MULTIPLE MYELOMA
Research Foundation

MULTIPLE MYELOMA
DISEASE OVERVIEW

themmrf.org

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Research Foundation

ABOUT THE **MMRF**

The Multiple Myeloma Research Foundation (MMRF) is the largest nonprofit in the world solely focused on accelerating a cure for each and every multiple myeloma patient. We drive the development and delivery of next-generation therapies, leverage data to identify optimal and more personalized treatment approaches, and empower myeloma patients and the broader community with information and resources to extend their lives.

Central to our mission is our commitment to advancing health equity so that all myeloma patients can benefit from the scientific and clinical advances we pursue. Since our inception, the MMRF has committed over $600 million for research, opened nearly 100 clinical trials, and helped bring 15+ FDA-approved therapies to market, which have tripled the life expectancy of myeloma patients.

To learn more about the MMRF, visit **themmrf.org**.

To speak to a patient navigator at the Patient Navigation Center, call **1-888-841-6673** or email **patientnavigator@themmrf.org**.

Accredited by:

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INTRODUCTION

Multiple myeloma is a treatable cancer, with many new therapies under investigation that are bringing ever closer the promise of a cure. There have been significant advances in myeloma diagnosis, treatment, and **supportive care** over the last two decades. In this time, several new drugs have been approved by the US Food and Drug Administration for use in the treatment of myeloma, and survival rates of myeloma patients have tripled.

This booklet has been designed to help you better understand multiple myeloma: what it is and how it develops within the body. Words that may be unfamiliar are **bolded** and defined in the Glossary (page 24).

It is our hope and belief that learning about multiple myeloma will give you the knowledge and confidence you need to be more involved in making decisions about your treatment together with your care team.

For more information about multiple myeloma and its treatment, refer to the companion booklets ***Multiple Myeloma Treatment Overview, Newly Diagnosed Multiple Myeloma, Multiple Myeloma Learn Your Labs***, and ***Multiple Myeloma Immunotherapy***, as well as the MMRF website, **themmrf.org**.

The information in this booklet is not intended to replace the services or advice of trained health care professionals. Please consult with your health care team regarding specific questions relating to your health, especially questions about myeloma diagnosis or treatment.

OVERVIEW

Patients with **active multiple myeloma** typically have a preceding phase of disease characterized by changes in the cells and materials present in the **bone marrow**, but no symptoms or organ damage. This is referred to as either **monoclonal gammopathy of undetermined significance (MGUS)** or **smoldering multiple myeloma (SMM)** (also called asymptomatic myeloma)—collectively known as **myeloma precursor conditions**—depending on the nature of the changes in the bone marrow.

Precursors to active multiple myeloma

Monoclonal gammopathy of undetermined significance (MGUS)

MGUS is an abnormal growth of plasma cells, which results in an excess of **monoclonal protein** (or **M protein**), a substance produced by plasma cells that is detectable in the blood. In MGUS, the plasma cells have not formed a tumor or multiple bone lesions, no symptoms have occurred, and the other criteria for a myeloma diagnosis are absent. MGUS almost always precedes myeloma and is associated with a risk of progression to active multiple myeloma of approximately 1% per year.

MGUS occurs in about 1% of the general population and in about 5% of healthy individuals older than 50. Because MGUS does not cause symptoms or damage to the body, no treatment is needed. However, MGUS progresses to active multiple myeloma or another **malignant** plasma cell disease (**lymphoma** or **amyloidosis**) in about 20% to 25% of individuals over the course of their lifetime. MGUS can also be associated with other diseases, including **osteoporosis**.

Smoldering (asymptomatic) multiple myeloma (SMM)

SMM is a stage between MGUS and active myeloma that is associated with a higher risk of progression to active multiple myeloma: approximately 10% per year for the 5 years after diagnosis, then 1% per year. If you have SMM, the level of M protein in your blood and plasma cells in the bone marrow is higher than in MGUS. You would not have any of the symptoms or signs typically associated with active multiple myeloma, such as bone lesions or **anemia**.

If you have SMM, you will receive close follow-up (also called observation), with visits to your doctor and/or testing approximately every 3 months. Treatment directed at myeloma is started once your SMM progresses to active multiple myeloma.

Some patients with SMM are more likely to develop active myeloma than others; this is referred to as high-risk SMM, and identifying and treating these patients could potentially slow or prevent that progression from occurring. Currently, **clinical trials** are studying whether patients with high-risk SMM do better when they receive earlier treatment and what type of treatment is best.

IDENTIFYING MYELOMA PRECURSOR CONDITIONS

Researchers are investigating ways to slow or prevent active multiple myeloma from developing in patients who have high-risk myeloma precursor conditions. Screening studies to identify these patients earlier in their disease course are under way.

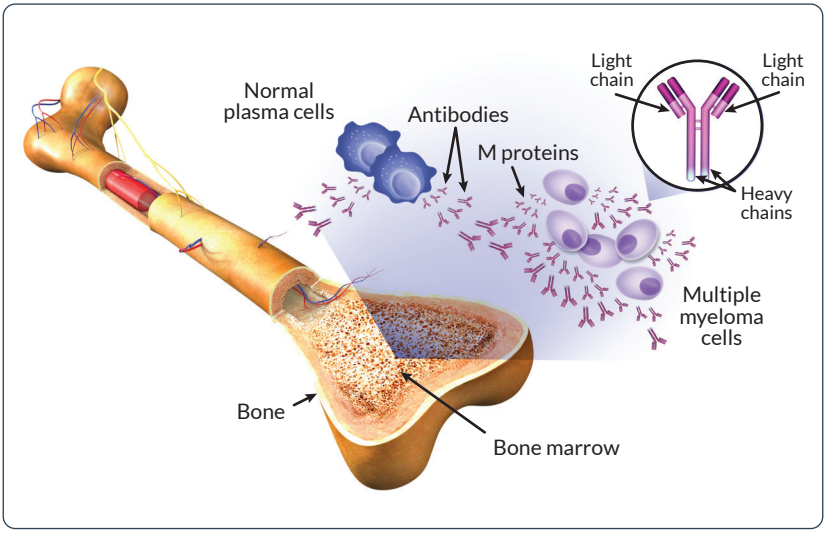
Data collected from these individuals will help researchers to identify specific clinical factors that may be associated with progression to active myeloma.

ACTIVE MYELOMA

What Is Multiple Myeloma?

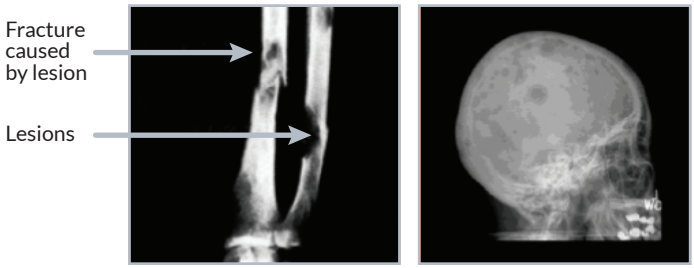
Multiple myeloma is a blood cancer that develops in the bone marrow, the soft, spongy tissue found in the center of many bones and the location where blood cells are produced. In myeloma, **plasma cells**, which are normal cells that produce **antibodies** (or **immunoglobulins**) that help protect your body from foreign invaders such as bacteria and viruses, transform into cancerous myeloma cells. Myeloma cells produce large quantities of M proteins (which are actually abnormal forms of immunoglobulins), as well as incomplete parts of antibodies (called **light chains** or **Bence Jones proteins**). These cancer cells crowd out and inhibit the production of normal blood cells in the bone marrow.

Multiple myeloma in the body.



In addition, groups of myeloma cells cause other cells in the bone marrow to remove the solid part of the bone and cause **osteolytic lesions**, or soft spots in the bone, weakening the bones and increasing the risk of fractures. Although common, lesions or other signs of bone loss do not occur in all patients with myeloma.

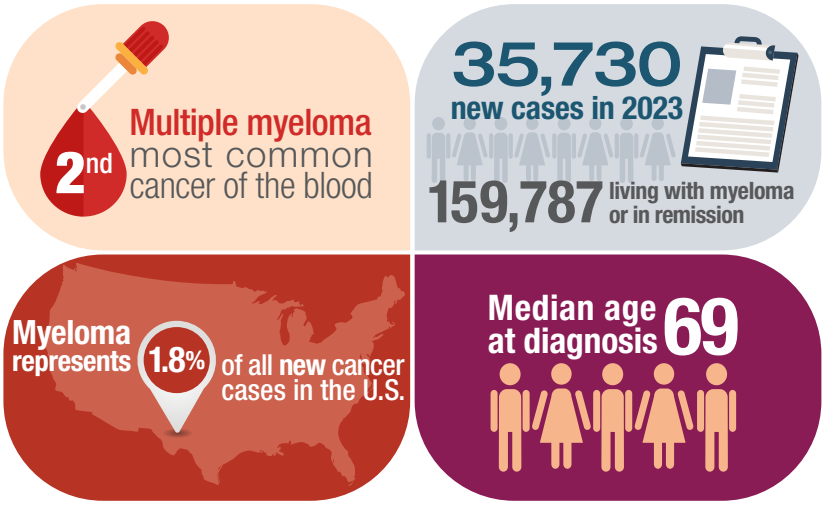
Bone disease in multiple myeloma.



How Common Is Multiple Myeloma?

More than 150,000 people in the United States are living with multiple myeloma today, and the American Cancer Society estimates that multiple myeloma will be diagnosed in 35,730 people in 2023. Multiple myeloma is second to non-Hodgkin's lymphoma as the most common blood cancer and represents 1.8% of all cancers.

Prevalence of multiple myeloma in the United States.



In general, myeloma is a disease of people who are older (the average age at diagnosis is 69). People in any decade of life are at some risk, and risk increases with age. Multiple myeloma is more common among men than women. People of African descent are twice as likely to develop multiple myeloma than are individuals of other races.

The number of patients living with multiple myeloma has increased over the last few years. It's not because the number of patients diagnosed with myeloma has increased significantly, but rather because people with multiple myeloma are living longer.

The reason people are living longer with multiple myeloma is that a number of new therapies have been developed, and this has had a significant impact on survival.

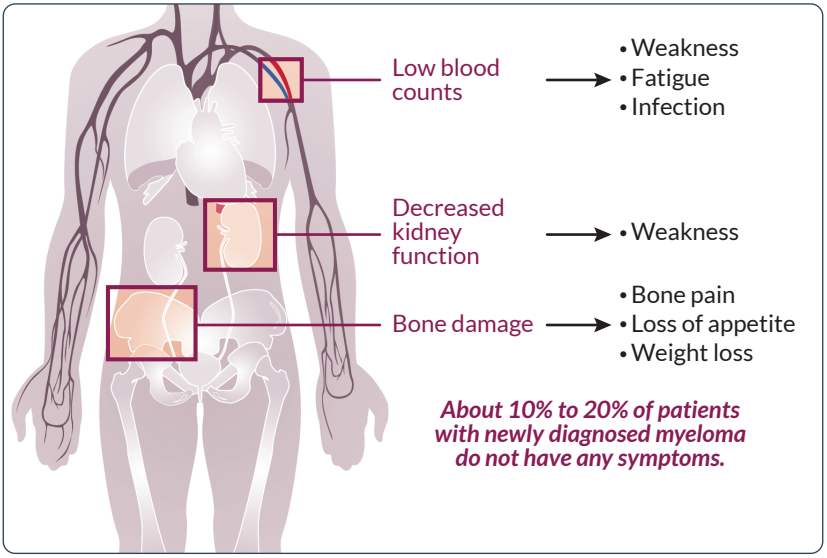
What Causes Multiple Myeloma?

To date, no cause for myeloma has been identified. Research suggests that the disease could be related to a decline in the immune system, certain occupations, exposure to certain chemicals, and exposure to radiation. However, these connections are not proven. In most cases, multiple myeloma develops in individuals who have no known risk factors. Multiple myeloma may be the result of several factors acting together. It is uncommon for myeloma to develop in more than one member of a family.

How Does Multiple Myeloma Affect the Body?

Multiple myeloma affects your bones, blood, and kidneys.

Common symptoms of myeloma patients.



Bone

Bone loss is the most common effect of multiple myeloma, occurring in 85% of myeloma patients. The most commonly affected bones are the spine, pelvis, and rib cage.

Myeloma leads to bone loss in two ways. First, the myeloma cells form masses in the bone marrow that may disrupt the normal structure of the surrounding bone. Second, myeloma cells secrete substances that interfere with the normal process of bone repair and growth. Bone destruction can also increase the level of **calcium** in the bloodstream, a condition called **hypercalcemia** that may cause symptoms like thirst and confusion and can be a serious problem if appropriate treatment is not given immediately.

Blood

The growing number of myeloma cells can interfere with the production of all types of blood cells.

A reduction in the number of **white blood cells** can increase the risk of infection. Decreased **red blood cell** production can result in anemia, which is present in approximately 60% of patients at diagnosis. A reduction in **platelets** can interfere with blood clotting.

Kidneys

The accumulation of M protein and calcium in the blood can overwork the kidneys. The amount of urine produced may decrease, and the kidneys may fail to function normally. More than half of myeloma patients experience a decrease in their kidney function (also called renal function) at some point in the course of the disease.

Symptoms of active myeloma

There are often no symptoms in the early stages of myeloma. When symptoms are present, they may be vague and similar to those of other conditions.

Some of the more common symptoms are:

- Bone pain
- Fatigue
- Weakness
- Infection
- Loss of appetite and weight loss

Symptoms related to hypercalcemia or kidney problems may include:

- Increased or decreased urination
- Increased thirst
- Restlessness, eventually followed by extreme weakness and fatigue
- Confusion
- Nausea and vomiting

DIAGNOSING MULTIPLE MYELOMA

Multiple myeloma is a highly diverse disease, meaning that it is different in every patient. There are several different forms of myeloma. Each patient differs in terms of their genomic features, clinical features (that is, symptoms and disease course), and **prognosis**.

If you have been diagnosed with myeloma, it is important for you to find a doctor who specializes in myeloma care—that is, a myeloma specialist. Once you find a specialist, you must have all the appropriate tests, as the results will help determine the extent of your disease, its prognosis, and the best options for treatment and monitoring. Finally, you should discuss with your myeloma specialist the option of sharing your data on registries (secure online platforms designed to record and store patient data) which help clinicians and researchers identify trends, learn about the most effective treatments, and work toward bringing more personalized treatment approaches to all patients. With assistance from the MMRF's Patient Navigation Center, following this path will help you obtain the best treatment and results for your specific type of myeloma.

The first two steps of The Right Track are key when you first learn that you may have multiple myeloma.

Key steps for the best possible care for patients with myeloma.

THE RIGHT TRACK

Right Team

Access experts and centers that have extensive experience treating multiple myeloma

Right Tests

Get the information, tests and precise diagnoses to make the right treatment decisions

Right Treatment

Work with your team to decide on the best treatment plan and identify clinical trials that are right for you

Share at Every Step

You can help yourself while helping others.

THE RIGHT TEAM

For diseases that are rare or particularly complicated, such as multiple myeloma, specialized medical understanding is especially important. When considering potential doctors, don't be afraid to ask about their experience treating multiple myeloma. Ideally, a **hematologist** or **hematologist-oncologist** who focuses on multiple myeloma will be aware of the latest research and up-and-coming treatment options. If seeing a hematologist or hematologist-oncologist is not possible, you can receive treatment from another specialist, such as a medical oncologist, who may consult with a hematologist-oncologist about your care.

Often, specialists work out of specialized cancer treatment centers. Treatment centers that frequently see patients with multiple myeloma have been shown to produce better outcomes than centers that see fewer multiple myeloma patients.

You may not live close enough for a specialist at a cancer center to be your only source of treatment. Nevertheless, consulting with a specialist at important times and obtaining specific types of care at a specialized center may help you get the best care possible.

Should you get a second opinion?

An increasingly important part of establishing a myeloma diagnosis is getting a second opinion from a myeloma specialist—a doctor who only sees myeloma patients. Obtaining a second opinion—getting that second set of eyes—can be crucial to confirming a myeloma diagnosis and helping a patient and his or her health care team move with confidence toward the management plan that will yield the best results.

Many health insurance companies authorize second opinions for myeloma patients.

An MMRF patient navigator in the MMRF Patient Navigation Center can help you find a myeloma specialist in your area.

Call **1-888-841-6673**, Monday to Friday from 9:00 AM to 7:00 PM ET or email **patientnavigator@themmrf.org**.

THE RIGHT TESTS

During your doctor visits, it can seem like—whenever you turn around—someone from the health care team is asking for a blood or urine sample. Blood and urine tests are an essential part of diagnosing multiple myeloma.

Diagnosing myeloma: common blood and urine tests.

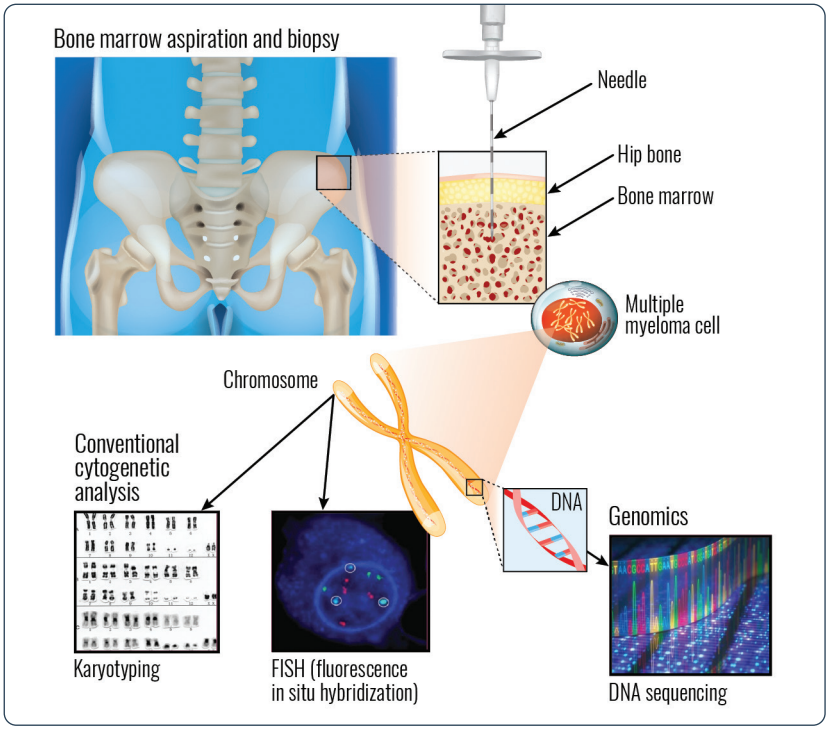
Sample	Test	What is assessed	What it means
Blood	**Complete blood count (CBC)**	Number of red blood cells, white blood cells, and platelets	Can indicate problems such as anemia, **neutropenia** (low white blood cells), or bleeding disorders (low platelets)
	Complete metabolic panel (CMP)	Levels of electrolytes, **albumin**, calcium, **BUN**, and creatinine	Indicates function of kidney and liver, bone status, and the extent of disease
	Lactate dehydrogenase	Level of LDH enzyme	Helps your doctor stage your myeloma and determine your prognosis
	Beta-2 microglobulin (ß2M)	ß2M, a type of protein released by many cells	The level of ß2M in the blood reflects kidney function and indicates the presence and severity of myeloma
	Serum protein **electrophoresis** (SPEP)	The presence and level of M protein; also called the M spike	Provides insight into the type of myeloma a patient has and helps doctors follow the disease's progression
	Immunofixation electrophoresis (IFE)	Identify the type of abnormal M proteins	Confirms the SPEP result and indicates which type of abnormal antibody is present (such as IgG or IgA)
	Serum **free light chain** (SFLC) assay	Detects light chains	Indicates the type and level of light chain (kappa or lambda) that is associated with the M protein
Urine	Urine protein electrophoresis (UPEP)	Detects Bence Jones proteins/light chains	Indicates the type and level of light chain (kappa or lambda) that is associated with the M protein

Bone Marrow Biopsy

Bone marrow biopsy, in which a needle is inserted into the bone to extract a small amount of marrow for analysis, is conducted to determine the level of abnormal plasma cells (a level over 10% indicates that myeloma is present) and to identify **mutations** that may have contributed to development of the disease.

Cytogenetic testing (analysis that measures the number and structure of **chromosomes**) is performed on the extracted material by means of two tests: **karyotyping** and **fluorescence in situ hybridization** (or FISH).

Bone marrow biopsy tests.



Fluorescence in Situ Hybridization (FISH)

The FISH analysis highlights the chromosomes that are present in the biopsy sample. This makes it possible to examine them in sufficient detail to identify the nature of any abnormalities, which can include **chromosomal translocations** (when a piece of one chromosome swaps places with a piece of another chromosome), **chromosomal deletions** (when a piece of a chromosome is missing), and an increase in the number of chromosomes (also called **hyperdiploidy**).

Genomic Sequencing

Researchers are continually working to better understand the biology of multiple myeloma and, through **genomic sequencing** (studies of the tumor cell **DNA**), have learned that there are many DNA alterations in myeloma cells. Today, we know that certain DNA alterations can be indicative of how aggressive the myeloma is.

Genomic sequencing is conducted by analyzing the DNA from the myeloma cells taken from a small amount of bone marrow. Tests are conducted as part of the initial diagnosis and may be repeated periodically. During a relapse, DNA test results can help guide treatment decisions or determine eligibility for clinical trials.

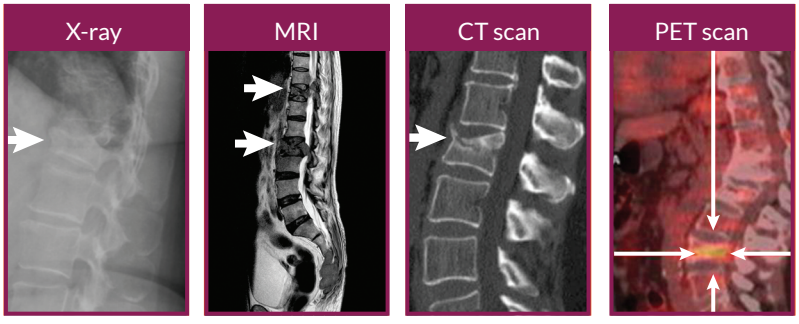
The development of personalized treatments based on genomics is an active area of research, and clinical trials are ongoing. This is not yet a standard of care.

Imaging

Imaging technologies are used to locate and assess lytic lesions, or holes, in your bones—one hallmark of multiple myeloma. A series of x-rays (often called a complete skeletal survey) will be taken and used to diagnose and monitor your myeloma.

Other tests that are even more sensitive than x-rays are used when appropriate; these include **magnetic resonance imaging (MRI), computed tomography (CT)**, and **positron emission tomography (PET) scans**.

Types of imaging used to detect multiple myeloma.



MRI, magnetic resonance imaging; CT, computed tomography; PET, positron emission tomography

These imaging tests are also used to detect **extramedullary disease**—that is, the presence of myeloma outside of your bone marrow.

Some of the same tests used at diagnosis are repeated to monitor your progress once you start treatment.

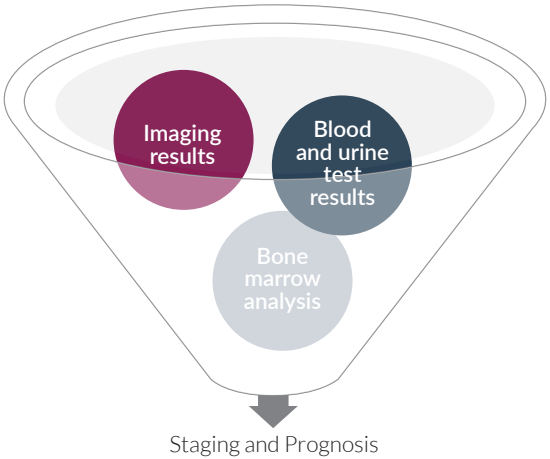
STAGING AND RISK STRATIFICATION

Myeloma is classified based on the results of diagnostic testing. These results tell whether or not immediate treatment is needed. In addition, a stage is assigned to indicate the extent of disease.

Certain test results provide important information about prognosis. These **prognostic indicators** may also help decide when treatment should begin and aid in monitoring the disease. Many tests can be performed routinely in any laboratory, whereas others are performed only in specialized laboratories or a research setting.

Your age and myeloma stage are important factors in predicting your prognosis.

Interpreting test results.



Myeloma staging, which is the categorization of myeloma based on test results, is crucial to developing an effective treatment plan.

The **Revised International Staging System (R-ISS)** is the most commonly used staging system. It is based on the results of three blood tests (lactate dehydrogenase [LDH], beta-2 microglobulin [ß2M], and albumin) and FISH testing of the bone marrow.

Multiple myeloma staging system.

R-ISS Stage	Criteria
I	ISS stage I (ß2M <3.5 mg/L + albumin ≥3.5 g/dL) and standard-risk CA by iFISH and normal LDH
II	Not R-ISS stage I or III
III	ISS stage III (ß2M ≥5.5 mg/L) and either high-risk CA by iFISH or high LDH

The R-ISS uses ISS stages, LDH levels, and detection of CA by FISH to determine stage

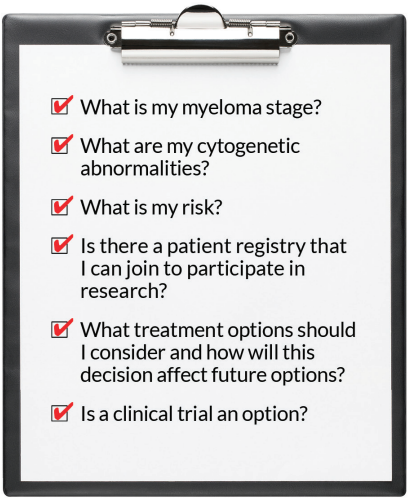
- Stages I, II, or III
- High risk CA by FISH:
  - del(17p)
  - t(4;14)
  - t(14;16)

Revised International Staging System (R-ISS)

ß2M; beta-2 microglobulin; LDH, lactate dehydrogenase; CA, chromosomal abnormality; iFISH, interphase fluorescent in situ hybridization

The more you know about your myeloma, the better you will be able to communicate with your health care team. The best way for you to get answers is to talk to your doctor.

Questions to ask your doctor.



LIVING WITH MULTIPLE MYELOMA

SUPPORTIVE CARE AND MAINTAINING QUALITY OF LIFE

Myeloma often weakens bones, damages kidney function, and leads to anemia and infection. Additionally, the drugs used to treat myeloma often produce side effects. Therapies are available to address the symptoms of myeloma and the complications of its treatment; these are called supportive therapies or supportive care.

Bone Health

Bone damage (lesions and osteoporosis) is common in multiple myeloma, occurring in approximately 85% of patients. Weakened bones can result in fractures and compression of the spinal cord, and there is the potential for spinal cord collapse.

Maintaining Bone Health

Eating calcium-rich foods, taking calcium and vitamin D supplements (only as recommended by a doctor), and performing weight-bearing exercise (with caution) can help you maintain bone health.

Bisphosphonates and Other Medications

Bisphosphonates (such as Zometa) are drugs that can decrease bone pain, reduce the likelihood of fracture, and prevent myeloma bone disease from getting worse. Some of the more potent bisphosphonates are also used to treat hypercalcemia. Research has shown that bisphosphonates can increase survival time; they are prescribed for the majority of myeloma patients.

Xgeva (denosumab) is another medication used to help stop bone damage caused by myeloma. Though it works in a similar way to bisphosphonates, Xgeva is from a different class of drugs called **monoclonal antibodies**.

Bisphosphonates are given **intravenously** every 3 to 4 weeks, and Xgeva is administered under the skin (**subcutaneously**).

Like all drugs, bisphosphonates and Xgeva carry risks of side effects.

Some studies indicate that long-term use of bisphosphonates and Xgeva may be associated with a risk of developing **osteonecrosis of the jaw (ONJ)**, a painful condition in which bone erosion and bone death occurs in the mouth and jaw, potentially resulting in an open sore that leaves the jawbone exposed.

To reduce the chance of developing ONJ, you should maintain your oral health. Interrupting or stopping bisphosphonates may be considered in severe cases.

Recommendations for reducing the risk of ONJ

- Complete major dental work before beginning treatment for bone disease
- Practice good oral hygiene
- Schedule regular dental visits
- Let your dentist know that you are receiving treatment for bone disease
- Keep your doctor informed of dental issues/need for dental work
- Be attentive! ONJ seems to be related to the length of time patients are on treatment for bone disease

Bisphosphonates may cause reduced kidney function (renal impairment) and, as a result, you will usually receive reduced doses of bisphosphonates when starting treatment if you have existing kidney impairment.

Prior to receiving a dose of bisphosphonate, you will undergo blood tests to monitor levels of **creatinine** (a protein that can indicate if there is a problem with your kidney function) to reduce the risk of developing kidney impairment. Also, it is important that you stay hydrated.

Some studies have suggested that bisphosphonates have an anti-myeloma effect. Therefore, experts recommend that bisphosphonate therapy be considered in all patients receiving initial myeloma treatment, even if bone damage is not seen on imaging tests.

If you cannot take bisphosphonates (because, for example, you have renal insufficiency), Xgeva may be a good choice. This monoclonal antibody offers anti-myeloma and bone-sparing benefits similar to those seen with bisphosphonates and has little or no effects on the kidney.

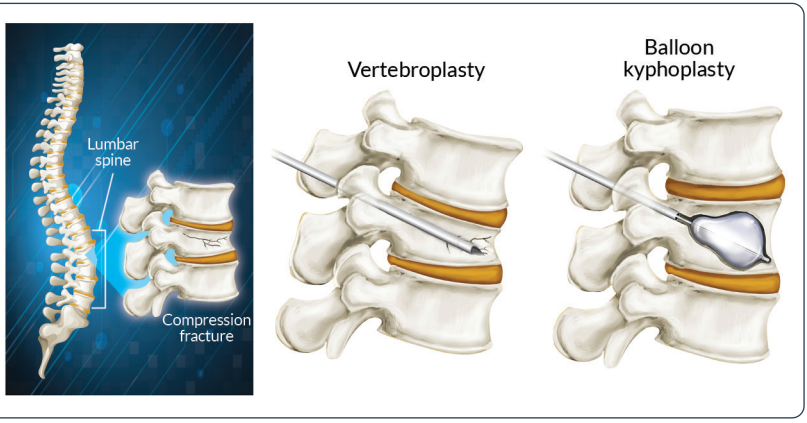
If you have bone disease, tell your health care team about treatments you receive from other care providers such as chiropractors, massage therapists, and holistic medicine practitioners. Inform all providers of any treatments you receive for your bone disease.

Orthopedic Interventions

Orthopedic interventions may be required to help control pain or maintain function or mobility. These may include physical therapy, splinting of bones, surgery to prevent or treat fractures, or procedures to repair compression fractures of the spine. Two minimally invasive surgical procedures, **vertebroplasty** and **balloon kyphoplasty**, are used to reinforce the vertebra of the spine and usually can be done without hospitalization.

Vertebroplasty involves the injection of a cement-like material to reinforce the vertebra. Balloon kyphoplasty involves the insertion of an inflatable balloon to restore the height of the compressed vertebra, followed by injection of bone cement to maintain the re-established height; this procedure has the potential to provide relatively rapid relief (approximately 1 month following the procedure).

Orthopedic procedures to stabilize the spine.



Radiation Therapy

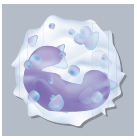
Low-dose **radiation therapy** is sometimes used to reduce bone pain. It is directed to specific bone lesions that are causing problems. However, it can affect the bone marrow and result in reduced blood counts, which may cause anemia, a weakened immune system, and blood clotting problems.

Anemia

Most myeloma patients have anemia when they are first diagnosed. Further, some of the medications used to treat myeloma can lower red blood cell counts, resulting in anemia.

Anemia has many symptoms, including fatigue, depression, mood changes, difficulty breathing, weight loss, rapid heartbeat, nausea, dizziness, and difficulty sleeping. If you experience these symptoms, you should inform your doctor so that your blood counts can be checked for anemia.

The first step in treating anemia is to identify and treat any causes of anemia other than myeloma or myeloma medications (for example, deficiencies in iron, folate, or vitamin B12 can also cause anemia). Moderate or severe anemia is usually treated with medications to stimulate production of red blood cells. If you have severe anemia, you may require blood transfusions.



Infection

When you have myeloma, you are more susceptible to infections because the disease reduces your number of white blood cells, which help fight infections. Moreover, some treatments may also reduce your white blood cells, leaving you with a 7- to 10-fold greater risk of infections. Additionally, the myeloma cells can crowd out the normal plasma cells that make antibodies, further weakening your immune system.

To reduce your risk of infections, you should adopt general infection-prevention practices, including good personal hygiene (skin, oral) and environmental control (wash your hands, wear a mask, avoid crowds and sick people, etc). Your health care team may also recommend one or more of the following to help with infection prevention:

- **Intravenous immunoglobulin (IVIG)** for **hypogammaglobulinemia** for serious recurrent infections
- Growth factors to stimulate the growth of white blood cells (Neupogen [filgrastim])

- Immunizations (for example, against COVID-19, influenza, pneumonia, shingles; NO live vaccines)
- Medications to prevent or treat infection (antibacterial, antiviral, antifungal), including COVID-19 prevention (antibody levels, exposure minimization)

If you experience a fever of 100°F, shaking chills even without fever, dizziness, shortness of breath, or low blood pressure, report it to your health care provider.

Kidney Impairment

More than half of patients with myeloma experience kidney problems at some point in the course of their disease. Kidney impairment can also be caused by other conditions, such as hypertension and diabetes, and some medications can affect the kidney as well.

Blood tests can detect certain proteins (such as creatinine) that are indicative of reduced kidney function. A decrease in the amount of urine is one sign of kidney problems; you should let your doctor know if you experience any changes in your urination.

If you develop kidney problems, make sure you drink plenty of fluids and avoid taking non-steroidal anti-inflammatory drugs such as Aleve (naproxen) and Advil/Motrin (ibuprofen) or other drugs that can affect kidney function.

In some cases, a procedure called **plasmapheresis** may help slow or prevent kidney failure. The large amount of M protein produced by myeloma cells can cause your blood to become thick, which can affect the kidneys. With plasmapheresis, blood and fluid are withdrawn, and the excess M protein is separated out. The fluid is then returned to you through an infusion.

The MMRF would like to thank Jesus G. Berdeja, MD, Director of Multiple Myeloma Research and Senior Investigator, Hematologic Malignancies at the Sarah Cannon Research Institute in Nashville, Tennessee, and Faith E. Davies, MBBCh, MRCP, MD, FRCPath, Director of the Center for Blood Cancers and Director of the Clinical Myeloma Program at the Perlmutter Cancer Center at New York University Langone Health in New York, New York, and our patient advocates Allan and Deb Osborne of Millis, Massachusetts, and Cindy Chmielewski of Lawrenceville, New Jersey, for their contributions to this booklet.

MMRF PATIENT SUPPORT AND RESOURCES

The MMRF is dedicated to supporting the myeloma community by providing a broad range of resources for myeloma patients and their family members and caregivers. The MMRF is available to help guide you through your multiple myeloma journey every step of the way.

YOUR QUESTIONS ANSWERED

Speak to an MMRF patient navigator at the Patient Navigation Center for answers to your questions about disease management, treatments, clinical trials, and assistance with finding financial and other available resources.

Telephone: 1-888-841-6673
Monday–Friday, 9:00 AM to 7:00 PM ET
Email: **patientnavigator@themmrf.org**

Connect with an MMRF Myeloma Mentor™:
themmrf.org/resources/myeloma-mentors

This is a phone-based program offering the opportunity for patients and/or caregivers to connect one-on-one with a trained patient and/or caregiver mentor to share their patient journeys and experiences.

FIND AND PARTICIPATE IN A CLINICAL TRIAL

Search for a clinical trial in your area or let an MMRF patient navigator help guide you through the process.

Clinical Trial Finder: **themmrf.org/resources/clinical-trial-finder**

The MMRF has partnered with Lazarex Cancer Foundation to help patients access clinical trials by helping with travel expenses. Patients who qualify will be reimbursed for out-of-pocket travel expenses for themselves and a travel companion. To learn more about this program, contact the MMRF Patient Navigation Center (1-888-841-6673 or **patientnavigator@themmrf.org**).

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GLOSSARY

active multiple myeloma Multiple myeloma in which the percentage of plasma cells in the bone marrow is greater than 10% and in which the patient shows one or more CRAB symptoms (see definition at *CRAB*)

albumin Major protein found in the blood; albumin level can indicate a person's overall health and nutritional status

amyloidosis Disorder in which abnormal protein is deposited in organs and tissues

anemia Decrease in the number of red blood cells in the blood

antibody Protein produced by plasma cells that helps protect the body from infection and disease (also called *immunoglobulin*)

balloon kyphoplasty Procedure used to treat spinal compression fractures; in this procedure a balloon is inserted into the area of compression and inflated to elevate the collapsed section; the resulting space is then filled with bone cement, which strengthens the area

Bence Jones protein Short protein (immunoglobulin light chain) that is produced by myeloma cells and found in the urine

beta-2 microglobulin (ß2M) Protein normally found on the surface of various cells in the body; levels of ß2M in the blood are elevated in inflammatory conditions and in certain blood cell disorders, such as myeloma

bisphosphonate Type of drug used to treat osteoporosis and bone disease

blood urea nitrogen (BUN) Byproduct of protein metabolism that is normally filtered out of the blood and found in the urine; elevated levels in the blood can indicate decreased kidney function

bone marrow Soft, spongy tissue found in the center of many bones and site of blood cell production

bone marrow biopsy Removal of a sample of bone marrow for examination; performed using a needle

calcium Mineral that is important in bone formation; elevated serum levels occur when there is bone destruction

chromosomal deletion Chromosomal abnormality in which a segment of a chromosome is missing; del(17p) is an example of a chromosomal deletion

chromosomal translocation Chromosomal abnormality in which segments of two chromosomes switch positions; t(4;14) and t(11;14) are examples of chromosomal translocations

chromosome Thread-like structure in a living cell that contains DNA (genetic information)

clinical trial Study of the safety and effectiveness of a therapeutic agent using consenting human subjects

complete blood count (CBC) Blood test that measures the number of red blood cells, white blood cells, and platelets in the blood and the relative proportions of the various types of white blood cells

complete metabolic panel (CMP) Blood test that measures levels of albumin, calcium, lactate dehydrogenase (LDH), blood urea nitrogen (BUN), and creatinine to assess bone status, the extent of disease, and the function of the kidneys and liver (also known as *chemistry profile*)

computed tomography (CT) Imaging technique that uses a computer to generate three-dimensional x-ray pictures (also referred to as *computerized axial tomography [CAT]*)

CRAB Acronym for the following group of clinical indicators of organ damage: increased **c**alcium level, **r**enal (kidney) failure, **a**nemia, **b**one lesions; the presence of one or more of these indicators can help establish a diagnosis of multiple myeloma

creatinine Product of energy metabolism of muscle that is normally filtered out of the blood and found in the urine; elevated levels in the blood can indicate decreased kidney function

cytogenetic testing (chromosome analysis) Laboratory test that measures the number and structure of chromosomes (see *karyotyping*)

DNA Genetic material of the cell located in the chromosomes

electrophoresis Laboratory test used to measure the levels of proteins in the blood or urine; uses an electrical current to sort proteins by their charge

extramedullary disease Myeloma cells found in other organs of the body beyond the bone marrow

fluorescence in situ hybridization (FISH) Laboratory technique used to measure the number of copies of a specific DNA segment in a cell and the structure of chromosomes

free light chain (FLC) Short protein (immunoglobulin light chain) that is produced by myeloma cells and found in the blood

genomic sequencing Study of DNA sequences of myeloma cells to detect mutations and to see how DNA changes over time

hematologist Doctor who specializes in diagnosing and treating blood diseases

hematologist-oncologist Doctor who specializes in diagnosing and treating cancers of the blood

hypercalcemia Presence of elevated levels of calcium in the blood; occurs as a result of bone destruction

hyperdiploidy Extra copies of one or more chromosomes

hypogammaglobulinemia Condition in which the levels of serum immunoglobin or antibodies in the body are reduced

immunoglobulin (Ig) Protein that helps protect the body from infection (also called *antibody*)

intravenous (IV) Administration of a drug directly into a vein

intravenous immunoglobulin (IVIG) Biologic agent consisting of pooled antibodies used to treat immunodeficiencies and other conditions

karyotyping Test that looks at the number and structure of a patient's chromosomes to identify genetic problems

lactate dehydrogenase (LDH) Enzyme found in body tissues; elevated levels in the blood indicate tissue damage and may occur in myeloma

light chains The shorter of two protein chains that make up an antibody, characterized as either kappa or lambda type; light chains produced by myeloma cells are also referred to as *Bence Jones proteins* when they occur in the urine

lymphoma Blood cancer that develops in the lymph nodes

magnetic resonance imaging (MRI) Scanning technique that uses magnetic energy to provide detailed images of bone and soft tissue

malignant Cancerous, continuing to divide

monoclonal antibody Antibody that is produced in a laboratory and used to diagnose and treat some diseases

monoclonal (M) protein Abnormal antibody found in large quantities in the blood and urine of individuals with myeloma

monoclonal gammopathy of undetermined significance (MGUS) Condition that can occur before a patient develops or shows any symptoms of cancer; indicated by the presence of M protein in the serum or urine, MGUS may eventually progress to active multiple myeloma

multiple myeloma Blood cancer that develops in the bone marrow as a result of plasma cells transforming into cancerous myeloma cells

mutation A defect or error in a gene

myeloma precursor conditions Any of the preceding phases of active multiple myeloma, called monoclonal gammopathy of undetermined significance (MGUS) or smoldering multiple myeloma (SMM), which are characterized by changes in the cells and the presence of materials in the bone marrow, but no symptoms or organ damage

neutropenia Below-normal number of neutrophils (type of white blood cell that destroys bacteria)

osteolytic lesion Soft spot in the bone where bone tissue has been destroyed; appears as a hole on a standard x-ray

osteonecrosis of the jaw (ONJ) Death or destruction of bone tissue in the jaw due to trauma, loss of blood supply, or disease; can be associated with long-term bisphosphonate treatment in myeloma patients

osteoporosis Bone loss typically associated with old age; can occur in myeloma

plasma cell Antibody-secreting immune cell that develops from a B cell; in myeloma, it is this cell that has become cancerous or abnormal

plasmapheresis Method of removing blood plasma from the body by withdrawing blood, separating it into plasma and cells, and transfusing the cells back into the bloodstream; it is often performed when treating autoimmune conditions and may be used in myeloma

platelets Small cell fragments in the blood that help it to clot

positron emission tomography (PET) Imaging technique in which radioactive glucose (sugar) is used to highlight cancer cells

prognosis Prediction of the course and outcome of a disease

prognostic indicator Any of several factors that help predict the course and outcome of a patient's disease, such as symptoms, age, and disease stage

radiation therapy (or radiotherapy) Use of high-energy rays; sometimes used to relieve bone pain

red blood cell Blood cell that carries oxygen

Revised International Staging System (R-ISS) System for using laboratory test results to determine the severity of multiple myeloma

smoldering (asymptomatic) multiple myeloma (SMM) Myeloma characterized by increased M protein and slightly increased numbers of plasma cells in the bone marrow and an absence of symptoms; patients with SMM are monitored and only treated if their disease progresses

subcutaneous (SC) Administration of a drug under the skin

supportive care Treatment that addresses the symptoms and complications of a disease rather than the disease itself; examples in myeloma include bisphosphonates, growth factors, antibiotics, orthopedic interventions, and pain control measures

vertebroplasty Procedure used to treat fractures of the spine

white blood cell One of the major cell types in the blood; attacks infection and cancer cells as part of the immune system

MMRF RESOURCES
IN PERSON OR ONLINE

Attend a Multiple Myeloma Patient Summit

Learn about standard and emerging therapies, including stem cell transplants, promising clinical trials, and more for optimal disease management. Attend a complimentary symposium for all the information you need to make well-informed decisions about your treatment and care.

To register or to view the complete calendar, visit:
themmrf.org/resources/education-programs

View Past Programs on Demand

Access our archive of recorded Patient Summits and webcasts. Hear expert perspectives on key clinical research and the rapidly evolving myeloma treatment landscape.

All available online, and free, at:
themmrf.org/resources/education-programs

Find a Clinical Trial Near You

Clinical trials are critically important to developing new myeloma treatments and better understanding the biology of the disease. The more people who enroll, the faster we can find answers. Patients who enroll in clinical trials have the opportunity to be among the first to receive the newest drugs or drug combinations in development and receive close monitoring.

To find a clinical trial near you, visit:
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