. You may need to pay for it. To hold these documents, you might want to create a binder or file folder, or you can create electronic or online versions of them.

Many survivors 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. A 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/cell type, stage and grade
- type(s) of treatment you had and when, including drug names and doses
- related medical findings during treatment, such as side effects
- supportive services provided during your treatment
- contact information for your healthcare team

## *Creating your follow-up care plan*

As well as creating a record of your treatment that happened in the past, you may find it useful to gather together information about the follow-up healthcare you will need in the future. A follow-up care plan is a detailed summary for cancer survivors that may include:

- your schedule for follow-up medical appointments
- your schedule for follow-up 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 long-term side effects of treatment
- recommendations for healthy living and a wellness plan that includes eating well and being active

## What happens during checkups?

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 relative or friend to appointments to take notes and offer support.

### *Coping with anxiety before your checkups*

“ My first mammogram after finishing treatment was absolutely one of the worst experiences I've ever had to live through. It was terrifying. I started tearing up in the treatment room. And then afterwards I went into the bathroom and bawled for 5 minutes. It was guttural, horrible. ~ Julie

Going to your follow-up appointments 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 because going back to the hospital brings back bad memories of your treatment, tests and side effects.

Eight years after treatment, Allan says that he doesn't usually think about cancer returning. Still, he doesn't sleep well the night before his yearly follow-up appointment for tongue cancer. “On the drive to the doctor's office, I get sweaty palms, sweaty underarms. I'm thinking, He's going to put that scope down my nose, and what's he going to see?”

Once you've had a few checkups and all is okay, your anxiety should begin to lessen.

## Questions to ask about follow-up

The first thing that many survivors ask about 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 any other health conditions you have. 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.

- What symptoms should I watch for? What signs or symptoms should I report right away? Which ones can I wait to report at my regular follow-up visits?
- How likely is it that my cancer will return?
- How long will I have to take the medications 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 long-term effects, like pain or fatigue?
- Can I get a written summary of my personal health record and my follow-up care plan?
- Who will be overseeing my follow-up medical care?
- How often, and for how long, will I have follow-up appointments? Where will these take place?
- What follow-up or screening tests will I need? How often will I need these tests, and for how long?
- What can I do to reduce the chances of cancer coming back?
- What type of physical activity would you recommend for me?
- Could I benefit from genetic counselling and testing? Should my family members consider this as well?

## Side effects



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

### Changes in weight and eating habits

“ I was the perfect weight right before I got diagnosed. I was toned. My arms looked awesome. And then this all happened. ~ Julie

Weight gain or weight loss are common side effects for cancer survivors. Certain treatments may have made you hungrier than usual or not hungry at all. 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 be very upsetting and affect your self-esteem.

After surgery for breast cancer, Julie found it hard to lift weights or swim. Chemotherapy and hormonal changes to her body made it easier for her to gain fat tissue while losing muscle. “And then they put me on steroids,” she says. “I ate my 18-year-old nephew under the table at an all-you-can-eat buffet one night. It was embarrassing. I gained about 15 pounds by the end of it. That was really hard for me.”

Allan had the opposite problem. Because of radiation therapy to his head and neck, he lost his salivary glands. For months, eating and swallowing was very painful and slow. As a result, he lost 30 pounds. “I'm really skinny now,” he says.

Your doctor may be able to refer you to other healthcare professionals who can help. 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 vary across the country, but there should be something available to you.

Try to be patient with yourself and with your body. Weight gain or loss after cancer treatment isn't simply about willpower – it's about accepting and understanding the different way your body might work now.

### Want more information?

Our booklet *Eating Well When You Have Cancer* has detailed information on managing weight issues, eating-related side effects and more. It was written for people who are in treatment, but survivors may find it helpful as well.

## 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 one of the most common late effects that cancer survivors 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 have a big impact on 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 okay 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 improving 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 a regular exercise program. Even starting with a 10-minute walk at first and working up to a half-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.



- Let others know that you still need help. If no one offers, 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 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 to lift.

## 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.

It's okay to cry or express your feelings as you cope with the changes that come after treatment ends. You don't have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with what you've gone through.

But sometimes survivors find that their sadness never lifts or that it gets worse over time. When a sad, despairing mood won't go away, you may have clinical depression. It's an illness – 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:

- not sleeping or sleeping too much
- overeating or having no interest in eating
- crying a lot
- loss of interest in sex
- feeling hopeless
- thoughts of harming yourself

Talk to your doctor if you have any of these signs of depression. You may need to see a psychiatrist or another mental health professional. Treating depression can improve your sleep, appetite, energy and self-esteem.

## Fertility problems

Sometimes treating cancer can lead to infertility, which is the inability of a woman to get pregnant or a man to father a child.

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 receiving 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.

### Want more information?

Our booklet *Sexuality and Cancer* has detailed information on cancer-related fertility issues.



## Incontinence

“ When I’ve got to go, I’ve got to go.  
~ Julie

Cancer and its treatments can sometimes lead to incontinence, which is a temporary or permanent loss of control over your bladder and bowel. Bladder and bowel problems can be very upsetting and may make you feel ashamed or embarrassed.

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 travel.

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.

If you’re still not improving, your doctor may suggest medication or surgery. Ask your doctor what you can do if you’re having issues – including emotional difficulties – with bladder or bowel control.

“ 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 years it was that way, but now it’s gone back to once a night. ~ Allan

## Lymphedema

“ I probably worry about the lymphedema more than I do the recurrence of cancer. I’m always measuring my arm. I’m doing all the exercises I can. Every time I have a nick or anything I’m always putting ointment on it and being very careful. ~ Julie

Lymphedema is swelling caused by the buildup of lymph fluids in the body. It often happens in the arm, leg, face or neck. You may be at risk for lymphedema if lymph nodes have been removed by surgery or they’ve been damaged by radiation therapy or the cancer itself.

Lymphedema can happen soon after treatment, months or even years later. It can be a temporary or long-term condition. Common symptoms of lymphedema include:

- swelling of the arms, legs or trunk on the affected side of the body
- feeling of heaviness or discomfort in an arm or leg
- decreased flexibility in the 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. It’s easier to manage lymphedema when it is caught and treated early.

## Memory and concentration changes

“ I left my bank card in the bank machine. I would put soup in the microwave with the spoon in the bowl. I was taking Tylenol 3 for my radiation burns and accidentally took two Percocet-codeine pills instead. As I popped them in my mouth and swallowed I thought, What are you doing, Julie? This isn't you. I got the best sleep of my life that night. But it was hard. It makes me feel stupid. ~ Julie

Many cancer survivors 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 and then coming to terms with 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. After her treatment for breast cancer, Julie, who used to be on time or early for everything, found that she was constantly late. Sometimes, she had trouble with simple conversations: “I'll be in the middle of a story and suddenly the words escape me or I forget what the question was.” 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. Talk to your doctor if you think that a medication 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.
- Record dates, times and important details in a journal or on your mobile device.
- Highlight different activities in your journal in different colours.
- Use a chart board or whiteboard in the kitchen to develop a system of reminders.
- 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 cellphone) 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.
- Don't try to do too much at one time.
- Do crosswords or play games to keep your brain active.
- Tell people about your symptoms instead of hiding them.
- Learn about your symptoms and what you can do to cope. It might be useful to talk to others who have gone or are going through the same thing.
- Laugh or use humour about your situation to help ease tension.
- Try to recognize and accept your abilities as they are. You might find that meditation or other stress-reduction activities are useful.

## Menopausal symptoms

“ The chemo put me on a crash course with menopause. It didn't happen gradually. I had just terrible sweats at night, terrible hot flashes. But I was given medication to control that. ~ Ebe

Menopause is the time in a woman's life – usually between the ages of 45 and 55 – when the ovaries stop producing estrogen and menstrual periods stop. If your ovaries are removed because of cancer or are affected by chemotherapy or radiation to the pelvis, loss of estrogen can cause early menopause. Early menopause can cause more severe symptoms than natural menopause. Your interest in sex may decrease, and you may have symptoms like hot flashes, weight gain, loss of bone density, sweating, vaginal atrophy (when the vagina becomes tight and dry), irritability or changes in sleep patterns.

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

### Want more information?

Our booklet *Sexuality and Cancer* has detailed information on menopausal symptoms and tips on how to manage them.

## Neuropathy

“ Now, when I sign my name, my left hand shakes. That wasn't there before. ~ Allan

Some cancer treatments can damage your nervous system. This nerve damage is called neuropathy. Most people first notice symptoms of neuropathy 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 medications, topical creams and pain patches. Acupuncture, guided imagery, meditation, 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 special 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 or 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.
- Steady yourself when you walk by using a cane or other device. Walk slowly.
- 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 or food. If possible, lower the temperature setting on your hot water heater.
- If you're having trouble with your shoes and clothes, your local home healthcare pharmacy may be able to help. Shoes can be made easier to get on and off, and there are tools 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 cancer survivors may experience osteoporosis – a condition where there is a loss of bone mass. This weakens the bones, which means they can break (fracture) more easily. Osteoporosis can exist for years without symptoms – you may not realize that you have it until you fracture a bone.

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

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

## Pain

Some cancer survivors continue to have pain after treatment has ended. But over time, as your body heals, you may find that your pain eases. Immediately after radiation treatment for tongue cancer, Allan felt as though he had razor blades in his throat every time he swallowed. “It was excruciating,” he says. “I had to feed myself with a G-tube. I self-medicated with morphine for 3 months. I had to spray my throat with a topical anesthetic just to be able to swallow a mouthful of yogurt.” Over time, though, Allan’s throat pain became manageable. He has to be careful now, but eating is a pleasure again.

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 medications, or suggest options like physiotherapy, hot and cold packs, massage and relaxation techniques.

### Want more information?

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 survivors 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.

Cancer survivors 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 are at increased risk for another type.

Talk to your doctor about your personal 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, as a cancer survivor, 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 bodies look or work. These kinds of concerns about body image, and their effect on sexuality, are very common.

For women, hormonal treatments, pelvic surgery or radiation therapy – as well as early 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.

Men who've had surgery (for example, for prostate or colorectal cancer) may have problems 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 find pleasure together.

### Want more information?

Our booklet *Sexuality and Cancer* has detailed information on this topic.

## Speech problems

“ I suffer from what they call fasciculation of the tongue. It's a muscle loss in the tongue and the tongue vibrates a little bit. So, sometimes my words start to slur. I have difficulty pronouncing some words. It's frustrating at times because I say something and people are like, “Pardon me?” ~ Allan

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 temporary or permanent.



Losing the ability to speak clearly or at all, even temporarily, can be frightening 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 your listener 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 communicate 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 produce 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.

## Healthy living after cancer treatment



“ I was in the best shape of my life when I was diagnosed. That helped me get through treatment. Now, I’m working to get back to where I was before – I’m just trying to eat healthily, allow myself the occasional treat, work out and do the best that I can. Of course, I’ve been through a lot in the last year. It’s not going to be easy. ~ Julie

Now that treatment is over, you may be thinking about some healthy goals to work toward. You’ve been through a lot, so it’s okay to start small. While you may be tired of hearing messages about the importance of a healthy lifestyle, as a cancer survivor they take on more meaning. Being active, good nutrition, maintaining a healthy body weight and being a non-smoker can help you:

- regain or build strength
- reduce side effects
- reduce the risk of second cancers or other health problems
- manage stress
- reduce fatigue
- enjoy life more

### Your wellness plan

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 tailored to your personal needs, preferences, health and fitness level – it may look very different from another survivor’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 maintain the changes in the long term. Having the support of your family, friends and healthcare team can make it much easier to stick with 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 achieve and work toward them bit by bit. Even a cancer survivor who used to run marathons needs to start with a walk around the block.

### **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 cancer survivors 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, start slow and gradually increase the amount you move.

### **Why be physically active?**

Moderate, regular exercise (like brisk walking) has lots of benefits for cancer survivors. It can:

- ease side effects like fatigue, nausea and pain
- help you rebuild the strength you may have lost during treatment
- help you achieve or maintain a healthy body weight
- improve heart health and reduce your risk of developing type 2 diabetes
- boost your self-esteem and reduce anxiety and depression
- improve your quality of life

Studies have suggested that staying active after cancer treatment can help lower the risk of cancer returning and lead to longer survival. Plus, it's a great way to relieve stress.

“ Hockey, baseball, squash, running, whatever. I find that physical activity really helps me relieve a lot of stress and anxiety. ~ John

### **What kind of activity is best?**

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 small activities like 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.

What you need to work toward is getting moderately active for about 30 minutes a day or almost every day. Moderate physical activity includes activities such as brisk walking, tai chi or water aerobics, but it can also include raking leaves, vacuuming or doing the laundry. You can achieve your overall goal of 30 minutes a day in 3 separate sessions of 10 minutes each.

When you're ready, you might want to move on to more vigorous activities such as hiking uphill, digging in the garden, doing martial arts, playing a sport like soccer or hockey or swimming laps. 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 be able to join a rehabilitation or exercise program staffed by physiotherapists and other healthcare professionals.

#### > TIPS

- Talk to your doctor before getting started. Gentler forms of exercise such as brief, slow walks, stretching and swimming are almost always okay to start with, but if you're planning to get back to something vigorous (such as heavy gardening, lifting weights or playing a contact sport), your doctor needs to know.
- Try to exercise when your energy level is highest.
- Park further away from your office, the doctor's office or the grocery store so you can get a few more steps into your day – or get off the bus or train a few stops early and walk.
- Find an indoor place, such as a local mall, to walk when the weather is bad.
- If you find the idea of physical activity dull or are bored with your usual routine, combine it with something you like to do. For example, do arm curls, squats or sit-ups while you watch TV.
- Find an exercise partner or group. Exercising with other people can keep you motivated and provide some friendly support. Perhaps someone who went through treatment with you or someone from a local support group would be interested in meeting up and going for walks.
- Try line dancing, belly dancing or zumba if you enjoy music.
- Find activities you can do as a family, such as bowling or playing physically interactive video games.
- Walk the dog around that extra block. If you like animals and don't have one of your own, check with a local animal shelter about volunteering.

#### **Eat well**

“ I will take care of myself. I will not eat junk food if I'm hungry. I'm going to try to make a salad or something nutritionally beneficial. ~ Ebe

Eating a healthy diet has many benefits for cancer survivors. It can:

- help you get your strength back
- help you get to and stay at a healthy body weight after treatment

It's also important for cancer survivors to eat well because they may be at increased risk for other health conditions, such as heart disease, type 2 diabetes and osteoporosis (weakening of the bones). Healthy eating can lower your risk of these and other conditions, including the 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.

#### **Get to and stay at a healthy body weight**

“ The type of chemo I had made it easier for me to gain weight. It was like adding insult to injury. ~ Julie

Maintaining a healthy body weight is an important part of healthy living for survivors. It can:

- make you feel better
- improve self-esteem
- help you regain strength and fight infection

Maintaining a healthy weight after cancer treatment can help prevent other health problems, such as type 2 diabetes and heart disease, that you may now be at higher risk for. It can reduce the risk of some cancers occurring.



Unfortunately, the very fact that you had cancer treatment may make it harder to maintain a healthy weight. For example, certain kinds of chemotherapy, steroids and hormonal therapies can lead to weight gain. Sometimes the added pounds stay 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 cancer survivors 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.

As a cancer survivor, you may find that the usual ways to lose or gain weight may not 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 the surgery. "I'd gained about 15 pounds by the end of it all. 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."

If you're having trouble with your weight after cancer treatment, be patient with yourself and know that you're not alone. Look for the positive things that you can control, such as eating a healthy diet and being as active as you can. You may want to see a registered dietitian to talk about your food choices and help you create a food plan that works for you.

### **Live tobacco-free**

There are many reasons for cancer survivors to not smoke:

- Research shows that smoking can increase the chances of getting cancer at the same site 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. Tobacco is very addictive, and many smokers use cigarettes and tobacco products as a way of relaxing and relieving stress. While you probably couldn't imagine quitting 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 okay if you need help to quit smoking – most people do. You don't have to do it alone. Smokers' Helpline is here to help. It's a free, confidential service for smokers.

- Call us toll-free at 1-888-939-3333 (TTY 1-866-786-3934).
- Email us at [info@cis.cancer.ca](mailto:info@cis.cancer.ca).
- Visit our website at [cancer.ca](http://cancer.ca) to connect with your local Smokers' Helpline.

### **Protect yourself from the sun**

“ Two minutes in the sun and I can feel the skin on my neck burning. ~ Allan

Some cancer treatments, including radiation and chemotherapy, can make your skin more sensitive to the sun. This increased sensitivity can last for years. Radiation therapy to the neck left Allan with a very high sensitivity to the sun. He finds it best to have a couple of lines of defence: "I put on lots of sunscreen *and* wear a hat and a collared shirt." To protect your skin:

- Plan your outdoor activities before 11 a.m. or after 4 p.m. (when the sun is not at its strongest) or any time of the day when the UV Index is 3 or less.
- Seek shade, cover up with loose-fitting clothing and a wide-brimmed hat, and remember your sunglasses.
- Use a broad-spectrum sunscreen with a sun protection factor (SPF) of 15 or higher. Sunscreen should be used along with shade, clothing and hats – not instead of them.



## Dealing with practical issues



After cancer treatment is over, you may find that your focus turns to practical issues. You may worry about your job or dwell on money concerns. You may need to pay for new expenses, like help around the house or renovations to accommodate your needs. Things such as travelling may need to be thought about in a whole new way.

### Financial 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 how you'll manage financially.

- You may continue to take unpaid time away from work.
- You may find that you can't return to work as soon as you had hoped, or at all.
- You may have had to spend money on medications or therapies not covered by provincial or private health insurance plans, or for travel to and from treatment or extra child care expenses.
- You may have deferred or fallen behind on mortgage or credit card payments or student loans.
- You may have expenses for home care or renovations.

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

For information on government services and how to apply for them, contact your local Human Resources and Social Development Canada office at 1-800-0-Canada (1-800-622-6232) or visit [www.servicecanada.ca](http://www.servicecanada.ca).

## Returning to work

Most cancer survivors who are physically able to work do go back to their jobs. They 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 survivors 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. Some survivors may think that co-workers are treating them differently when they 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. Employers have to make reasonable changes, such as changes in work hours or duties, to help you do your job after cancer treatment. However, they don't have to make changes that would be overly costly 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."

But survivors 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 fail to be hired or 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 [www.chrc-ccdp.ca](http://www.chrc-ccdp.ca).

### What if you can no longer work?

Some cancer survivors find that they can't return to work 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. Find out 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. The *Guide to Government of Canada Services for People with Disabilities* has information

on employment, health, income support and tax benefits. Again, social workers at your hospital can help you learn more about these benefits.

You may 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. The Financial Planners Standards Council (FPSC) has helpful information on finding a certified financial planner.

## Changing your living arrangements

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 if you need help with housing costs or to make renovations because of the effects of cancer treatment. The *Guide to Government of Canada Services for People with Disabilities* has information on these programs. You can also get information on federal programs at [www.servicecanada.ca](http://www.servicecanada.ca). A social worker can also tell you about grants or programs in your province or community.

## Home care

Especially at first, you may find that you need some help around the house and with personal care, like eating, dressing, bathing or taking care of your body as it heals. Some survivors are most comfortable when their partner or 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 cancer survivors with access to home care. The *Guide to Government of Canada Services for People with Disabilities* has information on employment, health, income support and tax benefits. Ask your social worker at your hospital about getting home care, as well as about the costs of this care.

## Travel

“ On my first trip, we drove to Washington. I enjoyed it. It was really, really nice. Eventually, I'll get a little more adventuresome because I love to travel. ~ Julie

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 a normal chick, 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 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 three, 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.

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

- It may be harder or more expensive 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 you've had cancer and any other health conditions you have.
- 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 medications 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 medication to last the whole time you're away, even if you're delayed by a few days. You may want to divide your medications between your carry-on and checked baggage so that you won't be without medication if the airline loses a bag.

“ I have to take more stuff with me when I travel. Because I don't have saliva, I have dental trays and gel. I'm always carrying a water bottle. I have to brush my teeth 4 times a day. There are other little issues that come into play, but they're not major. It's the same kind of thing if you're travelling with a young child. ~ Allan

- Some cancer treatments interfere with the types of vaccinations 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 recommended guidelines for any travel vaccinations you do have. You may also need to be vaccinated again for diseases you were previously vaccinated against.
- Take your detailed personal health record with you, including information on the type of cancer and treatments you had, any medications you're on, your doctor's name and contact information, and your insurance information.



## Finding meaning after cancer treatment



“ You can say it doesn't change you, and you may not be able to put your fingers on the pulse of that change – but it does. I think those changes manifest themselves in ways you'd never expect. I knew after I finished treatments I had to do something about this. It didn't happen for happenstance. It happened for a reason. ~ Allan

Many 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 survivors say that the life-changing experience of cancer gave them the chance to grow, learn and appreciate what's important to them.

### A change in perspective

“ You know how when sometimes you cross the street and it's a yellow light and you just hurry up and cross? I said, No, no I'm not going to cross. I'm going to wait. That realization that nothing really is worth the hassle or the rush because I was going to die or maybe die. So now I'm just like, Hey, back off. Relax. I see life differently. ~ Ebe

Surviving cancer can change your outlook on life. Many survivors say they feel lucky or blessed to have survived treatment 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 survivors find this outlook frustrating or too simple – they may be relieved to have survived treatment, 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 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, for example, describes this process as “tailoring your life to fit you like you tailor a dress to fit you: a little bit by a little bit I tailored my life to fit to me to exactly what I like to do after the cancer.”

## 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. Cancer survivors 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. Survivors 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 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 survivors pursue spirituality through organized religion and find this to be a source of comfort and strength. Allan, for example, says that being a cancer survivor “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.

“ I believe in a higher power. I’m quite pleasantly pleased that at the end of this I still have that faith. I thought I might lose it. I thought I might be angry, bitter. ~ Julie

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, gardening. Through these kinds of activities – in particular, out in nature, in her garden – she says, 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.”

Six 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 survivors 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 activities such as:

- volunteering at a cancer centre
- joining a patient advocate group
- becoming a peer support volunteer
- enrolling in a research study for survivors
- volunteering your time and car to drive patients to treatment
- helping raise funds for research
- donating 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. Allan, for example, is now a peer support volunteer with the Canadian Cancer Society, talking to people who've been diagnosed with cancers like his. He loves the experience and thinks it adds a lot to his life.

“ It's an amazing thing when somebody invites you into their life at what's probably the worst time of their life. I am so grateful and honoured for the opportunity to do that. It makes me a better person too, I think. ~ Allan

Other people prefer to keep their volunteer or charitable work separate from their cancer experiences. Julie, for example, doesn't want much to do with the “whole pink-ribbon scene.” She says, “I'm still too close to it, I guess. I want to help humanity in any way I can. But for me, I don't want this experience to define who I am as a person.”

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](http://cancer.ca) for more information on giving your time.

## Going forward



The challenge facing survivors is to celebrate the joys of the present and get on with living – and to recognize when they need help and ask for it. 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 as you approach life as a cancer survivor and no right or wrong way to feel about the impact this disease has had on your life.

Life after cancer is a time of adjustment and change – you may move between the positive and the negative, 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.

“ 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

“ When you’re in a dark place and you cannot see anything and you see a glimpse of light, what would anybody do? Just follow that glimpse of light. This is how it was for me. This is a glimpse of light, go towards it. You follow that glimpse of hope, that glimpse of light, hoping that there will be an end for you on the other side. And there was. ~ Ebe



### Canadian Cancer Society

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

All of our services are free and confidential.

#### *Getting the information you need*

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

- managing late and long-term side effects
- sexual issues
- healthy living after treatment
- finding a counsellor

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

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

*Pain Relief: A guide for people with cancer*

*Sexuality and Cancer*

*Complementary Therapies: A guide for people with cancer*

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

#### *Talking to someone who's been there*

If you would like to talk to another survivor who's had a similar cancer experience, we can help. Let us connect you with a volunteer who can listen, provide hope, offer encouragement and share ideas for coping - all from the unique perspective of someone who's "been there."







## Canadian Cancer Society division offices

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## We'd like to hear from you

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

## What we do

The Canadian Cancer Society fights cancer by:

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

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



Canadian Cancer Society  
Société canadienne du cancer

1 888 939-3333 | [cancer.ca](http://cancer.ca)  
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This is general information developed by the Canadian Cancer Society.  
It is not intended to replace the advice of a qualified healthcare provider.

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