

Mantle Cell
Lymphoma
MCL

WHAT YOU NEED TO KNOW

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

This fact sheet will help you:

Learn about
MCL and how
it is diagnosed

Get an overview
of treatment
options

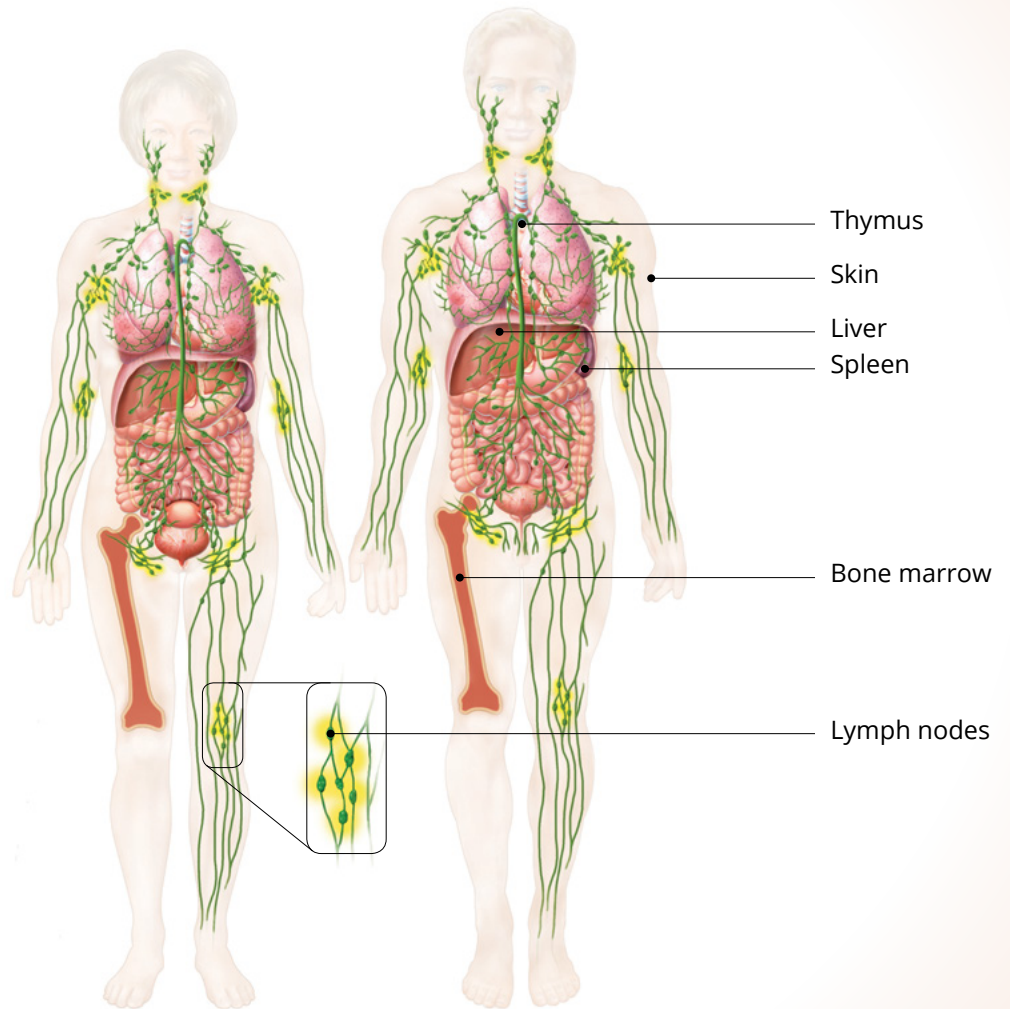
Understand
what happens
next



About lymphoma

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

About MCL

- MCL is an aggressive subtype of non-Hodgkin lymphoma.
- It is a blood cancer of the B-lymphocytes (type of white blood cell that fights infections) found in the bone marrow.
- With MCL, there is a malignant (cancerous) change to the B-lymphocyte in the outer edge of a lymph node follicle, known as the mantle zone.
- These cancerous MCL cells grow and multiply uncontrollably, enlarging the lymph nodes.
- MCL cells can spread to your bloodstream and other lymph nodes, tissues, or organs.
- MCL usually appears in adults (average age is mid-60s).
- It is twice as common in men as in women.

Signs and symptoms

In most people with MCL, the disease is found in many lymph nodes and other areas of the body. This may include your spleen, bone marrow, blood, tonsils, adenoids, liver, and gastrointestinal tract (stomach or colon). Other areas may include your skin, tear glands, lungs, and central nervous system (brain and spinal cord).

You may experience:

- Fatigue and weakness
 - When your red blood cell count is low (anemia)
 - Fever and night sweats
 - Possibly a response from your immune system
 - Weight loss and loss of appetite
 - When you are eating less or using more energy
 - Masses in your neck or abdomen and/or painless swelling in one or more lymph nodes
 - When your lymph nodes are enlarged or swollen
 - Feeling bloated, uncomfortable, or full
 - When your liver, spleen, or tonsils are enlarged
 - Nausea, vomiting, and indigestion
 - When your spleen is enlarged and you have a blockage in your lymph nodes
 - Swelling or pain in your back or abdomen
 - When you have large lymph nodes in your abdomen
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After your diagnosis

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

Name of test	Description
Medical history and physical exam	The doctor reviews past illnesses, injuries, and symptoms. They examine your lungs, heart, and other organs. They pay close attention to your lymph node areas (such as your head, neck, armpits, and groin).
Performance evaluation	This test looks at your ability to perform certain activities of daily living without help.
Complete blood count	This test measures the number of red blood cells, white blood cells, and platelets in a sample of your blood to find out if the counts are high or low.
Comprehensive metabolic panel	This test measures serum lactate dehydrogenase (LDH) in your blood. A high LDH level may be a sign of cancer. The test can show how widespread the cancer is.

Name of test	Description
Lymph node biopsy	A surgical biopsy of the enlarged lymph node looks at the types and number of cells there.
Bone marrow aspiration and biopsy	These two tests look at bone marrow cells for anything unusual in your chromosomes. They are usually done at the same time. They can check to see if the MCL has gone into your bone marrow.
Immunophenotyping	This test helps find 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.
Computed tomography (CT) scan	A CT scan uses a computer linked to an x-ray machine to make a series of detailed pictures of areas inside your body.
PET (positron emission tomography) scan	This test uses radioactive material to create a 3D image of your cells. It can identify changes in the bone marrow and pockets of lymphoma cells.

Stages of MCL

Identifying the stage of your disease is an important step in planning your treatment. The stage of MCL refers to how your disease has progressed. It does not determine how well you will respond to treatment.

Your doctor will find out the stage of your disease using imaging, lab tests, and a physical exam of your body. This helps them to know:

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

Most people with MCL have either stage III or stage IV. MCL has often spread widely by the time it is diagnosed.

Stages

Stage I	The cancer is in one group of lymph nodes or in an organ.
Stage II	The cancer is in two or more groups of lymph nodes on the same side of your diaphragm.
Stage III	The cancer is in groups of lymph nodes on both sides of your diaphragm.
Stage IV	The cancer is in lymph nodes and/or other parts of your body or bone marrow.



MCL treatment

Your treatment is focused on destroying as many lymphoma cells as possible. When there are no signs of lymphoma cells in your body, you are said to be in complete **remission**. Your treatment may result in **partial remission**. This means your tests still show signs of MCL, but it is under control.

Most people with MCL have an aggressive (fast-growing) form of the disease. In this case, you need treatment after you are diagnosed and learn the stage of your MCL.

A small number of people have a slow-growing (indolent) type of MCL. The doctor may recommend a “watch and wait” period of close observation until you experience symptoms. Treatment starts when you have symptoms.

Types of treatment

Watch and wait or active surveillance	delays treatment until the disease progresses. This approach is for people with slow-growing (indolent) MCL.
Chemotherapy	uses medicine (chemicals) to kill cancer cells. A combination chemotherapy procedure uses two or more chemotherapy drugs.
Immunotherapy	(using an intravenous drug called rituximab) boosts or pauses your immune system to help your body fight cancer. Immunotherapy is done in addition to chemotherapy.
Stem cell transplantation	transfers a healthy person’s (donor) stem cells to your body to slow the growth of the disease. This is an option for some people with MCL who have relapsed and/or refractory disease, where they have not responded to therapy.

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:

- Your age and overall health
- The type and extent of your symptoms
- The stage of MCL and your risk category
- Your Mantle Cell Lymphoma Prognosis (MIPI) score
- How quickly your cancerous B-cells are spreading
- The subtype of the MCL cell



Treatment side effects

When you begin your treatment for MCL, you may experience mild to severe side effects, depending on your age, your overall health, and your treatment plan. Most side effects disappear once your treatment ends. New drugs and therapies can help control most side effects. Speak to your doctor if you are having side effects.

Common side effects

You may experience side effects such as:

- Nausea, diarrhea, vomiting, loss of appetite, and temporary hair loss from chemotherapy treatments
- Fatigue and shortness of breath from low blood counts and chemotherapy
- Fever, chills, infection, rash, mouth sores, and swelling
- Neuropathy, or nerve damage from treatment that can make your fingers and toes feel numb or tingle
- Tumour Lysis Syndrome (TLS) can happen when many cancer cells die quickly; TLS changes your metabolism and can lead to other health complications

Long-term or late effects of treatment

Medical follow-up is important after treatment for MCL. You may need blood tests, bone marrow tests, or molecular tests to determine if you need further treatment. Your medical team should provide you with a care plan listing how often you will need 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 chronic fatigue and problems concentrating (known as chemo brain).
- **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 and secondary cancers.



Living with MCL 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 MCL. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.

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This publication was
made possible thanks
to the support of:



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