

What you need to know about Multiple Myeloma

Based on a brochure from
National Institutes of Health
National Cancer Institute



CENTER FOR BLOOD CANCERS

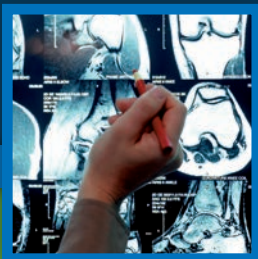
at St. David's South Austin Medical Center

A Member of the Sarah Cannon Blood Cancer Network

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Introduction

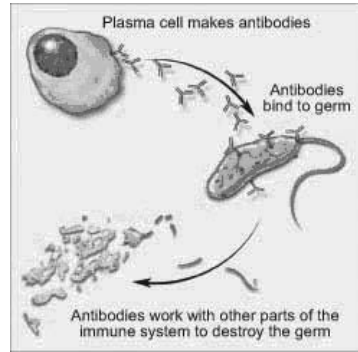
Multiple myeloma is cancer that begins in plasma cells, a type of white blood cell. To understand multiple myeloma, it is helpful to know about normal blood cells.

Normal Blood Cells

Most blood cells develop from cells in the bone marrow called stem cells. Bone marrow is the soft material in the center of most bones.

Stem cells mature into different types of blood cells. Each type has a special function:

- White blood cells help fight infection. There are several types of white blood cells.
- Red blood cells carry oxygen to tissues throughout the body.
- Platelets help form blood clots that control bleeding.



Normal plasma cells help protect the body from germs and other harmful substances.

Plasma cells are white blood cells that make antibodies. Antibodies are part of the immune system. They work with other parts of the immune system to help protect the body from germs and other harmful substances. Each type of plasma cell makes a different antibody.

Myeloma Cells

Myeloma, like other cancers, begins in cells. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die, and new cells take their place. In cancer, this orderly process goes wrong. New cells form when the body does not need them, and old cells do not die when they should. These extra cells can form a mass of tissue called a growth or tumor.

Myeloma begins when a plasma cell becomes abnormal. The abnormal cell divides to make copies of itself. The new cells divide again and again, making more and more abnormal cells. The abnormal plasma cells are myeloma cells. Myeloma cells make antibodies called M proteins.

In time, myeloma cells collect in the bone marrow. They may crowd out normal blood cells. Myeloma cells also collect in the solid part of the bone. The disease is called "multiple myeloma" because it affects many bones. (If myeloma cells collect in only one bone, the single mass is called a plasmacytoma.)

Multiple myeloma is the most common type of plasma cell tumor. This booklet does not deal with other kinds of plasma cell tumors. The Cancer Information Service (1-800-4-CANCER) can send information about those diseases. Multiple myeloma is not bone cancer. Although multiple myeloma affects the bones, it begins in blood cells, not bone cells.

Bone cancer is a different disease. It begins in bone cells, not blood cells. Bone cancer is diagnosed and treated differently from multiple myeloma.

Risk Factors

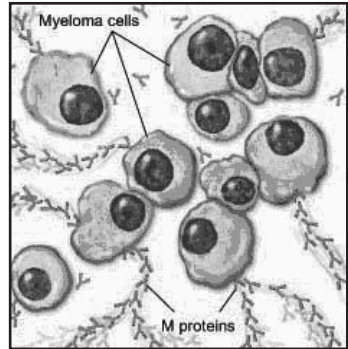
No one knows the exact causes of multiple myeloma. Doctors can seldom explain why one person develops this disease and another does not. However, we do know that multiple myeloma is not contagious. You cannot “catch” it from another person.

Research has shown that people with certain risk factors are more likely than others to develop multiple myeloma. A risk factor is something that may increase the chance of developing a disease.

Studies have found the following risk factors for multiple myeloma:

- **Age:** Growing older increases the chance of developing multiple myeloma. Most people with myeloma are diagnosed after age 65. This disease is rare in people younger than 40.
- **Race:** The risk of multiple myeloma is highest among African Americans and lowest among Asian Americans. The reason for the difference between racial groups is not known.
- **Personal history of monoclonal gammopathy of undetermined significance (MGUS):** MGUS is a condition in which abnormal plasma cells make a low level of M proteins. MGUS is a benign condition, but it increases the risk of certain cancers, including multiple myeloma.

Scientists are studying other possible risk factors for multiple myeloma. Radiation, pesticides, hair dye, certain viruses, obesity, and diet are under study. But it is not clear that these factors are involved in the development of the disease.



Myeloma cell (abnormal plasma cell) making M proteins.

Researchers also are studying families in which more than one person has multiple myeloma. However, such families are extremely rare.

Most people who have known risk factors (being older, being African American, or having MGUS) do not get multiple myeloma. On the other hand, most people who do get the disease have no known risk factors. If you think you may be at risk, you should discuss this concern with your doctor.

Symptoms

Common symptoms of multiple myeloma include:

- Bone pain, usually in the back
- Broken bones, usually in the spine
- Feeling weak and very tired
- Feeling very thirsty
- Frequent infections and fevers
- Weight loss
- Nausea or constipation
- Frequent urination

Most often, these symptoms are not due to cancer. Other health problems can cause the same symptoms. Anyone with these symptoms should tell the doctor so that problems can be diagnosed and treated as early as possible.

Diagnosis

Doctors sometimes find multiple myeloma after a routine blood test. More often, doctors suspect multiple myeloma after an x-ray for a broken bone. Usually though, patients go to the doctor because they are having other symptoms.

To find out whether such problems are from multiple myeloma or some other condition, your doctor may ask about your personal and family medical history and do a physical exam. In addition, your doctor may order some of the following tests and exams:

- **Blood tests:** The lab checks the level of blood cells and other substances. Myeloma causes a high level of plasma cells and calcium. Most people with myeloma have anemia. Myeloma also causes high levels of certain proteins. The lab checks for M protein, beta-2-microglobulin, and other proteins.

- **Urine tests:** The lab checks for Bence Jones protein, a type of M protein, in urine. The lab measures the amount of Bence Jones protein in urine collected over a 24-hour period.

If the lab finds a high level of Bence Jones protein in your urine sample, doctors will monitor your kidneys. Bence Jones protein can clog the kidneys and damage them.

- **X-rays:** You may have x-rays to check for broken or thinning bones.
- **Biopsy:** The doctor removes tissue to look for cancer cells. A biopsy is the only sure way to know whether myeloma cells are in the bone marrow. The doctor removes some bone marrow from your hipbone or another large bone. Local anesthesia helps reduce the discomfort. A pathologist uses a microscope to check the tissue for cancer cells.

There are two ways the doctor can obtain bone marrow:

- **Bone marrow aspiration:** The doctor uses a thin needle to remove samples of bone marrow.
- **Bone marrow biopsy:** The doctor uses a thick needle to remove a small piece of bone and bone marrow.

You may want to ask the doctor these questions before having a biopsy:

- How will the biopsy be done?
- Where will I have my biopsy?
- How long will it take? Will I be awake? What will I feel? Will it hurt?
- Are there any risks? What are the chances of infection or bleeding after the procedure?
- How long will it take me to recover?
- How soon will I know the results? Who will explain them to me?
- If I do have cancer, who will talk to me about the next steps? When?

Staging

If the biopsy shows that you have multiple myeloma, your doctor needs to know the extent (stage) of the disease to plan the best treatment. Staging may involve having more tests. You may have blood tests (including beta-2-microglobulin), CT scans, or an MRI of your bones.

Doctors may describe the disease as Stage I, Stage II, or Stage III. Higher numbers

mean that a larger number of myeloma cells are in the body. The stage also takes into account whether the cancer is causing problems with your bones or kidneys.

Treatment

Many people with multiple myeloma want to take an active part in making decisions about their medical care. It is natural to want to learn all you can about your disease and your treatment choices. However, shock and stress after the diagnosis can make it hard to think of everything you want to ask the doctor. It often helps to make a list of questions before an appointment.

To help remember what the doctor says, you may take notes or ask whether you may use a tape recorder. You may also want to have a family member or friend with you when you talk to the doctor - to take part in the discussion, to take notes, or just to listen.

You do not need to ask all your questions at once. You will have other chances to ask your doctor to explain things that are not clear and to ask for more information.

Your doctor may refer you to a specialist, or you may ask for a referral. Specialists who treat multiple myeloma include medical oncologists, radiation oncologists, and hematologists.

Getting a Second Opinion

Before starting treatment, you might want a second opinion about the diagnosis and treatment plan. Many insurance companies cover a second opinion if you or your doctor requests it. It may take some time and effort to gather medical records and arrange to see another doctor. Usually it is not a problem to take several weeks to get a second opinion. In most cases, the delay in starting treatment will not make treatment less effective. To make sure, you should discuss this delay with your doctor. Some people with multiple myeloma need treatment right away.

There are a number of ways to find a doctor for a second opinion:

- Your doctor may refer you to one or more specialists. At cancer centers, several specialists often work together as a team.
- A local or state medical society, a nearby hospital, or a medical school can usually provide the names of specialists in your area.
- The American Board of Medical Specialties (ABMS) has a list of doctors who have had training and passed exams in their specialty. You can find this list in the Official ABMS Directory of Board Certified Medical Specialists. This

Directory is in most public libraries. Or you can look up doctors at <http://www.abms.org>. (Click on “Who’s Certified.”)

- The NCI provides a helpful fact sheet called “How To Find a Doctor or Treatment Facility If You Have Cancer.”
- Nonprofit organizations with an interest in multiple myeloma may be of help. See the NCI fact sheet “National Organizations That Offer Services to People With Cancer and Their Families.”

Methods of Treatment

The choice of treatment depends mainly on the stage and symptoms of your disease. If you have multiple myeloma without symptoms, you may not need treatment for the cancer. The doctor monitors your health closely so that treatment can start when you begin to have symptoms.

If you have symptoms, your treatment will probably involve anticancer drugs (including steroids). Sometimes stem cell transplantation or radiation therapy is part of the treatment plan. Your doctor can describe your treatment choices and the expected results of each. You and your doctor can work together to develop a treatment plan that meets your needs.

Because standard treatment may not control myeloma, you may want to talk to your doctor about taking part in a clinical trial. Clinical trials are research studies of new treatment methods. The section on “The Promise of Cancer Research” has more information about clinical trials.

At any stage of disease, you may receive supportive care to control health problems (such as infections) caused by multiple myeloma. (See the “Supportive Care” section.)

You may want to ask the doctor these questions before treatment begins:

- What is the stage of my disease?
- Is the disease affecting my kidneys?
- What are my treatment choices? Which do you recommend for me? Will I have more than one kind of treatment? How will my treatment change over time?
- What are the expected benefits of each kind of treatment?
- What are the risks and possible side effects of each treatment? What can we do to control my side effects?

- How will treatment affect my normal activities?
- What can I do to take care of myself during treatment?
- What is the treatment likely to cost? Does my insurance cover this treatment?
- How often will I need to have checkups?
- Would a clinical trial (research study) be appropriate for me?

Anticancer Drug Therapy

Treatment of myeloma usually involves anticancer drugs. This treatment is called systemic therapy because the drugs enter the bloodstream and can affect myeloma cells all over the body. Many different types of drugs are used to treat myeloma. Each type kills cancer cells in a different way.

Types of chemotherapy in common use include melphalan, cyclophosphamide, vincristine, and doxorubicin. Prednisone is a steroid that is often used. In some cases, the doctor may suggest new options, such as thalidomide and bortezomib. People often receive a combination of drugs.

You may receive the drugs by mouth or through a vein. The treatment usually takes place in an outpatient part of the hospital, at your doctor's office, or at home. Patients rarely need to stay in the hospital during treatment.

You may want to ask the doctor these questions before having anticancer drug therapy:

- Which drug or drugs will I have?
- What are the expected benefits of the treatment?
- What are the risks and possible side effects of treatment? What can we do about them?
- Are there any long-term effects?
- When will treatment start? When will it end?
- How will treatment affect my normal activities?

Stem Cell Transplantation

Some people with multiple myeloma have stem cell transplantation. A stem cell transplant allows a person to receive high doses of chemotherapy, radiation therapy, or both. The high doses destroy both myeloma cells and normal blood cells in the bone marrow. Later, the patient receives healthy stem cells through a flexible tube placed in a large vein in the neck or chest area. New blood cells develop from the transplanted stem cells.

Stem cell transplants take place in the hospital. Some patients have two or more transplants.

Stem cells may come from the patient or from a donor:

- **Autologous stem cell transplantation:** This type of transplant uses the patient's own stem cells. The stem cells are removed from the patient, and the cells may be treated to kill myeloma cells that may be present. The stem cells are frozen and stored. After the patient receives high-dose treatment, the stored stem cells are thawed and returned to the patient.
- **Allogeneic stem cell transplantation:** Sometimes healthy stem cells from a donor are available. The patient's brother, sister, or parent may be the donor. Or the stem cells may come from an unrelated donor. Doctors use blood tests to be sure the donor's cells match the patient's cells.
- **Syngeneic stem cell transplantation:** This type of transplant uses stem cells from the patient's healthy identical twin.

You may want to ask the doctor these questions before having a stem cell transplant:

- What are the possible benefits and risks of different types of transplants?
- What kind of stem cell transplant will I have? If I need a donor, how will we find one?
- Will I need to be in the hospital? If so, for how long? Will I need special care?
- How will we know if the treatment is working?
- What can we do about side effects?
- How will treatment affect my normal activities?
- What is my chance of a full recovery?

Radiation Therapy

Radiation therapy (also called radiotherapy) uses high-energy rays to kill myeloma cells and to help control pain. People receive radiation therapy at a hospital or clinic.

Radiation therapy is given two ways for people with myeloma:

- **Local radiation:** A large machine aims radiation at the bone or the part of the body where myeloma cells have collected. It is local therapy because it affects cells only in the treated area. This is the main treatment for people with a single plasmacytoma. People receive radiation for 4 to 5 weeks. A shorter

course of radiation therapy can be used to control the growth of tumors in bones and help relieve pain.

- **Total-body irradiation:** Some patients receive radiation to their whole body before stem cell transplantation. The radiation treatments may be given 2 to 3 times a day for several days.

You may want to ask the doctor these questions before having radiation therapy:

- Why do I need this treatment?
- What are the risks and side effects of this treatment? What can we do about them?
- Are there any long-term effects?
- When will the treatments begin? When will they end?
- How will I feel during therapy?
- How will treatment affect my normal activities?

Side Effects of Treatment

Because cancer treatment often damages healthy cells and tissues, unwanted side effects are common. Side effects depend mainly on the type and extent of the treatment. Side effects may not be the same for each person, and they may change from one treatment session to the next. Before treatment starts, your healthcare team will explain possible side effects and suggest ways to help you manage them.

Anticancer Drug Therapy

The side effects of anticancer drugs depend mainly on the specific drugs and the dose. The drugs affect cancer cells and other cells that divide rapidly:

- **Blood cells:** When drugs affect your healthy blood cells, you are more likely to get infections, bruise or bleed easily, and feel very weak and tired.
- **Cells in hair roots:** Anticancer drugs can cause you to lose your hair. The hair will grow back, but it may be somewhat different in color and texture.
- **Cells that line the digestive tract:** Anticancer drugs can cause poor appetite, nausea and vomiting, diarrhea, or mouth and lip sores.

The drugs used for myeloma also may cause skin rash, blisters, cramps, blurred vision, lung problems, headache, dizziness, drowsiness, numbness or tingling in hands or feet, and blood clots. Your doctor can suggest ways to control many of these side effects.

Stem Cell Transplantation

People who have stem cell transplantation face an increased risk of infection, bleeding, and other side effects because of the large doses of chemotherapy or radiation they receive. In addition, graft-versus-host disease (GVHD) may occur in people who receive stem cells from a donor. In GVHD, the donated stem cells react against the patient's tissues. Most often, GVHD affects the liver, skin, or digestive tract. GVHD can be serious. It can occur any time after the transplant, even years later. Steroids or other drugs may help treat or control GVHD.

Radiation Therapy

The side effects of radiation therapy depend mainly on the dose of radiation and the part of the body that is treated. For example, your skin in the treated area may become red, dry, and tender. You also may lose your hair in the treated area.

You are likely to become very tired during radiation therapy, especially in the later weeks of treatment. Resting is important, but doctors usually advise patients to try to stay as active as they can. Although the side effects of radiation therapy can be distressing, your doctor can usually relieve them.

Supportive Care

Multiple myeloma and its treatment can lead to other health problems. You probably will receive supportive care to prevent or control these problems and to improve your comfort and quality of life.

Infection

People with multiple myeloma get infections very easily. You may receive antibiotics and other drugs to help protect you. Your healthcare team may advise you to stay away from crowds and from people with colds or other contagious diseases. If an infection develops, it can be serious and should be treated promptly. Some people need to stay in the hospital for treatment.

Anemia

Myeloma and its treatment can lead to anemia, which may make you feel very tired. Drugs or blood transfusions can help with this problem.

Pain

Multiple myeloma often causes bone pain. Your healthcare provider can suggest ways to relieve or reduce pain. For example, drugs and local radiation therapy

can help control bone pain. A brace may relieve pain in the neck or back. Some people get pain relief from massage or acupuncture when used along with other approaches. Also, the patient may learn relaxation techniques such as listening to slow music or breathing slowly and comfortably. Sometimes surgery is needed if the spinal cord is compressed (squeezed).

Thinning Bones

Myeloma cells keep new bone cells from forming, and bones become thin wherever there are myeloma cells. Your doctor may give you drugs to prevent bone thinning and help reduce the risk of fractures. Physical activity, such as walking, also helps keep bones strong.

Too Much Calcium in the Blood

Multiple myeloma may cause calcium to leave the bones and enter the bloodstream. If you have a very high level of calcium in your blood, you may lose your appetite. You also may feel nauseated, restless, or confused. A high calcium level can also make you very tired, weak, dehydrated, and thirsty. Drinking a lot of fluids and taking drugs that lower the calcium in the blood can be helpful.

Kidney Problems

Some patients with multiple myeloma have kidney problems. If the problems are severe, they may need dialysis. Dialysis removes wastes from the blood. In some cases, people with serious kidney problems may need a kidney transplant.

Amyloidosis

Some people with myeloma develop amyloidosis. Abnormal protein collects in tissues of the body. The build-up of protein can cause many problems, some of them severe. For example, protein can build up in the heart, causing chest pain and swollen feet. Drugs are used to treat amyloidosis.

Complementary and Alternative Medicine

Some people with cancer use complementary and alternative medicine (CAM) to ease stress or to reduce side effects and symptoms:

- An approach is generally called complementary medicine when it is used along with standard treatment.

- An approach is called alternative medicine when it is used instead of standard treatment.

Acupuncture, massage therapy, herbal products, vitamins or special diets, visualization, meditation, and spiritual healing are types of CAM. Many people say that such approaches help them feel better.

However, some types of CAM may interfere with standard treatment. Combining CAM with standard treatment may even be harmful. Before trying any type of CAM, you should discuss its possible benefits and risks with your doctor.

Some types of CAM are expensive. Health insurance may not cover the cost.

Nutrition

It is important for people with multiple myeloma to eat well and to drink plenty of fluids. Eating well means getting enough calories to maintain a good weight and enough protein to keep up your strength. Good nutrition often helps people with cancer feel better and have more energy.

But eating well can be difficult. You may not feel like eating if you are uncomfortable or tired. Also, the side effects of treatment (such as poor appetite, nausea, vomiting, or mouth sores) can be a problem. Some people find that foods do not taste as good during cancer therapy.

The doctor, a dietitian, or another healthcare provider can suggest ways to maintain a healthy diet.

Follow-up Care

Follow-up care after treatment for multiple myeloma is important. Your doctor will monitor your health and check for recurrence or changes in the cancer. Checkups help ensure that any changes in your health are noted and treated as needed. Checkups may include a physical exam, lab tests, bone marrow aspiration, and x-rays. Between scheduled visits, you should contact the doctor right away if you have any health problems.

Sources of Support

Living with a serious disease such as multiple myeloma is not easy. You may worry about caring for your family, keeping your job, or continuing daily activities. Concerns about treatments and managing side effects, hospital stays, and medical

bills are also common. Doctors, nurses, and other members of the healthcare team can answer questions about treatment, work, or other activities. Meeting with a social worker, counselor, or member of the clergy can be helpful if you want to talk about your feelings or concerns. Often, a social worker can suggest resources for financial aid, transportation, home care, or emotional support.

Support groups also can help. In these groups, patients or their family members meet with other patients or their families to share what they have learned about coping with the disease and the effects of treatment. Groups may offer support in person, over the telephone, or on the Internet. You may want to talk with a member of your healthcare team about finding a support group.

The Promise of Cancer Research

Doctors all over the country are conducting clinical trials (research studies in which people volunteer to take part). Many are studying new ways to treat multiple myeloma.

Clinical trials are designed to answer important questions and to find out whether the new treatments are safe and effective. Research already has led to advances, such as stem cell transplantation, and researchers continue to look for better ways to treat multiple myeloma.

Researchers are testing anticancer drugs (such as thalidomide and bortezomib) and drug combinations. They are also testing ways to improve stem cell transplantation for people with multiple myeloma.

People who join clinical trials may be among the first to benefit if a new approach is effective. And even if participants do not benefit directly, they still make an important contribution to medicine by helping doctors learn more about the disease and how to control it. Although clinical trials may pose some risks, researchers do all they can to protect their patients.

If you are interested in being part of a clinical trial, you should talk with your doctor.

Questions for Your Doctor

This booklet is designed to help you get information you need from your doctor, so that you can make informed decisions about your healthcare. In addition, asking your doctor the following questions will help you further understand your condition. To help you remember what the doctor says, you may take notes or ask whether you may use a tape recorder. Some people also want to have a family member or friend with them when they talk to the doctor – to take part in the discussion, to take notes, or just to listen.

Diagnosis

- What tests can diagnose multiple myeloma? Are they painful?
- How soon after the tests will I learn the results?

Treatment

- What treatments are recommended for me?
- What clinical trials are appropriate for my type of cancer?
- Will I need to be in the hospital to receive my treatment? For how long?
- How might my normal activities change during my treatment?

Side Effects

- What side effects should I expect? How long will they last?
- What side effects should I report? Whom should I call?

Followup

- After treatment, how often do I need to be checked?
- What type of follow-up care should I have?
- Will I eventually be able to resume my normal activities?

The Healthcare Team

- Who will be involved with my treatment and rehabilitation? What is the role of each member of the healthcare team in my care?
- What has been your experience in caring for patients with multiple myeloma?

In Fall 2013, St. David's HealthCare will open the area's first blood cancer and bone marrow transplant center, bringing to Central Texans a more complete spectrum of oncology services. The program will be located at St. David's South Austin Medical Center, which is the organization's leader in cancer care.

Consistent with its commitment to providing the finest care and service, St. David's HealthCare has developed affiliations with a team of world class physicians, organizations and technology. Three industry leaders – Sarah Cannon Research Institute, Texas Transplant Institute and Texas Oncology – are working together with St. David's HealthCare to provide patients and families with access to leading edge cancer care closer to home. Support from these renowned programs provides national expertise in a community setting.

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