LEUKEMIA & LYMPHOMA SOCIETY OF CANADA®

ABOUT BLOOD CANCERS

Follicular Lymphoma FL

WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with follicular lymphoma (FL). What does it mean and how will it affect you?

This fact sheet will help you:

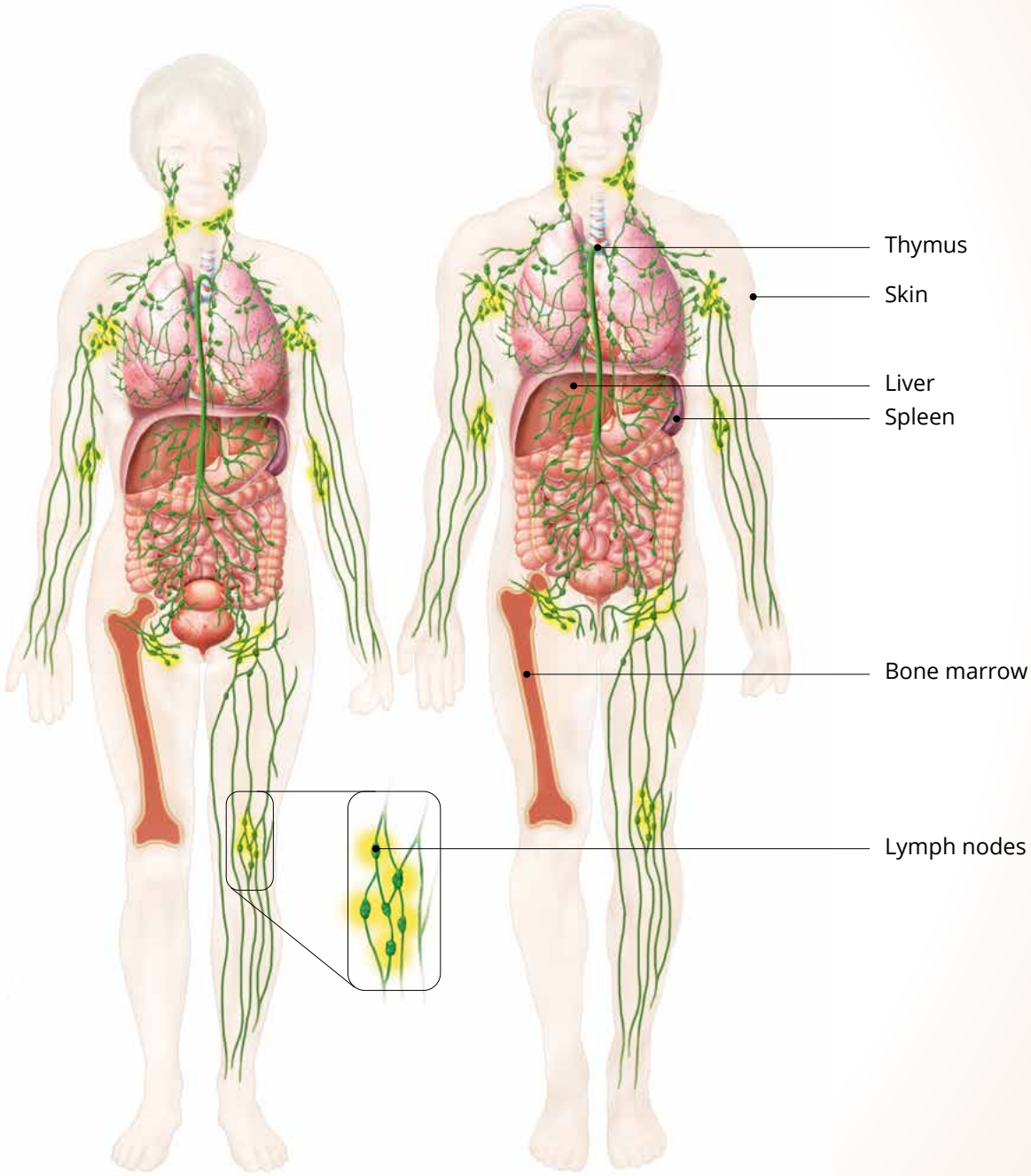
- Learn about FL and how it is diagnosed
- Get an overview of treatment options
- Understand what happens next

About lymphoma

Lymphoma is the most common form of blood cancer.

Lymphoma is cancer of the lymphatic system, which includes the bone marrow, lymph nodes, thymus, liver, skin, and spleen.

Your lymphatic system defends your body against infection by creating white blood cells called lymphocytes. If these cells become abnormal, you may develop lymphoma.



What is lymphoma?

Lymphoma is the name of a group of blood cancers that develop in your lymphatic system. The two main types are Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). FL is a subtype of NHL.

About FL

- It is the most common subtype of slow-growing NHL in Canada and the second most common type of lymphoma overall
- It starts in the B cells and has often already spread through the lymphatic system at diagnosis
- It most often appears at age 50 or older
- In a small number of people, it can change into a different, more aggressive lymphoma called diffuse large B-cell lymphoma (DLBCL)
- It usually responds well to treatment, but it often returns

Symptoms of follicular lymphoma

The most common early sign of follicular lymphoma is painless swelling of one or more lymph nodes throughout your body.

You may experience:

- Large masses in the neck, armpit, or groin and/or painless swelling in one or more lymph nodes
  - When your lymph nodes are enlarged or swollen
- Fever and drenching night sweats
  - Possibly a response from your immune system
- Weight loss
  - When you are eating less or using more energy

Your diagnosis

With a diagnosis, your healthcare team can determine the right treatment for you. Your healthcare team includes an oncologist (the primary cancer doctor), who works with a range of professionals such as your family doctor, nurse practitioners, nurses, pharmacist, and social worker to manage your treatment and provide support. Depending on the type of cancer, other specialists like a pathologist, radiologist, or surgeon may also be involved in your care.

Your test results help them predict how FL will likely progress and how you may respond to treatment.

Here are some possible tests you may undergo:

Name of test	Description
Medical history and physical exam	Your healthcare provider will review past illnesses, injuries, and symptoms. They will examine your lungs, heart, and other organs
Blood tests	Blood tests help determine your need for treatment and the extent of the disease. Blood tests help identify several NHL subtypes.
Immunophenotyping	This test finds specific types of cells within a blood sample to confirm a diagnosis. It identifies the lymphoma cells as B cells, T-cells, or natural killer cells.
Lymph node biopsy	A biopsy involves taking a sample of the tumour or lymph node and looking at the size, shape, and arrangement of the lymphoma cells.
Bone marrow biopsy	This test confirms whether the lymphoma has spread to the bone marrow. It helps your healthcare team determine the benefits of specific therapies.
X-ray	An x-ray uses electromagnetic radiation to produce images of the inside of your body.
Imaging tests	A computed tomography (CT) scan uses a computer linked to an X-ray machine to make a series of detailed pictures of areas inside your body.

Stages of follicular lymphoma

Identifying the stage of the disease is an important step in planning your treatment. The stage of lymphoma refers to where the disease is located and how much of it is in your body.

Your healthcare team will use imaging, lab tests, and a physical exam to determine the stage of the disease, confirm whether it has spread, and monitor how it progresses.

The stage of the disease depends on:

- The extent of tumours present
- If lymph nodes are involved and if they contain cancer cells
- If the FL has spread to other internal organs
- The amount of lymphoma cells in your blood

Stages I and II (1 and 2) are early stages. Stages III and IV (3 and 4) are advanced.

Stage I	The lymphoma is in one group of lymph nodes or one extranodal site (outside the lymph nodes)
Stage II	The lymphoma is in two or more groups of lymph nodes on the same side of the diaphragm
Stage III	The lymphoma is in lymph nodes above and below the diaphragm
Stage IV	The lymphoma is found in many areas of the body (in the lymph nodes and beyond)

Understanding how the disease will progress

Your healthcare team needs to understand the likely progression of the disease and your prognosis, meaning how the cancer will affect you and how it will respond to treatment. They use the Follicular Lymphoma International Prognostic Index (FLIPI) to determine the prognosis, how likely you are to respond to treatment, and the chances of the disease returning.

You are at a higher risk based on the following factors:

- Age (60 years or older)
- Lymphoma cells in more than four lymph node areas
- Stage 3 or 4 diagnosis
- High levels of lactate dehydrogenase (LDH)
- Low blood hemoglobin levels

Here's how the scoring works:

- Low risk: 0 to 1
- Intermediate risk: 2
- High risk: more than 3

Your healthcare team will make treatment decisions based on your score.

Treatment for follicular lymphoma

New treatment approaches will help manage your FL symptoms and complications, including infections and fatigue. The types of treatment can vary widely and may include clinical trials.

You may experience mild to severe side effects during treatment, depending on your age, overall health, and treatment plan. If you do, let your healthcare team know.

Side effects can affect people in different ways. Most side effects improve or go away after treatment ends. New drugs and therapies can help control most side effects.

Types of treatment

Common FL treatments and possible side effects include:

- **Watch and wait or active surveillance** delays treatment until the disease progresses. It is used for people with slow progressing, early-stage FL who have no symptoms.
- **Chemotherapy** uses medicine (chemicals) to kill cancer cells. Chemotherapy is often given in combination with immunotherapy.
  - **Potential side effects:** low blood cell counts (white, red, and platelets), infection, bleeding, anemia, nausea, diarrhea, vomiting, loss of appetite, brain fog (chemo brain), fatigue, shortness of breath, diseases or disorders affecting the heart (cardiopathy), temporary hair loss, mouth sores, rashes, secondary cancers, and nerve damage (neuropathy)
- **Radiation therapy** uses high-energy X-rays or other types of radiation to kill cancer cells. It may be combined with other treatments, such as chemotherapy.
  - **Potential side effects:** redness, dryness, itching, blistering, nausea, diarrhea, vomiting, loss of appetite, headaches, swelling, fatigue, shortness of breath, cardiopathy, temporary hair loss, and secondary cancers
- **Targeted therapies** are a type of drug therapy that targets specific substances or markers on cancer cells. These drugs are often given in pill form. Some targeted therapies are available in Canada; others are available through a clinical trial.
  - **Potential side effects:** low blood cell counts (white, red, and platelets), infection, bleeding, anemia, skin problems, high blood pressure, fatigue, diarrhea, neuropathy, and slower healing time for wounds
- **Immunotherapy** uses an intravenous drug that can either boost or pause your immune system to help your body fight cancer. Immunotherapy is done in addition to or instead of chemotherapy. In Canada, it may be available in your province or territory or through a clinical trial.
  - **Potential side effects:** rashes, fatigue, diarrhea, nausea, vomiting, and decreased thyroid hormone levels
- **CAR T-Cell therapy** is a form of immunotherapy that helps the immune system attack cancer cells by modifying your white blood cells (T cells) in a lab. They are then put back into your bloodstream.
  - **Potential side effects:** low white blood cell count (increased risk of infection), fever, fatigue, nausea, vomiting, diarrhea, low blood pressure, difficulty breathing, neurological changes, muscle or joint pain, rash or skin changes

Clinical trials are research studies that aim to improve the care and treatment of people living with cancer.

For some people with a blood cancer, a clinical trial may be the best treatment choice. Talk to your healthcare team for more information.

Types of treatment (cont'd)

- A **stem cell transplant (SCT)** gives you healthy stem cells to replace those damaged by cancer or intense chemotherapy and radiation treatments. Your body relies on stem cells to produce blood cells. There are two main types of SCT used to treat blood cancers:
- **Autologous:** The stem cells are removed from your body before treatment and placed back into your body after treatment. This allows you to receive high doses of chemotherapy (sometimes with radiation). Using your own stem cells helps your bone marrow produce new blood cells and reset your immune system.
  - **Potential side effects:** low white blood cell count (increased risk of infection), low platelet count (increased risk of bleeding or bruising), low red blood cell count (causes fatigue, dizziness, shortness of breath, and feeling unwell), pain and issues with your digestive system, skin and hair problems, issues with your organs or central nervous system
- **Allogeneic:** The stem cells come from a donor. These donor cells replace the damaged ones in your bone marrow, potentially offering a long-term cure.
  - **Potential side effects:** low white blood cell count (increased risk of infection), low platelet count (increased risk of bleeding or bruising), low red blood cell count (causes fatigue, dizziness, shortness of breath, feeling unwell), pain and issues with your digestive system, skin and hair problems, issues with your organs or central nervous system, and possible graft-versus-host disease (GvHD) or veno-occlusive disease (affecting the small vessels leading to your liver)

Factors that affect treatment

Discuss your treatment options with your healthcare team to make sure you understand the benefits and risks of each approach. Your treatment plan is based on:

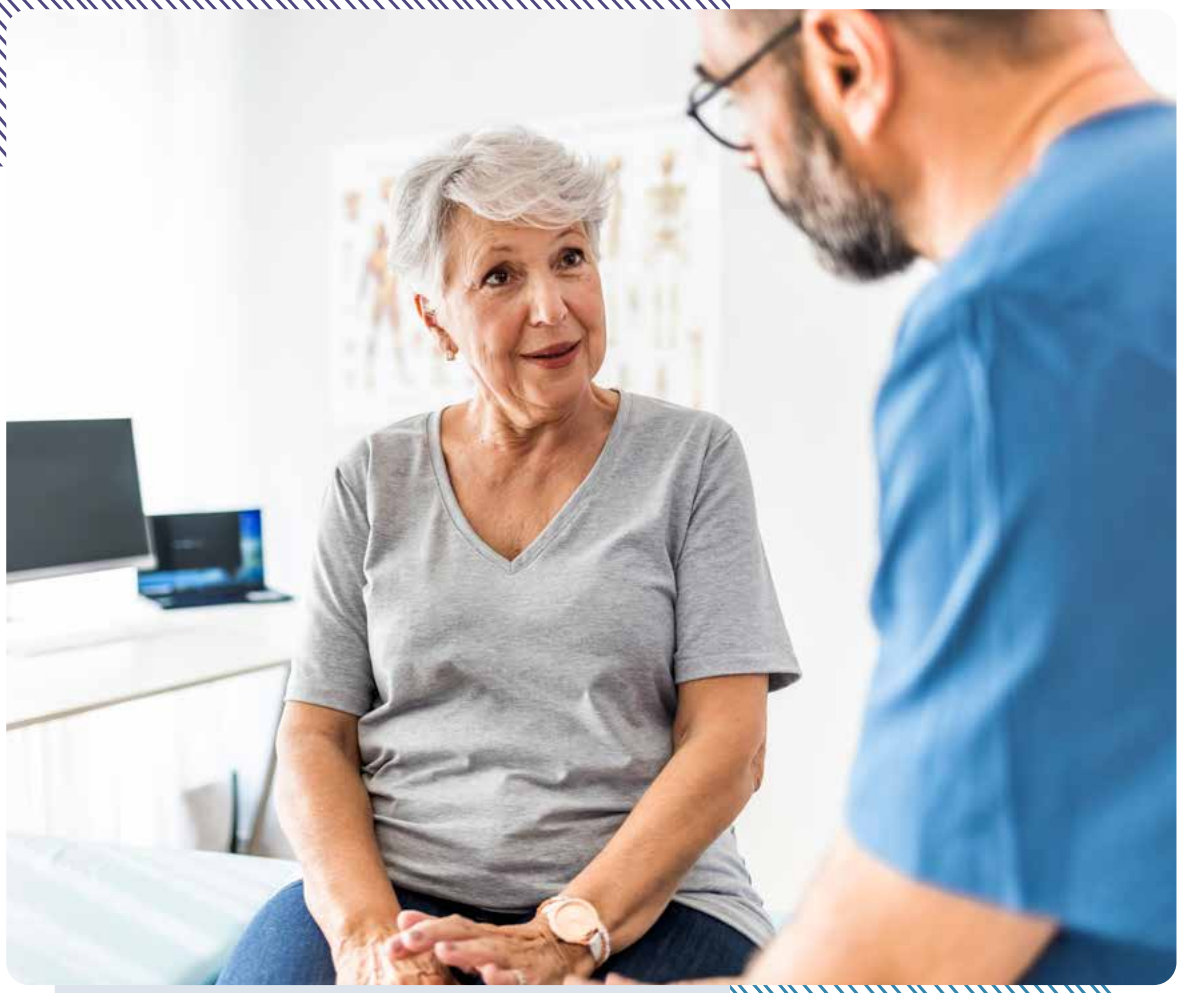
- Your age and overall health
- Your symptoms and blood counts
- The stage of FL and FLIPI score
- Whether the disease does not respond to initial treatment (refractory) or returns after initial treatment (relapsed)
- Any other health issues you may have
- Your lifestyle and preferences

Long-term or late effects of treatment

Medical follow-up is important after treatment for FL. You may need blood, bone marrow, or imaging tests to determine if you need further treatment. Your healthcare team should provide a care plan listing how often you will need follow-up visits and which tests you will have at those visits.

You may experience long-term or late effects of your treatment:

- **Long-term side effects** can last for months or years after treatment ends. Examples include fatigue, fertility issues (the ability to conceive and have children), secondary cancers, and neuropathy.
- **Late effects** are medical problems that do not show up until years after treatment ends. See your healthcare team to get follow-up care for possible early detection of heart disease, secondary cancers, fertility issues, thyroid problems, trouble concentrating, or chronic fatigue.



Living with FL can be overwhelming. Seek medical help if you feel “down” or “blue” or don’t want to do anything and your mood does not improve over time. These could be signs of depression, an illness that should be treated even when you’re undergoing treatment for FL. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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