

NCCN Guidelines for Patients®

Version 1.2015

Multiple Myeloma



Available online at NCCN.org/patients



Multiple Myeloma

Learning that you have cancer can be overwhelming. The goal of this book is to help you get the best care. It explains which tests and treatments are recommended by experts in multiple myeloma.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 26 of the world's leading cancer centers. Experts from NCCN® have written treatment guidelines for doctors who treat multiple myeloma. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of multiple myeloma. NCCN also offers patient books on breast cancer, kidney cancer, melanoma, and many other cancer types. Visit NCCN.org/patients for the full library of patient books as well as other patient and caregiver resources.

Credits

NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of books for patients called the NCCN Guidelines for Patients®. Each book presents the best practice for a type of cancer. The patient books are based on clinical practice guidelines written for cancer doctors. These guidelines are called the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Clinical practice guidelines list the best health care options for groups of patients. Many doctors use them to help plan cancer treatment for their patients. Panels of experts create the NCCN Guidelines®. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

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LLS is dedicated to developing better outcomes for blood cancer patients through research, education and patient services and is happy to have this comprehensive resource available to patients with myeloma.

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Multiple Myeloma

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Who should read this book?

This book is about treatment for multiple myeloma, a type of cancer that starts in plasma cells. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It may help you talk with your treatment team, understand what doctors say, and prepare for treatment.

Does the whole book apply to me?

This book includes important information for many situations. Thus, you will likely not get every test and treatment listed. Your treatment team can point out what applies to you and give you more information. As you read through this book, you may find it helpful to make a list of questions to ask your doctors.

The recommendations in this book are based on science and the experience of NCCN experts. However, each patient is unique and these specific recommendations may not be right for you. Your doctors may suggest other tests or treatments based on your health and other factors. This book does not replace the knowledge and suggestions of your doctors.

Making sense of medical terms

In this book, many medical words are included that describe cancer, tests, and treatments. These are words that you will likely hear from your treatment team. Some of this information may be new to you, and it may be a lot to learn.

Don't be discouraged as you read. Keep reading and review the information. Be sure to ask your treatment team to explain a word or phrase that you don't understand.

Words that you may not know are defined in the text or in the *Dictionary*. Words in the *Dictionary* are underlined when first used on a page. Acronyms are defined in the text when first used and are also defined in the *Glossary*. Acronyms are words formed from the first letters of other words. One example is CBC for complete blood count.

About multiple myeloma



1 About multiple myeloma

6	What are plasma cells?
8	How does multiple myeloma start?
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Learning that you have cancer can be overwhelming and confusing. Part 1 explains some basics about multiple myeloma that may help you better understand this disease. These basics may also help you start planning for treatment.

What are plasma cells?

Blood is made of many types of cells, called blood cells. The three main types of blood cells are platelets, red blood cells, and white blood cells. Each type of blood cell has a certain job in the body. Platelets help control bleeding. Red blood cells carry oxygen throughout the body. White blood cells (also called immune cells) are part of the immune system and help fight infections in the body.

Most blood cells are made in the bone marrow. Bone marrow is the soft, sponge-like tissue found in the center of most bones. **See Figure 1.1.** Blood cells are made from special, immature cells called blood stem cells. Blood stem cells can develop into all types of mature blood cells.

Many types of white blood cells are made from a blood stem cell. **See Figure 1.2.** Types of white blood cells include granulocytes, B-cells, and T-cells. The types of white blood cells fight germs in different ways. When germs invade the body, B-cells change into plasma cells. In a healthy person, less than 5 out of 100 cells in the bone marrow are plasma cells.

Plasma cells make antibodies. Antibodies (also called immunoglobulins) are proteins that help your body find and kill germs. Each type of plasma cell makes only one type of antibody, which is designed to attack the specific germ that is causing the infection or illness. There are five types of antibodies, and each differs in how it fights germs. Without enough different plasma cells to make all five types of antibodies in response to germs, the body can't fight illnesses.

Plasma cells also play an important role in the maintenance of bone health. They are part of the repair process that keeps your bones healthy. Plasma cells recognize weaknesses in your bones and release hormones that recruit other cells to break down damaged bone and make new bone to repair.

Figure 1.1
Blood cells in bone marrow

Bone marrow is the soft, sponge-like tissue in the center of most bones. Blood stem cells in the bone marrow make all types of blood cells.

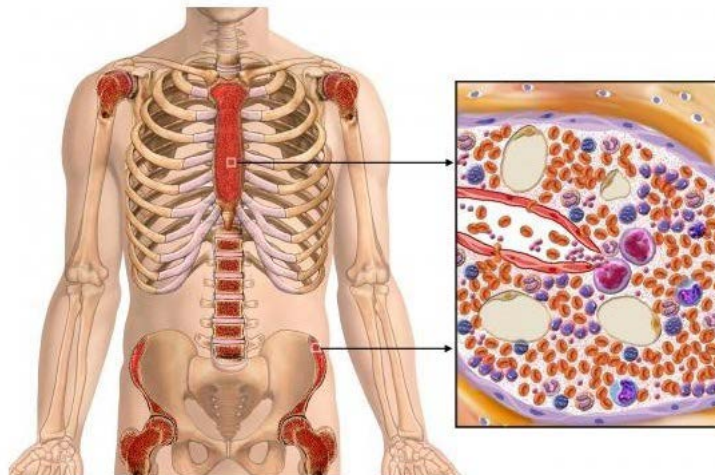
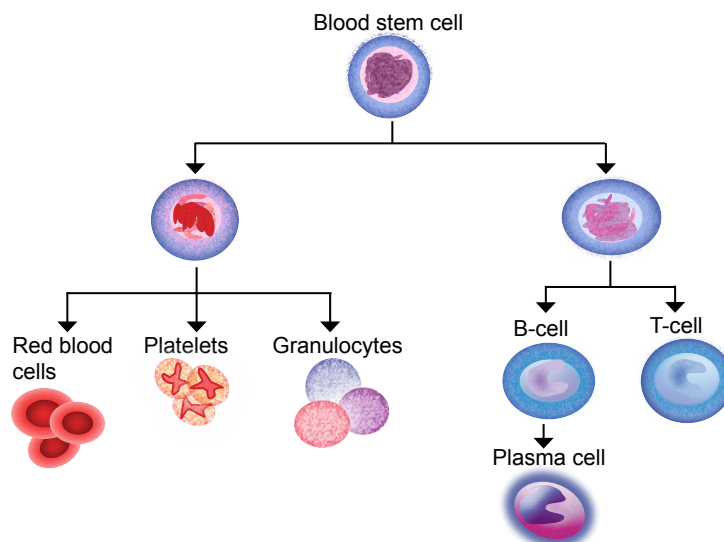


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Figure 1.2
Blood stem cells make all types of blood cells

Blood stem cells are immature cells from which all types of blood cells are made. B-cells are a type of white blood cells that turn into plasma cells.



How does multiple myeloma start?

Multiple myeloma (also simply called myeloma) is a cancer that starts in plasma cells. Plasma cells grow and then divide to make new cells. New cells are made as the body needs them. When plasma cells grow old or get damaged, they die.

Genes are the instructions in cells for making new cells and controlling how cells behave. Changes in their genes turn plasma cells into myeloma cells. An abnormal change in a gene is called a gene mutation or defect.

In contrast to plasma cells, myeloma cells make new cells that aren't needed and don't die quickly when old or damaged. **See Figure 1.3.** The myeloma cells continue to make more and more copies of themselves. As a result, a group of myeloma cells with the same gene mutation forms. A mass of myeloma cells is called a plasmacytoma.

When there is only one mass of myeloma cells, it is called a solitary plasmacytoma. Over time, the myeloma cells can grow enough to spread throughout the bone marrow. This is called multiple myeloma. The myeloma cells can crowd out normal blood cells in the bone marrow, invade bone tissue, and spread all over the body.

Figure 1.3
Plasma versus myeloma cell growth

Normal plasma cells divide to make new cells as the body needs them. Normal cells die once they get old or damaged. Myeloma cells make new cells that aren't needed and don't die quickly when old or damaged.

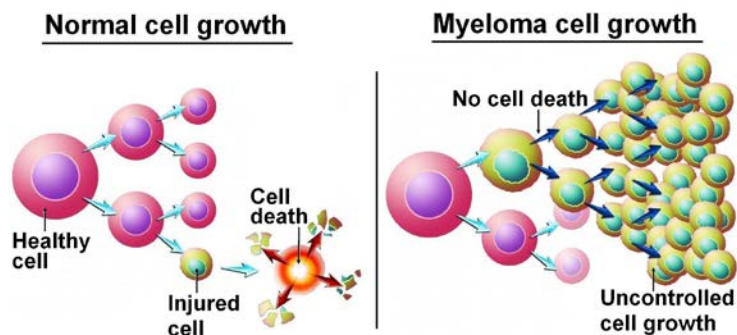


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What are M-proteins?

Like plasma cells, myeloma cells also make antibodies. But, the antibodies made by myeloma cells aren't normal. They are all copies (clones) of one type of antibody. Thus, these are called monoclonal proteins or M-proteins. Myeloma cells make M-proteins without control and not in response to a specific germ in the body. M-proteins don't help to fight infections.

In most patients, myeloma cells make very large amounts of M-proteins. Rarely, people with myeloma make very little or no M-protein. This is called oligosecretory or nonsecretory myeloma.

Normal antibodies are made of two heavy protein chains and two light protein chains. **See Figure 1.4.**

Heavy chains are one of five forms—A, D, G, E, or M. And light chains are one of two forms—kappa or lambda. The form of heavy chain present defines the type of antibody. Most people with myeloma—about 60 out of every 100—have myeloma cells that make G antibodies.

As shown in **Figure 1.4**, myeloma cells also tend to make more light chains than needed to form a complete M-protein. These are called free light chains because they aren't attached to a heavy chain as in a normal antibody. High levels of free light chains are found in the urine of most people with myeloma (75 out of every 100 people). In about 20 out of 100 people with myeloma, the myeloma cells only make free light chains and no complete M-proteins. Doctors call this light chain myeloma or Bence Jones myeloma.

Figure 1.4
Antibodies made by a plasma cell versus a myeloma cell

Antibodies are made of 2 heavy chains and 2 light chains. Myeloma cells tend to make more light chains than needed to form an antibody. These are called free light chains.

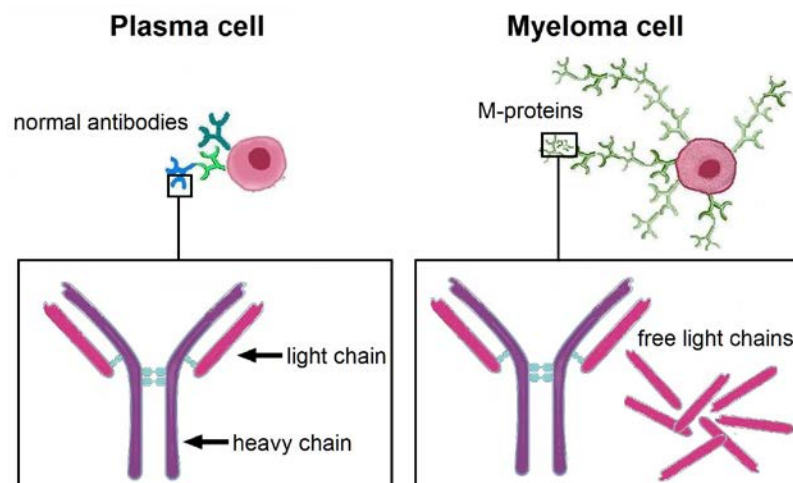


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Symptoms of multiple myeloma

In a healthy person, there are plenty of normal blood cells and all five types of antibodies. In a person with myeloma, too few normal blood cells are made when the bone marrow is full of myeloma cells. Likewise, normal antibodies are outnumbered by the one type of flawed antibody—M-protein—made by the myeloma cells. As a result, symptoms of the cancer will appear. When myeloma is causing symptoms, it is called active myeloma. When myeloma isn't causing symptoms, it is called smoldering myeloma or asymptomatic myeloma. Common symptoms of active myeloma include:

Fatigue and feeling weak

Fatigue is severe tiredness despite getting enough sleep. Fatigue and feeling weak are symptoms of anemia. Anemia is a condition in which the number of red blood cells is low. Anemia can be caused by too many myeloma cells crowding out red blood cells in the bone marrow.

Bruising or bleeding easily

Platelets are blood cells that help heal wounds and

stop bleeding by forming blood clots. Bruising or bleeding easily is a symptom of having a low number of platelets. Too many myeloma cells in the bone marrow can crowd out platelets.

Frequent infections and fevers

Fever is a sign that your body is trying to fight off an infection. Frequent fever and infections is a symptom of having too few white blood cells, but this can also be due to low levels of normal antibodies. A low number of white blood cells can result from too many myeloma cells in the bone marrow.

Bone damage and pain

Myeloma cells can cause bone damage when they crowd out normal cells in the bone marrow. They also release (secrete) hormones that begin to break down bone. Areas of bone damage are called bone lesions and can be very painful. Bone lesions also weaken bones so they may break (fracture) easily. Common sites of bone damage from myeloma are the spine, skull, hip bone, ribs, and shoulders. **See Figure 1.5.** The most common fracture site is in the bones (vertebrae) of the spine. These fractures can be very painful, but they can also occur without any pain.

Figure 1.5
Common areas of bone damage by myeloma

Myeloma cells can cause much damage to bones. This can be very painful and can cause bones to break easily. Common sites of bone damage include the ribs, skull, spine, and hip bone.

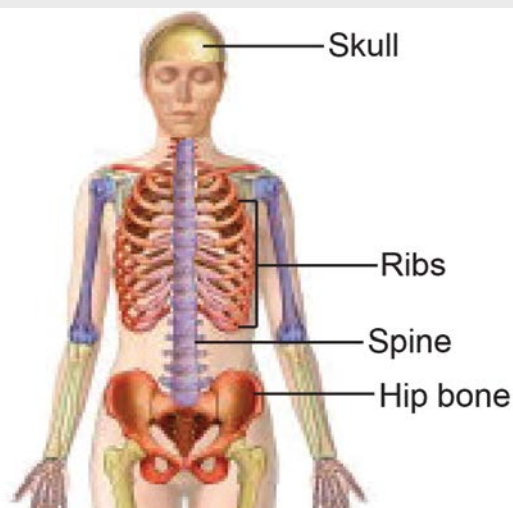


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Kidney problems

The kidneys are a pair of organs that filter blood to remove waste, which leaves the body in urine. Increased or decreased urine output is a symptom of kidney damage. The high levels of M-proteins made by the myeloma cells can cause kidney damage.

Myeloma can damage bones, and this bone damage causes calcium to be released into the bloodstream. Calcium is a mineral needed for healthy bones. But, high levels of calcium in the bloodstream can damage the kidneys.



Review

- Myeloma is a cancer of plasma cells.
- Plasma cells make antibodies that help to fight infections and play a key role in bone repair.
- Myeloma cells make too many copies of themselves.
- Myeloma cells make abnormal antibodies called M-proteins that don't help to fight germs.
- One mass of myeloma cells is called a solitary plasmacytoma.
- When myeloma cells have spread throughout the bone marrow, it is called multiple myeloma.
- Smoldering myeloma doesn't cause symptoms.
- Active myeloma causes symptoms by taking over bone marrow and destroying bone.

Tests for myeloma



2 Tests for myeloma

14 General health tests

15 Blood tests

16 Urine tests

17 Tissue tests

19 Imaging tests

20 Review



Treatment planning starts with testing. The tests used for myeloma are described on the next pages. This information can help you use the *Treatment guide* in Part 4. It may also help you know what to expect during testing. Not every person with myeloma will receive every test listed.

General health tests

Medical history

Before and after cancer treatment, your doctor will assess your medical history. Your medical history includes any health events in your life and any medications you've taken. This information may affect which cancer treatment is best for you. It may help to make a list of old and new medications while at home to bring to your doctor's office. Since some health problems run in families, your doctor may want to ask about the medical history of your blood relatives.

Physical exam

Doctors often give a physical exam along with taking a medical history. A physical exam is a review of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and intestines. Parts of your body will likely be felt to see if organs are of normal size, are soft or hard, or cause pain when touched.

Blood tests

Doctors test blood to look for signs of myeloma in the bloodstream. Blood tests are done along with other initial tests to help confirm (diagnose) myeloma. Blood is made of red blood cells, white blood cells, and platelets. It also has many proteins and other chemicals. Different types of blood tests are used to look for and measure different substances in the blood. These tests help doctors learn more about the myeloma and your health.

Some blood tests are used to assess the extent or amount of myeloma in your body. This is referred to as the tumor burden. Other tests are used to check the health of your bones, kidneys, and other organs. Blood tests may be repeated to check how well cancer treatment is working and to check for side effects.

For a blood test, your doctor will insert a needle into your vein to remove a sample of blood. The blood sample will then be sent to a lab for testing. The types of blood tests used for myeloma are described next.

Tumor burden

SPEP. SPEP (serum protein electrophoresis) is a test that measures the amount of M-proteins in the blood. High levels may be a sign of advanced myeloma.

SIFE. SIFE (serum immunofixation electrophoresis) is a test that finds the type of M-proteins present in the blood. It finds the type of M-proteins by showing which form of heavy chains and light chains they have.

Serum quantitative immunoglobulins. This test measures the amount of each type of antibody in the blood. It will show if the level of any type of antibody is abnormal—too high or too low.

Serum free light chain assay. This test measures the number of free light chains in the blood. This test is helpful when it isn't possible to measure the amount of M-proteins with SPEP or in urine.

Beta-2 microglobulin. Beta-2 microglobulin is a small protein made by many types of cells, including myeloma cells. It is measured with a blood chemistry test. High levels of this protein may be a sign of advanced myeloma.

LDH. LDH (lactate dehydrogenase) is a protein made by myeloma cells. It is measured with a blood chemistry test. High levels of LDH may be a sign of advanced myeloma.

Albumin. Albumin is the main protein in blood plasma and is measured with a blood chemistry test. Low levels of this protein may be a sign of advanced myeloma.

Blood cells

CBC. A CBC (complete blood count) is a test that measures the number of white blood cells, red blood cells, and platelets. As myeloma cells take over the bone marrow, too few normal blood cells are made.

HLA typing. HLAs (human leukocyte antigens) are special proteins found on the surface of most cells in the body. These proteins help the body to tell its own cells apart from foreign cells. The unique set of HLA proteins on a person's cells is called the HLA type. HLA types differ among people just like blood types differ among people. HLA typing is a blood test that finds a person's HLA type. HLA typing is done before treatment that transfers blood stem cells from another person to the patient (see page 27). The patient's HLA type and the donor's HLA type must be a near-perfect match for this treatment to work. This is because the HLA type affects how the body responds to foreign substances.

Bone and kidney health

Calcium. Calcium is a mineral that is found in many body tissues, but mostly in the bones. It is measured with a blood chemistry test. High levels of calcium in the blood may be a sign of myeloma destroying bone.

Creatinine. Creatinine is waste from muscles that is filtered out of blood into urine by the kidneys. It is measured with a blood chemistry test. High levels of creatinine in the blood may be a sign of kidney damage.

BUN. BUN (blood urea nitrogen) is a waste product made by the liver and filtered out of blood into urine by the kidneys. BUN is measured with a blood chemistry test and high levels may be a sign of kidney damage.

Electrolytes. Electrolytes are minerals in the blood needed for organs to work well. They are measured with a blood chemistry test. High levels of electrolytes such as sodium, potassium, and calcium may be a sign of kidney damage.

Serum viscosity. Serum viscosity is a blood test that measures the thickness of your blood. A large amount of M-proteins in your blood can cause blood to become very thick—a condition called hyperviscosity. This can damage your kidneys and other organs. High levels of light chains in the urine can also cause kidney damage.

Urine tests

Besides blood, doctors also test urine to look for signs of disease. Urine tests can be used to confirm (diagnose) myeloma, assess if organs are working well, and check the results of cancer treatments. Urine tests are also used to assess the tumor burden—the extent or amount of myeloma in your body. The types of urine tests used for myeloma are described next.

Tumor burden

UPEP. UPEP (urine protein electrophoresis) is a test that measures the amount of M-proteins in the urine. For this test, urine is collected for 24 hours and then sent to a lab for testing.

UIFE. UIFE (urine immunofixation electrophoresis) is a test that identifies the type of M-proteins present in urine. Only light chains, not heavy chains, are found in urine.

Total protein. Total protein is a test that measures the amount and type of protein in urine. For this test, urine is collected over a 24-hour period. Testing 24-hour urine for light chains (also called Bence Jones protein) helps to measure the tumor burden in patients with myeloma cells that mainly or only make light chains.

Tissue tests

To confirm if you have cancer, a sample of tissue or fluid must be removed from your body for testing. This is called a biopsy. A biopsy is generally a safe test and can often be done in about 30 minutes. The types of biopsies used for myeloma are described below.

Bone marrow aspiration and biopsy

Bone marrow is the soft, sponge-like tissue in the center of most bones where blood cells are made. A bone marrow biopsy removes a small piece of solid bone along with a small amount of soft bone marrow inside the bone. A bone marrow aspiration removes a small amount of liquid bone marrow from inside the bone. Usually both tests are done at the same time on the back of the hip bone.

These biopsies are done as outpatient tests—this means you do not have to spend the night in the hospital. First, you may be given a sedative injected with a needle into your vein. Your doctor will then clean the area of skin where the biopsy will be performed. Next, you will receive local anesthesia to numb the area of skin and bone beneath. After the area is numbed, a hollow needle will be inserted into your skin and then pushed into the bone to remove the liquid bone marrow with a syringe. Then, a wider needle will be inserted into the bone to remove the solid bone and marrow sample. [See Figure 2.1](#). You may feel some pain while the samples are being removed and your skin may be bruised afterward.

Figure 2.1
Bone marrow biopsy

Doctors use a bone marrow biopsy and aspiration to remove a sample of bone marrow for testing. These tests are often done at the same time on the back of the hip bone.

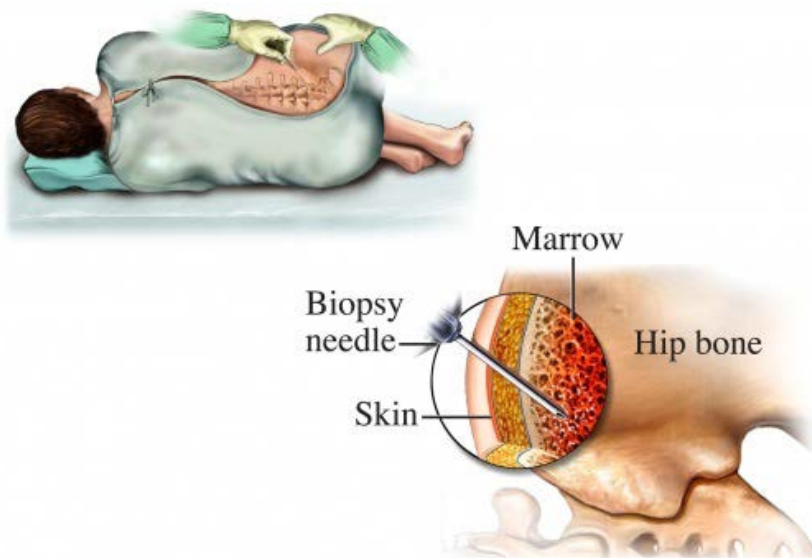


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Tissue biopsy

If you have a solitary plasmacytoma, a tissue biopsy may be done to remove a sample of the mass for testing. The sample is often removed with a needle. This can be done with a fine-needle aspiration biopsy or with a core needle biopsy. A fine-needle aspiration biopsy uses a very thin needle to remove a small sample from the mass. A core needle biopsy uses a larger needle to collect a larger sample of tissue. For a tissue biopsy, an imaging test may be used to guide the needle through the skin and into the mass.

Lab tests

After the tissue samples are collected, they will be sent to a lab for testing. A pathologist will examine the samples with a microscope to look for myeloma cells. The pathologist may also perform other tests on the samples. It often takes several days before the test results are known. The lab tests that may be performed on the tissue samples are described below.

Genetic tests. Genetic tests are used to check for abnormal genes. These tests are done in three parts. Bone marrow cells are grown to make the cells divide. Next, the dividing cells can be examined by karyotyping. Karyotyping looks at a map (karyotype) of the chromosomes in the myeloma cells. Myeloma cells can also be examined with a test called FISH (fluorescence in situ hybridization). FISH uses probes that attach to certain parts of the chromosomes known to be affected in myeloma. The newest testing looks for certain genes that may be turned on or turned off in myeloma cells.

Staining of marrow and fat pad for amyloid.

Amyloid is an abnormal protein found in people with myeloma cells that make too many light chains. Amyloid can collect and build up in tissues and organs throughout the body. The buildup of amyloid, called amyloidosis, can damage organs such as the heart and kidneys. Tests for amyloid can be done on a sample of bone marrow or the fat pad—fat from just under the skin of the belly.

Flow cytometry. This is a test that measures the amount of myeloma cells in the bone marrow. Doctors use this test to judge the risk of progression to active myeloma in patients without symptoms. A high number of myeloma cells is a sign that the myeloma will likely progress.

Immunohistochemistry. This test is performed on the bone marrow biopsy sample. It is used to measure the number of myeloma cells in the bone marrow.

Plasma cell labeling index. This test shows what percentage of the myeloma cells are dividing and how fast they are doing it. Cells that are dividing quickly are a sign of cancer that will spread fast.

Imaging tests

Imaging tests take pictures (images) of the inside of your body. These tests are often easy to undergo. Before the test, you may be asked to stop eating or drinking for several hours. You should also remove any metal objects that are on your body. Some imaging tests may use a contrast dye to make the pictures clearer. This contrast dye can cause more damage to frail kidneys. Thus, it should not be used in patients with multiple myeloma. The types of imaging tests used for multiple myeloma are described below.

Bone survey

A bone survey—also called a skeletal survey—is a test that uses a set of x-rays to take pictures of your entire skeleton. A bone survey is done to check for broken or damaged bones caused by myeloma.

Bone densitometry

Bone densitometry uses x-rays to make pictures that show how strong or thin bones are. This test may be used to decide if you need bisphosphonates—drugs that help to strengthen bones.

CT scan

A CT (computed tomography) scan takes many pictures of a body part from different angles using x-rays. **See Figure 2.2.** A computer combines all the pictures to make one clear picture. A CT scan may be given to further check for bone damage when a bone survey doesn't show any problems.

MRI scan

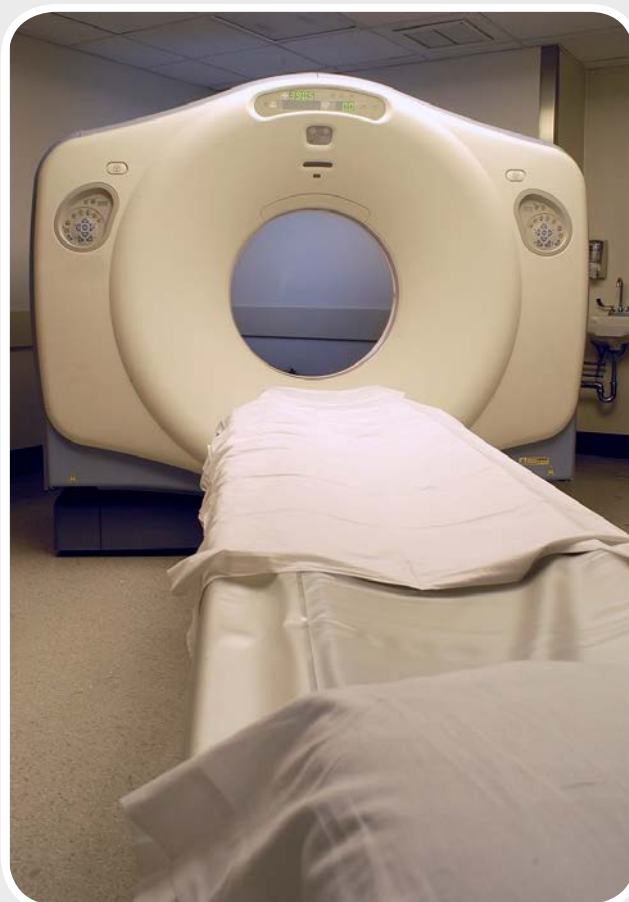
An MRI (magnetic resonance imaging) scan uses radio waves and powerful magnets to take pictures of the inside of the body. It makes very clear pictures of bone and may show if any bone has been damaged by myeloma. An MRI scan may be given when the bone survey doesn't show any problems.

PET scan

A PET (positron emission tomography) scan shows how your cells are using a simple form of sugar. To create pictures, a sugar radiotracer first needs to be put into your body. The radiotracer emits a small amount of energy that is detected by the machine that takes pictures. Myeloma cells appear brighter in the pictures because they use sugar more quickly than normal cells. A PET scan is very good at showing active myeloma and how far it has spread. PET is often used with CT. PET/CT may be used when a bone survey doesn't show any problems.

Figure 2.2 CT scan machine

A CT machine is large and has a tunnel in the middle. During the test, you will lie on a table that moves slowly through the tunnel.



- Cancer tests are used to plan treatment and check how well treatment is working.
- Your health history and a body exam inform your doctor about your health.
- Blood and urine tests check for signs of disease.

- Tests of tissue or fluid from the bone marrow are used to confirm myeloma.
- Tests that take pictures of the inside of your body may show bone damage from the cancer.

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Overview of myeloma treatments



3 Overview of myeloma treatments

22	Radiation therapy
23	Surgery
23	Targeted therapy
24	Chemotherapy
24	Steroids
26	Stem cell transplant
28	Adjunctive treatment and supportive care
30	Clinical trials
32	Review



Part 3 describes the main types of treatments for multiple myeloma and its symptoms. This information may help you use the *Treatment guide* in Part 4. It may also help you know what to expect during treatment. Radiation therapy and surgery are types of local therapy, which treats cancer cells in only one part of the body. Targeted therapy, chemotherapy, and steroids are types of systemic therapy, which treats cancer cells throughout the body. Not every person with myeloma will receive every treatment listed.

Radiation therapy

Radiation therapy is a type of local therapy. Local therapy treats cancer cells in one small, specific area of the body only. Thus, radiation therapy is only used to treat solitary plasmacytomas. A solitary plasmacytoma is a single mass of myeloma cells.

Radiation therapy uses high-energy rays to treat cancer. The rays damage the genes in cells. This either kills the cancer cells or stops new cancer cells from being made. EBRT (external beam radiation therapy) is the most common type of radiation therapy used to treat solitary plasmacytomas. For EBRT, a machine outside the body delivers radiation to the cancer site. But, the radiation may also damage normal cells.

Side effects of radiation therapy

A side effect is an unhealthy or unpleasant physical or emotional condition caused by treatment. Side effects of radiation therapy may not occur in the first few visits. Over time, you may have nausea, diarrhea, and fatigue. Other common side effects are changes in your skin and hair loss in the treated area.

Surgery

Surgery is an operation to remove or repair a body part. It is a type of local therapy. Surgery is rarely used as a treatment for myeloma. It is only used to remove a solitary plasmacytoma located outside of the bone. Radiation therapy is often given before or after the surgery. Surgery may also be used to fix fractures in bones caused by myeloma.

Side effects of surgery

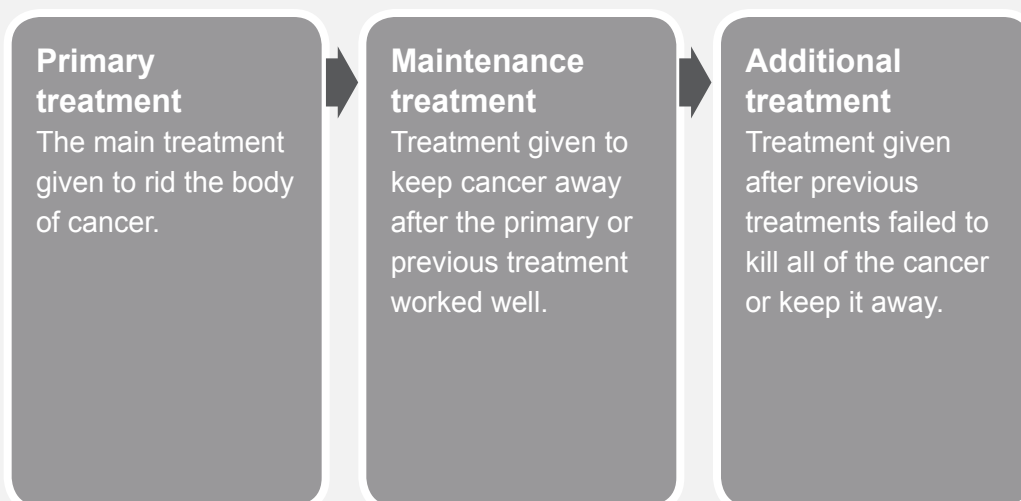
You may experience weakness, tiredness, and pain after the surgery. Other common side effects are swelling, surgical scars, and, less frequently, infections.

Targeted therapy

Targeted therapy is treatment with drugs that target a specific or unique feature of cancer cells. Targeted therapy is less likely to harm normal cells than chemotherapy. Targeted therapy drugs treat myeloma in a few different ways. Some block the growth of new blood vessels that feed myeloma cells in the bone marrow. Others block the action of groups of proteins (proteasomes) that help the myeloma cells grow and survive. An immunomodulator is a type of targeted therapy that helps the immune system find and attack

Order of treatments

Most people with myeloma will receive more than one type of treatment. When and why treatments are given can be hard to understand. Part 4 gives full details. Here, the terms that describe the order of treatments are explained.



cancer cells. [See Chart 3.1](#) for a list of the targeted therapy drugs and other drugs that are used to treat myeloma.

Side effects of targeted therapy

A side effect is an unhealthy or unpleasant physical or emotional condition caused by treatment. Each treatment for myeloma can cause side effects. How your body will respond can't be fully known. Some people have many side effects. Others have few. Some side effects can be very serious while others can be unpleasant but not serious.

The side effects of targeted therapy depend on the drug and dose. Some of the side effects listed are caused by only one targeted drug. Others are caused by many targeted drugs but differ in how likely they are to occur. Some common side effects of targeted therapy drugs are tiredness, weakness, nausea or vomiting, diarrhea, constipation, low red blood cell count (anemia), low white blood cell count (can increase risk of infection), low platelet count (can increase risk of bruising and bleeding), blood clots, numbness or tingling in the hands or feet, skin rash, and muscle aches.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. Many people refer to this treatment as “chemo.” Chemotherapy drugs kill fast-growing cells throughout the body, including cancer cells and normal cells. Some chemotherapy drugs can also cause much damage to your bone marrow.

Different types of chemotherapy drugs attack cancer cells in different ways. Thus, more than one drug is often used. A combination regimen is the use of two or more drugs. When only one drug is used, it is called a single agent.

Chemotherapy is given in cycles. A cycle includes days of treatment followed by days of rest. Giving chemotherapy in cycles lets the body have a chance to rest before the next treatment. The cycles vary in length depending on which drugs are used. Often, the cycles are 14, 21, or 28 days long. Most of the chemotherapy drugs listed in [Chart 3.1](#) are liquids that are slowly injected into a vein. Some are a pill that is swallowed. The drugs travel in the bloodstream to treat cancer throughout the body.

Side effects of chemotherapy

Like targeted therapy, the side effects of chemotherapy depend on many factors. This includes the drug, the dose, and the person. In general, side effects are caused by the death of fast-growing cells, which are found in the intestines, mouth, and blood. As a result, common side effects include low blood cell counts, infections, diarrhea, nausea, vomiting, mouth sores, tiredness or weakness, numbness or tingling of hands or feet, skin and nail changes, hair loss, swelling, and not feeling hungry.

Steroids

Steroids are a type of drug used to relieve swelling and inflammation, but some steroids have anti-cancer effects. Steroids are often used in the treatment of myeloma. Steroids can be used alone to treat myeloma or used with chemotherapy, targeted therapy, or both. [See Chart 3.1](#) for a list of steroids used to treat myeloma.

Side effects of steroids

Most side effects of steroids go away over time once the drugs are stopped. Some common side effects are feeling hungry, trouble sleeping, slow wound healing, upset stomach, and swelling in the ankles, feet, and hands.

Chart 3.1 Drug treatments for multiple myeloma

Generic name	Brand name (sold as)	Type of drug
Bendamustine	Treanda	Chemotherapy
Bortezomib	Velcade	Targeted therapy
Carfilzomib	Kyprolis	Targeted therapy
Cisplatin	Platinol	Chemotherapy
Cyclophosphamide	Cytosan	Chemotherapy
Dexamethasone	Decadron	Steroid
Doxorubicin	Adriamycin	Chemotherapy
Etoposide	VePesid	Chemotherapy
Interferon	–	Immunomodulator
Lenalidomide	Revlimid	Immunomodulator
Lipsomal doxorubicin	Doxil	Chemotherapy
Melphalan	Alkeran	Chemotherapy
Panobinostat	Farydak	Targeted therapy
Pomalidomide	Pomalyst	Immunomodulator
Prednisone	–	Steroid
Thalidomide	Thalomid	Immunomodulator
Vincristine	Oncovin	Chemotherapy
Vorinostat	Zolinza	Targeted therapy

Stem cell transplant

A stem cell transplant is a treatment that uses high doses of chemotherapy to destroy diseased and normal cells in the bone marrow and then replaces them with healthy blood stem cells. The transplanted stem cells should make new bone marrow. The steps of treatment with a stem cell transplant are described on the next pages.

Collecting the stem cells

The first step of a stem cell transplant is to collect, or harvest, the blood stem cells. Blood stem cells are found in the bone marrow and in the bloodstream. The stem cells can be collected from you or from another person, called a donor. Your doctor will likely collect enough stem cells from you for two transplant procedures.

For myeloma treatment, stem cells are usually collected from circulating blood in the bloodstream. With this method, the first step is to remove blood from a large vein in the arm using a central venous catheter. The blood is then filtered through a machine that removes the stem cells and returns the rest of the blood to you, or the donor, through the catheter. This process is called apheresis. Next, the harvested cells are combined with a preservative, frozen, and stored to keep them alive until they are transplanted into you. This process is called cryopreservation. Apheresis typically takes 4 to 6 hours and does not require anesthesia. It usually causes only mild discomfort such as lightheadedness, chills, numbness around the lips, and cramping in the hands during the procedure.

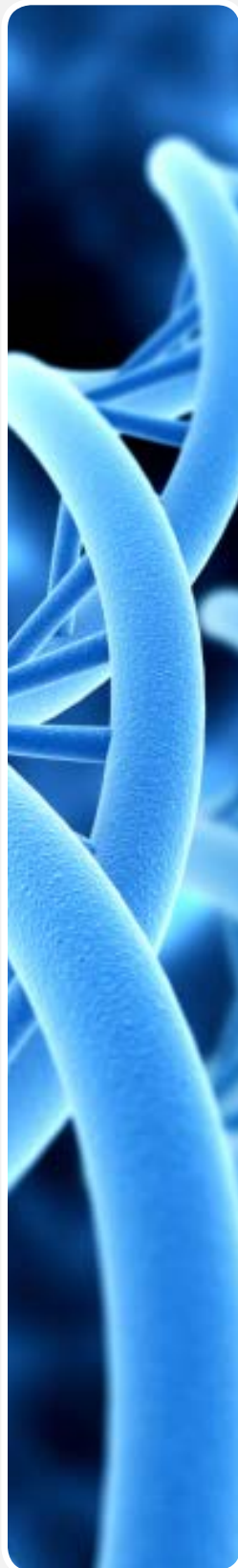
Blood stem cells can also be collected from your bone marrow using bone marrow aspirations. In this procedure, you will be given either regional anesthesia or general anesthesia. Next, a needle will be inserted through your skin into your hip bone (or,

rarely, the breastbone) to draw out the bone marrow. The needle must be inserted many times into one or more spots in the bone to collect enough bone marrow. The bone marrow will then be processed to collect the stem cells. The stem cells will be cryopreserved until the transplant. Collection of the bone marrow takes about 1 hour and will likely cause some pain and soreness for a few days afterward. Other side effects, related to the anesthesia, may include nausea, headache, and tiredness.

High-dose chemotherapy

After the stem cells have been harvested, high doses of chemotherapy are given to destroy any remaining myeloma cells in your bone marrow. The high-dose chemotherapy also destroys normal cells in the bone marrow, including plasma cells and blood stem cells. This greatly weakens your immune system so that your body doesn't kill the transplanted stem cells. However, not every person can tolerate the high-dose chemotherapy before the transplant.

Types of stem cell transplants



Autologous stem cell transplant

This type of transplant uses your own stem cells that are collected after primary treatment. Autologous stem cell transplant is the most common type of transplant used for active myeloma. But, it is not considered a cure because the myeloma may come back even after long periods of disease control.

Tandem stem cell transplant

This is a type of autologous transplant. A tandem stem cell transplant is when a planned second round of high-dose chemotherapy and a second autologous stem cell transplant are given. These treatments are done within 6 months after the first transplant.

Allogeneic stem cell transplant

This type of transplant uses stem cells collected from another person, called a donor. Before the transplant, HLA typing is needed to check if you and the donor are a good match. See page 15 for details on HLA typing.

This transplant may provide the best chance to cure myeloma, although chances are low. A cure may be possible because the donor's healthy stem cells create a new immune system for your body. This transplant also causes the GVT (graft-versus-tumor) effect. The GVT effect is when the transplanted stem cells see the myeloma cells in your body as foreign and attack them.

Allogeneic stem cell transplants aren't used very often for three reasons. First, it's hard to find a matching donor. Second, side effects are serious and include death. Third, the risk of the myeloma coming back is still high.

Mini transplant

This is a type of allogeneic transplant. It is called a "mini" transplant because lower doses of chemotherapy, radiation therapy, or both are given before the transplant. The purpose of a mini transplant is to reduce the severity of side effects but still have the GVT effect.

Donor lymphocyte infusion

A donor lymphocyte infusion is a procedure in which the patient receives lymphocytes from the same person who donated stem cells for the allogeneic transplant. A lymphocyte is a type of white blood cell that helps the body fight infections. The purpose of a donor lymphocyte infusion is to stimulate the GVT effect. This treatment may be used if the myeloma comes back after the first allogeneic stem cell transplant.

Transplanting the stem cells

Once the high-dose chemotherapy is complete, the harvested blood stem cells are put into your body with a transfusion. A transfusion is when you receive whole blood or parts of blood put directly into your bloodstream through a vein. This process can take 1 to 5 hours to complete.

The transplanted stem cells then travel to your bone marrow and grow to make new healthy blood cells. This is called engraftment and it usually occurs about 2 to 4 weeks after the transplant. Until then you have little or no immune defense and so you are at high risk for infection and bleeding. Therefore, you likely will need to stay in a hospital in a very clean (sterile) unit for about 2 weeks. You may be given antibiotic drugs to prevent or treat infection. You may also be given blood transfusions to prevent bleeding and to treat anemia. It may take a few weeks or months for blood cells to fully recover so that your immune system is back to normal.

Side effects of stem cell transplants

Side effects can occur at each step of treatment with a stem cell transplant. You may feel dizzy or have tingling in your hands and feet during apheresis. Common side effects of chemotherapy are listed on page 24. While waiting for the cells to engraft, you will likely feel tired and weak.

Allogeneic stem cell transplants have a high risk of GVHD (graft-versus-host disease). GVHD is when the donated cells (the graft) see the cells in your body (the host) as foreign and attack them. The parts of the body most commonly damaged by GVHD include the skin, liver, and intestines. GVHD is a serious side effect that can cause the transplant to fail by stopping the donated stem cells from growing in your bone marrow. GVHD can develop within a few weeks after the transplant or much later.

Adjunctive treatment and supportive care

Adjunctive treatment is another treatment given at the same time as the main (primary) cancer treatment. It is given to “assist” the main treatment, such as by improving its safety or how well it works. For myeloma, adjunctive treatment includes supportive care to manage the symptoms of myeloma and side effects of myeloma treatment. It is an important part of overall myeloma treatment. Some of the ways to treat the health problems caused by myeloma and myeloma treatment are described on the next pages.

Bone damage

Multiple myeloma often weakens and destroys bones. This can lead to problems such as bone pain, bone fractures, and compression of the spine. Drugs called bisphosphonates can help strengthen bones and reduce the risk of bone problems such as bone fractures. Thus, bisphosphonates are recommended for all patients receiving primary treatment for myeloma. But, these drugs can also cause side effects such as osteonecrosis of the jaw. Bisphosphonates are given as a liquid that is injected into a vein—called an IV (intravenous) injection.

You may be referred to an orthopedic surgeon to help prevent or treat a bone fracture. Surgeons can prevent bone fractures by placing a splint to support the bone and hold it in place. Surgery may be used to treat fractures in the bones of the spine—called vertebrae. Two similar procedures that may be used are vertebroplasty and kyphoplasty.

Vertebroplasty is used to treat compression fractures in the bones of the spine. A compression fracture is a break in a bone caused by the collapse of bones in the spine. This surgery involves injecting a type of cement into the bones. The cement supports and strengthens the bones for pain relief and to hold them in place.

With kyphoplasty, a balloon-like device is placed in the fractured vertebrae and then inflated. This spreads out the vertebrae to restore the normal shape and height of the spine. Then the balloon is removed and a type of cement is injected to support the vertebrae and hold them in place.

Bone damage can be painful. Radiation therapy can be used to treat this pain. It is very helpful for large bone lesions that may cause bone fractures.

Kidney damage

Bone death causes calcium to be released into the bloodstream. A high level of calcium in the blood is dangerous for the kidneys. If this happens, you will be treated with IV fluids and other drugs to help your kidneys flush out the calcium.

Very high levels of M-proteins can cause the blood to become very thick—a condition called hyperviscosity. This can damage the kidneys and other organs. Blood thickness can be treated by filtering blood through a machine to remove M-proteins. This treatment is called plasmapheresis.

High levels of light chains can also damage the kidneys. Free light chains combine with another protein in the kidneys, which causes them to be too large to pass through. The damage caused by this blockage is called myeloma kidney. Prompt treatment of myeloma is required to prevent permanent kidney damage.

Anemia

Myeloma cells may crowd out the normal blood cells in the bone marrow. This can cause anemia—a condition in which the number of red blood cells is too low. Anemia can be treated with a drug called erythropoietin. Erythropoietin stimulates the bone marrow to make more red blood cells.



Infections

Myeloma and certain myeloma treatments can increase the risk of infection. The risk of infection can be reduced with vaccines for pneumonia, the flu, and shingles. Shingles is an infection that causes a painful skin rash and it is a side effect of bortezomib and carfilzomib. Intravenous immunoglobulins may be given to treat frequent, serious infections.

Blood clots

Some drugs, specifically thalidomide and lenalidomide, can cause serious blood clots. If these drugs are used, then adjunctive treatment with blood thinners may be needed. Blood thinners are medications that thin out the blood to reduce the risk of blood clots.

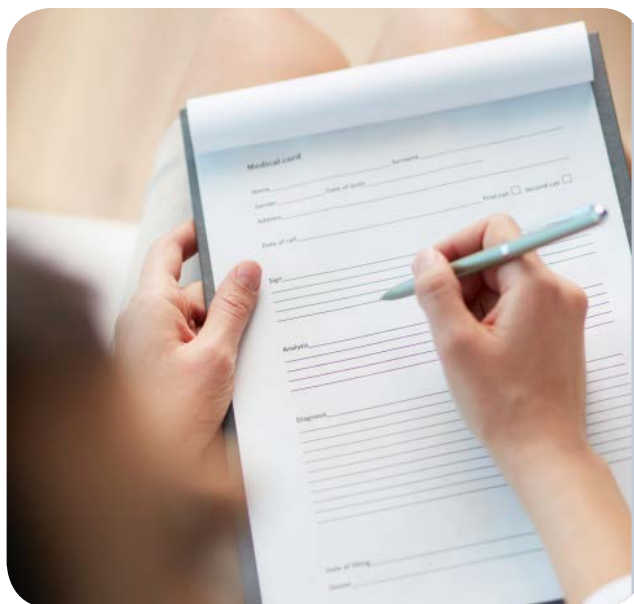
Clinical trials

New tests and treatments aren't offered to the public as soon as they're made. They need to be studied first. New uses of tests and treatments also need to be studied.

A clinical trial is a type of research that studies a test or treatment. Clinical trials study how safe and helpful tests and treatments are. When found to be safe and helpful, they may become tomorrow's standard of care. Because of clinical trials, the tests and treatments in this book are now widely used to help patients.

Tests and treatments go through a series of clinical trials to make sure they're safe and work. Without clinical trials, there's no way to know if a test or treatment is safe or helpful. Clinical trials are done in a series of steps, called phases. The four phases of clinical trials are described next using the example of a new drug treatment:

- **Phase I trials** aim to find the best dose and way to give a new drug with the fewest side effects. If a drug is found to be safe, it will be studied in a phase II trial.
- **Phase II trials** assess if a drug works for a specific type of cancer. They are done in larger groups of patients with the same type of cancer.
- **Phase III trials** compare a new drug to the standard treatment. These are randomized, meaning patients are put in a treatment group by chance.
- **Phase IV trials** test new drugs approved by the FDA (U.S. Food and Drug Administration) to learn about short-term side effects, long-term side effects, and safety. They involve many patients with different types of cancer.



Joining a clinical trial has benefits. First, you'll have access to the most current cancer care. Second, you will receive the best management of care. Third, the results of your treatment—both good and bad—will be carefully tracked. Fourth, you may help other patients with cancer.

Clinical trials have risks, too. Like any test or treatment, there may be side effects. Also, new tests or treatments may not work better than current treatments. Another downside may be that paperwork or more trips to the hospital may be needed.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial often have a similar cancer type and general health. This helps ensure that any response is because of the treatment and not because of differences between patients. You also must review and sign a paper called an informed consent form to join a clinical trial. This form describes the study in detail, including the risks and benefits.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you're getting treatment or at other treatment centers nearby.

My notes

[illegible]

Review

- Surgery and radiation therapy are used when there is a single mass of myeloma cells—called a solitary plasmacytoma.
- Systemic therapy is the use of drugs to kill myeloma cells throughout the body.
- Chemotherapy drugs kill fast-growing cells, including cancer cells and normal cells.
- Targeted therapy drugs target a specific or unique feature of cancer cells.
- A stem cell transplant replaces damaged or diseased bone marrow with healthy blood stem cells.
- An autologous stem cell transplant uses your own stem cells.
- An allogeneic stem cell transplant uses stem cells from another person, called a donor.
- Adjunctive treatment for the symptoms of myeloma and side effects of myeloma treatment is very important.
- A clinical trial studies a test or treatment to see how safe it is and how well it works.

Treatment guide



4 Treatment guide

36 4.1 Multiple myeloma testing

Presents the first set of tests that are recommended to confirm multiple myeloma and plan treatment.

38 4.2 Solitary plasmacytoma

Presents the recommended treatments for a single mass of myeloma cells.

40 4.3 Smoldering multiple myeloma

Presents the recommended treatments for multiple myeloma that isn't causing symptoms.

42 4.4 Active multiple myeloma

Presents the recommended treatments for multiple myeloma that is causing symptoms.





Part 4 is a guide through the treatment options for people with multiple myeloma. It shows which tests and treatments are recommended under which conditions. This information is taken from the treatment guidelines written by NCCN experts for multiple myeloma doctors.

Much effort has been made to make this guide easy to read. Charts list the treatment options and map the steps through the treatment process. The text along with each chart explains the information presented in the chart. Some words that you may not know are defined on the page and in the *Dictionary* on page 64. Words defined in the *Dictionary* are underlined when first used on a page. More information about the tests and treatments in this guide can be found in Parts 2 and 3.

4.1 Multiple myeloma testing

Chart 4.1 Tests for multiple myeloma

Initial tests for diagnosis	Possible other tests
<ul style="list-style-type: none"> • Medical history and physical exam • Bone survey • CBC • Blood chemistry tests: BUN, creatinine, electrolytes, LDH, albumin, calcium, beta-2 microglobulin • Serum free light chain assay • Serum quantitative immunoglobulins • SPEP and SIFE • 24-hour urine for total protein • UPEP and UIFE • Bone marrow aspiration and biopsy • Immunohistochemistry and/or flow cytometry • Genetic tests 	<ul style="list-style-type: none"> • MRI scan • CT scan without contrast • PET/CT scan • Bone densitometry • Tissue biopsy for solitary plasmacytoma • Staining of marrow and fat pad for amyloid protein • Plasma cell labeling index • Serum viscosity • HLA typing

Chart 4.1 shows the initial tests that are recommended when your doctor thinks you may have multiple myeloma. These tests are used to confirm (diagnose) myeloma and to assess if the cancer is causing symptoms. For full details on each test, see Part 2 on page 14.

The first list of tests in the chart above includes the initial tests that are recommended for everyone. The second list includes the tests that may be useful for some people, in addition to the first set of tests.

Initial tests for diagnosis

The medical history and physical exam help your doctors assess if you're having myeloma symptoms, such as fatigue or bruising. A bone survey may show if there's any bone damage. Some blood tests are

also used to assess for symptoms of myeloma. A CBC will show if the number of blood cells is low for each blood cell type. A blood chemistry test checks if certain substances in your blood are too low or too high. This test is used to measure BUN, electrolytes, and creatinine levels to check if your kidneys are working well. It is used to measure calcium levels to check for bone damage. It also measures LDH, albumin, and beta-2 microglobulin to assess the extent or severity of myeloma.

The other blood tests and the urine tests are used to check for and measure M-proteins. Very often, the serum free light chain assay along with SPEP and SIFE can detect multiple myeloma correctly when it is present. The serum free light chain assay is also useful for cancer prognosis and follow-up of amyloidosis and oligosecretory myeloma.

A bone marrow aspiration and bone marrow biopsy are recommended to confirm (diagnose) multiple myeloma. Immunohistochemistry shows if M-proteins are present in the bone marrow. Flow cytometry counts the number of myeloma cells present. Genetic tests of bone marrow can find changes in genes linked to myeloma. Genetic tests may show if genes from two cells have been switched, if genes are missing, or if too many copies of a gene have been made.

Possible other tests

In addition to the initial tests described above, a few more tests may be useful for some people. An MRI scan, CT scan, or PET/CT scan may be used to view areas of your body where symptoms are present. These imaging tests may show cancer or show if you have bone damage. Bone densitometry can be used to assess bone strength to see if you need drugs that prevent or treat bone damage.

If imaging tests show a solitary plasmacytoma, it must be confirmed with a tissue biopsy. Staining of the bone marrow and fat pad is used to check for a protein called amyloid. It is an abnormal protein found in people with myeloma cells that make too many light chains. Plasma cell labeling index is a test that is used to assess how fast myeloma cells are dividing.

A serum viscosity test is done to assess for increased blood thickness, a condition called hyperviscosity. HLA typing is needed if you will have treatment with an allogeneic stem cell transplant. (See Part 2 on page 14 for more test details.)

Next steps:

For a solitary plasmacytoma, see Chart 4.2 on page 38 for treatment recommendations. For multiple myeloma that is not causing symptoms—called smoldering myeloma—see Chart 4.3 on page 40 for treatment recommendations. For multiple myeloma that is causing symptoms—called active myeloma—see Chart 4.4.1 on page 42 for treatment recommendations.

4.2 Solitary plasmacytoma

Chart 4.2 Primary treatment and follow-up for solitary plasmacytoma

Cancer type	Primary treatment	Follow-up tests
Solitary osseous plasmacytoma	Radiation therapy	Testing every 3 to 6 months with: <ul style="list-style-type: none"> • Bone marrow aspiration and biopsy as needed • CBC • Blood chemistry tests: creatinine, albumin, and calcium • LDH and beta-2 microglobulin as needed • Serum free light chain assay • Serum quantitative immunoglobulins • SPEP and SIFE • 24-hour urine for total protein • UPEP and UIF • Bone survey as needed or every year • MRI, CT, PET/CT scans as needed
Solitary extraosseous plasmacytoma	Radiation therapy,	
	Surgery, or Both	

Chart 4.2 shows the recommended primary treatment options for a solitary plasmacytoma. A solitary plasmacytoma is when there is only a single mass of myeloma cells. This chart also shows the recommended tests for follow-up after primary treatment.

Primary treatment is the main treatment given to rid the body of cancer. Treatment options are based on where the solitary plasmacytoma is located in the body. An osseous solitary plasmacytoma begins in bone marrow. An extraosseous solitary plasmacytoma begins in soft tissue outside the bone.

Primary treatment

Because there is only one cancer mass in a solitary plasmacytoma, treatment includes radiation, a local therapy. For an extraosseous plasmacytoma, another option is to remove the mass with surgery. (See Part 3 on page 22 for more details about each treatment.)

Follow-up tests

After completing primary treatment, follow-up tests are recommended every 3 to 6 months. These tests are used to check how well treatment worked. An outcome or improvement related to treatment is called a treatment response. See page 41 to read about the types of treatment responses.

Most of the follow-up tests given after treatment are the same as those described in Chart 4.1 for diagnosis and assessing symptoms. Ongoing, frequent tests to measure M-protein levels are used to check the status of the cancer to make sure treatment is still working. (See Part 2 on page 14 for more details on each test listed in the chart.)

Next steps: ➡

If test results show that the plasmacytoma has come back after primary treatment, local therapy may be an option depending on the location and size of the mass. If the cancer has spread, see Chart 4.1 on page 36 for recommended testing.



4.3 Smoldering multiple myeloma

Chart 4.3 Smoldering myeloma treatment

Primary treatment

Clinical trial, or

Observation with testing every 3 to 6 months:

- CBC
- Blood chemistry tests: BUN, creatinine, and calcium
- Serum quantitative immunoglobulins
- SPEP and SIFE
- Serum free light chain assay as needed
- 24-hour urine for total protein
- UPEP and UIFE
- Bone survey every year or for symptoms
- MRI scan as needed
- PET/CT scan as needed
- Bone marrow aspiration and biopsy as needed
- Flow cytometry as needed

Chart 4.3 shows the recommended primary treatment options for multiple myeloma that isn't causing symptoms. This is called smoldering multiple myeloma. Primary treatment is the main treatment given to rid the body of cancer.

Smoldering myeloma often takes months or years to progress to active (symptomatic) myeloma. For this reason, treatment isn't needed right away. Joining a clinical trial is strongly recommended if one is open and is the right fit for you. Observation is another option. Observation means that your doctor will watch for cancer growth with regular follow-up tests. Many of the tests used for follow-up are the same as those described in Chart 4.1 for diagnosis and assessing symptoms. During observation, follow-up tests are

recommended every 3 to 6 months to check the status of the cancer. (See Part 2 on page 14 for more details about each test.)

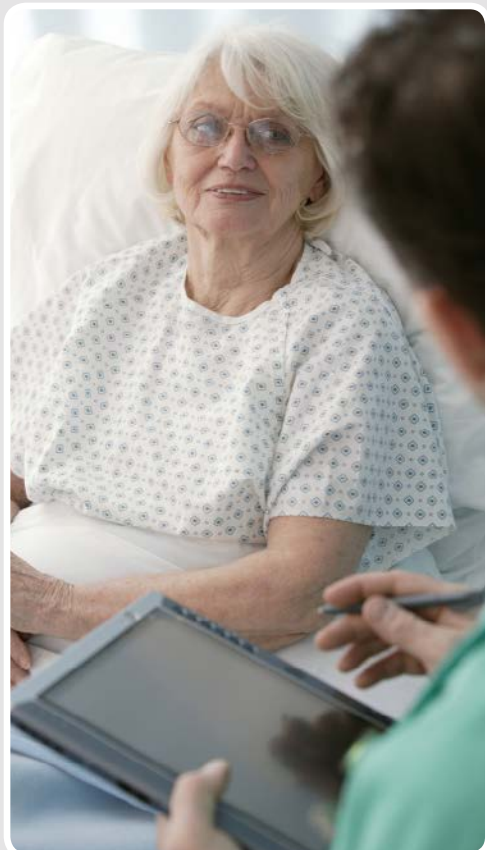
Next steps: 

If the cancer grows and starts causing symptoms, see Chart 4.4.1 on page 42 for recommended treatments for active myeloma.

Measuring treatment response

A treatment response is an outcome or improvement related to treatment.

The response is defined by how well treatment is killing myeloma cells and the severity of symptoms. The main types of treatment responses are listed to the right. “Complete” and “partial” responses are often jointly referred to as “response.”



Complete response

No M-proteins are found in the blood or urine and less than 5 out of 100 cells in the bone marrow are plasma cells.

Partial response

The amount of M-proteins in the blood has decreased by at least 50%. The amount of M-proteins in the urine has decreased by at least 90%. There is no increase in the size or number of bone lesions.

Stable disease

Tests do not show a complete or partial response as defined above or progressive disease as defined below. And, there is no increase in the size or number of bone lesions.

Progressive disease

One or more of the following has occurred: at least a 25% increase in the amount of M-proteins in the blood and urine, a 25% increase in the number of plasma cells in the bone marrow, an increase in size or number of bone lesions, or an increase in calcium levels not explained by other conditions.

Clinical relapse

One or more of the following has occurred: there are direct signs of cancer growth, signs of organ damage, an increase in the number or size (at least 50% larger) of plasmacytomas or bone lesions, increased calcium levels, an increase in creatinine levels in blood, or a decrease in the number of red blood cells.

Relapse from complete response

One or more of the following has occurred: a return of M-proteins in blood or urine, 5 or more out of 100 cells in the bone marrow are plasma cells, new or enlarging bone lesions, or high calcium levels not explained by other conditions.

4.4 Active multiple myeloma

Chart 4.4.1 Primary treatment for active myeloma

Transplant status	Primary treatment	
Treatment will not include a stem cell transplant →	Preferred regimens	+ Adjunctive treatment
	• Bortezomib/dexamethasone,	
	• Lenalidomide/low-dose dexamethasone,	
	• Melphalan/prednisone/bortezomib,	
	• Melphalan/prednisone/lenalidomide, or	
	• Melphalan/prednisone/thalidomide	
	Other regimens	
	• Dexamethasone,	
	• Liposomal doxorubicin/vincristine/dexamethasone,	
	• Melphalan/prednisone, or	
	• Thalidomide/dexamethasone	
Treatment will include a stem cell transplant →	Preferred regimens	+ Adjunctive treatment
	• Bortezomib/dexamethasone,	
	• Bortezomib/cyclophosphamide/dexamethasone,	
	• Bortezomib/doxorubicin/dexamethasone,	
	• Bortezomib/lenalidomide/dexamethasone,	
	• Bortezomib/thalidomide/dexamethasone, or	
	• Lenalidomide/dexamethasone	
	Other regimens	
	• Carfilzomib/lenalidomide/dexamethasone,	
	• Dexamethasone,	
	• Liposomal doxorubicin/vincristine/dexamethasone, or	
	• Thalidomide/dexamethasone	

Chart 4.4.1 shows the primary treatment options that are recommended for multiple myeloma that is causing symptoms. This is called active myeloma. Primary treatment is the main treatment given to rid your body of cancer. Primary treatment includes systemic therapies such as chemotherapy, targeted therapy, and steroids. These drugs may be given alone or in combination. Treatment for active myeloma may or may not include a stem cell transplant. When deciding if a stem cell transplant is a good option for you, your doctor will consider a number of factors. Some key factors include the health of your liver, kidneys, and heart, as well as your age and other current health problems.

Primary treatment

Your primary treatment options depend on whether or not a stem cell transplant might be part of your overall treatment. Some drugs can cause severe damage to healthy cells in the bone marrow. This can make it harder to harvest blood stem cells for a transplant. Melphalan is an example of this type of drug. Thus, melphalan is not recommended for primary treatment if you might have a stem cell transplant later.

The primary treatment options are also split into two groups—preferred regimens and other regimens. Compared to “other” regimens, “preferred” regimens work better, have less severe side effects, or both. (See Part 3 on page 22 for more details about each type of myeloma treatment.)

Adjunctive treatment

Adjunctive treatment is given along with primary treatment for myeloma. It is given to “assist” the primary treatment, such as by improving its safety or how well it works. For myeloma, adjunctive treatment includes supportive care to manage the symptoms of myeloma and side effects of myeloma treatment. A

side effect is an unplanned or unwanted physical or emotional response to treatment.

Recommended adjunctive treatments include:

- Bisphosphonates for bone health (recommended for all patients),
- Drugs, radiation therapy, or surgery for bone pain,
- Drug treatment for high calcium levels,
- Plasmapheresis for hyperviscosity,
- Erythropoietin for anemia,
- Vaccines and treatments for infections,
- Blood thinners to prevent blood clots, and
- Liquids and possible plasmapheresis to prevent kidney damage.

Adjunctive treatments are recommended as needed based on the symptoms and side effects you have. Thus, you may not need every adjunctive treatment listed above. Bone damage from myeloma is very common, so bisphosphonates are recommended for all patients. Drugs such as thalidomide and lenalidomide can cause serious blood clots. If these drugs are part of the primary treatment given, then blood thinners are recommended. Blood thinners are medications that thin out blood to treat or reduce the risk of blood clots. Other adjunctive treatments may be given as symptoms of myeloma or side effects of myeloma treatment appear. For more details about each adjunctive treatment, read page 28 in Part 3.

Next steps: 

See Chart 4.4.2 on page 44 for recommended follow-up after starting primary treatment.

Chart 4.4.2 Follow-up after primary treatment

Follow-up tests	Test results	Next treatment
<ul style="list-style-type: none"> • Bone marrow aspiration and biopsy as needed • CBC • Blood chemistry tests: BUN, creatinine, and calcium • Serum quantitative immunoglobulins • SPEP and SIFE • Serum free light chain assay as needed • 24-hour urine for total protein • UPEP and UIFE • Bone survey yearly or for symptoms • MRI scan as needed • PET/CT scan as needed 	<p>Treatment response</p> <p>No treatment response</p>	<p>Autologous stem cell transplant,</p> <p>Allogeneic stem cell transplant on clinical trial, or</p> <p>Stay on primary treatment until best response, then observation \pm maintenance treatment</p> <p>Treatment for relapse or progressive disease</p>

Maintenance treatment options:**Preferred regimens**

- Bortezomib,
- Lenalidomide, or
- Thalidomide

Other regimens

- Bortezomib + prednisone,
- Bortezomib + thalidomide,
- Interferon,
- Steroids, or
- Thalidomide + prednisone

Chart 4.4.2 shows the follow-up tests that are recommended to check how well primary treatment is working. It also shows the next treatments that are recommended after primary treatment, based on results of the follow-up tests.

Follow-up tests

Follow-up tests are recommended after 2 cycles of primary treatment for active myeloma. These tests are used to check for a treatment response—an outcome or improvement related to treatment.

Many of the tests used for follow-up will be the same as those described in Chart 4.1 for diagnosis. A bone marrow aspiration and biopsy may be done to check if plasma cell levels in the bone marrow are falling. A CBC will show if the number of blood cells is low for each blood cell type. Blood chemistry tests check if certain substances in your blood are too low or too high. Tests of BUN, creatinine, and calcium levels assess for symptoms of myeloma such as kidney damage and bone damage. The other blood tests and urine tests assess if M-protein levels are falling. (See Part 2 on page 14 for more test details.)

Test results and next treatment

The next treatment recommendations are based on how the myeloma responded to primary treatment. To read about the types of treatment responses, see “Measuring treatment response” on page 41.

If the myeloma responded to primary treatment,

then you have three treatment options to choose from next. The first two options are only for patients who are able to have a stem cell transplant. This treatment destroys cells in the bone marrow with chemotherapy and then replaces them with healthy blood stem cells. An autologous stem cell transplant uses your own stem cells. An allogeneic stem cell transplant uses stem cells from another person, called a donor.

For an autologous stem cell transplant, your stem cells will be harvested after primary treatment when the number of myeloma cells is low. Enough stem cells must be collected for two transplants. This is needed since you may have a tandem stem cell transplant or a second transplant as later treatment. (See Part 3 on page 26 for more details about stem cell transplants.)

After the allogeneic or autologous stem cell transplant, the follow-up tests listed in Chart 4.4.2 will be repeated to check for a treatment response. Tests to check the level of M-proteins in your blood and urine should be done at least every 3 months.

If you aren't able to have a stem cell transplant, or you don't want a transplant right away, then there is a third option to choose from. The third option, for all patients, is to continue primary treatment until no further treatment response is seen with follow-up tests. Afterward, you will begin observation and your doctor will monitor the cancer with the follow-up tests listed in Chart 4.4.2. During observation, tests to check the level of M-proteins in your blood and urine should be done at least every 3 months. Along with follow-up tests you may also be given maintenance treatment.

Maintenance treatment is medicine given in a lower dose or less frequently to “maintain” good primary treatment results. Maintenance treatment options are listed in the lower part of Chart 4.4.2. Compared to “other” regimens, “preferred” regimens work better, have less serious side effects, or both.

If the myeloma didn't respond to primary treatment,

then you will receive treatment for relapse or progressive disease. A relapse is the return of myeloma signs or symptoms after a period of improvement (response). Progressive disease is when myeloma continues to grow, spread, or get worse. See *Next steps*.

Next steps:

If you had an allogeneic stem cell transplant, see Chart 4.4.3 on page 46 for recommendations. If you had an autologous stem cell transplant, see Chart 4.4.4 on page 48 for recommendations. If tests showed that the myeloma didn't respond to primary treatment, see Chart 4.4.5 on page 50 for treatment recommendations. Chart 4.4.5 also covers recommended treatments for myeloma progression or relapse after observation or maintenance treatment.

Chart 4.4.3 Treatment after allogeneic stem cell transplant

Test results	Treatment options
Treatment response or stable disease	<ul style="list-style-type: none"> Maintenance treatment on clinical trial, or Observation
Progressive disease	<ul style="list-style-type: none"> Additional treatment on or off clinical trial, or Donor lymphocyte infusion

Maintenance treatment options:**Preferred regimens**

- Bortezomib,
- Lenalidomide, or
- Thalidomide

Other regimens

- Bortezomib + prednisone,
- Bortezomib + thalidomide,
- Interferon,
- Steroids, or
- Thalidomide + prednisone

Chart 4.4.3 shows the treatment options that are recommended after an allogeneic stem cell transplant. An allogeneic transplant is a treatment in which you receive healthy blood stem cells from another person. Which treatment is recommended next depends on how the myeloma responded to the stem cell transplant. A treatment response is an outcome or improvement related to treatment. See page 41 to read about the types of treatment responses.

If tests show a treatment response or stable disease, then you have two treatment options to choose from. One option is to receive maintenance treatment as part of a clinical trial. Maintenance

treatment is medicine given in a lower dose or less frequently to “maintain” good initial treatment results. Maintenance treatment options are listed in the lower part of Chart 4.4.3. Compared to “other” regimens, “preferred” regimens work better, have less serious side effects, or both. The second option is to begin observation—a period of testing to watch for cancer growth. If myeloma returns or gets worse after either of these options, then you will have treatment for progressive disease as described below.

If tests show progressive disease, then you have two treatment options to choose from. The first option is to receive additional treatment, possibly within a clinical trial. Additional treatment is given

after prior treatments failed to kill all of the cancer or keep it away. (Options for additional treatment are listed in Chart 4.4.6 on page 51.) The second option is to receive a donor lymphocyte infusion. A donor lymphocyte infusion is when you are given white blood cells called lymphocytes from the same donor used for the allogeneic stem cell transplant. (See Part 3 on page 22 to read more about each type of treatment for myeloma.)



Chart 4.4.4 Treatment after autologous stem cell transplant

Test results	Treatment options	Next treatment
Response or stable disease	<div> Maintenance treatment, Tandem stem cell transplant ± maintenance treatment, or Observation </div>	<div> Progressive disease </div>
Progressive disease	<div> Additional treatment on or off clinical trial, or Allogeneic stem cell transplant on clinical trial </div>	<div> Additional treatment on or off clinical trial ± autologous stem cell transplant, or Allogeneic stem cell transplant on clinical trial </div>

Maintenance treatment options:**Preferred regimens**

- Bortezomib,
- Lenalidomide, or
- Thalidomide

Other regimens

- Bortezomib + prednisone,
- Bortezomib + thalidomide,
- Interferon,
- Steroids, or
- Thalidomide + prednisone

Chart 4.4.4 shows the treatments that are recommended after an autologous stem cell transplant. An autologous stem cell transplant is a treatment in which your blood stem cells are removed, stored, and then returned. Which treatment is recommended depends on how the myeloma responded to the transplant. A treatment response is an outcome or improvement related to treatment. See page 41 to read about the types of treatment responses.

If tests show a treatment response or stable disease, you have three treatment options to choose from. The first option is to receive maintenance treatment—medicine given in a lower dose or less frequently to “maintain” good initial treatment

results. Maintenance treatment options are listed in the lower part of Chart 4.4.4. Compared to “other” regimens, “preferred” regimens work better, have less serious side effects, or both. The second option is to receive a tandem stem cell transplant with or without maintenance treatment. A tandem transplant is a second round of high-dose chemotherapy followed by a second autologous stem cell transplant given within 6 months of the first transplant. The third option is to begin observation—a period of testing to watch for cancer growth. (See Part 3 on page 22 to read more about each type of treatment for myeloma.)

If tests show progressive disease after any of the treatments described above, you have two more treatment options to choose from. The first option

is to receive additional treatment, possibly within a clinical trial. Additional treatment is the treatment given after prior treatments failed to kill all the cancer or keep it away. (Options for additional treatment are listed in Chart 4.4.6 on page 51.) Additional treatment may be given with or without another autologous stem cell transplant. A treatment response lasting at least 2 to 3 years prior to progression is suggested for consideration of another transplant. The second option is to receive an allogeneic stem cell transplant within a clinical trial. (See page 27 for more details about the different types of stem cell transplants.)

If tests show progressive disease, then you have two treatment options to choose from. One option is to receive additional treatment, possibly within a clinical trial. (Options for additional treatment are listed in Chart 4.4.6 on page 51.) The other option is to receive an allogeneic stem cell transplant as part of a clinical trial. An allogeneic transplant is a treatment in which you receive healthy blood stem cells from another person. (See Part 3 on page 22 to read more about each type of treatment for myeloma.)



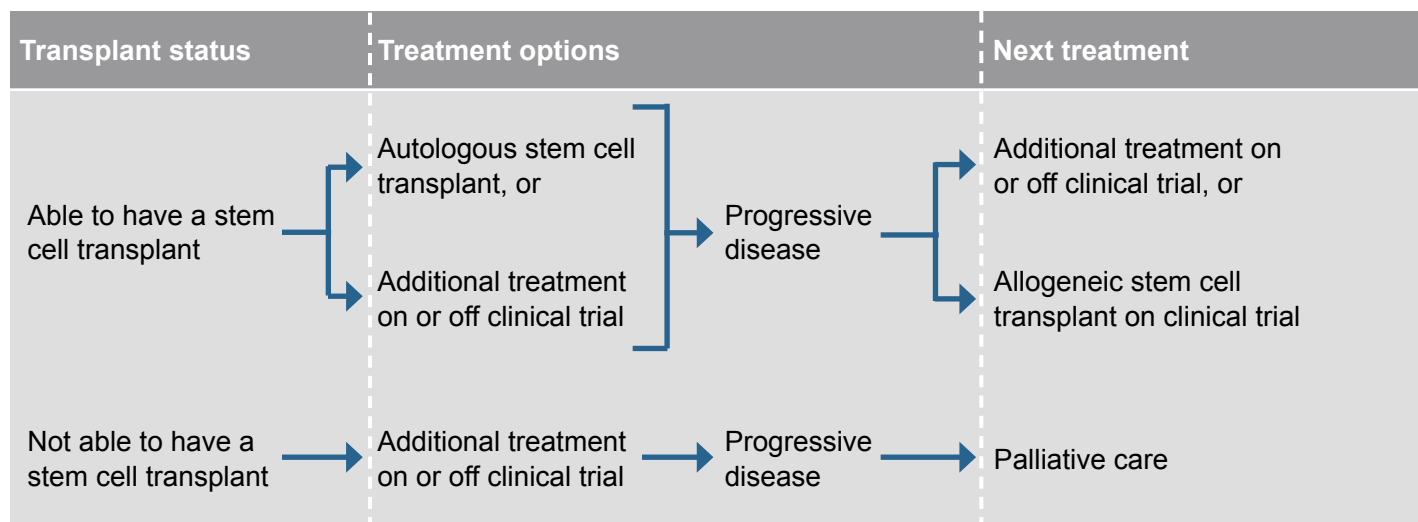
Chart 4.4.5 Treatment for relapse or progressive disease after primary treatment

Chart 4.4.5 shows the treatments that are recommended for a relapse or progressive disease after primary treatment. A relapse is the return of myeloma signs or symptoms after a period of improvement. Progressive disease is when myeloma continues to grow, spread, or get worse.

Chart 4.4.5 includes options for myeloma that didn't respond to primary treatment or that progressed or relapsed after an initial treatment response. Which treatment option is recommended depends on whether or not you are able to have a stem cell transplant. A stem cell transplant is a treatment that destroys cells in the bone marrow with chemotherapy and then replaces them with healthy blood stem cells. An autologous stem cell transplant uses your own stem cells. An allogeneic stem cell transplant uses stem cells from another person, called a donor. (See page 26 for more details about stem cell transplants.)

If you are able to have a stem cell transplant, then you have two treatment options to choose from.

The first option is to receive an autologous stem cell transplant. The second option is to receive additional treatment—the treatment given after prior treatments failed to kill all the cancer or keep it away. Options for additional treatment are listed in **Chart 4.4.6** on page 51. If follow-up tests show progressive disease after the transplant or additional treatment, then you have two more options. One option is to receive additional treatment, possibly within a clinical trial. The other option is to have an allogeneic stem cell transplant within a clinical trial.

If you are not able to have a stem cell transplant, then additional treatment is recommended on or off a clinical trial. Options for additional treatment are listed in Chart 4.4.6 on page 51. If tests show progressive disease during or after additional treatment, then palliative care is recommended. Palliative care (also called supportive care) is given to relieve symptoms of cancer and side effects of cancer treatment. It doesn't aim to treat the cancer, but aims to improve quality of life.

Chart 4.4.6 Additional treatment

Preferred regimens
• Repeat primary treatment if it ended >6 months ago,
• Bortezomib,
• Bortezomib/dexamethasone,
• Bortezomib/lenalidomide/dexamethasone,
• Bortezomib/liposomal doxorubicin,
• Bortezomib/thalidomide/dexamethasone,
• Carfilzomib,
• Carfilzomib/lenalidomide/dexamethasone
• Cyclophosphamide/bortezomib/dexamethasone,
• Cyclophosphamide/lenalidomide/dexamethasone,
• Dexamethasone/cyclophosphamide/etoposide/cisplatin,
• Dexamethasone/thalidomide/cisplatin/doxorubicin/cyclophosphamide/etoposide ± bortezomib,
• High-dose cyclophosphamide,
• Lenalidomide/dexamethasone,
• Panobinostat/bortezomib/dexamethasone,
• Pomalidomide/dexamethasone, or
• Thalidomide/dexamethasone
Other regimens
• Bendamustine,
• Bortezomib/vorinostat, or
• Lenalidomide/bendamustine/dexamethasone

My notes

[illegible]

Making treatment decisions



5 Making treatment decisions

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Cancer can be stressful. While absorbing the fact that you have cancer, you must also learn about tests and treatments. And, the time you have to decide on a treatment plan may feel short. Parts 1 through 4 aimed to teach you about multiple myeloma, its treatment, and other challenges. Part 5 aims to help you talk with your doctor and make treatment decisions that are right for you.

Have a treatment plan

Learning you have cancer starts an unplanned journey to an unknown place. A treatment plan is like having a roadmap for your journey. It is a written course of action through treatment and beyond. It can help you, your loved ones, and your treatment team.

A treatment plan addresses all cancer care needs while respecting your beliefs, wishes, and values. It is likely to change and expand as you go through treatment. The plan will include the role of your doctors and how you can help yourself. A treatment plan often has the following parts:

Cancer information

Cancer can greatly differ even when people have cancer in the same organ. Test results that describe the cancer are reported in the treatment plan. Such test results include the number of plasma cells and levels of M-proteins, calcium, and creatinine. If done, test results of known gene changes are also included. See Part 2 on page 14 to read more about the tests used for multiple myeloma.

Your treatment team

Treating multiple myeloma takes a team approach. A hematologist is a doctor who's an expert in treating diseases of the blood. A medical oncologist is a doctor who's an expert in treating cancer with drugs. A radiation oncologist is an expert at treating cancer with radiation. A surgeon is an expert in operations to remove or repair a part of the body. A pathologist is an expert in testing cells and tissue to find disease.

Your primary care doctor can also be part of your team. He or she can help you express your feelings about treatments to the team. Treatment of other medical problems may be improved if he or she is informed of your cancer care. Besides doctors, you may receive care from nurses, social workers, and other health experts. Ask to have the names and contact information of your health care providers included in the treatment plan.

Cancer treatment

There is no single treatment practice that is best for all patients. There is often more than one treatment option, including clinical trials. Clinical trials study how well a treatment works and its safety.

A guide to myeloma treatment options can be found in Part 4. The treatment that you and your doctors agree on should be reported in the treatment plan. It is also important to note the goal of treatment and the chance of a good treatment outcome. All known side effects should be listed and the time required to treat them should be noted. See Part 3 for a list of some of the possible side effects of myeloma treatments.

Your treatment plan may change because of new information. You may change your mind about treatment. Tests may find new results. How well the treatment is working may change. Any of these changes may require a new treatment plan.

Stress and symptom control

Cancer and its treatments can cause bothersome symptoms. The stress of having cancer can also cause symptoms. There are ways to treat many symptoms, so tell your treatment team about any that you have.

You may lose sleep before, during, and after treatment. Getting less sleep can affect your mood, conversations, and ability to do daily tasks. If possible, allow yourself to rest, let people do things for you, and talk with your doctor about sleep medication. Behavioral sleep medicine—a type of talk therapy—may also help.

Feelings of anxiety and depression are common among people with cancer. At your cancer center, cancer navigators, social workers, and other experts can help. Help can include support groups, talk therapy, or medication. Some people also feel better by exercising, talking with loved ones, or relaxing.

You may be unemployed or miss work during treatment. Or, you may have too little or no health insurance. Talk to your treatment team about work, insurance, or money problems. They will include information in the treatment plan to help you manage your finances and medical costs.

Survivorship care

Cancer survivorship begins on the day you learn of having myeloma. For many survivors, the end of active treatment signals a time of celebration but also of great anxiety. This is a very normal response. You may need support to address issues that arise from not having regular visits with your cancer care team. In addition, your treatment plan should include a schedule of follow-up cancer tests, treatment of long-term side effects, and care of your general health.

Advance care planning

Talking with your doctor about your prognosis can help with treatment planning. If the cancer can't be controlled or cured, a care plan for the end of life can be made. However, such talks often happen too late or not at all. Your doctor may delay these talks for fear that you may lose hope, become depressed, or have a shorter survival. Studies suggest that these fears are wrong. Instead, there are many benefits to advance care planning. It is useful for:

- Knowing what to expect,
- Making the most of your time,
- Lowering the stress of caregivers,
- Having your wishes followed,
- Having a better quality of life, and
- Getting good care.

Advance care planning starts with an honest talk between you and your doctors. You don't have to know the exact details of your prognosis. Just having a general idea will help with planning. With this information, you can decide at what point you'd want to stop chemotherapy or other treatments, if at all. You can also decide what treatments you'd want for symptom relief, such as radiation therapy, surgery, or medicine.

Another part of the planning involves hospice care. Hospice care doesn't include treatment to fight the cancer but rather to reduce symptoms caused by cancer. Hospice care may be started because you aren't interested in more cancer treatment, no other cancer treatment is available, or because you may be too sick for cancer treatment. Hospice care allows you to have the best quality of life possible. Care is given all day, every day of the week. You can choose to have hospice care at home or at a hospice center.

One study found that patients and caregivers had a better quality of life when hospice care was started early.

An advance directive describes the treatment you'd want if you weren't able to make your wishes known. It also can name a person whom you'd want to make decisions for you. It is a legal paper that your doctors have to follow. It can reveal your wishes about life-sustaining machines, such as feeding tubes. It can also include your treatment wishes if your heart or lungs were to stop working. If you already have an advance directive, it may need to be updated to be legally valid.



Your role in planning

The role patients want in treatment planning differs. Your doctors and treatment team will give you the information you need to make informed choices. But, you may prefer to let others take the lead in deciding your treatment. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may have never heard the words used to describe myeloma, tests, or treatments. Likewise, you may think that your judgment isn't any better than your doctors'.

You may rely on your doctors alone to make the right decisions. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may prefer to take the lead or share in decision-making. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science of treating myeloma. But, you know your personal concerns and goals. By working together, you may feel more comfortable and satisfied with your care and treatment plan. You'll likely get the treatment you want, at the place you want, and by the doctors you want.

Getting a 2nd opinion

The time around a cancer diagnosis can be very stressful. People with cancer often want to start treatment as soon as possible. They want to make the cancer go away before it spreads any farther. While cancer can't be ignored, there is time to think about and choose which treatment plan is best for you.

You may wish to have another doctor review your test results and the treatment plan your doctor has recommended. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which treatment is right for you can help.

Copies of all of the test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2nd opinion. If your health plan doesn't cover the cost of a 2nd opinion, you have the choice of paying for it yourself. Choosing your cancer treatment is a very important decision. It can affect length and quality of life.

Questions about testing

1. What tests will I have?
2. Where will the tests take place? Will I have to go to the hospital?
3. How long will it take? Will I be awake?
4. Will it hurt? Will I need anesthesia?
5. What are the risks? What are the chances of infection or bleeding afterward?
6. How do I prepare for testing? Should I not take aspirin? Should I not eat beforehand?
7. Should I bring a list of my medications?
8. Should I bring someone with me?
9. How long will it take for me to recover? Will I be given an antibiotic or other drug afterward?
10. How soon will I know the test results and who will explain them to me? If a biopsy is done, will I get a copy of the results?
11. Who will talk with me about the next steps? When?
12. For a bone marrow aspiration or bone marrow biopsy: Will you remove the sample of bone marrow from the hip or from another bone?

Questions about treatments

1. What are my treatment options?
2. Is there a clinical trial I can take part in?
3. Will I have more than one treatment?
4. What are the risks and benefits of each treatment for multiple myeloma?
5. Will my age, general health, extent of multiple myeloma, and other medical conditions limit my treatment choices?
6. Do I have to get treated?
7. Where will I be treated? Will I have to stay in the hospital or can I go home after each treatment?
8. What can I do to prepare for treatment? Should I stop taking my medications?
9. How soon should I start treatment? How long does treatment take?
10. How much will the treatment cost? How can I find out how much my insurance company will cover?
11. How likely is it that I'll be cancer-free after treatment?
12. What symptoms should I look out for while being treated for multiple myeloma?
13. When will I be able to return to my normal activities?
14. What is the chance that the myeloma will come back or spread?
15. What should I do after I finish treatment?
16. Are there supportive services that I can get involved in? Support groups?

Questions about stem cell transplants

1. Am I considered a candidate for high-dose chemotherapy and autologous stem cell transplant?
2. If two autologous transplants are considered, what is the optimal timing? For example, should the second one be planned in advance or deferred until a relapse?
3. Am I a candidate for an allogeneic stem cell transplant? If so, how should my family members be tested to see if their bone marrow matches mine?
4. Should the allogeneic transplant be the first transplant, or should this transplant only be done if the cancer worsens after a prior autologous transplant?
5. What are the risks of each of these strategies, both short-term and long-term?
6. How long does each strategy control the myeloma, and what are the chances of long-term control or even cure?
7. If I can't have a stem cell transplant, what are the other options?

Questions about clinical trials

1. Is there a clinical trial that I could take part in?
2. What is the purpose of the study?
3. What kinds of tests and treatments does the study involve?
4. What does the treatment do?
5. Has the treatment been used before? Has it been used for other types of cancers?
6. Will I know which treatment I receive?
7. What is likely to happen to me with, or without, this new treatment?
8. What are my other choices? What are their benefits and risks?
9. How might the study change my daily life?
10. What side effects can I expect from the study? Can the side effects be controlled?
11. Will I have to stay in the hospital? If so, how often and for how long?
12. Will the study cost me anything? Will any of the treatment be free?
13. If I'm harmed as a result of the research, what treatment might I get?
14. What type of long-term follow-up care is part of the study?

Websites

American Cancer Society

www.cancer.org/cancer/multiplemyeloma/detailedguide/index

National Cancer Institute

www.cancer.gov/types/myeloma/patient/myeloma-treatment-pdq

Multiple Myeloma Research Foundation

www.themmr.org/

International Myeloma Foundation

www.myeloma.org

Leukemia & Lymphoma Society

www.lls.org/disease-information/myeloma

National Coalition for Cancer Survivorship

www.canceradvocacy.org/toolbox

NCCN

www.nccn.org/patients/

Review

- A treatment plan can help you through treatment and beyond.
- It covers many issues—test results, treatments, and supportive programs.
- You can choose how active a role to have in planning your treatment.
- You may wish to get a 2nd opinion on your treatment plan.

Glossary

Dictionary Acronyms

Dictionary

active myeloma

Myeloma that has spread throughout the bone marrow (soft tissue in the center of bones where blood cells are made) and is causing symptoms.

additional treatment

Treatment given after previous treatments failed to kill all the cancer or keep it away.

adjunctive treatment

Medicine for symptoms of myeloma and side effects of myeloma treatment that is given at the same time as the main cancer treatment.

albumin

The main protein in blood plasma (yellowish part of blood).

allogeneic stem cell transplant

A treatment in which the patient receives healthy, immature blood-forming cells (blood stem cells) from another person.

amyloid

An abnormal protein that is formed by clumps of excess light chains and can damage organs.

amyloidosis

A health condition in which a protein called amyloid builds up in and damages organs.

anemia

A health condition in which the number of red blood cells is low.

anesthesia

Loss of feeling with or without loss of wakefulness caused by drugs.

antibiotic

A drug used to treat infections caused by bacteria.

antibody

Protein made by plasma cells (a type of white blood cell) that helps the body fight off infections. Also called immunoglobulin.

apheresis

A procedure in which stem cells are removed from blood.

asymptomatic

Having no signs or symptoms of disease.

autologous stem cell transplant

A cancer treatment that removes, stores, then returns a patient's immature blood-forming cells (blood stem cells).

B-cell

A type of white blood cell that turns into a plasma cell in response to germs.

Bence Jones myeloma

Condition in which myeloma cells make only free light chains and no complete M-proteins. Also called light chain myeloma.

beta-2 microglobulin

A small protein made by many cells, including white blood cells and myeloma cells.

biopsy

Removal of small amounts of tissue from the body to be tested for disease.

bisphosphonates

Drugs that help improve bone strength and prevent loss of bone mass.

blood chemistry test

A test that measures the amount of certain substances in the blood to check for signs of disease.

blood clot

A mass of blood that forms when blood platelets, proteins, and cells stick together.

blood stem cell

An immature cell from which all other types of blood cells are made.

bloodstream

Blood that flows throughout the body in small tubes called blood vessels

blood test

A test done on a sample of blood to check for signs of disease.

blood thinner

A drug that thins out the blood to treat or reduce the risk of blood clots.

blood urea nitrogen (BUN)

A waste product made by the liver and filtered out of blood into urine by the kidneys.

bone densitometry

A test that uses x-rays to make pictures that show how strong or thin bones are.

bone lesion

An area of bone damage or abnormal tissue in the bone.

bone marrow

The soft, sponge-like tissue in the center of most bones where blood cells are made.

bone marrow aspiration

The removal of a small amount of liquid bone marrow (soft tissue in the center of bones where blood cells are made) to test for disease.

bone marrow biopsy

The removal of a small amount of solid bone and bone marrow (soft tissue in the center of bones where blood cells are made) to test for disease.

bone survey

A set of x-rays of the entire skeleton to look for broken or damaged bones. Also called skeletal survey.

calcium

A mineral needed for healthy teeth, bones, and other body tissues.

cells

The “building blocks” of tissues in the body.

central venous catheter

A thin, flexible tube that is inserted into a vein in the upper arm, thigh, neck, or below the collarbone.

chemotherapy

Drugs that kill fast-growing cells throughout the body, including normal cells and cancer cells.

chromosomes

Long strands that contain bundles of coded instructions in cells for making and controlling cells.

clinical trial

Research on a test or treatment to assess its safety or how well it works.

combination regimen

The use of two or more drugs.

complete blood count (CBC)

A test of the number of blood cells.

compression fracture

A break (fracture) in a bone caused by the collapse of bones in the spine.

computed tomography (CT) scan

A test that uses x-rays from many angles to make a picture of the inside of the body.

contrast

A dye put into your body to make clearer pictures during imaging tests.

core needle biopsy

Use of a wide, hollow needle to remove a large sample of tissue from the body to test for cancer cells.

creatinine

A waste product of muscles that is filtered out of blood into urine by the kidneys.

cryopreservation

The process of cooling and storing cells, tissues, or organs at very cold temperatures.

cycle

Days of treatment followed by days of rest.

cytogenetics

Test that analyzes chromosomes (long strands of bundles of genes) in cells to check for abnormal changes in genes (coded instructions in cells for making and controlling cells).

diagnosis

The process of identifying a disease.

donor

A person who gives blood, cells, tissue, or an organ to another person.

donor lymphocyte infusion

Treatment in which the patient receives white blood cells called lymphocytes from the same donor used for the allogeneic stem cell transplant.

electrolytes

Minerals in blood that carry an electric charge and control some body functions.

erythropoietin

A drug used to treat patients with low red blood cell counts.

external beam radiation therapy (EBRT)

Radiation therapy (use of high-energy rays to destroy cancer cells) received from a machine outside the body.

extraosseous

Occurring outside the bone.

fatigue

Severe tiredness despite getting enough sleep.

fat pad

The fat that is just under the skin of the belly area (abdomen).

fine-needle aspiration biopsy

Use of a thin needle to remove a small amount of tissue from the body to test for cancer cells.

flow cytometry

A test that measures myeloma cells in the bone marrow (soft tissue in the center of bones where blood cells are made).

fluorescence in situ hybridization (FISH)

A lab test that assesses genes (coded instructions for making and controlling cells) or chromosomes (long strands containing bundles of genes) in cells to check for abnormal changes in genes.

follow-up test

Tests done after the start of treatment to check how well treatment is working.

fracture

A crack or break in a bone.

free light chain

The unattached, shorter fragments of M-proteins that are made by myeloma cells.

gene

A set of coded instructions in cells needed to make new cells and control how cells behave.

gene mutation

Abnormal change in the instructions in cells for making and controlling cells.

general anesthesia

A controlled loss of wakefulness from drugs.

genetic tests

Tests of the instructions in cells for making and controlling cells.

graft-versus-host disease (GVHD)

A disease that occurs when transplanted stem cells (immature blood-forming cells) attack a patient's normal cells.

graft-versus-tumor (GVT) effect

An attack on cancer cells by transplanted stem cells (immature blood-forming cells).

granulocyte

A type of white blood cell named for its small particles (granules).

harvest

The process of removing blood stem cells from a person.

heavy chain

The longer protein chain that is part of an antibody (protein that helps the body fight off infections).

hematologist

A doctor who's an expert in diseases of the blood.

high-dose chemotherapy

An intensive drug treatment to kill cancer and disease-fighting cells so transplanted stem cells aren't rejected by the body.

hormone

A chemical in the body that activates cells or organs.

human leukocyte antigen (HLA)

Special proteins on the surface of cells that help the body to tell its own cells apart from foreign cells.

human leukocyte antigen (HLA) type

The unique set of proteins on the surface of cells that helps the body to tell its own cells apart from foreign cells.

human leukocyte antigen (HLA) typing

A blood test that finds a person's HLA type—the unique set of proteins on the surface of cells that helps the body to tell its own cells apart from foreign cells.

hyperviscosity

A condition in which the blood becomes very thick because of too many proteins in the blood.

imaging test

A test that makes pictures (images) of the inside of the body.

immune cell

A cell that helps fight disease or infection.

immune system

The body's natural defense against infection and disease.

immunoglobulin

A protein made by plasma cells that helps fight off infection. Also called antibody.

inflammation

Redness, heat, pain, and swelling from injury or infection.

intestine

The organ that food passes through after leaving the stomach.

intravenous (IV)

Given by a needle or tube inserted into a vein.

karyotyping

A process that examines a map, or karyotype, of a cell's chromosomes—long strands of bundles of coded instructions for controlling cells.

kidneys

A pair of organs that filter blood and remove waste from the body through urine.

kyphoplasty

Surgery to support the spine with a balloon-like device and a type of cement.

lactate dehydrogenase (LDH)

A protein found in the blood that is involved in energy production in cells.

light chain

The shorter protein chain that is part of an antibody.

light chain myeloma

Condition in which myeloma cells make only free light chains and no complete M-proteins. Also called Bence Jones myeloma.

liver

Organ that removes waste from the blood.

local anesthesia

A controlled loss of feeling in a small area of the body caused by drugs.

local therapy

Treatment that affects cells in one specific area of the body only.

lymphocyte

A type of white blood cell that helps to protect the body from infection.

magnetic resonance imaging (MRI) scan

A test that uses radio waves and powerful magnets to view parts of the inside of the body and how they are working.

maintenance treatment

Treatment given in a lower dose or less frequently to “maintain” good treatment results.

medical history

All health events and medications taken to date.

medical oncologist

A doctor who's an expert in treating cancer with drugs.

microscope

A tool that uses lenses to see very small things the eyes can't.

mini transplant

A cancer treatment that uses low doses of chemotherapy before giving the patient healthy, immature blood-forming cells (blood stem cells) taken from another person called a donor.

M-protein

An abnormal antibody made by myeloma cells that doesn't fight germs. Also called monoclonal protein.

multiple myeloma

A cancer of plasma cells (white blood cells that make germ-fighting proteins) that has spread throughout the bone marrow (soft tissue in the center of bones where blood cells are made).

myeloma cell

An abnormal plasma cell that grows and divides all the time.

observation

A period of testing without treatment or right after treatment to check for cancer growth.

oligosecretory myeloma

Myeloma that makes very few or no M-proteins. Also called nonsecretory myeloma.

organ

A part of the body that performs a certain function.

orthopedic surgeon

A surgeon who's an expert in operations of the bones.

osseous

Occurring inside the bone.

osteonecrosis

The death of bone cells.

pathologist

A doctor who's an expert in testing cells and tissue to find disease.

physical exam

A review of the body by a health expert for signs of disease.

plasma

The yellowish liquid part of blood that carries blood cells.

plasma cell

A type of white blood cell (immune cell) that makes germ-fighting proteins.

plasma cell labeling index

A test that shows how many myeloma cells are dividing and how fast they are doing it.

plasmacytoma

A mass formed by abnormal plasma cells (myeloma cells).

plasmapheresis

A process that removes excess proteins, such as M-proteins, from the blood.

platelet

A type of blood cell that forms blood clots to control bleeding.

pneumonia

A severe inflammation of the lungs.

positron emission tomography (PET) scan

A test that uses radioactive material to see the shape and function of organs and tissues inside the body.

positron emission tomography/computed tomography (PET/CT) scan

A test that uses radioactive material and x-rays to see the shape and function of organs and tissues inside the body.

primary treatment

The main treatment used to rid the body of cancer.

prognosis

The likely or expected course and outcome of a disease.

progression

The course of disease as it gets worse or spreads in the body.

progressive disease

Cancer that is growing, spreading, or getting worse.

protein

A chain of small chemical compounds important to every cell.

radiation oncologist

A doctor who's an expert in treating cancer with radiation.

radiation therapy

The use of high-energy rays (radiation) to destroy cancer cells.

radiotracer

Matter with energy that is put into the body to make pictures clearer.

red blood cell

A type of blood cell that carries oxygen from the lungs to the rest of the body.

regimen

A treatment plan that specifies the dose, schedule, and duration of treatment.

regional anesthesia

A controlled, temporary loss of feeling or awareness in a part of the body caused by drugs without loss of wakefulness.

relapse

The return of myeloma signs or symptoms after a period of improvement.

sedative

A drug that helps a person to relax or go to sleep.

serum free light chain assay

A blood test that measures the amount of the shorter fragments of the proteins made by myeloma cells.

serum immunofixation electrophoresis (SIFE)

A test used to identify the type of M-proteins in the blood.

serum protein electrophoresis (SPEP)

A test that measures the amount of M-proteins in the blood.

serum quantitative immunoglobulins

A test that measures the amount of each type of antibody in the blood.

serum viscosity

A test that measures the thickness of blood.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

single agent

The use of one drug.

smoldering myeloma

Myeloma that isn't causing symptoms or damaging organs.

solitary plasmacytoma

Cancer that is one mass of myeloma cells (abnormal plasma cells that grow and divide all the time).

spine

The bones, muscles, and other tissues along the back from the base of the skull to the tailbone.

splint

A device used to support a broken bone and hold it in place.

stable disease

Cancer that is not getting worse or better in terms of extent or severity.

stem cell

An immature cell from which other types of cells develop.

stem cell transplant

Treatment that uses chemotherapy to destroy bone marrow (soft tissue in the center of bones where blood cells are made) and then replaces it with healthy blood stem cells.

steroid

A drug used to reduce swelling, redness, and pain, but also to kill myeloma cells.

supportive care

Treatment for symptoms of cancer or side effects of cancer treatment.

surgeon

A doctor who's an expert in operations to remove or repair a part of the body.

surgery

An operation to remove or repair a part of the body.

symptom

A physical or mental problem a person experiences that may indicate a certain disease or health condition.

systemic therapy

Drugs used to treat cancer cells throughout the body.

tandem stem cell transplant

Treatment in which a planned second round of high-dose chemotherapy and autologous stem cell transplant are given within 6 months of the first transplant.

targeted therapy

Treatment with drugs that target a specific or unique feature of cancer cells.

tissue biopsy

Removal of a small amount of tissue from the body to test for disease.

total protein (urine)

A test that measures the amount and type of protein in urine collected over a 24-hour period.

transfusion

Replacing lost blood with new blood.

treatment plan

A written course of action through cancer treatment and beyond.

treatment response

An outcome or improvement related to treatment.

tumor burden

The amount or extent of cancer in the body.

U.S. Food and Drug Administration (FDA)

A federal government agency that regulates drugs and food.

urine immunofixation electrophoresis (UIFE)

A test that identifies the type of M-proteins in the urine.

urine protein electrophoresis (UPEP)

A test that shows the amount of M-proteins in the urine.

vaccine

A biological agent inserted into the body to prevent a disease.

vein

A small tube that carries blood to the heart from anywhere in the body.

vertebrae

The chain of 33 bones in the back that protect a vital group of nerves.

vertebroplasty

A procedure to strengthen bones in the spine with bone cement.

white blood cell

A type of blood cell that fights infection.

Acronyms

BUN

blood urea nitrogen

CBC

complete blood count

CT

computed tomography

EBRT

external beam radiation therapy

FDA

U.S. Food and Drug Administration

FISH

fluorescence in situ hybridization

GVHD

graft-versus-host disease

GVT

graft-versus-tumor

HLA

human leukocyte antigen

IV

intravenous

LDH

lactate dehydrogenase

MRI

magnetic resonance imaging

PET

positron emission tomography

PET/CT

positron emission tomography/computed tomography

SIFE

serum immunofixation electrophoresis

SPEP

serum protein electrophoresis

UIFE

urine immunofixation electrophoresis

UPEP

urine protein electrophoresis

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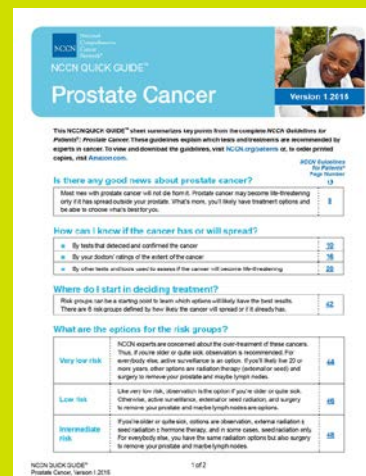


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