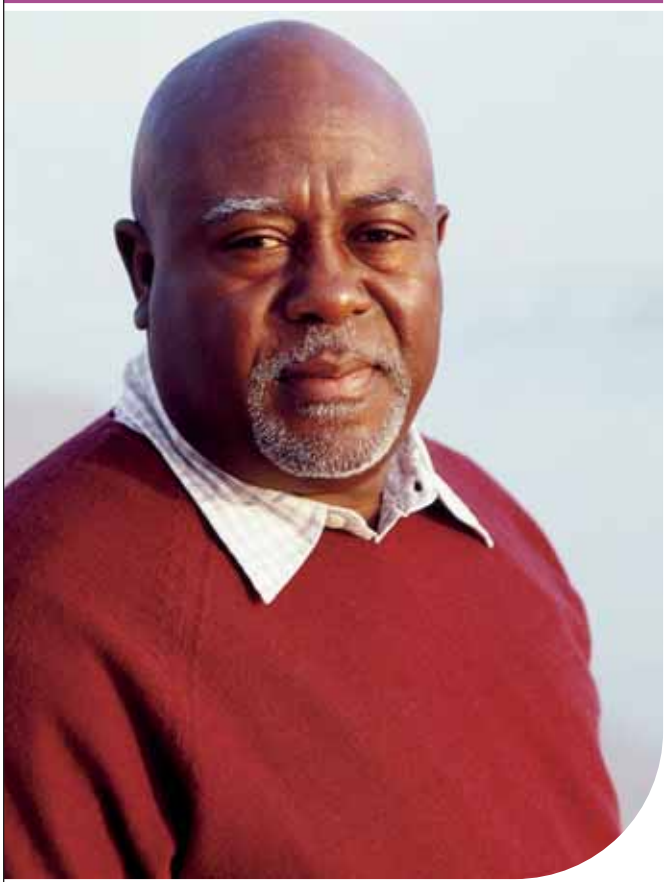
Canadian Cancer Society
Société canadienne du cancer

Multiple Myeloma

Understanding your diagnosis



Let's Make Cancer History

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Multiple Myeloma
Understanding your diagnosis

When you first hear that you have cancer you may feel alone and afraid. You may be overwhelmed by the large amount of information you will have to take in and the decisions you will need to make.

The introductory information in this brochure can help you and your family take the first step in learning about multiple myeloma. A better understanding may give you a sense of control and help you work with your healthcare team to choose the best care for you.

What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

But sometimes the instructions in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably.

Abnormal cells from most organs form solid lumps, or tumours. Abnormal cells from the immune system or the blood, however, do not usually form tumours. Instead, these cancer cells circulate in the blood, bone marrow and lymphatic system.

What is multiple myeloma?

Multiple myeloma is a cancer that starts in plasma cells, which are made in the bone marrow. Bone marrow is the soft, spongy material that fills the centre of most bones (those where blood cells are made). Plasma cells are a type of white blood cell. Their job is to make antibodies that help fight infections.

Myeloma begins when a plasma cell becomes abnormal and begins to divide uncontrollably, making more and more abnormal plasma cells. Abnormal plasma cells are called myeloma

cells. Eventually, the growing number of myeloma cells:

- crowd out the normal blood cells in the bone marrow and prevent them from working properly
- can spread to the solid part of the bone and cause pain or fractures
- upset the balance of certain body minerals, such as calcium, and prevent other organs, such as the kidneys and nerves, from working properly

The disease is called *multiple myeloma* because it affects many bones. (If myeloma cells form a tumour in only one bone, it's called a *plasmacytoma*.*)

Causes of multiple myeloma

More men than women develop multiple myeloma. There is no single cause of multiple myeloma, but some factors increase the risk of developing it:

- growing older – particularly after 60
- family history of multiple myeloma
- history of plasma cell disorders, such as monoclonal gammopathy of undetermined significance (MGUS) and solitary plasmacytoma
- African ancestry
- Being obese
- Farming

* For information about plasmacytoma and other plasma cell cancers, contact our *Cancer Information Service* at 1 888 939-3333.

Other factors, such as exposure to high doses of radiation and workplace exposure to chemicals, are being studied as possible causes of multiple myeloma.

Most people develop multiple myeloma without any of these risk factors.

Symptoms of multiple myeloma

Multiple myeloma often does not cause any symptoms in its early stages. Symptoms start as the number of myeloma cells in the bone marrow increases and the normal number of blood cells cannot be made. Symptoms may also develop when the bone structure becomes weaker or when the kidneys can't work properly.

Symptoms may include:

- bone pain, usually in the back
- broken bones, usually in the spine
- feeling weak and very tired, fatigue
- bruising
- unusual bleeding – usually from the nose or gums
- feeling very thirsty
- frequent infections and fevers
- weight loss
- nausea or vomiting

Other health problems can cause some of the same symptoms. Testing is needed to make a diagnosis.

Diagnosing multiple myeloma

After taking your medical history and completing a physical examination, your doctor may suspect you have multiple myeloma. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to "stage" the cancer. You may have one or more of the following tests.

Blood tests: Blood is taken and studied to see if the different types of blood cells (red blood cells, white blood cells and platelets) are normal in number and appearance. Blood tests also show how well your kidneys and other organs are working and may suggest whether or not you have cancer.

M-protein is a cancer marker used to help diagnose multiple myeloma. Blood tests can show if there is M-protein, abnormal levels of calcium or other signs of disease in the blood.

Urine tests: Urine samples are checked for the presence of M-protein. To check for the Bence Jones protein, a type of M-protein, urine is collected over a 24-hour period.

Imaging studies: Imaging studies (x-rays, CT scans and MRIs) allow tissues, organs and bones to be looked at in more detail. For diagnosing multiple myeloma, x-rays are most commonly used. X-rays of the skull, spine, upper legs and upper arms are taken to look for broken or thinning bones. A special x-ray may be done to measure bone loss. This is called a *bone density test*. X-rays are usually painless and do not require an anesthetic.

Bone marrow aspiration and biopsy: A biopsy is usually necessary to make a definite diagnosis of cancer. It is the only sure way to know whether there are myeloma cells in the bone marrow. Marrow is removed from your hip bone or another large bone and checked under a microscope. If the cells are cancerous, they may be studied further to see how fast they are growing. There are two ways to get a bone marrow sample.

- For a *bone marrow aspiration*, the doctor uses a thin needle to remove samples of bone marrow.
- A *bone marrow biopsy* uses a thicker needle to remove a sample of bone marrow and a small piece of bone.

An aspiration and biopsy of the bone marrow are often done at the same time. Both types of biopsies use a local anesthetic (freezing) to numb the area. It can be painful when cells are pulled into the syringe, but this lasts only a few seconds. Usually, bone marrow aspirations and biopsies are done in a clinic or hospital on an outpatient basis (you will not stay overnight).

Staging

Once a definite diagnosis of cancer has been made and your healthcare team has the information it needs, the cancer will be given a stage.

The cancer stage describes the extent of the disease and how much it affects the body. The Durie-Salmon system is the most common staging system for multiple myeloma.

Stage	Description
1	• There is a small number of myeloma cells. • Hemoglobin (a protein in red blood cells) level is normal or slightly low. • The calcium level is normal. • There is a small amount of M-protein. • Bones are normal or have only one area of damage.
2	• The number of myeloma cells is moderate. • Levels of hemoglobin, calcium and M-protein, and the amount of bone damage are between stage 1 and stage 3.
3	• The number of myeloma cells is high and there is one or more of the following: > Hemoglobin level is low. > The calcium level is high. > M-protein level is high. > Bones have 3 or more areas of damage.

Multiple myeloma is further staged according to how well the kidneys are working.

A: normal or almost normal kidney function

B: abnormal kidney function

It is important to know the stage of the cancer. This information helps you and your healthcare team choose the best treatment for you.

Treatments for multiple myeloma

Your healthcare team will consider your general health and the stage and symptoms of the myeloma to recommend what treatments will be best for you. You will work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

Multiple myeloma often develops very slowly and does not always cause symptoms. If you have multiple myeloma without symptoms, you may not need treatment right away. Your healthcare team will monitor your health closely. This is called *watchful waiting*. Your doctor will discuss your treatment choices with you when you begin to have symptoms.

Treatments affect everyone in different ways. It's hard to predict which side effects you will have. Your healthcare team will tell you what to expect with each treatment. They will also let you know what side effects you should report right away and which ones you can wait to tell them about at your next appointment. If you notice any side effects or symptoms that you did not expect, talk to a member of your healthcare team as soon as possible.

Patients often worry about the side effects of cancer treatment. However, side effects can often be well managed and even prevented with medicine. Be open with your healthcare team. Tell them your concerns and ask questions. They will help you get the care and information you need.

Once symptoms of multiple myeloma begin, you might receive one or more of the following treatments.

Chemotherapy: Chemotherapy may be given as pills or by injection. Chemotherapy drugs interfere with the ability of cancer cells to grow and spread, but they also damage healthy cells. Although healthy cells can recover over time, you may experience side effects from your treatment like nausea, vomiting, loss of appetite, fatigue, hair loss and an increased risk of infection. Chemotherapy is the most common treatment for multiple myeloma. Sometimes chemotherapy drugs are combined with other drugs, such as steroids or some biological therapy drugs.

Stem cell transplant: Sometimes high doses of chemotherapy are used to treat multiple myeloma. High-dose chemotherapy destroys the bone marrow as well as the myeloma cells, so the bone marrow will need to be replaced with a transplant of stem cells. All blood cells develop from stem cells found in the bone marrow and in the bloodstream.

Before high-dose chemotherapy is given, stem cells will be taken from you or from a donor whose bone marrow is a close match to your own. Soon after the chemotherapy treatment, the stem cells are put back into your blood. Within a few weeks, the new stem cells will start to make blood cells.

A stem cell transplant is a complex procedure. For this reason, stem cell transplants are done in specialized transplant centres or hospitals by a team of highly trained healthcare professionals. Side effects can be very serious and may even be life-threatening. You will be watched very closely after a stem cell transplant and carefully followed up for a period of time after leaving the hospital. It may take several months to fully recover after a stem cell transplant.

Radiation therapy: In *external beam radiation therapy*, a large machine is used to carefully aim a beam of radiation at a specific part of the body. The radiation damages the cells in the path of the beam – normal cells as well as cancer cells. For multiple myeloma, radiation may be used to control symptoms, such as bone pain. Sometimes radiation may be given to the whole body as part of the preparation for a stem cell transplant. This is called *total body irradiation*.

Radiation side effects are usually mild. Side effects will be different depending on what part of the body receives the radiation. You may feel more tired than usual, have some diarrhea, or notice changes to the skin (it may be red or tender) where the treatment was given.

Clinical treatment trials: Clinical treatment trials investigate new approaches to treating cancer, such as new drugs, new types of treatments or combinations of existing treatments. They are closely monitored to make sure that they

are safe for the participants. Ask your doctor if there is a clinical trial suitable as a treatment option for you. You may benefit and so may future cancer patients.

Complementary therapies: Complementary therapies are used *together with* conventional treatments. More research is needed to understand if these therapies are effective and how they work.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested for safety or effectiveness. It is still unknown whether they will harm you or be effective in the treatment of cancer.

If you are thinking about using a complementary or alternative therapy, it is important to find out as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might interfere with test results or regular treatments.

After treatment

Follow-up care helps you and your healthcare team monitor your progress and your recovery from treatment. At first, your follow-up care may be managed by one of the specialists from your healthcare team. Later on it may be managed by your family doctor.

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year after treatment, especially if you had a stem cell transplant. It can take the immune system a year or longer to recover. The time between follow-up appointments may become longer as time goes on.

The end of cancer treatment may bring mixed emotions. You may be glad the treatments are over and look forward to returning to your normal activities. But you could feel anxious as well. If you are worried about your treatment ending, talk to your healthcare team. They are there to help you through this transition period.

Living with cancer

There are many sources of help available for people with cancer and for their caregivers.

Your healthcare team: If you need practical help or emotional support, members of your healthcare team may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

Family and friends: Those closest to you can be very supportive. Accept offers of help. When someone says "Let me know how I can help," tell them what they can do. Maybe they can run errands, cook a meal or give you a ride to your doctor's office.

People who have had a similar experience: Consider visiting a support group or talking with a cancer survivor in person, over the telephone or online. Talking with and learning from others who have had similar experiences can be helpful. Try more than one option to see which one suits you best.

Yourself: Try to stay positive. Staying positive is about figuring out how to deal with cancer in the best way that you can – and everyone will do this their own way. It doesn't mean that you must seem happy or cheerful all the time or avoid talking or thinking about the difficulties of having cancer. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically.

The Canadian Cancer Society
Helping you understand cancer

Now that you have been introduced to the basics of multiple myeloma, you may want to learn more. Please contact the Canadian Cancer Society for more detailed information on multiple myeloma. Our services are free and confidential.

To contact the Canadian Cancer Society:

- Call an information specialist toll-free at **1 888 939-3333** Monday to Friday 9 a.m. to 6 p.m.
- E-mail us at **info@cis.cancer.ca**.
- Visit our website at **cancer.ca**.
- Contact your local Canadian Cancer Society office.

We'd like to hear from you

E-mail us at publicationsfeedback@cancer.ca if you have comments or suggestions to help us make this brochure more useful for you and other readers.

What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

Contact us for up-to-date information about cancer, our services or to make a donation.

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