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
What is lymphoma?

Lymphoma is the name for a group of blood cancers that develop in your lymphatic system. The two main types are Hodgkin lymphoma and non-Hodgkin lymphoma. FL is a type of non-Hodgkin lymphoma.

About follicular lymphoma

- Most common sub-type of indolent (slow growing) non-Hodgkin lymphoma
- Most often appears at age 50 or older
- In a small number of people, FL can change into a different, more aggressive lymphoma

Signs and symptoms

The most common early sign of follicular lymphoma is painless swelling of one or more lymph nodes throughout your body. Most people with FL have enlarged lymph nodes in their neck, armpit, or groin. 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
- Fevers and drenching night sweats
  - Possibly a response from your immune system
- Weight loss
  - When you are eating less or using more energy
After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how your FL will likely progress and how you may respond to treatment.

<table>
<thead>
<tr>
<th>Name of test</th>
<th>Description</th>
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<tr>
<td>Medical history and physical exam</td>
<td>The doctor reviews past illnesses, injuries, and symptoms. They examine your lungs, heart, and other organs.</td>
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<tr>
<td>Lymph node biopsy</td>
<td>A biopsy draws out a sample of the tumour or lymph node. This is used to look at the size, shape, and arrangement of the lymphoma cells and the pattern characteristic of FL.</td>
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<tr>
<td>Immunophenotyping</td>
<td>This test helps find specific types of lymphoma cells within a blood sample or tissue biopsy sample to confirm an FL diagnosis.</td>
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**Stages of follicular lymphoma**

Identifying the stage of your disease is an important step to planning your treatment. The stage of FL refers to the number of lymph nodes that are affected and where they are located. **It does not determine how well you will respond to treatment.**

Your doctor will determine the stage of your disease using imaging, lab tests, and physical examination. This helps to figure out:

- Which lymph nodes are larger than normal
- Whether your disease affects organs other than your lymph nodes
- If you have large masses of tumours

**Stages**

- **Stage I** involves one group of lymph nodes.
- **Stage II** involves two or more groups of lymph nodes on the same side of your diaphragm.
- **Stage III** involves groups of lymph nodes on both sides of your diaphragm.
- **Stage IV** involves one or more organs that are not part of a lymphatic area and/or your lymph nodes. Or it may involve the liver, bone marrow, or lungs.

**Categories**

- **Category E** means your lymphoma has spread to areas or organs outside of your lymph nodes or to tissues beyond, but near, your major lymphatic areas.
- **Category S** means your testing has found lymphoma in your spleen.
- **Category X** means your testing has shown large masses of lymphocytes (bulky disease.)

**Example**

A diagnosis of Stage IIIS means your disease involves lymph node groups on both sides of your diaphragm as well as your spleen.
Follicular lymphoma treatment

Your treatment is focused on destroying as many lymphoma cells as possible. When you no longer have evidence of lymphoma cells in your body, you are said to be in remission. Your treatment may result in partial remission, meaning that your tests still show evidence of FL. Your treatment is based on your stage and certain treatment factors.

Types of treatment

- **Watch and wait or active surveillance** delays treatment until the disease progresses.
- **Chemotherapy** uses medicine (chemicals) to kill cancer cells. A combination chemotherapy procedure uses two or more chemotherapy drugs.
- **Immunotherapy** (rituximab) uses the body’s immune system to treat cancer. Immunotherapy is done in addition to chemotherapy.
- **Radiation therapy** uses x-rays or other high-energy rays that can kill FL cells.
- **Combined modality therapy** uses both chemotherapy and radiation. This is a common treatment option for FL.

Factors that affect treatment

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

- Age and overall health status
- Disease subtype
- Stage
- If your FL is refractory (does not respond to initial treatment) or relapsed (returns after you are in remission)
Treatment side effects

When you begin your treatment for follicular lymphoma, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan. It can vary from person to person. Most side effects disappear once your treatment ends. New drugs and therapies can help control side effects, such as nausea and vomiting. Speak to your doctor if you are experiencing side effects.

**Common side effects**

You may experience side effects such as:

- Nausea, vomiting, diarrhea, extreme fatigue, fever, cough, rash, and hair loss from your chemotherapy treatments
- Infection from a decrease in white blood cells from your chemotherapy treatments
- Neuropathy, which is nerve damage from treatment that can make your fingers and toes feel numb or tingle
- Fatigue, changes in the skin, hair loss, mouth sores, dry mouth, changes in taste, dry cough, difficulty swallowing, nausea, vomiting, diarrhea, and cramps from your radiation treatments

**Long-term or late effects of treatment**

Medical follow-up is important after treatment for follicular lymphoma. You may need blood tests, bone marrow tests, or molecular tests. Your medical team should provide you with a care plan listing the frequency of follow-up visits and the tests you will have at those visits.

- Long-term side effects are common and can last for months or years after treatment ends. Examples include problems concentrating (chemo brain) and chronic fatigue.
- Late effects are medical problems that do not show up until years after treatment ends. See your doctor to get follow-up care for possible early detection of heart disease, secondary cancers, fertility issues, and thyroid problems.

Living with FL can be overwhelming. Seek medical help if you are feeling “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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