



Canadian
Cancer
Society

Multiple Myeloma

Understanding your diagnosis



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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 have to take in and the decisions you need to make.

“ *All I could hear was ‘cancer.’ I heard my doctor say something like, ‘We’re going to try to start your treatment as soon as possible.’ I didn’t hear one word after that.* ”

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

For more information

You can find more in-depth information about multiple myeloma on cancer.ca. Or call us at 1-888-939-3333 to learn more about cancer, diagnosis, treatment, support and services near you.

Check out our video series on common cancer topics. These short, simple videos cover subjects like *What is cancer?* and *Coping when you’re first diagnosed*.

Find the series at cancer.ca/cancerbasics.

What is cancer?

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

But sometimes the instructions in some cells get mixed up and the cells behave abnormally. Cancer starts when cells grow out of control.

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 inside of bones. Plasma cells are a type of white blood cell. Their job is to make antibodies (also called immunoglobulins) that help fight infections.

People with multiple myeloma have many abnormal plasma cells, called myeloma cells. Myeloma cells divide uncontrollably and crowd out normal cells in the bone marrow. Over time, the growing number of myeloma cells prevents the normal blood cells in bone marrow from developing and working properly. This can lead to more infections than normal, bleeding and anemia. The abnormal plasma cells can also weaken and damage bones.

The disease is called multiple myeloma because it often affects many bones. (When abnormal plasma cells form a single tumour, it's called a plasmacytoma.*)

Myeloma cells make large amounts of one type of immunoglobulin (called a monoclonal immunoglobulin, or M-protein) and release it into the blood and urine. M-proteins can be measured in the lab to see if there is a problem with the plasma cells.

Diagnosing multiple myeloma

Your doctor may suspect you have multiple myeloma after hearing about your symptoms, taking your medical history and doing a physical exam. To find out for sure, your doctor will arrange special tests. These tests may also be used to help plan treatment.

Symptoms: 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. Symptoms may also develop when the bone structure becomes weak or when the kidneys aren't working properly because of a buildup of M-protein. The most common signs and symptoms of multiple myeloma include:

- bone pain, usually from a fracture (break) in the back, chest, ribs, hips or skull
- feeling weak, tired, short of breath or dizzy
- frequent infections and fevers

* For information about plasmacytoma and other plasma cell cancers, contact us at 1-888-939-3333.

- unusual bleeding, such as nosebleeds or bleeding gums
- feeling very thirsty
- frequent urination
- muscle weakness, numbness or tingling

The process of diagnosing cancer may seem long and frustrating. But the doctor has to make sure there are no other possible reasons for a health problem.

The tests your doctor will do to make a diagnosis include the following:

Blood tests: Blood is taken to see if the different types of blood cells are normal in number and how they look. The blood is also tested for M-protein, calcium and other chemicals to see how well your organs are working or if there are signs of disease. The results of these tests may suggest whether you have cancer.

Urine tests: Urine samples may also be taken to check for M-protein.

Bone marrow aspiration and biopsy: A small amount of bone marrow and bone is removed from your hip bone or another large bone and checked under a microscope to look for abnormal plasma cells. There are 2 ways to get a bone marrow sample.

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

Both of these types of biopsies use a local anesthetic (freezing) to numb the area. You may also be given medicine to help you relax. You may feel pain during the procedure but this usually lasts only a few seconds. Bone marrow aspirations and biopsies are often done at the same time in a clinic or hospital.

Imaging tests: The healthcare team uses x-rays, CT scans, MRIs or PET scans to look at your tissues, organs and bones in more detail. For diagnosing multiple myeloma, x-rays are most commonly used. X-rays of the skull, spine, legs, arms, ribs and pelvis 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.

Chromosome tests: Chromosome tests may be done to look for changes in a person's chromosomes. In people with multiple myeloma, some chromosomes are missing or rearranged.

Further testing: Your doctor may order other tests during diagnosis or to help plan your treatment.

Will I be OK?

Most people with cancer want to know what to expect. Can they be cured?

A prognosis is your doctor's best estimate of how cancer will affect you and how it will respond to treatment. It looks at many factors including:

- the type and stage of the cancer
- your age, sex and overall health

Even with all this information, it can still be very hard for your doctor to say exactly what will happen. Each person's situation is different.

Your doctor is the only person who can give a prognosis. Ask your doctor about the factors that affect your prognosis and what they mean for you.

Staging

Once a diagnosis of cancer has been made, the cancer is given a stage. This information helps you and your healthcare team choose the best treatment for you.

The cancer stage describes the extent, or amount, of cancer and how much it affects the body.

In Canada, doctors use 2 systems to stage multiple myeloma:

- the International Staging System (ISS)
- the Durie-Salmon Staging System

Each system contains 3 stages, and the higher the stage the more advanced the cancer.

Treatments for multiple myeloma

Your healthcare team considers your general health and the type and stage of the cancer to recommend the best treatments for you. You'll 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.

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

Targeted therapy: Targeted therapy uses drugs or other substances to target specific molecules (usually proteins) on the surface of cancer cells. This stops the growth and spread of cancer cells and limits the harm to normal cells.

You may have some side effects from targeted therapy such as drowsiness, fatigue, constipation or nerve pain. These side effects usually disappear after treatment.

Chemotherapy: Chemotherapy uses drugs to treat cancer. Chemotherapy drugs may be given as pills or injected with a needle into a vein. They damage cancer cells, but they also damage some healthy cells.

Although healthy cells can recover over time, you may experience side effects from your treatment, like hair loss, sore mouth, loss of appetite, fatigue or an increased risk of infection. Chemotherapy is also often given before or after a stem cell transplant.

Stem cell transplant: A stem cell transplant (or bone marrow transplant) replaces your stem cells. It is used to restore bone marrow when it has been damaged by the disease or by high doses of chemotherapy or radiation therapy. Stem cells are the basic cells that develop into different cell types such as blood cells.

Before the transplant, stem cells are taken from you or from a donor whose stem cells are a close match to your own. Later, the stem cells are put back into your blood. Within a few weeks, the new stem cells 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 highly trained healthcare professionals. Side effects can be very serious and may even be life-threatening. Your healthcare team will watch you very closely after the transplant. It may take several months to fully recover after a stem cell transplant. The most common side effects are infection, bleeding and anemia.

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 cells that are in the path of the beam - both cancer cells and normal cells. Radiation therapy is not often used to treat multiple myeloma. It is used for plasmacytoma (when myeloma cells form a single tumour in the bone). Radiation therapy may also be used to control symptoms, such as bone pain.

Radiation side effects depend 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.

For more information on treatment, you may want to read our booklets *Chemotherapy and Other Drug Therapies* and *Radiation Therapy*.

Surgery: Surgery is sometimes used to treat multiple myeloma. It may be used to support and prevent fractures in weakened bones, for urgent treatment of spinal cord compression or to remove a tumour outside the bone or the bone marrow.

The type of surgery depends mainly on where the tumour is, the symptoms you're having and other factors, such as your age and general health. Side effects depend on the type of surgery done. Pain, as well as nausea and vomiting, are common. These side effects are temporary and can be controlled.

Warning – Taking medicines for bone pain

Bone pain is a common symptom in people with multiple myeloma. Medicines can help relieve the pain. But certain types of pain medicines can increase the risk of kidney damage in people with multiple myeloma. Talk to your doctor before taking nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Motrin, Advil) or naproxen (Naprosyn, Aleve).

Clinical trials: Clinical trials test new ways to treat cancer, such as new drugs, types of treatments or combinations of treatments. They provide information about the safety and effectiveness of new approaches to see if they should become widely available. Ask your doctor if any clinical trials are available as a treatment option for you. You may benefit and so may future cancer patients.

Our brochure *Clinical Trials* has more information, including how to find a clinical trial.

Complementary therapies: Complementary therapies – for example, massage therapy or acupuncture – are used *together with* conventional cancer treatments, often to help ease tension, stress and other side effects of treatment. They don't treat the cancer itself. More research is needed to understand if these therapies are effective and how they work.

If you're thinking about using a complementary therapy, learn as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might affect other treatments or test results.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested enough for safety or effectiveness. Using alternative treatments alone for cancer may have serious health effects. Talk to your healthcare team before you try an alternative therapy.

Side effects of treatments

Some cancer treatments cause side effects, such as fatigue, hair loss or nausea. Because treatments affect everyone differently, it's hard to predict which side effects – if any – you may have.

Side effects can often be well managed and even prevented. If you're worried about side effects, tell your healthcare team about your concerns and ask questions. They can tell you which side effects you should report right away and which ones can wait until your next visit.

If you notice any side effects or symptoms that you didn't expect, talk to a member of your healthcare team as soon as possible. They'll help you get the care and information you need.

Living with cancer

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

Our booklet *Coping When You Have Cancer* has more detailed information and resources.

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: People 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 drive you to your doctor’s office.

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

Yourself: Coping well with cancer doesn’t mean that you have to be happy or cheerful all the time. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically. Take some time to find ways to cope. You may also want to talk to a counsellor for more help.

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with people online?

If you'd like to join our online community, visit CancerConnection.ca. You can read news, join discussion groups, get support and help others at the same time. You'll find caring, supportive people there.

After treatment

Follow-up care helps you and your healthcare team follow your progress and your recovery from treatment. At first, you might meet with one of the specialists from your healthcare team. Later on, it may be 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 and less often after that. After treatment has ended, you should report new symptoms or symptoms that don't go away to your doctor right away, without waiting for your next scheduled visit.

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're worried about your treatment ending, talk to your healthcare team. They can help you through this transition period.

What causes multiple myeloma?

There is no single cause of multiple myeloma, but some factors increase the risk of developing it. More men than women get multiple myeloma. Older people and people of African ancestry have a higher risk of getting multiple myeloma. The reasons for the increased risk are not known.

Some people can develop cancer without any risk factors, while others have some of these factors but do not get cancer.

Risk factors for multiple myeloma include:

- history of monoclonal gammopathy of undetermined significance (MGUS), a plasma cell disorder
- family history of multiple myeloma
- being overweight or obese
- working on a farm

Researchers are studying other factors as possible causes of multiple myeloma, such as autoimmune disorders and being exposed to chemicals at work.

Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.



Ask a trained cancer information specialist your questions about cancer. Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others. Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer. Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.



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 and our services or to make a donation.



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