

Treatment decisions



“For my first appointment, I asked my husband to go with me because I was terrified and along with needing emotional support, it was important to have someone else to listen to all of the information because it was so overwhelming. The doctors and nurses are very supportive and encourage family and friends to be involved.”

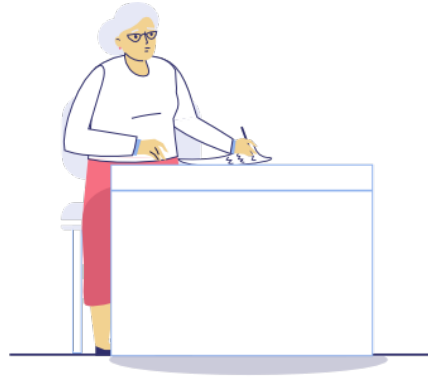
Ana
Cancer survivor

How does this affect me?

Making a decision about your cancer treatment can be a challenging process. The decision usually depends on many things. This includes your type of cancer, its location, and stage. You may be given several treatment options or you may be given one or two choices, depending on these factors. Your oncologist and healthcare team will guide you. They will suggest treatment options based on your specific cancer and overall health. They will ask for your input based on how involved you want to be in the decision-making process. Choosing between treatments is a common challenge faced by cancer patients. Every treatment option will have pros and cons. You can feel more confident by taking time to understand your treatment and considering the pros and cons. The cancer journey does not involve a one-time decision. It often requires you to make a set of decisions with your healthcare team and your loved ones. Depending on how your cancer is improving or progressing, you and your oncologist may choose to make adjustments to your treatment. You will not have to make these decisions on your own. There are plenty of supports and resources available to you. Talking to your healthcare team, your loved ones, and asking for information tools are ways to facilitate your decision.

Examples of decisions you may need to make are:

- Where to get treatment/what hospital or cancer centre to go to
- Who will be your oncologist
- What treatment to take
- How involved you want to be in decision-making



What can I do to make treatment decisions easier?

The first appointment with an oncologist is usually a consultation appointment. Your oncologist will speak to you about your cancer. There may be more tests ordered to understand your cancer better. Your oncologist may also present some treatment options to you. You may have to wait until your second appointment when your tests results have come back to know more about your options. During this time, you can practice some of the following ways to learn more about your decision-making style. This will help you determine what might work for you. These can prepare you to make a necessary decision later on.



Find out your decision-making style

How a person makes decisions varies. You might feel either nervous or confident about making decisions that affect your health. It can be useful to know your decision-making style.

It is important to share this with your healthcare team as well as the people closest to you. This will help you to have the level of feedback that you want. Good communication can create a positive experience for you and your healthcare team when making a decision.

Three different decision-making styles are:

Active: “I prefer to make the final decision about my treatment. I decide after seriously considering the opinion of my healthcare team and the information they have provided.”

Shared: “I prefer shared responsibility between me and my healthcare team when we make decisions about my treatment.”

Passive: “I prefer to leave all my treatment decisions to my healthcare team. However, I will shared my thoughts and feelings with them.”

Think about which statement you identify with the most. Your confidence in your decisions will increase when you match your style with the level of involvement in your care.



Write down a list of questions

It is useful to write down what questions you have and to bring these to your healthcare appointment. Preparing your list of questions will help you remember to ask them in the moment. Asking questions about your cancer and treatment options will help you get the information you need. This can help you feel more confident when making decisions. These are examples of questions you could write down:

- What type of cancer do I have?
- What is the stage of my cancer?
- What are my treatment options?
- What are the goals of the proposed treatments?
- What are the benefits of treatment?
- What are the most common side effects?
- How can these side effects be managed?
- What could happen if I don't take the treatment?
- Where would I receive treatment? Do I need to stay in the hospital overnight?
- When would my treatments start?
- How long will the treatments be?
- Should I drive or take public transport the day of my treatment?
- If this treatment doesn't work, are there other options for me?
- Am I eligible to participate in clinical trials? If yes, who would I contact for information about clinical trials?
- Can I use complementary and alternative medicine?
- Will I need help to manage at home? Will I be able to manage by myself? Will my level autonomy be the same as before starting treatment?

You will receive a lot of information at your first appointments. Therefore, it can be very helpful to bring someone with you. It can be overwhelming to remember everything on your own. Think about who you will ask to accompany you to your first appointment. This could be your partner, a friend, or a family member.



What should I consider when making a treatment decision?

Your cancer journey is not something you have to go through alone. You can lean on your loved ones for support. You can also ask your healthcare team for help when you need it. Your family can help you by encouraging you or listening to your concerns about making a treatment decision. Your oncologist and healthcare team are there to help and guide you to make the choice that is best suited for you. Do not be afraid to ask questions! Together, you, your doctors, and your loved ones can make a plan that you are confident in.



Ask about your treatment options and write them down

You can ask if you can record the consult or the answers to your questions. This way you can listen to them again at home. Many doctors are open to this idea. There is often a lot of information to absorb which can be overwhelming. This is where your support person can be very helpful. Ask them to write things down as the doctor gives you information. Once your oncologist has given you the details of the cancer and its stage, they will talk about possible treatments. Knowing your options will allow you to make the best decision.

Some treatment options include:

- Radiation therapy.
- Brachytherapy.
- Surgery.
- Chemotherapy.
- Hormone therapy.
- Immunotherapy.
- Watchful waiting (active surveillance).
- Combination therapy.
- Palliative and comfort care.
- Participation in a clinical trial.



Understand your goals of care

The type of treatment you need will be determined by your cancer, its stage, and your goals of care. Ask your oncologist and healthcare team about the goal of the treatment that they suggest. This can help clarify and guide you in the right direction. For example, a specific goal may be to:

- Reduce the tumor size.
- Kill all the cancer cells.
- Manage your cancer symptoms (such as a bleed or pain).
- Prevent the progression of the disease.

Understanding the goals of your care and discussing this with your healthcare team is key to choosing the treatment that is right for you.



Take the time you need

It is common for patients to ask their oncologist for some time to think about all the information they received. You can select a later date to schedule an appointment. Then you can come back and talk more about your treatment plan. Take the time you need to think about and process the information. This will help you feel more confident when you actually make a decision about your treatment. Try talking to a trusted family member or friend about your feelings. They can help you sort things out by simply listening and asking questions.



Ask for a second opinion

Some patients ask for a second or even third opinion after receiving a diagnosis and before starting treatments. This can be helpful if you feel as though you have not explored all your options or if the first oncologist was not the right fit. A second opinion may reinforce what you already know and give you more confidence in your treatment options. It could give you a different perspective from the one you had received. Doctors are used to patients asking for second opinions and sometimes encourage it. It is important to let your doctor know you are seeking a second opinion so that they can send your health records and test results to the other oncologist. Your doctor may also refer you to another oncologist and make the process of finding a second opinion faster. Ask a family member or a nurse to be there with you if you feel uncomfortable talking to your doctor about this. If the second opinion is different from the first, ask both doctors for more information to better understand the reasons. If you still feel unsure, you may benefit from a third opinion. Lastly, ensure you let both doctors know with whom you will follow up for treatment. This will prevent confusion and avoid any delay in starting your treatment.



Consider the pros and cons of the suggested treatments

Weigh the pros and cons carefully by making a list or a chart to compare different treatment options. You can ask your oncologist to explain the side effects and the expected positive outcomes of the treatments you are considering. Side effects and other factors to consider may include:

- Physical side effects (e.g. hair loss, sexual and fertility changes, scars, etc.).
- Psychological side effects (e.g. anxiety, depression).
- Finances (e.g. the cost of oral medication and whether it will be reimbursed by your insurance, leave of absence from work).
- Location, distance, and travel time to and from the treatment centre.
- Personal or family preferences.



Use a decision aid

A decision aid is an information tool. It can be helpful when comparing treatment options. They include information on your cancer, possible treatments, and possible results and side effects. Ask your oncologist if there are decision aids that you can use. If your doctor has provided them, you can be sure they come from a trusted source. If you look for these online, you may find some are more accurate and trusted than others. You want to have accurate information in order to make a treatment decision. Read the decision aid and discuss it with a trusted family member or friend. Make note of any questions you have and reach out to your doctor for answers. Please refer to the resources table for examples of decision aids.



Consider the DECIDE strategy

The DECIDE strategy is another approach you can use when making treatment decisions. You can do this instead of using a decision aid or in addition to it. It really depends on what works best for you.

Step 1: Define the problem.

Step 2: Establish the criteria. What factors need to be considered to make the decision?

Step 3: Consider your options. Think about the pros and cons of each option.

Step 4: Identify the best option. Use the pros and cons to make a decision.

Step 5: Develop a plan of action and action it.

Step 6: Evaluate and re-evaluate the decision.



Asking about clinical trials

Clinical trials are studies that test new cancer treatments. These studies monitor the results closely and carefully. They are usually led by doctors and take place at an outpatient clinic or in a cancer centre. If you are interested in exploring this option, you can ask your oncologist for information about any clinical trials you may be eligible for. It is important to understand the potential risks and benefits before deciding to join a clinical trial. This is the case with any treatment decision. Clinical trials are often 'randomized studies'. This means that you would be randomly assigned one of two available treatment groups. In the clinical trial you can either receive the new treatment (study group) or the receive the best-known standard of care without the new treatment (control group). You may not know which group you were assigned to until the study is finished. If you do not receive the new treatment you can rest assured you will receive the best standard of care in the control group. Visit the Canadian Cancer Society's [website](#) for more information on clinical trials and to see what is available in your healthcare region.

Here are some questions you can ask your doctor and healthcare team when considering a clinical trial:

- What is involved in this clinical trial treatment?
- How does the trial compare to the best standard treatment?
- What are the possible side effects? Benefits? Risks?
- What can I do if the trial doesn't work for me?
- Who will follow me during this study?
- What extra tests will I need to take if I choose to participate?
- How will this trial affect my day-to-day life?
- How long can I take to think about this?
- Are there any costs I should be aware of? Are there any extra costs, travel, or time I need to be aware of for this trial?
- Once I am on the trial, can I choose to leave it at any time without harm?
- How long does the trial last?



Where can I find help?

Your Healthcare team

Your healthcare team is there to support you and guide you in the process of making a decision. You can ask your oncologist, nurses, family doctor, pharmacist, and any other professional involved in your care to help you understand your treatment options. You can also ask them for support or additional information when you need it. In order to meet your needs, your care team may refer you to other resources. Some of these could include a palliative care team or a psychosocial oncology team.

It is important to note that palliative care is an approach used to care for the emotional, physical, and spiritual well-being of a person and their families when they are faced with a serious illness. Some people mistakenly think it is only something offered for patients at end of life. Palliative care is much broader than that. It provides the help you and your family may need to improve your quality of life. It can be helpful at any stage of your cancer journey. Ask your doctor for information on how to get in touch with a palliative care team. They will be happy to help you with any difficulties you face.



Support groups

You can find support groups that meet online, in person, or by phone. Support groups can provide resources. They can connect you with others who have already had or are going through a similar experience. You may find it helpful to talk to other patients who went through the difficulty of making treatment decisions. They will be able to discuss and share their experiences with you.

The Canadian Cancer Society offers a free program that matches people dealing with cancer with trained volunteers who have had a similar cancer experience. They are there to listen, offer hope, and support with the challenges you may be facing. Visit their [website](#) or call 1 888 939-3333 for more info.



What can I do to look after myself?

The process of making a treatment decision takes time and energy. It is important to look after yourself and do what you can to decrease your stress levels. Here are a few suggestions of what you can do to look after yourself.



Plan what you eat

Eating healthy food and ensuring you drink plenty of fluids can help your body feel better.

- Try to eat a whole and balanced diet. This includes eating lots of vegetables, fruits, protein, and whole grains.
- Consult your healthcare professional or nutritionist for help with meal planning. Ask if there are any foods you should avoid.
- Stay hydrated by drinking plenty of fluids.
- Reach out to your doctor if you are experiencing nausea or vomiting or have trouble eating for any other reason.
- For more information see [Looking after yourself](#).

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Exercise

Exercise can help strengthen your body and help you clear your mind as you undergo cancer treatments.

- Choose an activity you like to do alone or with a family member or friend.
- Walking, light stretching, or breathing exercises can help your body, mind, and brain feel better.
- In general, light exercise can be done while you are undergoing treatment. Check with your healthcare provider before starting a new exercise routine.
- For more information see [Looking after yourself](#).



Practice relaxation strategies

Taking care of yourself by finding ways to relax can help your mind and body. This can lead to better sleep and reduced stress. These easy relaxation strategies can be done anywhere!

- **Breathing exercises.** Even a few minutes of deep breathing can help your body relax. Try breathing exercises such as slow, deep, counted breathing.
- **Progressive muscle relaxation.** This involves tensing and relaxing a muscle, or groups of muscles, one at a time.
- **Guided imagery or visualization.** Imagine being in a place that makes you feel calm in real life. You can use a recording to guide your visualization or find help from a trained instructor.
- **Massage therapy.** Use a certified massage therapist who has experience working with cancer patients.
- For more information see [Relaxation strategies](#).

Resources

For more information on making treatment decisions and for other helpful resources, check out the resources below.

[Canadian Cancer Society – Choosing care and treatment for advanced cancer](#)

[Canadian Cancer Society – Information on Clinical Trials](#)

[Canadian Cancer Society – Information on Treatment](#)

[Canadian Cancer Society – Making Treatment Decisions](#)

[Canadian Cancer Society – Questions to ask about treatment](#)

[The Ottawa Hospital – Patient Decision Aids by Health Topic](#)

[Queen’s University – Decision support for early-stage prostate cancer](#)

[National Cancer Institute – Treatment Choices for Men with Early-Stage Prostate Cancer](#)

[Info-aidant](#) is open every day from 8 a.m. to 8 p.m. to listening, and provide information and references. info-aidant@lappui.org 1 855 852-7784

Acknowledgement of sources

The content of this document has been adapted from the following sources:

- Leukemia & Lymphoma Society of Canada. Getting a second opinion. 2020.
- Leukemia & Lymphoma Society of Canada. Making Treatment decisions. 2020.
- NSHA. Cancer Care: A guide for patients, families, and caregivers. 2017.
- TEMPO. Making decisions about treatment. 2018.
- TEMPO We feel that we don’t have enough options. 2018.
- UHN. Princess Margaret Centre. Deciding to take part in clinical trials. 2018.

Healthcare professional endorsement

The content of this document has been reviewed and approved by a team of healthcare professionals and clinical experts.

Disclaimer

Please note that this fact sheet is not intended as a substitute for consultation with a healthcare professional. If you have questions about your health, or any medical issue, you should contact a healthcare professional right away. You should not delay seeking medical advice, or disregard professional medical advice, because of information in this fact sheet. Before beginning any health treatment, always consult your doctor. All care has been taken to ensure that the information contained in this document is accurate at the time of publication. e-IMPAQc is not responsible for any injury or damage to persons or property arising out of, or related to, any use of the fact sheet, or because of any errors or omissions.

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