LEUKEMIA & LYMPHOMA SOCIETY OF CANADA

YOUNG ADULTS with a blood cancer

YOUNG ADULTS

(18-39 YEARS)

GETTING A CANCER diagnosis at this early stage in your adult life can be life-changing. You may have just started your post-secondary education or a new career or being a parent for the first time. We know more about blood cancers today than ever before. There are treatment options available to you. During your treatment, you will likely face challenges specific to your age group. That's why it is important that you stay informed so that you can be better prepared for what's ahead. Getting information about your diagnosis can help you regain a feeling of control and help to decrease any fear or anxiety you might have. There's no ideal time for cancer, but know that you are not alone.

Sharing your diagnosis

Telling people about your diagnosis is a very personal decision. Some people choose to tell only close family members and friends. Others find that it helps to let more people know about their diagnosis like classmates, co-workers, and teammates. Only you can decide what is best for you.

By letting friends and family know about your diagnosis, it gives them an opportunity to offer their support or lend a hand when you need it. Take some time to decide what information and details related to your cancer experience you want to share. It may help to practice what you want to say and anticipate questions they may have. Be prepared for different reactions. Some people may not know what to say or do, but most will be supportive.

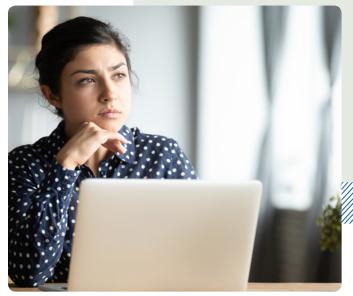
Social media

You may be thinking about sharing your cancer experience with others through social media. Perhaps you want to express your feelings – good or bad – along the way, gain encouragement and empathy from those in your social network or have a place to document this major life event. Whatever your reason, take time to think it over.

Questions you should first ask yourself

- Would it upset me to look back on my cancer experience in the future through my social feed?
- Would it affect me if an important person, like a potential employer, or partner learned about my diagnosis from a Web search?
- Can this information be taken down in the future, if I choose to?

Exactly who can see or use this information on social media?



Always check your privacy settings first. Remember that anything shared online may be less private than you think. You may want to consider using group email or a private website to share updates with only a select number of people.

If you decide not to share your diagnosis online, ask your friends and family to also respect your privacy and to do the same.



Activities with friends and family

Once you are diagnosed, your daily routine may change. How much changes will depend on the course of treatment you need to follow and how well you feel.

Going through cancer treatment may not always mean stopping everything you used to enjoy all at once. At some point in your treatment, it may be more difficult for you to see your friends or other family members who don't live with you. Activities like playing sports, going out with friends, or even going to a restaurant with your loved ones may be off-limits until you are considered healthy enough or have the energy to take part. At other times during your treatment, you may be able to take part in activities that you used to do with friends and family, but in a different way or only at certain times.

It is common to feel frustrated about those changes, but know that this is temporary. You may find it helps to talk to your friends and family about what you can and can't do, or what you feel or don't feel like doing, so they can better understand your situation. Being open with them can avoid a lot of frustration for both you and them.

School, work and finances

Some people continue to go to school or to work throughout their treatment, while others cannot. Talk to your healthcare team to decide what is best for you.

Students in post- secondary programs	If you are a post-secondary student, speak with your university or college to see what their policy is in the event you need to miss classes or even a whole semester. If you have student loans you should contact your student loan provider to see if they can defer payment while you are in treatment. Once you return to school, you may want to speak with the administrators or your professors about any accommodations you may need to ease your transition back to class.
Work	If you are currently working part-time or full-time, you may need to limit your availability or take a leave of absence. If you need to stop working, you may have the right to take medical leave under your employer's policies. Speak with your employer to find out if you can take a leave of absence while you are away. Other sick leave options include the following: employment insurance, disability insurance or long-term disability insurance, Canada Pension Plan or Quebec Pension Plan.
Finances	When it comes to your personal finances, even with health insurance, cancer treatment can have an impact for you and your family. Most aspects of your cancer care will be covered by your provincial health insurance, but there are exceptions depending on where you live in Canada. You can avoid surprises for any out-of-pocket or indirect costs like lost time from work, childcare or transportation and lodging by taking steps to manage your finances now.
	Where to start
	 Talk to your doctor about the expected timing and length of your treatment.
	 Become familiar with your provincial health insurance for cancer treatment and other related expenses like overnight hospital stays in a private room and drug coverage.
	 Review what your employee health benefits or personal health insurance covers including any exceptions or rules, and how to make a claim.
	Don't wait to review your personal finances.
	 Keep and organize any bills, receipts and other important documents. They may be helpful for your income tax.

Parenting

Parenting can be especially tough when you are going through treatment. You may worry about how you will care for your child. You may worry about how your child will handle your diagnosis. You may wonder if you will need to be apart for treatment. Young children can often sense when something is wrong and being honest about your cancer from the start will help them understand why you are not your usual self and offer help when you need it. Before speaking with your child about your cancer diagnosis and treatment, prepare what and how much you will tell them.

Whenever possible, try to maintain a normal schedule for your child. If you have a co-parent or partner, discuss how parenting responsibilities may need to shift during and after your treatment. Ask for help and accept help when offered. Friends and loved ones will likely want to help you, but they may not know how. Make a list of specific tasks you know you'll need help with.

Dealing with your emotions

You may be feeling scared, anxious, and stressed right now, but know that all of those feelings are a natural reaction. If these feelings become overwhelming or unbearable, it is important that you speak with a member of your healthcare team. Social workers and psychologists are available as part of your cancer care team.

Some people with cancer find that speaking to another person who has gone through a similar experience with a blood cancer can make them feel less anxious and alone. Contact us to speak with a Community Services Manager in your area to get information on programs available to help young adults with a blood cancer. For example, we can match you with a volunteer who experienced a similar cancer diagnosis as a young adult for you to talk to. The volunteer is trained to listen and to give you support while sharing their own perspective on the treatment and recovery process. Ask about our peer support program to learn more.

Changes to your body

As part of your treatment, your body may experience physical changes. You may feel self-conscious about those changes such as hair loss, weight changes, swelling, scars, or having a central venous access device (CVAD) inserted. Remember that most or all of these changes are only temporary.



Intimacy and sexual health

A cancer diagnosis can be difficult on both you and your partner so it's important for both of you to communicate how you are feeling. You and your partner may hit some rough patches so it is best to be open and honest with one another and seek professional counselling when needed.

You may be wondering how cancer or the treatments will affect your current or future romantic relationships and sexuality. For example, will it be safe for me to be intimate with my partner during my treatment? How will treatment affect my interest or ability for sexual activity now and later? Will this cancer or cancer treatment affect my fertility? Answers to these and other questions are different for everyone because no two blood cancer experiences are exactly alike. What may be safe or possible for another person with cancer may not be for you or vice versa.

Cancer treatment may affect your sexuality and the way you feel about your body. It is possible that you might experience side effects of cancer treatment that affect your sexual health.

Possible side effects

- pain
- erectile dysfunction
 lack of desire
- other side effects that may interfere with your
- desire for sex

 infertility
- fatigue

vaginal dryness

• nausea

If you are continuing to have, or are starting a new, sexual relationship while in treatment, the best thing to do is to speak with your healthcare team. There may be a wait period or some precautions you will need to take before continuing or starting sexual activity. There are also risks associated with sexual intercourse that will need to be discussed. It is important that if you are sexually active that you always use condoms to protect against sexually transmitted infections (STIs) and unwanted pregnancy. Speak with your healthcare team about which forms of birth control are right for you.

Telling your spouse or partner

Cancer can be difficult on everyone affected by the diagnosis. Deciding when is the right time to talk to your spouse or partner about your diagnosis is personal. There is no right or wrong choice. If you are in a steady relationship or a new one, your diagnosis may bring about some positive and negative reactions or feelings between you and your partner.

Each person reacts to cancer differently. Your spouse or partner may be understanding and become your primary caregiver. Your partner may also have a difficult time coping. Expect that your relationship may change over the course of your experience with cancer. If you are concerned about your relationship, it may be beneficial for you and your spouse or partner to do couples counselling. Look to your healthcare team, your network of support or contact us for available resources and recommendations.

Fertility

Your ability to have children (fertility) in the future may also be affected by cancer treatment. Even if you may not be thinking about having children anytime soon, having cancer may require you and your spouse or partner to think seriously about your plans to conceive in the future. It's best to speak with your healthcare team about your options if you do decide to have children later.

Long-term and late effects

Treatment for your blood cancer may include chemotherapy, other drug therapies, radiation, and a stem cell transplant. These treatments can be very effective but they also come with risks of long term effects (medical problems that continue for months or years after treatment ends) and late effects (medical problems that do not develop or become apparent until years after treatment ends) that may pose challenges as you get older.

Possible health risks of treatment		 bone or joint pain increased risk for developing a secondary cancer later on in life
	These health challenges may begin during or shortly after treatment, or later on in life. Early intervention and healthy lifestyle practices (not smoking, good nutrition, exercise, regular health screenings and follow-up) can help reduce these risks and their severity. Talk to your healthcare team about possible long-term and late effects of your cancer treatment.	

Life after cancer

In the time between rounds of treatment or once your treatment has ended entirely, you may have a number of different emotions. It is possible that you will feel happiness and excitement about completing your course of treatment, but also anxiety and fear about the future and what comes next. It is normal to need support even after treatment and it is important to reach out to family, friends, and your healthcare team.

Visit bloodcancers.ca for more information and to get access to resources specific to young adults experiencing a blood cancer. You can also contact us to speak with a Community Services Manager who can help you understand or find the information or support in your region.



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Never hesitate to contact us, we're here to help! 1833 222-4884 • info@bloodcancers.ca • bloodcancers.ca

