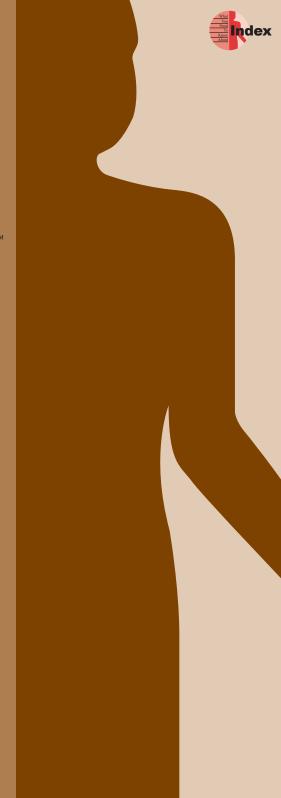
What
You
Need
To
Know
About
Multiple
Myeloma



U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute



This booklet is about multiple myeloma. The Cancer Information Service can help you learn more about this disease. The staff can talk with you in English or Spanish.

The number is 1–800–4–CANCER (1–800–422–6237). The number for callers with TTY equipment is 1–800–332–8615. Your call is free.

Este folleto es acerca del mieloma múltiple. Llame al Servicio de Información sobre el Cáncer para saber más sobre esta enfermedad. Este servicio tiene personal que habla español.

El número a llamar es el 1–800–4–CANCER (1–800–422–6237). Personas con equipo TTY pueden llamar al 1–800–332–8615. Su llamada es gratis.



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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health National Cancer Institute





# What You Need To Know About™ Multiple Myeloma

his National Cancer Institute (NCI) booklet has important information about *multiple myeloma*,\* cancer that starts in certain white blood cells (plasma cells). You will read about possible causes, symptoms, diagnosis, treatment, and supportive care. You also will find ideas about how to cope with the disease.

Each year, about 15,000 Americans learn they have multiple myeloma. Scientists are studying this disease to find out more about how it develops. And they are looking at better ways to treat it.

The NCI provides information about cancer, including the publications mentioned in this booklet. You can order these materials by telephone or on the Internet. You can also read them on the Internet and print your own copy.

- Telephone (1–800–4–CANCER): Information
   Specialists at NCI's Cancer Information Service can
   answer your questions about cancer. They also can
   send NCI booklets, fact sheets, and other materials.
- Internet (http://www.cancer.gov): You can use NCI's Web site to find a wide range of up-to-date information. For example, you can find many NCI booklets and fact sheets at http://www.cancer.gov/publications. People in the United States and its territories may use this Web site to order printed copies. This Web site also explains how people outside the United States can mail or fax their requests for NCI booklets.

<sup>\*</sup>Words that may be new to readers appear in italics. The

<sup>&</sup>quot;Dictionary" section explains these terms. Some words in the

<sup>&</sup>quot;Dictionary" have a "sounds-like" spelling to show how to pronounce them.



You can ask questions online and get help right away from Information Specialists through *LiveHelp*. (Click on the "Need Help?" at http://www.cancer.gov. Then click on "Connect to LiveHelp.")

# What Is Multiple Myeloma?

ultiple 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

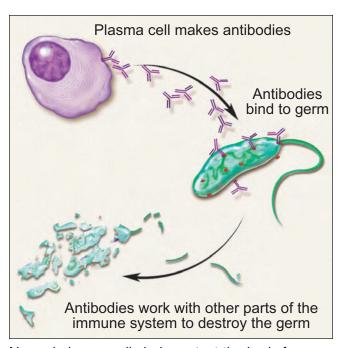
Most blood cells develop from cells in the *bone* marrow called *stem cells*. Bone marrow is the soft material in the center of most bones.

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.

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.





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

# Myeloma Cells

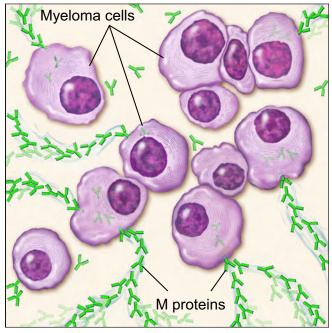
Myeloma, like other cancers, begins in cells. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die, and new cells take their place. In cancer, this orderly process goes wrong. New cells form when the body does not need them, and old cells do not die 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



Myeloma cells (abnormal plasma cells) making M proteins.



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.

The NCI's fact sheet "Bone Cancer: Questions and Answers" provides information about bone cancer. This fact sheet and other materials are available from the Cancer Information Service (1–800–4–CANCER) and on NCI's Web site (http://www.cancer.gov).

## Risk Factors

o 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. 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



ommon *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

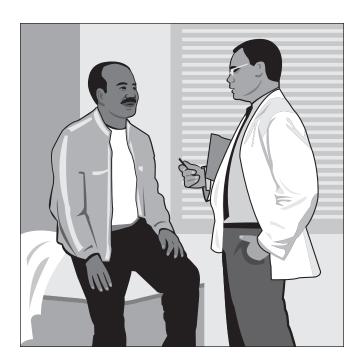
Most often, these symptoms are not due to cancer. Other health problems can cause the same symptoms. Anyone with these symptoms should tell the doctor so that problems can be diagnosed and treated as early as possible.

# Diagnosis

octors 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

f 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

any 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.
- The NCI's Cancer Information Service, at 1–800–4–CANCER, can tell you about nearby treatment centers. Information Specialists also can provide online assistance through *LiveHelp* at http://www.cancer.gov.
- 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" on page 26 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 on page 20.)



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. They may be treated to kill myeloma cells that may be present. The stem cells are frozen and stored. After the patient has 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?
- How long will I need to be in the hospital?
   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 having 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

ecause 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 health care team will explain possible side effects and suggest ways to help you manage them.

The NCI provides helpful booklets about cancer treatments and coping with side effects, such as *Chemotherapy and You*, *Radiation Therapy and You*, and *Eating Hints for Cancer Patients*.



#### **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 severe or even fatal. It can occur any time after the transplant, even years later. Steroids or other drugs may help treat or control GVHD.



The NCI offers a fact sheet called "Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation: Questions and Answers."

## **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

ultiple 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*.

This section tells about health problems that myeloma may cause and describes the supportive care people may need. Detailed information about supportive care is available on NCI's Web site at <a href="http://www.cancer.gov/cancerinfo/coping">http://www.cancer.gov/cancerinfo/coping</a> and from NCI's Cancer Information Service at 1–800–4–CANCER.



#### Infection

People with multiple myeloma get infections very easily. You may receive antibiotics and other drugs to help protect you. Your health care 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 health care 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).

The NCI offers booklets called *Pain Control: A*Guide for People with Cancer and Their Families, Get
Relief from Cancer Pain, and Understanding Cancer
Pain



# **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

ome 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.

The NCI offers a fact sheet called "Complementary and Alternative Medicine in Cancer Treatment: Questions and Answers."



#### Nutrition

t 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 health care provider can suggest ways to maintain a healthy diet.



The NCI booklet *Eating Hints for Cancer Patients* has many useful ideas and recipes.

# Follow-up Care

ollow-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.

To help answer questions about follow-up care and other concerns, the NCI has a booklet for people who have completed their treatment. *Facing Forward Series: Life After Cancer Treatment* provides tips for making the best use of medical visits. It describes how to talk with the doctor about creating a plan of action for recovery and future health.

# Sources of Support

iving 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 health care 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 health care team about finding a support group.

Cancer Information Specialists at 1–800–4–CANCER and at *LiveHelp* (http://www.cancer.gov) can help you locate programs, services, and publications. Also, you may want to see the NCI fact sheets called "Cancer Support Groups: Questions and Answers" and "National Organizations That Offer Services to People With Cancer and Their Families."

## The Promise of Cancer Research

octors 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. You may want to read the NCI booklet *Taking Part in Clinical Trials: What Cancer Patients Need To Know.* The NCI also offers an easy-to-read brochure called *If You Have Cancer...* What You Should Know About Clinical Trials. These NCI publications describe how clinical trials are carried out and explain their possible benefits and risks.

NCI's Web site includes a section on clinical trials at http://www.cancer.gov/clinical\_trials. It has general information about clinical trials as well as detailed information about specific ongoing studies of multiple myeloma. Information Specialists at 1–800–4–CANCER or at *LiveHelp* at http://www.cancer.gov can answer questions and provide information about clinical trials.



# Dictionary

**Abnormal**: Not normal. An abnormal lesion or growth may be cancerous, premalignant (likely to become cancer), or benign.

**Acupuncture** (AK-yoo-PUNK-chur): The technique of inserting thin needles through the skin at specific points on the body to control pain and other symptoms. It is a type of complementary and alternative medicine.

Allogeneic stem cell transplantation (AL-o-jen-AY-ik): A procedure in which a person receives stem cells (cells from which all blood cells develop) from someone else, a genetically similar, but not identical, donor. This is often a sister or brother, but could be someone the person does not know (an unrelated donor).

Alternative medicine: Practices used instead of standard treatments. They generally are not recognized by the medical community as standard or conventional medical approaches. Alternative medicine includes dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.

Amyloidosis (am-uh-loy-DOE-sis): A group of diseases in which protein is deposited in specific organs (localized amyloidosis) or throughout the body (systemic amyloidosis). Amyloidosis may be either primary (with no known cause) or secondary (caused by another disease, including some types of cancer). Generally, primary amyloidosis affects the nerves, skin, tongue, joints, heart, and liver; secondary amyloidosis often affects the spleen, kidneys, liver, and adrenal glands.



**Anemia** (a-NEE-mee-a): A condition in which the number of red blood cells is below normal.

Antibody (AN-tih-BOD-ee): A type of protein made by certain white blood cells (plasma cells) in response to a foreign substance (antigen). Each antibody can bind to only one specific antigen. The purpose of this binding is to help destroy the antigen. Antibodies can work in several ways, depending on the nature of the antigen. Some antibodies destroy antigens directly. Others make it easier for white blood cells to destroy the antigen.

Autologous stem cell transplantation (aw-TAHL-ogus): A procedure in which blood-forming stem cells (cells from which all blood cells develop) are removed, stored, and later given back to the same person.

**Bence Jones protein**: A small protein made by plasma cells, a type of white blood cell. It is found in the urine of most people with multiple myeloma (cancer that arises in plasma cells).

**Benign** (beh-NINE): Not cancerous. Benign tumors do not spread to tissues around them or to other parts of the body.

**Beta-2-microglobulin** (MY-kroh-GLOB-yoo-lin): A protein sometimes found in an increased amount in the blood that may suggest the presence of some types of cancer, such as myeloma or lymphoma.

**Biopsy** (BY-op-see): The removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests. When only a sample of tissue is removed, the procedure is called an incisional biopsy. When an entire lump or suspicious area is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy, core biopsy, or fine-needle aspiration.



**Blood transfusion**: The administration of blood or blood products into a blood vessel.

**Bone marrow**: The soft, sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.

**Bone marrow aspiration** (as-per-AY-shun): The removal by suction of a small sample of bone marrow (usually from the hip) through a needle for examination under a microscope.

**Bone marrow biopsy** (BY-op-see): The removal of a sample of tissue from the bone marrow with a needle for examination under a microscope.

**Bortezomib** (bore-TEZ-oe-mib): A drug that is being studied in the treatment of cancer. It belongs to the family of drugs called dipeptidyl boronic acids. Also called PS-341.

*Calcium* (KAL-see-um): A mineral found in teeth, bones, and other body tissues.

Cancer: A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body. There are several main types of cancer. Carcinoma is cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the bloodstream. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system.

**Chemotherapy** (kee-mo-THER-a-pee): Treatment with anticancer drugs.



*Clinical trial*: A type of research study that tests how well new medical interventions work in people. Such studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Studies may be carried out in a clinic or other medical facility. Also called a clinical study.

Complementary and alternative medicine: CAM. Forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments. These practices generally are not considered standard medical approaches. CAM may include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.

Complementary medicine: Practices often used to enhance or complement standard treatments. They generally are not recognized by the medical community as standard or conventional medical approaches. Complementary medicine may include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.

*Core biopsy*: The removal of a tissue sample with a needle for examination under a microscope.

*CT scan*: Computed tomography scan. A series of detailed pictures of areas inside the body taken from different angles; the pictures are created by a computer linked to an x-ray machine. Also called computerized tomography and computerized axial tomography (CAT) scan.

*Cyclophosphamide*: An anticancer drug that belongs to the family of drugs called alkylating agents.

**Dehydration**: A condition caused by the loss of too much water from the body. Severe diarrhea or vomiting can cause dehydration.



*Dialysis* (dye-AL-ih-sis): The process of filtering the blood when the kidneys are not able to cleanse it.

**Dietitian**: A health professional with special training in nutrition who can help with dietary choices. Also called a nutritionist.

*Digestive tract* (dye-JES-tiv): The organs through which food and liquids pass when they are swallowed, digested, and eliminated. These organs are the mouth, esophagus, stomach, small and large intestines, and rectum.

**Doxorubicin** (DAK-suh-ROO-buh-sun): An anticancer drug that belongs to the family of drugs called antitumor antibiotics. It is an anthracycline. Also called Adriamycin.

*Graft-versus-host disease*: GVHD. A reaction of donated stem cells against the patient's tissue.

*Hematologist* (hee-ma-TOL-o-jist): A doctor who specializes in treating blood disorders.

*Immune system* (im-YOON): The complex group of organs and cells that defends the body against infections and other diseases.

*Infection*: Invasion and multiplication of germs in the body. Infections can occur in any part of the body, and can spread throughout the body. The germs may be bacteria, viruses, yeast, or fungi. They can cause a fever and other problems, depending on where the infection occurs. When the body's natural defense system is strong, it can often fight the germs and prevent infection. Cancer treatment can weaken the natural defense system.

**Local anesthesia** (an-es-THEE-zha): Drugs that cause a temporary loss of feeling in one part of the body. The patient remains awake but has no feeling in the part of the body treated with the anesthetic.



**Local therapy**: Treatment that affects cells in the tumor and the area close to it.

*M protein*: An antibody or part of an antibody found in unusually large amounts in the blood or urine of people with multiple myeloma. Also called monoclonal protein.

Medical oncologist (MED-i-kul on-KOL-o-jist): A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often is the main health care provider for someone who has cancer. A medical oncologist also provides supportive care and may coordinate treatment provided by other specialists.

*Melphalan*: An anticancer drug that belongs to the family of drugs called alkylating agents.

Monoclonal gammopathy of undetermined significance (MAH-no-KLO-nul gam-OP-uh-the): MGUS. A benign condition that affects plasma cells, a type of white blood cell. These abnormal plasma cells make proteins that often show up in blood or urine tests. MGUS sometimes leads to cancer.

MRI: Magnetic resonance imaging (mag-NET-ik REZ-o-nans IM-a-jing). A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue. MRI makes better images of organs and soft tissue than other scanning techniques, such as CT or x-ray. MRI is especially useful for imaging the brain, spine, the soft tissue of joints, and the inside of bones. Also called nuclear magnetic resonance imaging.

*Multiple myeloma* (my-eh-LOW-ma): Cancer that arises in plasma cells (white blood cells that produce antibodies). Also called Kahler's disease, myelomatosis, or plasma cell myeloma.



*Obesity*: Having an abnormally high, unhealthy amount of body fat.

**Pathologist** (pa-THOL-o-jist): A doctor who identifies diseases by studying cells and tissues under a microscope.

**Pesticide** (PES-tuh-side): A chemical that kills insects and other pests.

*Plasma cell*: A type of white blood cell that produces antibodies.

*Plasma cell tumor*: Cancer of the plasma cells (white blood cells that produce antibodies). Multiple myeloma is the most common type.

*Plasmacytoma* (PLAZ-ma-sye-TOE-ma): Tumor made up of cancerous plasma cells (white blood cells that produce antibodies). It sometimes turns into multiple myeloma.

**Platelet** (PLATE-let): A type of blood cell that helps prevent bleeding by causing blood clots to form. Also called a thrombocyte.

**Prednisone**: Belongs to the family of drugs called steroids and is used to treat several types of cancer and other disorders. Prednisone also inhibits the body's immune response.

**Quality of life**: The overall enjoyment of life. Many clinical trials assess the effects of cancer and its treatment on the quality of life. These studies measure aspects of an individual's sense of well-being and ability to carry out various activities.

**Radiation** (ray-dee-AY-shun): Energy released in the form of particles or electromagnetic waves. Common sources of radiation include radon gas, cosmic rays from outer space, and medical x-rays.

**Radiation oncologist** (ray-dee-AY-shun on-KOL-o-jist): A doctor who specializes in using radiation to treat cancer.



Radiation therapy (ray-dee-AY-shun THER-ah-pee): The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy, implant radiation, or brachytherapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy.

**Recurrence**: The return of cancer, at the same place as the original (primary) tumor or in another location, after the tumor had disappeared.

*Red blood cell*: RBC. A cell that carries oxygen to all parts of the body. Also called an erythrocyte.

**Risk factor**: Something that may increase the chance of developing a disease. Some examples of risk factors for cancer include age, a family history of certain cancers, use of tobacco products, certain eating habits, obesity, exposure to radiation or other cancer-causing agents, and certain genetic changes.

*Side effect*: A problem that occurs when treatment affects healthy tissues or organs. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

*Stage*: The extent of a cancer within the body. If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body.

**Staging** (STAY-jing): Performing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body. It is important to know the stage of the disease in order to plan the best treatment.



*Stem cell*: A cell from which other types of cells develop.

*Stem cell transplantation*: A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells.

*Steroid* (STAIR-oyd): A type of drug used to relieve swelling and inflammation. Some steroids also have antitumor effects.

Supportive care: Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and symptom management.

**Symptom**: An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

*Syngeneic stem cell transplantation* (SIN-juh-NAY-ik): A procedure in which a patient receives stem cells donated by his or her healthy identical twin.

*Systemic therapy* (sis-TEM-ik THER-a-pee): Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body.

**Thalidomide**: A drug that belongs to the family of drugs called angiogenesis inhibitors. It prevents the growth of new blood vessels into a solid tumor.

*Tissue* (TISH-oo): A group or layer of cells that work together to perform a specific function.

**Total-body irradiation**: Radiation therapy to the entire body. It is usually followed by bone marrow or peripheral stem cell transplantation.



*Tumor* (TOO-mer): An abnormal mass of tissue that results when cells divide excessively or do not die when they should. Tumors may be benign (not cancerous), or malignant (cancerous). Also called neoplasm.

*Vincristine*: An anticancer drug that belongs to the family of plant drugs called vinca alkaloids.

*Virus* (VYE-rus): A microorganism that can infect cells and cause disease.

White blood cell: WBC. Refers to a blood cell that does not contain hemoglobin. White blood cells include lymphocytes, neutrophils, eosinophils, macrophages, and mast cells. These cells are made by bone marrow and help the body fight infection and other diseases.

*X-ray*: A type of high-energy radiation. In low doses, x-rays are used to diagnose diseases by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.



# National Cancer Institute Information Resources

ou may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

## **Telephone**

The Cancer Information Service (CIS) provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information Specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment. Calls to the CIS are free.

Telephone: 1–800–4–CANCER (1–800–422–6237)

TTY: 1-800-332-8615

#### Internet

The NCI's Web site (http://www.cancer.gov) provides information from numerous NCI sources. It offers current information on cancer prevention, screening, diagnosis, treatment, genetics, supportive care, and ongoing clinical trials. It has information about NCI's research programs and funding opportunities, cancer statistics, and the Institute itself. Information Specialists provide live, online assistance through *LiveHelp*.



#### National Cancer Institute Publications

ational Cancer Institute (NCI) publications can be ordered by writing to the address below:

ordered by writing to the address below:

Publications Ordering Service

Publications Ordering Service
National Cancer Institute
Suite 3035A
6116 Executive Boulevard, MSC 8322
Bethesda, MD 20892–8322

Many NCI publications can be viewed, downloaded, and ordered from http://www.cancer.gov/publications on the Internet. In addition, people in the United States and its territories may order these and other NCI publications by calling the Cancer Information Service at 1–800–4–CANCER.

## **Publications About Cancer Treatment**

- Radiation Therapy and You: A Guide to Self-Help During Treatment (also available in Spanish: La radioterapia y usted: una guía de autoayuda durante el tratamiento del cancer)
- Chemotherapy and You: A Guide to Self-Help During Treatment (also available in Spanish: La quimioterapia y usted: una guía de autoayuda durante el tratamiento del cancer)
- Helping Yourself During Chemotherapy: 4 Steps for Patients
- Biological Therapy: Treatments That Use Your Immune System to Fight Cancer
- Eating Hints for Cancer Patients: Before, During & After Treatment (also available in Spanish: Consejos de alimentación para pacientes con cáncer: antes, durante y después del tratamiento)
- *Understanding Cancer Pain* (also available in Spanish: *El dolor relacionado con el cáncer*)



- Pain Control: A Guide for People with Cancer and Their Families (also available in Spanish: Control del dolor: guía para las personas con cáncer y sus familias)
- Get Relief From Cancer Pain
- Taking Part in Clinical Trials: What Cancer
  Patients Need To Know (also available in Spanish:
  La participación en los estudios clínicos: lo que los
  pacientes de cáncer deben saber)
- If You Have Cancer...What You Should Know About Clinical Trials (also available in Spanish: Si tiene cáncer...lo que debería saber sobre estudios clínicos)
- "Complementary and Alternative Medicine in Cancer Treatment: Questions and Answers" (also available in Spanish: "La medicina complementaria y alternativa en el tratamiento del cáncer: preguntas y respuestas")
- "Biological Therapies: Questions and Answers" (available in Spanish as: "Terapias biológicas: el uso del sistema inmune para tratar el cáncer")
- "Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation: Questions and Answers"

# **Publications About Living With Cancer**

- Advanced Cancer: Living Each Day
- Facing Forward Series: Life After Cancer Treatment (also available in Spanish: Siga adelante: la vida después del tratamiento del cáncer)



- Facing Forward Series: Ways You Can Make a Difference in Cancer
- Taking Time: Support for People With Cancer and the People Who Care About Them
- When Cancer Recurs: Meeting the Challenge
- "How To Find a Doctor or Treatment Facility If You Have Cancer" (also available in Spanish: "Cómo encontrar a un doctor o un establecimiento de tratamiento si usted tiene cáncer")
- "Followup Care: Questions and Answers"
- "Understanding Prognosis and Cancer Statistics" (also available in Spanish: "La interpretación de los pronósticos y las estadísticas del cáncer")
- "Cancer Support Groups: Questions and Answers"
- "National Organizations That Offer Services to People With Cancer and Their Families" (also available in Spanish: "Organizaciones nacionales que brindan servicios a las personas con cáncer y sus familias")
- "How To Find Resources in Your Own Community If You Have Cancer" (also available in Spanish: "Cómo encontrar recursos en su comunidad si usted tiene cáncer")



The National Cancer Institute (NCI) is part of the National Institutes of Health. NCI conducts and supports basic and clinical research in the search for better ways to prevent, diagnose, and treat cancer. NCI also supports the training of scientists and is responsible for communicating its research findings to the medical community and the public.

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