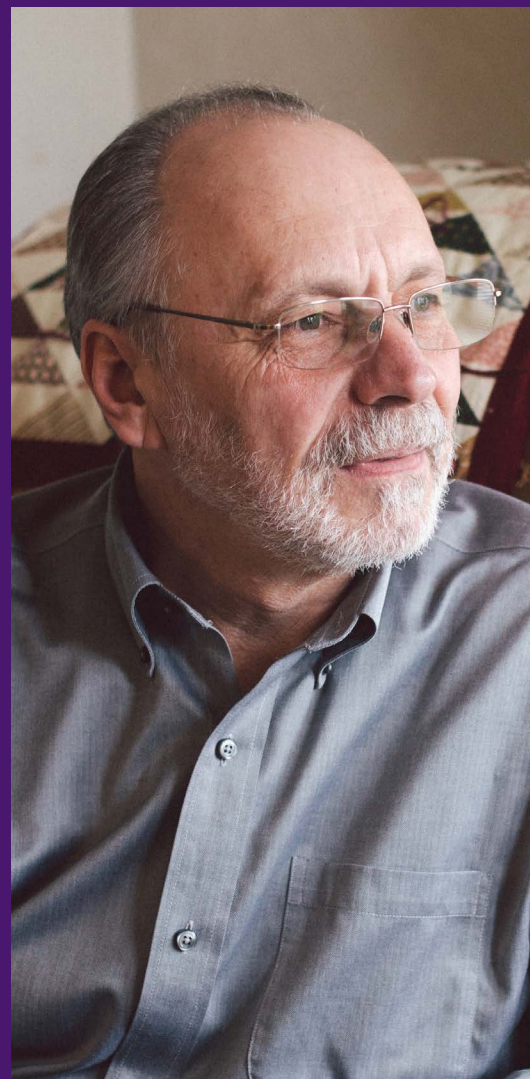
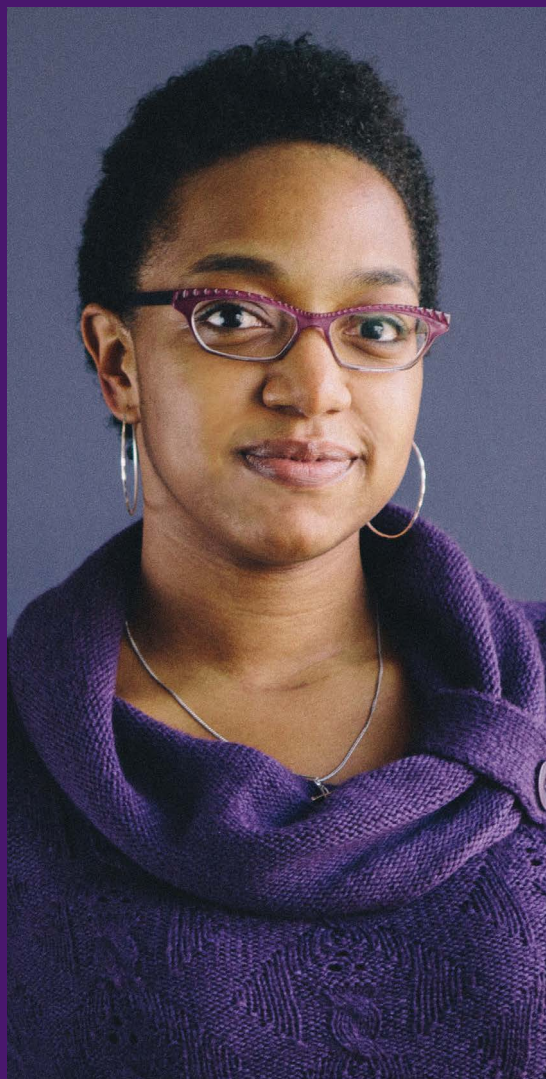


Lymphoma Report Card 2013



We've Listened and Learned:
Where Do We Go From Here?



LYMPHOMA
CANADA

CONTENTS

<i>We've Listened and Learned</i>	3
Respondent Profiles	4
Before the Diagnosis	6
<i>Staying Positive Through the Battle</i>	7
Diagnosis	8
<i>In Sickness and in Health</i>	9
Treatment	11
Well-Being and Quality of Life	12
<i>Navigating Through the World of Clinical Trials</i>	13
Patient Services and Support	14
<i>Lymphoma Canada Empowers Through Education and Support</i>	15
<i>Where Do We Go From Here?</i>	16

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The Lymphoma Report Card 2013 provides general information to the lymphoma community based on a survey that was conducted in 2012 with patients across Canada.

Several years ago Lymphoma Canada felt it would be important to survey patients, family members, healthcare professionals, and volunteers in the lymphoma community.

While our daily work with lymphoma patients and families across Canada helps to connect and inform us of the issues facing the lymphoma community, we felt the only way to be clear was to ask you. Your responses have allowed us to create this "We've listened and learned: Where do we go from here? Lymphoma Report Card 2013," a summary that will help inform, educate, and bring awareness to the important realities facing the lymphoma community today.

We could not have accomplished this without your participation and expertise. 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. Thank you for your participation and partnership with Lymphoma Canada.

ABOUT LYMPHOMA CANADA

We are Canada's only national organization focused entirely on lymphoma.

Lymphoma affects many people, from patients, family and caregivers, to medical professionals and researchers. Lymphoma Canada connects and empowers this community through education, support, and research. Together we are promoting early detection, finding new and better treatments, helping patients access those treatments, learning lymphoma's many causes, and finding a cure.

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WE'VE LISTENED AND LEARNED

In the fall and winter of 2012 we conducted an anonymous survey of lymphoma patients.

The respondents were recruited online, through email and social media. Some respondents were referred by their specialists and others were contacted through direct mail.

We received responses from all over Canada and patients of varying demographic backgrounds. The results were translated into graphs and statistics to give the general public, patients, and medical professionals a better understanding of lymphoma and the implications of a lymphoma diagnosis.

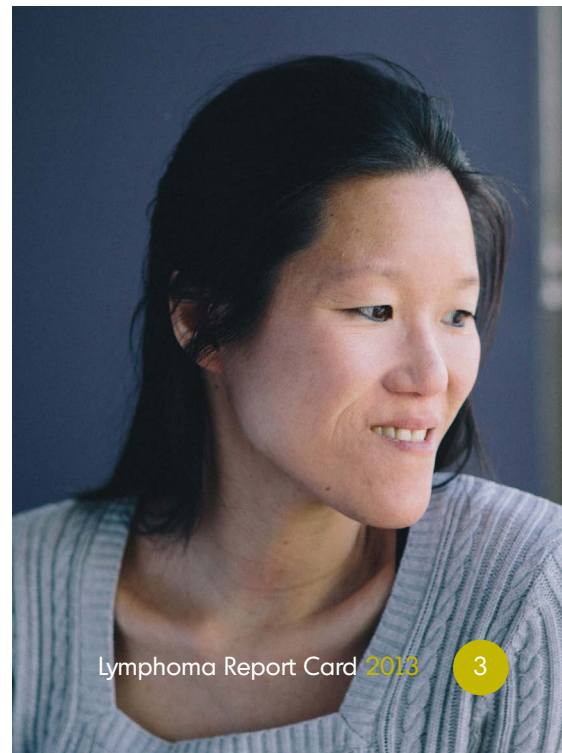
The information in the subsequent pages suggests that lymphoma is a vague disease. While the breadth of knowledge is continuing to grow, there is still a lot we don't understand and there are definite obstacles that need to be hurdled.

The medical community has made many strides in the past few years in helping those with the disease—through clinical trials and the introduction of innovative treatments.

Yet, even with these advancements and in spite of the fact that lymphoma is the fifth most common cancer in Canada, it remains a little known disease. Our survey showed that 60 per cent of respondents were initially diagnosed with something other than lymphoma. Close to half of those who participated had two or more diagnoses before discovering the cause was lymphoma.

One of the reasons for the length of time it can sometimes take to diagnose a patient is that the symptom presentation can be similar to common ailments like the flu. Such symptoms include fatigue, night sweats, and persistent cough. 39% of those surveyed had to wait longer than five months to receive a proper diagnosis.

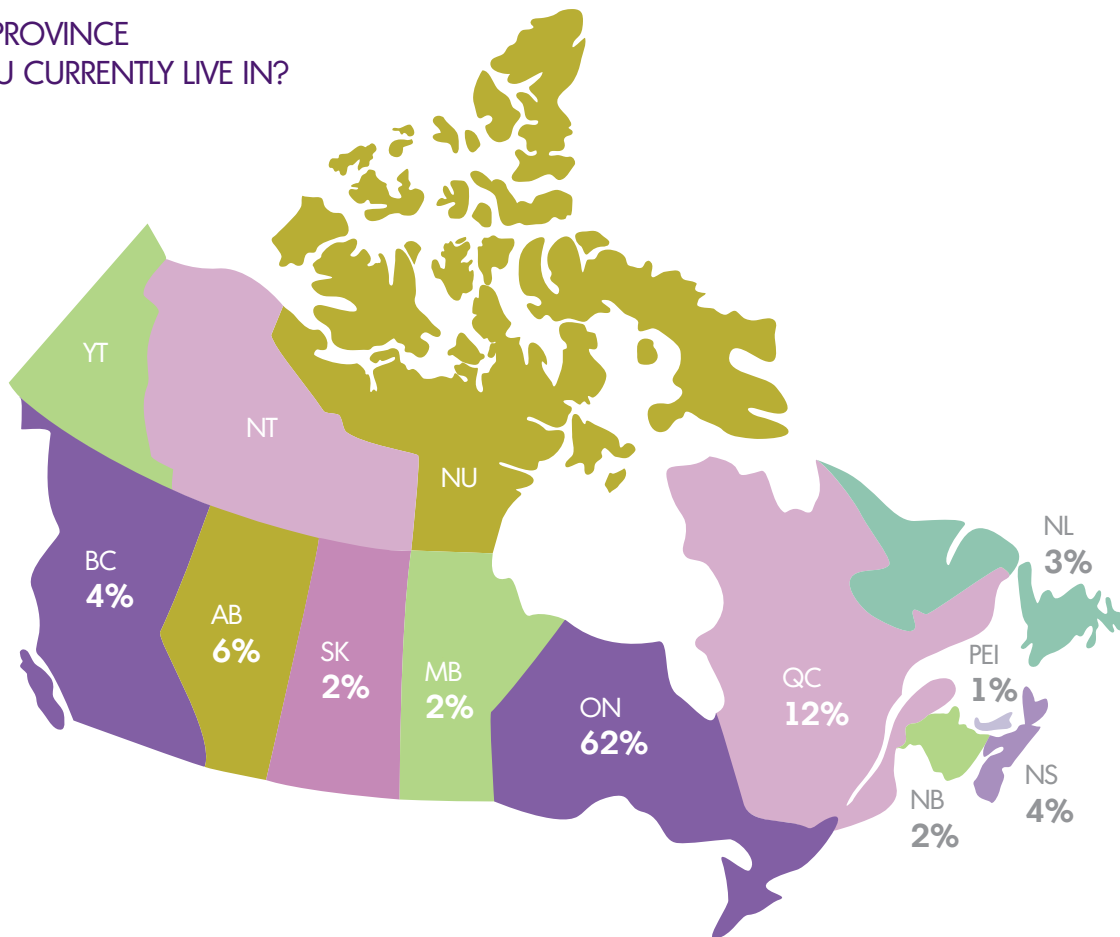
Clearly, more needs to be done to raise the level of awareness. And the problem doesn't stop there. The same survey results showed that gaps exist after diagnosis as well. Patients and their families are asking for more information and support across the board. Whether it is pre- or post-diagnosis, it is clear that we need to put a spotlight on lymphoma. This is a task we can accomplish together.



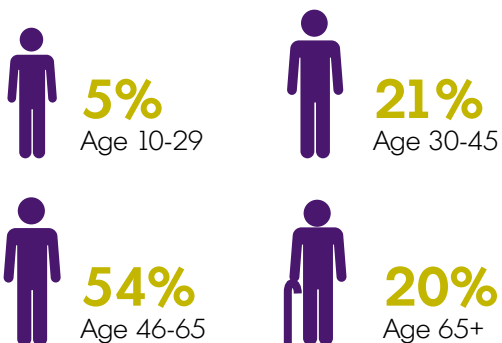
RESPONDENT PROFILES

The people who responded to the survey came from different stages of the lymphoma experience.

WHAT PROVINCE DO YOU CURRENTLY LIVE IN?

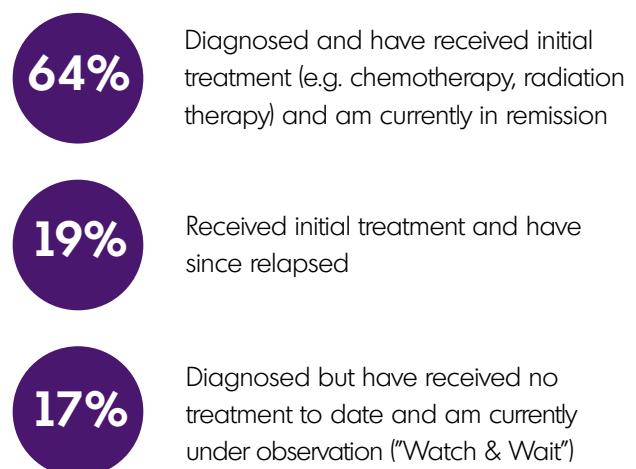


HOW OLD ARE YOU?



More than 1/4 of those surveyed were 45 years old or younger

WHAT BEST DESCRIBES YOUR TREATMENT STAGE?



HOW LONG AGO WERE YOU DIAGNOSED?



HODGKIN LYMPHOMA VERSUS NON-HODGKIN LYMPHOMA

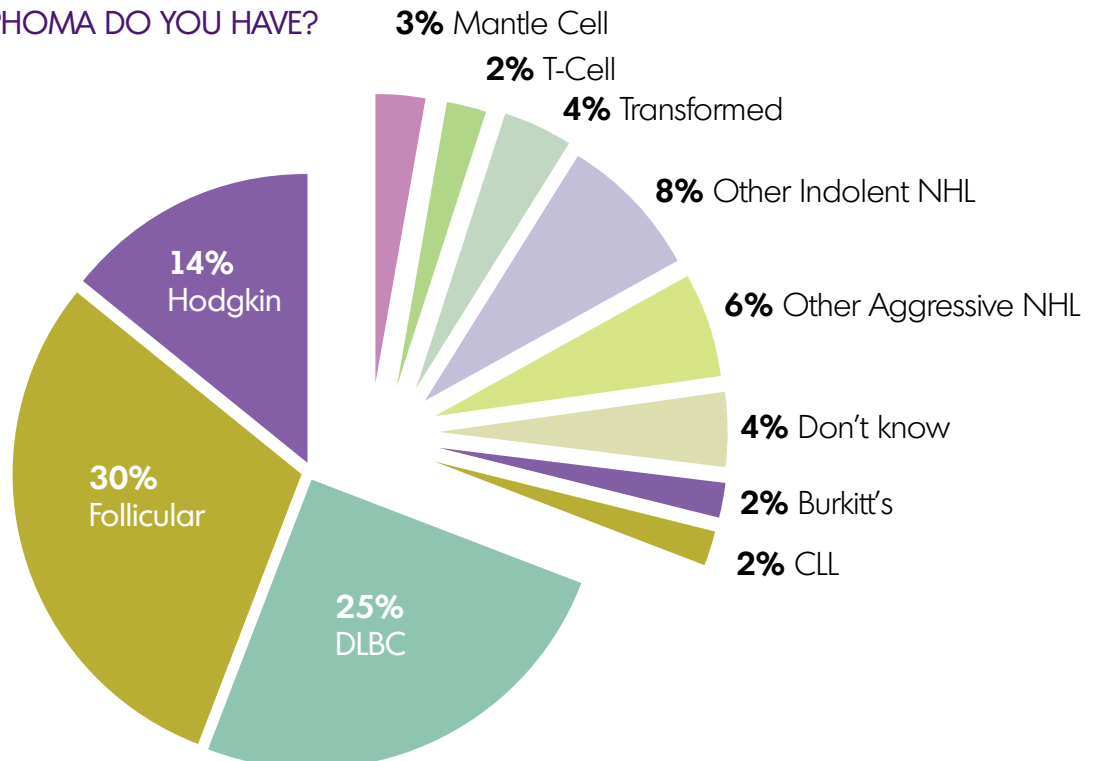
Hodgkin lymphoma (HL)

- The presence of a Reed-Stenberg cell along with other features characteristic of Hodgkin lymphoma
- HL is less common than NHL, occurring about one-tenth as often
- Has a high survival rate

Non-Hodgkin lymphoma (NHL)

- No Reed-Stenberg cell
- NHL is a group of about 50 closely related cancers that represent 89% of Canadian lymphoma patients
- Not necessarily curable but treatment can often provide long cancer-free periods, reduced symptoms and improved quality of life

WHAT TYPE OF LYMPHOMA DO YOU HAVE?



BEFORE THE DIAGNOSIS

We wanted to discover what it was like for a lymphoma patient before he or she was diagnosed. We gauged the extent of lymphoma knowledge and found the following:

HOW MUCH DID YOU KNOW ABOUT LYMPHOMA PRIOR TO TREATMENT?



Almost a 1/3 of the population did not know lymphoma was a type of cancer

12%

I had never even heard the word 'lymphoma'

16%

I had heard the word 'lymphoma' but did not know what it was

34%

I understood it was a type of cancer

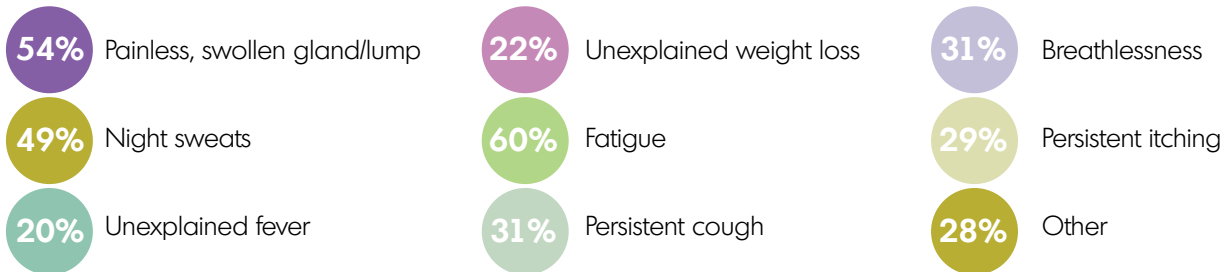
34%

I understood it was a cancer of the lymphatic system

4%

I had an in-depth understanding of lymphoma

SYMPTOMS FELT

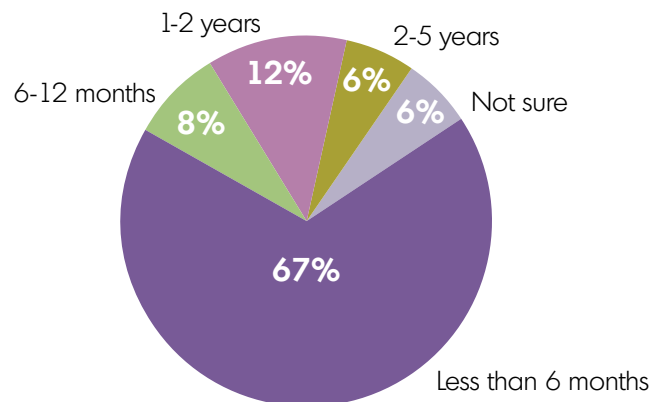


Many of those surveyed said that not feeling well and the discovery of a lump were two of the more common symptoms that prompted them to seek medical attention.

WHAT PROMPTED YOU TO GO TO THE DOCTOR?



HOW LONG DID YOU WAIT TO GO TO THE DOCTOR?



18% of respondents waited between 1 and 5 years before seeking medical consultation for their symptoms

STAYING POSITIVE THROUGH THE BATTLE

Ryan Leal was at the prime of his life, but a persistent itch changed things forever.

Ryan Leal considers his battle with Hodgkin lymphoma (HL) a secret blessing. He discovered the importance of perseverance and maintaining a positive attitude.

“Over the course of the fight I had so much time to reflect and self-motivate about what I wanted in my life. I set so many goals and stopped looking at life as though I have forever to do all the things I want,” says Leal.

Ryan was diagnosed right after his 24th birthday. He was at the prime of his life, enjoying his days and going out with friends. “I had just graduated from Brock University and I had my first real job, no responsibilities, and a huge appetite for good times,” says Leal.

As a young and physically active individual, Ryan never thought he’d have to worry about cancer. “I didn’t know too much about the disease...and I never thought I’d get it either... I had heard of Hodgkin disease because of Mario Lemieux and non-Hodgkin because of Saku Koivu since I am a huge hockey guy.”

One of Ryan’s earliest symptoms was feeling tired all the time. “I just thought that’s how everyone was at that stage of life because we were just partying so much, it made sense to be tired,” says Leal.

Later on Ryan developed an intense itching sensation all over his body, “I was scratching my legs, feet, back and generally all over sometimes to the point of drawing blood.”

Ryan could not figure out why this was happening to him. Frustrated and confused he changed his laundry detergent thinking something in the soap was reacting with his skin.

When the itching continued, he tried different creams and was even tested for allergies, all with negative results.

“I remember telling my mom that I think I needed to see a shrink because if nothing was wrong physically then obviously it was all in my head,” says Leal.

Around the time the fatigue and itching began, Ryan noticed a lump under his collarbone. He dismissed the lump and thought it was a swollen gland, “I didn’t make a big deal of it at first but then it kept growing and I started to take notice.”

His lump became larger and he found another one under his armpit. Ryan knew something was wrong and that he needed to see a doctor.



Ryan Leal

“When I saw my doctor and told him about the itching and the lumps, the look on his face told me all I needed to know,” says Leal.

After a series of tests, Ryan was formally diagnosed with HL and was told that the cancer was advanced. “I had Stage Three,” says Leal.

Leal was treated by oncologist Dr. Michael King, at Trillium Health Centre in Mississauga where he underwent a nine month chemotherapy regimen. He was administered ABVD which is a first-line treatment of Hodgkin lymphoma.

Ryan didn’t want to be treated differently by family or friends so he decided to continue on with his normal routine. “I worked out throughout treatment more than I ever had in my life. I didn’t want to look sick... I rested when I needed to but I tried to continue playing hockey and doing things I enjoyed,” says Leal.

Ryan believes that half the battle is mental. Maintaining a positive attitude and not giving up was key to his recovery.

“There are two types of people, there are the fighters and those who have already lost; I was going to be a fighter,” says Leal.

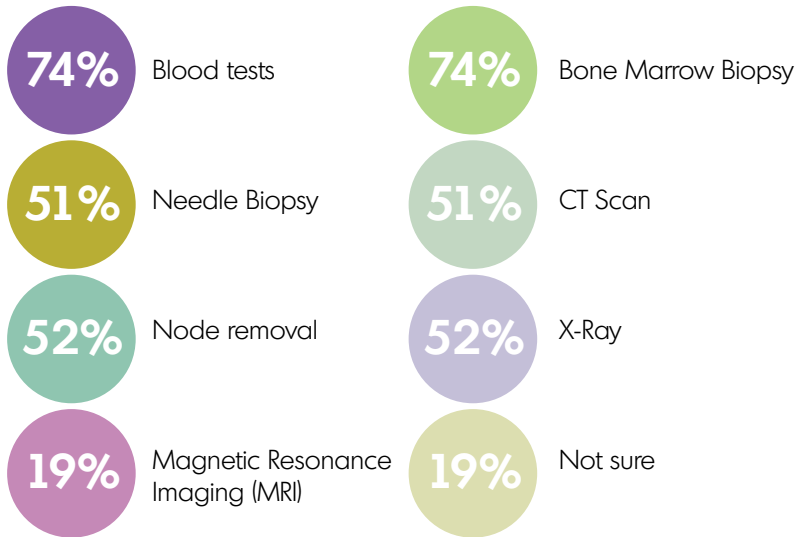
Ryan beat the disease and is now cancer free. He says that living through the experience changed his life, “I grew up and decided to make goals for myself.”

Today, Ryan is the founder and president of Canada Connect Sales. His company helps American companies establish themselves in the Canadian market. He is also a partner in Underground Golf Apparel, a unique brand that brings Californian influence to the golf course.

DIAGNOSIS

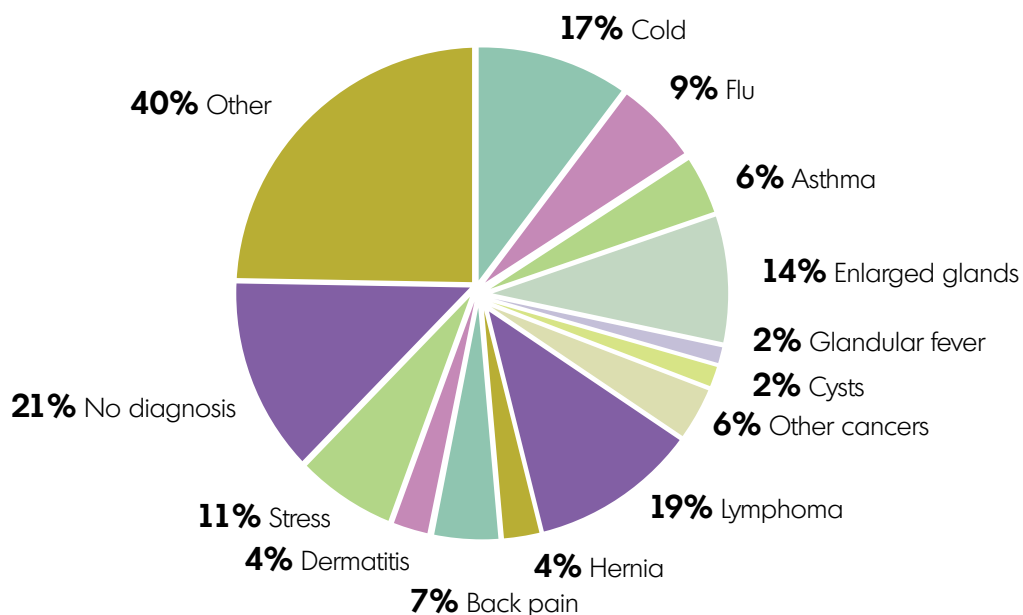
For someone to be diagnosed with lymphoma, a person must go through a series of diagnostic tests. Our survey respondents listed the following as tests that were prescribed by their doctor:

INITIAL DIAGNOSTIC TESTS



of respondents had 2 or more diagnoses before an official diagnosis of lymphoma

RESPONDENTS' INITIAL DIAGNOSES INCLUDED THE FOLLOWING:



60% of participants were initially diagnosed with something other than lymphoma; only 19% were diagnosed with lymphoma right away

IN SICKNESS AND IN HEALTH

Amy Maraone's doctors told her she had pneumonia but she and her husband knew they were wrong.

Amy Maraone and her husband Tom Fabry had only been married for one year when they received news that would change their lives forever. Maraone had lymphoma.

"We definitely got the 'sickness and in health' part out of the way," she says with a laugh.

She describes that time as frustrating for both of them. Eight months of living in the unknown, to be exact.

It all started when Maraone thought she had a cold. She had a cough and was feeling tired and went to the doctor to see what was wrong. Pneumonia was the first diagnosis. She took antibiotics as the doctor had ordered, but they didn't work.

"I had a cough—a non-stop cough, probably until I was diagnosed," she says.

Five specialists and numerous diagnostic tests including needle biopsies and a bronchoscopy weren't enough to diagnose Maraone with something concrete. Specialists said she had a lung disorder and others speculated tuberculosis.

"I've said it many times and I would happily say it again, I would thank (my family) for all the support and for really being a champion for me...at times when I couldn't be one for myself."

But one night Maraone started coughing up copious amounts of blood. She was rushed to the emergency room and once again, tests showed that nothing was wrong.

"When (the doctor) came back and said I had pneumonia that's when my husband went 'WOAH!'," she says.

She describes the anger her husband was feeling having not received a definite answer yet again. Adamantly, he asked the doctor if he was sure that pneumonia was the culprit.

"(The doctor) turned to us and said, 'I do this for a living, I think I know what I'm talking about.' That's when we were just about to punch him," Maraone recalls.

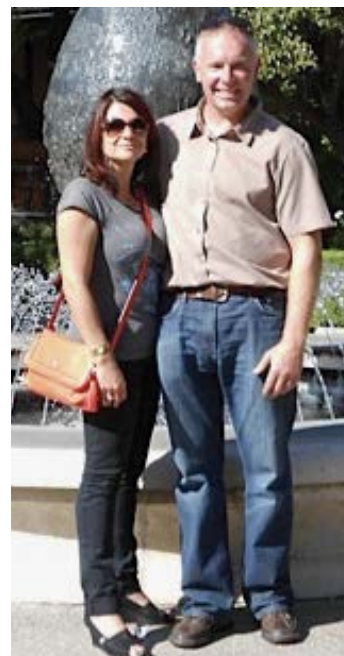
Her husband's persistence finally led to an official diagnosis. The doctor in the ER called the on-call specialist, who admitted Maraone and ordered for a series of tests including surgery.

In that surgery, doctors found a tumor in her lungs and diagnosed her with a rare type of lymphoma called Pulmonary Hodgkin lymphoma. No longer could physicians credit Maraone's eight months of suffering to pneumonia.

This was roughly 11 years ago. Maraone is now cancer free but lymphoma will always remain a part of her.

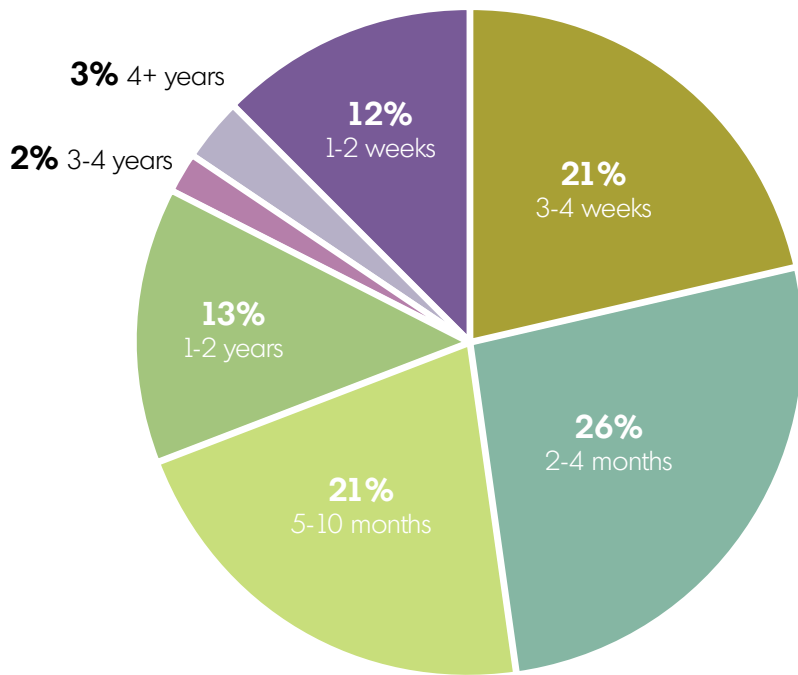
"Sometimes it feels like it's been 20 years, sometimes it feels like it's been a month," she says.

"There's always that fear that it could come back, but otherwise I am free and clear."



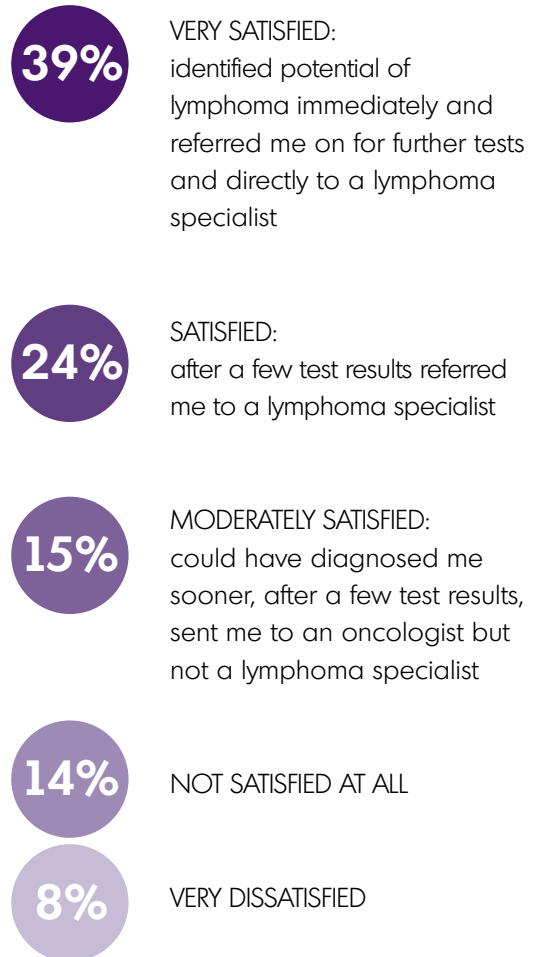
Amy Maraone and Tom Fabry

HOW LONG DID IT TAKE TO BE ACCURATELY DIAGNOSED WITH LYMPHOMA?



39% of the people surveyed had to wait longer than 5 months for an accurate diagnosis

WERE YOU HAPPY WITH THE INITIAL MEDICAL CARE YOU RECEIVED DURING DIAGNOSIS?



DID YOU GET A SECOND OPINION?



74% No 24% Yes 2% Not sure

About a quarter of patients sought a second opinion

TREATMENT

The next stage of the lymphoma patient's journey is to examine treatment options.

WE ASKED ABOUT PATIENTS' INITIAL TREATMENT PROTOCOL.



73%

Intravenous chemotherapy



25%

Watch and Wait



1%

Oral therapy



1%

Topical medication

WERE THE PROS AND CONS OF DIFFERENT TREATMENT OPTIONS DISCUSSED?

51%

Options were not discussed

21%

Extensive discussion of options

27%

Some discussion of options

1%

Do not recall

WERE ANY UNFUNDED TREATMENT PLANS SUGGESTED BY YOUR DOCTOR?



YES

9%



NO

91%

WELL-BEING AND QUALITY OF LIFE

THE FOLLOWING BARRIERS WERE IDENTIFIED AS PART OF THE LYMPHOMA EXPERIENCE:



43%

Financial struggles



43%

Access to most up to date therapy



36%

Medication and/ or treatment not available in Canada



36%

Wait time to treatment was too long



21%

Treatment not funded at my hospital

RESPONDENTS REPORTED THE FOLLOWING CHALLENGES TO THEIR WELL-BEING:

60%

Changes in relationships with loved ones, friends, or co-workers/social life

46%

Stresses related to financial issues

24%

Low self-esteem

34%

Concerns about body image changes

43%

Loss of employment/reduced employment/career change/retired

30%

Difficulty on the job or in school

27%

Problems getting health or life insurance coverage

22%

Not understanding my options

22%

Difficulty working through the health system effectively

We asked the question, "HOW DID YOUR DIAGNOSIS AFFECT YOUR QUALITY OF LIFE?" Respondents reported that the following were adverse effects to their physiological health.

- Fatigue
- Sleeplessness
- Muscle weakness
- Trouble concentrating
- Aching joints
- Changes in taste and smell
- Bowel changes
- Hair loss
- Problem fighting infections
- Changes in sexual function
- Weight gain
- Memory loss

NAVIGATING THROUGH THE WORLD OF CLINICAL TRIALS

Clinical trials seem daunting and scary for many and are sometimes seen in a science-fiction light. The reality is that clinical trials are responsible for many of the successful cancer treatments we see today, but unfortunately they are often not presented as options for lymphoma patients.

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 are categorized by four phases. The goal of trials in Phase 1 is to ascertain whether a drug is safe. Phases 2 and 3 look at the effectiveness of drugs and compare new treatments to standard treatment plans respectively. Phase 4 trials analyze the safety and effectiveness of new drugs in the long-term.

Dr. Sarit Assouline is a Hematologist at the Jewish General Hospital in Montreal, QC. Assouline works in the clinical research unit of the hospital and is a strong advocate of clinical trials. She recommends them for eligible lymphoma patients.

“Even though it is an experiment, it’s not as though you are being thrown into a strange new voodoo thing and (that) nobody knows what’s happening to you,” she says.

“We know...what’s happening to you. We may not know exactly the side effects you might get but we know how to deal with them. We follow you so closely that if these things do happen we are able to catch them early and are able to deal with them.”

She adds that drugs being developed today are very sophisticated and well designed. The reduction of possible side effects is always top of mind.

Assouline says that clinical trials are a very sophisticated way of testing new drugs. “It really benefits people to have access to these (drugs) to treat their cancers.”

She says that clinical trials have given people more years of life than expected. Assouline makes the point that this doesn’t happen a lot but it does occur. “While a patient may not directly reap the rewards of a clinical trial, lymphoma patients down the line will,” she says.

The survey conducted by Lymphoma Canada found that only 14 per cent of those surveyed were approached by their healthcare professional to participate in a clinical trial.

This is a disconnect from the number of patients willing to participate in one since the same survey found that 71 per cent would participate in a clinical trial if asked (see accompanying graph).

A significant roadblock is that patients are not being asked to participate in a clinical trial or are not being referred to a hospital that conducts them. More often than not, patients are unaware of the options available to them.

For the remaining number of respondents that did not want to participate in a clinical trial, one barrier was lack of knowledge. Eighteen per cent said that they were not equipped with enough information to make a decision.

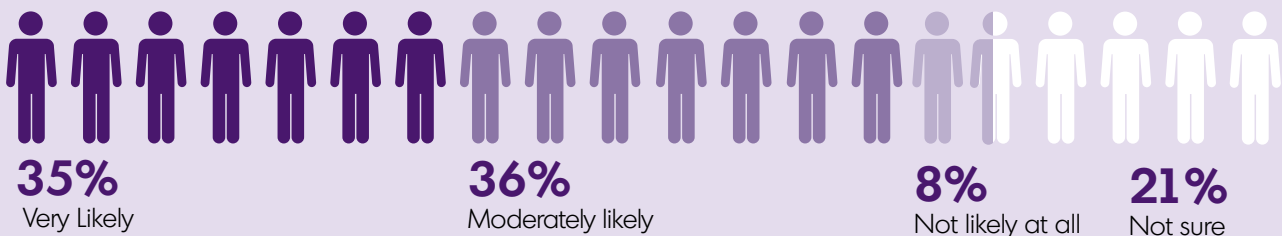
Assouline shares the following words of advice: “If offered a clinical trial, and it seems reasonable to you, I would advise people not to turn it down,” she says.

While the openness to clinical trials is high, they are not for everyone. Assouline shares some eligibility requirements:

- 1) The type of lymphoma you have
- 2) How many prior therapies you’ve had
- 3) Adequate liver and kidney function
- 4) Adequate blood counts
- 5) The existence of other conditions that the tested drug can exacerbate

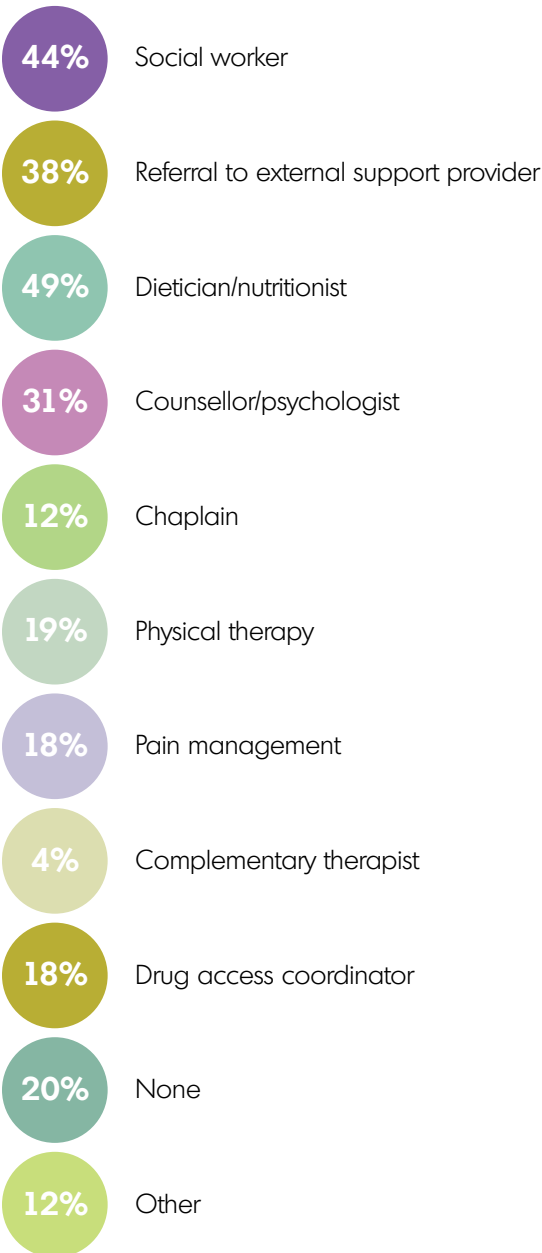
But without endorsement from physicians and with barriers to clinical trial information this may not even be an option.

WOULD YOU PARTICIPATE IN A CLINICAL TRIAL IF ASKED?



PATIENT SERVICES AND SUPPORT

RESPONDENTS WERE ASKED TO ASSESS THE SERVICES AVAILABLE TO THEM.



In many instances, patient support services were limited. 20% of those surveyed said no services were available to them

PATIENTS IDENTIFIED SEVERAL SUPPORT SERVICES THAT THEY WOULD LIKE TO HAVE AVAILABLE TO THEM.

SUPPORT SERVICES

- Support groups
- Materials on my type of lymphoma
- Clinical Trials information
- Financial support
- Telephone support
- Online informational presentations (videos/webinars)
- Online forum

EDUCATIONAL PROGRAMS THAT PATIENTS WOULD FIND USEFUL

80%

Latest lymphoma treatment overviews

48%

Interviews with lymphoma experts

63%

Patient education events featuring lymphoma experts

49%

Description of current standards of care

LYMPHOMA CANADA EMPOWERS THROUGH EDUCATION AND SUPPORT

Many respondents of our survey have experienced the benefit of support groups, with 82 per cent rating them either helpful or very helpful.

But still, respondents pointed out a number of areas for improvement. They've indicated that they're interested in more materials on specific types of lymphoma, clinical trials, and more community resources.

When asked to identify the gaps, respondents shared that they would benefit from a library of expert interviews in the form of webinars and videos, a description of current lymphoma standards of care, and overall access to a wider variety of information.

Patients are asking for more knowledge about what is happening to their bodies; they want to be champions of their own health and they want to know more about their diagnosis. Today's patients have the desire to be educated and informed, more than ever.

In fact, Amy Maraone urges lymphoma patients to do just that. She was a lymphoma patient herself and is now 11 years clear.

"The best advice I could give anyone is to be a champion for yourself. Really learn to listen to your body. You have the right to ask for second opinions; you are in charge," Maraone says.

"You have to take control of your health and ensure that you're getting the best possible care."

Lymphoma Canada agrees that empowering the individual to partner in their care will help them to better manage their own health and life care plans. It is essential for patients and their loved ones to be able to have confidence in knowing that everything that can be done is being done and that they have the best chance at a cure.

We have taken the survey results to heart, and as we listen to what patients are telling us, we are committed to improving patient education and support.

Through our Regional Connections for patients, families, and caregivers, and our numerous Living Well With Lymphoma education sessions, we are working to ensure the lymphoma community feels connected and has what they need. In our Google Hangouts, our recently updated Know Your Nodes lymphoma awareness campaign, and the upcoming education conferences, we want to be sure patients and families have access to experts, and feel equipped and informed for the path ahead.

We see change on the horizon as we advocate for national Follicular Lymphoma Guidelines, implement our new Patient Support Strategy, and work towards developing a Clinical Trial and New Treatment database.

Patients in Quebec and Nova Scotia are in the process of building their own Connection groups, with the help of Lymphoma Canada. They are motivated to come together and share their lymphoma stories; in doing so, they have found a place where they can ask questions and share tools and understanding. They have found a community. This is just one example of what we can achieve together.

Change is coming, but to achieve all that we want to achieve—all that patients want to see accomplished—we must work harder than ever and we are motivated to do just that. Together we can do more.

WHERE DO WE GO FROM HERE?

While the survey demonstrates that the national lymphoma landscape has room for improvement, Lymphoma Canada sees this as an opportunity. The survey suggests that more awareness is necessary and points to the need for a greater number of resources for people with lymphoma. Funding research will pave the way for more clinical trials and clinical trials will lead to ground-breaking treatments.

But before all of this can be done there needs to be a better understanding about what lymphoma is. Public awareness is key. With an increased understanding of their signs and symptoms, people will seek medical attention sooner. As family physicians and other frontline healthcare professionals broaden their scope of knowledge and learn more about lymphoma and its various presentations, we will begin to see earlier and more accurate diagnoses.

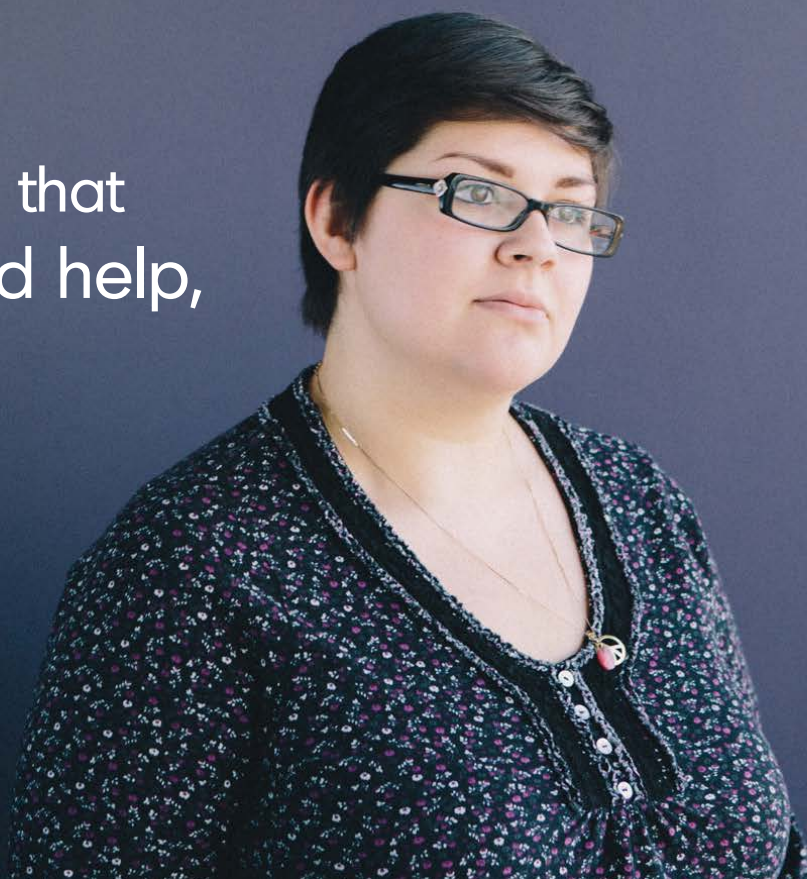
Patients diagnosed with the disease, along with their loved ones, are asking for more resources and there is a thirst for more information on specific types of lymphoma. More than half of those surveyed saw the need for a support group. Thirty-one per cent requested more information on

clinical trials and a quarter of participants would like to see lymphoma subtype-specific information. Finances are among the biggest stressors for people with lymphoma and 25% of those surveyed felt they needed some form of financial support.

The provincial governments need to act as pillars in the eradication of lymphoma. Funding of innovative drugs could treat patients who don't have the financial means of doing so. But funding and approval of life-saving treatments stems from awareness. Public advocacy, media involvement, and a broad network of supporters are necessary to ensuring patients can access the newest and best treatments for their situations.

Lymphoma Canada advocates for this change. Our mission is to empower lymphoma patients and the lymphoma community through education, support, and research. We are listening to what patients are sharing, and are taking important steps to bridge the gap, but there is still work that needs to be done. We gladly take on this necessary task and work hard to accomplish this, but your support is crucial.

If these survey results teach us anything, it is that with information and help, there is hope for a better tomorrow.





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