





Understanding and managing **myeloma** 

# What is this booklet for?

This booklet was designed to answer some questions you may have about myeloma. It summarizes the treatment options that are available in Canada. It can also serve as a starting point for discussions with your doctor, so that you can decide together what is best for you.

Once you have a better understanding of each treatment option, you can stay informed and take an active role in your myeloma treatment process.





# What is myeloma?

Multiple myeloma (also simply called myeloma) is a rare type of blood cancer that develops in bones and other areas of the body. **Myeloma is a cancer of the plasma cells.** 



- Plasma cells come from white blood cells called B cells.
  - They help your body fight infection and disease by making **antibodies**, which are proteins released into blood and other body fluids that help find and kill germs.
- Myeloma develops when there is a buildup of many abnormal plasma cells (called myeloma cells) in the bone marrow.
  - The antibodies made by myeloma cells are all copies of a single type of antibody. These are called monoclonal proteins, M-proteins, or M-spike. M-proteins don't help to fight infections.
- Myeloma cells may also accumulate in any part of your body, including skin, muscles, blood, or lungs. These accumulations are known as **plasmacytomas**.

More Canadian men than women develop multiple myeloma.

# Are there different types of myeloma?

Yes, there are **two** basic types of myeloma: **active and smouldering**.

### Active myeloma

- Active (or symptomatic) myeloma causes symptoms or affects organs.
- Symptoms such as bone pain, frequent infections and fatigue may occur (please see next page for an overview of signs and symptoms of active myeloma).
- Myeloma that's causing symptoms should be treated.

### **Smouldering myeloma**

- When myeloma isn't causing symptoms and doesn't require immediate treatment, it's called **smouldering (or asymptomatic)** myeloma.
- People with smouldering myeloma have **M-protein** in blood and plasma cells in the bone marrow, but usually at lower levels than people with active myeloma.
- Smouldering myeloma doesn't need treatment, but people are tested regularly for signs of active myeloma.
- They can also be considered for **clinical trials** that explore the benefits of early treatment.



# What are the signs and symptoms of active myeloma?

Some of the most common signs and symptoms of active myeloma are referred to as **CRAB**. See your doctor if you have these signs and symptoms.



#### Thirst, frequent urination, upset stomach, bone pain, confusion, and muscle weakness

• When your **C**alcium levels in your blood are high (hypercalcemia)



# Kidney problems, including Renal failure

• Caused by monoclonal protein deposits in your kidneys



#### Fatigue, shortness of breath during normal physical activities, dizziness, and pale complexion

• When your red blood cell count is low (Anemia)



# Abnormalities, fractures, or other damage to your bones

• Myeloma can cause osteoporosis or thinner, weaker **B**ones

# What are the possible tests for myeloma?

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



# Complete blood count (CBC) with differential

A CBC is a test that measures the number of blood cells in a blood sample. It includes the number of white blood cells, red blood cells, and platelets. The CBC should include a differential. **The differential measures the different types of white blood cells in the sample**. This is important to know because when myeloma cells take over the bone marrow, too few normal blood cells are made.



# Bone marrow aspiration and biopsy

These two tests look at bone marrow cells to see if there are myeloma cells. They are usually done at the same time.

- Myeloma cells are most frequently found in the bone marrow. The biopsy sample is usually taken out of the pelvic bone (near the hip), which contains a large amount of bone marrow.
- This is a two-part test that results in two samples.
  - A bone marrow biopsy removes a small piece of solid bone along with a small amount of soft bone marrow inside the bone.
  - A bone marrow aspiration removes a small amount of liquid bone marrow from inside the bone.





## **Imaging tests**

Your doctor may use x-rays, computed tomography (CT) scans, magnetic resonance imaging (MRI) scans or positron emission tomography (PET) scans to look at your tissues, organs and bones in more detail.

#### X-rays and CT scan

- A CT scan uses a computer linked to an x-ray machine to make a series of detailed pictures of areas inside the body.
- Your doctor will use these tests to see if there are holes, breaks, or thinning of the bones.
- A special x-ray may also be done to measure bone loss. This is called a **bone density test**.

#### **MRI scan**

- An MRI scan uses magnets and radio waves to create images of your organs and tissues.
- Doctors may request a scan of your head and/or spinal cord to look for changes in the bone marrow and pockets of myeloma cells.
- MRI is particularly useful for telling the difference between smouldering myeloma and active myeloma.

#### **PET scan**

- This test uses radioactive material to create a 3D image of your cells to look for changes in the bone marrow and pockets of myeloma cells.
- A PET scan is very good at showing active myeloma and how far it has spread. It can also help show bone damage from myeloma.

#### Lab tests

- These tests look for the M-protein.
- Myeloma often causes you to have large amounts of M-protein in your blood or urine.

# How is myeloma treated?

# Factors affecting treatment choice for myeloma

Your doctor will determine the best course of treatment for you based on these factors:

- Age and overall health status
- Characteristics of the disease
- Symptoms you are experiencing (e.g. bone pain or fractures)
- How fast the disease is progressing
- If you have other conditions, such as heart or kidney disease, diabetes, or neuropathy
- Previous treatments and how your myeloma responded to them
- Ability to tolerate intensive therapy

## Goals of myeloma treatment

Each patient is assessed individually. What works for one patient may not work for someone else. Regardless of the treatment you are given, the goals of therapy are similar, which are listed below.

- Stop the production of abnormal (myeloma) plasma cells
- Strengthen bones and prevent fractures
- Increase hemoglobin count and reduce fatigue
- Reduce the risk of infections
- Promote your well-being and quality of life

After considering the above factors and goals, your doctor will recommend one or more of the treatment options listed on pages 12–15.

# What treatment options are available for myeloma?

Myeloma treatment is based on whether or not a person has **symptoms** of the disease. In other words, your doctor would decide on a treatment approach based on whether you are diagnosed with **smouldering myeloma or active myeloma**.

Not everyone receives the same treatment. Various factors (listed on the previous page) will help your doctor determine the types of treatments that are most appropriate for you. Treatment for myeloma is also increasingly being tailored to meet the needs of individual people diagnosed with the condition. Speak with your doctor to help you make informed decisions.

Now let's take a closer look at the available treatment options for both types of myeloma.

# **Treatment options for myeloma**

### **Smouldering myeloma**

#### **Active Surveillance**

- This is the typical treatment for people with **slow growing** (asymptomatic) myeloma.
- This means that your doctor will watch for cancer growth with regular follow-up tests.
- During this type of treatment, you should have follow-up tests every 3 to 6 months to check the status of smouldering myeloma to see if treatment is needed.

A clinical trial is a preferred primary treatment option for people with **smouldering myeloma**.



### **Active myeloma**

#### **Treatment phases**

#### **Induction therapy**

- This is the first phase of treatment.
- The goal is to lower the number of plasma cells (myeloma cells) in the bone marrow and the M-proteins made by the myeloma cells.

#### **Consolidation therapy**

- This is given after a stem cell transplant.
- It's a short course of chemotherapy, sometimes given with targeted therapy and a corticosteroid, which can help improve the outcome of a stem cell transplant.

#### Maintenance therapy

- This is given after other treatments to help myeloma stay in remission.
- It is used after a stem cell transplant or when chemotherapy is given alone.
- The drugs used in maintenance therapy usually fall under targeted therapy.



Remission is defined as complete or partial disappearance of the signs and symptoms of myeloma.

Please read further to know more about the treatment options for active myeloma.

# **Treatment options for myeloma**

#### Active myeloma

#### **Treatment options**

#### **Targeted therapy**

- Most people with active myeloma will be treated with targeted therapy.
- It may be used before a stem cell transplant or as part of treatment in people who can't have a stem cell transplant.
- It is often **first given as induction therapy**.
- It may also be used right after a stem cell transplant, and after consolidation therapy to help active myeloma stay in remission.

#### Chemotherapy

- It may be given before a stem cell transplant.
- It is first given as induction therapy and then again as high-dose chemotherapy (called conditioning) in preparation for a stem cell transplant.
- It may also be given right after a stem cell transplant (as consolidation therapy) and to help active myeloma stay in remission (as maintenance therapy).
- There are many types of chemotherapy drugs that are used to treat active myeloma.

#### Stem cell transplant

- Your doctor will tell you if you are able to have a stem cell transplant.
- If you can have a stem cell transplant, you will have high-dose chemotherapy first to destroy the cells in the bone marrow.

#### **Radiation therapy**

- This may be used if other treatments, such as chemotherapy, aren't working and bone tumours are causing pain.
- It is used to destroy a localized mass of myeloma cells.
- It may also be used to prevent a fracture in a diseased bone and to treat fractures or spinal cord compression.

#### Surgery

- In rare cases, surgery is used to treat active myeloma.
- It may be used to support and prevent fractures in weakened bones and/or for urgent treatment of spinal cord compression.



Joining a clinical trial can be a good option for you. A clinical trial is a type of research that studies a test or treatment in people. It gives people access to healthcare options that otherwise wouldn't be available. Ask your medical team if there is an open clinical trial that is right for you.

# What else should you know about your myeloma treatment?

## **Treatment side effects**

- When you begin your treatment, you may experience reactions to it.
- New drugs and therapies can help control most side effects.

Speak to your doctor if you are experiencing side effects.

## **Advances in treatment**

- Advances in myeloma treatment are extending survival and improving quality of life.
  - Although myeloma is incurable, less toxic and more targeted therapies are making it possible for more people to manage myeloma and live longer with a better quality of life.



# What questions should you ask your doctor?



Being an active participant in your cancer care can give you and your family a greater sense of control. One way to achieve this is by building a relationship with your medical team based on open communication.

Consider bringing this list of questions to your next doctor's appointment.

# Diagnosis

- What type of myeloma do I have? From what type of cell did it form? Is this cancer common?
- Will I need to have other tests before we can decide on treatment?
- What tests do you recommend for me?
- Where will the tests take place? How long will the tests take?
- How do I prepare for testing? How will the test be done? What can I expect?

# **General treatment**

- What will happen if I do nothing?
- Should I start treatment now? Why or why not?
- What should I do to be ready for treatment?
- What are my treatment options?
- Which one do you recommend for me? Why?
- What is the treatment frequency?
- How do you know if my treatment is working?
- What should be avoided or taken with caution while receiving treatment?

# Side effects of treatment

- What are the possible risks or side effects of my treatment? How serious are they and what should I report right away?
- How can I manage the side effects?

# **Other considerations**

- Can treatments be taken at home?
- How will treatment affect my daily activities?
- What if I miss a treatment?
- Are there any limits on what I can do?
- Should I still take the other medications I am on?
- Is it okay to continue with the supplements I am currently taking?
- What costs will I encounter?
- In cases of emergency, how can I reach your office on nights, holidays, or weekends?



Be sure to write down any questions you have that are not on this list. For instance, you may want to ask about qualifying for clinical trials.



# Notes

# What resource is available to you?



Visit our website to learn more about myeloma and its treatment.

bloodcancers.ca 

> For more information. never hesitate to contact us. We're here to help you!

1833222-4884 info@bloodcancers.ca 



Please download the LLS Health Manager<sup>™</sup> app by visiting

#### bloodcancers.ca/health-manager-app

You can use this app to note down any questions that you may have to bring to your next doctor's appointment.

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