



LYMPHOMA  
CANADA

# THE CLL PATIENT EXPERIENCE

## 2020 Canadian Chronic Lymphocytic Leukemia (CLL) Report Card

### WHAT IS CHRONIC LYMPHOCYTIC LEUKEMIA?

CLL is a type of blood cancer. In people with CLL, the body makes too many abnormal lymphocytes that do not function properly. It is often referred to as a chronic blood cancer because it develops slowly and does not yet have a cure.

As a chronic lymphoid leukemia, CLL can be referred to as both a subtype of lymphoma and a type of leukemia.

**Your Feedback;  
Our Goals**

Lymphoma Canada is Canada's only national organization focused entirely on lymphoma. We connect and empower this community across the country. Together we promote early detection, new and better treatments, and help patients access those treatments. We provide lymphoma education and work to find a cure. Lymphoma Canada provides electronic and print resource materials on Hodgkin and Non-Hodgkin Lymphomas and Chronic Lymphocytic Leukemia (CLL), hosts patient and caregiver support groups, promotes our educational webinars and forums, funds Canadian lymphoma research, and advocates on behalf of patients.



## OUR MISSION

Empower patients and the lymphoma community through education, support, advocacy, and research.



## OUR VISION

Life unlimited by lymphoma.

### SPECIAL THANKS

Lymphoma Canada would like to thank all CLL patients across Canada who participated in this survey and who shared their CLL care experiences.

Thank you to the Lymphoma Coalition for creating this survey opportunity for patients and for generously sharing the results with Lymphoma Canada to create this report.

### DISCLAIMER

Lymphoma Canada created the 2020 Canadian CLL Report Card to summarize findings from the 2020 Global Patient Survey on Lymphomas and CLL and to provide statistics from Canadian CLL respondents as well as additional information that is relevant and supportive of these results. While Lymphoma Canada makes every effort to ensure accurate representation of the data and up-to-date information, there is information included from various public and private sources. No responsibility can be assumed by Lymphoma Canada for the accuracy or timeliness of this information. All quotes contained herein are actual patient comments derived from the Canadian CLL survey results.

### WARNING

Lymphoma Canada's 2020 Canadian CLL Report Card was created to provide a summary of CLL patient experiences. The supportive information included comes from the Lymphoma Canada website and has been reviewed by our Scientific Advisory Board which is made up of hematologists/oncologists across Canada.

*The results in this report should not be used for any determinants of your healthcare including diagnosis, treatment, and management of side effects, symptoms, or other health concerns. Please consult your healthcare team and physician about any concerns related to your health.*



# CONTENTS

Message From the Chief Executive Officer	3
Report Card Overview	4
About Lymphoma Canada	5
Your Feedback; Our Goals	7
<i>Introduction to Survey</i>	7
<i>Your Feedback</i>	7
<i>Our Goals</i>	7
CLL Patient Experience and Feedback	8
<i>CLL Patient Demographics</i>	9
<i>Pre-Diagnosis Symptoms</i>	10
<i>Diagnosis</i>	11
<i>CLL Treatments and Clinical Trials</i>	13
<i>Side Effects and Impacts on Quality of Life</i>	16
<i>Quality of Life</i>	18
<i>CLL Relapse and Recurrence</i>	20
<i>Follow-Up Care and Day-to-Day Management</i>	22
<i>CLL Patient Education, Information and Decisions, and Support</i>	23
Summary and Data Trends	26
<i>Key Findings for Canadian CLL Patients</i>	27
Our Goals	29
How You Can Help	30

# MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

*Antonella Rizza is the Chief Executive Officer of Lymphoma Canada, the country's only national charity devoted solely to lymphoma and CLL.*

Lymphoma Canada has been supporting the Canadian lymphoma community for more than 20 years. The mission of our organization is to empower the lymphoma community through education, support, advocacy and research. We are proud to help patients and their caregivers throughout their CLL journey.

Each year, over 2,200 people in Canada are diagnosed with CLL. This report highlights the CLL patient experience throughout different stages of their clinical course and is a summary of first-hand responses from Canadian CLL patients. This feedback and the gaps in treatment identified become our goals to address. This information is so powerful in helping to discover the positive and negative experiences in a patient's journey and in turn, how we, as a patient-focused organization can advocate for and work with healthcare professionals, support groups, and other stakeholders to address any gaps in care revealed in the survey responses.

Thank you to all that made this report possible. Without the involvement of CLL patients, the Lymphoma Coalition, and financial supporters, we would not be able to undertake this important work to help patients in dealing with a CLL diagnosis and care.



*Antonella Rizza*

**ANTONELLA RIZZA**  
Chief Executive Officer

## Writers and Editors

Antonella Rizza  
Laura Dinnarr  
Kaitlyn Beyfuss-Laski

## Lymphoma Coalition

Lorna Warwick  
Natalie Dren

## Creative Design

OutIndr Design Co.

## Board of Directors

Claudio Grossi | **Chair**  
Woodbridge, ON

Sabina Vohra-Miller | **Vice Chair**  
Toronto, ON

Neil James | **Treasurer**  
Calgary, AB

Dr. Nathalie Johnson  
Montréal, QC

Dr. John Kuruvilla  
Toronto, ON

Kathy Mannas  
Richmond, BC

Barbara Pollock  
Regina, SK

Robert Michon  
Gatineau, QC

Mari-Claude Doucet  
Dieppe, NB

Johnathan Greenbaum  
Toronto, ON

Lina Ciaccia  
Toronto, ON

Pranav Bhardwaj  
Toronto, ON

## Scientific Advisory Board

Dr. John Kuruvilla | **Chair**  
Princess Margaret  
Hospital

Dr. David MacDonald  
The Ottawa Hospital

Dr. Graeme Fraser  
McMaster University

Dr. Doug Stewart  
University of Calgary

Dr. Tony Reiman  
University of New  
Brunswick

Dr. Kerry Savage  
BC Cancer Agency

Dr. David Hodgson  
Princess Margaret  
Hospital

Dr. Isabelle Bence-  
Bruckler  
Ottawa General Hospital

Dr. Jean-Francois  
Larouche  
Centre hospitalier affilié  
universitaire de Québec

Dr. Mark Bosch  
Saskatchewan Cancer  
Agency

Dr. Joanne Hickey  
Memorial University

Dr. Pamela Skrabek  
CancerCare Manitoba

# REPORT CARD OVERVIEW

Several years ago, in 2013, Lymphoma Canada created its first Report Card summarizing the results of a Canada-wide survey. This survey was created to provide patients, family members, healthcare professionals and volunteers in the lymphoma community, with the opportunity to speak not only about their experience with their lymphoma diagnosis and treatment, but also about social impacts and any concerns or challenges they have faced. This survey provided patients with a voice that was then collectively summarized into a report to inform, educate, and bring awareness to the important realities facing the lymphoma community.

While our daily work with lymphoma and CLL patients and families across Canada helps to connect and inform us of the issues facing the community, we and other lymphoma organizations felt the most accurate representation of these challenges would come directly from asking you. To address this, the Lymphoma Coalition, a worldwide network of lymphoma patient groups, created a survey in 2020 for patients and caregivers to provide information about the lymphoma journey and their experiences caring for lymphoma and CLL patients, respectively. This survey was made available globally, with responses received from patients and caregivers across 91 countries.

Your responses have allowed us to create two Report Cards:

- 1) **2020 Canadian Lymphoma Report Card**, which provides the combined responses from all lymphoma and CLL patients across Canada, and also includes survey results from Canadian caregivers. To access this report, please visit the Lymphoma Canada website ([www.lymphoma.ca](http://www.lymphoma.ca)).
- 2) **2020 Canadian CLL Report Card** (this report) which solely summarizes the survey results of Canadian CLL patients.

These report cards provide a summary that will help inform, educate, and bring awareness to the important realities facing lymphoma communities today. We hope that the information in these reports will highlight unmet needs and challenges faced by the lymphoma and CLL community as well as serve as a call to action for patient organizations, healthcare professionals, and provincial health centres and systems to address these gaps. Your feedback; Our goals.

We could not have accomplished this without your participation. We thank you for sharing your experiences, which have helped us to identify the issues today and bring change as we move forward into the future. We acknowledge the Lymphoma Coalition in creating this opportunity for CLL patients to provide their feedback and for sharing the results with us. Thank you.

---

*The 2020 Canadian CLL Report Card provides general information to the CLL community based on a subset of Canadian results from a global survey that was conducted in 2020 with CLL patients.*



# ABOUT LYMPHOMA CANADA

Lymphoma Canada connects and empowers the lymphoma community through education, support, advocacy, and research. This community is made up of patients, family and caregivers, medical professionals, researchers, stakeholders, and many others. Together we are promoting early detection, finding new and better treatments, helping patients access those treatments, learning about lymphomas many causes, and finding a cure.

Lymphoma Canada is Canada's only national organization focused entirely on lymphoma. For over 20 years, we have empowered lymphoma patients through our pillars of advocating for access to innovative therapies in Canada, creating Canadian educational resources and events, funding and supporting Canadian lymphoma research, and supporting patients through numerous programs. All of our resources are derived from Canadian statistics and feature only Canadian specific information.

As a registered charity, Lymphoma Canada is led by a volunteer Board of Directors drawn from the Canadian lymphoma community including lymphoma and CLL patients and medical and research professionals. We are guided by expert members of a Scientific Advisory Board comprised of Canadian researchers and clinicians. We have a small, dedicated staff involved in program implementation, educational resources, advocacy campaigns, communications, fundraising, and administration. We work together to provide lymphoma and CLL patients with the opportunity to engage and participate in educational events, support groups, online webinars, and fundraising events.

Together, our vision of a life unlimited by lymphoma, will one day be fulfilled.



**Lymphoma Canada**

6860 Century Avenue, Suite 202 | Mississauga, ON L5N 2W5  
Toll Free 1.866.659.5556 Email [info@lymphoma.ca](mailto:info@lymphoma.ca)



## EDUCATION

Lymphoma Canada provides education for lymphoma patients, their families, and support systems. You can access information about lymphoma through printed or downloadable resources, or by attending virtual educational sessions taking place throughout the year.

Lymphoma resources can be accessed through our website: <https://www.lymphoma.ca/resources/patient-resource-manuals/>

Recordings from past webinars on lymphoma and special topics can be accessed through our website: <https://www.lymphoma.ca/resources/info-sessions-and-webinars/>



## ADVOCACY

Lymphoma Canada advocates for access to innovative therapies in Canada and equal distribution of these therapies across all provinces and territories. This is done via Lymphoma Canada's participation in the Health Technology Assessment process through the solicitation and summarization of patient experiences with a particular drug/therapy for submission to decision-making bodies in Canada. Lymphoma Canada collaborates and works with other patient groups to further the oncology patient experience. Please visit our website for more information about our advocacy efforts: <https://www.lymphoma.ca/public-advocacy/>



## SUPPORT

Getting a cancer diagnosis can be an overwhelming experience. Although each person is different and each response to therapy is unique, knowing someone who has been through the same treatment and who may have had similar concerns can be a source of great comfort. Learn more about Lymphoma Canada's peer-to-peer support and mentoring program: <https://www.lymphoma.ca/resources/support/peer-support-program/>

Lymphoma Canada also promotes support groups across the country: <https://www.lymphoma.ca/resources/support/support-groups/>



## RESEARCH

Lymphoma Canada's Research Grants support small, well-defined research studies that have the potential to effect improvements in healthcare, health systems, or health outcomes for malignant lymphoproliferative diseases. Each year, Lymphoma Canada supports Canadian researchers, and their lymphoma and hematology projects. <https://www.lymphoma.ca/2020-research-grant/>

# YOUR FEEDBACK; OUR GOALS

## INTRODUCTION TO SURVEY

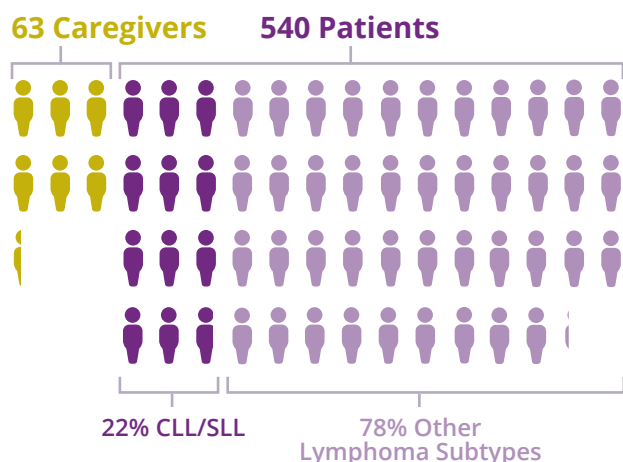
In 2020, Lymphoma Canada collaborated with the Lymphoma Coalition, a non-profit organization comprising of a world-wide network of lymphoma patient groups, to conduct an anonymous and voluntary web-based global survey of lymphoma patients and caregivers. This survey was available in 19 languages

and promoted to the lymphoma patient and caregiver population across the world through numerous avenues including lymphoma and CLL patient organizations, healthcare professionals, community alliances, and social media and web properties.

### YOUR FEEDBACK

The Lymphoma Coalition received thousands of responses from lymphoma and CLL patients and caregivers from around the world. Responses were received from across the country. Overall, there were 603 Canadian respondents, 540 of which were lymphoma and CLL patients, and 63 of whom were caregivers. From this number, there were 120 CLL and SLL patients, and 12 caregivers. This patient group will be referred to throughout this report as the CLL group, however it encompasses both CLL and SLL patients. This report will provide a summary of the responses from the Canadian CLL patient population.

The results captured in this report present the data from Canadian respondents. Of the **603** completed responses, there were:



Twenty-two percent of all Canadian patient respondents were CLL and SLL patients.

### OUR GOALS

- + Summarize statistics from Canadian patients and caregivers on their experiences with lymphoma

#### PRE-DIAGNOSIS SYMPTOMS

#### DIAGNOSIS

#### TREATMENT AND SIDE EFFECTS

#### RELAPSE

#### FOLLOW-UP CARE

- + Provide supportive information for each stage of the CLL patient journey
- + Identify key issues and challenges throughout each stage of the CLL patient experience
- + Determine where and how organizations, healthcare professionals, support groups, and stakeholders can work together to help improve the CLL patient journey



# CLL PATIENT EXPERIENCE AND FEEDBACK

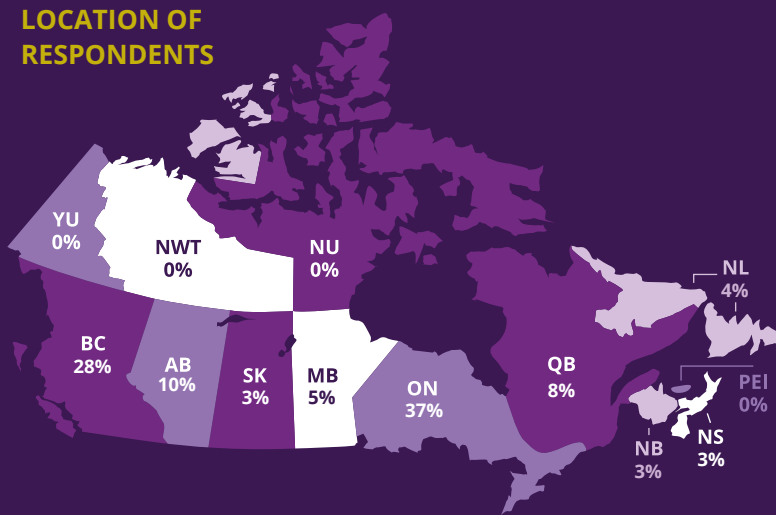
## Executive Summary of the CLL Patient Experience

- + The most prominent physical condition reported both as both a symptom and treatment side effect, was fatigue (71%). Twenty-six percent of patients that discussed their side effects with their doctor expressed that their clinician was unable help.
- + Ten percent of patients waited over 6 months to receive their CLL diagnosis following symptom presentation to their doctor.
- + Of patients diagnosed within the last two years, 25% were not told their lymphoma subtype of CLL at diagnosis.
- + Fifty-four percent of patients were unaware whether they received a molecular test to determine their CLL molecular profile and what mutations they had.
- + Thirty-three percent of CLL patients did receive a second opinion regarding their treatment options. 14% of patients did not ask for a second opinion but wanted to, their reasons for not asking for a second opinion included trusting their current doctor's advice and information and not wanting to affect their relationship with their current doctor.
- + All CLL patients who experienced treatment-related side effects discussed their side effects with their doctor,, of which 20% shared this information with their doctor to some extent. Doctors were able to manage patients side effects fully (14%) or to some extent (58%).
- + The key psychosocial issue identified by patients was fear of lymphoma progression (50%) or relapse (26%). Only 50% of patients discussed their fear of recurrence with their doctor, and those that did found their doctor was able to help.
- + The majority of patients did not discuss the impact of a CLL diagnosis on their personal relationships with their doctor (89%) but did discuss medical impacts of their care such as anxiety/depression.
- + Twenty-two percent of CLL patients who are experiencing health issues wait until they can no longer be ignored before seeking help.
- + Important outcomes for CLL patients include finding a cure (62%), maintaining their quality of life (56%), and fewer treatment side effects to tolerate and manage (53%).
- + Forty-five of patients were not provided with enough information at diagnosis including information on topics such as treatment options (60%), diagnosis and what it means (55%), and treatment side effects (29%).

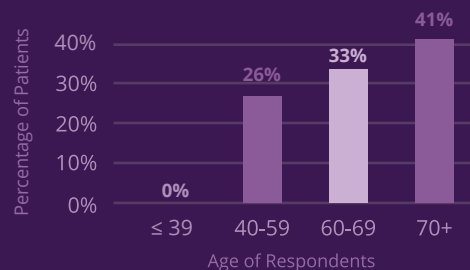
# CLL PATIENT DEMOGRAPHICS

Survey respondents were from various demographics and stages of their CLL journey.

## LOCATION OF RESPONDENTS

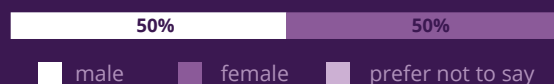


## AGE OF CANADIAN PATIENT RESPONDENTS



The majority of CLL patients were over 60 years of age.

## GENDER OF CANADIAN PATIENT RESPONDENTS



## WHAT BEST DESCRIBES YOUR TREATMENT STAGE

**46%** Treatment is not yet needed (watch & wait or active surveillance)

**7%** I have had treatment and I am now back in watch & wait

These patients have been in Watch & Wait (without treatment) or back in Watch & Wait after treatment for:



For those that reported they were in **Watch & Wait** the majority (53%) have been undergoing active monitoring for more than five years and have not required treatment.

<2 years 2-5 years >5 years

**27%** I am currently receiving treatment

**3%** I have finished treatment and I am on maintenance therapy

**12%** I am in remission

These patients in remission have been treatment free for:



**1%** I am not having or have stopped treatment

**4%** Other

## WATCH & WAIT

If your CLL is slow-growing and not causing you serious symptoms, you likely will not have treatment right away. This approach is called 'watch and wait' or 'watchful waiting' or 'active monitoring'. Watch and wait is a strategy where doctors monitor you closely but do not treat you until symptoms appear or change. Watch and wait is the recommended care for those who do not meet any of the indications for treatment.

This does not mean your cancer is being ignored by your medical team. During the watch and wait period, you will meet regularly with your cancer specialist to monitor changes in your disease and overall health. Understandably, many people worry their CLL will get worse if they don't have treatment. Studies comparing watch and wait with early treatment have shown there is no benefit to early treatment for patients with asymptomatic CLL. With watch and wait, you can avoid the side effects of treatment until it is needed.



Watch and wait is mentally tough to deal with. As a "doer" I'd be happier with doing something but I do understand that this isn't necessary at this time.

- Anonymous, Canadian CLL patient



Patients were asked whether they had their CLL transform into a more aggressive type of lymphoma. The majority of patients (**98%**) have not had their CLL transform.

*Richter's Syndrome (RS), also known as Richter's Transformation, is a rare complication of CLL characterized by the sudden transformation of the CLL into a significantly more aggressive form of large cell lymphoma.*

# PRE-DIAGNOSIS SYMPTOMS

The symptoms of CLL can commonly be seen in other, less serious illnesses. There are some patients with CLL that do not experience any symptoms. A symptom is anything unusual, differing from a normal body function, appearance or sensation, that a patient experiences. Please see the table for common symptoms seen in CLL patients. Canadian CLL patients were asked to list all symptoms they experienced as a result of their CLL:

<b>71%</b>	Fatigue	<b>25%</b>	Frequent or repeated infections
<b>40%</b>	Easily bruising/bleeding	<b>19%</b>	Pain
<b>38%</b>	Abnormal painless swelling of lymph nodes	<b>18%</b>	Anemia
<b>35%</b>	Skin rashes	<b>16%</b>	Headaches
<b>31%</b>	Fever, chills, sweats and weight loss (B symptoms)	<b>13%</b>	No symptoms
<b>30%</b>	Shortness of breath	<b>9%</b>	Others

To understand the burden of impact, CLL patients were also asked how long they had experienced CLL symptoms. Symptoms that were experienced most frequently and for the longest duration included fatigue, B-symptoms, abnormal painless swellings(s) on the body/lymph nodes, skin rash/lesions and easy bruising/bleeding.

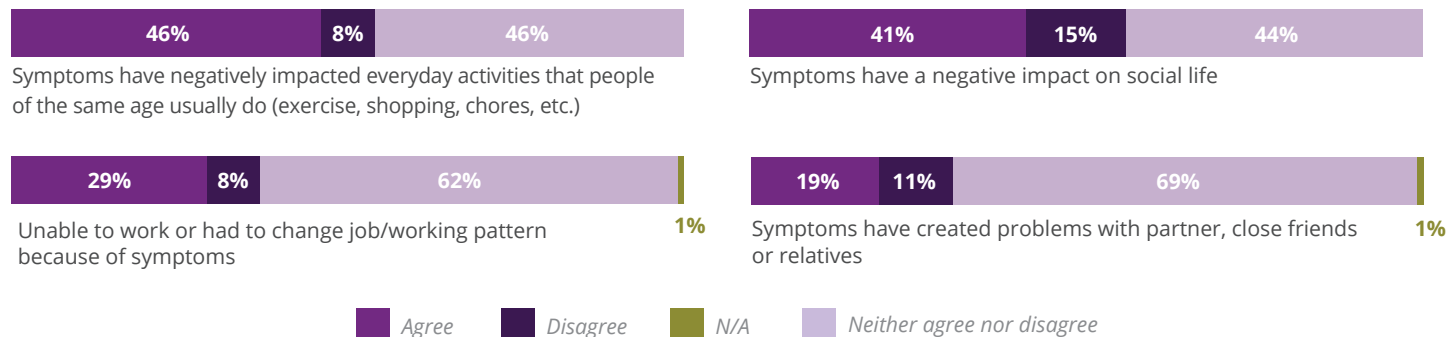
## SYMPTOMS FELT AND FOR HOW LONG

Under 1 year	1-2 years	2-5 years	5-8 years	>8 years
B Symptoms (17%)	B Symptoms (40%)	Fatigue (32%)	Skin rash/lesions (18%)	Skin rash/lesions (23%)
Abnormal painless swelling of body/lymph node (14%)	Easy bruising/bleeding (29%)	Abnormal painless swelling of body/lymph node (23%)	Easy bruising/bleeding (18%)	Easy bruising/bleeding (22%)
Skin rash/lesions (13%)	Abnormal painless swelling of body/lymph node (28%)	Skin rash/lesions (18%)	Abnormal painless swelling of body/lymph node (16%)	Fatigue (20%)
Easy bruising/bleeding (13%)	Skin rash/lesions (26%)	Easy bruising/bleeding (16%)	Fatigue (14%)	Abnormal painless swelling of body/lymph node (12%)
Fatigue (10%)	Fatigue (20%)	B Symptoms (14%)	B Symptoms (11%)	B Symptoms (11%)

*B symptoms can include one or more of the following: significant fatigue, high fevers, heavy night time sweats and unintentional weight loss*

Symptoms can have an impact on numerous aspects of a patient's life. Patients were asked about their level of agreement on whether symptoms have impacted their everyday activities, social life, employment, and relationships:

## COPING MECHANISMS FOR FATIGUE



# DIAGNOSIS

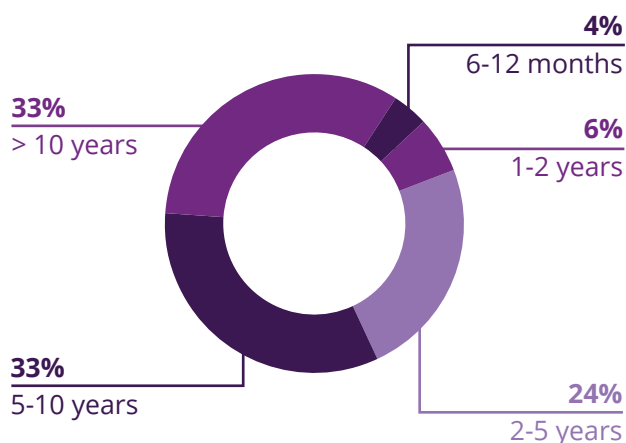
Receiving a CLL diagnosis or any cancer diagnosis can be shocking and overwhelming. The time from initial contact with your general practitioner regarding a symptom or complaint, to undergoing numerous tests and procedures and determining the cause of these symptoms, can be a long, exhausting, and emotionally draining process. To understand more about the diagnosis process, the following questions were asked of the Canadian CLL patient population.

Doctors need the results of various tests to determine if you have CLL and as a result, receiving a diagnosis can sometimes take a while. A CLL diagnosis is usually made from:

- + Complete blood count (CBC): measures how many blood cells are in your blood.
- + Blood smear examination: detect CLL cells in your blood

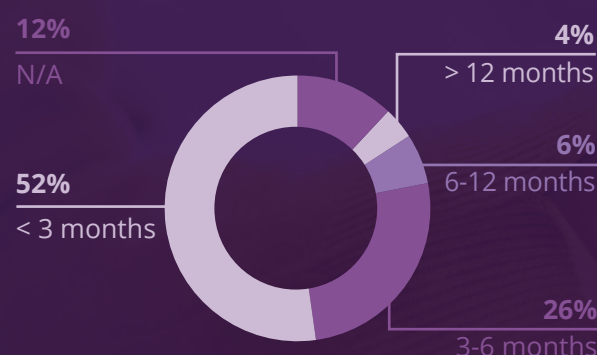
Other tests can include an ultrasound, CT (computed tomography scan) and biopsies.

## HOW RECENTLY WERE PATIENTS DIAGNOSED WITH CLL



Some patients experience very immediate and prominent symptoms that prompt a quick and rapid diagnostic process, while other patients may experience mild symptoms that last years before a diagnosis is made. We asked the CLL patient population how long it was from the first appointment with their General Practitioner regarding symptoms to receiving their CLL diagnosis:

## LENGTH OF TIME TO DIAGNOSIS IN MONTHS



Though the majority of patients received a diagnosis in less than three months from when they first reported their symptoms, it is important to note that 10% of patients had to wait more than 6 months to receive a diagnosis.

Patients who were diagnosed with lymphoma within the last two years were asked more about how they received their lymphoma diagnosis, and whether they were told important information about their diagnosis from their doctor.

*Since the word "cancer" is not in the CLL name, some do not know that CLL is a type of cancer. However, 100% of CLL patients understood from their doctor that they received a diagnosis of cancer.*

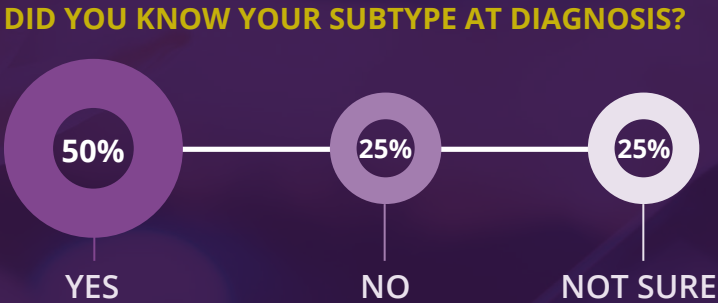
Lymphoma is an umbrella for over 80 related cancers, that are subdivided into the major categories of Non-Hodgkin Lymphoma, Hodgkin Lymphoma, and CLL. These overarching categories are then further subdivided. Each subtype has its clinical course and treatment options.

SLL and CLL are both B-cell lymphomas. The main difference between the two is that in SLL, the lymphoma cells are mainly found in the lymph nodes and spleen, and in CLL the lymphoma cells are mainly found in the blood and bone marrow.

SMALL LYMPHOCYTIC LEUKEMIA (SLL)

CHRONIC LYMPHOCYTIC LEUKEMIA (CLL)  
CLL subtypes can be defined by different mutations to a patient's genetic makeup. Molecular testing may be used to help determine a patient's mutational status and best treatment option.

It is extremely important to find out your subtype at diagnosis so that you can become educated and informed about your CLL journey and the options available to you. Patients were asked whether they were told of their CLL subtype at diagnosis.



Chronic Lymphocytic Leukemia (CLL) can be further subdivided into “subtypes” based on molecular characteristics. Molecular testing, such as the FISH (fluorescent in situ hybridization) test, can determine any abnormalities in the cancer cell genes. If identified, it may help your doctor determine the optimal treatment for your CLL. In Canada, not all patients will require molecular testing. Your doctor will be able to tell you more about what molecular testing is and if it is required for your CLL before treatment. CLL patients were asked to select all mutational statuses that apply to their CLL. A large majority of patients (54%) were not sure whether they had molecular testing and therefore any mutation, while the remainder of patients listed all mutational statuses:

Chromosome or Gene Mutations	Possible Impact on Treatment Response	% of CLL Respondents with Mutation
12+ or trisomy 12	Not known, Increased probability of Richter's Transformation, a rare complication.	5%
Deletion 11q	Might have poor outcome, but may have a good response to chemoimmunotherapy.	11%
Deletion 13q	Good outcome if this is the only cytogenetic change.	13%
Deletion 17p	Poor response to chemoimmunotherapy; better response to targeted therapies.	6%
TP53 gene mutation	Poor response to chemoimmunotherapy; better response to targeted therapies.	2%
IGHV mutation status	Mutated: Good response to chemoimmunotherapy. Unmutated: Poor response to chemoimmunotherapy.	16% unmutated 11% mutated

deletion= when part of the chromosome is missing | trisomy = an extra copy of a chromosome

# CLL TREATMENTS AND CLINICAL TRIALS

Following a CLL diagnosis, the next stage of the patient journey can differ depending if immediate treatment is required. Many people with CLL do not require treatment right away and some people never require treatment for their CLL. The decision to start treatment depends on whether you have signs or symptoms that are associated with progressive disease. **Some of these signs and symptoms can include the presence of B symptoms (weight loss, fatigue, fever), enlargement/swelling of lymph nodes, and changes in your blood counts.** Together, these signs and symptoms are called treatment indications. Patients may be able to stay in the watch and wait stage for months to years before requiring treatment.



I find this watch and wait approach since being diagnosed with CLL difficult. I have a range of blood tests every six months to monitor my CLL, and the few days until I get the results from my doctor are full of anxiety.

- Anonymous, Canadian CLL patient



Treatment is usually only started if the CLL progresses and results in the development of disease related symptoms. Although no cure has been found yet for CLL, there are many treatment options that allow patients to feel well and live for years in good health. If you require treatment for your CLL, your doctor may recommend one or more of the types of treatment listed below:

## Chemotherapy

## Targeted Therapy

## Surgery

## Stem-Cell Transplantation

## Antibody Therapy

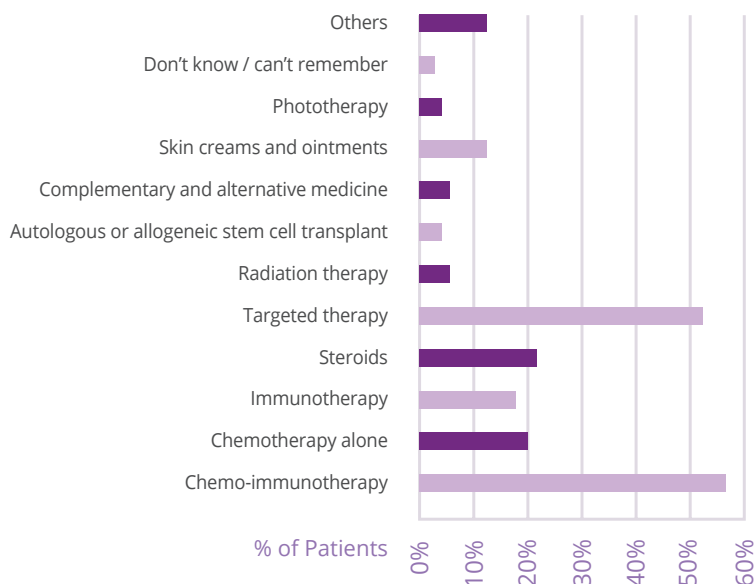
## Radiation Therapy

## Supportive Care

(i.e. vaccine, immunoglobulin)

*Patients were asked which treatments they are currently receiving or have received in the past:*

### PATIENT CLL TREATMENTS



Immunotherapy has been a game changer for me. I experience fatigue but it is manageable. I am so appreciative for the opportunity to live my life almost completely normally again!

- Anonymous, Canadian patient



It is important to have an open line of communication between a patient and clinician. There are many aspects to consider when determining the best treatment for your CLL. Your doctor will present the best options available to treat your CLL, however, there may be other aspects to consider when deciding between treatment options. This can include treatment side effects and their impacts to quality of life, reliance on a caregiver, oral versus intravenous administration, etc. Patients were asked whether they spoke with their physician within the last two years about changing their treatment to better meet their needs.

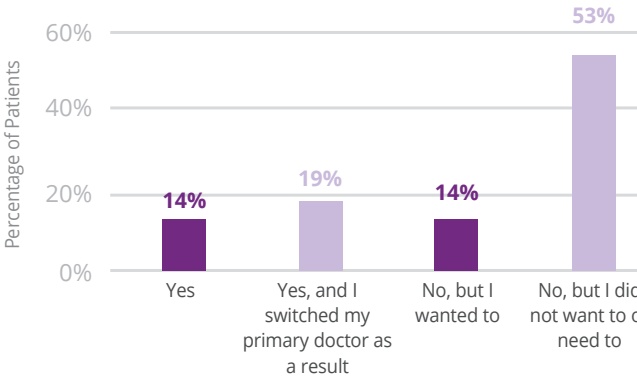
Thirty percent of patients did communicate their needs with a doctor and worked with their doctor to choose a treatment; only a small population of patients (2%) did not speak about their treatment, but would have liked to.

DID YOU COMMUNICATE YOUR TREATMENT NEEDS TO YOUR DOCTOR?	
30%	Yes, I communicated this with my doctor, and chose a treatment they recommended
7%	Yes, I communicated this with my doctor and chose treatment that was NOT suggested by my doctor
2%	No, I have not spoken with them about this, but I would have liked to
19%	No, I have not spoken with them about this, and I did not want to
32%	Not applicable - I haven't wanted to change my treatment within the last two years
10%	Not applicable - I haven't had any treatment(s) for my condition within the last two years

It is important that there is trust between a patient and their healthcare team, and to have confidence that the team is providing the best care possible while addressing all of a patient's needs. Patients were asked if they have confidence in the doctors treating them:

Before you start therapy, you may want a second opinion about your diagnosis and treatment plan. Trust in your healthcare team and confirming the next steps of your CLL care can be the most important reasons for a second opinion. You have the right to get a second opinion.

DID YOU GET A SECOND OPINION?

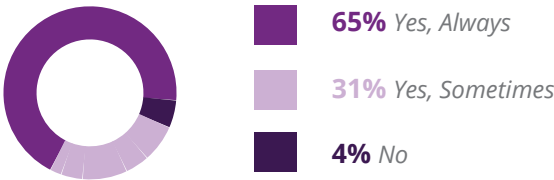


Thirty-three percent of CLL patients did receive a second opinion, with 19% of these patients switching their primary doctor as a result.

Patients selected all reasons as to why they did not ask for a second opinion:

WHY DIDN'T YOU GET A SECOND OPINION?	
79%	I trusted my doctor's advice and information
14%	I didn't want to affect the good relationship I have with my current doctor
7%	I could not access another doctor / not an option
7%	Something else

PATIENTS CONFIDENCE IN THEIR TREATING DOCTORS



## CLINICAL TRIALS

Clinical trials try to find new ways to treat, fight, diagnose, prevent, and manage symptoms of cancer. They often do this by administering promising new drugs to eligible patients and by meticulously observing health status. Clinical trials allow for testing the safety and efficacy and compare against currently available treatments.

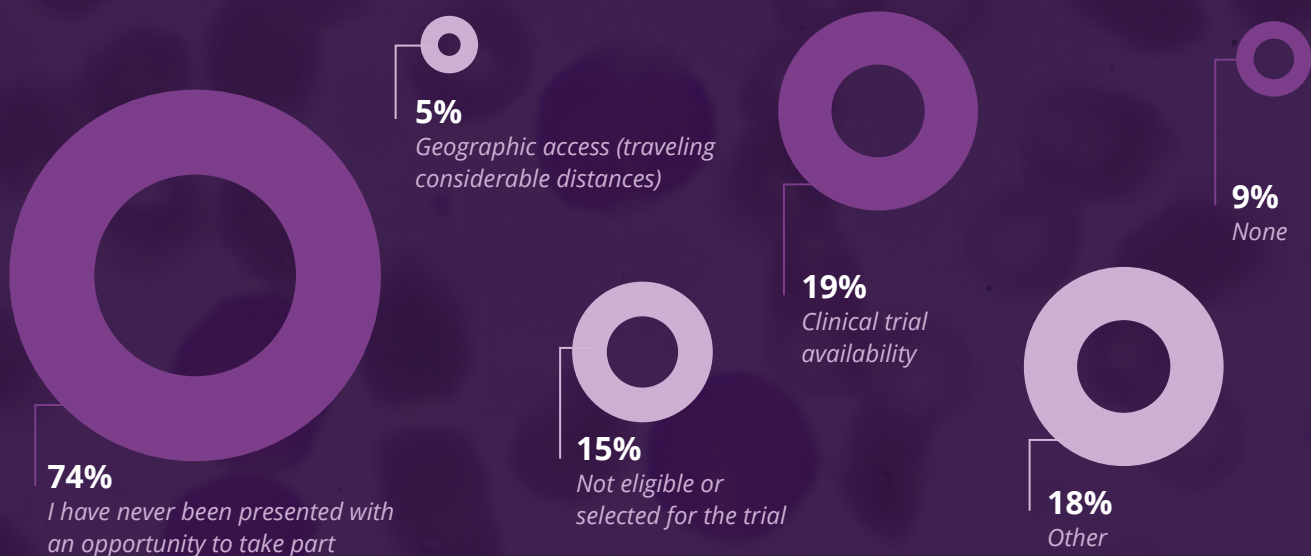
Significant roadblocks include not being asked to participate in clinical trials or not being referred to

a hospital that conducts them. More often than not, patients are unaware of the options available to them.

While patients are eager to access new treatments, clinical trials are not for everyone. There are often strict eligibility criteria. Speak with your doctor to see if a clinical trial may be available to you.

Patients were asked if they were currently or ever have been enrolled in a clinical trial. For those that responded to the survey, 17% were currently enrolled or had been enrolled in a clinical trial, while 83% did not receive therapy through a trial. Barriers to clinical trial access include:

### TOP REASONS FOR NOT ACCESSING A CLINICAL TRIAL



I would love to be part of a clinical trial for the new T cell therapy that might be able to eliminate my cancer.

- Anonymous, Canadian CLL patient



# SIDE EFFECTS AND IMPACTS ON QUALITY OF LIFE

Many people are frightened by the side effects of lymphoma therapies. However, it is important to understand that:

- + Not all patients who receive treatment experience side effects;
- + Side effects are not always severe, they can be mild;
- + Different drugs have different side effects;
- + Doctors are familiar with side effects and may be able to treat them so they are less severe and, sometimes, even prevent them from happening altogether.

Treatments can have immediate side effects that appear during treatment or shortly afterwards. There are also some side effects that can appear long after treatment has ended. Be sure to speak with your doctor about all the possible short-term and long-term side effects related to your lymphoma treatment.



Due to now being treated, my fatigue has largely disappeared... I did not realize how fatigued I had become until I started treatment and regained my energy to almost normal.

- Anonymous, Canadian CLL patient



*Patients were asked about the side effects they experienced as a result of their CLL treatments:*

**Fatigue 71%** Easy bruising/bleeding 38% Skin/hair/nail problems 34% Changes in sleep patterns 34% Numbness and or tingling of arms, legs, hands or feet 33% Pain in joints/muscles 33% Infections (Neutropenia) 29% Lack of concentration 27% Nausea & vomiting 26% Diarrhea 24% Constipation 22% Anemia 22% Pain 20% Hair loss 20% Mouth & throat symptoms 20% Inability to multitask 20% Loss of memory 18% Infusion reaction 14% Cardiovascular problems 13% Eyesight issues 13% Change in taste/smell 13% Headaches 11% Secondary cancer 11% None 9% Dental issues 7% Respiratory problems 7% Osteoporosis 5% Liver problems 5% Deep Vein Thrombosis 4% Kidney problems 2%



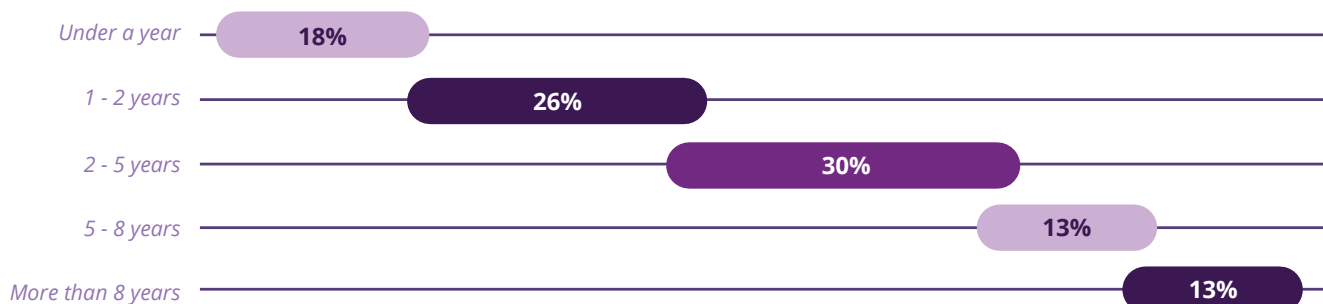
Finished treatment and had severe neutropenia for 9 months - 1 hospitalization for fever. Neutrophil levels are now normal and I no longer have any symptoms.

- Anonymous, Canadian CLL patient



Each treatment for CLL can have its own set of side effects that could last for months or longer. As fatigue was a side effect experienced by the majority of CLL patients, patients were asked how long they experienced this side effect for. Fifty-six percent of patients experienced fatigue for over two years, of whom 13% had treatment-related fatigue for more than eight years.

## HOW LONG DID YOU EXPERIENCE FATIGUE?



Open communication between a patient and their healthcare team regarding treatment side-effects is important as they can help manage and/or treat your side effects. Patients were asked if they discussed their side effects with their doctor. Eighty percent of patients provided a full description of their side effects, while the other 20% told their doctor about their side effects to some extent. For those that did speak about side effects with their doctor, patients found their doctor was able to help with their side effects definitely (14%) or to some extent (58%), while 26% found that their doctor was unable to help with their side effects; 2% could not remember. For those that did receive help from their doctor, this came in the form of medication to help with side effects (33%), information about their side effects (47%), and referrals to other support resources (25%).



There needs to be more information regarding cancer fatigue especially post chemo.

- Anonymous, Canadian CLL patient



Patients were asked about their level of agreement on whether side effects impacted their everyday activities, social life, employment and relationships.

## IMPACT OF SIDE EFFECTS ON EVERYDAY LIFE

Agree
  Disagree
  Neither agree nor disagree
  N/A



My side effects have negatively impacted everyday activities that people of the same age usually do (exercise, shopping, chores, etc.)



My side effects have a negative impact on social life



Unable to work or had to change job/working pattern because of my side effects

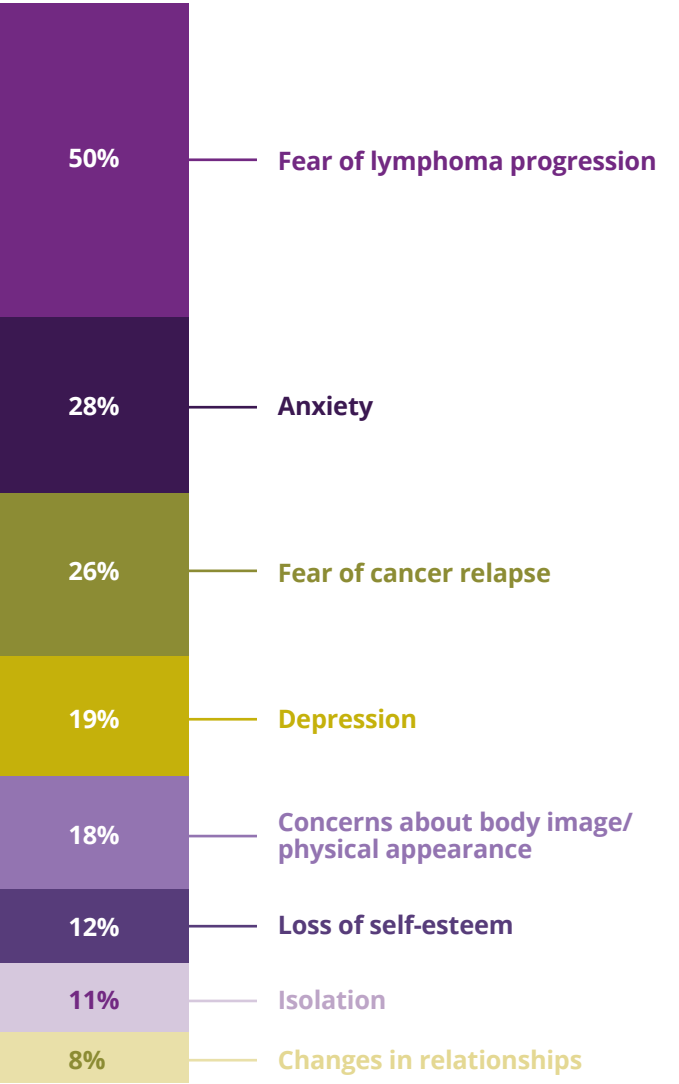


My side effects have created problems with partner, close friends or relatives

# QUALITY OF LIFE

In addition to the medical aspects of CLL, patients must cope with many additional challenges including emotional, psychological, and physical impacts. There is no “right” way to feel when going through this journey. Patients were asked how their quality of life has been impacted by their CLL. Patients reported that CLL affected their quality of life in the last 12 months through numerous psychological and emotional factors. The most prominent included fear of CLL progression or relapse, anxiety and depression, and concerns about body image/physical experience.

## IMPACT OF CLL ON EVERYDAY LIFE



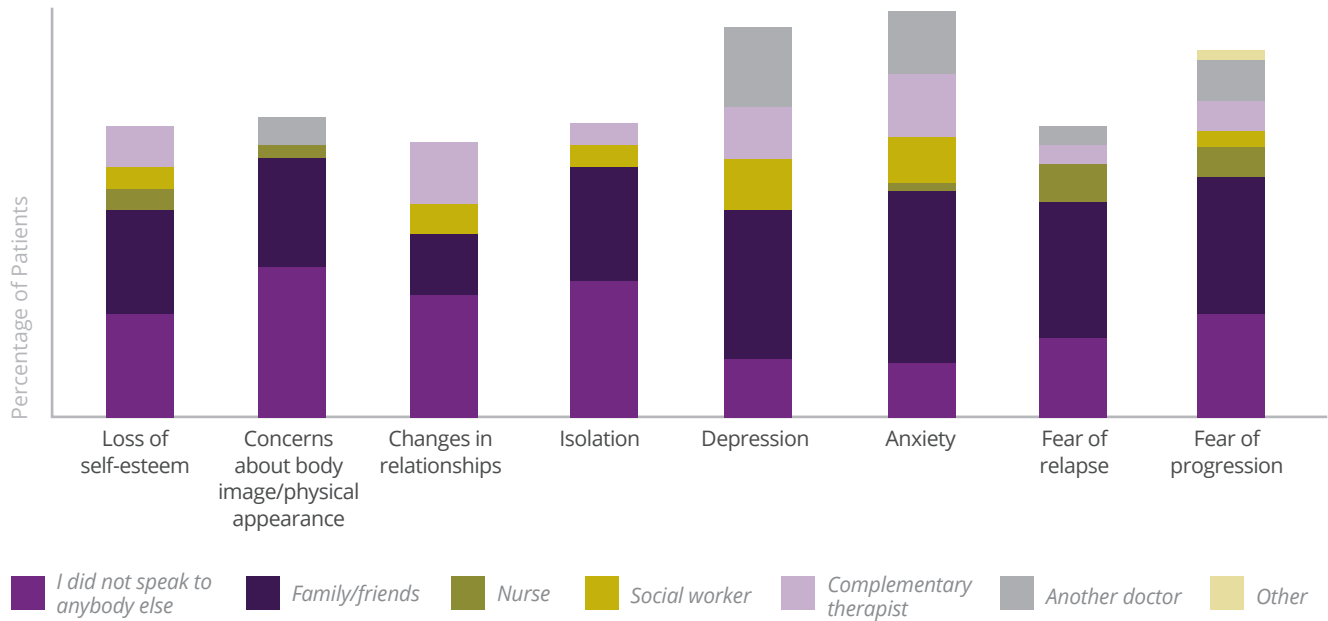
Thirty-three percent of patients did not experience any of these impacts in the last 12 months.

Patients were more inclined to speak with their doctor regarding the emotional impacts of anxiety (53%) and depression (62%), and fear of recurrence/relapse (50%). However, the majority of patients (89%) did not discuss the change in their relationships with friends and families. Some reasons for not discussing these worries or concerns with their doctor included thinking it could be handled by themselves, not thinking it was a big deal, and not wanting to bother their physician. For the patients that did discuss their concerns with their doctor, the majority found that doctors were able to help to some extent, however, there was a small portion of patients (8-19%) that did not receive the help they needed from their doctor with their anxiety, depression, and fear of recurrence/relapse. Doctors were able to provide patients with multiple types of support to manage these challenges:

	Medication to help	Further written or verbal information	Information on coping mechanisms	Signposting to another source of support	Other
DEPRESSION	17%	0%	42%	42%	25%
ANXIETY	46%	8%	23%	15%	31%
FEAR OF RELAPSE	17%	33%	0%	0%	50%

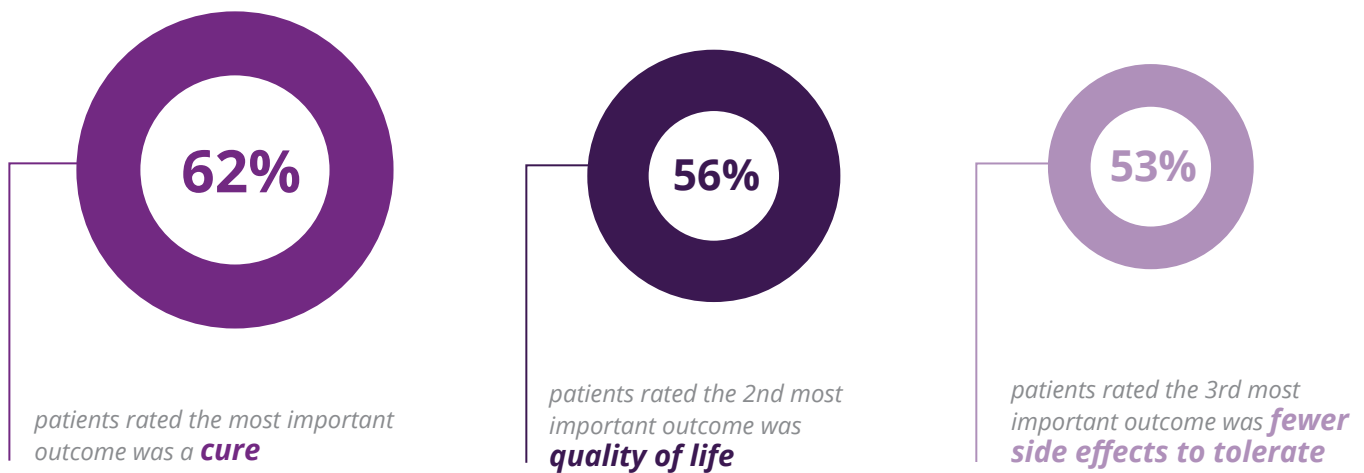
Other than a patient’s doctor, there are many other avenues of support where patients can express their worry or concern. This can include other members of the patient’s healthcare team including nurses, social workers, or therapists, and can also include the patient’s personal support system including friends and family. CLL patients were asked who they spoke to about specific worries and concerns. For most concerns, patients either did not speak to anyone about them, or used their family/friends as their main support group.

## WHO DID PATIENTS SPEAK TO ABOUT WORRIES/CONCERNS



## OUTCOMES BY IMPORTANCE

Patients were asked to rate on a scale of one to seven, outcomes by importance (one being the most important).



The top three outcomes rated the most important to CLL patients included finding a cure, maintaining high quality of life, and having fewer treatment-related side effects to tolerate.



I hope there is a cure someday.

- Anonymous, Canadian CLL patient



# CLL RELAPSE AND RECURRENCE

*Most patients undergoing treatment for CLL will have a partial or complete response to their treatment. If the CLL returns or doesn't respond to the initial treatment, more treatment may be necessary. Relapsed CLL means the CLL has returned after responding to treatment. This is sometimes also called a recurrence. There are many treatment options for people with relapsed CLL. The type of treatment that you will receive depends on factors such as age, extent and location of the disease, overall health, types of previous therapies you received, and the length of response to previous therapies.*

**Following frontline treatment, patients were asked whether their CLL has relapsed:**



Of the patients that responded to the survey, the top psychological impacts included fear of progression (50%) and fear of relapse (26%). This fear manifests through rumination and thinking about the return of their cancer returning, examining themselves for physical signs of cancer recurrence such as swollen lymph nodes, and having real thoughts about dying.

## MANIFESTATION OF FEAR OF RELAPSE

- 78%** I think about the cancer returning
- 67%** I examine myself to see if I have physical signs of cancer
- 44%** I have thoughts about dying
- 22%** I get waves of strong feelings about the cancer returning that are difficult to control
- 11%** I feel very alone
- 11%** These thoughts intrude on my day-to-day activities
- 11%** I feel very distressed by these thoughts
- 11%** I have difficulty making plans for the future



**I feel very fortunate to have had two 5 year remissions - with the 2nd one still ongoing.**

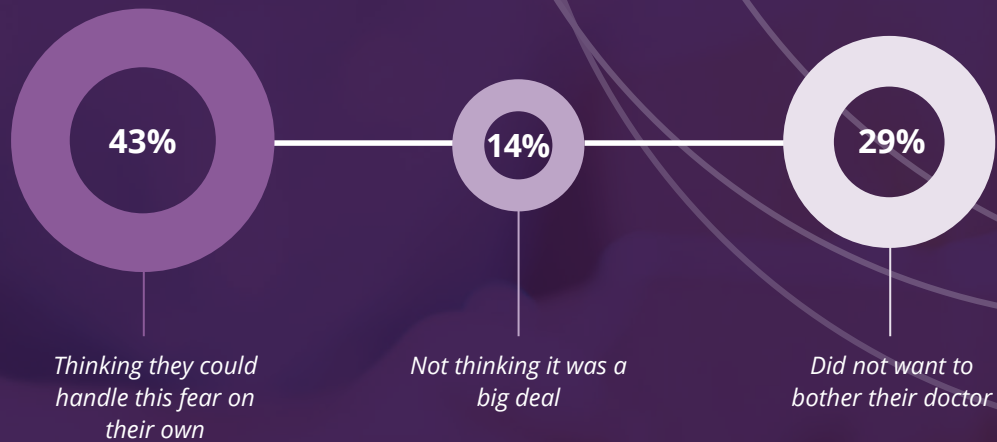
*- Anonymous, Canadian CLL patient*



*The fear of recurrence may begin during treatment and last well into remission. Fear of recurrence might include the fear of having to repeat treatment, losing control of your life, or facing death. Your fears are normal. While you cannot control whether your CLL recurs, you can control how much you let the fear of recurrence impact your life. Once you've collected all the medical facts you can begin to formulate your own method of coping.*

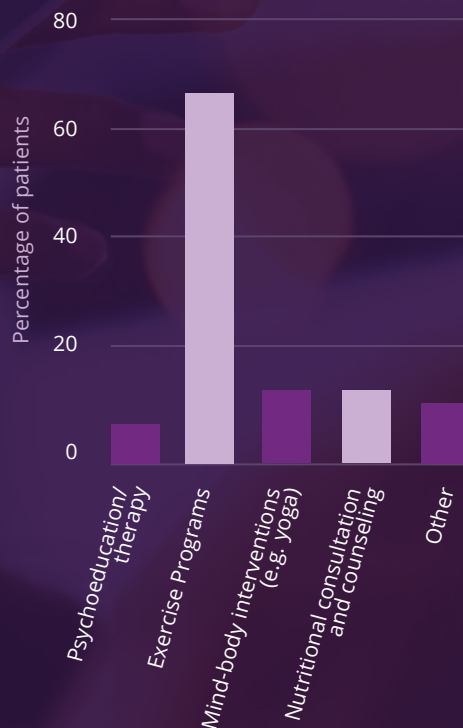
Fifty percent of CLL patients discussed their fear of recurrence with their clinician. For the patients that did discuss this with their doctor, 57% found that their doctor was able to help completely, with 29% stating their doctor was able to help to some extent. Information that was found to be helpful predominantly included written or verbal information (33%) or medication (17%).

## SOME OF THE REASONS PATIENTS DID NOT DISCUSS THEIR FEAR OF RECURRENCE WITH THEIR DOCTOR INCLUDED:



There are a numerous coping mechanisms that CLL patients may use to help manage their fear of recurrence. Patients listed all types of coping techniques used to manage this fear, some of which included exercise, mind-body interventions, and dietary/nutritional counseling.

## COPING MECHANISMS FOR FEAR OF RECURRENCE



I have made some lifestyle modifications as far as diet, exercise and stress reduction.

- Anonymous, Canadian CLL patient



I find that meditation and yoga helps.

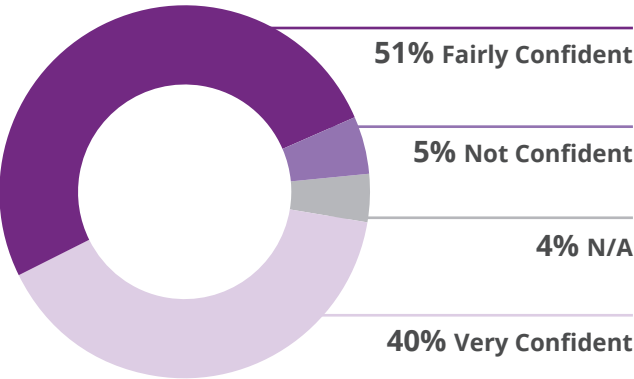
- Anonymous, Canadian CLL patient



# FOLLOW-UP CARE AND DAY-TO-DAY MANAGEMENT

As patients move into remission following treatment, patients will have different experiences with regards to managing their health, lifestyle, and any CLL symptoms and side effects from treatment. The majority of CLL patients (91%) were confident they could manage their health problems day-to-day.

## CONFIDENCE IN MANAGING DAY-TO-DAY HEALTH PROBLEMS

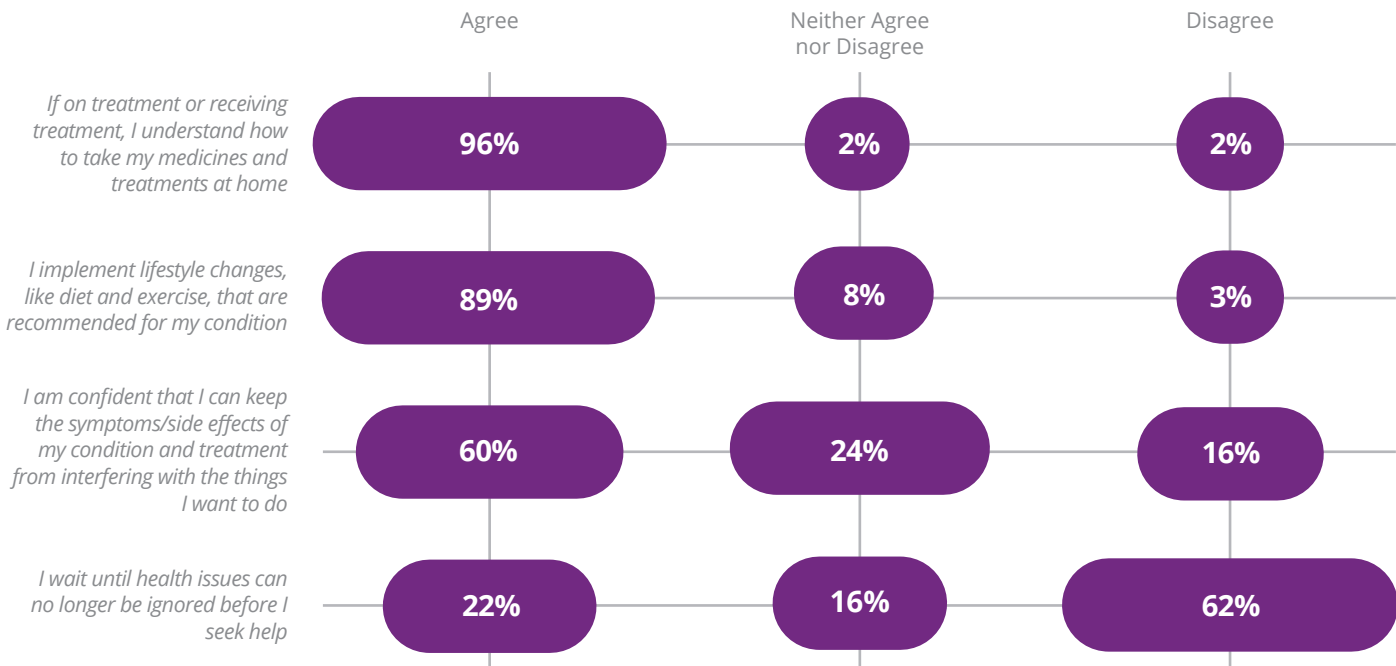


I do all I can to keep myself informed. Generally doing quite well and am planning on being around for a long time. Must keep pushing myself physically.

- Anonymous, Canadian CLL patient



## CONCERNING THE MANAGEMENT OF DAY-TO-DAY CONDITIONS, PATIENTS WERE ASKED ABOUT THEIR LEVEL OF AGREEMENT OR DISAGREEMENT WITH THE FOLLOWING:



# CLL PATIENT EDUCATION, INFORMATION, DECISIONS, AND SUPPORT

Every time a person requests for information or proactively works to resolve a problem, they are practicing self-advocacy. Patients that advocate for themselves have a more active role in their care. As the medical field becomes more complex, patients have had to become stronger self-advocates for their own care. If, as a patient, you do not understand what your care entails, it is okay to ask for more time to have your questions answered. The simple act of asking questions and fully understanding what will take place throughout your care is an act of self-advocacy.

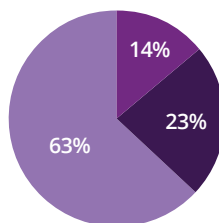
Patients revealed that their healthcare decisions were most influenced by recommendations from their healthcare providers and healthcare staff (74%), followed by personal preferences (16%). Other influential factors included suggestions from friends or family (2%), and financial considerations (1%).

Patients were questioned about their level of involvement when it came to their care and if they took an active role in their care. Eighty-eight percent of patients were involved in their own care, while 12% were not, even though they wanted to be. In regards to a patients role in making decisions about their own health and care, patients were asked to rate their level of agreement with the following statements:

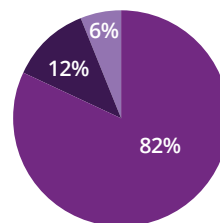
## PATIENTS INVOLVEMENT IN THEIR CARE

Agree Disagree Neither agree nor disagree

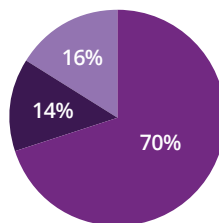
I feel overwhelmed by managing my health and condition:



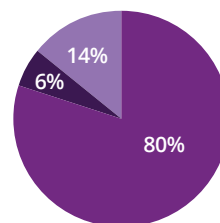
I am confident in my ability to positively impact my health:



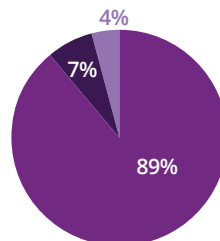
I have good conversations with my doctor about my care and treatment plan:



I am confident that I can tell my doctor my concerns even when he/she does not ask:



I seek clarification on things I do not understand:



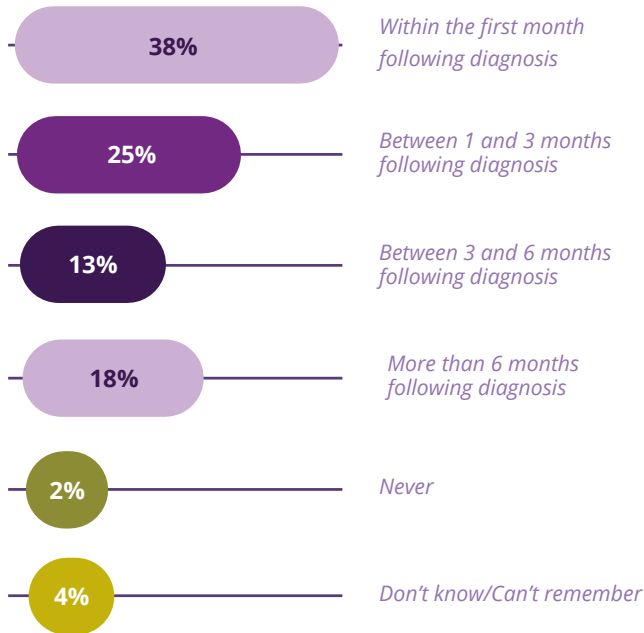
I was pretty overwhelmed at first. But as I learned about CLL and how it progresses I think that I will be able to deal with whatever comes my way.

- Anonymous, Canadian CLL patient



Patients were asked when they felt their need for information was the greatest. The majority of patients responded that this need was the greatest within the first month following diagnosis:

TIME WHEN NEED FOR INFORMATION WAS GREATEST



Patients who were diagnosed within the last two years revealed the type of information they were presented with at the time of diagnosis and whether they understood this information.

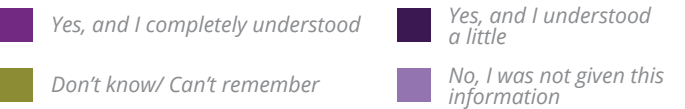
TYPES OF INFORMATION RECEIVED AT DIAGNOSIS



Medical Treatment Options including Active Surveillance (Watch & Wait)



Process and Stages of Care



I would like to know what symptoms to be to be aware of.

- Anonymous, Canadian CLL patient

At the time of diagnosis, 45% of patients believed that they were not given enough information.

PATIENTS WERE ASKED WHAT TYPES OF INFORMATION THEY FELT THEY NEEDED MORE OF	
Treatment options	60%
Diagnosis and what it means	55%
Side effects from treatments	29%
Psychological support/counseling	26%
Support for self-care	17%
Support for my family	10%

When patients have a need for information relating to their healthcare, the top three places patients look, include their doctors, websites, and patient organizations and advocacy groups.

The Lymphoma Canada Conference gave me a lot of information assessing not only the progression of my cancer but also all available medications side effects, combination of medication, remissions research, upcoming treatments information... etc. It was a God send for me to understand where I am at and what to expect in the coming future... gave me a sense of security and understanding.

- Anonymous, Canadian CLL patient

Patients were asked about their level of understanding regarding their CLL care when it came to seeking knowledge about the disease:

Agree
  Disagree
  Neither agree nor disagree



For those on treatment or received treatment in the past, I know what each of my prescribed medications do



I am confident in my ability to get the information I need from my doctor



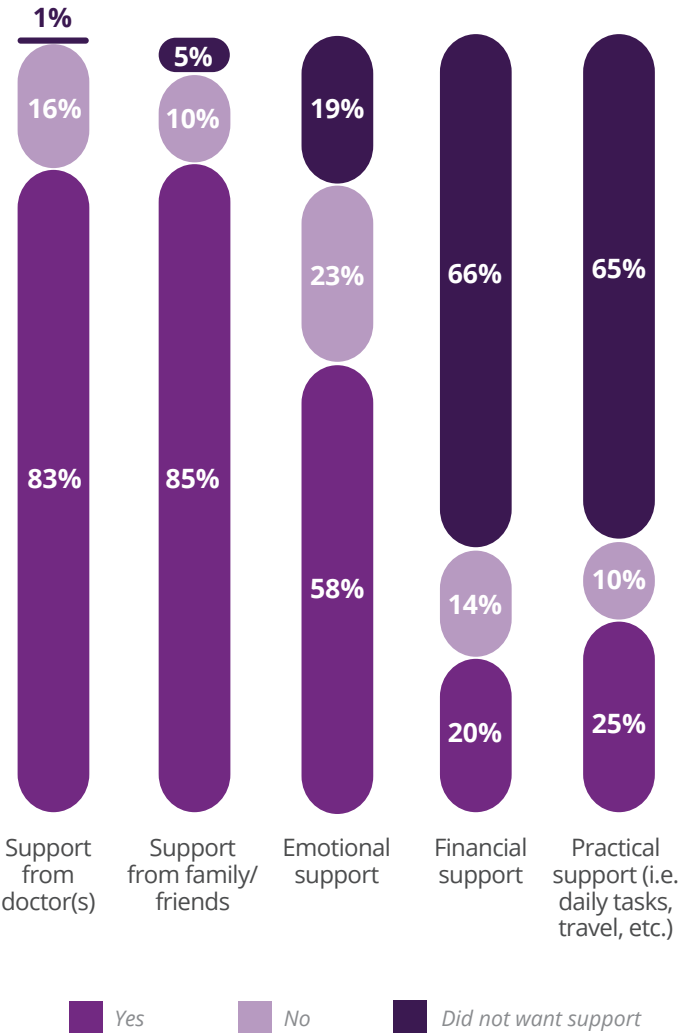
I am confident that I can find reliable information about my lymphoma/CLL (i.e. online resources)




I always understand my doctor's advice and treatment plans

There are numerous ways patients can access support. Support for patients can come from their family and friends, a healthcare team, support groups, etc.. Support is available in different forms such as emotional support, physical support, or financial support.


### DID PATIENTS RECEIVE ENOUGH SUPPORT IN THE FOLLOWING AREAS

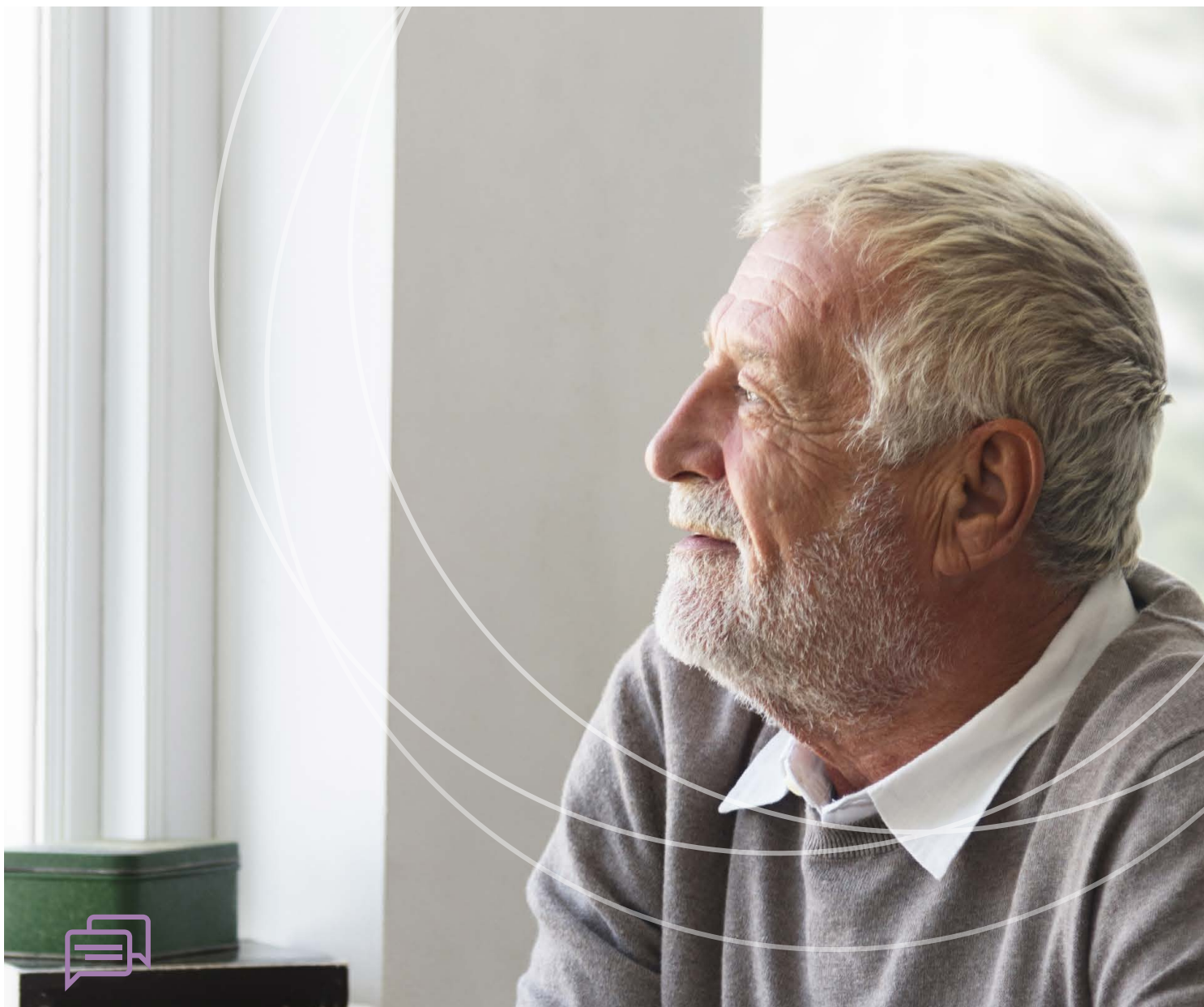




I wish there were individual volunteers who have CLL or know about CLL that I could call for advice.

- Anonymous, Canadian CLL patient





# YOUR FEEDBACK; OUR GOALS

## Summary and Data Trends

The 2020 Canadian CLL Report Card provides valuable information from Canadian CLL patients across various age groups, locations across Canada, and demographics. This information allows us to identify unmet needs or gaps in knowledge, support, and clinical care. With this information, we as patient organizations, healthcare professionals, provincial health systems, and support groups can enact change to help the CLL patient community across Canada.

# KEY FINDINGS FOR CANADIAN CLL PATIENTS

## Symptoms

- + Top CLL symptoms experienced lasting more than eight years include skin rash/lesions (23%), easy bruising/bleeding (22%), and fatigue (20%)
- + Approximately half of patients have found their symptoms negatively impact everyday activities, and the majority of patients have found that their symptoms do not impact their ability to work (62%) or cause problems with family and friends (69%).

## Diagnosis

- + Fifty-two percent of patients received their diagnosis less than three months from the time they presented their general practitioner with symptoms; however, there was a small percentage of patients (4%) that received a diagnosis after 12 months from symptom presentation to their doctor.
- + There was a population of patients (25%) that were not told their lymphoma subtype at diagnosis.
- + The majority of patients (54%) were not aware whether they received molecular testing at diagnosis, while the remainder were able to provide details on their specific CLL molecular profile.

## Treatment & Clinical Trials

- + Seven percent of patients communicated wanting to change their treatment with their doctor and chose a treatment that was not suggested by their doctor.
- + Thirty-three percent of patients received a second opinion regarding treatment, with 19% of patients switching their doctor as a result.
- + The majority of patients are confident in their doctors that are treating them (65% are always confident, and 31% are sometimes confident).
- + The large majority of patients (83%) have not participated in a clinical trial. Reasons include never being presented with the opportunity to participate, clinical trial availability, and not meeting the eligibility criteria for a trial.

## Treatment Side Effects

Side effects most experienced by CLL patients include fatigue (71%) and easy bruising/bleeding (38%). The most predominant side effect, fatigue, was experienced the most by patients for either 2-5 years (30%) or 1-2 years (26%).

The majority of patients discussed their side effects with their clinician, however 20% did not discuss the full extent of their side effects.

Seventy-two percent of patients received help from their doctor for their side effects, while 26% of patients did not have their doctor help with their side effects

The majority of patients did not have their side effects negatively impact everyday activities (48%), employment (58%), social life (52%), and relationships with family and friends (72%).

## Quality of Life (QoL)

- + Patients reported that fear of lymphoma progression (50%), anxiety (28%), and fear of cancer relapse (26%) have impacted their QoL in the last 12 months.
- + Patients discussed emotional impacts (anxiety/depression/fear of recurrence) with their doctor, however, 89% of patients were not inclined to speak with their doctor about changes to their relationships with family/friends.
- + Doctors that assisted with patient's depression, helped by providing information on coping mechanisms (42%) or referring the patient to another support source (42%), whereas doctors helped patients with their anxiety mostly by prescribing medication to help (46%).
- + For most psychological concerns (such as depression, anxiety, isolation fear of relapse or progression, etc.), patients either did not speak to anyone about them or if they did, they mostly consulted with their family/friends.
- + Discovering a cure for lymphoma, improving quality of life, and having fewer side effects are the top three most important outcomes for CLL patients.

## Relapse/Recurrence

- + Forty-four percent of respondents have had a relapse (35% just once, 9% more than once).
- + Fifty-six percent of patients have experienced a fear of recurrence and have ruminated about their cancer returning, examined themselves for physical signs of cancer recurrence, and have thoughts about dying.
- + Fifty-seven percent of patients that discussed fear of recurrence with their doctor found that their doctor was able to help completely, and 29% had their doctor help to some extent.
- + Coping mechanisms used to manage fear of recurrence mostly included exercise programs (64%).

## Follow-Up Care and Day-to-Day Management

- + Ninety-one percent of patients are confident that they can manage their day-to-day health care.
- + When managing health problems in particular, 16% of patients were not confident that they could manage their symptoms and side effects from day-to-day.
- + Twenty-two percent of patients wait until health issues can no longer be ignored before they go and seek help from their healthcare team.

## Information, Decisions, Support

- + Eighty-eight percent of patients have been actively involved in their own care, however, 12% of patients were not but wanted to be.
- + When asked about managing their health and condition, 14% of patients felt overwhelmed.
- + The majority of patients have had good conversations with their doctor (70%), sought clarification when they did not understand (89%), and were confident in sharing information with their doctor (80%).
- + Decisions for patients about their health and care were influenced most by their healthcare providers (74%).
- + Need for information was greatest within the first month following diagnosis (38%).
- + Forty-five percent of patients were not provided with enough information at diagnosis and wanted to know more about treatment options (60%) and diagnosis and what it means (55%).
- + Patients received enough support from doctor's (83%) and family/friends (85%), however there was a percentage of patients that did not receive enough support emotionally (23%).

## OUR GOALS

You've spoken – we listened. This report card on CLL patients, highlights the need for more information and support throughout every stage of the CLL journey.

In addition to tailoring our educational resources, support materials and webinars to address the unmet needs in care identified in this report, Lymphoma Canada will share our findings with healthcare professionals across Canada including our Scientific Advisory Board, our Nurse Advisory Board and other stakeholders involved in supporting CLL patients. Together as a community, we will improve the overall patient experience.

Lymphoma Canada constantly works toward improving the patient experience by expanding our educational resources and informational sessions, addressing patient concerns and advocating on their behalf with regards to health policies and equitable access to innovative therapies. We connect patients with support groups to share their stories and self-learn. Further, we support Canadian lymphoma-based research. It is our goal that through our efforts in education, support, advocacy and research that we continue to empower the lymphoma community.



## OUR MISSION

Empower patients and the lymphoma community through education, support, advocacy, and research.



## OUR VISION

Life unlimited by lymphoma.



# HOW YOU CAN HELP

Lymphoma Canada is a national charitable organization dedicated to supporting people, patients and caregivers, touched by lymphoma across the country. **We need the support of passionate people, like yourself**, to help us raise awareness about lymphoma in your community.



## DONATE

### Why Your Gift Means So Much

Your gift doesn't just make a difference for one individual. It enables us to reach lymphoma and CLL patients across the entire country! Your donation allows us to provide education and support services to patients and caregivers. It allows us to advocate for equity to the latest treatments and to fund Canadian-based lymphoma and CLL research. Your donation will directly impact the life of all many Canadians with a lymphoma or CLL diagnosis.

[www.lymphoma.ca/ways-to-give/](http://www.lymphoma.ca/ways-to-give/)



## VOLUNTEER

Lymphoma Canada is always seeking volunteers to help us achieve our mission to empower lymphoma and CLL patients and the lymphoma community, through education, support, advocacy and research. We recognize the wealth of knowledge, expertise and skills that volunteers bring to the organization. Please contact us if interested in volunteering with Lymphoma Canada.



## FUNDRAISE

Host a fundraiser for Lymphoma Canada to raise awareness and support for those affected by lymphoma and CLL. Lymphoma Canada staff can help generate ideas for your event. We can also provide you with an online fundraising page to promote your event and help you to meet your fundraising goal.



## SHARE YOUR STORY

Do you have a story to share? The sharing of experiences can be cathartic, educational, and inspiring for lymphoma patients. At Lymphoma Canada, we often hear from patients that being able to talk to and hear from other patients, is an important part of going through the lymphoma experience.

If you have more questions about getting involved with Lymphoma Canada, contact us at **1.866.659.5556** or email [info@lymphoma.ca](mailto:info@lymphoma.ca)



6860 Century Avenue, Suite 202 | Mississauga, ON L5N 2W5  
Telephone 905.858.5967 Toll Free 1.866.659.5556  
General inquiries [info@lymphoma.ca](mailto:info@lymphoma.ca)  
Website [lymphoma.ca](http://lymphoma.ca) or [lymphome.ca](http://lymphome.ca)

Charitable Registration Number | 87346 1040 RR0001



[facebook.com/LymphomaCanada](https://facebook.com/LymphomaCanada)



[twitter.com/LymphomaCanada](https://twitter.com/LymphomaCanada)



[youtube.com/LymphomaTV](https://youtube.com/LymphomaTV)



[instagram.com/LymphomaCanada](https://instagram.com/LymphomaCanada)

#### PERMISSION TO REPRODUCE

This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit or otherwise alter its content. The following credit must appear on any reprint: This information was provided by Lymphoma Canada. For more information contact Lymphoma Canada at 1-866-659-5556 or [www.lymphoma.ca](http://www.lymphoma.ca).