PATIENT AS PARTNER IN CARE
A Guide to Help You Be More Involved in Your Treatment Plan

Making Better Use of the Resources Available
Thousands of Canadians are now blood cancer free. You can be one of them.
The Step by Step Guide is an initiative of the Quebec Chapter of The Leukemia & Lymphoma Society of Canada (LLSC), produced in co-operation with members of the Patient Services Committee.

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The Step by Step Guide is a planning tool that informs you of the resources available in the steps following your blood cancer diagnosis.

The Step by Step Guide covers a number of aspects of patient care management, from the initial diagnosis, through the treatment period, to remission.

The proposed resources are complementary to the care you will receive at your cancer centre.

These resources are provided by The Leukemia & Lymphoma Society of Canada (LLSC) and by public health and recognized community service organizations.

The Step by Step Guide is also intended for those accompanying a person who has blood cancer.

By getting involved in your treatment plan and becoming an active member of your medical team, you can improve your well-being despite the difficulty of the situation.

Remember – everyone’s journey is different. This guide hopes to help you navigate your way through the process. A well-informed patient is his or her own best advocate and a physician’s ally.

Good luck!
Living with a blood cancer diagnosis involves many daily challenges. Managing your disease and getting involved as an active member of your medical team can help you better face the challenges and improve your overall well-being despite the disease.

### Announcement of the Diagnosis

Give yourself a few days to digest the information provided to you by your physician and step back. You need to let the news sink in and accept the situation regardless of how upsetting it may be.

### Questions About Your Illness

Make a list and ask your physician any questions you may have about your diagnosis and the proposed treatment choices. Ask your physician or nurse navigator for documentation on the subject.

### Your Family and Significant Others

Inform your family members and significant others about your disease. This will allow them to provide you with the support you might need.

### Psychological and Social Support

If you wish, when you are diagnosed, you can consult with your cancer centre psychologist or ask for access to a resource specializing in psychosocial support. They can help you respond better to the challenges awaiting you. Do not hesitate to ask to see them again if needed.

### Information Resource Centre

Consult the specialists at the LLSC Information Resource Centre. They will provide you with additional information on your illness to help you understand its impact on your daily life.

**1-800-955-4572**

### Documentation Available

You can obtain paper copies of information booklets on your type of blood cancer from the nurse navigator or by contacting LLSC Patient Services at: **1-866-637-0281**, ext. 1009 or 1045 **patientquebec@lls.org**

You can also obtain reliable information by contacting the websites of recognized organizations, such as The Leukemia & Lymphoma Society of Canada. Ask your significant others to find information and read it for you. **LLSCanada.org**
**First Connection Program**

Peer-to-Peer Support

You may find it helpful to speak to a volunteer on the phone who had a similar blood cancer diagnosis and who is trained to help people with a few phone calls. You can share your concerns and receive some valuable advice by talking to someone who has already faced the same challenges as you.

Sign up for our First Connection Program by contacting LLSC Patient Services at: 
1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

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**Portraits of Hope**

Get your copy of *Portraits of Hope* by author William Brock who presents the inspiring personal accounts of 47 blood cancer survivors. The book is made available for free by the William Brock Fund to people affected by blood cancer. Contact LLSC for more information.

portraits_of_hope.ca
1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

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**The Treatment Period**

Undergoing treatments for blood cancer requires stamina, some discipline and flexibility. By being well organized, but also open to change, you will be better able to cope with the reality of these treatments.

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**Questions About Treatments and Their Consequences**

Talk to your doctor about any worries or needs you may have regarding your treatment choices and other options available. Ask your doctor or nurse navigator for documentation on the topic.

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**Pharmacist**

Ask your pharmacist for additional information on medications that the doctor has prescribed, their possible interaction with other medications you take and their effects, taking into account your diet and your daily activities.

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**Fatigue and Pain**

Some treatments cause side effects such as fatigue and pain. Talk to the medical team about ways of relieving the side effects and ask for documentation on the topic.
Diet and Lifestyle Habits

Discuss any concerns about your lifestyle habits with your doctor. Consult the nutritionist at your cancer centre to find a diet adapted to your needs. Continue to refer to it regularly to maintain your healthy lifestyle. Other recommendations regarding the management of your illness are to limit smoking and drinking and incorporate appropriate physical activities into your routine.

Sexuality and Fertility

Ask the medical team any queries you may have about the possible impacts of your treatments on your sexuality and fertility and ask for documentation on the topic. You can also contact specialists at the LLSC Information Resource Centre for further information.

Services Offered by the CLSC

If you need services offered by your local CLSC, for example if you need to consult a psychologist, physiotherapist, social worker or nutritionist, ask the nurse navigator to assist you in this process.

Complementary Therapies

Complementary therapies, such as massages, acupuncture or vitamins, can give you relief and help you cope better with the treatments. However, they cannot replace conventional therapies to treat blood cancers. Some may even interact dangerously with the drugs prescribed by your doctor. It is therefore important that you speak to your doctor before undergoing such therapies.

Information Resource Centre

Consult the specialists at the LLSC Information Resource Centre for further information to help you better understand your different treatment options and their impact on your illness and your state of health.

Support Groups

LLSC has formed various groups that meet either in person or online, based on the participants’ type of cancer or on different themes, such as art therapy. It also organizes “Ask the Doctor” lunchtime conferences with medical specialists. You can sign up for these groups by contacting Patient Services. You can share your experience and talk with other patients who face the same challenges.

patientquebec@lls.org
Community Resources

Ask the nurse navigator or social worker for a list of community organizations in your area that provide assistance with housekeeping, meal preparation, transportation and other useful services. Also ask for the Resources Guide published by LLSC or obtain a copy by contacting Patient Services. The directory lists all the resources in every region of Quebec.

1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

Financial Assistance

Learn about your rights related to employment income: disability insurance from your employer or your personal insurance, federal Employment Insurance benefits and provisions for natural caregivers. You can also ask a social worker to help you with this.

You may also be eligible for financial assistance provided by the pharmaceutical company producing the drugs you are taking. To learn more about this, see the company’s website. The Canadian Cancer Society also offers last resort assistance. You can find information about this by visiting its website.

cancer.ca (Support and Services – Financial Assistance)

Temporary Accommodations

You may need temporary accommodations if you receive your treatments in a cancer centre located outside your region. Contact the Fondation québécoise du cancer to register for this service available in Montreal, Sherbrooke, Trois-Rivières and Gatineau.

fqc.qc.ca (Our Services)

Cosmetics

The Look Good Feel Better Program offered by Facing Cancer Together helps women counter the effects of cancer and treatments by learning about makeup and cosmetic application techniques and offering alternatives when they lose their hair. Contact the organization to sign up for the program.

facingcancer.ca (Look Good Feel Better)
Remission is a life-changing step for someone who has a blood cancer, which leads to new changes and the opportunity to return to a normal life.

**Symptoms to Watch for**

Ask your nurse navigator what symptoms to watch for when you are in remission and about the follow-up and testing procedures prescribed by the medical team.

**Post-Treatment Care at a CLSC**

If the post-treatment care prescribed by the medical team is available at your local CLSC, ask your nurse navigator to help you make the necessary arrangements to obtain it.

**Return to Normal Activities**

Discuss returning to work with your physician, who will approve the conditions of your return. To help you resume your normal family and social life, feel free to talk to your nurse navigator, psychologist or any other health care professional who can give you advice. Their advice will help you gradually return to your normal activities.

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**Life After Cancer Treatment**

Ask your nurse navigator to give you a copy of *Life after Cancer Treatment*, published by the Canadian Cancer Society, or contact the Canadian Cancer Society directly to obtain a copy, also available in PDF. cancer.ca (Support and Services – Publications)

**First Connection Program**

**Peer-to-Peer Support**

Now that you understand your blood cancer and are a survivor, you can help other people face one of the greatest challenges of their lives by being a volunteer for the LLSC First Connection Program. To volunteer, contact LLSC. 1-866-637-0281, ext. 1009 or 1045 patientquebec@lls.org
Team in Training (TNT)

If you enjoy walking, running and staying active, join the LLSC’s Team in Training to participate in local or international races. Take advantage of supervised training and support to achieve your goals. Ask your friends and family to encourage you and raise funds for blood cancer research and patient services.

Pineapple Challenge

Form a team with your family, friends and colleagues and participate in the Pineapple Challenge, a fun obstacle course which has hundreds of participants raising funds for research and patient services.

Contact Patient Services to register for the activities of The Leukemia & Lymphoma Society of Canada (LLSC), Quebec Chapter.

1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

Journey of Hope

Join hundreds of patients, survivors, caregivers, physicians, researchers and donors in the Journey of Hope event organized by the LLSC each year in Montreal in August to recognize individual contributions in the fight against blood cancer. The day features conferences, testimonials, discussion panels and the awarding of bursaries to researchers.

Light The Night

Thousands of patients, survivors, families and friends take part in the Light The Night Walk, organized by the LLSC each year in the fall in Montreal, Quebec City and other areas. This symbolic fund-raising walk testifies to the spirit of solidarity through which the LLSC is able to play a leading role in blood cancer research and patient services.
Useful Links

The Leukemia & Lymphoma Society of Canada

Quebec Chapter
1255 University Street, Suite 705
Montreal, Quebec H3B 3W1
Tel.: 514-875-1000
Toll-free: 1-866-637-0281

Information Resource Centre
Services offered in French, English, Spanish and in 170 other languages
1-800-955-4572

Patient Services
1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

Website
LLSCanada.org (Also visit the Quebec Chapter’s website at llscanada.org/mon)

Volunteers
If you would like to become a volunteer for The Leukemia & Lymphoma Society of Canada, Quebec Chapter, contact Patient Services, and contribute to the development and implementation of services and activities intended for people affected by blood cancer.
1-866-637-0281, ext. 1009 or 1045
patientquebec@lls.org

The Canadian Cancer Society
514-255-5151 or cancer.ca

La Fondation québécoise du cancer
1-800-363-0063 or fqc.qc.ca

Facing Cancer Together
Look Good Feel Better
lgfb.ca/en/look-good/

Canadian Cancer Trials
canadiancancertrials.ca

Association des médecins hématologues et oncologues du Québec
amhoq.org

Portraits of Hope
portraitsofhope.ca
Useful Information

Family Doctor ____________________________
Telephone _______________________________

Hematologist-Oncologist_____________________
Telephone _______________________________

Nurse Navigator __________________________
Telephone _______________________________
Email ______________________________________

Pharmacist_______________________________
Telephone _______________________________

Cancer Centre ____________________________
Telephone _______________________________

Psychologist_______________________________
Telephone _______________________________

Social Worker______________________________
Telephone _______________________________

Nutritionist _______________________________
Telephone _______________________________

CLSC ____________________________________
Telephone _______________________________
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The William Brock Fund
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