This resource manual is the result of generous efforts made by many individuals. A dedicated group of physicians, nurses and patients spent many hours reviewing and ensuring the accuracy and relevance of the information contained in this manual. We thank these caring individuals for dedicating their time to this important project. We especially thank Dr. Laurie Sehn, medical oncologist at the BC Cancer Agency, Dr. Harold Olney, medical oncologist and Chief of the Department of Hematology-Transfusion Medicine at Notre-Dame Hospital in Montréal, Tracey Nagy, nurse practitioner at Princess Margaret Hospital and Pamela West, nurse practitioner at the Rouge Valley Health System. Their input was invaluable. The ultimate goal of all people involved was to produce the most useful resource possible for patients with lymphoma.

Your feedback matters!
Please visit www.lymphoma.ca and let us know how we can improve this patient resource.
Being diagnosed with any type of cancer is frightening and something any person would prefer not to face. However, many people find themselves in the situation that you are in right now and are uncertain of what to do next. The good news is that there are many experienced people and resources that can help guide you on this journey.

This resource manual has been developed especially for someone like you who has been recently diagnosed with a cancer called lymphoma. Lymphoma is explained in depth and in uncomplicated language. Included is all the information you need to know right now, including an explanation of cancer, the lymphatic system and lymphoma in general. There is information on each type of lymphoma and how each one is diagnosed and treated.

It is very important for you to know that potential new treatments are being developed all the time for cancer and for lymphoma specifically. The treatment of lymphoma has advanced significantly in the last few years, giving patients with lymphoma more hope than ever before. With this in mind, review some recommended Web sites, do research at a library and talk to other people. The more you know, the more control you will have over your situation.

People need support when going through difficult times. Recruit friends and loved ones on this journey with you. Tell them what you need and how they can help. Whether it’s a conversation, a ride to the hospital, help with groceries, or better yet, going out and having fun, everyone needs help, especially when challenging situations arise. Don’t be afraid to ask for help. Friends and family can help by sharing the load.

Understand that you are not alone. Many people are also facing similar circumstances, and it is often very useful to share your experience with someone who understands, to gain insight from their experience. There are many resources for cancer in general and lymphoma specifically, including support centres, resource centres, knowledge networks and more. The more you reach out for support, the easier and less distressing this experience will be. This manual lists excellent resources for your referral and guidance.

We sincerely hope that this resource manual provides you with a thorough understanding of lymphoma. Lymphoma Foundation Canada is dedicated to providing support and information to all people with all types of lymphoma. It is our intention with the creation of this manual to arm you with the information you need to continue on your journey in a confident and empowered way.
The Lymphoma Resource Manual

How This Resource Manual Is Organized

This manual is meant to be used as a resource and reference guide for patients like yourself who have been diagnosed with lymphoma. It is organized in sections so that you can look up specific information as you need it. As such, information is repeated in various sections. This does not mean that the manual cannot be read from front-to-back. However, if you do read it front-to-back you may find the material is repetitive and not all sections relevant to your specific type of lymphoma.

A glossary of commonly used lymphoma terms appears at the end of the manual for your reference. You will undoubtedly come across many new words both in this manual and elsewhere and we have tried to include all such terms in the glossary.

The resource manual primarily describes the different types of lymphoma and how they are diagnosed and treated. It also contains useful materials to help you keep track of the various aspects of your healthcare, including information on your doctors and nurses, your medications, your treatment schedule and your symptoms. There is also a section on additional cancer and lymphoma resources that you may find useful.

How This Resource Manual Was Produced

This lymphoma manual was originally produced in February 2007 and updated in August 2009. All information is based on materials published up to and including this date. The manual was originally developed in response to the many concerns of patients with lymphoma and the questions received daily by Lymphoma Foundation Canada.

The majority of the information in this manual was gathered from major medical textbooks, published medical journals and reputable cancer organizations and Web sites. A patient focus group was conducted to understand the major gaps in lymphoma patient information and determine the main focus of the manual.

The manual was reviewed by a panel of patients, oncology nurses and medical oncologists to ensure accuracy, relevance and usefulness to patients with lymphoma.
This section contains useful records to help keep track of important information regarding your healthcare team and your personal treatment information. It may be useful for your nurse to fill out these forms with you, to ensure the accuracy of the information.

My Diagnosis .................................................................................................. 7
My Healthcare Team ....................................................................................... 8
My Drug Information ..................................................................................... 12
My Treatment Schedule and Symptom Diary ................................................. 14
My Visit Checklist .......................................................................................... 24
My Journal Pages ........................................................................................... 25
Before you begin using this record, it is very important that you know the exact type, stage and grade of lymphoma that you have. Please record that information here:

**The type of lymphoma I have is:**

**Stage:**

**Grade:**

This diagram shows the location of lymph nodes in the body. Your nurse can indicate on the diagram which of your lymph nodes have been affected by lymphoma.
My Healthcare Team

Many healthcare practitioners will be involved in your care during your lymphoma treatment. Teamwork among different practitioners is important in cancer treatment. Your cancer care team will recommend treatment options and talk to you about the choices that are available to you. Before deciding on treatment they will consider:

• The exact type, stage and grade of your lymphoma
• Your age
• Your general health status
• Any other medical problems you may have
• Your personal wishes and input.

All of this information is important in deciding which treatment option is best for you. Each practitioner is explained here to help you understand their unique roles, and how they can best help you. Please note that not all of these practitioners will be a part of your cancer care team.

Medical Oncologist:

Medical oncologists are doctors who have highly specialized training in cancer treatment. They often serve as the main caretakers of the cancer patient and coordinate treatments provided by both themselves and other specialists.

My medical oncologist:

Floor and room number:                                                                 Phone number:

Hematologist:

Hematologists (also called hematologist/oncologists or hematologic oncologists) treat diseases of the blood, including cancers such as lymphoma.

My hematologist:

Floor and room number:                                                                 Phone number:

Surgeon:

Surgeons are doctors who repair or remove a part of the body by operating on a patient. Surgery is not a common treatment for lymphoma. However, in some cases it may be helpful. Surgeons perform biopsy procedures, which are very important for the accurate diagnosis of lymphoma. Surgical oncologists (or oncological surgeons) are surgeons who have received specific training in removing cancerous tumours from the body.

My surgeon:

Floor and room number:                                                                 Phone number:
Family Doctor:

Between visits to the hospital you will often continue to see your family doctor who can give advice and further explanations of treatment. Your family doctor likely knows you better than many of these healthcare practitioners, and hence should continue to play an important part in your healthcare before, during and after your cancer treatment.

My family doctor:

Office address:  
Office phone number:

Oncology Nurse:

Oncology nurses have specific training and expertise in caring for people with cancer. They provide information and support to patients, and are often the people administering cancer treatment. You may have many different nurses; however, there may be one who is your main point of contact.

My oncology nurse:

Floor and room number:  
Phone number:

Nurse Practitioner (Advanced Practice Nurse):

Nurse practitioners are advanced practice (registered) nurses who have completed additional courses and specialized training in cancer care. They take on additional duties in diagnosis and treatment of patients and may be an important part of your cancer care team.

My nurse practitioner:

Floor and room number:  
Phone number:

Radiation Oncologist:

Radiation oncologists are doctors who specialize in using radiation to treat cancer. Medical oncologists usually specialize in chemotherapy, and radiation oncologists specialize in radiation treatment.

My radiation oncologist:

Floor and room number:  
Phone number:
**Occupational Therapist:**

Occupational therapists can help you manage your normal, daily activities. They can design and provide devices to help you regain your independence and improve your quality of life.

**My occupational therapist:**

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**Radiologist:**

Radiologists read and interpret X-rays and other imaging tests. Imaging and X-rays are an important part of the diagnosis procedure. Radiologists, who are sometimes called interventional radiologists, may also be involved in certain biopsy procedures that involve imaging studies.

**Pathologist:**

Pathologists look at the cells that were taken from the tumour during the biopsy procedure. They examine the cells under a microscope to determine if there is cancer present, and what type of cancer it is. Hematopathologists are pathologists with a specialization in blood diseases and may also be involved in your care.

**Oncology Pharmacist:**

Oncology pharmacists prepare and dispense your prescriptions for your cancer treatment. They can also help educate you about the medications, including dosage, side effects and precautions.

**My oncology pharmacist/pharmacy:**

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**Oncology Social Worker or Psychologist:**

Oncology social workers or psychologists are there to help you and your loved ones cope. They can provide support, information and resources for everyone involved.

**My social worker:**

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**Physiotherapist:**

Physiotherapists can help with the physical recovery from your illness and treatment. They can help return your level of health and fitness back to your original (pre-cancer) state.

**My physiotherapist:**

Floor and room number: 
Phone number:

**Registered Dietitian:**

Registered dietitians have special training in appropriate nutrition for specific disease states, like cancer. They can offer advice and instruction about your diet.

**My dietitian:**

Floor and room number: 
Phone number:
My Drug Information

My type of lymphoma is:

The type of treatment I am receiving is:

- Watchful waiting

- Chemotherapy (single-agent OR combination OR combined with rituximab [Rituxan®])
  Medication(s) and dosage:
  1. 
  2. 
  3. 
  4. 

- Radiation therapy
  Fields and dosage:
  1. 
  2. 

- Monoclonal antibody therapy
  Medication(s) and dosage:
  1. 
  2. 

- Radioimmunotherapy
  Medication(s) and dosage:
  1. 
  2.
- **Interferon**
  Medication(s) and dosage:
  1. 
  2. 

- **Bone marrow transplant/stem-cell transplant**

- **Experimental therapy (clinical trial):**
  - **Vaccine**
    Medication(s) and dosage:

  - **Gene therapy**
    Medication(s) and dosage:

  - **Anti-angiogenesis therapy**
    Medication(s) and dosage:

  - **Other (e.g., lenalidomide [Revlimid®], bortezomib [Velcade™], etc.)**
    Medication(s) and dosage:
    1. 
    2. 

# My Treatment Schedule and Symptom Diary

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# My Treatment Schedule and Symptom Diary

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# My Treatment Schedule and Symptom Diary

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Lymphoma Patient Resource
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My Visit Checklist

What I need to bring to my visit:

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“During my toughest time, I kept a positive outlook. I wanted to get back to school which I did and graduated. Seven years later I am cancer-free and feel great.”
— Jennifer Martin, 2005 LFC Beacon of Hope
“To climb steep hills requires a slow pace at first.” — Shakespeare
“The passion I have for life comes from the lessons I learned from living with lymphoma. I take every opportunity to do as much as I can because every day really counts and I appreciate the little things in life.” — Christina Loch, 2006 LFC Beacon of Hope
“The strongest oak tree in the forest is not the one that is protected from the storm and hidden from the sun. It’s the one that stands in the open where it is compelled to struggle for its existence against the winds and rains and the scorching sun.”

— Napoleon Hill, 1883-1970, author of Think and Grow Rich
“Stress occupied my life before my diagnosis and I couldn’t see what the important things in life were at the pace I was moving. My diagnosis forced me to slow down and really examine my life, for that I’m grateful. After my successful treatment program, I have returned to living a normal life, full-time work and the birth of a wonderful son.” — Amy Maraone, 2004 LFC Beacon of Hope
“I now feel that I live in a different world. On the outside nothing has changed, but inside, everything is different. Every day has meaning and I am determined to live that way.” — Maureen Paquet, 2006 LFC Beacon of Hope
Lymphoma describes any cancer that develops within the lymphatic system. In order to understand lymphoma, it is necessary to first develop an understanding of cancer in general as well as the function of the lymphatic system in the body.

Cancer .............................................................................................................................. 33
The Lymphatic System .................................................................................................... 33
Lymphoma ...................................................................................................................... 36
Cancer

What is cancer?

Cells make up every part of the human body: skin, hair, nails, lymph nodes, blood and body organs. Cell division is a normal part of a cell’s life cycle and is regulated by genes (segments of DNA that determine a person’s unique make-up and how their body functions). Under healthy conditions, the process of cell division is tightly controlled with numerous checks and balances in place. The definition of cancer is the abnormal, uncontrolled growth of cells.

Why does cancer occur?

This is a question that scientists have been trying to answer for a long time. One main reason that cancer may develop is due to genetic errors. There are many different genes present in all cells, and each one controls a different function in the body. When errors (called genetic mutations) occur in the genes that control cell division, the result is a cell that cannot divide normally. This results in an abnormal cell that cannot properly perform its intended function. The cells of the immune system are constantly circulating in the body to identify these abnormal cells and destroy them. However, in instances where the immune system doesn’t work properly, or if the genetic mutation is too severe, these abnormal cells remain and grow. Cancer occurs when these abnormal cells continue to grow at an uncontrolled rate. As these abnormal cells divide, they can eventually form a solid mass called a tumour. A malignant (cancerous) tumour will continue to grow at an uncontrolled rate and will eventually cause harm to other areas of the body.

The Lymphatic System

What is the lymphatic system?

The lymphatic system, a system of vessels, nodes and organs that run throughout the body, often seems mysterious and elusive as it doesn’t receive the same attention as other body systems, like the cardiovascular or digestive systems. Individuals may be aware of lymph nodes in the neck when they become swollen with a sore throat or infection.
The lymphatic system is a very important part of the body serving many life-preserving functions. The lymphatic system is a network primarily made up of:

- Lymph nodes: small, bean-shaped organs found throughout the body; and
- Lymphatic vessels: vessels which circulate lymphatic fluid (also called lymph) throughout the body.

Organs (other than lymph nodes) also considered part of the lymphatic system include:

- Bone marrow
- Thymus gland
- Tonsils
- Spleen
- Liver
- Lymphocyte accumulations in the lining of the intestinal, respiratory, genital and urinary tracts.
How does the lymphatic system work?

The lymphatic system has three main functions:

1. **To circulate and regulate fluid levels in the body:**
   
   Any excess fluid that escapes from the bloodstream is picked up by the lymphatic system and returned. This helps to prevent edema (swelling due to excess fluid) and keeps the fluid levels in the body and the bloodstream within normal limits.

2. **To absorb fats from the digestive system:**
   
   Special lymph vessels, called lacteals, are located in the lining of the digestive system where they are responsible for absorbing fat and fat-soluble vitamins from food. The fats are then transported to the bloodstream and used as needed.

3. **To defend the body against infection:**
   
   The vessels of the lymphatic system move lymphatic fluid and lymphocytes, a specific type of white blood cell, throughout the body. The lymphatic fluid, travelling through the lymphatic vessels, passes through lymph nodes, which are primarily made up of lymphocytes. The lymphocytes serve to filter the lymphatic fluid of any debris, removing bacteria, viruses and other foreign substances. This helps keep the body free of invading organisms and therefore, free of infection.

What are lymphocytes?

Lymphocytes are a type of white blood cell and are a major component of the lymphatic system. Lymphocytes are divided into two types: B- or T-lymphocytes (also called B- or T-cells), and function to fight infection and prevent disease. They are an integral part of a healthy immune system. Normally functioning B-cells transform into highly specialized cells called plasma cells in the face of infection. Plasma cells manufacture antibodies which function to fight infections. T-cells, the other type of lymphocyte, directly attack foreign invaders such as bacteria and viruses, and also kill cancer cells and rid them from the body. Lymphocytes can be found in the blood. However, the great majority of them are normally circulating within the lymphatic system.
Lymphoma

What is lymphoma?

Now that you have an understanding of the lymphatic system and cancer in general, lymphoma will be easier to understand. Lymphoma is a cancer of the lymphatic system. In lymphoma a tumour develops due to uncontrolled growth of abnormal lymphocytes. Because the lymphatic system exists throughout the body and involves many organs, there may be cancerous tumours in many parts of the body. There are two main categories of lymphoma: Hodgkin and non-Hodgkin.

Staging Lymphoma

The stage of a cancer provides information on whether the cancer has spread and the extent to which it has spread within the body. There are four stages of lymphoma, with stages I and II being limited (involving a limited area) and stages III and IV being advanced (more widespread). The stage is determined by:

- The number and location of lymph nodes affected;
- Whether the affected lymph nodes are above, below or on both sides of the diaphragm (the large, dome-shaped muscle under the ribcage that separates the chest [and/or neck] from the abdomen);
- Whether the disease has spread to the bone marrow or to other organs such as the liver.

The most common method for staging lymphoma is called the Ann Arbor Staging System, which can be summarized as follows:

<table>
<thead>
<tr>
<th>Stage</th>
<th>What It Means</th>
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<tr>
<td>I</td>
<td>The lymphoma is in only one group of lymph nodes.</td>
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<tr>
<td>II</td>
<td>Two or more groups of lymph nodes are affected but they are all either above or below the diaphragm, either all in the chest or all in the abdomen.</td>
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<tr>
<td>III</td>
<td>Two or more groups of lymph nodes are affected in both the chest and the abdomen.</td>
</tr>
<tr>
<td>IV</td>
<td>Lymphoma is in at least one organ (e.g., bone marrow, liver or lungs) as well as the lymph nodes.</td>
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Stage I  Stage II  Stage III  Stage IV

Staging lymphoma  ● = Site of lymphoma
Each stage of lymphoma may also be classified by A and B designations. Patients with a B designation have one or more of the following B symptoms:

- Unexplained weight loss of more than 10% in the six months before diagnosis
- Unexplained fever with temperatures above 38°C (100.4°F)
- Drenching night sweats.

The presence of B symptoms may be associated with more advanced-stage disease.

What is the difference between Hodgkin lymphoma and non-Hodgkin lymphoma (NHL)?

The difference between Hodgkin lymphoma and NHL is the presence of Reed-Sternberg cells. A Reed-Sternberg cell is a cell derived from a B-lymphocyte and is only present in Hodgkin lymphoma. If Reed-Sternberg cells are present when the tumour is examined under a microscope, the diagnosis is Hodgkin lymphoma. If there are no Reed-Sternberg cells in a lymphatic tumour, the diagnosis is most likely to be NHL. NHL is more common than Hodgkin lymphoma, outnumbering it by a ratio of over six to one. Of all diagnosed lymphoma cases, 85% of them are NHL.

Distinguishing between Hodgkin lymphoma and NHL is important to show different patterns of spread and that they require different treatments.

Hodgkin lymphoma and NHL will be covered separately in this manual.
Lymphoma can affect people of all ages, however, it may seem particularly devastating when it affects the young. This section of the resource has been developed especially for young adults. We encourage you to read through this section as well as the others to learn as much as you can about lymphoma. We understand what you are going through and we want to help you get through this difficult time in your life.

Here Are a Few Things You Need to Know from the Get-go ......................... 41
Where to Begin ........................................................................................................ 42
Key Issues for Young Adults .............................................................................. 43
When Treatment Is Over ................................................................................... 45
Resources for Young Adults with Cancer ......................................................... 45
So here you are – never in a million years did you think you would be dealing with this. Cancer? Me? Now? This can’t
be happening. You’re so young, it makes no sense. It isn’t fair!

The word “cancer” carries a huge weight with it – a weight that you likely took on the moment you heard your doctor
utter this word. Now you are struggling to understand this type of cancer – lymphoma – and what having lymphoma
is going to mean for your life and all the plans, hopes and dreams you’ve been working toward.

**Here are a few things you need to know from the get-go:**

1. **You are not the only one going through this.**
   Many people your age (15 to 39 years old) are dealing with this. Perhaps the most important thing you can do is to
   hook up with some of these people – via e-mail, Facebook, chat rooms, telephone, group talks – whatever. Just do it.
   Call Lymphoma Foundation Canada 1-866-659-5556 (www.lymphoma.ca) or a cancer centre or ask your doctor or
   nurse how you can get in touch with others your age. Hearing how others have dealt with this is huge. Not to
   mention hearing how others your age have tackled lymphoma head-on and won. Those are stories you need to hear.

2. **There are lots of resources for you.**
   Web sites, podcasts, books, blogs, this resource manual and more – resources that can provide you with the information
   you need right now and in the future. Most importantly, when you check out some of these sites, you will feel less
   alone, because you will know that there are others who understand. They have gone through it, or have helped
   others through it, and they understand that young adults dealing with cancer have a whole different set of concerns.
   The sooner you understand how to better navigate these concerns, the more you will feel in control of your situation.

3. **Knowledge is power.**
   The more you know about lymphoma, including the treatment options, side effects, follow-up care and particular
   information related to your specific type of lymphoma, the more you can be an active participant in your care.
   This will help you make educated decisions and feel in control. This resource manual contains a lot of detailed
   information on all of these topics. Be sure to check out the other sections to learn as much as you can.
Where to Begin

This manual is an excellent starting point and a valuable resource. It is written in layperson’s terms and aims to empower lymphoma patients by offering the information required to tackle this cancer head-on. It will help you understand lymphoma in general (see section called Lymphoma Explained) and distinguishes between the different kinds of lymphoma – both Hodgkin and non-Hodgkin lymphomas – breaking them down into simple terms (see sections called Different Types of NHL and Hodgkin Lymphoma). There are also sections outlining treatments and side effects (NHL Treatment section). Many diagrams and visual aids make the information easy to understand. The resource manual aims to empower all people who are dealing with lymphoma through information as well as resources. As such, there are sections of the manual specifically devoted to patient empowerment (Empowerment subsection found in NHL Treatment), patient resources (Resources section) and record keeping (My Records section).

Take Care of Yourself

First and foremost, take care of yourself. See your doctor, show up for all your appointments and treatments, keep track of the healthcare you receive, eat well and stay active if you can. Take on the responsibility of getting yourself well with all you’ve got. Take control of your health. You didn’t count on this, and no – it isn’t fair (not at all). But it’s here and it’s real and you’ve got to hit it full force.

Know the Issues

Read up on what the main issues and concerns are for people your age who are dealing with lymphoma. It may be worthwhile to get a sense of these issues from the outset, so that they don’t throw you for a loop down the road. Once you have a sense of this, you can seek out resources that will help you mitigate them should they come up.

Lymphoma Foundation Canada can help you determine some of these issues or discuss the best next steps to take.

You may begin by reading the following list of key issues and concerns facing young adults with lymphoma, including a brief explanation of each. Also, a list of resources follows and can be used to help you understand these topics.
Key Issues for Young Adults

Independence

- At a time in your life when you are becoming independent of family and may be living away from home (e.g., at university, working away from home, etc.), you may now need to consider moving back home as you may again need the support (physical, emotional and financial) of your parents.

Disclosure

- Deciding if and when to drop the “c-bomb” to friends and coworkers can be difficult.
- Once people know, it may change things, and it is important to try to maintain some sense of normalcy in your life.
- However, having close friends to lean on during this time can trump the need for privacy and/or normalcy.
- Telling your boss and/or coworkers can also be problematic, as you do not want your illness to affect how you are perceived in the workplace and do not want to put your career and/or healthcare benefits in any kind of jeopardy.

Isolation

- It may be hard to relate to friends as their problems now seem so small in comparison to your fight with cancer.
- It may be hard to know who to talk to or count on.
- People may act differently toward you once they know.

Relationships

- Relationships on all levels – family, friends, partners, dating – can become more complicated when you have cancer.
- However, maintaining important relationships in your life are critical to your well-being and recovery.
- Let people know how they can be a part of your life and how they can help you – they may not know.
- It may take time to find a new balance in these relationships, but working at them is an important process to tackle.
- You need people now more than ever – keep loved ones close.

Appearance

- Your appearance may change as you deal with cancer and cancer treatment.
- Your weight may change, chemotherapy could cause you to lose your hair.
- It is not vain to be concerned about these things.
Employment and Long-term Disability Coverage

- Disability insurance can replace a portion of your salary during periods when you are sick and not able to work.
- However, this can be a problem if you have only been working at your job for a short period of time, as disability benefits take time to kick in.

Inexperience with Making Major Medical Decisions

- Having to make critical decisions regarding the course of your treatment can be overwhelming.
- Signing consent forms with scary side effects can seem daunting.

Life-cycle Interruption

- You envisioned how your life was going to unfold and it did not include a battle with cancer.
- You may feel as though your life goals have been hijacked and are being held hostage by this diagnosis.
- Trying to keep up with studying, working, social life and relationships can become challenging when you are dealing with cancer and related treatments.
- Modifying your life to accommodate this new goal (treating your cancer and working toward recovery) is important and can make the process more manageable.

Fertility

- Cancer treatments can affect your ability to have children.
- While this may not be something you were ready to think about, it may be important to consider saving your sperm or eggs now so they can be used later in life to conceive a child.

Fear of Dying

- It is inevitable that with a diagnosis of cancer comes the fear of dying.
- It may seem unbelievable that you have to consider death at this point of your life and obviously the possibility is very frightening.
- It is important to know that every cancer diagnosis is different, and there are always reasons to be hopeful.
- Not all cancer patients die.

Survivorship

- While cancer is a definite hardship, it brings with it many opportunities for refocusing your life and bringing about positive change.
- Learning to embrace a new “normal” is a process that requires patience and awareness.
When Treatment Is Over

Ensure that you continue with your medical care once your cancer treatments are completed. This means keeping in contact with your medical team and attending your follow-up visits – this is crucial to your recovery and long-term survival. People in your age group have a tendency to become lax with their follow-up care, which can have detrimental effects. Again, be responsible about getting yourself well and staying well with all you’ve got. Be proactive and get checked out regularly.

Resources for Young Adults with Cancer

**Lymphoma Foundation Canada:** [www.lymphoma.ca](http://www.lymphoma.ca)
- Contains lymphoma-specific information including background on lymphoma, treatment and side effects, resources and support, as well as information for newly diagnosed patients.

**Lymphoma Association in the UK:** [www.lymphomas.org.uk/info/living-with-lymphoma.asp](http://www.lymphomas.org.uk/info/living-with-lymphoma.asp)
- This link is to their Living with Lymphoma section, from which you can download documents on various aspects relevant to lymphoma patients (not specific to young adults).

**Lymphoma Research Foundation:** [www.lymphoma.org](http://www.lymphoma.org)
- Features Web casts and podcasts on relevant topics including lymphoma-specific issues (e.g., indolent lymphoma, watch and wait), as well as more general issues for young adults with cancer, resources and support contacts.
- The resource list is a great list of on-line resources for young adults with cancer (US information).

**Young Adult Cancer Canada:** [www.youngadultcancer.ca](http://www.youngadultcancer.ca)
- A young adults Canadian site with very poignant YouTube videos featuring young cancer patients who are dealing with relevant issues.
- They also run cancer retreats for young adults.

**Lance Armstrong Foundation:** [www.livestrong.org/site/c.khLXK1PxHmF/b.4277405/k.6983/LIVESTRONG_Podcast_Series.htm](http://www.livestrong.org/site/c.khLXK1PxHmF/b.4277405/k.6983/LIVESTRONG_Podcast_Series.htm)
- This link is to the Livestrong Podcast Series for Young Adults with Cancer.
- Excellent podcasts on various topics – many of those mentioned above – featuring young cancer patients (US information).

**CancerCare:** [www.cancercare.org/get_help/special_progs/young_adults.php](http://www.cancercare.org/get_help/special_progs/young_adults.php)
- The Young Adult Program contains a link to useful information on counselling, support groups and podcasts, and offers downloadable publications including fact sheets on various topics (US information).

**Leukaemia Foundation of Australia:** [www.leukaemia.org.au](http://www.leukaemia.org.au)
- Contains useful information on counselling and support groups, as well as podcasts and downloadable publications (i.e., fact sheets on various topics).

**Leukaemia Foundation of Australia – Young Adult Program:** [www.teamrevive.org](http://www.teamrevive.org)
This section contains specific information for Hodgkin lymphoma as this type of cancer is different from those classified as NHL.

**Hodgkin Lymphoma Explained** ................................................................. 49

**Common Symptoms** .............................................................................. 50

**Diagnosis** .............................................................................................. 50

**Types of Hodgkin Lymphoma** ................................................................. 52

**Treatment for Hodgkin Lymphoma** ......................................................... 53
Hodgkin Lymphoma Explained

How common is Hodgkin lymphoma?

Hodgkin lymphoma is a relatively rare cancer. It accounts for around 0.5 per cent of all cancers and 15 per cent of all lymphomas diagnosed. Each year in Canada, approximately 900 people are diagnosed with Hodgkin lymphoma. Hodgkin lymphoma occurs more frequently in males than females in the primary age categories of young adults (15 to 39 years) and late adulthood (after 55 years).

What are the risk factors for Hodgkin lymphoma?

No one knows exactly what causes Hodgkin lymphoma.

The Epstein-Barr virus (EBV), which causes mononucleosis, may be linked to an increase in the risk of developing Hodgkin lymphoma. However, more than half of all Hodgkin lymphoma patients have no evidence of a previous EBV infection so a definitive relationship is still unclear.

In most cases, people who are diagnosed with Hodgkin lymphoma have no family history of the disease. There have been some cases, however, where a brother or sister also develops Hodgkin lymphoma but the significance of the family relationship as the primary cause is not known.

How does Hodgkin lymphoma develop?

Hodgkin lymphoma is a cancer of abnormal lymphocytes (a type of white blood cell) that infiltrates and affects the lymph nodes. Lymph tissues are connected throughout the body, providing a route for cancerous lymphocytes to travel. As a result, Hodgkin lymphoma often spreads from one lymph node to another throughout the body. Unlike other lymphomas, Hodgkin lymphoma will more often spread from one lymph node to the next in sequence, rarely skipping areas (which is more common in NHL). Hodgkin lymphoma can also spread to other areas and organs outside the lymph system.
Common Symptoms

Frequently, a diagnosis is made during a standard physical examination. Some may seek medical attention for cough and flu-like symptoms or have noted an enlarged lymph node.

Hodgkin lymphoma can present as a firm, usually \textit{painless} swelling of a lymph node, in the neck, under the arms or in the groin but is not limited to these areas. It is important to remember that most people who go to their doctor with enlarged lymph nodes do not have Hodgkin lymphoma. Swollen glands often result from an infection, however, in this case the glands in the neck are usually \textit{painful}.

Other symptoms may include:

- Recurrent fevers
- Excessive sweating at night
- Unintentional weight loss
- Persistent fatigue and lack of energy
- Generalized itching or a rash.

These symptoms are also seen in other illnesses such as viral infections. So, most people with these complaints do not have Hodgkin lymphoma. However, it is important to see your doctor if you have any symptoms that do not go away so that you can be examined and treated properly.

Diagnosis

How is Hodgkin lymphoma diagnosed?

To confirm the diagnosis, a biopsy is performed. The most definitive way to confirm the diagnosis of Hodgkin lymphoma is by way of an excisional lymph node biopsy, which removes the whole node or a section of the involved tissue.

The tissue is then examined by a pathologist and the cells are described. Many Hodgkin lymphoma patients will have the presence of a type of cell known as the Reed-Sternberg which is common for most subtypes of Hodgkin lymphoma.
Other tests your medical team may perform after the biopsy results have confirmed Hodgkin lymphoma (if not already completed) are:

- A complete medical history including symptoms
- A thorough physical examination (including lymph nodes)
- A blood work-up including complete blood count (CBC) (numbers of white and red blood cells and platelets), blood chemistry, and erythrocyte sedimentation rate (ESR)
- A total body CT scan
- A bone marrow aspiration and biopsy to determine if the bone marrow has been affected – this test may be omitted in patients with early-stage disease, normal blood counts and no clinical symptoms
- Certain medical centres may perform additional tests, such as a PET/CT scan but this is not a requirement and is not available in most centres across Canada.

Descriptions of these tests can be found on page 58 of this resource.

Prognosis of Hodgkin Lymphoma

Hodgkin lymphoma and NHL are described according to the same staging system. The stage of the cancer depends on the extent to which it has spread in the body. In stages I and II, the cancer is limited to one or two areas of the body (early stage). In stages III and IV, the cancer is more widespread (advanced stage). More information on staging can be found on pages 36 and 37 of this resource.

In addition to stage, you may also hear the letters 'A' and 'B' used to describe the stage of Hodgkin lymphoma that you have. 'B' means you have one or more of the following symptoms: weight loss, night sweats or fevers. 'A' means you do not.

There is an International Prognostic Score for Hodgkin lymphoma based on the results of various tests as well as your age and the stage of your disease. Your doctor will interpret all of these factors and give you this information if you wish.
Types of Hodgkin Lymphoma

There are two main and distinct cancers called: classical Hodgkin lymphoma and nodular lymphocyte predominant Hodgkin lymphoma. Classical Hodgkin lymphoma consists of nodular sclerosis, mixed cellularity, lymphocyte-rich and lymphocyte depleted subtypes. There are also a few patients where the cells do not ‘fit in’ to any of these subtypes. These are then considered to be Hodgkin lymphoma unclassifiable. Each type of lymphoma is described here:

1. Classical Hodgkin Lymphoma

   Nodular Sclerosis
   • 60 to 80% of patients have this type of Hodgkin lymphoma
   • More commonly seen in young adults
   • Usually involves the lymph glands of the neck and chest.

   Mixed Cellularity
   • 15 to 30% of patients have this type of Hodgkin lymphoma
   • More commonly seen in people over 50 years.

   Lymphocyte-rich
   • About 5% of patients have this type of Hodgkin lymphoma
   • Usually diagnosed at an early stage in adults (40 to 50 years).

   Lymphocyte Depleted
   • Less than 1% of patients have this type of Hodgkin lymphoma
   • Tends to be more widespread at diagnosis
   • More common in older patients and in non-industrialized countries
   • More common in HIV-positive patients.

2. Nodular Lymphocyte Predominant

   • Tends to be slow growing.

Most patients respond well to treatment regardless of the type of Hodgkin lymphoma they have. A more important consideration in the choice of treatment is how widely the lymphoma has spread in your body (i.e., the stage of the disease).
Cancer cells tend to reproduce and grow rapidly. Therefore, even though the cancer appears to be contained to one tumour or swollen gland, it has almost always spread beyond its origin. In order to kill all the lymphoma cells present throughout the body, a systemic treatment plan of chemotherapy is the preferred method.

The treatment recommended for your Hodgkin lymphoma will depend mainly on the stage determined. Early-stage Hodgkin lymphoma (stages IA and IIA) is usually treated with a combination of chemotherapy and involved field radiation. People who are prescribed this kind of treatment usually start with a short course of chemotherapy followed by a course of involved field radiation. This type of radiation treats only the lymph nodes that are enlarged and limits the damage to healthy tissue in the area. Some patients with early-stage Hodgkin lymphoma may also be appropriately treated with chemotherapy alone (depending on the response that is observed following initial therapy).

People with advanced-stage disease (stages III and IV) are usually treated with combination chemotherapy (chemotherapy involving a number of different drugs). See the sections below to learn more about chemotherapy and radiation therapy.

Other factors will also be considered in choosing the best treatment for you including your age, your general health, whether or not you have ‘B’ symptoms (explained previously), the size of your lumps and which part of your body is affected.

Research-based information gathered from hundreds of people around the world who have had Hodgkin lymphoma helps guide the doctor in recommending the best treatment for you. Remember, however, that no two people are the same. In helping you make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Chemotherapy

Chemotherapy may be used as a cure, to prevent spreading, slow growth or kill cancerous cells that may have spread to other parts of the body, or relieve symptoms. It is the use of powerful anticancer drugs that are carried through the body in the bloodstream. Chemotherapy may be taken by mouth or injected into a vein, and is often chosen when cancer is present in different parts of the body. Often, a combination of drugs is prescribed to improve the chances for success. The names of different combinations of drugs are commonly derived from the first letters of each of the drugs used. A very common chemotherapy used to treat Hodgkin lymphoma is ABVD (Adriamycin, Bleomycin, Vinblastine and Dacarbazine).

Each drug targets the cancer in a different way, so a combination of chemotherapy drugs is more effective than a single drug in destroying the lymphoma.

Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This allows the body to recover from the side effects of chemotherapy.

A typical chemotherapy regimen for Hodgkin lymphoma might involve six cycles of a combination of drugs, given over a period of six months. The actual number of cycles of chemotherapy you receive will depend on the type and stage of your Hodgkin lymphoma as well as your age and overall health.
See page 91 to learn how chemotherapy works; page 93 to learn how it is given and pages 94 to 99 to understand the side effects of chemotherapy.

**Radiation**

Radiation is used in localized areas to destroy cancer cells so they will not continue to spread. Radiation treatment is frequently used in addition to surgery or chemotherapy, and is usually applied in lymphoma through external high-energy ray beam or radioactive isotopes. Not all types of lymphoma respond to radiation treatment, therefore it will be up to your healthcare professional to determine if radiation is appropriate in your situation.

External radiation treatment is painless (similar to having an X-ray) and lasts for a few minutes. A complete course of treatment typically is five days a week for four to five weeks in an outpatient setting depending on the cancer type, tumour size and location in your body.

See page 100 to learn how radiation works and how it is given and pages 101 to 105 to understand the side effects of radiation therapy.

**Stem-cell Transplantation**

Stem-cell transplantation (also called a peripheral blood stem-cell or autologous bone marrow transplant) may be used in patients with relapsed Hodgkin lymphoma. In this type of treatment, some of your own bone marrow cells are removed before chemotherapy and given back to you afterwards. Stem cells are a group of cells within the bone marrow which are immature and grow and change into red blood cells, white blood cells and platelets. See pages 110 to 112 of this manual to learn more about stem-cell transplantation.

**Relapsed Hodgkin Lymphoma**

Finding out that your cancer has come back or relapsed can be devastating. If relapse does occur, there are usually ways of getting it back under control. These might involve using more chemotherapy or using more intensive or high-dose chemotherapy followed by a stem-cell transplant. There may still be curative options available to you. However, if your cancer is thought to be non-curable, chemotherapy and radiation may still be used to slow the growth of the cancer, prevent spreading and relieve symptoms.

Please use this resource manual to guide you through your journey. At any time please call Lymphoma Foundation Canada (1-866-659-5556) or visit www.lymphoma.ca for further support.
Being diagnosed with any cancer is often overwhelming. Learning more about the disease can ease confusion and allow you to feel more in control. This section contains general information on NHL including common symptoms and the (often complex) diagnosis procedure.

Incidence and Occurrence .............................................................. 57
Common Symptoms ..................................................................... 58
Diagnosis ..................................................................................... 58
Classifying and Grading NHL ...................................................... 59
Incidence and Occurrence

How common is NHL?

In the past 20 years the number of people diagnosed with NHL has increased significantly. Since the 1970s, the number of people diagnosed annually in Canada has almost doubled. NHL represents the fifth most common malignancy diagnosed in men and the sixth most common in women, with the incidence being approximately 39% higher in men.

What are the risk factors for NHL?

What causes people to develop NHL is not presently known. People with the following risk factors may have an increased chance of developing NHL:

- Previous infections with viruses such as Epstein-Barr virus, human immunodeficiency virus (HIV), human T-lymphotropic virus type 1 (HTLV-1) and hepatitis C
- Chemical exposure including pesticides, fertilizers or solvents
- Autoimmune diseases including rheumatoid arthritis, scleroderma and Sjögren’s syndrome
- Previous organ transplant
- Infections with certain bacteria including Helicobacter pylori
- A family history of NHL.

It is not known with certainty that NHL can be inherited through family history. Furthermore it is important to note that having these risk factors does not mean NHL will develop. Many people diagnosed with NHL have absolutely no risk factors.

How does NHL develop?

NHL can begin in any lymph node or lymph tissue found throughout the body. Tumours may involve just one lymph node or several lymph nodes at the same time. Since lymphocytes move throughout the body through either the bloodstream or more commonly the lymphatic system, any abnormal lymphocyte has a clear path to travel all through the body. This is why NHL can start in or spread to any part of the body. It is for this reason that many patients have widespread disease at the time of diagnosis.
Common Symptoms

As mentioned, NHL is the name given to a group of closely related cancers, each of which has its own unique symptoms. However, there are symptoms which are common among many types of NHL. They include:

- A swelling of the lymph nodes of the neck, underarm or groin. The swelling is often (but not always) painless and is called lymphadenopathy. This is the most common symptom of NHL;
- An enlarged liver and spleen, called hepatosplenomegaly, as well as masses within the abdomen. These may be found by physical examination in a doctor’s office;
- Fever, night sweats and weight loss. Together these three symptoms are called B symptoms. Not all patients with NHL have B symptoms;
- Fatigue, itching, reddened patches of skin, nausea, vomiting and abdominal pain;
- Symptoms in various parts of the body which suggest involvement of other organs including the stomach, skin, bones or lungs. This occurs in approximately 20% of patients with NHL.

Other signs and symptoms may be present. Their occurrence depends on the site of the tumour(s) and the extent of the disease.

Diagnosis

How is NHL diagnosed?

A number of different examinations and tests are usually required to diagnose NHL and determine how much the disease has spread. Depending on your situation, the doctor may use some or all of these tests to determine the best way to treat your disease. Information from the following sources helps doctors determine the diagnosis:

- **Your health history:** Your family’s history of disease, your personal illness history, your general health status, etc.
- **Physical examination.**
- **X-ray:** A procedure where low dose radiation beams are used to provide images of the inside of the body for diagnostic purposes.
- **CT scan/CAT scan:** A series of X-rays that provide detailed, three-dimensional images of the inside of the body.
- **MRI (magnetic resonance imaging):** A technique used to obtain three-dimensional images of the body. An MRI is similar to a CT scan, however, MRI uses magnets instead of X-rays.
- **Gallium scan:** Gallium is a chemical taken up by some cancer cells and can therefore help doctors visualize cancer in the body. In this procedure, a safe amount of radioactive gallium is injected into the patient, after which the patient undergoes an X-ray where the radioactive gallium makes the tumour(s) visible. This test is performed in the nuclear medicine facility at the hospital.
- **PET (positron emission tomography) scan:** A way to visualize cancer in the body. Radioactive glucose (a sugar molecule used as the energy source for cells) is injected into the patient and is taken up preferentially by cells with a high metabolic activity, such as cancer cells. A scanner is then used to visualize the areas of the body where the radioactive glucose is concentrated. PET scans are also performed in the nuclear medicine facility at the hospital.
- **Laboratory tests:** Blood tests and urine tests.
- **Biopsy:** A biopsy is one of the most important steps in diagnosing the type of NHL. It involves the removal of a sample of tissue (cells), usually performed by a surgeon. The cells are then examined under a microscope. Most patients have two types of biopsies: a lymph node biopsy and a bone marrow biopsy. A lymph node biopsy is used to confirm the diagnosis of NHL and the bone marrow biopsy determines if the NHL has invaded (spread to) the bone marrow. All of this information is used to obtain an accurate diagnosis and the best treatment for each person.
Microscopic examination: part of the biopsy procedure

Classifying and Grading NHL

Classifying NHL

Your healthcare team needs to determine the exact type, or classification, of NHL you have as this helps doctors decide on the most appropriate treatment for you. The biopsy procedure is critical in the classification process as it provides cells taken directly from the tumour in order for doctors to determine which type of cell the tumour originated from (B-cell or T-cell), as well as other important information about the tumour cells. B-cell lymphomas are far more common than T-cell lymphomas. The biopsy procedure is performed by a surgeon and the cells are examined under a microscope by a pathologist to determine if cancer is present. The biopsy is often called a tissue diagnosis (meaning the diagnosis is made through an examination of the tissue or cells) and the course of the patient’s treatment depends on these results.

Once the surgeon has performed the biopsy and the pathologist has examined the tissue and recorded the information about the tumour cells, they must then use this information to determine the exact type of NHL you have. The classification process is a complicated one. Many organizations have attempted to simplify the classification process and develop a standardized international classification system for NHL. The most commonly used system is the World Health Organization lymphoma classification system which allows different NHL types to be classified in a standardized way among doctors around the world. Once the NHL type, or classification, has been determined, it is then important to determine the stage and grade of the NHL.

Clinical Grading of NHL

The doctor must also determine the grade of the tumour. The grade of the tumour provides information on how aggressive the tumour is and helps predict how the tumour will behave. This information helps determine the aggressiveness of the treatment approach. The grade is determined by the appearance of the cancer cells, what unique characteristics they have, how they function and how quickly they grow and divide. The grade is referred to as low-grade, intermediate-grade or high-grade NHL. Low-grade NHLs are often called indolent, or slow-growing NHLs. Intermediate and high-grade NHLs are often called aggressive, or fast-growing NHLs.
The following table summarizes the specialized process of classifying, staging and grading NHL:

<table>
<thead>
<tr>
<th>NHL Description</th>
<th>What It Describes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classification</td>
<td>NHL type</td>
</tr>
<tr>
<td>Stage</td>
<td>Extent of spread</td>
</tr>
<tr>
<td>Grade</td>
<td>Aggressiveness</td>
</tr>
</tbody>
</table>

- **Indolent NHL** (low-grade, slow-growing)
- **Aggressive NHL** (intermediate and high-grade, fast-growing)

**Indolent and Aggressive NHL**

NHL is commonly referred to as either indolent or aggressive. Indolent NHL is a low-grade NHL, meaning the tumour grows very slowly and patients often do not show symptoms until late in the disease. As a result, indolent NHL tends to be widespread at the time of diagnosis. Patients diagnosed with indolent NHL often do not require immediate treatment, and a watchful waiting approach is often employed (see NHL Treatment section for a more in-depth explanation). Treatment is eventually required and is usually effective at shrinking tumours and giving the patient a disease-free period, called remission. However, indolent NHL may relapse and subsequent rounds of treatment are often required. Sometimes low-grade, indolent NHL will transform into an intermediate or high-grade (aggressive) lymphoma, at which point the patient will require more urgent, intensive treatment. However, patients with indolent NHL often live for a long time and enjoy a good quality of life, and some patients may never even require treatment. Examples of indolent NHL include follicular lymphoma, small lymphocytic lymphoma and MALT lymphoma.

Intermediate and high-grade NHLs generally grow a lot faster than the indolent lymphomas, and for this reason they are referred to as aggressive, or fast-growing lymphomas. Unlike indolent lymphomas, aggressive NHLs require intensive treatment immediately after diagnosis. Although the word aggressive sounds frightening, aggressive lymphomas show an excellent response to treatment and patients can often be cured. Indolent lymphomas that transform into aggressive lymphomas can be more difficult to treat. The following table gives an overview of the main differences between indolent and aggressive NHL. An explanation of all the different types of NHL follows.

<table>
<thead>
<tr>
<th></th>
<th>Indolent NHL</th>
<th>Aggressive NHL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Proportion of NHL cases</strong></td>
<td>40%–50%</td>
<td>50%–60%</td>
</tr>
<tr>
<td><strong>Rate of cancer growth</strong></td>
<td>Slow</td>
<td>Fast</td>
</tr>
<tr>
<td><strong>Symptoms</strong></td>
<td>Patients commonly have no symptoms at diagnosis.</td>
<td>Patients usually experience symptoms which prompt a doctor’s visit and subsequent diagnosis.</td>
</tr>
<tr>
<td><strong>Treatment timing</strong></td>
<td>Patients often may not require immediate treatment. The watchful waiting approach is often employed here.</td>
<td>Patients may require immediate, more intensive treatment.</td>
</tr>
<tr>
<td><strong>Prognosis</strong></td>
<td>Responds well to treatment. Relapse is common and subsequent treatment is often required.</td>
<td>Excellent response to treatment.</td>
</tr>
</tbody>
</table>
NHL is not a single disease but rather a group of at least 50 closely related cancers that affect the lymphatic system. NHL can be divided by the type of lymphocyte affected (either B- or T-cells) resulting in either B- or T-cell lymphomas. The World Health Organization’s classification of lymphomas is the most commonly used system for classifying the different types of NHL and is used here.
### Different Types of NHL

#### B-Cell Lymphomas

<table>
<thead>
<tr>
<th>Type</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precursor B-Cell Lymphoblastic Leukemia/Lymphoma</td>
<td>64</td>
</tr>
<tr>
<td>Follicular Lymphoma</td>
<td>65</td>
</tr>
<tr>
<td>Mantle Cell Lymphoma</td>
<td>67</td>
</tr>
<tr>
<td>Diffuse Large B-Cell Lymphoma</td>
<td>68</td>
</tr>
<tr>
<td>• Mediastinal Large B-Cell Lymphoma</td>
<td>68</td>
</tr>
<tr>
<td>Burkitt’s Lymphoma</td>
<td>69</td>
</tr>
<tr>
<td>Chronic Lymphocytic Leukemia (CLL)</td>
<td>70</td>
</tr>
<tr>
<td>Marginal Zone Lymphomas</td>
<td>75</td>
</tr>
<tr>
<td>• Extranodal Marginal Zone B-Cell Lymphoma of MALT Type</td>
<td>75</td>
</tr>
<tr>
<td>• Splenic Marginal Zone Lymphoma</td>
<td>76</td>
</tr>
<tr>
<td>• Nodal Marginal Zone Lymphoma</td>
<td>77</td>
</tr>
<tr>
<td>Lymphoplasmacytic Lymphoma (Waldenstrom’s Macroglobulinemia)</td>
<td>77</td>
</tr>
</tbody>
</table>

#### T-Cell Lymphomas

<table>
<thead>
<tr>
<th>Type</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precursor T-Cell Lymphoblastic Leukemia/Lymphoma</td>
<td>79</td>
</tr>
<tr>
<td>Adult T-Cell Leukemia/Lymphoma</td>
<td>80</td>
</tr>
<tr>
<td>Anaplastic Large Cell Lymphoma</td>
<td>81</td>
</tr>
<tr>
<td>Cutaneous T-Cell Lymphoma</td>
<td>82</td>
</tr>
<tr>
<td>• Sezary Syndrome</td>
<td>82</td>
</tr>
<tr>
<td>• Mycosis Fungoides</td>
<td>82</td>
</tr>
<tr>
<td>Peripheral T-Cell Lymphomas</td>
<td>83</td>
</tr>
<tr>
<td>• Subcutaneous Panniculitis-Like T-Cell Lymphoma</td>
<td>83</td>
</tr>
<tr>
<td>• Hepatosplenic Gamma-Delta T-Cell Lymphoma</td>
<td>83</td>
</tr>
<tr>
<td>• Enteropathy-Type Intestinal T-Cell Lymphoma</td>
<td>84</td>
</tr>
<tr>
<td>• Extranodal T-Cell Lymphoma, Nasal Type</td>
<td>84</td>
</tr>
<tr>
<td>• Angioimmunoblastic T-Cell Lymphoma</td>
<td>84</td>
</tr>
<tr>
<td>• Peripheral T-Cell Lymphoma, Unspecified</td>
<td>84</td>
</tr>
</tbody>
</table>
Different Types of NHL

As mentioned earlier, the most commonly used method for classifying NHL is the World Health Organization Classification of Lymphoid Malignancies. The different types of NHLs according to the World Health Organization are listed below and explained in detail immediately following.

World Health Organization Classification of B-Cell and T-Cell Lymphomas

B-Cell Lymphomas

Precursor B-cell lymphomas
- Precursor B-cell lymphoblastic leukemia/lymphoma

Mature B-cell lymphomas
- Follicular lymphoma
- Mantle cell lymphoma
- Diffuse large B-cell lymphoma
  - Mediastinal large B-cell lymphoma
- Burkitt's lymphoma
- B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma
- Marginal Zone Lymphomas
  - Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue (MALT) type
  - Splenic marginal zone B-cell lymphoma
  - Nodal marginal zone lymphoma
- Lymphoplasmacytic lymphoma (Waldenstrom's macroglobulinemia)

T-Cell Lymphomas

Precursor T-cell lymphomas
- Precursor T-cell lymphoblastic leukemia/lymphoma

Mature T-cell lymphomas
- Adult T-cell leukemia/lymphoma
- Anaplastic large cell lymphoma
- Cutaneous T-cell lymphoma (including mycosis fungoides and Sezary syndrome)
- Peripheral T-cell lymphomas:
  - Subcutaneous panniculitis-like T-cell lymphoma
  - Hepatosplenic gamma-delta T-cell lymphoma
  - Enteropathy-type intestinal T-cell lymphoma
  - Extranodal T-cell lymphoma, nasal type
  - Angioimmunoblastic T-cell lymphoma
  - Peripheral T-cell lymphoma, unspecified
I. Precursor B-Cell Lymphomas

Precursor B-Cell Lymphoblastic Leukemia/Lymphoma

What is it?

- A precursor B-cell, called a B-cell lymphoblast, is an immature lymphocyte that is eventually destined to become a mature B-cell. It is this cell that becomes cancerous in precursor B-cell lymphoblastic lymphoma.
- Precursor B-cell lymphoblastic lymphoma is a type of aggressive NHL that occurs mainly in children and adolescents, with two-thirds of patients being male. A second peak of occurrence happens later in life in patients over 40 years of age.
- Lymphoblastic cancers are classified as either lymphoblastic leukemias (called acute lymphoblastic leukemia or ALL) or lymphoblastic lymphomas. Both are cancers of immature lymphocytes with the major differences illustrated in the following table:

<table>
<thead>
<tr>
<th></th>
<th>Lymphoblastic Leukemia</th>
<th>Lymphoblastic Lymphoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of lymphocyte most</td>
<td>B-cells</td>
<td>T-cells</td>
</tr>
<tr>
<td>commonly affected</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where the cancer is</td>
<td>Bloodstream</td>
<td>Lymph nodes</td>
</tr>
<tr>
<td>located</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- The majority of precursor B-cell cancers are leukemias, which are far more common than precursor B-cell lymphomas.

What are the symptoms?

- The most common symptoms include pallor (paleness of skin), fatigue, bleeding, fever and infections.
- When a blood test is performed and blood cells are counted, red blood cells and platelets are usually lower than normal, while white blood cells may be low, normal or high in the bloodstream (although they are abnormal in the bone marrow).
- At the time of diagnosis other sites outside of the lymph nodes may also be affected and may cause symptoms such as swollen lymph nodes, enlarged liver or spleen, neurological disturbances, enlargement of testicles in men or skin involvement.
How is it diagnosed?

The diagnosis is usually made by bone marrow biopsy. A sample of bone marrow is removed from the patient and examined under a microscope. This usually shows high numbers of cancerous B-cell lymphoblasts.

How is it treated?

- The treatment of patients with precursor B-cell lymphoblastic leukemia/lymphoma involves combination chemotherapy, which is chemotherapy used in combination with different drugs.
- The overall cure rate in children is 85%, while about 50% of adults remain disease-free for long periods of time. In patients whose disease is confined to lymph nodes, a high cure rate is often possible.

II. Mature B-Cell Lymphomas

Follicular Lymphoma

What is it?

- Follicular lymphoma is a B-cell lymphoma where the tumour cells often create a circular or follicular pattern when viewed under the microscope.
- Follicular lymphoma is the most common subtype of indolent (slow-growing) NHL, comprising 20% to 30% of all NHLs.
- Follicular lymphoma typically affects middle-aged or older adults.
- Follicular lymphomas arise from B-lymphocytes, and as such are referred to as B-cell lymphomas.
- Like most indolent lymphomas, people diagnosed with follicular lymphoma usually have tumours in many parts of the body at the time of diagnosis.
- Follicular lymphomas can transform into a more aggressive form of NHL, usually a diffuse large B-cell lymphoma.

A section of a lymph node showing the origin of follicular lymphoma
What are the symptoms?

• The most common sign of follicular NHL is painless swelling in the lymph nodes of the neck, armpit or groin. Sometimes more than one group of nodes are affected.

How is it diagnosed?

• The diagnosis of follicular NHL is confirmed by a lymph node biopsy. To do this a sample of the lymph node is removed and examined under a microscope to check for cancerous cells.
• Other tests including X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.
• In the event that follicular NHL transforms to a more aggressive form of NHL, the NHL must then be re-diagnosed and a second lymph node biopsy or other tests may be required.

How is it treated?

• Treatment for follicular lymphoma depends on the stage of the lymphoma.
• Patients who are diagnosed at an early stage (stage I or II) may receive no treatment (watchful waiting approach), radiation therapy or chemotherapy. Local radiation therapy often produces excellent results, with remissions lasting longer than 10 years in 50% of patients.
• Patients who are at a later disease stage (stage III or IV) at the time of diagnosis but who are not experiencing symptoms may receive no treatment (watchful waiting approach) with very close monitoring.
• Once the need for treatment arises the most common treatments include:
  – Single-agent chemotherapy (e.g., chlorambucil) or combination chemotherapy (e.g., CVP or CHOP).
  – Rituximab (Rituxan®), a monoclonal antibody, is often used either alone or in combination with chemotherapy.
  – Radiation therapy.
  – Radioimmunotherapy, including medications such as tositumomab (Bexxar®) and ibritumomab tiuxetan (Zevalin®), may also be used.
  – Prolonged treatment with Rituxan®, called Rituxan® maintenance therapy, has recently been approved by Health Canada for the treatment of patients with follicular NHL who have responded to their initial treatment. This means that patients who have received treatment for follicular lymphoma and have achieved remission (complete or partial remission) may benefit from prolonged administration with Rituxan® (generally administered every three months for a period of two years). Rituxan® maintenance therapy has been shown to sustain the response obtained from the initial therapy and may improve survival for patients with follicular lymphoma.
• Follicular NHL usually responds quite well to chemotherapy. However, there is a risk that it may return in future years. At that time, treatment is given again and the disease can again be brought under control. This pattern may repeat itself over many years.
Mantle Cell Lymphoma

What is it?

- Mantle cell lymphoma is a type of aggressive B-cell lymphoma that most commonly affects men over the age of 50 years, although it can affect women.
- It is relatively uncommon and accounts for approximately 5% to 10% of all NHL cases.

What are the symptoms?

- The most common symptom is a painless swelling in the neck, armpit or groin, caused by enlarged lymph nodes. Often lymph nodes in more than one area of the body are affected. Splenomegaly (enlargement of the spleen) is relatively frequent and may cause patients to feel fullness in the abdomen after eating only small amounts.
- Mantle cell lymphoma is aggressive and may spread to other organs in the body, including the bone marrow, spleen and liver. It can also spread to the stomach or digestive tract.

How is it diagnosed?

- The disease is usually widespread at the time of diagnosis.
- The diagnosis of mantle cell lymphoma is confirmed by a lymph node biopsy. A sample of the lymph node is removed and examined under a microscope to check for cancer cells.
- Other tests including X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.
How is it treated?

- Mantle cell lymphoma is usually treated with combination chemotherapy, or combination chemotherapy plus rituximab (Rituxan®). This includes regimens such as:
  - CHOP chemotherapy or Rituxan® plus CHOP chemotherapy. CHOP chemotherapy is a combination of chemotherapy drugs including cyclophosphamide, doxorubicin, vincristine and prednisone.
- Mantle cell lymphoma can also be treated with radiation therapy, stem-cell transplant and other newer treatments.
- Treatment is often initially successful. However, mantle cell lymphoma frequently relapses. While newer treatments have been developed to treat this type of lymphoma, patients with mantle cell lymphoma are often encouraged to participate in clinical trials so they can receive newer treatments that are not yet on the market.

Diffuse Large B-Cell Lymphoma (DLBCL)

What is it?

- DLBCL is an aggressive B-cell NHL and is the most common type of NHL accounting for 30% to 40% of all cases.
- The average age of diagnosis for DLBCL is the mid-sixties, however, this cancer can also affect children.
- Mediastinal large B-cell lymphoma is a subtype of DLBCL, where the cancer arises in the thymus gland and lymph nodes behind the mediastinum, the area in the middle of the chest, between the lungs.
- Mediastinal large B-cell lymphoma can:
  - Lead to symptoms of shortness of breath, cough and pain in the chest.
  - Cause swelling of the neck, arms and face due to the swollen lymph nodes pressing on the veins in the chest. This swelling is known as superior vena cava obstruction.
  - Involve other lymph nodes, causing a painless swelling in the neck, armpit or groin.
  - Occur at any time from early adulthood to old age but is most common between the ages of 25 and 40 years. It is twice as common in women as in men.
What are the symptoms?

- The most common symptom of DLBCL is a painless swelling in the neck, armpit or groin caused by enlarged lymph nodes. Often lymph nodes in more than one area of the body are affected.
- The majority of patients have widespread disease at the time they are diagnosed and may have symptoms including weight loss, fever and night sweats.
- About 50% of patients have organ involvement at the time of diagnosis with the most common organs involved being the digestive (gastrointestinal) tract and the bone marrow.

How is it diagnosed?

- The diagnosis of DLBCL is confirmed by a lymph node biopsy. A sample of the lymph node is removed and examined under a microscope to check for cancerous cells.
- When looked at under a microscope, the tumour cells of DLBCL appear large in size and display a diffuse or scattered pattern.
- Other tests including X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.

How is it treated?

- The standard treatment for DLBCL is rituximab (Rituxan®) (monoclonal antibody therapy) plus CHOP chemotherapy.
- Other therapies include radiation therapy, stem-cell transplants and steroid therapy.
- This type of aggressive NHL is very sensitive to treatment and a large percentage of patients with DLBCL can be cured.

Burkitt’s Lymphoma

What is it?

- Burkitt’s lymphoma is a very aggressive (high-grade) form of NHL and commonly affects both children and adults, with males being affected more frequently than females.
- The disease can be associated with viral infection such as the human immunodeficiency virus (HIV) and the Epstein-Barr virus.
- Burkitt’s lymphoma accounts for 30% to 40% of all childhood lymphomas and occurs in children between the ages of five and 10 years and in adults between the ages of 30 and 50 years.

What are the symptoms?

- The most common symptoms of Burkitt’s lymphoma are swollen lymph nodes and abdominal swelling.
- Burkitt’s lymphoma may also affect other organs such as the eyes, ovaries, kidneys, central nervous system and glandular tissue such as breast, thyroid or tonsil. Disease in these organs may cause variable symptoms.

How is it diagnosed?

- The diagnosis of Burkitt’s lymphoma is confirmed by a lymph node biopsy. A sample of the lymph node is removed and examined under a microscope where it is checked for cancerous cells.
- Other tests including X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.
How is it treated?

- Although Burkitt’s lymphoma has a very aggressive course, survival rates with treatment are approximately 80%.
- The most common treatment for Burkitt’s lymphoma is intensive chemotherapy with drugs such as cyclophosphamide, doxorubicin, vincristine, methotrexate, cytarabine, ifosfamide and etoposide.
- Other treatments include monoclonal antibody therapy and stem-cell transplants.

Chronic Lymphocytic Leukemia (CLL)

What is it?

Chronic lymphocytic leukemia (CLL) is the most common type of adult leukemia in the Western world. It can be described as both a leukemia and a lymphoma because it is a cancer of the blood (leukemia) and because it originates in the lymphatic system (lymphoma). CLL is very similar to small lymphocytic lymphoma (SLL) and the two are often considered as a single entity. The distinction between CLL and SLL is based on where the cancer cells gather. When most of the cancer cells are in the bloodstream and the bone marrow, it is called CLL. When the cancer cells are primarily found in the lymph nodes, it is called SLL. CLL is a cancer that can progress very slowly – many patients live years without experiencing any symptoms. Most people with CLL are diagnosed during or after middle age.

The bone marrow is the “factory” for blood cells. It contains immature cells which develop into three main blood cells: red blood cells, white blood cells and platelets. Red blood cells carry oxygen to tissues; lymphocytes and neutrophils are types of white blood cells that help fight infection; and platelets are involved in clotting and prevent bleeding.

The lymphocytes in CLL, also called the leukemic cells, are abnormal in their function and as such do not fight infection very well. Over time, the numbers of CLL cells may build up in the bone marrow and bloodstream and can lower the number of normal healthy white blood cells, red blood cells, and platelets. This can result in an increase in infections, anemia, or easy bruising and bleeding.

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Symptoms

The signs and symptoms that may indicate the presence of CLL develop slowly. At first there may be no symptoms. CLL is often detected during a routine blood test, when results show abnormal numbers of white blood cells. When other signs occur, they may be easily confused with other conditions. These symptoms include:

- Swollen but painless lymph nodes in the neck, underarm, stomach or groin
- Feeling very tired
- Frequent fever and infection
- Unexplained weight loss or night sweats.

Diagnosis and Staging

To confirm the presence of CLL and to determine the stage of your cancer, tests that examine the blood, bone marrow and lymph nodes may be performed. Some of the tests that may be required are:

- Complete blood count (CBC) to verify the number of red blood cells, white blood cells, and platelets
- Flow cytometry to detect the presence of leukemic cells
- Bone marrow aspiration and biopsy to check for abnormal cells in the bone marrow
- Molecular genetics using a technique called FISH (fluorescence in situ hybridization) or cytogenetics to look for genetic mutations within the CLL cells (which may be associated with prognosis)
- Blood chemistry studies, to measure certain substances in the blood.

The results of these tests will help to assist you and your doctor to make decisions about your treatment. Some additional prognostic testing may be available only in specialized labs or may be performed only for research purposes. Currently, treatment decisions are usually based on clinical findings (symptoms, physical examination and blood tests).

<table>
<thead>
<tr>
<th>Prognostic Marker</th>
<th>Better Prognosis</th>
<th>Poorer Prognosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Routine</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rai stage</td>
<td>0</td>
<td>3 and 4</td>
</tr>
<tr>
<td>Lymphocyte doubling time</td>
<td>&gt;12 months</td>
<td>&lt;12 months</td>
</tr>
<tr>
<td>CD38</td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>Beta(2)-microglobulin</td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td><strong>Investigational</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IgVH mutation</td>
<td>Mutated</td>
<td>Unmutated</td>
</tr>
<tr>
<td>ZAP-70</td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>Cytogenetics</td>
<td>del 13q</td>
<td>del 17q, del 11q</td>
</tr>
</tbody>
</table>
Rai Staging

The Rai staging system is more commonly used in North America. There is another staging system called Binet staging that is used in Europe. Both classify CLL and assign risk categories based on:

- Number of lymphocytes found in the blood
- Enlargement of the lymph nodes, liver and spleen
- Number of platelets found in the blood
- Presence of anemia (low number of red blood cells in the blood).

<table>
<thead>
<tr>
<th>Risk Level</th>
<th>Rai Stage</th>
<th>Symptoms</th>
<th>Binet Equivalent</th>
</tr>
</thead>
</table>
| Low        | 0         | • Too many lymphocytes in the blood  
             • No other symptoms | A |
| Intermediate | 1         | • Too many lymphocytes in the blood  
             • Lymph nodes are larger than normal | B |
|            | 2         | • Too many lymphocytes in the blood  
             • Lymph nodes may be larger than normal  
             • Spleen or liver are larger than normal | |
| High       | 3         | • Too many lymphocytes in the blood  
             • Low red blood cells in the blood (anemia)  
             • Spleen, liver or lymph nodes may be larger than normal | C |
|            | 4         | • Too many lymphocytes in the blood  
             • Low red blood cells in the blood (anemia)  
             • Low platelets in the blood (thrombocytopenia)  
             • Spleen, liver or lymph nodes may be larger than normal | |
Treatment Options for CLL

Although no cure has been found yet for CLL, it is possible to feel well and live for years in good health. Treatment options are based on many factors including staging, the presence of symptoms such as fever or weight loss, or how a patient responds to treatment. Patients may be observed for many years without requirement for treatment but those who develop symptoms of advancing disease receive therapy in almost all cases.

The treatment of CLL primarily aims to:
- Slow down the accumulation of CLL cells
- Keep patients feeling well enough to carry on their day-to-day activities
- Maintain a patient’s quality of life
- Improve the number of normal blood cells (normal white cells, red cells and platelets).

Standard treatment options for CLL include:
- Watchful waiting
- Chemotherapy
- Biologic therapy
- Stem-cell transplantation
- Radiation therapy
- Splenectomy.

Watchful Waiting (also called Watch and Wait)

Watchful waiting is a strategy where healthcare professionals monitor a patient’s condition closely, but withhold treatment until symptoms appear or change. This period is also called watch and wait or observation.

During the watch-and-wait period, you will need to meet with your cancer specialist for follow-up visits to see if there are any changes with your health.

The reason watchful waiting is used as an approach is because studies have not shown that immediate treatment prolongs survival. And since treatment affects healthy cells as well as the cancer cells, for now experts believe that treatment should be delayed until necessary. Some people may never require therapy.

Chemotherapy

To learn more about how chemotherapy works, how it is given and the side effects, see pages 91 to 99.

Patients with CLL may receive chemotherapy as a single drug. Examples include:
- Chlorambucil may be administered orally with few immediate side effects
- Fludarabine is administered orally or intravenously and can be associated with some side effects.

Many patients with CLL will receive a combination chemotherapy regimen used in other lymphomas such as:
- FC chemotherapy (fludarabine and cyclophosphamide)
- CVP chemotherapy (cyclophosphamide, vincristine and prednisone)
- CHOP chemotherapy (cyclophosphamide, doxorubicin, vincristine and prednisone).

Patients should be aware of all of their treatment options and speak to their doctors about selecting the best treatment for them.
Biologic Therapy

Biologic therapy is a treatment that stimulates or restores the ability of your immune system to fight disease or infections. You can learn more about how biologic therapies work on page 106.

Rituximab (Rituxan®) and alemtuzumab (Campath®) are examples of monoclonal antibodies that can be used individually or in combination with chemotherapy. You will find more information on how these drugs are given and their side effects on page 107.

Stem-cell Transplantation

Patients with CLL may be candidates for stem-cell transplantation. In stem-cell transplantation, immature blood cells (stem cells) are taken from the blood or bone marrow of the patient (autologous transplantation) or a compatible donor (allogeneic transplantation). Stem-cell transplantation is an aggressive treatment that is still considered experimental but may be an option for younger CLL patients who no longer respond to treatment. Refer to pages 110 to 112 to learn more about stem-cell transplantation.

Radiation Therapy

Radiation therapy may be used:
- To reduce the size of an enlarged spleen (rarely used)
- To reduce the size of a specific lymph node.

See page 100 to learn how radiation works and how it is given and pages 101 to 105 to understand the side effects of radiation therapy.

Splenectomy

Surgery to remove an enlarged spleen is rarely necessary but can be done:
- To relieve the pressure caused by the enlarged spleen on other organs
- To stop the increased destruction of red blood cells and platelets.
Marginal Zone Lymphomas

- Marginal zone lymphomas are a type of indolent B-cell lymphoma that account for approximately 10% of all NHL cases.
- Marginal zone lymphomas can be categorized according to the area affected:
  - Mucosa-associated lymphatic tissue (called MALT lymphoma), which can affect the gastrointestinal tract, eyes, thyroid, salivary glands, bladder, kidney, lungs, neurological system or skin
  - Spleen (called splenic marginal zone B-cell lymphoma)
  - Lymph nodes (called nodal marginal zone B-cell lymphoma).
- The average age of diagnosis of marginal zone lymphoma is 65 years, although MALT lymphomas can occur earlier.

Extranodal Marginal Zone B-Cell Lymphoma of Mucosa-Associated Lymphatic Tissue (MALT) Type

What is it?

- MALT lymphomas mainly occur outside the lymph nodes, in extranodal sites.
- Many patients who develop this type of NHL usually have a separate autoimmune disease or inflammatory process such as Sjögren’s syndrome (salivary gland MALT), Hashimoto’s thyroiditis (thyroid MALT), or *Helicobacter* gastritis (gastric MALT).

What are the symptoms?

Patients may have symptoms such as upper abdominal discomfort or local symptoms relating to where the disease occurs.

How is it diagnosed?

The diagnosis is made by biopsy of the tumour and examination of the cells by a specialized doctor called a hematopathologist. The diagnosis is confirmed by the infiltration of small B-cells.
How is it treated?

- Extranodal marginal zone B-cell lymphoma of MALT type is often curable when localized.
- Surgery is not often a common treatment for NHL. However, in this particular type of NHL, local therapies such as radiation therapy or surgery can be curative.
- Patients with gastric MALT lymphomas who are infected with a bacteria called Helicobacter pylori can achieve lengthy remission in the majority of cases once the infection is effectively treated with antibiotics.
- Patients who present with more extensive disease are usually treated with single-agent chemotherapy such as chlorambucil or combination chemotherapy.
- In some cases this type of NHL can transform into an aggressive form of NHL called diffuse large B-cell lymphoma (DLBCL). The standard therapy for DLBCL is CHOP chemotherapy plus rituximab (Rituxan®) (a monoclonal antibody).

Splenic Marginal Zone Lymphoma (SMZL)

What is it?

- SMZL is a type of indolent B-cell NHL that predominantly involves the spleen. The spleen is located in the upper left corner of the abdomen.
- SMZL is a rare type of lymphoma accounting for less than 1% of all NHLs.
- It most commonly occurs in adults and is slightly more frequent in women than in men.

What are the symptoms?

- Symptoms do not normally appear until years after the disease has begun.
- The most common symptom is an enlarged spleen (splenomegaly). Unlike many other NHLs, there are normally no swollen lymph nodes.
- There is usually involvement of the peripheral blood and bone marrow at the time of diagnosis. This involvement will be evident on laboratory tests with the only symptom being fatigue.

How is it diagnosed?

Diagnosis is based on identification of the cell type in conjunction with the typical clinical findings. A biopsy of the bone marrow can often yield the diagnosis, however, removal of the spleen (splenectomy) is occasionally required for tissue examination.

How is it treated?

A number of different approaches may be taken with SMZL, including:

- Watchful waiting approach (common in many indolent lymphomas)
- Removal of the spleen (splenectomy)
- Radiation therapy
- Chemotherapy
- Biologic therapies with drugs such as rituximab (Rituxan®) (a monoclonal antibody).
Nodal Marginal Zone Lymphoma (NMZL)

What is it?

• NMZL is a type of indolent B-cell NHL that is primarily confined to the lymph nodes.
• It is a rare form of lymphoma, accounting for only 1% to 3% of all NHL cases.

What are the symptoms?

The most common symptom of NMZL is a painless swelling in the neck, armpit or groin caused by enlarged lymph nodes. Sometimes more than one group of nodes are affected.

How is it diagnosed?

NMZL is diagnosed by lymph node biopsy. A section of the lymph node is surgically removed and examined under a microscope.

How is it treated?

The most common treatments for NMZL include:

• Watchful waiting approach
• Radiation therapy
• Chemotherapy with medications such as chlorambucil or fludarabine.
• Rituximab (Rituxan®) (a monoclonal antibody) is often used in combination with chemotherapy.

Lymphoplasmacytic Lymphoma
(Also Called Waldenstrom’s Macroglobulinemia or Immunocytoma)

What is it?

• Lymphoplasmacytic lymphoma is a rare form of B-cell lymphoma, making up 1% to 2% of all NHL cases.
• It typically affects older adults and has a slow-growing, indolent course.
• It arises from mature B-cells that are on their way to developing into plasma cells (B-cells that produce antibodies). In this type of lymphoma an overproduction of a certain type of antibody, called IgM, can occur. When this IgM antibody is present, the lymphoma is also referred to as Waldenstrom’s macroglobulinemia. A large amount of IgM in the bloodstream causes thickening (hyperviscosity) of the blood.
What are the symptoms?

• Lymphoplasmacytic lymphoma normally develops over a long period of time. Symptoms are not usually very obvious and as such, the disease is often found by chance when getting a routine blood test or an examination for some other reason.
• Some symptoms can include weakness, fatigue and bruising as a result of altered blood cell levels. Lymph nodes may be enlarged, as may the liver and spleen.
• Because there may be a thickening of the blood when the IgM antibody is present, this can cause other symptoms including sight problems, headaches, hearing loss or confusion.

How is it diagnosed?

• This type of NHL is usually suspected after an abnormal blood test. Other tests that help confirm the diagnosis include:
  – A bone marrow biopsy to determine the exact type of NHL
  – An ultrasound to determine whether the spleen or liver are enlarged
  – A CT scan to accurately visualize the cancer in the body.

How is it treated?

Lymphoplasmacytic lymphomas are usually treated with the following therapies:

• **Chemotherapy:** The most common medications include chlorambucil, fludarabine and combination chemotherapies, such as CVP chemotherapy (cyclophosphamide, vincristine and prednisone).
• **Surgery:** Surgery for lymphoplasmacytic lymphoma may involve removal of an enlarged spleen.
• **Monoclonal antibody therapy** with agents like rituximab (Rituxan®) that specifically target and destroy cancerous B-cells. Rituxan® can be used alone or in combination with chemotherapy.
• **Plasma exchange/plasmapheresis:** This is a procedure specifically for the hyperviscosity (thickening of the blood) associated with this disease. It may be used to thin out the blood when high levels of IgM antibody cause increased thickness.
I. Precursor T-Cell Lymphomas

Precursor T-Cell Lymphoblastic Leukemia/Lymphoma

What is it?

- A precursor T-cell, called a T-cell lymphoblast, is an immature lymphocyte that is eventually destined to become a mature T-cell. It is this cell that becomes cancerous in precursor T-cell lymphoblastic lymphoma.
- Precursor T-cell lymphoblastic lymphoma is a type of aggressive NHL that occurs mainly in children and adolescents, with the majority of patients being male. A second peak of occurrence is seen later in life in patients over 40 years of age.
- Lymphoblastic cancers are classified as either lymphoblastic leukemias (called acute lymphoblastic leukemia or ALL) or lymphoblastic lymphomas. Both are cancers of immature lymphocytes with the major differences illustrated in the following table:

<table>
<thead>
<tr>
<th></th>
<th>Lymphoblastic Leukemia</th>
<th>Lymphoblastic Lymphoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of lymphocyte most commonly affected</td>
<td>B-cells</td>
<td>T-cells</td>
</tr>
<tr>
<td>Where the cancer is located</td>
<td>Bloodstream</td>
<td>Lymph nodes</td>
</tr>
</tbody>
</table>

What are the symptoms?

- The most common symptoms result from a large mass in the mediastinal area (the centre area of the upper chest), as well as fluid accumulation around the lungs. These symptoms include breathing difficulties and other problems.
- This type of NHL can spread to the central nervous system, and neurological symptoms may also be present at diagnosis.

How is it diagnosed?

- The diagnosis is usually made by lymph node biopsy. A sample of the lymph node is removed and examined under a microscope where it is checked for cancerous cells.
- X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.
How is it treated?

- Intensive chemotherapy is the most common treatment for older children and young adults with aggressive lymphoblastic lymphoma.
- Young patients whose disease is well localized have an excellent prognosis.
- Adults with later stage precursor T-cell lymphoblastic lymphoma are often offered stem-cell transplantation as part of their initial treatment plan.

II. Mature T-Cell Lymphomas

Adult T-Cell Leukemia/Lymphoma

What is it?

- Adult T-cell lymphoma is an aggressive type of T-cell lymphoma where the cancerous T-cells are found in the peripheral circulating blood.
- Adult T-cell leukemia/lymphoma is rare in North America and is more common in countries such as Japan and China where a viral infection called HTLV-1 infection is more common. HTLV-1 infection can make people more likely to develop this type of T-cell lymphoma.
- This type of NHL can occur at any age from young adulthood to old age. It occurs slightly more often in men than in women.

What are the symptoms?

- The most common symptoms include swollen, enlarged lymph nodes (lymphadenopathy) and an enlarged liver and spleen (hepatosplenomegaly).
- Upon examination the patient may show signs of skin involvement, high calcium levels in the blood (hypercalcemia), bone involvement and high levels of an enzyme called lactate dehydrogenase (LDH).

How is it diagnosed?

- The diagnosis of adult T-cell leukemia/lymphoma is made by lymph node biopsy. A sample of the lymph node is removed and examined under a microscope where it is checked for cancerous cells.
- X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.
- The presence of HTLV-1 virus must also be established.

How is it treated?

- Adult T-cell leukemia/lymphoma is treated using combination chemotherapy regimens.
- Some patients can survive for a long time with this cancer.
Anaplastic Large Cell Lymphoma (ALCL): Systemic-Type and Primary Cutaneous-Type

What is it?

• ALCL can occur in two different forms:
  – A systemic type, where it exists throughout the body
  – A primary cutaneous type, where it occurs only in the skin.
• Anaplastic refers to the appearance of the lymphoma cells, which look quite different from normal lymphocytes.
• Patients with ALCL are typically young, with an average age of 33 years, with 70% of patients being male.
• ALCL systemic-type is an aggressive NHL, whereas the primary cutaneous type follows a more indolent course.
• The cancerous cell in either type of ALCL can be a T-cell, or a cell that is lacking B-cell or T-cell markers (called “null”).

What are the symptoms?

ALCL systemic-type:
• Patients with ALCL systemic-type often have enlarged and swollen lymph nodes, as well as involvement of other organs.
• Systemic symptoms and elevated levels of an enzyme called lactate dehydrogenase (LDH) occur in approximately 50% of patients. Bone marrow and the gastrointestinal tract are rarely involved, but skin involvement is common.
ALCL primary cutaneous-type:
• Patients with ALCL primary cutaneous-type usually have a single lump or ulcerating tumour in the skin. Lymph nodes in the area may also become involved.
• The cells involved in this type of lymphoma have a certain protein on their surface called the CD30 antigen.
• Patients may experience spontaneous remissions with this disease. However, the remissions are inevitably followed by relapses.
• A benign condition that can mimic primary cutaneous ALCL is called lymphomatoid papulosis.

How is it diagnosed?

Both types of ALCL are diagnosed by biopsy of tumour tissue. A sample of the tumour is removed and examined under a microscope. Specific features of the disease are identified and the diagnosis is made.

How is it treated?

ALCL systemic-type:
• Treatment regimens appropriate for other aggressive lymphomas, such as diffuse large B-cell lymphoma (DLBCL), are generally utilized in patients with ALCL. They include:
  – CHOP chemotherapy (cyclophosphamide, doxorubicin, vincristine and prednisone), the standard therapy for ALCL systemic-type;
  – Other therapies including radiation therapy, stem-cell transplants and steroid therapy.
• With combination chemotherapy, many patients with ALCL will be cured.
ALCL primary cutaneous-type:
As mentioned, spontaneous remission may occur with this condition. If no spontaneous remission occurs the most common treatments include:

- Radiation therapy to the area;
- Surgery to remove the area of skin affected;
- Systemic chemotherapy (used only in patients who have extensive involvement that cannot be treated with localized therapies).

Cutaneous T-Cell Lymphoma (CTCL)

What is it?

CTCL is a rare type of NHL caused by cancerous growth of T-cells in the skin. It is most common in adults between 40 and 60 years of age.

There are a few sub-types of CTCL, the most common being:

- **Sezary syndrome:**
  A specific type of CTCL where large areas of skin or lymph nodes are affected. Patients with this lymphoma may have redness of the entire skin surface and tumour cells which circulate in the bloodstream. This type of CTCL often follows an aggressive course.

- **Mycosis fungoides:**
  This is the general name given to the other types of CTCL when the blood is not affected. It is a type of indolent lymphoma where patients often have several years of eczema-like skin conditions before the diagnosis is finally established. In the early stages of the condition, biopsies may be difficult to interpret and the correct diagnosis can only be made after observing the patient over time. In advanced stages, the lymphoma can spread to lymph nodes and other organs.

What are the symptoms?

- CTCL can manifest as small, raised, red patches on the skin, often on the breasts, buttocks, skin folds and face. These patches often look similar to eczema or psoriasis, and may be associated with hair loss in the affected area.
- Patients in later stages may have ulcerating tumours that appear on the skin.
- Lymph nodes in the affected region may also be involved.

How is it diagnosed?

The diagnosis is made by skin biopsy of the area of affected skin. A small piece of skin is removed from the affected area and examined under a microscope.
How is it treated?

Many therapies are used to treat CTCL. They include:

- **PUVA:** Also called photochemotherapy, this treatment is used if large areas of skin are affected. PUVA consists of a drug called psoralen plus ultraviolet A (UVA) light. Psoralen makes the skin more sensitive to the healing effects of the UVA light. The treatment is similar to sitting under a sunlamp and may be given several times a week.

- **UVB therapy:** Ultraviolet B (UVB) light slows the growth of the cancerous cells in the skin. This treatment does not include the use of a drug to make the skin more sensitive. Treatment may be given several times a week.

- **Radiation therapy:** Local radiation may be used for early-stage CTCL if only one or two small areas of skin are affected. Radiation therapy may also be used to treat the entire surface of the skin if the CTCL is more widespread. This type of radiation treatment is called total skin electron beam treatment. It is only given once and then may be followed up with further PUVA treatments if needed.

- **Chemotherapy:** Chemotherapy drugs may be applied directly to the skin in the form of an ointment. It is very important that you follow the instructions carefully and only put the cream on at the prescribed times. Intravenous chemotherapy may be used if the CTCL is more advanced.

- **Bexarotene (Targretin®):** This is a medication that may be used to treat advanced CTCL. It is taken daily in capsule form with food.

- **Interferon:** Interferon is a protein that occurs naturally in the body and is an important part of a healthy immune system. A synthetic form of interferon can be injected under the skin (subcutaneously) in an attempt to boost the immune response and fight the CTCL.

- **Photopheresis:** This treatment is used particularly for Sezary syndrome. It involves passing the patient’s blood through a machine where it is exposed to ultraviolet light.

---

Peripheral T-Cell Lymphomas (PTCLs)

What are they?

PTCLs are a group of aggressive NHLs that affect a certain type of T-cell. They account for approximately 7% of all NHL cases.

There are many distinct sub-types of PTCLs. They include:

- **Subcutaneous panniculitis-like T-cell lymphoma:** This type of PTCL is quite rare and is often confused with a condition called panniculitis, an inflammation of fatty tissue in the body. The most common symptoms include nodules under the skin (subcutaneous nodules) which can progress to open, inflamed sores. Hemophagocytic syndrome—a serious condition in which there is uncontrolled activation of certain parts of the immune system—is also common in this cancer.

- **Hepatosplenic gamma delta T-cell lymphoma:** This type of PTCL is a systemic (affecting the entire body) illness that presents with infiltration of the liver, spleen and bone marrow by cancerous T-cells. Usually there are no actual tumours. It is associated with systemic symptoms (e.g., fever, weight loss, night sweats, fatigue) and is quite difficult to diagnose.
• **Enteropathy-type intestinal T-cell lymphoma:** This type of PTCL is very rare and occurs in patients with untreated gluten-sensitive intestinal disease, called celiac disease. Patients are often in a very weakened state and may have intestinal perforation (an abnormal hole in the wall of the intestine).

• **Extranodal T-cell lymphoma, nasal type:** This type of PTCL, previously referred to as angiocentric lymphoma, is more common in Asia and South America than in North America and Europe. It most frequently affects the nose and nasal passages but can involve other organs as well. It has an aggressive course, and patients frequently have hemophagocytic syndrome, a serious condition in which there is uncontrolled activation of certain parts of the immune system.

• **Angioimmunoblastic T-cell lymphoma:** This is one of the more common sub-types of PTCL, accounting for approximately 20% of all T-cell lymphomas. The most common symptoms include generalized lymphadenopathy (swollen lymph nodes), fever, weight loss, skin rash and high levels of antibodies in the blood.

• **PTCL, unspecified:** PTCL, unspecified is the most common PTCL subtype in North America. It represents all of the PTCLs not classifiable as a specific subtype. It is evident that this represents a diverse group of diseases for which evidence is lacking a clearer definition. Most patients with PTCL, unspecified present with nodal involvement; however, a number of extranodal sites may also be involved (e.g., liver, bone marrow, intestinal tract, skin).

**What are the symptoms?**

The symptoms of PTCL are specific to the subtype. Refer to the specific subtype for a description of the most common symptoms.

**How are they diagnosed?**

• The diagnosis of PTCLs requires a biopsy and thorough examination of the cancerous tissue.
• Other diagnostic tests such as X-rays, bone marrow biopsy, CT scans and blood tests may also be performed.

**How are they treated?**

• Treatment of PTCLs generally involves combination chemotherapy. Treatment regimens are similar to those used for other aggressive lymphomas and include:
  – CHOP chemotherapy (cyclophosphamide, doxorubicin, vincristine and prednisone)
  – Radiation therapy, stem-cell transplants and steroid therapy.
• The response to treatment is not often as effective in PTCLs as it is in DLBCL. As a result, stem-cell transplantation is sometimes considered an early treatment option in appropriate cases.
There are many different treatments for NHL. Your individual treatment is chosen based on many factors that are outlined in this section. Your healthcare team will consider these factors in making the treatment decision and will also consider your personal situation and unique goals for treatment.

It is important for you to understand that you play a very important role in your treatment. This section includes support tools to help you understand your treatment pathway as well as a list of questions you may wish to ask your healthcare team.
NHL Treatment

Understanding Cancer Treatment ................................................................................................................... 87

NHL Therapies Defined ............................................................................................................................... ............................................................... ........................... 90

- Watchful Waiting ........................................................................................................................................... 90
- Chemotherapy .............................................................................................................................................. 91
- Radiation Therapy ....................................................................................................................................... 100
- Biologic Therapies ........................................................................................................................................ 106
  - Monoclonal Antibody Therapy ................................................................................................................... 106
  - Radioimmunotherapy ................................................................................................................................. 108
  - Interferons ................................................................................................................................................. 109
  - Vaccines ..................................................................................................................................................... 109
  - Anti-angiogenesis Therapy ......................................................................................................................... 109
  - Gene Therapy ............................................................................................................................................ 110
- Bone Marrow and Stem-cell Transplants .................................................................................................... 110
- Participating in Clinical Trials .................................................................................................................... 113
- Treatment for Relapsed NHL ...................................................................................................................... 115
- Empowerment and Patient Support Tools ................................................................................................. 116
  - Questions to Ask Your Healthcare Team .................................................................................................. 116
  - Understanding the Flow of Lymphoma Treatment ................................................................................. 117
  - Support Medications ................................................................................................................................. 120
  - Lymphoma Patient Charter ....................................................................................................................... 122
NHL Treatment

Understanding Cancer Treatment

NHL often responds very well to modern treatments. This does not mean that NHL is always curable but it does mean that treatment can often provide long cancer-free periods, reduced symptoms and improved quality of life for many patients. There are many different types of treatments for NHL, the most common of which include:

- Watchful waiting
- Chemotherapy
- Radiation therapy
- Biologic therapies, including:
  - Monoclonal antibody therapy
  - Radioimmunotherapy
  - Interferon
  - Vaccines (under clinical investigation)
  - Anti-angiogenesis therapies (under clinical investigation)
  - Gene therapies (under clinical investigation)
- Bone marrow or stem-cell transplants
- Experimental treatments obtained through patient participation in clinical trials.

What are the goals of NHL treatment?

The major goals of NHL treatment include:

- Cure (if possible)
- Bringing about and prolonging remission (cancer-free period)
- Minimizing the number of lymph nodes and/or organs affected
- Preventing the development of symptoms and treating existing ones
- Improving the patient’s quality of life.

What can I expect from treatment?

Each patient responds differently to treatment, as does each NHL type. Predicting response to treatment depends on many variables, including the exact type, stage and grade of NHL. For example, diffuse large B-cell lymphoma, a type of aggressive (fast-growing) NHL, is curable in 80% of patients when the disease is localized to one area of the body. Follicular lymphoma, a type of indolent (slow-growing) NHL, is usually spread throughout the body upon diagnosis. Follicular lymphoma can often remain dormant for years or decades requiring little or no treatment. It is responsive to treatment and will often go into remission (cancer-free period) for a period of time following treatment; however, it often relapses.
The variables, other than NHL type, stage and grade that can affect the success of treatment, are outlined in the following table:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Definition</th>
<th>Response Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Whether a patient is older or younger than 60 years of age.</td>
<td>Younger patients (younger than 60 years old) typically show better responses to treatment. Older patients often cannot tolerate side effects and less aggressive treatments are occasionally chosen.</td>
</tr>
<tr>
<td><strong>Prior Therapy</strong></td>
<td>Any previous cancer treatment the patient has received.</td>
<td>Patients who have had fewer previous cancer treatments are usually more responsive to new treatments.</td>
</tr>
<tr>
<td><strong>Performance Status</strong></td>
<td>A term describing how well a patient is able to perform daily tasks and activities.</td>
<td>The better the performance status, the more likely a patient will successfully tolerate and respond to treatment.</td>
</tr>
<tr>
<td><strong>Blood Proteins</strong></td>
<td>Proteins present in the blood that can be predictors of disease. The important blood proteins in NHL are lactate dehydrogenase (LDH) and beta (2) microglobulin (B2M), both of which indicate aggressive disease if present at high levels.</td>
<td>Patients with normal levels of LDH or B2M tend to respond better to treatment compared with patients who have higher levels.</td>
</tr>
<tr>
<td><strong>Extranodal Disease</strong></td>
<td>A term describing NHL that has spread outside of the lymphatic system.</td>
<td>Patients whose NHL is contained within the lymphatic system typically show a better response to treatment.</td>
</tr>
<tr>
<td><strong>Bulky Disease</strong></td>
<td>Any NHL tumour that is greater than 10 cm in diameter.</td>
<td>The presence of bulky disease can indicate a more advanced stage of NHL. Smaller tumours often respond better to therapy than larger ones.</td>
</tr>
<tr>
<td><strong>Stage of Disease</strong></td>
<td>The extent to which the cancer has spread in the body. NHL is divided into four stages: stages I and II are considered limited (involving a limited area) and stages III and IV are considered advanced (more widespread involvement).</td>
<td>Patients with stage I and II (limited stage) NHL usually have a better chance of a successful response to treatment.</td>
</tr>
</tbody>
</table>
The term prognosis is used to predict how a disease will likely progress after diagnosis and treatment. It refers to the outcome of the disease and the likelihood of recovery for that patient. The prognosis given to you from your doctor is based on statistical research from hundreds or thousands of patients who had your same type of cancer and other variables similar to yours. However, it is important to keep in mind that the prognosis is a prediction and does not always accurately reflect the course of disease for each person.

Doctors talk about results of treatment using certain terms that you may want to become familiar with. These are included in the glossary for easy reference but are also described here. They include:

- **Primary therapy:**
  The first treatment given after a patient is diagnosed with cancer. Also called induction therapy.

- **Complete remission:**
  Also called complete response. A term which means that all signs of the cancer have disappeared following treatment. Partial remission or partial response means that the tumour has decreased in size but is still detectable.

- **Partial remission:**
  Also called partial response. The term used when a cancer has decreased in size by half or more but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.

- **Improvement:**
  The term used when the tumour size has decreased but is still larger than half of its original size.

- **Cure:**
  The term used when no signs or symptoms of the disease have been present for a certain period of time and the tumour has been eradicated. The longer a patient is in remission (absence of signs or symptoms of cancer), the higher the likelihood of a cure.

- **Stable disease:**
  The term used when the cancer does not get better or worse following treatment.

- **Refractory disease:**
  A cancer that does not respond to treatment.

- **Disease progression:**
  A worsening of the disease despite treatment. The term is often used interchangeably with the term treatment failure.

- **Relapse:**
  The return of cancer after a period of improvement. NHL may recur in the same area as the original tumour or it may relapse in another body area.

- **Remission:**
  A patient is said to be in remission if the tumour has diminished by half or more (partial remission) or is undetectable (complete remission). Remission does not necessarily imply that the cancer has been cured. If a certain cancer, for example an aggressive lymphoma, remains in remission for a certain period of time, usually five or more years, it may be considered cured. However, indolent lymphomas are not commonly considered cured because these cancers can relapse even after a long period of remission.
Are there new treatments being developed?

NHL is a very active area of research and many new treatments or new combinations of existing treatments are being tested all the time. The goal of this research is to:

• Find more effective treatments for NHL;
• Decrease the side effects of NHL treatments, including both short- and long-term toxicities.

Significant advances have been made and continue to be made in NHL treatment. New hope for NHL is always on the horizon.

NHL Therapies Defined

Watchful Waiting (Also Called Watch and Wait)

Many patients who are diagnosed with indolent (slow-growing) NHL have no symptoms or other risk factors that require immediate treatment. These patients are closely monitored using a watchful waiting or watch and wait approach. They have regular visits with their doctor, including laboratory tests and tumour imaging (such as CT scans), but they do not receive treatment unless the disease progresses or symptoms appear.

Watchful waiting may initially cause distress to patients as it may seem a risky or passive approach to a serious disease. However, studies have demonstrated that the results are no different between those patients with indolent NHL who receive treatment immediately and those who wait until treatment is required. The benefit of watchful waiting is that it delays the side effects of cancer therapies, which can often be significant.

The watchful waiting approach does not mean nothing is done, the process is still an active one. Patients are seen regularly by their doctors and are very closely monitored for signs of disease progression. Patients in the watchful waiting category should be observant about the presence of disease symptoms, most notably the presence of B symptoms which may indicate that active treatment should begin. B symptoms include fever, night sweats and unexplained weight loss.

Most watchful waiting patients do go on to need active treatment for their NHL. However, some patients with indolent lymphomas never require treatment. If treatment is required, it typically begins about 18 months after the start of the watchful waiting approach.
Chemotherapy means using chemicals to treat disease. In cancer, chemotherapy means medications that kill cancer cells or prevent their growth. Most patients with NHL will have chemotherapy at some point during their treatment. Chemotherapy works to prevent lymphoma cells from multiplying and to remove or reduce the number of cancerous cells in the body. It is often part of a larger treatment plan, used in combination with other therapies such as radiation or biologic therapy.

How does chemotherapy work?

Chemotherapy is a systemic therapy (affecting the whole body) that targets and kills rapidly dividing cells in the body, such as cancer cells. There are normal cells in the body which are rapidly dividing as well, and chemotherapy may damage these healthy cells. This is why chemotherapy can have side effects including hair loss, diarrhea, nausea and vomiting. Not all patients experience side effects from chemotherapy; if side effects do occur they can often be mild and treated effectively.

Chemotherapy drugs work on the premise that cancer cells are always dividing and that normal cells, even those that have a fast turnover rate, are most often found in the resting (non-dividing) state in the body, dividing only when necessary. Chemotherapy tries to exploit this difference between normal and cancerous cells, aiming to preferentially attack tumour cells as they divide.

How chemotherapy works
What are the different types of chemotherapy?

There are many different ways of attacking rapidly dividing cells and hence, many different types of chemotherapy. Some types of chemotherapy drugs interact with receptors on the surface of cancer cells, some damage cell structures necessary for cell division and some directly target the cancer cell’s DNA, the genetic material of the cell. Because these are all different ways of achieving the same result—death of the cancer cells—chemotherapy drugs are often given in combination in order to attack the lymphoma cells from all possible angles to increase the odds of achieving remission.

Chemotherapy combinations are often known by the initials of the names of the drugs in the combination. Two of the most common combinations used in NHL are called CHOP and CVP. CHOP is a combination of four drugs, namely, three chemotherapy medications and one steroid medication:

- Cyclophosphamide
- Doxorubicin (also called Hydroxydaunorubicin)
- Vincristine (also called Oncovin)
- Prednisone (the steroid medication).

CVP is a combination of two chemotherapy drugs and a steroid:

- Cyclophosphamide
- Vincristine (also called Oncovin)
- Prednisone (the steroid medication).

Steroid medications are included in these regimens as they are effective therapies for lymphoma and can quickly get NHL symptoms under control.

The type of chemotherapy a patient with NHL receives depends on a number of variables, including:

- The type of NHL
- The grade of NHL (whether the NHL is indolent or aggressive)
- The stage of NHL
- Whether it’s the first NHL treatment for the patient or if the NHL has relapsed following prior therapy
- The symptoms the patient is experiencing
- The overall health of the patient including age, medical history and vitality (often referred to as the performance status of the patient)
- The recommendations of the medical oncologist
- The choice and participation of the patient in the treatment decision process.
How is chemotherapy given?

Each dose of chemotherapy kills only a percentage of cancer cells. Chemotherapy is, therefore, often given in multiple treatments in order to destroy as many cancer cells as possible. Treatments are scheduled as frequently as possible to minimize the growth of the tumour and achieve the best possible outcome.

Chemotherapy is often given in cycles where the treatment is given for a period of time (e.g., every three weeks) followed by a rest period where no treatment is given. The rest period allows the healthy cells to recover. Together each period of treatment and rest is called a chemotherapy cycle. A full course of chemotherapy (the number of chemotherapy cycles given in total, e.g., six cycles) often takes several months. Most chemotherapy treatments can be given in an outpatient clinic, so patients can go home the same day.

Chemotherapy may be given in different forms: pills, injections or intravenous administration (administered directly into the bloodstream over a period of time through a needle). If you are going to be receiving multiple cycles of intravenous chemotherapy, your doctor may recommend having a venous catheter inserted. A venous catheter is a device, usually a flexible tube, that is inserted into a vein for easier administration of intravenous drugs. A central line is a more permanent catheter that is usually inserted into a vein at the top of the chest. Both central lines and venous catheters can be left in place so you will not require a new needle with each intravenous treatment. As well, both central lines and venous catheters may be used to transfuse blood products into a patient or to easily remove blood for blood tests.

A cancer is often defined as chemosensitive or chemoresistant. Chemosensitive means that the tumour is responsive to chemotherapy and the chemotherapy treatment is effective in killing the cancer cells, whereas chemoresistant means that the tumour does not respond to chemotherapy and an alternate treatment is required.
Can the dose be reduced if I have a lot of side effects?

It is very important to try to maintain the highest tolerable dose during chemotherapy treatment. Studies have shown that reducing the dose or delaying chemotherapy treatments until side effects subside may decrease the likelihood of cure and the chances for long-term survival in some types of lymphomas. It is important for you as a patient to understand that changing the regimen to reduce short-term side effects may actually be harmful in the long run. However, your present quality of life is valuable as well, and you need to decide whether the side effects are tolerable or not. It is important to make this decision in an informed way and understand the potential consequences of your choice.

What are the side effects of chemotherapy?

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

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

Many of the side effects caused by chemotherapy are due to the effect the medications have on the healthy, non-cancerous cells of the body. The following table outlines the most common cell types affected as a result of chemotherapy, as well as the resulting side effects.

<table>
<thead>
<tr>
<th>Cells Affected</th>
<th>Associated Side Effects</th>
</tr>
</thead>
</table>
| Cells of the digestive system including the mouth, esophagus, stomach and intestines | • Mouth sores  
• Sore throat  
• Diarrhea  
• Nausea  
• Vomiting  
• Changes in taste  
• Loss of appetite |
| Cells of the skin and hair                                                      | • Hair loss                                                  |
| Cells of the bone marrow; red blood cells, white blood cells and platelets      | Decreased blood cell production (myelosuppression), including:  
• Anemia (decrease in red blood cells)  
• Neutropenia (decrease in white blood cells)  
• Thrombocytopenia (decrease in platelets) |
Mouth Sores and Sore Throat

What is it?

Mouth sores occur when the inside of your mouth becomes red, sore and irritated. It is often called mucositis. Your throat may also be sore. Infections of the mouth and throat may occur. If you have a persistently sore mouth or throat you should tell your doctor.

What can I do?

There are a number of things you and your doctor can do to prevent and treat mouth sores:

- Clean your teeth gently after each meal with a soft, nonabrasive toothbrush.
- Use lip moisturizer to avoid dry, irritated lips.
- Avoid mouthwashes that contain alcohol.
- Avoid citrus fruits, citrus juices and spicy foods.
- Rinse your mouth frequently with a salt and water combination or club soda (an easy-to-use salt and water combination).
- Eat softer foods so they are easier on the moist tissues of your mouth.
- Avoid flossing your teeth if your blood cell counts are low.

Diarrhea

What is it?

Frequent and watery bowel movements.

What can I do?

The most important consequence of diarrhea is dehydration (loss of body fluids). To avoid dehydration, the following tips may be useful:

- Drink plenty of water throughout the day.
- Avoid milk products as they may worsen your diarrhea.
- Pay attention to the signs of dehydration: dry mouth or skin, decreased urination, and dizziness or lightheadedness upon standing.
- Take the medications your doctor recommends for controlling diarrhea.
Nausea and Vomiting

What is it?
Chemotherapy can often be associated with both nausea (the urge to vomit) and vomiting. Nausea most commonly occurs on the day you receive the chemotherapy but can also occur in the few days following treatment.

What can I do?
Your doctor may prescribe an antiemetic (a drug that prevents vomiting) or an antinauseant (a drug that prevents nausea) to take before you begin chemotherapy. This can often prevent both the nausea and vomiting from occurring. If you do experience these symptoms, the following are ways to control them:

- Consume mostly liquids for the first one to two days after your chemotherapy treatment (returning to solid foods once the feeling has subsided); soups are a good choice including broths or consommés; however, avoid milk-based soups.
- Avoid foods that are too hot, sweet or spicy.
- Eat smaller meals more frequently throughout the day instead of three large meals.
- Get plenty of fresh air and try to avoid strong or unpleasant odours.
- Take the medication prescribed by your doctor.
- If you do experience vomiting, be sure to stay hydrated (see the tips in the diarrhea section on page 95).
- Take the antiemetic/antinauseant medication prescribed by your doctor.

Changes in Taste

What is it?
Chemotherapy can often alter the taste of foods. Familiar foods can taste different (called dysgeusia) or food flavours can taste less intense than normal (hypogeusia). Taste changes are usually temporary and disappear once your chemotherapy treatment is completed.

What can I do?
- Certain foods may be more appealing than others; if foods are not appetizing they may need to be avoided for a period of time and then gradually re-introduced.
- Keeping your mouth fresh and clean and frequently rinsed may help.
Loss of Appetite

What is it?
Loss of appetite is a common side effect of chemotherapy. It may be a result of other symptoms, such as nausea, vomiting or taste alterations.

What can I do?
It may help to eat smaller, more frequent meals throughout the day. You may find this symptom improves if strong odours are avoided, if you avoid food preparation and if you eat cold food instead of hot. Even though food is unappetizing, it is still very important to stay hydrated by consuming fluids and trying to eat healthy foods to stay strong.

Hair Loss

What is it?
Hair loss, also called alopecia, is a common side effect of chemotherapy and can affect the hair of the scalp, eyebrows, eyelashes, arms, legs and pelvic region. It affects different people in different ways. Some people may lose all their hair and some may only experience thinning of their hair. Hair loss or thinning usually begins gradually, within two to three weeks of your first chemotherapy treatment. This can be a very distressing side effect for patients. However, not everyone experiences hair loss and most people have a normal amount of hair within six months after their final chemotherapy treatment.

What can I do?
Here are some tips for minimizing and coping with hair loss:

- Pat your head dry rather than rubbing it vigorously with a towel.
- Avoid hair dryers, curling or straightening irons.
- Avoid dying your hair or using other chemicals.
- Wear a hat when exposed to the sun as areas of hair loss are very susceptible to sun damage.
- Consider wearing a hat, wig, scarf, turban or head wrap if it makes you feel better.
Decreased Blood Cell Production

What is it?

Blood cells, including red blood cells, white blood cells and platelets, are continually being produced in the bone marrow. Because these cells are always dividing, they are also targeted by chemotherapy and, therefore, the number of all blood cells can be reduced. This is called myelosuppression. There are different types of myelosuppression depending on which blood cell is affected. They are anemia, neutropenia and thrombocytopenia.

- **Anemia** is the term used to describe a decrease in the number of red blood cells, the oxygen carrying cells in the blood. Anemia can often cause patients to feel tired and lethargic and may require treatment if severe. Sometimes patients are prescribed injections to help stimulate the growth and production of red blood cells and decrease the side effects of anemia. Occasionally, blood transfusions are required for more severe anemia, especially when the bone marrow has been affected by the lymphoma.

- **Neutropenia** occurs when there is a decrease in the number of neutrophils, a certain type of white blood cell. Neutrophils are very important for fighting infection. When there are too few, patients are more at risk for developing serious infections. If the neutropenia is severe, the chemotherapy may have to be delayed or the dosage reduced, as the risk of infection is serious. Sometimes patients with neutropenia are prescribed antibiotics to help fight off any possible infections. Injections may also be required on a routine basis to stimulate the growth and production of white blood cells and decrease the side effects of neutropenia.

- **Thrombocytopenia** is the term used to describe a decrease in the number of platelets, cells that are very important for blood clotting. If platelet counts are low, a patient may experience increased bruising or excessive bleeding from cuts, nosebleeds and bleeding gums. Treatment may be needed if the thrombocytopenia is severe, with the usual treatment being a blood transfusion. Avoidance of blood-thinning medications (e.g., aspirin or anti-inflammatory drugs) may also be recommended.

What can I do?

The most important thing you can do is be alert for signs of myelosuppression. Signs of anemia include fatigue and lethargy. Signs of neutropenia include symptoms like fever, sore throat, rash, diarrhea, or redness, pain or swelling around a wound. Signs of thrombocytopenia include easy bruising or prolonged bleeding. If you notice these symptoms, inform your doctor immediately so appropriate action can be taken.
Fatigue

What is it?
Fatigue, or tiredness, is a common side effect of chemotherapy and usually goes away shortly after the treatment is complete. Severe fatigue can be a symptom of anemia and should be mentioned to your doctor. Fatigue is usually due to the strong chemotherapy medications and their effects on your body. It can also be due to the cumulative effects of many chemotherapy cycles, even those involving weaker chemotherapy drugs.

What can I do?
Some ideas about handling fatigue include:

• Keeping a diary to help you keep track of the times of day when you feel most tired. This can help you plan activities according to how you are feeling, that is to say rest when you need to and use the time when you’re not tired to go about your daily activities;
• Asking friends and family for help;
• Exercising when you have the energy and as long as your doctor says it’s all right to do so. Yoga, stretching and short walks can increase your energy and improve your overall vitality. Start slowly and build up your endurance to a comfortable range;
• Getting the rest and sleep you need while receiving chemotherapy. It may be important to take time off work and adjust your daily schedule to accommodate for rest and recuperation. Try not to rest more than necessary, as this can sometimes make you feel even more fatigued.
Radiation Therapy

Unlike chemotherapy which is a systemic therapy (affects the whole body as it is infused into the bloodstream), radiation therapy is a local therapy meaning that it only treats the area of the body where the cancer is located. Radiation therapy is often combined with chemotherapy but is sometimes used alone as the main treatment.

How does radiation therapy work?

Radiation therapy (also called radiation or radiotherapy) uses high-energy X-rays to kill cancer cells. The X-rays cause damage to the cell's DNA (the genetic material of the cell) which makes it impossible for the cancer cell to repair itself, ultimately causing the cell to die. The radiation does not decipher between cancerous and non-cancerous cells and, therefore, healthy cells in the area will be killed off as well. Care is always taken to plan the treatment properly and ensure that other areas of the body are affected as little as possible. Normal cells affected by the radiation have a greater capacity to heal themselves than the lymphoma cells.

How is radiation therapy given?

A radiation field is the area of the body marked to receive the radiation therapy. To clearly outline the radiation field the skin is marked with tiny ink dots called tattoos. This ensures that the appropriate area is targeted for the radiation and that the exact same area is treated each time. Radiation is usually confined to lymph nodes or the area immediately surrounding the lymph nodes. The radiation field is different in each person and depends on many factors including the type of lymphoma and the extent of the disease. Healthy areas are shielded from the radiation with lead shields similar to the ones you wear at the dentist when receiving an X-ray. Lead blocks the path of any stray radiation beams and prevents them from affecting the DNA of normal cells.
At the beginning of your treatment you may attend a session called planning. You will be in a room with a technician, a nurse and one or two doctors. Other than the fact that there will be no radioactive source in the room, the planning session will be very similar to what will happen when you receive your radiation therapy. For this reason it is often called a simulation.

Prior to the radiation treatment, you will be carefully positioned on a treatment table, with the parts of the body not being treated protected. You must lie completely still during the treatment. Often a mould is created or certain props such as pillows or rolled blankets are used to minimize movement. Above the treatment table is the large machine which delivers the radiation. The actual treatment lasts only for a few minutes and causes no pain or discomfort.

Radiation therapy is most often given on an outpatient basis. You may have to visit the hospital as many as five times per week during a course of radiation therapy. The total dose deemed appropriate for you is divided up and given over a period of one to six weeks. Each dose of radiation is called a fraction and the radiation oncologist prescribes a total number of fractions for your specific treatment.

**What are the side effects of radiation therapy?**

Although the radiation treatments are painless, there may be some associated side effects. The side effects are usually limited to the area of the body receiving the radiation and may vary based on the targeted site. The most common side effects are listed here followed by helpful coping suggestions.

<table>
<thead>
<tr>
<th>Targeted Area</th>
<th>Possible Side Effects</th>
</tr>
</thead>
</table>
| Head and neck (areas affected can include the scalp, mouth and throat) | • Hair loss  
  (on the scalp or anywhere the radiation is targeted)  
• Loss of appetite and taste  
• Dry mouth  
• Throat irritation  
• Skin reactions |
| Chest (areas affected can include the esophagus and breasts) | • Difficulty swallowing |
| Abdomen                                           | • Nausea  
• Diarrhea |
Hair Loss

What is it?
Hair loss from radiation is not like the general hair loss that occurs with chemotherapy. It involves only a patch of hair loss that occurs depending on the area of the body that receives the radiation. If the radiation was targeted at the head, a patch of hair loss may occur on the head. If the radiation was targeted at a specific lymph node in the groin area, there may be a loss of hair in the groin region. The hair loss is usually temporary; however, with high doses of radiation it may be permanent.

What can I do?
Here are some tips for minimizing and coping with hair loss:
- Pat your hair dry rather than rubbing it vigorously with a towel.
- Avoid hair dryers, curling or straightening irons.
- Avoid dying your hair or using other chemicals.
- Wear a hat when exposed to the sun, as areas of hair loss are very susceptible to sun damage.
- Consider wearing a hat, wig, scarf, turban or head wrap if it makes you feel better.
- You may require special shampoos or soaps. You can ask your radiation oncologist if these would be helpful for you.

Loss of Appetite and Taste

What is it?
Following radiation therapy you may find that foods you previously enjoyed no longer appeal to you. You may also not feel as hungry as you normally do.

What can I do?
It is very important to try to eat to keep your energy up and nutrition status optimal. It may help to eat smaller, more frequent meals throughout the day. You may find your appetite and taste improve if you can avoid strong odours and food preparation, and eat cold food instead of hot. Even though food is unappetizing, it is still very important to stay hydrated by consuming fluids, and trying to eat healthy foods to stay strong.
Dry Mouth and Throat Irritation

What is it?
After radiation therapy in the area of the mouth, saliva production may be decreased and patients may experience a dry mouth, also called xerostomia. Throat irritation may also occur from the decreased saliva or direct effects from radiation to that area.

What can I do?
Drink lots of fluids to keep your mouth as moist as possible. Saliva is important for fighting cavities so it may be necessary to use extra oral hygiene such as brushing your teeth after each meal and flossing (use caution with flossing if your blood cell counts are low). Your doctor may recommend you visit your dentist prior to receiving radiation treatments. Warm, gentle mouthwashes (non-alcohol based) may help refresh the area and decrease irritation. Eating foods that are more easily digested (soft foods or liquid dietary supplements) may be easier on your throat. Eating smaller meals and avoiding acidic foods like citrus fruits and citrus juices may also help.

Skin Reactions

What is it?
The area of skin that was exposed to the radiation may become red, irritated, itchy and flaky. Moist areas like the mouth may be more severely affected and may require treatment. It often looks and feels as though the area is sunburned and the skin may begin peeling. The skin reactions are usually short-lived and diminish over a few weeks.

What can I do?
It is important to protect these areas of skin from further damage. They should not be exposed to the sun, and should always be protected with sunscreen, even once the radiation therapy has finished. During treatment, your doctor may prescribe an alcohol-free, fragrance-free lotion or cream to apply to the affected area.

Difficulty Swallowing

What is it?
You may experience difficulty swallowing due to a dry mouth, or because the radiation has affected the esophagus which is involved in swallowing.

What can I do?
Staying hydrated and keeping the tissues in your mouth and throat as moist as possible may help. Eating softer, more digestible foods will cause less pain on swallowing and are easier to move through the digestive system. Healthy shakes and nutritious soups are good choices. Eating smaller meals more frequently may help ease the irritation.
Nausea

What is it?
Radiation therapy targeted towards the abdomen can sometimes cause nausea (the urge to vomit). The nausea may occur after the first radiation treatment.

What can I do?
Not eating in the few hours prior to your radiation treatment may help. Scheduling your treatments towards the end of the day may be helpful, so if you do feel nauseous, you can deal with it at home. Your doctor may prescribe an antiemetic (a drug that prevents vomiting) or antinauseant (a drug that prevents nausea) to be taken prior to the radiation treatment. If you experience nausea, the following are some ways to keep it under control:

- Consume mostly liquids leading up to your radiation treatment, including soups such as broths or consommés (avoid milk-based soups).
- Avoid foods that are too hot, cold, sweet or spicy, especially right before your treatment.
- Eat smaller meals more frequently throughout the day instead of three large meals.
- Get plenty of fresh air and try to avoid strong or unpleasant odours.
- Take the medication prescribed by your doctor.
- If you do experience vomiting, be sure to stay hydrated (see the tips in the Diarrhea section below).

Diarrhea

What is it?
Frequent and watery bowel movements.

What can I do?
The most important consequence of diarrhea is dehydration (a loss of body fluids). To avoid dehydration, the following tips may be useful:

- Drink plenty of water throughout the day.
- Avoid milk products as they may worsen diarrhea.
- Pay attention to the signs of dehydration: dry mouth or skin, decreased urination, and dizziness or lightheadedness upon standing.
- Take the medications your doctor recommends for controlling your diarrhea.
Are there long-term side effects with radiation therapy?

It is possible for radiation to cause long-term side effects. The following table outlines the possible consequences of radiation given to different areas of the body. It is important to discuss these risks with your doctor if you feel concerned.

<table>
<thead>
<tr>
<th>Treatment Area</th>
<th>Possible Long-Term Effect</th>
<th>What You Can Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pelvis or groin</td>
<td>Infertility</td>
<td>Ensure that the testes/ovaries are shielded from radiation if they are not the target of the treatment. If you have not yet had children, talk to your doctor about the risks associated with having children after radiation therapy.</td>
</tr>
<tr>
<td>Chest and breasts</td>
<td>Breast cancer</td>
<td>Long-term breast cancer screening is very important.</td>
</tr>
<tr>
<td>Skin</td>
<td>Skin cancer</td>
<td>Long-term skin cancer screening is very important. Protect your skin from the sun by using sunscreen and minimizing exposure.</td>
</tr>
<tr>
<td>Neck</td>
<td>Thyroid cancer</td>
<td>Discuss the risks with your doctor and have your thyroid checked on a regular basis.</td>
</tr>
</tbody>
</table>
Biologic Therapies

Biologic therapies are treatments that work by using the body’s own immune system to fight the cancer. There are different types of biologic therapies including:

- Monoclonal antibody therapy
- Radioimmunotherapy
- Interferons
- Vaccines (under clinical investigation)
- Anti-angiogenesis therapies (under clinical investigation)
- Gene therapies (under clinical investigation).

Monoclonal Antibody Therapy

How do monoclonal antibodies work?

The immune system is a network of specialized cells that defend the body against “foreign” invaders (antigens) including bacteria, viruses and parasites. Important parts of the immune system are proteins called antibodies. The immune system makes antibodies to attach to the antigens which are usually found on the surface of cells. The antigens can then be identified and destroyed by the immune system.

Monoclonal antibodies (MABs or MOABs) work on cancer cells in the same way natural antibodies work, by identifying and binding to the target cells. They then alert other cells in the immune system to the presence of the cancer cells. MABs are specific for a particular antigen and are classified as biological response modifiers. Since they affect the immune system, they are called immunotherapy as opposed to chemotherapy which are drugs that interfere in cancer cell growth.

For NHL, the monoclonal antibodies are specifically targeted to antigens found on lymphocytes, the normal body cell that lymphomas are derived from. The attachment of the monoclonal antibody to its target antigen triggers the cell to destroy itself and signals to the body’s immune system to attack and kill the cancer cell. Several monoclonal antibodies are available for the treatment of NHL and many more are under clinical investigation.

Rituximab (Rituxan®) is a monoclonal antibody that tightly attaches itself to the CD20 antigen on the surface of B-cells, the cancerous cell in many types of NHL. The CD20 antigen is also present on the surface of healthy, non-cancerous B-cells, which means that Rituxan® will also attach to and facilitate the destruction of these cells. However, normal B-cells, like all blood cells, are produced in the bone marrow from stem cells, and the stem cells do not have the CD20 antigen, meaning that they are not affected by monoclonal antibodies and are not destroyed. Stem cells can then replenish the store of healthy B-cells in the body. So although during treatment with Rituxan® the number of mature, normal B-cells is temporarily reduced, their levels return to normal once the treatment is completed.

Rituxan® is a commonly used treatment for patients with either indolent or aggressive NHL. It is used on its own or in combination with chemotherapy and has been shown to increase the length of remission in indolent (slow-growing) NHL. It can also increase a patient’s chance of cure in aggressive (fast-growing) NHL.

Alemtuzumab (Campath®) targets CD52, a protein present on the surface of mature lymphocytes but not on the stem cells from which these lymphocytes were derived. It is used in patients with CLL.

Monoclonal antibodies can also be combined with radiation therapy which delivers a dose of radiation directly to the lymphoma cell. These are called radioimmunotherapies and are discussed in the section titled Radioimmunotherapy on page 108.
How are monoclonal antibodies given?

Rituximab (Rituxan®) is given intravenously and can be given alone or in combination with chemotherapy, often increasing the effectiveness of chemotherapy treatments while alemtuzumab (Campath®) is given alone (monotherapy). Medications to prevent side effects are given prior to the monoclonal antibody treatment. If side effects occur the treatment can be given at a slower infusion rate or stopped until the side effects pass.

When given on its own Rituxan® is usually given as four weekly treatments over a 22-day period. When given in combination with chemotherapy, one dose of Rituxan® is administered with each cycle of treatment (typically eight cycles).

Alemtuzumab (Campath®) infusions generally take two hours. The first few doses are usually given in a dose-escalation format, until the recommended dose is reached. For example, the first day of treatment you are given a very low dose. If you do not have any serious side effects, you will be given a slightly higher dose the following day. Most patients are able to reach the recommended dose in three to seven days. Once you have reached the recommended dose, the schedule for treatment is every other day, three days per week. You can receive this treatment for up to 12 weeks, as long as the cancer cells continue to respond to this therapy and you are tolerating any side effects.

Prolonged treatment with Rituxan®, called Rituxan® maintenance therapy, is approved by Health Canada for the treatment of patients with follicular NHL who have responded to their initial treatment. This means that patients who have received treatment for follicular lymphoma and have achieved remission (complete or partial) may benefit from prolonged administration with Rituxan® (generally administered every three months for a period of two years).

Are there side effects from monoclonal antibody therapy?

Unlike the side effects associated with chemotherapy and radiation, most of the side effects from monoclonal antibody treatment are minor and short-lived, lasting only during the actual treatment and for a few hours afterwards. The chances of experiencing side effects also decrease with each treatment received because the patient adjusts to the treatment and, as treatment continues, there are fewer lymphoma cells to kill. The most common side effects are flu-like symptoms including fever, chills and sweating. Less common side effects include nausea, vomiting, rashes, fatigue, headache, wheezing, infection, and a sensation of tongue or throat swelling. Patients are monitored throughout the treatment session for signs of allergic reactions including itching, rashes, wheezing and swelling. If these symptoms occur, the treatment is slowed down or stopped for a short time until the symptoms subside. Antihistamines (e.g., Benadryl®) and acetaminophen are commonly given before treatment to avoid allergic reactions.
Radioimmunotherapy

Radioimmunotherapy uses both radiation therapy and monoclonal antibody therapy to fight lymphoma. A radioactive molecule (a molecule that emits radiation and is capable of killing cancer cells) is attached to a monoclonal antibody so that the radiation is delivered specifically to lymphoma cells (see the section entitled Monoclonal Antibody Therapy for a more detailed explanation of how this works). It uses the effective targeting mechanism of the monoclonal antibody and the cancer-killing effect of radiation.

How does radioimmunotherapy work?

Radioimmunotherapy uses monoclonal antibodies that have radioactive materials attached to them. These radioactive monoclonal antibodies circulate in the body until they find their target—the CD20 antigen of the B-cell (a protein found specifically on B-cells)—and attach themselves there. Once attached, the radiation kills the cancerous B-cell as well as any other lymphoma cells that are nearby.

How are radioimmunotherapies given?

Radioimmunotherapies are administered intravenously in the nuclear medicine clinic at the hospital. Two radioimmunotherapy agents are currently available for the treatment of NHL. These agents, called ibritumomab tiuxetan (Zevalin®) and tositumomab (Bexxar®), target the CD20 antigen on B-cells. They are commonly given to patients with relapsed indolent NHL who are no longer responding to conventional chemotherapy or monoclonal antibody treatment with rituximab (Rituxan®).

What are the side effects associated with radioimmunotherapy?

There are some side effects from radioimmunotherapy which you may want to discuss with your doctor. Certain blood-related side effects may be of concern. These include anemia (low red blood cell counts), thrombocytopenia (low platelet counts) and immunosuppression (decreased immune function, a condition which could leave you at increased risk of infection). Other common side effects include chills, fever, nausea and throat irritation. As with any radiation treatment, there are increased long-term risks of certain cancers.

It may be necessary to speak with a doctor about safety precautions following radioimmunotherapy, as a small amount of radiation may be present in the body, i.e., in the blood and urine, for a short period after treatment. These precautions may include washing hands thoroughly after urination and using a condom during sexual intercourse. Flushing the toilet twice after going to the washroom is also a good idea.

Your cancer care team can determine if radioimmunotherapy is the right treatment for you.
**Interferons**

Interferon is a protein molecule that is naturally produced by the body’s immune system to help fight infection and kill cancer cells in the body. A synthetic form of interferon has been produced and is used to treat certain kinds of NHL. It is thought that interferon kills tumour cells directly and signals to the rest of the immune system to do the same. Interferon can be given as a maintenance therapy to prolong the remission of patients previously treated with chemotherapy.

Flu-like symptoms are the most common side effects from interferon treatment. They include low-grade fever, fatigue, weakness, and muscle and joint aches. Staying well hydrated often helps with these side effects, as do non-prescription pain medications if recommended by your doctor. Interferon therapy can sometimes cause severe depression. Tell your doctor if you are feeling depressed. Less common side effects with interferon therapy include loss of appetite, aversion to food and a decrease in thyroid function. Due to the large number of associated side effects and the array of newer treatment options, interferon is rarely used in the management of NHL.

**Vaccines**

We are all familiar with standard vaccines for diseases such as polio and tetanus. Vaccines work by injecting an inactive portion of a disease molecule, too weak to cause the disease but strong enough to stimulate antibody production. Upon future exposure to the same disease, the body will be ready to mount a strong attack against it.

Vaccines are currently being studied as a potential treatment for lymphoma but are not yet approved for use. These vaccines are custom-made from each person’s unique tumour. A small amount of a patient’s tumour is taken from a lymph node, modified to make it look like a foreign invader (so the patient’s immune system will attack it), and reinjected back into the patient to stimulate antibody production and an immune response. The idea is that the immune system will then attack the tumour and break it down.

It is not yet known how effective these vaccines will be, but they do look promising. A major goal of cancer treatment is the development of therapies that are less toxic than chemotherapy or radiation therapy. Vaccines, like monoclonal antibodies, could provide a new option.

**Anti-angiogenesis Therapy**

Angiogenesis means the development of new blood vessels. Many cancers are able to stimulate angiogenesis causing new blood vessels to form to supply energy and nutrition to the growing tumour. Anti-angiogenesis therapies work to stop the development of new blood vessels and destroy existing abnormal vessels surrounding tumours. The goal is to cut off the fuel supply to growing tumours and facilitate tumour cell death. Anti-angiogenesis therapies are currently under investigation in the therapy of lymphoma.
Gene Therapy

The main goal of gene therapy is to alter the genetic structure of cancer cells so they can no longer grow, or so they can be recognized by the body’s immune system and destroyed. Other kinds of gene therapies may be able to make cancer cells more vulnerable to chemotherapy and normal cells less vulnerable. This could increase the effectiveness of the chemotherapy but decrease the toxic side effects. Gene therapies are still under investigation but hold promise for future cancer treatments.

Bone Marrow and Stem-cell Transplants

Bone marrow is the spongy material inside the large bones of the body that is responsible for all blood cell production: red blood cells, white blood cells and platelets. Red blood cells carry oxygen throughout the body, white blood cells make up the immune system and fight infection, and platelets are important for blood clotting. These cells are all developed from precursor cells called stem cells. These stem cells are also contained in the bone marrow.

How do stem-cell transplants work?

Stem cells, because they divide rapidly, can be killed off by chemotherapy and radiation therapy. Therefore, the doses of chemotherapy and radiation therapy used to treat lymphoma are limited due to the risk of damaging these stem cells. Patients with lymphomas that are difficult to treat or resistant to standard therapy may benefit from chemotherapy or radiation therapy given in very high doses (myeloablative therapy). However, this can potentially destroy all the stem-cells in the bone marrow and leave the patient at very high risk for infection. To combat this problem, the patient receives a bone marrow or a stem-cell transplant. This means that they receive stem cells (either their own stem cells that were stored prior to myeloablative therapy or stem cells from a donor) to replenish their bone marrow which had previously been destroyed by the high-dose therapy.

What is the difference between a bone marrow transplant and a stem-cell transplant?

There are two different types of transplants: bone marrow transplants and peripheral blood stem-cell transplants (PBSCTs). The difference between the two depends on where the stem cells are taken from. In bone marrow transplants, the stem cells are taken from the bone marrow. In PBSCTs, the stem cells are taken from the circulating blood. PBSCTs are now more commonly performed than bone marrow transplants, as the procedure is easier and the body is able to regenerate new stem cells faster.

Where do the transplanted stem cells come from?

Stem cells are transplanted into the patient after myeloablative therapy (chemotherapy or radiation therapy that destroys the stem cells in the bone marrow). The transplanted stem cells can come from two sources: the patient themselves, in which case it is called an autologous transplant, or from a compatible donor, in which case it is called an allogeneic transplant. Autologous transplants are more commonly performed in the management of NHL as they are better tolerated by the cancer patient.
How are transplants performed?

Four steps are involved in a bone marrow transplant or PBSCT:

1. **Harvesting stem cells or bone marrow:** Harvesting is the procedure by which the bone marrow or stem cells are obtained in preparation for the transplant. In a bone marrow transplant, the stem cells are withdrawn from the bone marrow under general anesthesia by inserting a needle into a bone in the pelvic region, called the iliac crest. This bone marrow is then filtered and stored until the day of the transplant. In a PBSCT, stem cells are taken from the bloodstream, a far easier and more commonly used procedure. The stem cells are separated from other components of the blood in a process called apheresis, with the rest of the blood being returned to the patient.

2. **Processing/preserving the stem cells or bone marrow:** Stem cells or bone marrow harvested from the patient (autologous transplant) are generally preserved and stored in a freezer until ready for use. Stem cells or bone marrow derived from a donor (allogeneic transplant) are usually collected immediately before use and not stored for any length of time.
3. **Administering myeloablative therapy:** High-dose chemotherapy, with or without myeloablative radiation therapy, is then administered to the patient to destroy the cancerous cells, as well as the healthy cells in the bone marrow.

4. **Reinfusing harvested stem cells or bone marrow:** The harvested stem cells or bone marrow (obtained from either the patient’s own healthy cells or from a donor) are then transplanted intravenously into the bloodstream of the patient. The stem cells travel through the body to the bone marrow where they settle and implant themselves. These stem cells slowly begin to produce new, healthy blood cells. Eventually, they will produce enough healthy cells to repopulate the whole bone marrow, replenishing all blood and immune cells. Before the immune system is able to regenerate, the patient is at an increased risk of infection and must be closely monitored. The patient may also be susceptible to bleeding complications.

### What are the side effects of transplants?

Transplants are very strenuous procedures and take weeks or months to complete. They also take a large toll on the body. As such, they are not an option for all patients. Various factors, including age, medical history, type of lymphoma and response to previous therapies are considered.

A major risk associated with transplants is infection, due to the loss of immune function from the myeloablative therapy. Owing to the loss of platelets (necessary for effective blood clotting), bleeding also becomes an important concern. Both of these side effects are treatable, with antibiotics given to prevent infection and platelet transfusions to prevent bleeding. Transfusions of red blood cells may also be required for anemia. Other side effects may include nausea, vomiting, fatigue, loss of appetite, mouth sores, hair loss and skin reactions. These are mainly due to the side effects of the myeloablative therapy.

Some long-term side effects of myeloablative therapy can include infertility (the inability to have children), cataracts (a clouding of the lens of the eye that can result in decreased vision), damage to various organs including the liver, kidneys, lungs and heart, and the potential for a new cancer to develop.

A complication called graft-versus-host disease (GVHD) can occur with allogeneic transplants (when the bone marrow or stem cells come from a donor and not the patient themselves). The immune cells from the donated tissue (the graft) can react against the cells of the patient who received the transplant (the host) and attack them. This can cause damage to the patient’s organs, including skin, liver and digestive tract. This reaction can occur within a few weeks of the transplant procedure (called acute GVHD), or much later (called chronic GVHD). GVHD can be serious and difficult to treat. Doctors commonly try to prevent it ahead of time using medications and specific procedures that can reduce the immune reaction of the donor and the patient.
Participating in Clinical Trials

Many patients respond excellently to NHL therapy. However, there are some patients who do not respond as well to treatment and there are some types of NHL where treatment is less successful. As such, research is constantly underway to develop new treatments and to improve existing ones. A major part of developing new treatments involves clinical trials—carefully planned research that is conducted on patients in order to test new medications or new treatment approaches. The new treatment is usually compared with an existing treatment to determine if the outcome is more beneficial for patients.

What is a clinical trial?

A clinical trial is a type of study where disease treatments are tested on patients. A clinical trial can test many aspects of treatment, including the safety and effectiveness of new medications, the addition of new medications to standard treatments and potential new methods of administering standard treatments. Trials usually compare a new treatment with a standard treatment. These trials are called randomized controlled trials. In these trials, half the patients receive the new treatment and half receive the standard treatment. This is why the trial is called controlled, as the new treatment is compared with treatment whose effects are already known. A computer determines which patient receives which treatment to ensure that the comparison is truly objective and not biased. This is the process of randomization and hence the term randomized trial. If the doctors who treat the patients were to decide who receives the new treatment and who does not, they might be biased towards choosing the sickest patients to receive the new treatment, making the results less accurate and less reliable for the future.

The protocol of a clinical trial is examined and approved by ethics committees and must meet rigorous government and medical standards. A significant amount of careful, detailed research is conducted on the new medication before it reaches the stage where it is tested on patients.

There are different types of trials in which a patient may participate. They are listed in the following table:

<table>
<thead>
<tr>
<th>Trial Type</th>
<th>Major Differences</th>
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| Phase I   | • Tests for safety and appropriate dose of a new treatment (does not compare it with another treatment)  
• Increased risk of side effects  
• Usually includes only a small number of patients who often have advanced disease that has not responded to current treatments |
| Phase II  | • Tests for side effects and efficacy of new treatment (does not compare it with another treatment)  
• Larger number of patients than a phase I trial |
| Phase III | • Further tests the new treatment on large numbers of patients once the phase II trial has shown the treatment to be effective and safe  
• The new treatment is compared with a standard treatment to determine if the outcome is more beneficial for patients (randomized controlled trial) |
| Phase IV  | • Further study of the treatment after the treatment has been licensed for use in standard practice |
What are the benefits of participating in a clinical trial?

Experimental treatments are not available to patients outside of a clinical trial. For a treatment to be given to patients, it must have been rigorously studied and tested, and must be approved by Health Canada. The main benefit of participating in a clinical trial is that patients can receive new treatments that are not yet on the market. If a patient has received the standard therapy for their particular type of NHL and has not achieved the desired response, a clinical trial may be a good option.

What are the risks associated with participating in a clinical trial?

You should be aware of the risks before participating in a clinical trial. They include:
• The treatment may be toxic such that you may experience severe side effects.
• The treatment may prove less effective than standard therapies and offer little or no benefit.
• You may be in the control group of the clinical trial, and as such may receive a standard NHL therapy and not the experimental drug.

Patients who choose to take part in a clinical trial must give informed consent. This means that they are aware of the potential benefits and associated risks and that they are a willing participant. No patient should be forced or pressed into participating in a clinical trial. Furthermore, once a patient is in a trial they have the right to leave the trial at any time without explanation. Leaving a trial will in no way affect the attitude of your healthcare team, and you will still receive the best current standard treatments.
Treatment for Relapsed NHL

Indolent NHL

The majority of patients with indolent NHL experience a relapse of their disease, despite having had treatment. The duration between treatment and relapse can vary, but it is typically between 18 months and four years.

There are numerous options for the treatment of relapsed NHL, and the decision depends on many factors including age, health status, the time from the end of the treatment to relapse and NHL grade and stage. Possible treatments include:

- The watchful waiting approach, which may be the best option for patients who have no symptoms that are troubling them.
- Chemotherapy, which is the most common treatment for relapsed disease.
- Monoclonal antibodies like rituximab (Rituxan®) are often used for certain types of relapsed NHL, usually in combination with chemotherapy to increase the effectiveness of chemotherapy without significantly increasing the side effects.

When indolent NHL relapses, it has sometimes changed, or transformed, into an aggressive form of the disease. Treating patients with transformed NHL can be difficult. They may be treated with high-dose chemotherapy with or without a peripheral blood stem-cell transplant (PBSCT). This can also be combined with monoclonal antibody therapy in order to destroy any residual lymphoma cells in the bone marrow.

If high-dose treatment is not possible then medical management is likely to be aimed at controlling symptoms, often called palliative treatment.

Aggressive NHL

Approximately 20% of patients with aggressive NHL do not respond to treatment and 30% of those who do respond to treatment experience a relapse after a remission. Although treatment is difficult, cure or remission can be achieved in up to 50% of such patients with a second line of treatment, called salvage treatment. Salvage treatment for aggressive NHL usually consists of combination chemotherapy (chemotherapy with combination drugs). High-dose chemotherapy and autologous PBSCT may also be performed if necessary.

If neither cure nor remission is possible, the aim is to relieve symptoms. This is called palliative treatment. Some patients may consider taking part in a clinical trial to help evaluate a new treatment or combination of treatments.
Questions to Ask Your Healthcare Team

It is common for people newly diagnosed with lymphoma to feel confused and to have difficulty finding answers to help them feel more in control of their situation. The questions below may be helpful in initiating a discussion with your doctor and understanding your cancer.

General Questions
• What type of lymphoma do I have? (There are over 50 kinds of lymphoma so be sure you know exactly what type you have. For example, diffuse large B-cell lymphoma, follicular non-Hodgkin lymphoma.)
• What is the stage or extent of my cancer?
• What is my prognosis, as you view it?
• What tests will I need to take?
• How will this cancer affect my life? My work? My family?
• What changes should I expect to happen (to my appetite, appearance, energy levels, etc.)?
• What adjustments should I make to my everyday life?
• How much experience do you have in treating my type of lymphoma?

Treatment Options
• What are my treatment choices?
• What treatment do you recommend and why?
• How does the treatment work?
• What are the names of the drugs I will be given? What are they for and what will each one do?
• What outcome do you hope for through treatment? Do you hope to cure or control the cancer?
• What other treatments may I have after my initial treatment?
• How will you know that my treatment is working?
• Is there any recent research or are there any clinical trials that I should know about?
• What can I do to prepare for treatment?
• How will treatment affect my life? My work? My family?
• How is my type of lymphoma normally treated?
• How long will my treatment last?
• What are the chances that the treatment will be successful?
• Would it be appropriate for me to participate in a clinical trial for a new therapy?

Side Effects of Treatment
• What are the possible risks or side effects of treatment?
• How serious are the side effects?
• Can the side effects be managed with treatment?
• What symptoms or problems should I report right away?
• If I get radiation therapy, what are the long-term side effects to that area of my body?
• If I do not feel sick, does that mean the treatment is not working?
• Will my ability to conduct my daily activities be affected? If so, for how long?
• How long will the effects of treatment last?


**Practicalities of Treatment**

- How often will I need to come in for treatment or tests?
- What if I miss a treatment?
- What is my treatment schedule?
- If I get radiation therapy, how will it be given to me? Is it painful?
- How long will my treatments last?
- Why do I need blood tests and how often will they be required?
- Are there any special foods I should or should not eat?
- Can I drink alcoholic beverages?
- Should I still take the other drugs I am on?
- Is it okay to continue with the supplements I am currently taking?
- What costs will I encounter?
- What should I do if I can’t afford it?
- Who should I call if I have questions? What is the best time to call?
- What should I do to try to stay healthy and strong during my treatment?
- Can I come for my chemotherapy treatments alone or do I need assistance?

**Support**

- Who will manage my treatment program?
- What resources are available to me through the treatment centre? Are there support groups or networks?
- Where can I go for more information?
- Are there any patient groups in the community?

**The Future**

- What are the chances that my cancer may return after remission? What are the signs?
- What life changes should I plan for in regards to my work, family, etc?
- Will I still be able to have children after treatment?

**Understanding the Flow of Lymphoma Treatment**

The flow of treatment in lymphoma is important because, in some cases the first treatment you get may affect your next treatment (if it becomes necessary). The goal of this section is to help you understand the flow of treatment and talk to your doctor about what may come next. At the end of this section you will find some additional information on things like maintenance and relapse therapies that you should be aware of and discuss with your doctor early on in your treatment journey. You will also find information on support medications that may help you better tolerate therapy.
Diagnosis:
Indolent Lymphoma
(e.g., follicular lymphoma)

How will my lymphoma be treated?

Watchful Waiting
(Also called Watch and Wait)

If symptoms/risk factors never appear, treatment may never be needed
Treatment will begin when symptoms/risk factors appear

Primary (First Time) Therapy

What will my treatment be?

- Radiation
- Chemotherapy plus rituximab (Rituxan®)
- Radiation and chemotherapy plus rituximab (Rituxan®)
- Clinical trial

What happens after treatment?

Response to treatment (complete or partial)
- Maintenance therapy
- Remission

No response to treatment
- Additional therapy
- Regular follow-up visits with oncologist
- Relapse

How long until I get treatment?

Treatment will begin when symptoms/risk factors appear

How will my lymphoma be treated?
Diagnosis:
Aggressive Lymphoma
(e.g., DLBCL)

What will my treatment be?
- Steroid therapy
- Radiation
- Chemotherapy plus rituximab (Rituxan®)
- Radiation and chemotherapy plus rituximab (Rituxan®)
- Clinical trial
- Stem-cell transplant

What happens after treatment?
- Regular follow-up visits with oncologist
  - Remission/cure
  - Relapse

Diagnosis:
Hodgkin Lymphoma

What will my treatment be?
- Steroid therapy
- Radiation
- Chemotherapy
- Surgery
- Clinical trial
- Stem-cell transplant

What happens after treatment?
- Regular follow-up visits with oncologist
  - Remission/cure
  - Relapse
Maintenance Therapy

- Maintenance therapy is treatment that is given to patients who go into remission after initial therapy. The goal of maintenance therapy is to help prevent a relapse and improve overall survival. It includes treatment with drugs or antibodies that kill cancer cells, and it may be given for a long time.
- Maintenance therapy is approved in Canada for patients with follicular non-Hodgkin lymphoma who have responded to their primary therapy. This means that if you have received R-CHOP or R-CVP as your initial therapy, you may be eligible for this treatment.
- Maintenance therapy should be discussed early on in your treatment plan.

Relapse

If your cancer should come back (relapse), you may require more treatments. In some cases, the options available to you at this point in time depend on what your initial therapy was. For this reason it is important to discuss options early on with your doctor and consider your personal treatment goals so the best treatment plan can be selected for you.

Support Medications

- There are certain medications that can help offset some of the side effects of treatment. You should inquire about these medications should the need arise. For example:
  - In the case of neutropenia (a decrease in infection-fighting white blood cells), you may want to discuss the medications filgrastim (Neupogen®) or pegfilgrastim (Neulasta®).
  - With anemia (a decrease in oxygen-carrying red blood cells), the drugs epoetin alfa (Eprex®) or darbepoetin alfa (Aranesp®) may be an option.
  - If oral mucositis occurs (a condition causing painful mouth ulcerations), supportive medications such as an opioid-like analgesic may be helpful.
  - Do not leave the clinic without your prescription for an anti-emetic such as ondansetron (Zofran®) or granisetron (Kytril®). With them you lessen the chances of experiencing nausea or vomiting.
  - Other drugs that may help with pain should be discussed as well.
- Get patient data sheets for each of the drugs you are getting. These sheets explain what the drugs are, what their side effects are and which side effects require immediate treatment. If you do not already have those sheets you can download them on-line at: www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPt/default.htm
Funding Issues

• The use and funding approval process for drug therapies may vary from province to province and from country to country.
• There may be some therapies that have been approved by Health Canada which may not be funded by your provincial ministry of health.
• Be sure to discuss all possible treatment options with your doctor as alternative access may be available to you.
• For more information on drug funding, consult the Lymphoma Foundation Canada Web site (www.lymphoma.ca) and click the “Support” tab, or contact by phone at 1-866-659-5556.

Clinical Trials

• It may be important to find out whether you are eligible to participate in a clinical trial. A benefit of this option is that clinical trials may offer access to more recent medication(s) that would otherwise be unavailable in your province.
• For more information on clinical trials, please go to pages 113 and 114 of this resource manual. You may also wish to check the Lymphoma Foundation Canada Web site (www.lymphoma.ca) by clicking on the “Treatment” tab and follow the link to “Clinical Trials.”
Vision Statement

This international charter was created to ensure that the more than one million people living with lymphoma worldwide have access to the best available care, information and support. The number of lymphoma cases is increasing rapidly and there is a critical need for patients to be better informed regarding their disease. Much can be done to improve the current situation and this is the responsibility of society as a whole, including healthcare professionals, patient groups/advocates, governments, insurers, payors/funders, clinicians, researchers and industry. To ensure that lymphoma patients receive the best treatment available, it is vital that the rights outlined in this charter are adopted globally.

All patients are entitled to the rights outlined in this charter regardless of age, gender, marital status, ethnicity, religion, sexual orientation, educational or economic background. This charter supports every stage of the patient journey through diagnosis, treatment, follow-up care and monitoring.

Diagnosis

All lymphoma patients are entitled to timely investigation and an accurate diagnosis by a qualified medical expert with a specialty in blood diseases such as haematopathology. It is critical that specialised imaging and scanning procedures are utilised to determine the extent of disease progression for appropriate treatment planning. All patients are entitled to a second opinion and referral to a haematopathologist, who can review their case and diagnostic material.

Treatment

Patients are entitled to have access to optimal treatment, based on an accurate diagnosis, stage of the disease and current evidence-based medicine. Patients have a right to know about all available treatment options and should be informed of relevant clinical trials. Financial status should neither be a barrier nor a determining factor in informing patients about treatment options, as all patients have a right to optimal treatment and it is in their best interest to know about the latest advances in the field. Patients are entitled to be an active participant in the treatment decision-making process.

Follow-up

Because lymphoma can recur, patients are entitled to regular follow-up care and close monitoring. Lymphoma patients have a right to receive a continuum of care provided by a dedicated team of healthcare specialists, counsellors, nurses, nutritionists and palliative care specialists, if required.

Long-term follow-up and ongoing interaction between all of these parties and the patient is crucial to determine the best course of action.

Information

Patients are entitled to be provided with all necessary information regarding their diagnosis, treatment and overall disease management and should be encouraged to become active participants in the treatment decision process.

This information should include:
1) nature of the disease
2) treatment options
3) risks and side effects of treatment
4) clinical trial opportunities
5) patient support tools and advocacy groups

Support

Patients are entitled to be informed of all available support systems, including patient support tools and advocacy groups. Patients are entitled to have a “voice” in their own disease management. Patient support tools and advocacy groups can play a key role in a patient’s recovery process and can help them access a host of resources, from psychological support to family counselling. Through advocacy groups, patients can also become involved in health policy discussions that can impact disease management for all lymphoma patients. Having the right support network is invaluable for patients at all stages of their illness.

References:
1. GLOBOCAN 2002: Descriptive Epidemiology Group of the International Agency for Research on Cancer (IARC)
3. NOP September 2005 data on file

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Glossary of Commonly Used Lymphoma Terms

**Absolute neutrophil count (ANC):** The number of mature neutrophils in the bloodstream. Neutrophils are a type of white blood cell whose function is to fight infection in the body. If the ANC is low, the patient may be at a higher risk of infection.

**ABVD chemotherapy:** A combination chemotherapy treatment that consists of four individual chemotherapy drugs (adriamycin, bleomycin, vinblastine and dacarbazine). ABVD is one of the most common chemotherapy regimens used in Hodgkin lymphoma.

**Acute:** Sudden onset of disease or symptoms.

**Adjuvant therapy:** Anti-cancer treatment given after the primary treatment to increase the chance of remission.

**Advanced disease:** Disease that has spread from the original site, often to multiple locations.

**Allogeneic transplant:** A procedure where a patient receives stem cells from the bone marrow or peripheral blood of a compatible donor.

**Aggressive lymphoma:** Lymphomas that grow at a fast rate. They are also referred to as intermediate or high-grade lymphomas.

**Alopecia:** Loss of hair, either from the head or elsewhere on the body. Alopecia during cancer treatment most commonly occurs from chemotherapy drugs and is almost always temporary. Hair will re-grow once chemotherapy treatment is finished.

**Anaplastic:** A term used to describe cells that divide rapidly and no longer resemble their original appearance. Anaplastic cells grow without form or structure and are seen in most (but not all) cancers.

**Anemia:** A condition where the number of red blood cells is below the normal limit. The most common symptoms associated with anemia include fatigue, weakness and shortness of breath.

**Antibody:** A protein produced by mature B-cells that binds to foreign substances (called antigens) and inactivates and/or removes them from the body. These foreign substances can include toxins, bacteria and cancer cells.

**Antiemetic:** A medication that reduces or prevents nausea and vomiting.

**Antigen:** A protein present on the surface of all cells that serve to identify the cell type. Antigens are also present on the surface of foreign substances and stimulate the body’s immune system to produce antibodies. Antibodies bind to antigens and facilitate the killing and/or removal of the foreign substance.

**Antinauseant:** A medication that prevents nausea.

**Antipyretic:** A medication that reduces fever.
Apheresis: The part of a stem-cell transplantation where the stem cells are removed from the blood.

Autologous transplant: A type of bone marrow or stem-cell transplant where the patient receives their own cells instead of those from a donor.

Axilla (axillary): Refers to the area under the arm (armpit).

B

B-cell: Also called a B-lymphocyte, B-cells are a type of lymphocyte that produce antibodies to fight disease in the body. Lymphocytes are a type of white blood cell and are an important part of the immune system.

B-cell lymphoma: A type of NHL where the cancer affects B-cells.

B symptom: Symptoms that some people may experience with lymphoma. B symptoms include fever, night sweats and weight loss. They are often associated with more advanced disease.

Benign tumour: A tumour that is not cancerous and does not spread. Benign tumours can grow large enough to impact surrounding tissues.

Beta (2) microglobulin (B2M): A protein found in the bloodstream that, if found in large amounts, could mean a more aggressive form of lymphoma.

Binet staging: The staging system for chronic lymphocytic leukemia (CLL) that is mostly commonly used in Europe. The Binet staging system classifies CLL based on clinical findings that include the number of lymph node sites involved and the degree of involvement of the lymph nodes, liver and spleen.

Biologic therapy: Treatments that stimulate the patient’s immune system to fight infection or disease. Also called immunotherapy.

Biopsy: Removal of a small piece of the tumour for examination under a microscope. A biopsy is an effective method of determining whether a tumour is malignant (cancerous) or benign.

Blood cell: A general term that describes the three major cell types that circulate in the blood: red blood cells, white blood cells and platelets. All are made in the bone marrow.

Bone marrow: The material inside the large bones of the body that produces red blood cells, white blood cells and platelets. Red blood cells carry oxygen throughout the body, white blood cells make up the immune system, and platelets are important for blood clotting. The bone marrow contains immature forms of these cells, called stem cells, which can be harvested for transplant.

Bone marrow aspiration and biopsy: A test routinely done on patients with NHL as part of staging their cancer and to determine whether the cancer has invaded the bone marrow.

Bone marrow transplant: The patient receives high-dose chemotherapy and/or radiation to kill off all the cancer cells, and then receives healthy bone marrow cells that can come from the patient themselves (autologous transplant) or from a compatible donor (allogeneic transplant).

Bone scan: A procedure where the bones of the body are viewed. The patient is injected with a radioactive substance that is absorbed into the bones allowing them to be viewed during a scan. The procedure is commonly performed to determine if the cancer has spread to the bones.
Cancer: Abnormal, uncontrolled growth of cells. Cancer cells can multiply and form a tumour that can spread throughout the body.

Carcinogen: A substance that is known to cause cancer.

CAT scan or CT scan: A series of X-rays that provides detailed, three-dimensional images of the inside of the body.

Catheter (see also venous catheter): A device, usually a flexible tube, that is used to transport medications into the body (through a vein) or take fluids (e.g., urine) out of the body.

CD5 antigen: A protein on the surface of some B-cells. This protein can be found during the biopsy procedure and, if present, is used to confirm the diagnosis of certain types of NHL.

CD20 antigen: A protein found on the surface of B-cells. The CD20 antigen is used as a target for monoclonal antibody therapy in certain types of NHL.

CD30 antigen: A protein found on the surface of some T-cells. This protein can be found during the biopsy procedure and, if present, is used to confirm the diagnosis of a certain type of T-cell NHL: anaplastic large cell lymphoma, primary cutaneous-type.

CD38 antigen: A protein on the surface of some immune cells. The presence of CD38 in CLL can be used to determine prognosis.

Cell: The building block of all living tissues, it is the most basic structural and functional unit of life.

Central line: An intravenous catheter that is inserted into a large vein, usually in the neck or near the heart. It is used to administer medication or withdraw blood.

Cerebrospinal fluid: Watery fluid that surrounds the brain and spinal cord. In NHL, it may be examined to determine if the cancer has spread to these areas.

Chemosensitive: A term used to describe a tumour that responds to chemotherapy.

Chemoresistant: A term used to describe a tumour that does not respond to chemotherapy.

Chemotherapy: Treatment with drugs that kill rapidly dividing cells. The type of chemotherapy given depends on the type of cancer and the health status of the patient.

Chemotherapy cycle: A term used to describe the method of administering chemotherapy. It includes the duration the treatment is given and the rest period for the patient to recover. Chemotherapy for NHL may require three or more cycles.

CHOP chemotherapy: A combination chemotherapy treatment that consists of three individual chemotherapy drugs (cyclophosphamide, doxorubicin and vincristine) and a steroid medication (prednisone). CHOP is one of the most common chemotherapy regimens used in NHL.

Chronic: A disease that lasts for a long period of time or is recurrent in nature.

Classification (of NHL): The determination of the exact type of NHL a patient has. There are many different types of NHL (e.g., follicular lymphoma, mantle cell lymphoma, etc.) and it is important to classify the tumour in order to choose the most appropriate treatment.

Clinical trial: A research study performed on volunteer patients under strictly controlled conditions to evaluate a new treatment. The ultimate goal is to find the most effective, least toxic treatment for a specific disease.
Combination chemotherapy: The use of a number of drugs together to combat cancer.

Complete blood count (CBC): A routine blood test used to determine the number of blood cells (red blood cells, white blood cells and platelets) in the bloodstream. A CBC is commonly done during a normal check-up with a doctor, and is often done during cancer treatment to determine if the patient can go ahead with their chemotherapy treatment.

Complete remission: Also called complete response, it means that all signs of the cancer have disappeared following treatment. Partial remission/partial response means that the tumour has decreased in size but is still present.

CT scan or CAT scan: A series of X-rays that provides detailed, three-dimensional images of the inside of the body.

Cure: The term used when no signs or symptoms of the disease have been present for a certain period of time. The longer a patient is in remission (absence of signs or symptoms of cancer), the higher the likelihood of cure.

CVP chemotherapy: A combination chemotherapy treatment that consists of two chemotherapy drugs (cyclophosphamide and vincristine) and a steroid medication (prednisone). CVP is a common chemotherapy regimen used in NHL.

Debulking: Treating cancer to reduce the size of the tumour. Debulking is usually achieved via surgery or radiation.

Diaphragm: The thin, dome-shaped muscle below the heart and lungs that separates the chest from the abdomen.

Disease progression: A term used to describe a worsening of the disease despite treatment. The term is often used interchangeably with treatment failure.

DNA (deoxyribonucleic acid): The building block for all genetic material. It is a molecule inside cells that carries genetic information and passes it on from one generation to the next.

Dose intensity: The total amount of a chemotherapy drug delivered to a patient in a certain period of time. The ultimate goal is to reach the highest dose possible where the side effects remain at an acceptable level.

Drug resistance: Occurs when cancer cells do not respond to chemotherapy.

Durable remission: The term used to describe cancer that has been in remission for many years. The longer the remission, the greater the chance for cure.

Dysgeusia: An altered sense of taste.

Echocardiogram: An imaging technique where an ultrasound machine is used to visualize the heart. Some chemotherapy medications can affect the heart and as such, cancer patients may require an echocardiogram.

Edema: Swelling caused by excessive amounts of body fluid.

Epstein-Barr virus (EBV): A common virus that remains dormant in most people. It causes infectious mononucleosis and has been associated with certain cancers, including Hodgkin lymphoma, Burkitt lymphoma and immunoblastic lymphoma.
Erythrocyte sedimentation rate (ESR): The distance red blood cells travel in one hour in a sample of blood as they settle to the bottom of a test tube. The sedimentation rate is increased in inflammation, infection, cancer, rheumatic diseases, and diseases of the blood and bone marrow.

Etiology: The cause(s) of disease. The cause of NHL is not known.

Extranodal disease: A term describing NHL that has spread outside of the lymphatic system.

Fatigue: Excessive tiredness and lack of energy, with a decreased capacity for daily activities.

FC chemotherapy: A combination chemotherapy treatment that consists of two individual chemotherapy drugs (fludarabine and cyclophosphamide). FC is a common chemotherapy treatment used in CLL.

FISH (fluorescence in situ hybridization): a blood test can be performed that looks for mutations within the CLL cells. The presence of certain chromosomal changes may mean that your CLL is a more aggressive type. This test is done in specialized labs.

Flow cytometry: A procedure that examines the cancer cells and their DNA. It is helpful in the diagnosis of cancers where a mediastinal mass (a mass/tumour behind the breastbone in the central area of the upper chest) is present.

Fraction: A single dose of radiation.

G

Gallium (radioisotope) scan: An imaging technique to detect cancer. Gallium is a chemical taken up by some cancer cells. In this procedure, a safe amount of radioactive gallium is injected into the patient, after which the patient undergoes an X-ray procedure where the radioactive gallium makes the tumour(s) visible. Gallium scans are performed in the nuclear medicine clinic in the hospital.

Generalized disease: Cancer that has spread throughout the body.

Genes: Made up of DNA and found in all cells, genes determine heredity. Genes contain the information to determine an individual’s unique characteristics. Errors in genes can predispose a person to cancer.

Genetic mutation: A permanent change to the normal sequence of a gene, usually caused by external agents such as chemicals or radiation. Genetic mutations may cause certain cancers.

Grade (clinical grade): NHL can be classified as low, intermediate or high-grade depending on how fast the cancer is growing. The term indolent is often used to describe low-grade NHL, whereas aggressive denotes a higher grade NHL.

Graft-versus-host-disease (GVHD): A complication that can occur after a patient has received a bone marrow or stem-cell transplant from a donor (an allogeneic transplant). The immune cells from the donor (the graft) react to the patient’s body cells (the host) and mount an immune response against them.
Harvesting: A procedure where stem cells are removed from the bone marrow or peripheral blood of a patient or donor. The harvested stem cells are transplanted to the patient following high-dose chemotherapy.

Hemaphagocytic syndrome: A serious condition in which there is uncontrolled activation of certain parts of the immune system. It can occur in certain types of NHL: subcutaneous panniculitis-like T-cell lymphoma and extranodal T-cell lymphoma of nasal type.

Hematologist: Doctors specializing in diseases of the blood. As NHL affects lymphocytes (a type of white blood cell), hematologists are often involved in the care of NHL patients.

Hepatosplenomegaly: Abnormal enlargement of both the liver and spleen.

High-grade NHL: An aggressive, fast-growing form of NHL.

Hodgkin lymphoma: One of the two main types of lymphoma, Hodgkin lymphoma is distinguished from NHL by the presence of Reed-Sternberg cells. It commonly affects individuals between 15 and 35 years of age and, if caught early, has a high rate of remission.

Hyperviscosity: Abnormal thickening of the blood.

Hypogeusia: A diminished sense of taste.

HTLV-1 infection: HTLV stands for human T-lymphotropic virus. It is a family of viruses that infects T-cells and can make people more likely to develop a certain type of NHL: adult T-cell lymphoma. This virus is rare in North America and is more common in countries such as Japan and China.

IgVH mutation: A marker that can be used to determine the prognosis of patients with CLL.

Immune system: The body’s defence system against infection and disease.

Immunosuppression: Suppression of the immune system due to the side effects of medications.

Immunotherapy: Treatments that stimulate the patient’s immune system to fight infection or disease. Also called biologic therapy.

Improvement: The term used when the tumour size has decreased but is still larger than half of its original size.

Indolent lymphoma: A slow-growing form of NHL. Indolent NHL and low-grade NHL are terms often used interchangeably.

Induction therapy: Cancer treatment used as the first step towards shrinking the tumour(s). If necessary, induction therapy is followed by additional therapy to treat the remaining cancer cells/tumours.

Intermediate-grade NHL: A form of NHL that is growing at a moderate rate. Often considered an aggressive form of NHL that usually requires prompt treatment.
Lactate dehydrogenase (LDH): An enzyme found in the blood that indicates damage to cells. If elevated, it may indicate a more aggressive form of NHL.

Lacteals: Small lymphatic vessels found in the digestive tract. They collect digested fat from the intestines and transport it to the circulatory system.

Leukemia: A cancer of white blood cells. In leukemia, the cancerous cells are in the blood, whereas in lymphoma the cancerous cells (lymphocytes) are primarily found outside the bloodstream (in lymph nodes).

Leukopenia: A low level of white blood cells. Since white blood cells are the main cells of the immune system, low levels leave a person at increased risk of infection.

Localized disease: A cancer that is contained in a certain area of the body and has not spread throughout the body.

Local therapy: Treatment that only affects a small area of the body.

Low-grade NHL: Also referred to as indolent NHL, low-grade indicates a slow-growing lymphoma.

Lymph (lymphatic fluid): The watery fluid contained in lymphatic vessels. Lymph circulates lymphocytes throughout the lymphatic system.

Lymph nodes: Small, bean-shaped organs that contain lymphocytes. Lymph nodes filter the lymphatic fluid and remove any foreign invaders. There are over 100 lymph nodes throughout the body located in clusters in the lymphatic system. The major lymph node clusters are found in the neck, under the arms, and in the chest, abdomen and groin.

Lymph node biopsy: Usually the first step in the diagnosis of NHL. Either a section or the entire lymph node is removed (by a surgeon) for examination under a microscope. A lymph node biopsy is an effective method of determining whether a lymph node is malignant (cancerous) or benign.

Lymphadenopathy: Swelling or enlargement of the lymph nodes due to infection or cancer.

Lymphatics: Lymphatic vessels and channels that carry lymphatic fluid and lymphocytes throughout the body.

Lymphatic system: The network of lymphatic vessels, lymph nodes and other organs that transport lymphocytes throughout the body to fight infection and disease.

Lymphoblast: An immature lymphocyte (B-cell or T-cell).

Lymphocytes: A type of white blood cell found in the lymphatic system and the bloodstream. Lymphocytes fight infection and disease and are an important part of the immune system.

Lymphoma: Cancer of the lymphatic system. There are two major types of lymphoma: Hodgkin and non-Hodgkin lymphoma.

Lymphomatoid papulosis: A non-cancerous skin disorder that can progress into some forms of NHL, including anaplastic large cell lymphoma, primary cutaneous-type.

Lymphoid: Pertaining to lymphocytes or the lymphatic system.
**Maintenance therapy:** Extended treatment, usually given after the original treatment has brought the cancer under control. It is done to prevent the disease from relapsing or to keep the cancer in remission.

**Malignant:** A malignant tumour is a cancerous tumour. Malignant tumours are characterized by progressive and uncontrolled growth and they can invade local tissue and spread to distant areas of the body. Benign tumours are not invasive and do not spread.

**MALT:** Mucosa-associated lymphatic tissue. Extranodal marginal zone B-cell lymphoma of MALT-type is a certain type of NHL that can affect the lymphatic tissues of the gastrointestinal tract, eye, thyroid, salivary glands, bladder, kidney, lungs, neurological system or skin. Mucosa-associated tissue means tissue that is lined with a moist, mucous-producing layer of cells.

**Mediastinum:** The central area of the upper chest, located behind the breastbone.

**Medical oncologist:** A doctor who is specially trained to diagnose and treat cancer and who specializes in the use of chemotherapy, biologic therapy and hormone therapy.

**Metastasis:** The spread of cancer within the body from the original tumour site to other sites or organs.

**Monoclonal antibody therapy:** A type of biologic therapy (or immunotherapy) used for cancer treatment. A synthetic antibody is created to target a specific antigen (a protein on the surface of cells). For the treatment of some forms of NHL, monoclonal antibodies target B-cells (the cancerous cell in many NHLs ) and facilitate their removal from the body.

**MRI (magnetic resonance imaging):** A technique used to obtain three-dimensional images of the body. While similar to a CT scan, an MRI uses magnets instead of X-rays.

**Mucositis:** Inflammation of the lining of the digestive tract, most commonly of the mouth, causing painful sores.

**Myeloablative chemotherapy:** High-dose chemotherapy that destroys the bone marrow. This is performed prior to a bone marrow or stem-cell transplant.

**Myelosuppression:** A reduction in bone marrow activity resulting in decreased red blood cells, white blood cells and platelets.


**N**

**Nausea:** A sensation characterized by an urge or need to vomit.

**Neutropenia:** A reduction in the number of neutrophils, the white blood cells that fight bacterial infection. This may put a patient at a higher risk of infection.

**Neutrophils:** The most common type of white blood cell in the body.

**Non-bulky tumour:** A tumour that is small in size.

**Non-Hodgkin lymphoma (NHL):** A group of related cancers that affect the lymphatic system. There are many different kinds of NHL and although they have similarities, they differ in many ways including how they develop and how they are treated.

**Night sweats:** Extreme sweating during sleep at night. Night sweats are considered a B symptom in lymphoma, which may be associated with more aggressive disease.
Null: In a certain type of NHL called anaplastic large cell lymphoma, the cancerous cell can be either a T-cell or a null cell. The null cell is a cell of unknown type.

O

Oncologist: A doctor who specializes in the treatment of cancer. There are different types of oncologists who specialize in certain treatments including medical oncologists (specializing in chemotherapy), radiation oncologists (specializing in radiation therapy) and surgical oncologists (specializing in cancer surgery).

Oncology: The branch of medicine that focuses on the diagnosis and treatment of cancer.

P

Palliative: Treatment that is designed to relieve symptoms rather than cure disease.

Partial remission: Also called partial response. The term used when a tumour has decreased in size by half or more, but has not been completely eliminated. The cancer is still detectable and more treatment may be necessary.

Pathologist: A doctor who specializes in identifying diseases by examining and studying cells under a microscope.

Peripheral blood: Blood circulating in the blood vessels and heart as opposed to the bone marrow.

Peripheral blood stem-cell transplant (PBSCT): A procedure similar to a bone marrow transplant. Healthy stem cells are harvested from the bloodstream of a donor (allogeneic transplant) or from the patient themselves (autologous transplant). The patient then receives high-dose chemotherapy and/or radiation to obliterate the cancerous cells, after which time the harvested stem cells are re-infused into the patient’s body to repopulate the immune system.

Performance status: A term describing how well a patient is able to perform daily tasks and activities.

Peripheral neuropathy: Altered nerve sensations in the hands and feet, including numbness, tingling and weakness as a result of nerve damage. Some medications can cause nerve damage leading to peripheral neuropathy.

PET scan (positron emission tomography): A way to visualize cancer in the body. Radioactive glucose (a sugar molecule used as the energy source for cells) is injected into the patient and is taken up preferentially by cells with a high metabolic activity, such as cancer cells. A scanner is then used to visualize the areas of the body where the radioactive glucose is concentrated.

Pleural effusion: A collection of fluid inside the chest cavity around the lungs.

Planning: A session with technicians, nurses and oncologists to simulate radiation treatment.

Plasma cell: A mature B-cell. The main function of plasma cells is antibody production. Thus, they play an important role in the defense against infection and disease.

Primary therapy: The first treatment given after a patient is diagnosed with cancer.

Prognosis: The prediction of how a patient/cancer will progress after diagnosis. Prognosis refers to the outcome of the cancer and the likelihood of recovery.

Psoralen: A drug that is part of a therapy called PUVA, used for a type of NHL called cutaneous T-cell lymphoma. Also called photochemotherapy, PUVA consists of psoralen plus ultraviolet A (UVA) light. Psoralen makes the skin more sensitive to the healing effects of the UVA light.
Radiation field: The area of the body that receives radiation therapy.

Radiation oncologist: A type of oncologist (cancer specialist) specializing in treating cancer with radiation therapy.

Radiation therapy: A type of therapy where high-dose radiation beams (X-rays) are carefully focused on a tumour site. Exposure to the X-ray beams kills the cancer cells.

Radioimmunotherapy: A highly specific therapy where a radioactive isotope (a molecule that emits radiation) is attached to a monoclonal antibody. Once injected into the body the radioactive monoclonal antibody attaches to tumour cells and kills them.

Rai staging: The staging system for chronic lymphocytic leukemia (CLL) that is mostly commonly used in North America. The Rai staging system classifies CLL and assigns risk categories based on the number of lymphocytes found in the blood; the enlargement of the lymph nodes, liver and spleen; the number of platelets found in the blood and the presence of anemia (low number of red blood cells in the blood).

Reed-Sternberg cell: A type of cell found in Hodgkin lymphoma but not in non-Hodgkin lymphoma (NHL).

Refractory disease: A cancer that does not respond to treatment.

Randomized controlled trial: A clinical trial that involves the testing of an experimental drug treatment in comparison with a control treatment.

Regimen: The administration of a specific combination and dose of cancer medications following an arranged schedule.

Relapse: The return of cancer after a period of improvement. NHL may recur in the same area as the original tumour or it may relapse in another body area.

Remission: A patient is said to be in remission if the tumour has diminished by half or more (partial remission) or is undetectable (complete remission). Remission does not necessarily imply that the cancer has been cured. If a certain cancer, for example an aggressive lymphoma, remains in remission for a certain period of time, usually five or more years, it may be considered cured. However, indolent lymphomas are not commonly considered cured because the cancer can relapse even after a long period of remission.

Salvage therapy: Treatment that is used when the cancer has not responded to standard treatments or after the cancer has relapsed.

Single-agent chemotherapy: Chemotherapy treatment that utilizes only one chemotherapy drug.

Spleen: An organ that is an important part of the lymphatic system. The spleen is located in the top left-hand corner of the abdomen, below the ribcage. The spleen is involved in lymphocyte production and storage, and also works to store and filter the blood and remove aging blood cells from the circulation.

Splenectomy: Surgery to remove the spleen.

Splenomegaly: Abnormal enlargement of the spleen.

Stable disease: A term used when the cancer does not get better or worse following treatment.
Stage: Describes the extent to which a cancer has spread within the body. There are four stages of lymphoma: stages I and II are limited (involving a limited area) and stages III and IV are advanced (more widespread).

Standard therapy: Treatment that has been proven effective and is widely used as primary therapy for cancer.

Stem cell: A precursor cell produced in the bone marrow that gives rise to all different kinds of blood cells (red blood cells, white blood cells and platelets). Stem cells are often harvested for transplantation.

Stem-cell transplant: A procedure that replaces diseased stem cells with healthy stem cells. The patient receives high-dose chemotherapy and/or radiation to kill off all the cancer cells, and then receives healthy stem cells that can come from the patient themselves (autologous transplant) or from a compatible donor (allogeneic transplant). Stem cells can be harvested from either the peripheral (circulating) blood, called a peripheral blood stem-cell transplant (PBSCT), or from the bone marrow, called a bone marrow transplant.

Synergism: A term used in cancer treatment when two or more drugs given in combination provide a more beneficial effect than either drug alone.

Systemic: Affecting the entire body.

Systemic symptoms: Symptoms that affect the whole body rather than just one area or organ. Examples of systemic symptoms include fever, night sweats and weight loss.

Tattoo: In radiation therapy, the term used for the ink markings made on the body to clearly outline the radiation field. This ensures that the appropriate area is targeted for radiation and that the same area is treated each time.

T-cell (T-lymphocyte): A subset of lymphocytes that recognize and destroy abnormal body cells (e.g., virus-infected cells and cancer cells) and play an important role in fighting infection. The "T" stands for thymus, the gland where T-cells mature.

Thrombocytopenia: A lower than normal level of platelets in the blood. Platelets are important in blood clotting, such that a shortage may result in increased bleeding or bruising.

Thymus gland: A gland that is part of the lymphatic system where T-cells complete their development. The thymus is located behind the sternum (breastbone) in the chest.

Toxicities: The unwanted side effects of medications. Common toxicities of cancer treatments include hair loss, nausea and vomiting.

Transformed NHL: The term used when an indolent NHL changes, or transforms, into a more aggressive form of NHL.

Transplant: The transfer of healthy tissue to replace damaged tissue. The healthy tissue can come from the patient themselves (autologous transplant) or from a matched donor (allogeneic transplant).

Treatment failure: A worsening of the cancer despite treatment. The term is often used interchangeably with the term disease progression.

Tumour: An abnormal mass of dividing cells that serves no useful bodily function. Tumours can be either benign (non-cancerous) or malignant (cancerous).

Tumour burden: The amount of cancer cells present in a patient’s body.

Tissue: A group of cells that work together to perform a specific function in the body.
Vaccine: A substance used to stimulate the body’s immune system to respond to a specific invader. Vaccines can be used in cancer to stimulate an immune response against cancer cells. Lymphoma vaccines are made using a sample of the tumour obtained from the patient’s lymph nodes.

Venous catheter: A device, usually a flexible tube, that is used to transport medications into the body (through a vein) or take fluids (e.g., urine) out of the body.

Watchful waiting: Also called the watch and wait approach, it is an approach to cancer where no immediate treatment is given following diagnosis. Patients are closely monitored to ensure the cancer is not progressing. This strategy is often appropriate for patients with indolent (slow-growing) NHL.

Xerostomia: A reduction in the production of saliva resulting in a dry mouth. It can be a side effect of cancer treatment.

X-ray: Radiation beams that are used in two ways: in low doses to provide images of the inside of the body for diagnostic purposes and in high doses to treat cancer (radiation therapy).

ZAP-70: A marker that can be used to determine the prognosis of patients with chronic lymphocytic leukemia.
Resources and Bibliography

Lymphoma and Cancer Resources ............................................................... 139
Bibliography ............................................................................................... 140
Lymphoma and Cancer Resources

Web Sites

- Lymphoma Foundation Canada: www.lymphoma.ca
- Canadian Cancer Society: www.cancer.ca
- Lymphoma Research Foundation: www.lymphoma.org
- Lymphoma Information Network: www.lymphomainfo.net
- Cancer Backup: www.cancerbackup.org
- National Cancer Institute: www.cancer.gov
- Hoffmann-La Roche-sponsored NHL Web site: www.lymphoma-net.org
- The Canadian Association of Psychosocial Oncology: www.caPO.ca
- The Non-Hodgkin’s Lymphoma Cyberfamily: www.nhlcyberfamily.org
- Ontario Clinical Trial Information: www.ontario.canadiancancertrials.ca

Support Centres in Canada

- Wellspring: www.wellspring.ca
- Hearth Place Cancer Support Centre: Oshawa, Ontario. www.hearthplace.org
- Canadian Cancer Society: search for support services in your area at info.cancer.ca/e/srv/srvsearch.asp
- Lymphoma Foundation Canada provides information on patient support resources across Canada.
  You can e-mail them at info@lymphoma.ca

Books

- *Peace, Love and Healing*. Bernie S. Siegel, MD.
- *Cancer as a Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals*. Lawrence LeShan, PhD.
- *The Emotional Facts of Life with Cancer: A Guide to Counselling and Support for Patients, Families and Friends*. Beth Kapusta and the Canadian Association of Psychosocial Oncology (CAPO) and TransCanada Pipelines.
- *It’s Not About the Bike: My Journey Back to Life*. Lance Armstrong.
- *How to Prevent and Treat Cancer with Natural Medicine*. Michael Murray, ND.
- *Living with Lymphoma: A Patient’s Guide*. Elizabeth M. Adler, PhD.
- *Take the Wheels off Your Worry Bus*. Sharron Orovon-Johnston, RNBA.
- *Picking up the Pieces: Moving Forward After Surviving Cancer*. Sherri Magee and Kathy Scalzo.
Bibliography


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