

# Understanding Multiple Myeloma



Learn about **Multiple Myeloma**, how it is diagnosed, treatment options, and resources for building a support team.

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# About Multiple Myeloma

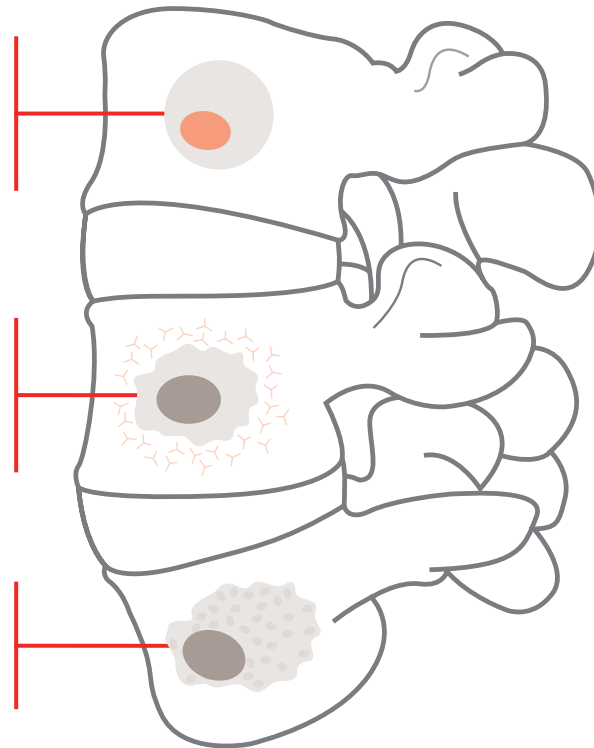
## What is it?

Multiple **myeloma** (MM) is a blood cancer that affects a type of **white blood cell** called a **plasma cell**. These white blood cells are found mostly in **bone marrow**, the soft substance inside some hollow bones where blood cells are made.

Normal, healthy **plasma** cells are white blood cells that produce **antibodies**. Antibodies are part of the **immune system** and help the body fight infections.

When plasma cells acquire genetic abnormalities, they can overproduce. This can weaken the immune system and can lead to abnormal production of **M-protein** instead of normal antibodies that can injure **kidneys** and weaken the **immune system**.

These damaged (**cancerous**) plasma cells rapidly spread and replace normal cells with tumors, usually in the bone marrow.

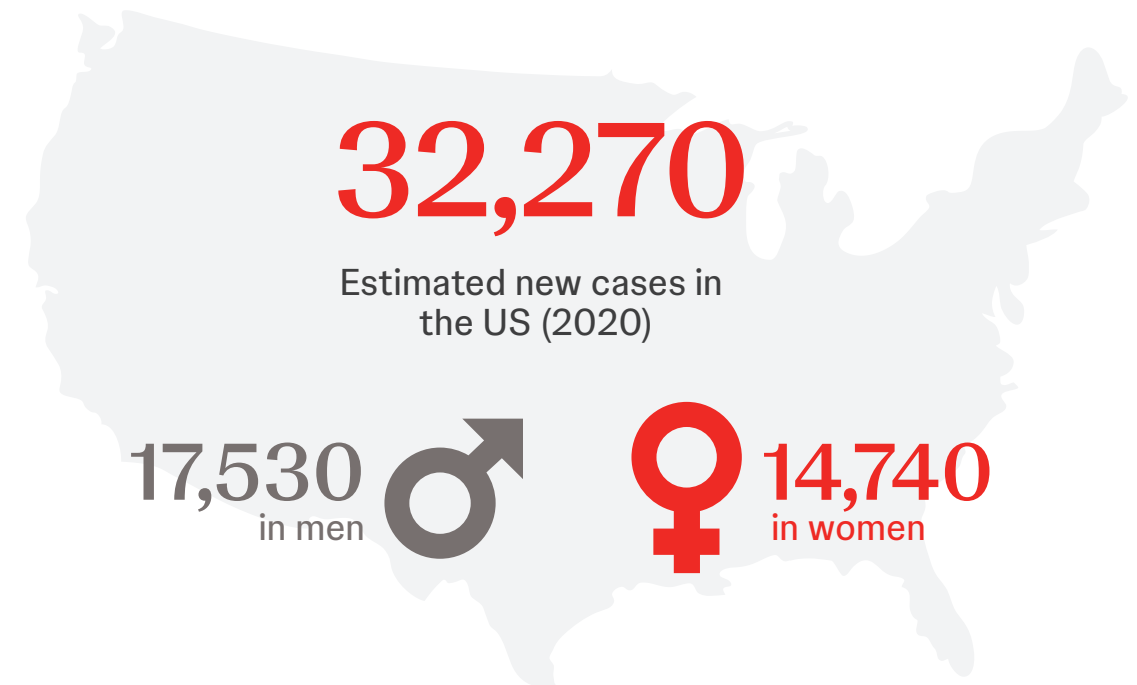


**Cancerous plasma cells inside the bone marrow can damage surrounding bone, resulting in pain and fractures (broken bones).**

## Who gets it and why?

A **risk factor** is anything that changes a person's chance of getting a disease. Having a risk factor does not mean that a person will get the disease. Some people are **diagnosed** without having any risk factor.

It can vary from person to person, but myeloma is more common in men, African Americans, and older adults (ages 65-74). However, myeloma can occur in adults younger than 65.



## Common Risk Factors

- Older age
- Male gender
- African American heritage
- Obesity
- Family history
- Monoclonal gammopathy of unknown significance (MGUS)

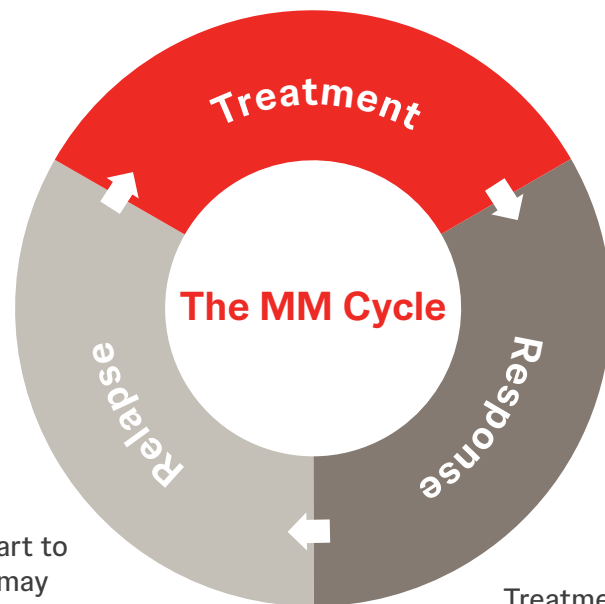
## About Multiple Myeloma (cont'd)

### The back and forth of multiple myeloma

Multiple myeloma is not yet curable, but treatment can fight these cancerous cells. A **response** can help your doctor determine if your treatment is working. When you respond well to treatment, the few cancerous cells that remain in your body can stop responding to that therapy. This is called a **relapse**, where the cycle of multiple myeloma starts again. It's common to go through many of these cycles.

With each relapse, your healthcare team will discuss treatment options to help get your multiple myeloma back under control. It may mean you get the same treatment again or you could receive a different **regimen**. It's important to stick with your prescribed treatment plan so you get the full benefit from your medicine.

Your doctor will start or adjust your medicines based on your symptoms and the stage of your MM




MM cells may start to change, which may cause your symptoms to return


Treatment fights your MM


## Diagnosis


### What are common signs and symptoms?


**Symptoms** can vary by person, and in early stages there may be no symptoms. Symptoms might be general or overlap with other diseases.


- 

**Bone damage** and pain (often in the back, hips, and skull), weakness, and **fractures**.
- 

**Low red blood cell counts** (**anemia**) may cause weakness and tiredness.
- 

**Low immunoglobulins/antibodies** (**hypogammaglobulinemia**) may increase risk of infection.
- 

**Low platelet counts** (**thrombocytopenia**) may increase the risk of bleeding.
- 

**Kidney problems** that make it harder for your body to remove excess salt, fluid, and body waste.
- 





**High levels of calcium** in blood that can cause constipation and confusion.

**While bone pain and tiredness are the most common symptoms, some people have no symptoms.**

# Diagnosis (cont'd)

## How is it diagnosed?

Blood tests and a **bone marrow biopsy** are used to confirm the **diagnosis**. Urine tests are also done initially and at various points throughout treatment.

Initial tests	Advanced tests
<p><b>Blood Tests</b> </p> <p>The first tests check for levels of <b>albumin, calcium, lactate dehydrogenase (LDH), B2M, blood urea nitrogen (BUN), and creatinine</b> (a marker of how well the kidneys are working). Your number of red blood cells, white blood cells, and platelets are also tested.</p>	<p><b>Blood and Urine Tests</b> </p> <p>These tests help doctors measure M-protein produced by cancerous plasma cells and use it to assess response to treatment: <b>SPEP, sFLC, SIFE</b> and <b>UPEP</b>.</p>
<p><b>Imaging Tests</b> </p> <p>These <b>imaging tests</b> help check for bone loss and evidence of myeloma inside and outside of the bones.</p> <ul style="list-style-type: none"> <li>• Radiologic imaging, such as <b>CT, PET/CT, MRI, skeletal survey</b></li> </ul>	<p><b>Procedures</b> </p> <p>A bone marrow biopsy provides tissue samples to perform a <b>flow cytometry</b> and other tests to measure abnormal cells and determine their <b>cytogenetics</b>.</p>

B2M = **beta-2-microglobulin**  
 CT = **computed tomography**  
 MRI = **magnetic resonance imaging**  
 PET = **positron emission tomography**


sFLC = **serum free light chain**  
 SIFE = **serum immunofixation electrophoresis**  
 SPEP = **serum protein electrophoresis**


Please see “Key Terms Defined” on page 21.


## What is staging?


**Staging** describes how much of the disease is in the body and how long a patient may stay in remission. Knowing the stage helps you and your healthcare provider decide the best course of treatment. Kidney function, age, and overall health can also affect treatment choices and outcomes.

## Disease staging is based on 4 factors\*:

- 

**Albumin level**  
 Albumin is the main protein found in blood.
- 

**Beta-2-microglobulin level**  
 Beta-2-microglobulin is a protein that indirectly measures volume of the disease.
- 

**Lactate dehydrogenase (LDH) level**  
 Lactate dehydrogenase is a protein that helps indicate how fast myeloma cells are multiplying (in scientific terms: indicates high proliferation rate).
- 

**Cytogenetics**  
 Cytogenetics is a lab test that looks at changes to genetic information (DNA) in cancer cells.

**Staging can be complex, so discuss it with your doctor.**

\*According to Revised International Staging System.



You and your doctor will work together to determine the treatment regimen that is right for you.

## Treatment Options

### What are my options?

After your diagnosis, you and your doctor will work together to find the treatment approach that is right for you. The initial treatment to induce remission with a combination of myeloma targeting medicines is referred to as induction treatment.

If you are eligible (and not every patient is), a **stem cell transplant** may be part of your treatment.

Later on, you may receive **maintenance treatment**, which helps "maintain" the results of prior treatments you've received.

Treatment Options	
Eligible for transplant	Not Eligible for transplant
Induction treatment	Continued treatment <sup>†</sup>
Transplant	
Consolidation*	
Maintenance treatment	

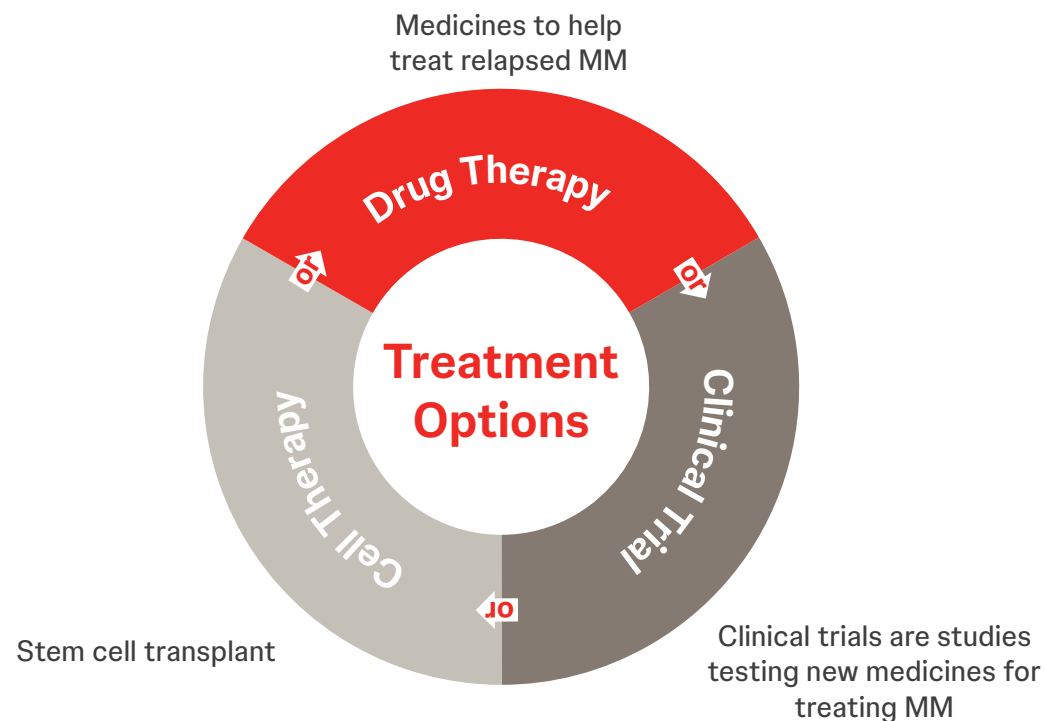
\*Applies to certain regimens.

<sup>†</sup>Continued treatment with one or more of your previous medicines.

## Other Treatment Options for Relapse

### What if I need a different treatment?

If the disease comes back (relapses) or is **resistant** (or **refractory**) to therapy, new treatments—including those available through **clinical trials**—may work even if other treatments have stopped working. Significant advances have been made in recent years in the treatment of myeloma.



**Clinical trials can also be considered if you are newly diagnosed.**

### What factors can affect my treatment?

While there are many treatment options to choose from, usually treatment is decided based on your staging and **health status**, disease characteristics and prior treatments, including how long they worked, and what **side effects** you had. Health status includes any other medical conditions, transplant eligibility, and overall physical fitness.

This includes dosage, how long it worked, and what side effects you had.

### A tailored treatment plan depends on:



#### Current health

- Age and general health
- Other medical conditions (also known as comorbidities)



#### Previous experience

- Signs and symptoms experienced with relapse—high calcium levels, reduced kidney function, anemia, and bone problems



#### What's happening now with your myeloma?

- Extent of the disease
- Symptoms and complications
- New myeloma disease, new tumors, or high-risk cytogenetics



#### Your preferences—let your healthcare provider know

- Quality of life
- Side effect tolerance
- Symptom relief
- Personal lifestyle or situation

## Treatment Options (cont'd)

### What medicines might be used in my treatment?

It is important to discuss with your doctor all of the potential benefits and risks associated with the treatment options that you are considering.

#### Monoclonal antibodies

- **Monoclonal antibodies** kill cancer cells directly and help the immune system attack them.

#### Immunomodulatory agents

- **Immunomodulatory agents** can send signals to the immune system to destroy cancerous cells.

#### Proteasome inhibitors (PIs)

- **Proteasome inhibitors (PIs)** interfere with actions inside cancer cells that help them grow and spread.

#### Steroids

- **Steroids** help decrease **inflammation** and swelling.

#### Conventional chemotherapy

- **Chemotherapy** either kills cancer cells or stops them from spreading.

#### Conditioning and stem cell transplants

- **Conditioning** (high-dose chemotherapy and other drugs) used as preparation for a stem cell transplant destroys cells in the blood, including the cancerous plasma cells, then the stem cell transplant replaces them with healthy stem cells.

#### Bone support medication

- Bisphosphonates help improve bone strength and prevent loss of bone mass.

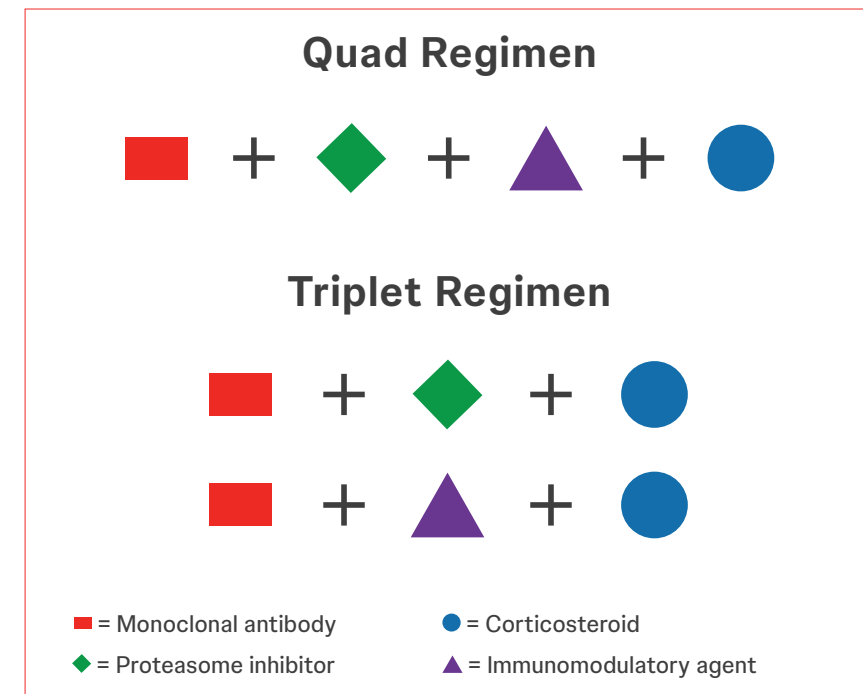
**In addition to these options, there are also clinical trials with drugs in development that may be considered.**

Note: Not everyone is eligible for stem cell transplant or clinical trials.

### How do the medicines work together?

Ultimately, treatment depends on many factors, including staging and the risk of side effects. Often treatments are combined because they fight the cancer and/or symptoms in different ways. It's common to be on a combination of two or more drugs. Four drugs at the same time is called a quad regimen. Taking three medicines at the same time is called a triplet regimen. Two drugs at the same time is called a doublet regimen.

Some examples of how these medicines can be combined for your individual treatment regimen are listed below.



## Meeting the Challenge

### Managing the day-to-day

It's helpful to speak with your doctor about challenges that may come with myeloma. If you are unsure or overwhelmed, don't be afraid to ask for more information or have the doctor explain it again.

You may want to bring someone as support during your appointments. Together you can take notes to better understand your options.

Ask your healthcare provider about...

### Protecting your bones

- Maintain **bone density** to reduce fractures and bone pain.

### Reducing the risk of infection

- Keep up-to-date on **vaccinations** against pneumonia, shingles, the flu, and any others recommended for you.

### Managing side effects of treatment

- Be aware of possible side effects and how to prevent and manage them.

### Considering other chronic conditions

You may have other chronic conditions that put you at risk for additional health problems. When such conditions exist, it's important to ask about how treatments may affect each other to help lessen these risks.

**If you have additional health concerns, ask your doctor about supportive services to help minimize your risk of hospitalization.**

## DOs

- ✓ **DO** go to follow-up appointments and let your healthcare providers know about any new symptoms or side effects.
- ✓ **DO** talk with your healthcare provider about how to stay well hydrated and help your kidneys.
- ✓ **DO** take as directed all medications your healthcare providers prescribe, and tell your healthcare provider about any other medications, vitamins, or supplements you may be taking.
- ✓ **DO** ask your healthcare team for counseling and support group recommendations if you feel depression, stress, or anxiety.
- ✓ **DO** call your healthcare providers immediately if you have symptoms of spinal cord compression: back pain, weakness in your arms and legs, tingling or numbness in feet or hands, or loss of bowel or bladder control.
- ✓ **DO** ask your healthcare team for help maintaining a healthy body to reduce fatigue.

## DON'Ts

- ⊘ **DON'T** participate in high-impact activities or lift heavy items. It can increase the risk of bone fractures.
- ⊘ **DON'T** suffer. Let your doctor know if you have new or worsening pain.
- ⊘ **DON'T** miss follow-up appointments. Your doctor needs to repeat blood, imaging, and urine tests to check and identify changes as early as possible, or decide to start or change treatment.



## Building a support team.

### Don't be afraid to share your emotions.

Experiencing a wide range of emotions is normal. It may be helpful to talk with family or friends, see a counselor, or join a support group.

**Share decision-making.** Working with your doctor is one way to ensure the best care. Ask questions and let the doctor know your preferences to help create the best treatment decisions and goals.

## Caring for yourself or a loved one

- ✓ Make a plan that addresses more than just the symptoms and disease and takes care of your mind, body, and spirit.
- ✓ There's a powerful mind-body connection that may affect your health. Learning **mindfulness** meditation (a practice that involves focusing thoughts on what you are feeling in the present moment) or other relaxation techniques may help anxiety, stress, sleep disturbances, and general mood.
- ✓ A nutritious, well-balanced diet can help you stay as healthy as possible for as long as possible.
- ✓ Staying active with regular exercise can help reduce stress and relieve **fatigue**. Talk to your healthcare provider before starting an exercise routine.
- ✓ Get proper rest. Sleep problems are common during treatment. Experts say you should try to sleep 7 to 8 hours each night.
- ✓ We all need emotional support, but sometimes you may not feel comfortable opening up to loved ones about your concerns. If you feel that way or are just looking to connect with others who are sharing your experience, consider joining a patient support group.
- ✓ If you're a caretaker, remember to set aside time for yourself, ask for help when you need it, and learn about support groups for caregivers. It's important to take care of yourself, too!

## Education & Support Groups

**American Cancer Society**  
www.cancer.org | 800.227.2345

**CancerCare®**  
www.cancercares.org | 800-813-HOPE (4673)

**National Comprehensive Cancer Care Network® (NCCN®)**  
https://www.nccn.org/patients

**National Cancer Institute**  
https://www.cancer.gov/ | 1-800-4-CANCER

**Multiple Myeloma Research Foundation**  
https://themmrf.org | 866-603-MMCT (6628)

**International Myeloma Foundation**  
www.myeloma.org | 800-452 CURE (2873)

**Cancer Support Community**  
www.cancersupportcommunity.org | 888-793-9355

**Leukemia and Lymphoma Society**  
www.LLS.org | 800.955.4572

**Myeloma Crowd**  
www.myelomacrowd.org

**The Myeloma Beacon™**  
https://myelomabeacon.org/

**Cancer.com**  
www.cancer.com | 1-800-7736

*Cancer.com is owned by Johnson & Johnson*

## Key Terms Defined

These are some terms that are used within this brochure and/or that you may hear throughout your treatment journey—either in conversations with your healthcare providers or in other materials.

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

**Anemia** – A condition marked by a low level of red blood cells, which may cause weakness, fatigue, shortness of breath, and dizziness.

**Antibody** – Also called “immunoglobulin,” a protein produced by plasma cells that helps protect the body from infection and disease.

**Asymptomatic** – Having no signs or symptoms of disease.

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

**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.

**Bone densitometry** – A test that uses x-rays to make pictures that show bone density—how strong or thin bones are.

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

**Bone marrow biopsy** – The removal of a small amount of solid bone and bone marrow to test for disease.

**Blood urea nitrogen (BUN)** – A test that helps show how well your kidneys are working.

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

**Cancerous** – Affected by cancer.

**Chemotherapy** – Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

**Clinical trial** – Research on a test or treatment to assess its safety or how well it works.

**Complete response** – The disappearance of all signs of cancer in response to treatment. This does not always mean the cancer has been cured. Also called complete remission.

**Computed tomography (CT) scan** – A test that uses x-rays from many angles to make a picture of the inside of the body.

**Conditioning** – A regimen that uses chemotherapy to destroy as many myeloma cells as possible before a stem cell transplant.

**Consolidation** – Treatment that is given after cancer has disappeared following the initial therapy in order to kill any cancer cells that may be left in the body.

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

**Cycle** – Days of treatment followed by days of rest.

**Cytogenetics** – Study of chromosomes (strands of DNA and protein that hold genetic information) to help diagnose a disease, plan treatment, or find out how well treatment is working.

**Diagnose** – To confirm or identify a disease or health condition.

**Diagnosis** – Identifying a disease by its signs or symptoms, and by using imaging tests, lab tests, or biopsy.

**DNA** – Deoxyribonucleic acid, the main component of chromosomes, and the carrier of genetic information.

**Fatigue** – Severe tiredness despite getting enough sleep.

**Flow cytometry** – A test that measures myeloma cells in the bone marrow.

**Fracture** – A crack or break in a bone.

**Free light chain** – The unattached, shorter fragments of M-proteins that are made by myeloma cells.

## Key Terms Defined (cont'd)

**Health status** – A generic term referring to the health of a person.

**Heavy chain** – The longer protein chain that is part of an antibody.

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

**Immune system** – Several types of cells and organs that work together to help the body fight infections and other diseases.

**Immunomodulatory agents** – Drugs that change a patient's immune response by enhancing or suppressing the immune system.

**Immunotherapy** – Drugs that stimulate the immune system to help treat or prevent disease.

**Induction treatment** – The first treatment given to destroy as many myeloma cells as possible before a stem cell transplant or continued treatment with medicines.

**Inflammation** – Redness, heat, pain, and swelling from injury or infection.

**Intravenous (IV) infusion** – A way of giving medicines or other fluids by inserting them into the bloodstream through a needle or tube in a vein.

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

**Lactate dehydrogenase (LDH)** – A protein found in the blood that is involved in energy production in cells.

**Leukopenia** – Low levels of white blood cells, which can increase your risk of infections and weaken the immune system.

**Light chain** – The shorter protein chain that is part of an antibody.

**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 see how they are working.

**Maintenance treatment** – Medicine that is given in a lower dose or less often to keep (maintain) good results of prior treatments.

**Malignant (cancerous)** – Malignant cells can invade and destroy nearby tissue and spread to other parts of the body.

**Mass spectrometry (MS)** – A new method of measuring plasma cells to help determine the presence of M-proteins in the blood.

**Mindfulness** – The practice of maintaining a state of complete awareness of one's thoughts, emotions, or experiences on a moment-to-moment basis.

**Minimal residual disease negativity (MRD negativity)** – MRD-negative status means to have a low level of disease. This assessment tool may be used to determine the effectiveness of therapy.

**Monoclonal antibodies** – A man-made molecule that binds to substances in the body, including cancer cells.

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

**Myeloma** – Cancer that arises in plasma cells, a type of white blood cell.

**Partial response** – A decrease in the size of a tumor, or in the extent of cancer in the body, in response to treatment. Also called partial remission.

**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 that makes germ-fighting proteins.

**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.

**Prognosis** – The likely outcome or course of a disease; the chance of recovery or recurrence.

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

**Proteasome inhibitors (PIs)** – Drugs that slow down cancer cell growth by interfering with processes that play a role in cell function.

**Protein** – A chain of small chemical compounds that are needed for the body to function properly. Proteins are the basis of skin, hair, and other substances in the body.

**Radiation therapy** – The use of high-energy rays (radiation) to destroy cancer cells.

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

**Relapse** – The return or worsening of a disease that had previously responded to therapy.

**Resistance (refractory)** – To remain unaffected by treatment.

**Response** – An improvement related to medical treatment, determined by a healthcare professional or clinical trial.

**Risk factor** – Something that increases the chance of developing a disease.

**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.

**Side effect** – An unwanted or unexpected reaction to a drug. Side effects can vary from minor problems like a runny nose to life-threatening events, such as a heart attack. Sometimes referred to as an adverse event.

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

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

**Staging** – Doing exams and tests to learn the extent of the multiple myeloma and how far it has progressed.

**Stem cell** – A cell that grows and divides to produce red blood cells, white blood cells, and platelets. Stem cells are found in bone marrow and blood.

**Stem cell transplant** – Treatment that uses chemotherapy to destroy cells in the bone marrow and then replaces them with healthy blood stem cells.

**Steroid** – A drug used to reduce swelling, redness, and pain.

**Supportive care** – Treatment for symptoms of cancer or side effects of cancer treatment.

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

**Systemic therapy** – Drugs that spread to reach cells, including cancer cells, throughout the body.

**Targeted therapy** – A type of systemic therapy that targets a specific or unique feature of cancer cells.

**Thrombocytopenia** – A low blood platelet count.

**Urine protein electrophoresis (UPEP)** – A test that shows the amount of M-proteins in the urine.

**Vaccinate** – To insert a biological agent (vaccine) into the body to prevent a disease.

**White blood cell** – A type of blood cell that fights infection.

**X-ray** – A type of radiation used to take pictures of the inside of the body, such as bones.

