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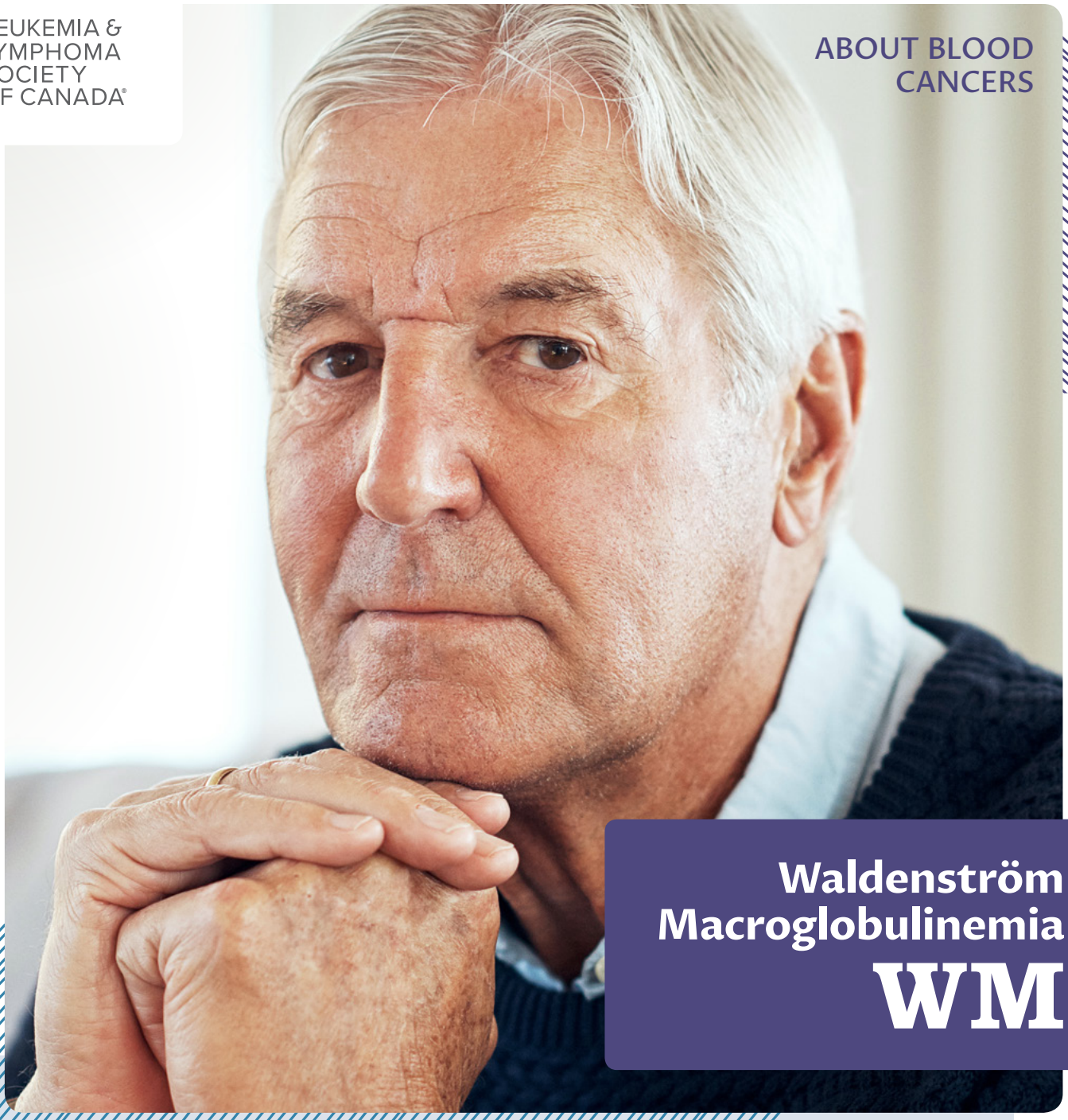
ABOUT BLOOD CANCERS



Waldenström Macroglobulinemia

WM

WHAT YOU NEED TO KNOW

You or your loved one has been diagnosed with Waldenström macroglobulinemia (WM). What does it mean and how will it affect you?

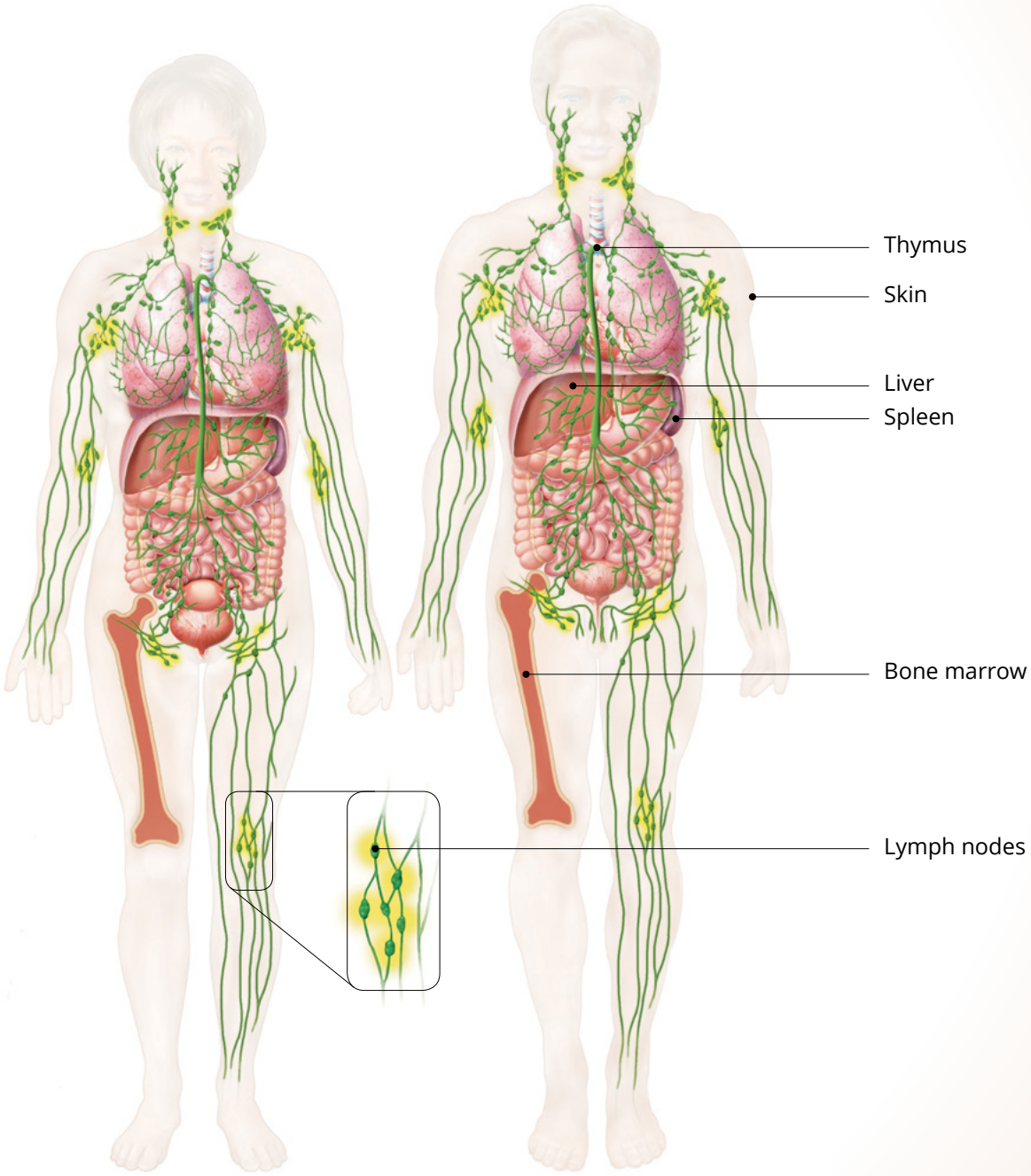
This fact sheet will help you:

- Learn about WM 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. WM is a type of non-Hodgkin lymphoma.

About WM

- This is a rare, slow-growing (indolent) subtype of non-Hodgkin lymphoma that is often found in the bone marrow, spleen, and/or lymph nodes.
- It is a blood cancer of the B lymphocytes (type of white blood cell that fights infections) found in the bone marrow.
- A protein called immunoglobulin M (IgM) overproduces, crowding out healthy blood cells.
- There is no cure, but the disease is treatable.
- It usually appears in adults (median age of 73).
- It is more common in men.

Signs and symptoms

Up to 25% of people with WM have no symptoms. Often the disease is uncovered during a doctor's visit that shows abnormal blood test results.

Over time, people may develop complications or a more progressive form of the disease. The symptoms of WM are mostly related to the effects of WM cells in the bone marrow and IgM protein in the blood. You may experience:

- Fatigue and weakness (the most common early symptoms)
  - When your red blood cell count is low (anemia)
- Fever and night sweats
  - Possibly a response from your immune system
- Weight loss
  - When you are eating less or using more energy
- Large 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 or full
  - When your liver or spleen is enlarged
- Pain, tingling, and numbness in your feet, legs, and hands
  - When you have peripheral neuropathy (nerve damage) caused by treatment

After your diagnosis

With your diagnosis, your doctor can determine the right treatment for you. Your test results help your doctor predict how WM 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.
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.
Serum protein electrophoresis	This test measures the amount of all five types of immunoglobulin in your blood. When you have a very high level of IgM, it's a sign of WM.
Serum viscosity	This test measures how thick your blood is. High levels of IgM will cause the blood to thicken. This leads to abnormal blood flow.
Beta-$_2$ microglobulin (B_2M)	This test looks for elevated levels of B_2M (a protein found on the surface of many cells, including lymphocytes). This is a sign of WM.
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.
Immunophenotyping	This test helps find specific types of cells in a blood sample to confirm a diagnosis. It identifies the lymphoma cells as B-cells, T-cells, or natural killer cells.
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. **Magnetic resonance imaging (MRI)** uses magnetic fields and radio waves to create images of the body's organs and tissues. The **positron emission tomography (PET) scan** uses radioactive material to create a 3D image of your cells to look for changes in the bone marrow and pockets of lymphoma cells.

WM treatment

One in four people with WM have no symptoms (called asymptomatic) when they are diagnosed. Many of them may not require treatment for years. Active treatment begins when symptoms develop.

WM grows slowly. It is not curable. After the first course of therapy, some people may experience relapse. This means the cancer returns. Or they may have refractory disease, where the cancer resists treatment. This will require more treatment. In rare cases, WM may turn into diffuse large B-cell lymphoma, an aggressive subtype of non-Hodgkin lymphoma. This may happen at any time when you have WM.

There are several treatment options to prevent or control symptoms and improve your quality of life. There is no standard treatment.

Name of treatment	Description
Watch and wait or active surveillance	delays treatment until the possibility exists that the disease will progress. This approach is for people with slow-growing (indolent) WM.
Drug therapy	involves taking a Bruton tyrosine kinase (BTK) inhibitor, such as ibrutinib, by mouth.
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 WM who have relapsed and/or did not respond to prior therapy (called refractory disease). This is especially used for younger patients who have had one or more relapses.

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 symptoms
- How quickly your cancer needs to be controlled
- The potential need for a stem cell transplant in the future

Treatment side effects

When you begin your treatment for WM, 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 experiencing side effects.

Common side effects

Depending on the type of therapy, you may experience side effects such as:

- Nausea, diarrhea, vomiting, and temporary hair loss from chemotherapy
- Fever or chills, coughing, sore throat, frequent/loose bowel movements, mouth sores, and hair loss
- Neuropathy, which is nerve damage from treatment that can make your fingers and toes feel numb or tingle
- Tumour Lysis Syndrome (TLS) happens 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 WM. You may need blood or bone marrow 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 secondary cancers and fertility problems.

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

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