

WHAT YOU NEED TO KNOW

After your blood cancer diagnosis, you will want to learn about your treatment options and get the best possible care. However, a cancer diagnosis also affects your emotions, self-image, family, relationships, and plans for the future.

This fact sheet will help you:

- Learn about the emotions people living with cancer commonly experience
- Understand the symptoms and know when to get help
- Find strategies and resources for living better with cancer



of people living with cancer experience significant emotional distress such as depression

(Canadian Association of Psychosocial Oncology)

Your cancer experience

People living with cancer go through emotions that can change from one moment to the next. There is no right or wrong attitude and no ideal way to approach the disease or manage its impact on your life. Some days, you will feel like you're in control of the situation and others days you may feel despair.

Here are the emotions you may feel during your cancer experience:

Shock A blood cancer diagnosis can be surprising and upsetting. It can take some time to absorb everything.

Anger You may have a hard time understanding why cancer is happening to you. It may seem unfair or as though no one can understand your situation.

Denial Some refuse to believe or accept the cancer diagnosis. This is a normal reaction that may provide you the time you need to better absorb the news. "I tried to stay positive throughout my journey because I was so well supported, but inside I was panicking. Everyone offered their support, but I didn't dare take them at their word because I didn't want to be a burden to anyone. I didn't want my children to know I had cancer. I had to protect everyone around me."

- Survivor

Disbelief or confusion	Getting a cancer diagnosis is upsetting. You may have trouble absorbing information about your cancer because the information may be complex. It's natural to feel overwhelmed by the amount of information.
Fear and uncertainty	It's normal to worry about your future. You may feel like you no longer have control over your life.
Guilt	You may think you are to blame for your cancer diagnosis or the emotions your loved ones are feeling.
u may feel that no one, not even the people you love, understands what u are going through. You may also feel like everyone is going on with their es while yours is on hold. You could feel too sick to participate in activities at you normally enjoy.	
u may feel grief over the loss of your health or your ability to enjoy life.	

Loneliness You and isolation you lives that Sadness You Stress and It's also common to feel nervous or unable to stop your thoughts from racing. You and your loved ones will sometimes feel stressed and worried. This period anxiety of adjustment comes with several challenges that can make you feel anxious. Helplessness You may feel like you're losing control, giving up your independence, or losing your ability to manage your daily life. **Distress** You could feel overwhelmed by the situation, the amount of information you need to absorb and the number of changes to come. Relief Once you can put your disease into words and play an active role in what happens to you, you may feel relief. Hope There's also a feeling of hope that comes when you feel you will be able to overcome obstacles and look to the future with optimism.

The cancer experience

This section will help you understand emotions at various stages of the cancer journey.

Waiting for a diagnosis

The wait between various tests and your diagnosis may seem endless. During this period, you may feel uncertain, worried, or anxious. These emotions may have a big impact on your regular activities. The most difficult part of waiting is feeling that you've lost control. You may also fear the unknown. These feelings can create worry and anxiety.

"To say that a cancer diagnosis changes your life is an understatement. The challenges of cancer and subsequent treatments may seem insurmountable, but you can reap powerful rewards. We have been inundated with kindness beyond what I could have imagined. I am immensely grateful."

- Survivor

Diagnosis

The news that you have cancer is always a shock. The diagnosis can trigger a lot of emotions. There is no right way to react, and no one is ever completely prepared. You may have concerns about pain, symptoms, treatment choices, or physical changes. You may feel overwhelmed by the amount of information you have to remember and the decisions to make.

Living with cancer - mourning your old life

Each step of the grieving process will help you adjust to your new life and play an active role in your care. If you feel unable to do this, ask for help. For example, being in denial for too long could prevent you from making the best decisions about your health or seeking the support you need from your family.

You may have concerns about pain and symptoms, choosing the best treatment option, or deciding whether to use alternative or complementary therapies.

During this time, you may need support to help overcome shock, anxiety, fear, and feelings of losing control. Your diagnosis can trigger many fears about:

- Death
- Physical changes
- Unpleasant treatments or side effects
- The reaction of your family and friends
- Day-to-day tasks, work, or financial resources

It's important that you ask for help when anxiety takes over your life and prevents you from functioning. Resources are available. Contact your healthcare team, a psychologist or LLSC at info@bloodcancers.ca. Your loved ones will also support you throughout this experience.



"Thanks to information and advice from self-help group participants and facilitators, I don't feel alone in my cancer experience."

Survivor

Active surveillance (watch and wait approach)

When you are diagnosed with cancer, you will probably want to start your treatment right away and the wait may be hard. For some types of blood cancer, the best option is to watch and wait, also known as active surveillance. Through regular checkups, your healthcare team will closely monitor your health and the cancer's progress so treatment can begin when you need it.

Treatment

The wait between diagnosis and the start of treatment can be especially difficult. Throughout your treatment, you may experience fear and anxiety. You may, for example, be afraid of certain medical procedures (needles, enclosed areas, etc.) or physical changes, such as hair loss.

Relapse

Relapse, or the recurrence of cancer, can cause you to feel despair, anxiety about undergoing additional treatments, distress, and growing fears, similar to how you felt after your first diagnosis. Just because you are going through a relapse does not mean you now know how to handle the emotions you are feeling.

Life after cancer or finding your new normal

The period following your treatment may have challenges. You may feel abandoned by the system. Or you may not feel prepared to make the transition from cancer care to a normal life.

After your cancer treatment, you may experience short, medium, or long-term physical and psychological effects, including:

- Fatigue and brain fog
- Fertility problems (in young adults)
- Premature menopause
- Post-traumatic shock
- · Anxiety and depression
- Fear of cancer relapse or recurrence
- · Fear of death
- Guilt
- Difficulty returning to work or school
- · Financial problems

"My wife and I both volunteered for the peer support program – me as a survivor, and her as a caregiver. It was very rewarding to be able to help other survivors in various ways."

- Survivor

"Being afraid is normal but being angry is another thing altogether. I was really irritated. I was confused, too. I thought that once I reached the doctor's office, everything would be easy, but that wasn't the case. At that point, it would have been helpful to know that what I was feeling was normal and that I wasn't alone."

- Survivor

The importance of looking after your mental health

Since you may experience a range of emotions throughout your cancer experience, it's important to know the symptoms that could indicate mental health problems. Your mental health is just as important as physical health. Some symptoms need immediate attention.

Get help right away if you experience one or more of the following symptoms:

- Suicidal thoughts
- Self-harm
- Substance abuse (alcoholism, drug addiction)
- · Eating disorder (anorexia, bulimia, hyperphagia, orthorexia)

If you suspect any of the issues below, reach out for help. These symptoms should be treated, even if you are going through cancer treatment.

Anxiety

- · Difficulty relaxing, feeling constantly tense
- Lack of sleep
- Difficulty concentrating
- Faster heartbeat

- · Headaches, muscle pain
- · Appetite disorders
- Diarrhea
- · Weakness or dizziness
- Tight feeling in the throat or chest

Depression

- Sadness that does not go away
- Little or no interest or pleasure
- Feeling indifferent
- Feeling guilty or like a burden on your family
- Helplessness or despair
- Irritability
- Crying (for long periods or several times a day)
- Trouble seeing solutions

Post-traumatic stress disorder (PTSD)

- · Persistent and invasive negative thoughts
- Avoidance behaviour
- Overexcitement
- · Reactive behaviour
- Hypervigilance
- · Feeling of wanting to control everything

19 % of cancer survivors report experiencing post-traumatic shock

Strategies to live better with cancer

Get the facts

Gather information from reliable resources. Validate your information and make sure it's up to date. Collect information in small doses, only as much as you can comfortably handle. Since treatment can make reading and understanding difficult, use tools like explainer videos or podcasts.

"I wanted information, but I found it overwhelming... because it was a lot of information. I was still in shock and needed information that I could digest. But as I moved forward, I was able to absorb more information."

- Survivor

Find help

People often think asking for help is a weakness. Yet, when cancer strikes, help can take on different forms and come from different sources. These sources will help you deal with the situation:

- Family and friends
- Support groups
- Work colleagues and expanded network
- Volunteer organizations
- Psychologists and social workers
- · Financial advisors
- Religious or spiritual leaders

Join forces with your healthcare team

Your healthcare team will answer your questions and keep you informed throughout your cancer journey. Here's how you can play an active role in your cancer experience:

- Participate in decisions that affect your treatment.
- Set achievable goals and plan how to reach them.
- Look for professionals who specialize in your type of cancer.
- Do not skip any medical appointments, even if you feel well.
- Maintain your insurance coverage, if possible.
- Talk about your experience. Psychologists, psychiatrists, nurses, and social workers can provide support.

Improve your health

Although you can't control cancer, there are many things you can do to live a healthy lifestyle. You can:

- Adopt a healthy diet
- Exercise
- Quit smoking
- Reduce your alcohol intake

Take care of your mental health

- Join an LLSC virtual support group or participate in the First Connection Peer Support program to voice your feelings and concerns. You will benefit from hearing from those with similar experiences.
- Take your mind off things with activities you enjoy.
- · Keep your life as normal as possible.
- Write down reasons to be hopeful or talk about it with your loved ones.
- Spend time in nature.
- Reflect on your personal beliefs.
- Listen to stories of people living with cancer who lead active lives.
- Try relaxation strategies like mindfulness meditation, yoga, or mental imagery.

Remember your caregivers

Several studies have found that family members experience as much, and sometimes more, distress than people living with cancer. Often, caregivers:

- Fear being alone
- · Feel powerless
- See their lifestyle disrupted
- · Are unsure of everything

"Through the First Connection program, I was able to hear the stories of other survivors, which helped me regain the hope and faith I lost earlier in my treatment."

- Survivor

"It's often harder on the family than it is on me, because I know what's going on in my head."

– Survivor

Although it can be difficult, tell your loved ones or friends how you feel. Some days are harder than others and you may need to express your sadness. Don't shy away from difficult conversations. Encourage your caregivers to seek help if needed.

Towards a new normal

Everyone experiences cancer in their own way and the same is true for life after treatment. In fact, your new normal will be shaped by the changes that cancer causes.

For some, it may be a returning to the life they were leading before they had cancer. For others, life will never be the same. You may experience new physical problems, lifestyle changes, or different financial realities. Some people living with cancer report changes in their relationships, personal strengths, and spiritual beliefs. Some find a greater appreciation of life and new opportunities.

Although cancer can be negative, it can also motivate you to look for new meaning in your life. Whatever your journey with cancer, remember you are not alone.



"For years, I thought I had to learn to live with myeloproliferative neoplasms on my own. Then I contacted the LLSC. The community services team really reassured me and I realized that I was not alone."

- Survivor

We're here to help

You will face challenges at each step of your cancer journey. When you call us, one of our Community Service Leads can help. If you or your loved one is living with a blood cancer, we can:

- Listen carefully and compassionately to the difficulties you're facing
- Direct you to information specific to your type of blood cancer or treatment
- Help you get organized to manage and pay for your care
- · Identify the services that will benefit you

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Never hesitate to contact us, we're here to help!

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