# **Understand Illness**



"Well, the trouble is in ignorance, you don't know how one choice is better than the next...if I was offered choices, I would try and rely on the information I got from the doctor, the specialist."

# Eric Diagnosed with prostate cancer

#### How does this affect me?

Being diagnosed with cancer can mean you are sorting through new and complex information. This can feel stressful when information isn't clear to you. It's normal to feel that way. You and your family might want to learn as much as you can about the diagnosis and what to expect during treatment and beyond.

Finding the right information can help you to:

- feel more confident and in control
- decrease feelings of stress
- participate in your care more actively
- be better able to consider your options
- think of questions for your healthcare team
- feel less alone and put your mind at ease



### What can I do to learn more about my illness and treatment?

It is important to voice your personal needs for information. Information should be tailored to your expectations and preferences, as well as to the diagnosis and clinical situation. You may notice that the level of information you need changes over time, for example, during and after treatment. The information provided by your care team are specific to the type and stage of cancer, treatment, and prognosis. The information may also be related to rehabilitation, reaching and maintaining better health, coping, and financial/legal concerns. Relevant and accurate information is key to successful self-management and promoting an improvement in your overall health.

#### First, figure out the amount of information you want:

Do you need to know everything or do you prefer just enough information to make an informed decision?

- Make sure to let other people know the kind of information you want, so they don't give you more than you want.
- If someone gives you a booklet or DVD about cancer and you aren't interested in this information, it's ok to put it aside for later. If ever you change your mind, that can become a handy resource later on.

#### Find information from reliable sources:

Only read information from trusted sources. For example, these can be pamphlets from your clinic, or information from the Canadian Cancer Society or the Quebec Cancer Foundation. Let your healthcare professionals know that you would like information to help you better manage treatment and your health.

- Use the internet with caution. Unless the information is from a reliable resource, it may not be accurate or current. Try public, non-profit websites. See the section <a href="Where can I find help">Where can I find help</a>? for more information.
- For information about different types of cancers and treatments (for example, chemotherapy or radiation therapy), see the Resources section.



#### What help do I need?



### Make a list of questions and bring it to your appointments

A question checklist is a great way to reduce anxiety about remembering what you want to ask. Writing your list of questions can help you get the most out of your time and help to make sure all your concerns are addressed. You can also ask the doctor or their assistant if you can email them your list ahead of time. That way they know what you need in advance. Some examples of guestions you may have:

- Type of cancer, stage?
- Symptoms of cancer?
- Chance of cure, recurrence?
- Available treatment options?
- Side effects/benefits of treatment?
- Getting a second opinion?
- Alternative and complementary treatments?
- Available resources (dietitian, social worker, community clinic...)?



### Book a longer appointment

If you have many questions, mention it when booking your appointment! If possible, your care team may adjust the length of your appointment as needed.



# Take someone with you

There is a lot of new information to take in. It can be helpful to have someone with you to listen and take notes. Some of those close to you (family, friends, caregivers, etc.( may wish to join you for your appointments. They can provide moral support or help speak to you healthcare team about your needs.

For more information see Getting Support.



#### Where can I find help?

The following sources can help you find the resources you need.



### Your healthcare team

This can include your oncologist, psycho-social team (psychologist, social worker, supportive care), nurse or family doctor. If one person on the team can't answer your questions, they will help you find someone who can. If you are having a difficult time making sense of something your healthcare professional has told you, don't feel shy to ask for help:

- You can ask them to explain further
- Ask for a summary, a memory aid, or a diagram for example, in order to help you better understand certain concepts or information
- Repeat back to your healthcare professional what you've heard in your own words to make sure you've understood correctly



### Your friends, colleagues and family

Ask someone you trust to gather or keep information for you. They can help you search for information at the library or through cancer organizations.



### • Canadian Cancer Society

Canada has many agencies working to fight cancer while supporting patients and families. They usually have many resources to share. You can start with the Canadian Cancer Society. To find a support group in your community, you can call 1-800-265-6750. To access the main webpage visit www.cancer.ca.

For a checklist of questions, you can ask your healthcare team visit Questions to ask about treatment.

To join the virtual community or join a free support group visit CancerConnection.ca.



### **Quebec Cancer Foundation**

The Foundation provides a resource directory where you can search for the organizations near you offering a variety of services including home help, lodging, transportation, and other supportive resources.

### Online searches

The internet is a great resource to help build knowledge on cancer. To save time, here are a few ways to filter through the most useful information:

- Look for a trusted source. For example, a government agency, university, research organization or medical institution. Be cautious of information sponsored by someone who is looking to make a profit.
- Make sure you really understand the language being used.
- Check that the information is recent, meaning it is up to date.
- Question whether something sounds too good to be true. If it does, then it probably is. Bring this up with a health professional to double-check!
- You can also use online chat rooms to connect with other people going through a similar experience.

## Bookshops and libraries

- You can take out a book, journal or a movie from the library if you prefer to find information in physical documents as compared to online.
- If you would like to search the internet but don't have access at home, you can try using the computers at your local library.

### Other cancer survivors and their families

Everyone's life and cancer experience is different. However, it might help to share thoughts, concerns and ideas with someone who has lived through a similar situation. Here are a few ideas on where to find someone to connect with:

- Cancer-related organizations like the Canadian Cancer Society or Quebec Cancer Foundation.
- Support groups. You can ask your healthcare team to connect you with this.
- A family member or someone else you are close to may know someone who has had cancer who can share their experience with you.

For more information see **Getting support**.



#### What can I do to look after myself?

Keeping up healthy habits can help your overall wellbeing and decrease anxiety as you take the time to learn and process all this new information. For more information see <u>Looking after yourself</u>.

# Plan what you eat

- You might need more energy or calories during treatment to maintain your weight.
- Drink plenty of liquids so you don't get dehydrated, especially on days when you are unable to eat.
- Protein can help your body heal and maintain a healthy immune system. Protein is found in fish, poultry, eggs, nuts, dried beans, lean red meat.
- Check with your healthcare team to find out if there are any foods or beverages that you should avoid because of your cancer or treatment.
- Ask if there are any nutrition services that can help you with making decisions about healthy eating.
- For further information see <u>Looking after yourself</u>.

# **术** Stay active

- In general it is fine to exercise during treatment (while ensuring that you are respecting your limits), but check with your healthcare team before starting any exercise.
- Physical activity can improve your sleep and appetite and lessen treatment side-effects (such as nausea and fatigue).
- Choose an activity or exercise that you enjoy doing or would like to try. Find one that you can fit into your schedule without too much difficulty.

### Practice good sleep habits

A good night's sleep can help your body and mind feel better.

- Try to keep a regular bedtime routine and minimize distractions before going to bed. For example, turn off your electronics and choose a quiet place to sleep.
- Avoid drinking caffeine or alcohol close to bedtime.
- Try relaxation strategies or meditation before you go to bed. You could also try listening to soothing music.

#### Resources

For more information on understanding your illness and treatment, check out the resources below.

Government of Quebec - Info-Santé Telehealth line (8-1-1)

De Souza Institute - Cancer Chat Canada

Cancer Care Manitoba - Anticancer Drug Therapy (Chemotherapy & Other)

Quebec Cancer Foundation - Chemotherapy

Quebec Cancer Foundation - Radiotherapy

**Quebec Cancer Foundation - Side Effects** 

Quebec Cancer Foundation - Being a Caregiver

<u>Princess Margaret Cancer Centre - Get Informed</u>

#### Acknowledgement of sources

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

- Understanding the Diagnosis and Treatment to Make a Decision. TEMPO. 2018.
- Getting More Information About Cancer and Treatment. TEMPO. 2018.
- What Can I Do To Look After Myself. Canadian Cancer Society 2020.

#### 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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