



LYMPHOMA  
CANADA



# THE PATIENT AND CAREGIVER EXPERIENCE

2020 Canadian Lymphoma Report Card

| 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

Empowering 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 lymphoma patients and caregivers across Canada who participated in this survey and who shared their lymphoma care experiences.

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

### DISCLAIMER

Lymphoma Canada created the 2020 Canadian Lymphoma Report Card to summarize findings from the 2020 Global Patient Survey on Lymphomas and CLL and to provide statistics from Canadian 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 and caregiver comments derived from the Canadian survey results.

### WARNING

Lymphoma Canada's 2020 Canadian Lymphoma Report Card was created to provide a summary of patient and caregiver 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.*



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# 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.*

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 lymphoma journey.

This report highlights the patient experience throughout different stages of the clinical course and is a summary of first-hand responses from Canadian patients and caregivers. 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 the patient 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 patients, the Lymphoma Coalition, and financial supporters, we would not be able to undertake this important work to help patients and their caregivers in dealing with a lymphoma 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

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Woodbridge, ON

Barbara Pollock  
Regina, SK

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Chair  
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Johnathan Greenbaum  
Toronto, ON

Dr. John Kuruvilla  
Toronto, ON

Lina Ciaccia  
Toronto, ON

Kathy Mannas  
Richmond, BC

Pranav Bhardwaj  
Toronto, ON

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Dr. John Kuruvilla | Chair  
Princess Margaret  
Hospital

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Bruckler  
Ottawa General Hospital

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The Ottawa Hospital

Dr. Jean-Francois  
Larouche  
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McMaster University

Dr. Mark Bosch  
Saskatchewan Cancer  
Agency

Dr. Doug Stewart  
University of Calgary

Dr. Tony Reiman  
University of New  
Brunswick

Dr. Joanne Hickey  
Memorial University

Dr. Kerry Savage  
BC Cancer Agency

Dr. Pamela Skrabek  
CancerCare Manitoba

Dr. David Hodgson  
Princess Margaret  
Hospital

# 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 a lymphoma diagnosis and treatment, but also about social impacts and any challenges they faced. This survey provided patients with a voice that was then collectively summarized into a report to educate, and bring awareness to the important realities facing the lymphoma community.

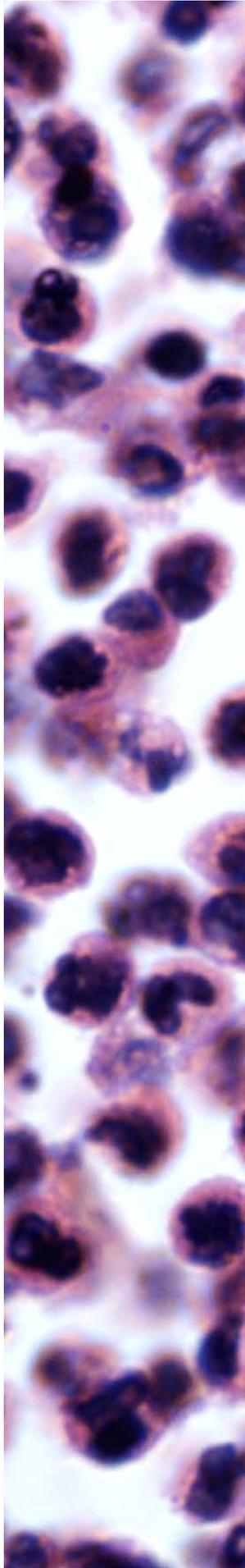
While our daily work with lymphoma patients and families across Canada helps to inform us of issues facing the lymphoma community, we and other lymphoma organizations felt the most accurate representation of these challenges would come from directly asking you. To address this, the Lymphoma Coalition, a worldwide network of lymphoma patient groups, created a survey in 2020 for patients and caregivers to provide information about their lymphoma journey and their experiences caring for lymphoma 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 the 2020 Canadian Lymphoma Report Card. We hope that the information in this report will highlight the unmet needs and challenges faced by the lymphoma community and 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 patient feedback and for sharing the results with us. Thank you.

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



# 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 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 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. Further, 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

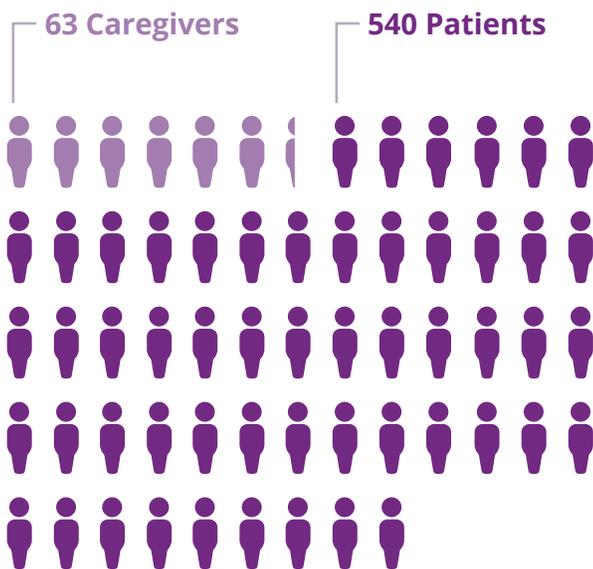
In 2020, Lymphoma Canada collaborated with the Lymphoma Coalition, a non-profit organization comprising of a world-wide network of lymphoma patient groups, to conduct an anonymous and voluntary web-based global survey of lymphoma patients and caregivers. This survey was available in 19 languages

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

### YOUR FEEDBACK

The Lymphoma Coalition received thousands of responses from lymphoma patients and caregivers from around the world. In Canada, responses were received from across the country. Overall, there were 603 Canadian respondents, 540 of whom were patients, and 63 were caregivers.

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



### 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 lymphoma journey for patients and caregivers
- + Identify key issues and challenges throughout each stage of the patient and caregiver experience
- + Determine where and how organizations, healthcare professionals, support groups, and stakeholders can work together to help improve the patient and caregiver experience



# CANADIAN LYMPHOMA PATIENTS

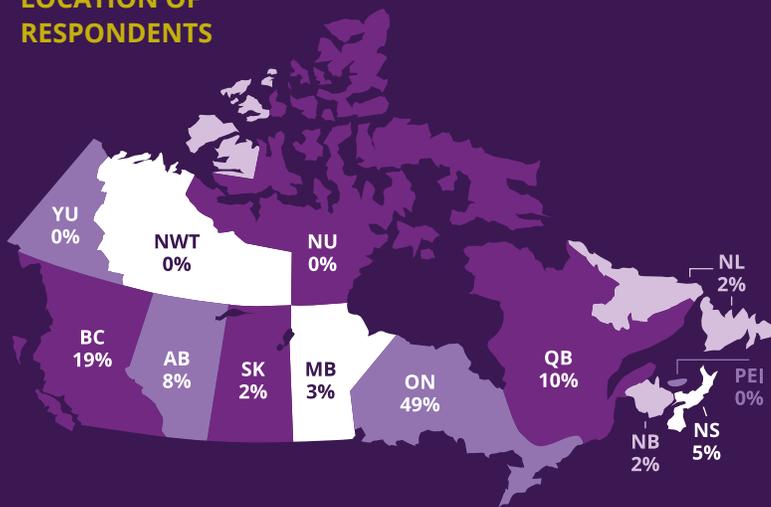
## Executive Summary of the Lymphoma Patient Experience

- + The most prominent physical condition reported as both a lymphoma symptom (71%) and treatment side effect (74%), was fatigue. Of patients that discussed fatigue with their doctor, 32% expressed that their clinician did not take action to help them manage their fatigue.
- + Nine percent of lymphoma patients did not know they were diagnosed with cancer when they received their lymphoma diagnosis, while 19% of patients did not know their subtype at diagnosis
- + Thirty-one percent of lymphoma patients did receive a second opinion regarding their treatment options. While 13% of patients did not ask for a second opinion but wanted to, their reasons included not having access another doctor or not wanting to affect their relationship with their current doctor.
- + Ninety-eight percent of patients discussed their treatment side effects with their clinician, 56% of whom found their doctor was able to help with their side effects to some extent.
- + The key psychosocial issue identified was fear of progression (47%) or relapse (36%).
- + Twenty-one percent of patients who are experiencing health issues wait until they can no longer be ignored before seeking help.
- + Important outcomes for lymphoma patients include finding a cure (68%), maintaining quality of life (54%), and fewer treatment side effects to tolerate and manage (51%).
- + Thirty-five percent of patients were not provided with enough information at diagnosis including information on topics such as treatment options (55%), diagnosis and what it means (51%), and treatment side effects (39%).

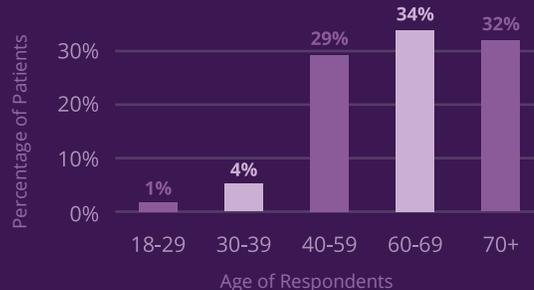
# PATIENT DEMOGRAPHICS

Survey respondents were from various demographics and stages within their lymphoma journey.

## LOCATION OF RESPONDENTS



## AGE OF CANADIAN PATIENT RESPONDENTS

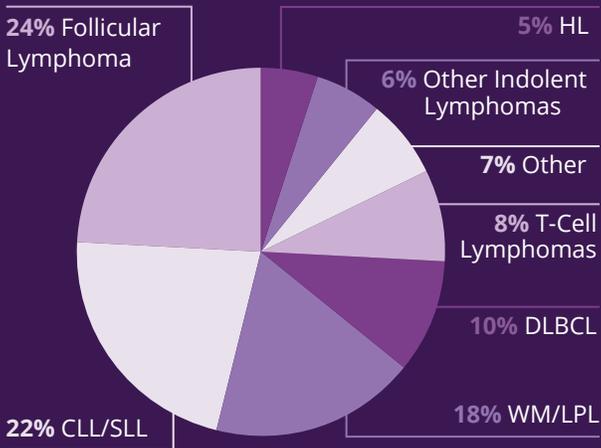


## GENDER OF CANADIAN PATIENT RESPONDENTS



## LYMPHOMA SUBTYPES OF CANADIAN PATIENT RESPONDENTS

To learn more about each patient's current experience with lymphoma, patients were asked about their disease specific subtype and to describe their stage of treatment.



**Abbreviations:** DLBCL (Diffuse Large B-Cell Lymphoma), CLL (Chronic Lymphocytic Leukemia), SLL (Small Lymphocytic Leukemia), HL (Hodgkin Lymphoma), WM (Waldenström Macroglobulinemia), LPL (Lymphoplasmacytic lymphoma).

## WHAT BEST DESCRIBES YOUR TREATMENT STAGE

- 1% I am newly diagnosed and not yet sure of my treatment options
- 20% Treatment is not yet needed (watch & wait or active surveillance)
- 21% 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:



- 15% I am currently receiving treatment
- 8% I have finished treatment and I am on maintenance therapy
- 31% I am in remission

These patients in remission have been treatment free for:



- 1% I am not having or stopped treatment
- 3% Other

Legend: <2 years (dark purple), 2-5 years (medium purple), >5 years (light purple)

## PATIENTS WITH A LYMPHOMA TRANSFORMATION



It is possible for low-grade, slow-growing, less aggressive lymphoma to become more aggressive in a process called transformation. This can happen because the cells in low-grade lymphomas survive beyond their natural lifetime and may become damaged causing the cells to grow rapidly, similar to high-grade lymphomas. Transformation will result in a change to your treatment and care. For patients that responded to this survey, 11% have had their indolent lymphoma transform into a more aggressive lymphoma.

# PRE-DIAGNOSIS SYMPTOMS

Lymphoma symptoms can be similar to symptoms observed in other, less serious illnesses, such as influenza or other viral infections. Because of the common nature of these symptoms and because lymphoma symptoms do not appear in all cases, diagnosis can sometimes take longer. With lymphoma, it is important to note that these symptoms persist over time and cannot be explained by an infection or another disease.

*Patients were asked to list all symptoms they experienced as a result of their lymphoma:*

- 71%** Fatigue

---

- 33%** Abnormal painless swelling(s) on the body/enlarged lymph nodes

---

- 32%** Shortness of breath

---

- 28%** Skin rashes/lesions

---

- 27%** Fever, chills, night sweats and weight loss (B symptoms)

---

- 25%** Easily bruised or bleed

---

- 23%** Pain

---

- 18%** Frequent or repeated infections

---

- 17%** Headaches

---

- 17%** Anemia

---

- 16%** Others

---

- 13%** No symptoms

Fatigue was the most common symptom experienced (71%), followed by abnormal painless swelling of lymph nodes (33%), and shortness of breath in 32% of patients. As fatigue was a significant symptom and side effect experienced by the lymphoma population, further questions were asked to understand further about patients' experience with fatigue

The majority of patients that experienced fatigue did discuss this symptom with their doctor, while 20% of patients did not. Patients were asked to list the reasons

why they did not speak to their doctor about their fatigue. Top reasons included not thinking their doctor could resolve this symptom (40%), thinking they could deal with it on their own (28%), and not thinking it was relevant (21%).

## REASONS FOR NOT DISCUSSING FATIGUE WITH DOCTOR

<b>40%</b>	I did not think anything could help
<b>21%</b>	I did not think it was relevant
<b>28%</b>	I thought I could deal with it on my own
<b>16%</b>	The doctor never started a discussion
<b>12%</b>	I was unsure how to bring it up or speak about it

For patients that did discuss fatigue with their clinician (76%), 32% expressed that their clinician did not take action. For patients that did receive help from their clinician for their fatigue, the top three actions performed by the clinician included asking more about the different aspects of their fatigue (27%), recommending non-medical help (nutrition, exercise, etc.) (24%), and delving into the patient's medical history and other possible causes (22%).

While 23% of patients communicated their challenges with fatigue to their clinicians only, the remainder of patients reached out to their many networks including family/friends (59%), nurses (16%), and complementary therapists (8%).

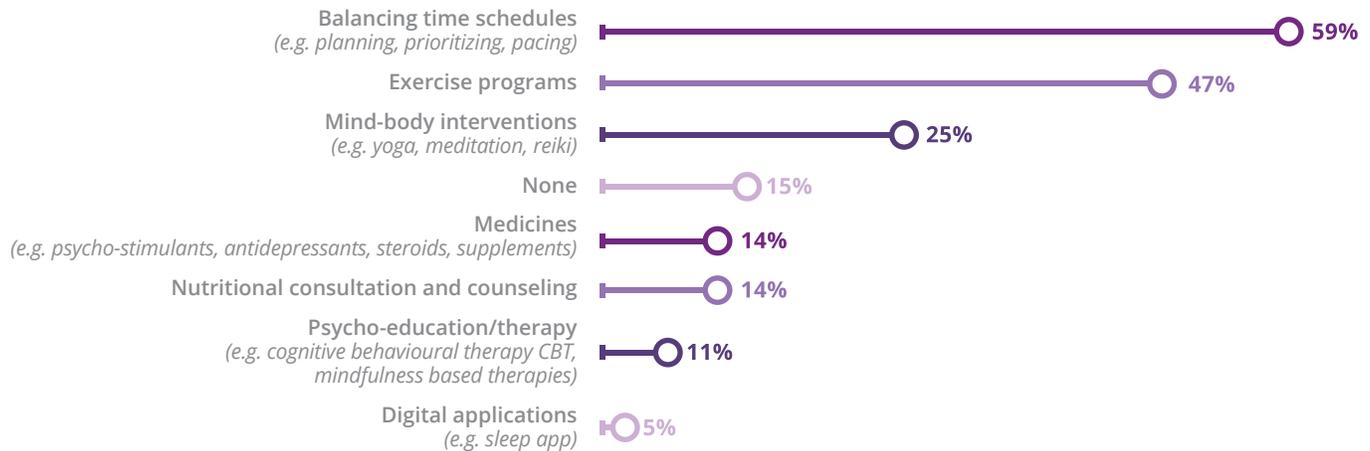


In the years prior to my diagnosis the symptoms I described were either ignored or minimized. In fact, my blood work showed some abnormalities but they were not taken seriously.

- Anonymous, Canadian patient



**COPING MECHANISMS FOR FATIGUE** Patients were asked to list the different ways they manage their fatigue.



To gain greater insight, patients were asked how long they experienced lymphoma symptoms. Symptoms that were experienced most frequently and for the longest duration included fatigue, skin rashes/lesions, easy bruising/bleeding, frequent or repeated infections, and abnormal painless swelling(s) on the body/enlarged lymph nodes.

**SYMPTOMS FELT AND FOR HOW LONG**

Under 1 year	1-2 years	2-5 years	5-8 years	>8 years
Shortness of breath (17%)	Fatigue (26%)	Fatigue (29%)	Fatigue (29%)	Fatigue (31%)
Fatigue (16%)	Shortness of Breath (13%)	Shortness of Breath (10%)	Easy bruising/bleeding (13%)	Skin rashes/lesions (15%)
Lymph node swelling (14%)	B Symptoms (11%)	Pain (10%)	Skin rashes/lesions (13%)	Easy bruising/bleeding (10%)
B Symptoms (14%)	Easy bruising/bleeding (10%)	Easy bruising/bleeding (9%)	Anemia (10%)	Lymph node Swelling (9%)
Pain (11%)	Lymph node Swelling (10%)	Lymph node Swelling (9%)	Lymph node Swelling (8%)	Frequent/ repeated infections (9%)

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

**IMPACTS OF LYMPHOMA SYMPTOMS**

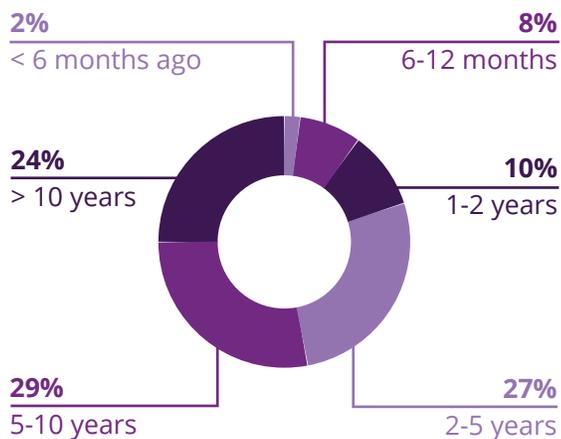
Symptoms can have an impact on numerous aspects of a patient's life. Patients were asked about their level of agreement on how symptoms impacted their everyday activities, social life, employment, and relationships:



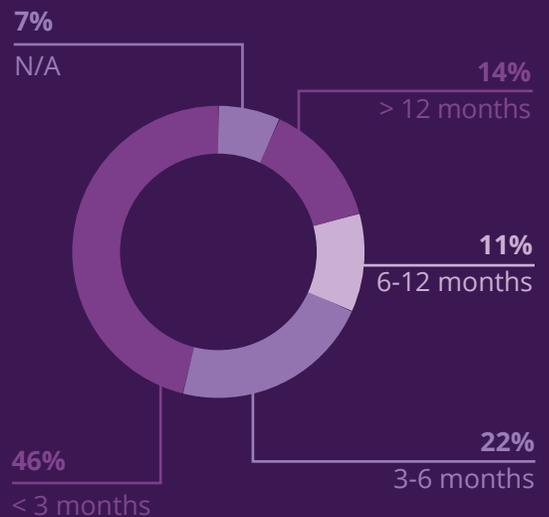
# DIAGNOSIS

Receiving a lymphoma diagnosis or any cancer diagnosis can be shocking and overwhelming. The time from initial contact with a 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 lymphoma patient population.

## HOW RECENTLY WERE PATIENTS DIAGNOSED WITH LYMPHOMA



## LENGTH OF TIME TO DIAGNOSIS IN MONTHS



I had recurring pneumonias. It took a long time to get diagnosed. Neither my GP [general practitioner] or the internist that I was referred to had ever seen a person with my subtype of lymphoma.

- Anonymous, Canadian patient



I got my diagnosis pretty quick. But the staging took over two months. I found the waiting very hard, the unknown. It had a big impact on my emotional health.

- Anonymous, Canadian patient



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

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

Therefore, it is extremely important to find out your subtype at diagnosis so that you can become educated and informed about your lymphoma journey and the options available to you. Patients were asked if they were told their lymphoma subtype at diagnosis:

### NON-HODGKIN LYMPHOMAS (NHL)

This includes over 60 subtypes of lymphoma and can be further subdivided into Mature B-Cell Lymphomas and Mature T-Cell Lymphoma.

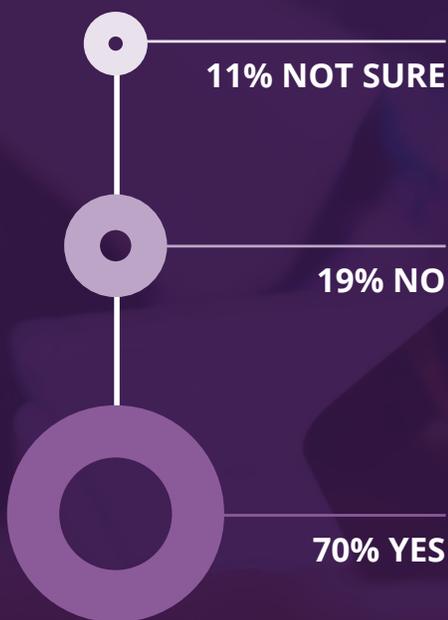
### HODGKIN LYMPHOMAS (HL)

Can be further subdivided into Classic HL and Nodular Lymphocyte Predominant HL.

### CHRONIC LYMPHOCYTIC LEUKEMIA (CLL)

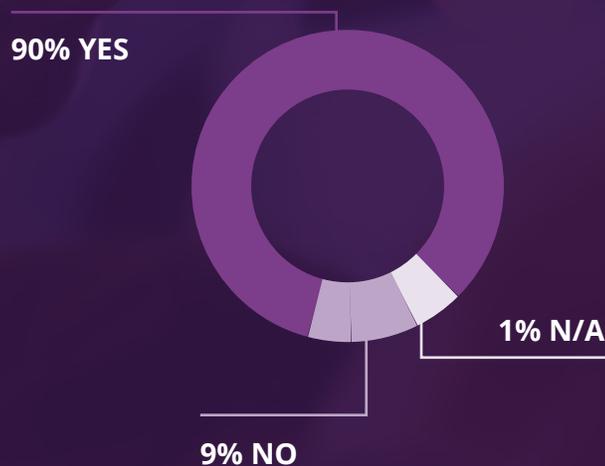
CLL subtypes can be defined by different mutations to a patient's genetic makeup.

### DID YOU KNOW YOUR SUBTYPE AT DIAGNOSIS?



Since the word “cancer” is not in the lymphoma name, some do not know that lymphoma is a type of cancer.

### AT THE TIME OF YOUR DIAGNOSIS, WAS IT CLEAR THAT YOU HAD RECEIVED A CANCER DIAGNOSIS?



# LYMPHOMA TREATMENTS AND CLINICAL TRIALS

The next stage of the lymphoma patient journey, following diagnosis, is treatment. There are many different treatment options available to patients depending on their lymphoma subtype, the molecular features of their lymphoma, stage of lymphoma, and

whether a patient is undergoing first-line treatment or treatment for relapsed/refractory lymphoma. Watch and wait or active surveillance of lymphoma symptoms may be an option for some patients before requiring treatment.

## TREATMENT OPTIONS FOR PATIENTS CAN INCLUDE

**Chemotherapy**

**Radiation Therapy**

**Biologic Therapies**

*(antibody therapy, gene therapies, Interferon)*

**Targeted Therapy**

**Bone Marrow or Stem-Cell Transplant**

**Clinical Trials**

More detail was provided from patients on the types of therapy they received. Patients selected the different ways in which they received their treatment, i.e. intravenous, oral, subcutaneous, and provided details on types of complementary/alternative therapies.

## TYPE OF THERAPY AND ADMINISTRATION:

### Chemotherapy

*Intravenously (76%), Orally (21%), Subcutaneous (3%)*

### Chemo-immunotherapy

*Intravenously (97%), Orally (15%), Subcutaneous (12%), Intramuscular (2%), Intrathecal (1%)*

### Immunotherapy

*Intravenously (82%), Orally (3%), Subcutaneous (22%), Other (3%)*

### Targeted Therapy

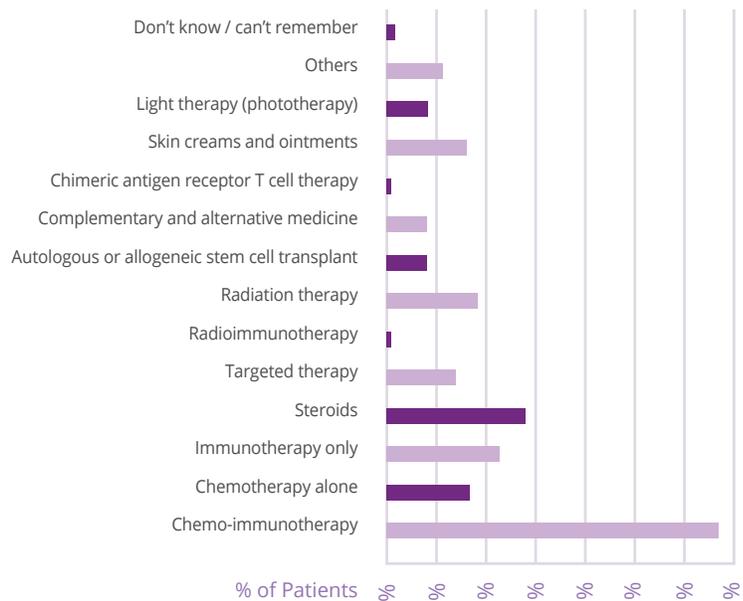
*Intravenously (9%), Orally (89%), Other (4%)*

### Complementary / Alternative Therapy

*Supplements/Diet: Vitamin (77%), Herbal (45%), Special Diet (35%)  
Therapy: Acupuncture (61%), Massage (58%), Reiki (45%),  
Chiropractor (16%), Marijuana/CBD Oil (39%)*

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

## PATIENTS LYMPHOMA TREATMENTS



Please lobby the federal and provincial government to approve and fast-track groundbreaking new treatments like CAR-T.

*- Anonymous, Canadian patient*



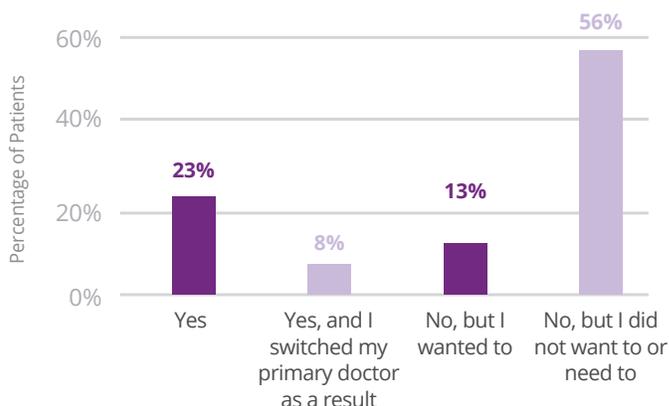
It is important to have an open line of communication between a patient and their clinician. Your doctor will present the best options available to treat your lymphoma subtype, however, there may be other aspects to consider when deciding between treatment options. This can include consideration of treatment side effects and impacts to quality of life, reliance on a caregiver, and oral versus intravenous administration. Patients were asked whether they had spoken with their clinician about wanting to change their treatment to better meet their needs. Twenty-two 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 with their doctor about their treatment but would have liked to.

### DID YOU COMMUNICATE YOUR TREATMENT NEEDS TO YOUR DOCTOR?

22%	Yes, I communicated this with my doctor, and chose a treatment they recommended
4%	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
15%	No, I have not spoken with them about this, and I did not want to
28%	Not applicable - I haven't wanted to change my treatment within the last two years
29%	Not applicable - I haven't had any treatment(s) for my condition within the last two years

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 lymphoma 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-one percent of patients did receive a second opinion, with 8% of the patients switching their primary doctor as a result.*

### WHY DIDN'T YOU GET A SECOND OPINION?

74%	I trusted my doctor's advice and information
9%	I could not access another doctor / not an option
9%	Something else
9%	I didn't want to affect the good relationship I have with my current doctor



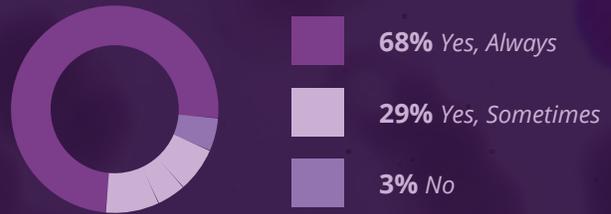
I am fortunate to be in a 'watch and wait' phase but do have considerable confidence in my oncologist when my disease turns active.

- Anonymous, Canadian patient



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 about their level of confidence in the doctors treating them:

## PATIENTS' CONFIDENCE IN THEIR TREATING DOCTORS



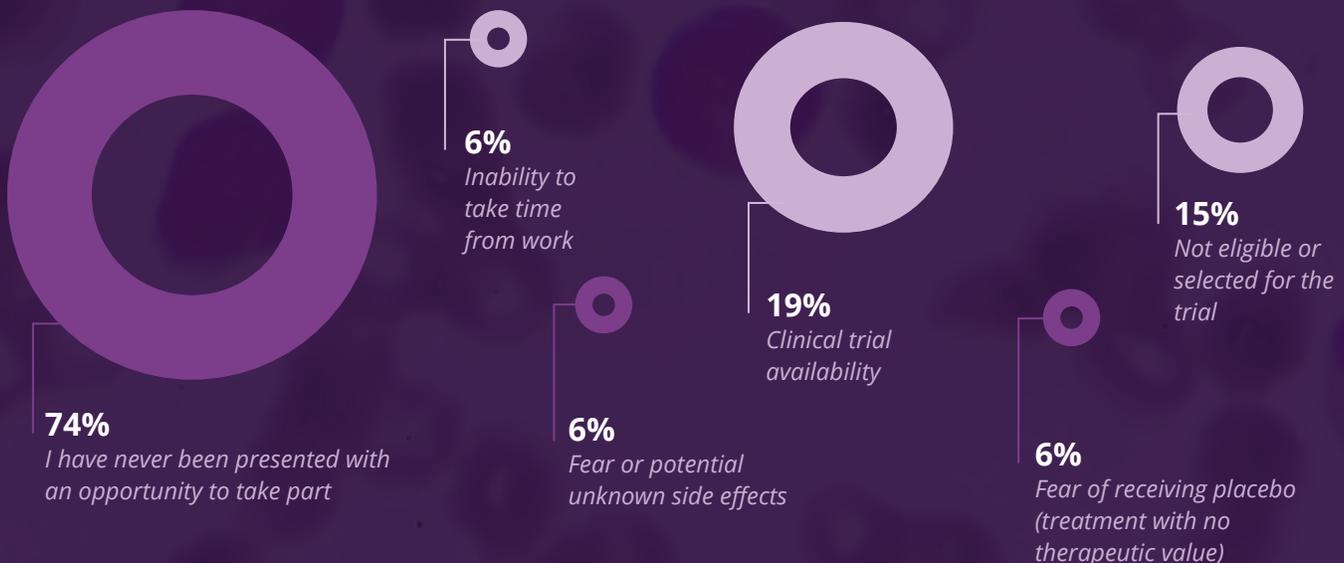
## CLINICAL TRIALS

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. Clinical trials allow for testing the safety and efficacy of a new treatment and compare against new therapies currently available treatments.

A significant roadblock exists when patients are not asked to participate in clinical trials or are not 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.

## TOP REASONS FOR NOT ACCESSING A CLINICAL TRIAL



# SIDE EFFECTS AND 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, shortly after or even 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.

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

**Fatigue 74%** Numbness and or tingling of arms, legs, hands or feet 44% **Hair loss 41%** Changes in sleep patterns (i.e. trouble sleeping etc.) 36% **Lack of concentration 35%** Constipation 34% **Nausea and vomiting 34%** Pains in joints and muscle pain 32% **Loss of memory 29%** Diarrhea 27% **Skin, hair and nail problems 27%** Pain 26% **Changes in taste and smell 26%** Infections (neutropenia) 25% **Easy bruising and bleeding 25%** Inability to multitask 23% **Mouth and throat symptoms 23%** Eyesight issues 18% **Headaches 17%** Anemia 16% **Respiratory problems (breathing) 14%** Infusion reaction 13% **Dental issues 11%** None 9% **Cardiovascular (heart) problems 8%** Osteoporosis 5% **Secondary cancer 4%** Infertility 5% **Kidney problems (swelling of arms/legs) 5%** Liver problems 5% **Deep vein thrombosis 3%**

Each type of treatment for lymphoma has its own set of side effects that could last for months or longer. Patients were asked to list how long they experienced the treatment-related side effects that most affected them.

## TIME PATIENTS EXPERIENCED TREATMENT-RELATED SIDE EFFECTS



Patients were asked if they discussed their side effects with their doctor. Seventy-four percent of patients reported definitely discussing their treatment side effects with their doctors, and 24% of patients reported only discussing their side effects with their doctor to some extent. Only 1% of patients did not discuss treatment side effects with their doctors, and 1% could not remember.

For the small percentage of patients that **did not** discuss their side effects with their doctor, reasons for not discussing this included thinking they could handle their side effects on their own and not thinking their side effects were a big deal.

For those patients that **did** speak about their side effects with their doctor, 19% had their side effects helped by their doctor, 56% found that their doctor was able to help with their side effects to some extent, and 23% said 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 help came in the form of medication to help with side effects, information about their side effects, and referrals to other support resources.

*Open communication with your healthcare team about the side-effects you experience as a result of your treatment(s) is important. Your healthcare team can help manage and/or treat your side effects!*



As treatments get better and better and the survival rate is higher, these long-term effects are going to be more prevalent and the medical field needs to be aware of these and plan for them. I would suggest, encourage, and implore someone to look into these effects so that we survivors, can seek and access help, or at least, answers to these issues that are affecting us.

- Anonymous, Canadian patient



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

## IMPACT OF SIDE EFFECTS ON EVERYDAY LIFE



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

Agree
  Disagree
  N/A
  Neither agree nor disagree

# QUALITY OF LIFE

In addition to the medical related aspects of lymphoma, patients must cope with 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 was impacted by their lymphoma. Based on the responses received, the majority of patients had their general activity, physical activity, and general work around the home impacted by fatigue.

## IMPACT OF FATIGUE ON EVERYDAY LIFE

**General activity 63%** **Physical activities 62%** **General work around the home (daily chores/housework) 51%** **Mood 46%** **Social activities 44%** **Enjoyment of life 42%** **Ability to think clearly/concentrate 42%** **Ability to sleep 38%** **Ability to remember things 36%** **Employment (working fewer hours, stopped working) 25%** **Relationships with other people 25%** **My fatigue hasn't affected any areas of my life over the last two years 14%** **My financial situation 12%**

Seventy-five percent of patients reported that their lymphoma impacted their quality of life within the last 12 months, affecting both psychological and emotional experiences. The most prominent impacts included fear of lymphoma progression or relapse, anxiety and depression, and concerns about body image/physical appearance.

## IMPACT OF LYMPHOMA ON QUALITY OF LIFE

**Loss of self-esteem 16%** **Concerns about body image/physical appearance 23%** **Isolation 17%** **Depression (persistent sadness/low mood, and/or loss of interests or pleasure, fatigue or low energy most of your time for at least 2 weeks) 25%** **Anxiety (e.g. intense, excessive and persistent worry/ feeling afraid/feeling restless/**

**sudden feelings of intense anxiety/ nightmares/panic attacks) 30%** **Fear of relapse 36%** **Fear of progression of the lymphoma 47%** **Changes in relationships 15%**

Twenty-five percent of patients did not experience any impacts within the last 12 months.

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

## OUTCOMES BY IMPORTANCE

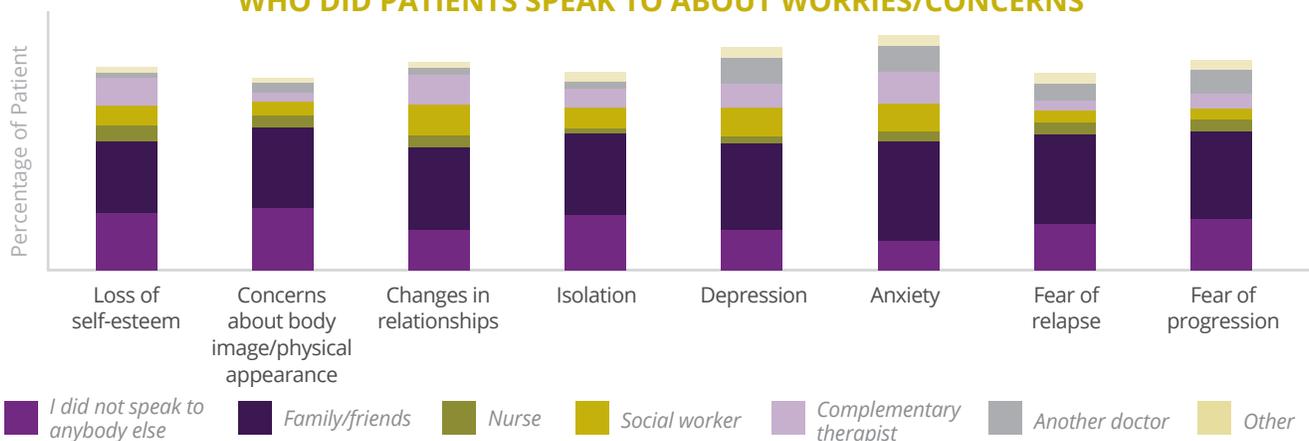
**68%** of patients rated the most important outcome was **a cure**

**54%** of patients rated the second most important outcome was **Quality of Life**

**51%** of patients rated the third most important outcome was **fewer side effects to tolerate**

Patients were more inclined to speak with their doctor regarding the emotional effects of lymphoma, including anxiety (61%), depression (54%), and fear of recurrence/relapse (56%). However, the majority of patients (69%) 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 this could be handled by themselves, not believing 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 of patients found that doctors were able to help to some extent. There are many avenues of support where patients can express their thoughts and feelings. For most concerns, patients either did not speak to anyone or used their family/friends as their main support group.

## WHO DID PATIENTS SPEAK TO ABOUT WORRIES/CONCERNS



# LYMPHOMA RELAPSE AND RECURRENCE

When lymphoma comes back after a period of time it is called a recurrence or relapse. Depending on the type of lymphoma, recurrence can happen weeks, months, or even many years after the original lymphoma was treated. If recurrent lymphoma is detected or suspected, much like when you were first diagnosed, your doctor will order a set of new tests which may include blood tests, imaging studies, and biopsies to learn as much as possible about the recurrence. After testing is completed, you and your doctor will discuss whether treatment is needed and what options are available to you.

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



Of the patients that responded to the survey, the top psychological impacts included fear of progression (47%) and fear of relapse (36%) This fear manifests through ruminating and thinking about the 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

- 88%** I think about the cancer returning

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- 65%** I examine myself to see if I have physical signs of cancer

---

- 39%** I have thoughts about dying

---

- 25%** I have difficulty making plans for the future

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- 22%** I get waves of strong feelings about the cancer returning that are difficult to control

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- 17%** I feel very alone

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- 15%** I feel very distressed by these thoughts

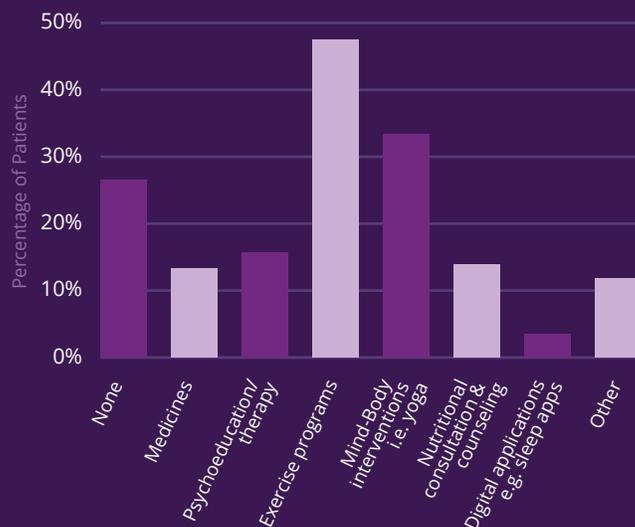
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- 13%** These thoughts intrude on my day-to-day activities

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 lymphoma recurs, you can control how much you let the fear of recurrence impact your life. Once you have collected all the medical facts you can begin to formulate your own method of coping.

There are numerous coping mechanisms that 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 and mind-body intervention, medicines, and counseling.

## COPING MECHANISMS FOR FEAR OF RECURRENCE



I still worry about its return, but not so much that it holds me back from living life to the fullest.

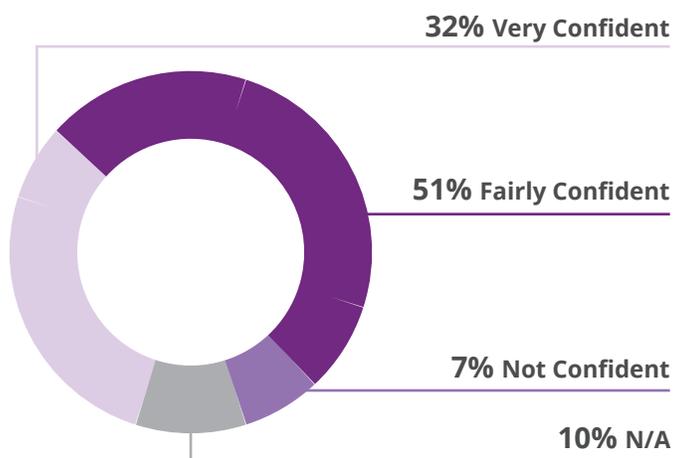
- Anonymous, Canadian patient



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

As patients move into the remission stage following treatment, patients will have different experiences with regards to managing their health, lifestyle, and any lymphoma symptoms and side effects from treatment. The majority of lymphoma patients (83%) were confident they could manage their health problems day-to-day.

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

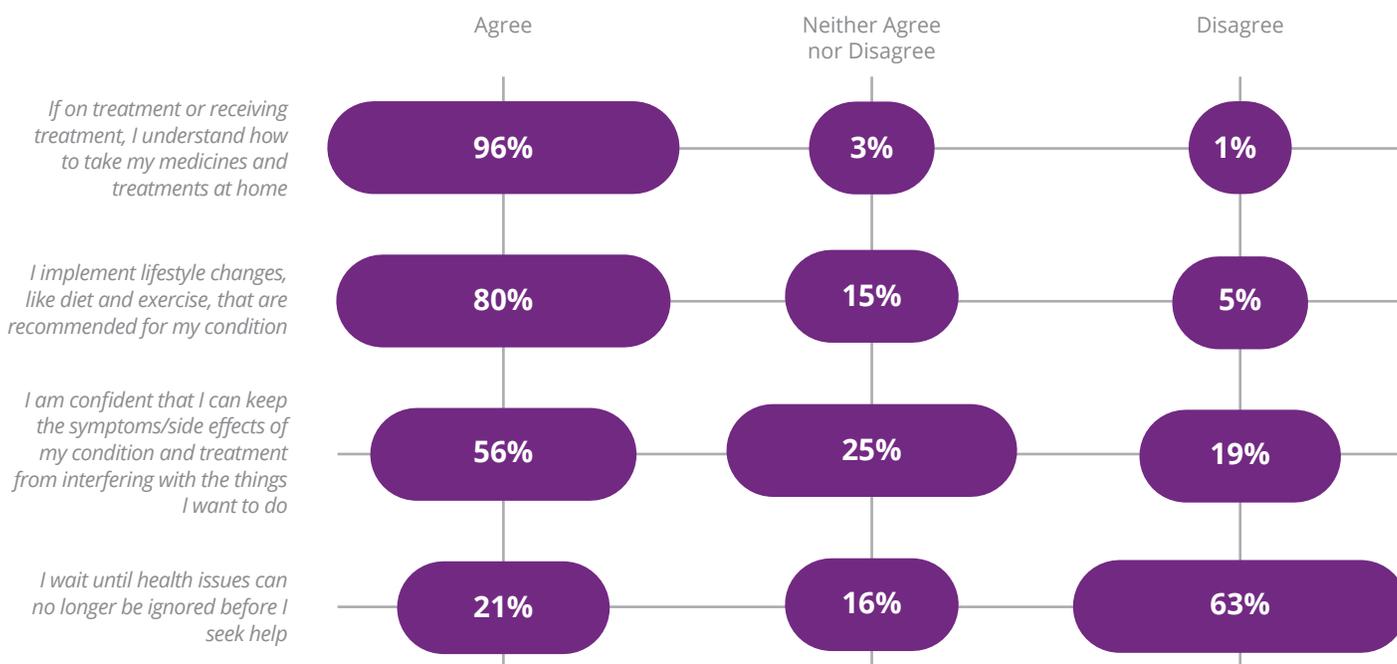


We are all of course so grateful to be alive, but we also want to thrive and not just survive cancer. I believe there is much to learn with aftercare in the years following a cancer diagnosis and survival. I also feel a strong need for alternative care to be offered throughout the process, during treatment as well as in the following years.

- Anonymous, Canadian patient



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



# PATIENT EDUCATION, DECISIONS, AND SUPPORT

Every time a person requests for more 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 needed 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 were questioned about their level of involvement when it came to their care and if they took an active role in their care. Ninety-two percent of patients felt they were involved in their care, while 7% were not even though they wanted to be; 1% were not involved but did not want 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:



The nurses and doctors were so good at answering questions about EVERYTHING. My experience with the medical professionals was exemplary. Patient attitude makes a difference. I went on this particular part of my lymphoma journey with an attitude of gratitude. The care I received made this possible.

- Anonymous, Canadian patient



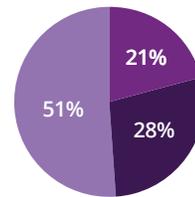
Patients revealed that their healthcare decisions were most influenced by recommendations from their healthcare providers and healthcare staff (76%), followed by personal preferences (17%). Other influential factors included suggestions from friends or family (2%) and financial considerations (1%).

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

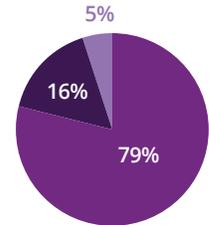
## INVOLVEMENT OF PATIENTS IN THEIR OWN CARE



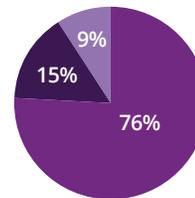
*I feel overwhelmed by managing my health and condition:*



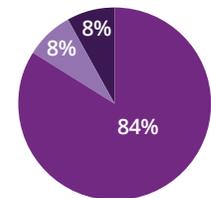
*I am confident in my ability to positively impact my health:*



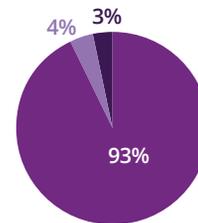
*I have good conversations with my doctor about my care and treatment plan:*



*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:*

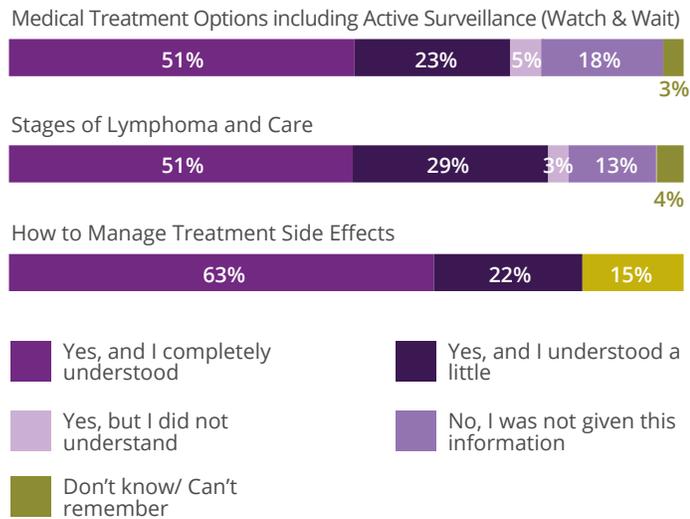


## TIME WHEN NEED FOR INFORMATION WAS GREATEST:

- 52%** Within the first month following diagnosis
- 27%** Between 1 and 3 months following diagnosis
- 6%** Between 3 and 6 months following diagnosis
- 11%** More than 6 months following diagnosis
- 1%** Never
- 3%** Don't know/ Can't remember

Patients who were diagnosed in 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



At the time of diagnosis, 35% of patients believed that they were not given enough information. Patients were asked what types of information they felt they needed more of:

- + Diagnosis and what it means (51%)
- + Treatment options (55%)
- + Support for self-care (18%)
- + Psychological support/counseling (27%)
- + Support for my family (11%)
- + Side effects from treatment (39%)
- + Fertility (3%)

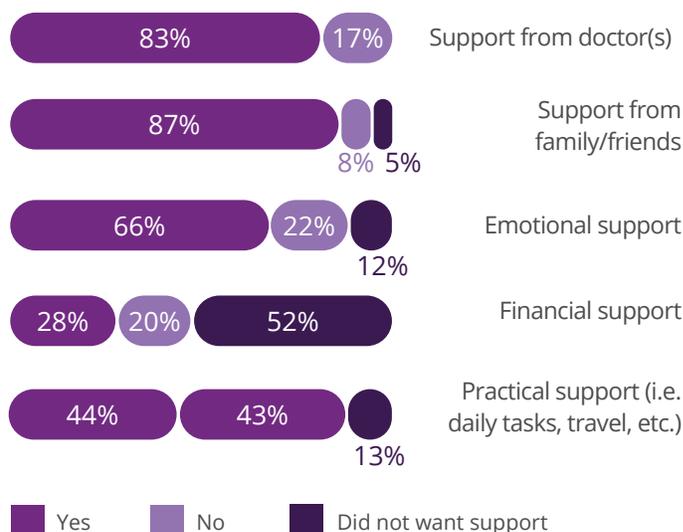
When patients have a need for information about their healthcare, the top three places patients look include their doctors, websites, and patient organizations and advocacy groups.

My best support came from online groups and websites.  
- Anonymous, Canadian patient

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



In addition to resources available to patients, there are numerous ways patients can access support. Support for patients can come from family and friends, a healthcare team, and support groups, etc.. Support is also available in different forms such as emotional, physical, or financial. Patients were asked whether they received enough support in the following areas:





# CANADIAN CAREGIVER FEEDBACK AND EXPERIENCE

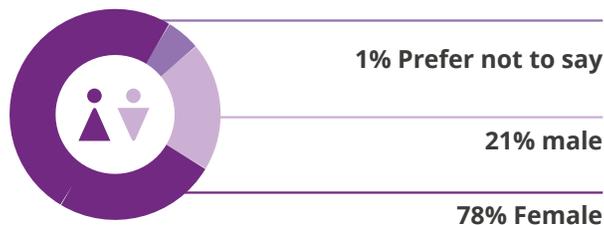
- + Thirty-two percent of caregivers seek information themselves about lymphoma and then relay this to the patient.
- + Sixty-two percent of caregivers, who provide practical and emotional support daily, find it most difficult to provide emotional support to the lymphoma patient they are caring for.
- + Sixteen percent of caregivers do not feel supported or recognized by the patient's healthcare team.
- + Throughout the care of a lymphoma patient caregivers are most effected by worry/anxiety (89%), being emotionally tired/worn-out (71%), and putting the patient's needs above their own needs (68%).

# SUPPORT AND TYPES OF CARE PROVIDED FOR LYMPHOMA PATIENTS

If a friend, relative or someone you care about has been diagnosed with lymphoma it is often difficult to know what to expect or how you can support them. For every lymphoma patient there is often one or more caregiver that is supporting the patient, either in dealing with the practical aspects of medical care, and/or being emotionally available for the patient. To be a caregiver involves regularly caring for a loved one with lymphoma, which can include a spouse, child, sibling, friend or other family member.

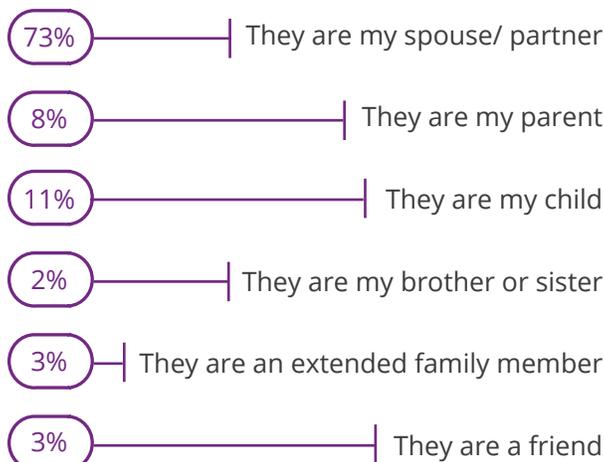
To understand the needs of caregivers of Canadian lymphoma patients, **63** caregivers were surveyed.

## GENDER OF CAREGIVER



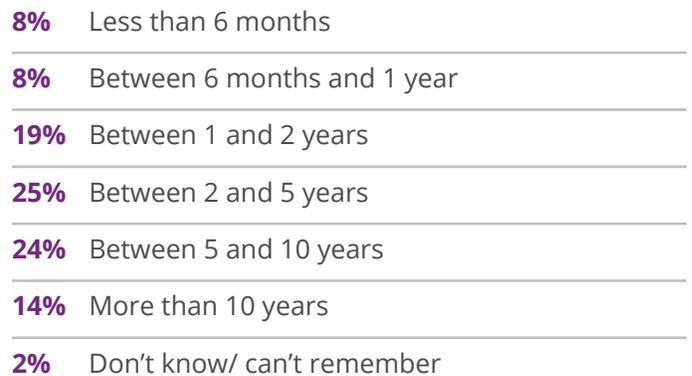
Caregivers were predominantly caring for an immediate family member, with the majority caring for a spouse (73%), followed by a child (11%) or parent (8%).

## RELATIONSHIP BETWEEN PATIENT AND CAREGIVER

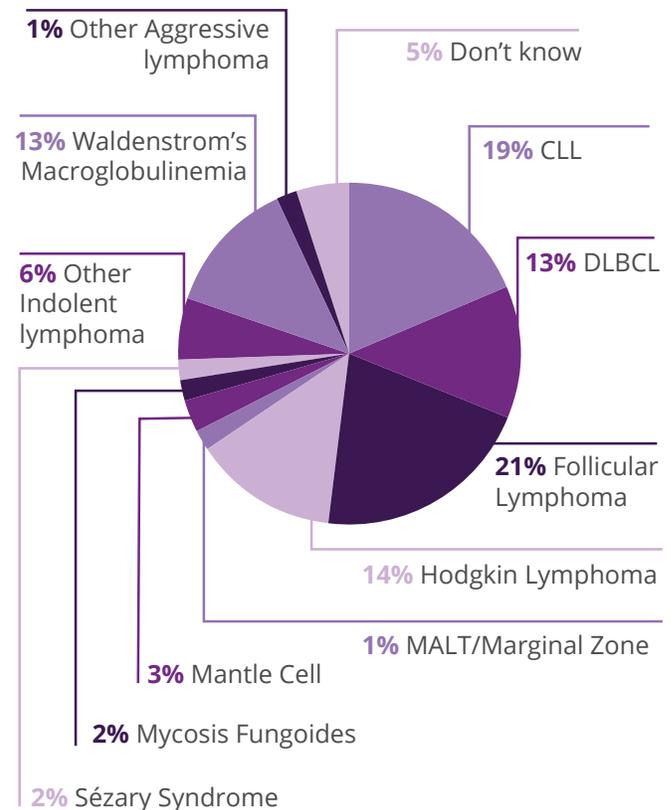


Canadian caregivers were asked about the lymphoma subtype of the person they are caring for, how long it had been since that patient received their diagnosis, and how long they have been caring for this individual.

## CAREGIVERS PROVIDED SUPPORT FOR THEIR LOVED ONE FOR:



## LYMPHOMA SUBTYPE OF CAREGIVER'S PATIENT



Abbreviations: CLL (Chronic Lymphocytic Leukemia), DLBCL (Diffuse Large B Cell Lymphoma), MALT (mucosa-associated lymphoid tissue)

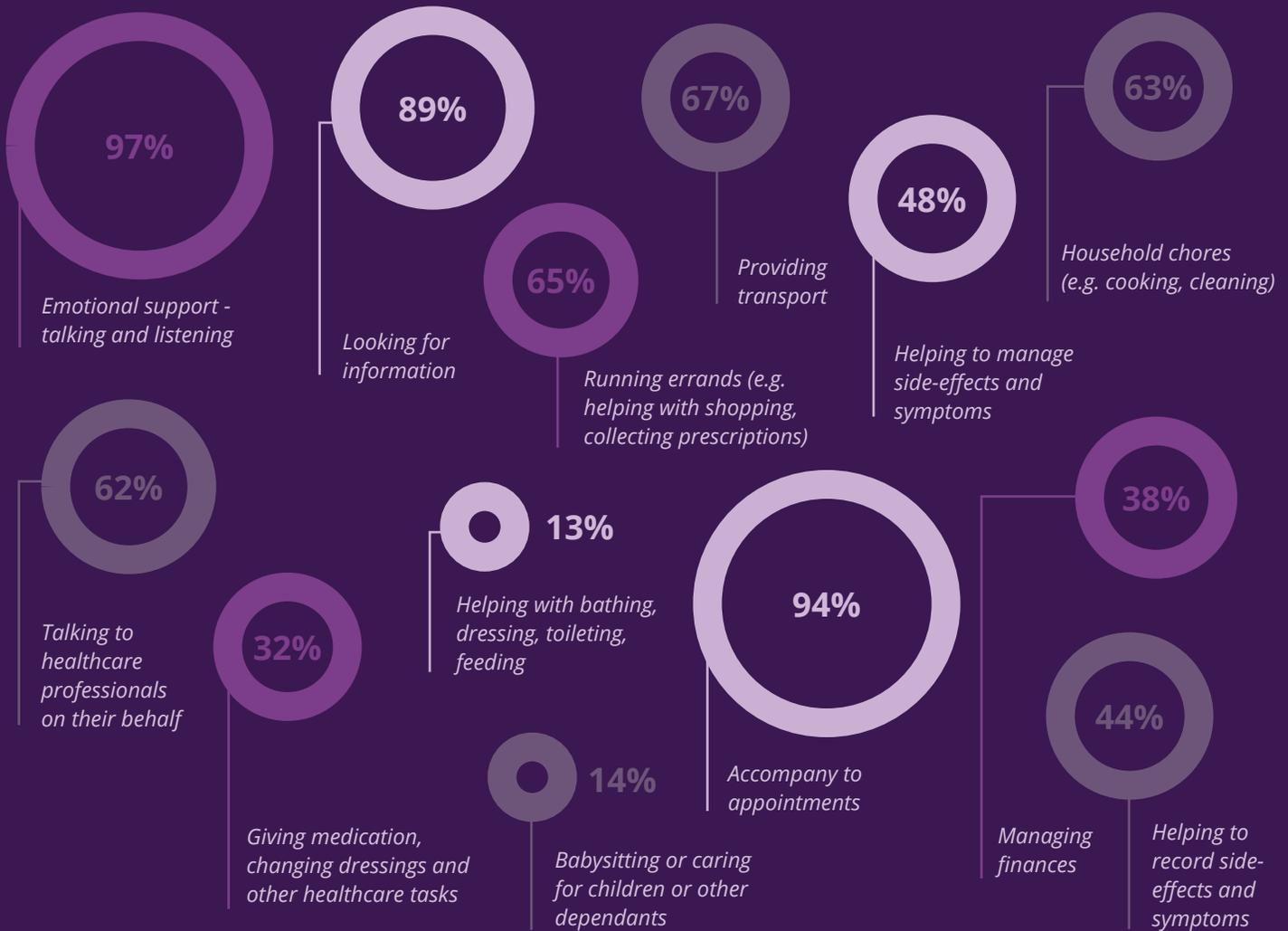
Twenty-eight percent of caregivers were involved in the care of a loved one who had experienced relapse(s).

There may be times when a person with lymphoma may require additional assistance and care - i.e. when they are going through treatment or experiencing symptoms or side effects. There also may be other times when they are relatively symptom-free and may not require much help. Canadian caregivers were asked to list the ways that they care for a lymphoma patient:

As a caregiver - how often do I ask my partner how he is doing or how he is feeling? Am I just reminding him that he has cancer? How can I get him to talk about it in a way that is productive? How can I help him accept this diagnosis. Right now, he is suffering with depression - I wish I could do more to help.

- Anonymous, Canadian Caregiver

### TYPES OF CARE PROVIDED BY CAREGIVER TO PATIENT



Of caregivers, the majority (62%) found it most difficult to provide emotional support to the lymphoma patient they are caring for.

# INFORMATIONAL NEEDS

Those who provide care for a friend/family member with lymphoma are considered to be vital members of the healthcare team. Most caregivers do not have formal training and rely to a great degree on what they learn from the healthcare team and from their own self-education.

Caregivers were asked whether the patient, caregiver, or both would seek out information about lymphoma including treatment options. The majority of caregivers (53%) responded that both the caregiver and patient work together to obtain relevant information, however, there was a large population of caregivers that sought this information for themselves (32%) and relayed it to the patient.

The patient's healthcare team can also provide support to the caregiver. As a caregiver and patient, be sure to speak to physicians, nurses, social workers, physiotherapists, occupational therapists and other members of the healthcare team.

*At no point are you alone in the caregiving journey.*

## WHO SEARCHES FOR LYMPHOMA INFORMATION?

- 32% Me (caregiver)
- 5% The patient
- 53% Me (caregiver) and the patient jointly
- 10% We don't seek additional information other than what our doctor/healthcare staff tell us, as they are the experts



We go together to every medical appointment each of us has, eye examinations, oncologist, nephrologist, endocrinologist... two pairs of ears are better than one. And sometimes, when it is something serious, one of our children comes along to write a report to the siblings.

- Anonymous, Canadian Caregiver



# PHYSICAL AND PSYCHOSOCIAL IMPACTS TO CAREGIVERS

A caregiver may be so focused on the person they are caring for that they forget to take care of themselves. It is important to pay attention to your own health and well-being while you care for the person with cancer. Self-care also benefits those around you.

Canadian caregivers were asked to what extent the following issues affected them in the past 12 months. Impacts to caregivers that occurred more frequently (sometimes, often or always) included being worried/anxious (89%), being emotionally tired/worn out (71%), putting the needs of the lymphoma patient above their own as a caregiver (68%), being sad/depressed (66%), and sleeping difficulties (64%). Patients listed the many ways they are impacted financially, socially, physically and emotionally:

## TIPS FOR LOOKING AFTER YOURSELF

- + Look after your health.
- + Make time just for you and take breaks
- + Make time for other family members
- + Try to live in the moment and take things one day at a time rather than thinking about the future
- + Consider respite care when you need a break from caregiving.

## IMPACTS ON CAREGIVERS EVERYDAY LIFE



### Financial Impacts

Taking time off work to care for the person with lymphoma/CLL



Paying for childcare because me and/or the person with lymphoma/CLL are focused on their cancer care



Encountering difficulties in administrative tasks (health insurance paperwork and other paperwork related to the illness)



Paying for a professional caregiver for the person with lymphoma/CLL



Financial hardship because my work hours are reduced



### Emotional Impacts

I get upset that my life will not be as planned



Been worried, anxious



Been emotionally tired and worn-out



Experienced feelings of guilt



PTSD (post traumatic stress disorder)



### Physical Impacts

Been physically tired, worn out



Sleeping difficulties



### Social Impacts

My children find it difficult living with someone with lymphoma/CLL



Changes in my relationship with the person with lymphoma/CLL that I care for



Getting frustrated with the person with lymphoma/CLL



Been sad, depressed



Been stressed



Fear that the person with lymphoma/CLL will relapse



Poor health because all my energy goes into caring for the person with lymphoma/CLL



Changes in my personal relationships e.g. with my partner, friends or family



Always putting the needs of the person with lymphoma/CLL above my own

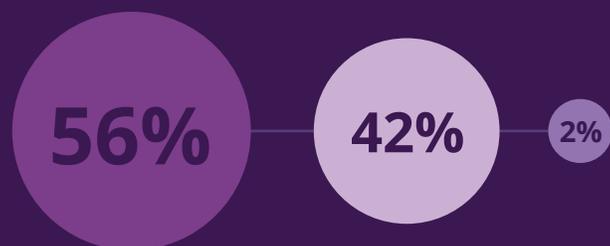


Caregivers identified that they were most affected emotionally when caring for someone with cancer. This was followed by the effects that their role had on the relationship with the person they are caring for and social interactions with others, as well as their own personal well-being. It is important to note that caregivers also have specific needs that should be addressed by healthcare professionals.

Caregivers were asked about their interaction with the healthcare team:

### CAREGIVER RELATIONSHIP WITH HEALTHCARE STAFF

*I have been satisfied with information given by healthcare providers (doctors and nurses)*



*I have felt assisted, supported, understood by healthcare staff*



*I have felt that my role as caregiver is recognized by healthcare providers (doctors and nurses)*



Yes, definitely
  Yes, to some extent
  No



I am impressed by how much time the staff spent/spend with us. A GP [general practitioner] visit is 5 - 15 minutes and often leave unsatisfied. When we see my husband's cancer team they have all the time in the world for us. Information is provided and guidance through areas such as chemo side effects... I am amazed and respect these professionals.

- Anonymous, Canadian patient



I am very blessed and pleased with the support we receive from the health care community. They lift our spirits and the knowledge they have provides a reassurance for us both as we continue with the treatments provided by a drug trial.

- Anonymous, Canadian patient





# YOUR FEEDBACK; OUR GOALS

## Summary and Data Trends

The 2020 Report card provides valuable information from Canadian patients and caregivers from various age groups, locations across Canada, and specific lymphoma subtypes. 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 lymphoma community across Canada.

# KEY FINDINGS FOR CANADIAN LYMPHOMA PATIENTS

## Pre-Diagnosis Symptoms

- + Twenty percent of patients that experienced fatigue as a symptom or side effect were significantly affected in their day-to-day life and did not speak to their doctor about it. The top reason for not discussing their fatigue was the belief that their doctor could not help.
- + Patients communicated with family/friends (59%) about their symptoms, while only 23% of patients communicated their challenges with symptoms to their doctors.
- + Top lymphoma symptoms lasting more than eight years included fatigue, skin rashes/lesions, and easy bruising/bleeding.
- + Symptoms have negatively impacted patients' everyday activities (54%) and have a negative impact on patients' social lives (48%).
- + Coping mechanisms used to help with fatigue included balancing time schedules (59%) and exercise programs (47%).

## Diagnosis

- + Forty-six percent of patients received their diagnosis less than three months from the time they presented their doctor with symptoms; however, there were 14% of patients that received a diagnosis of more than 12 months from the time they presented their General Practitioner with symptoms.
- + Nine percent of patients that received a lymphoma diagnosis, did not know that they had received a diagnosis of cancer.
- + There was a population of patients (19%), that reported not being told their lymphoma subtype at diagnosis.

## Treatments & Clinical Trials

- + Thirty-one percent of patients received a second opinion regarding treatment for their lymphoma, with 8% of patients switching their doctor as a result; 13% of patients did not get a second opinion but wanted to.
- + The majority of patients (97%) were confident in the doctors that were treating them.
- + The large majority of patients (92%) have not participated in a clinical trial. Reasons for not accessing a clinical trial included not 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 patients include fatigue (74%), numbness/tingling of limbs (44%), and hair loss (41%). Following treatment, side effects that were experienced for over eight years included numbness in limbs, and cognitive issues such as lack of concentration and loss of memory.
- + The majority of patients discussed their side effects with their clinician, however 24% did not discuss the full extent of their side effects.
- + Seventy-five percent of patients were able to receive help from their doctor for their side effects, while 24% of patients did not feel that their doctor was able to help with their side effects.
- + Side effects have had a negative impact on patients' ability to perform everyday activities (52%).

## Quality of Life (QoL)

- + Patients have had their physical activity, emotions and mood, social activities and relationships affected by their fatigue symptom and side effect.
- + Seventy-five percent of patients have had aspects of their lymphoma impact their QoL in the last 12 months, including fear of progression/relapse, anxiety/depression, and concerns about body image/physical appearance.
- + Patients discussed emotional impacts (anxiety/depression/fear of recurrence) with their doctor, however they were not as inclined to discuss changes to their relationship with family/friends.
- + Reasons patients did not discuss lymphoma's impact on their QoL with their doctor included thinking it could be handled on their own, not believing it was a big deal, and not wanting to bother their doctor.
- + For most concerns (such as loss of self-esteem, body image concerns, isolation, etc.), patients either did not speak to anyone 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 lymphoma patients.

## Relapse/ Recurrence

- + Twenty-nine percent of respondents have had a relapse (17% just once, 12% more than once).
- + Nineteen percent of patients have experienced a fear of relapse and have ruminated about their cancer returning, examined themselves for physical signs of cancer recurrence, and have thoughts about dying.
- + Coping mechanisms used to manage fear of recurrence included exercise programs (48%), mind-body interventions (33%), or none (27%).
- + Twenty-seven percent of patients did not use any coping mechanisms to help manage their fear of recurrence.

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

- + Eighty-three percent of patients are confident that they can manage their health care day-to-day.
- + When managing health problems in particular, 19% of patients were not confident that they could manage their symptoms and side effects day-to-day.
- + Twenty-one percent of patients wait until health issues can no longer be ignored before they seek help from their healthcare team.

## Information, Decisions, Support

- + Ninety-two percent of patients were involved in their own care, however, 7% of patients were not but would have wanted to be.
- + When asked about managing their health, 21% of patients felt overwhelmed.
- + The majority of patients had good conversations with their doctor (76%), sought clarification when they did not understand (93%), and were confident in sharing information with their doctor (83%).
- + Decisions for patients about their health care were influenced most by their healthcare providers (76%).
- + Patients need for information was greatest within the first month following diagnosis (52%).
- + Thirty-five percent of patients were not provided with enough information at diagnosis and wanted more information on treatment options (55%) and their diagnosis and what it means (51%).
- + Patients received enough support from doctors (83%) and family/friends (87%), however, there was a percentage of patients that did not receive enough support emotionally (22%) or practically (13%).

# KEY FINDINGS FOR CANADIAN CAREGIVERS

## Care for Patients

- + Caregivers have been providing support for individual(s) with lymphoma/CLL from 2-5 years (25%) and 5-10 years (24%).
- + Twenty-eight percent of caregivers were involved in the care of their loved one who had experienced relapse(s).
- + Caregivers provided help to patients emotionally (talking/listening) (97%), accompanied patients to their appointments (94%), and looked for more information (89%).
- + Majority of caregivers (62%) found it difficult to provide emotional support for the patient they were caring for.

## Impacts to Caregivers

- + Caregivers were affected emotionally while caring for a lymphoma patient, including being worried/anxious (89%), emotionally tired and worn out (71%), and sad/depressed (64%).
- + Caregivers put the needs of the lymphoma patients they care for above their own needs (69%).

## Information Needs

- + Majority of caregivers (53%) indicated that both the patient and caregiver work together to obtain relevant information; 32% of caregivers seek this information themselves and relay it to the patient.
- + The majority of caregivers have been satisfied with information provided by the healthcare team (56% definitely, 42% yes to some extent, 2% no).
- + Sixteen percent of caregivers have not felt that their role as a caregiver is recognized by healthcare providers, and 10% have not felt assisted/supported or understood by family/friends.

## OUR GOALS

You've spoken – we listened. This report card on lymphoma patient and caregiver experiences, highlights the need for more information and support to be provided throughout every stage of the lymphoma 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 patients with a lymphoma diagnosis. Together as a community we will improve the overall patient and caregiver experience.

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

### OUR MISSION

**Empowering 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 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 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 research. Your donation will directly impact the life all many Canadians with a lymphoma 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 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. 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)



LYMPHOMA  
CANADA

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



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