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FOR PATIENTS & CAREGIVERS

# Myeloma Guide:

## Information for Patients and Caregivers



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## A six-word narrative about living with blood cancer from patients in our LLS Community

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Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at  
[www.LLS.org/Community](http://www.LLS.org/Community)

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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New treatments may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

This LLS Guide about myeloma is for information only. LLS does not give medical advice or provide medical services.

## Introduction

Myeloma is a type of cancer that forms in a plasma cell. Plasma cells are white blood cells found in the bone marrow.

Advancements in the treatment of myeloma have resulted in a better overall survival rate, allowing many patients to maintain a good quality of life for years.

- About 32,110 people in the United States are expected to be diagnosed with myeloma in 2019.
- About 124,483 people in the United States are living with or in remission from myeloma as of 2015.

In recent years, new therapies have been approved for myeloma, and other new treatments are being studied in clinical trials. Progress toward a cure is underway.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Myeloma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

**Feedback.** Visit [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback) to make suggestions about this booklet.

## PART 1 Myeloma

### Overview of This Section

- Blood cells begin as stem cells, which develop in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets. After they have matured, the red blood cells, white blood cells and platelets leave the bone marrow and enter the bloodstream.
- Plasma cells are a type of white blood cell that make antibodies to help the body fight infection.

- Myeloma starts with a change (mutation) to a single plasma cell.
- Myeloma is diagnosed with bone marrow tests, blood and urine tests, and imaging tests.

## About Bone Marrow, Blood and Blood Cells

The general descriptions below may help you understand the information in the rest of this Guide.

**Bone marrow** is the spongy tissue located inside the center of most bones. This is where blood cells are made.

**Blood cells** begin as stem cells in the bone marrow. Stem cells grow and mature into different type of cells: red blood cells, white blood cells and platelets. After the cells have matured, the red blood cells, white blood cells and platelets enter the bloodstream.

**Red blood cells** carry oxygen around the body. When the number of red blood cells is below normal, a condition called **anemia** usually develops. Anemia may make you feel tired or short of breath. It may make your skin look pale.

**White blood cells** fight infection in the body. There are five types of white blood cells, which are usually categorized into two groups, lymphocytes and germ-eating cells:

- Lymphocytes are infection-fighting cells:
  1. B cells
  2. T cells
  3. NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria:
  4. Neutrophils
  5. Monocytes

**Platelets** help stop bleeding by clumping together (**clotting**) at the site of an injury.

**Plasma** is the liquid part of the blood. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it. Blood plasma is not the same as plasma cells, which are a type of white blood cell.

## Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. They may be a little different from lab to lab and for children and teens.

### Red blood cell (RBC) count

- Men: 4.5 to 6 million red cells per microliter of blood
- Women: 4 to 5 million red cells per microliter of blood

### Hematocrit (the part of the blood made up of red cells)

- Men: 42% to 50%
- Women: 36% to 45%

### Hemoglobin (amount of the red cell pigment that carries oxygen)

- Men: 14 to 17 grams per 100 milliliters of blood
- Women: 12 to 15 grams per 100 milliliters of blood

### Platelet count (PLAT C)

- 150,000 to 450,000 platelets per microliter of blood

### White blood cell (WBC) count

- 4,500 to 11,000 white cells per microliter of blood

### Differential (also called diff)

- Shows the part of the blood made up of different types of white cells.
- The types of white cells counted are neutrophils, lymphocytes, monocytes, eosinophils and basophils.
- Adults usually have about 60% neutrophils, 30% lymphocytes, 5% monocytes, 4% eosinophils and less than 1% basophils in the blood.

# About Myeloma

Myeloma is a cancer of plasma cells, a type of white blood cell. Healthy plasma cells are part of the immune system—they make proteins called **antibodies** that help fight infection.

Myeloma begins in the bone marrow. It starts with a change (mutation) to a single plasma B cell. Normally, in the bone marrow, immature B cells will develop into normal plasma cells. But in myeloma, a change in one plasma B cell can cause it to become a myeloma cell instead of a normal plasma cell. This mutated myeloma cell multiplies into many myeloma cells. As the myeloma cells multiply in the bone marrow, they crowd out the other types of healthy cells: red blood cells, white blood cells and platelets. As a result, the number of red blood cells, white blood cells and platelets may become lower than normal.

Instead of producing helpful antibodies that fight infection, the myeloma cells produce abnormal antibodies that are not needed by the body and do not help fight infection. These abnormal antibodies can also damage the kidneys.

While the myeloma cells are most commonly found in the bone marrow, they may build up in other parts of the body. These collections of myeloma cells are known as **plasmacytomas**. They most commonly occur in the bones, skin, muscles or lungs. If the myeloma cells form a single cell mass, it is called a **solitary plasmacytoma**.

Myeloma that is found in several areas of the body is called **multiple myeloma**. Most patients with myeloma have multiple myeloma.

The term **smoldering myeloma** refers to a slow-growing type of myeloma. Usually, there are no symptoms at diagnosis and patients do not need treatment right away.

**Causes and Risk Factors of Myeloma.** Myeloma starts with a change to a single cell in the bone marrow. Doctors do not know why some people get myeloma and others do not. There is no way to prevent myeloma. You cannot catch myeloma from someone else.

While the cause of myeloma is unknown, the risk of developing myeloma may be increased by certain factors, such as:

- Age—Most people who develop myeloma are older than 50 years.
- Gender—More men than women develop myeloma.
- Race—Blacks are more likely to develop myeloma than whites.
- Obesity—Research suggests that obese people have a higher incidence of myeloma.
- Firefighting—Some studies indicate that firefighters are at a higher risk for many types of cancer, including myeloma.

## WANT MORE INFORMATION?



You can view, print or order the free LLS awareness postcard **Firefighters and Cancer Risk** at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies. For information on the World Trade Center Health Program, see page 32.

**Signs and Symptoms.** Healthy people often have a sign or a symptom when they get an illness or a disease.

A **sign** is a change in the body that the doctor sees in an exam or a test.

A **symptom** is a change in the body that the patient can see or feel.

In the early stages of myeloma, some people have no signs or symptoms of the disease. These people may find out they have myeloma after a regular medical checkup that shows changes in their blood and/or urine.

When people do have symptoms of myeloma, the most common include:

- Fatigue, severe tiredness
- Bone pain or bone fractures with no known cause
- Frequent infections and fevers
- Bruising or bleeding easily

Doctors sometimes use the acronym **CRAB** to describe signs of myeloma. The letters stand for:

**C**—Calcium elevation: high levels of calcium in the blood, also known as **hypercalcemia**

**R**—Renal failure: poor function of the kidneys that may be caused by deposits of myeloma protein in the kidneys

**A**—Anemia: low red blood cell count

**B**—Bone abnormalities: called “lesions”

Treatment is usually recommended for patients who have one or more of the four signs listed above.

# Diagnosis

It is important for patients to receive the right diagnosis. When a person has signs and symptoms of myeloma, the doctor does special tests to find out the cause. Myeloma is diagnosed with blood and urine tests, bone marrow tests, and imaging tests.

**Here are some questions you may want to ask your healthcare team.** See pages 39-44 for a full list of questions.

1. What kind of testing will be done to diagnose my disease and to monitor my treatment?
2. How long does it take to get the results?
3. How will the results be communicated to me?
4. How often will testing be needed?
5. Where will the testing be done?

**Blood and Urine Tests.** Tests are done to see if a protein called “M protein” is in the patient’s blood and urine. M protein is short for **monoclonal protein**, an antibody found in large amounts in the blood or urine of people with myeloma. Measuring the amount of M protein is one way to tell the severity (in cancer, this is called the “stage”) of the myeloma.

Other proteins, called “light chains” (also known as Bence Jones protein), may be found in the myeloma patient’s urine. A special test to check for light chains is called a **serum free light chain test**.

**Bone Marrow Tests.** People with myeloma have too many plasma cells in their bone marrow. Bone marrow tests are done to find out the percentage of plasma cells in the bone marrow.

## How Are the Blood and Bone Marrow Tests Done?

**Blood Test** — A small amount of blood is taken from the patient's arm with a needle. The blood is collected in tubes and sent to a lab.

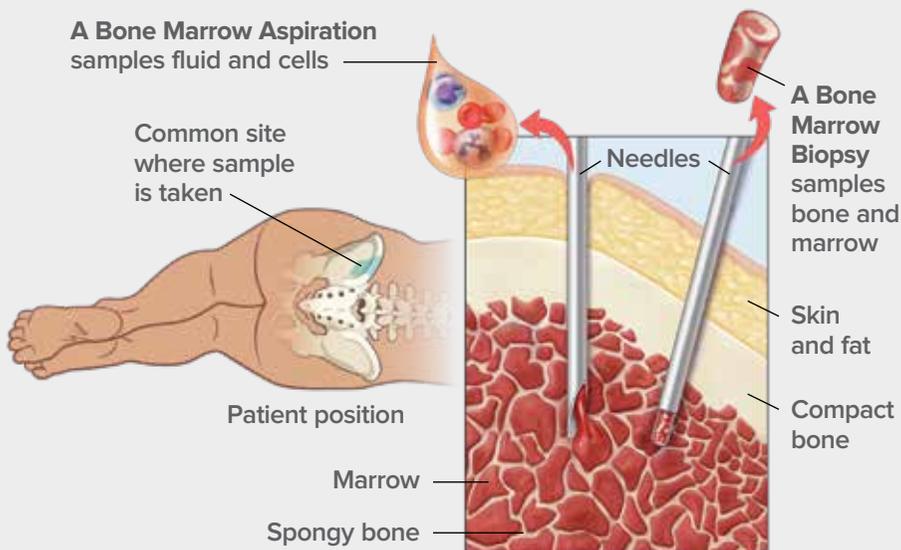
**Bone Marrow Aspiration** — A sample of fluid with cells from the bone marrow is removed.

**Bone Marrow Biopsy** — A very small amount of bone filled with marrow cells is taken from the body.

Both bone marrow tests are done with a special needle. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to take the sample of cells. Some patients are given a drug that makes them sleep during this procedure. The sample of cells is usually taken from the patient's hip bone.

Blood and marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and biopsy are almost always done at the same visit.

## Bone Marrow Aspiration and Biopsy



**Left:** The place on the back of the patient's pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where one needle goes into bone marrow to get a liquid sample for aspiration and the other needle goes inside the bone for a bone biopsy. The needles are different sizes.

**Cytogenetic Analysis.** Fluorescence in situ hybridization (FISH) is a type of laboratory test that is used to see if there are changes to the chromosomes of the myeloma cells taken from the bone marrow. Chromosomes are the part of a cell that contains genetic information. Normal human cells contain 23 pairs of chromosomes, each of which are a certain size, shape and structure. In some cases of myeloma, the chromosomes of the myeloma cells have abnormal changes. The results of the cytogenetic analysis test help your doctor plan your treatment.

**Next-Generation Sequencing (NGS).** Molecular tests are very sensitive DNA tests that check for specific gene mutations in the myeloma cells. Results from these tests may be used for treatment planning. This test may be helpful in better predicting outcomes and developing new and improved targeted therapies. This is currently being done only in research but may soon be used in routine practice.

**Imaging Tests.** Imaging tests make pictures (images) of the inside of the body. They are a very important part of the diagnosis, staging and management of myeloma. These include:

- **Bone/skeletal survey.** X-rays of all the bones in the body are taken and examined to identify areas of decreased bone density and bone lesions, and to see if there are any holes or breaks in any bones or thinning of the bones.
- **Magnetic resonance imaging (MRI).** This imaging test is done in select cases. It uses a powerful magnet to detect abnormalities in the bone marrow.
- **Positron emission tomography imaging and computed tomography (PET-CT) scan.** A PET/CT scanner combines the techniques of both PET and CT in one machine. It provides a more detailed picture of where the cancer is located in the body than either test alone. PET-CT is the only imaging test used to evaluate treatment response.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Myeloma* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# Tracking Your Myeloma Tests

These tips may help you save time and learn more about your health.

- Ask your doctor why certain tests are being done and what to expect.
- Discuss your test results with your doctor.
- Ask for and keep copies of lab reports in a file folder or binder. Organize reports by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

## WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Understanding Lab and Imaging Tests* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## PART 2 Treating Myeloma

### Overview of This Section

- People with myeloma should choose a doctor who is a specialist in both blood diseases and cancer. This doctor is called a **hematologist-oncologist**.
- Ask questions about your treatment choices and do not be afraid to be involved in making decisions about your own care. See the *Treatment and Follow-Up Care Question Guides* on pages 41-44.
- For most people with myeloma, treatment begins with systemic drug therapy (meaning treatment travels through the bloodstream to kill the cancer cells).
- Many myeloma drugs are taken orally (by mouth). It is important for patients to take these drugs on the right day at the right time.
- It is very important to measure your response to treatment. The results are used to help your doctor determine if your myeloma is well-controlled.

### Finding the Right Doctor

Choose a doctor who specializes in treating myeloma and knows about the most up-to-date treatments. This type of specialist is called a **hematologist-oncologist**. A hematologist is a doctor who has special training in disorders of the blood.

An oncologist is a doctor who has special training in cancer. A hematologist-oncologist has special training in both diagnosing and treating blood cancers.

Your local cancer specialist may work with a hematologist-oncologist. Always check to see if the doctor's affiliated hospital or your chosen hospital is covered under your health insurance plan.

## How to Find a Myeloma Specialist

- Ask your primary care doctor for a recommendation.
- Contact your community cancer center.
- Reach out to doctor and/or health plan referral services.
- Call an LLS Information Specialist at (800) 955-4572.
- Use online doctor-finder resources, such as
  - The American Medical Association's (AMA) "DoctorFinder" online at <https://doctorfinder.ama-assn.org/doctorfinder/>
  - The American Society of Hematology's (ASH) "Find a Hematologist" online at <https://www.hematology.org/Patients/FAH.aspx>

When you meet with the specialist, ask questions to get a better idea of the doctor's experience and to understand how the office works. Some sample questions are below. See pages 39-44 for a full list of questions.

1. How many patients have you treated who have myeloma?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. Is there a release form available so my family/caregiver can be given medical information?

Make sure you feel comfortable interacting with the doctor and the rest of the staff. You will be spending a lot of time speaking with this staff and others at this treatment center.

### WANT MORE INFORMATION?



You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# Ask Your Doctor

Talk with the doctor and ask questions about how he or she plans to treat your myeloma. This will help you become actively involved in making decisions about your care.

When you meet with your doctor

- Ask questions. Below are a few questions to ask. See pages 39-44 at the end of this Guide for a full list of questions. Visit [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) to find our other healthcare question guides.
  - What are my treatment choices?
  - Are there any clinical trials that I can join?
  - When do you think treatment should begin?
  - How long will treatment last?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later. Ask the doctor and staff if recording is okay (cell phones have a “record” function, ask someone how to use it if you are not sure).
- Bring a caregiver, friend or family member who can listen to the doctor along with you, take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain it again.

If you need more information or are not sure about your treatment choices, consider getting another opinion (a **second opinion**) from a different qualified doctor. If you are unsure or feel uncomfortable about how to tell your doctor you are getting a second opinion, call one of our Information Specialists at (800) 955-4572 to discuss a way that makes you comfortable. You may also want to check with your insurance to ensure that a second opinion is covered.

# Goals of Treatment

While there is no cure for myeloma, new treatments have improved patient quality of life and survival rates. The goals of myeloma treatment are to

- Slow the growth of myeloma cells
- Reduce symptoms such as bone pain and fatigue
- Provide long periods of remission (when there are no signs of myeloma and/or the myeloma is not causing health problems)
- Lengthen survival while preserving quality of life.

# Treatment Staging and Planning

The treatment plan for a patient depends on

- The type and stage of myeloma
- The patient's age
- The patient's overall health

**Staging.** Once doctors diagnose cancer, they need to know how much cancer is in the body and where it is located. This process is called **staging**. Figuring out the stage of the cancer helps doctors determine how serious the cancer is and how best to treat it.

Myeloma has three stages numbered from 1 to 3. Often doctors write the stage down in Roman numerals. You may see stage 1 written as Stage I, stage 2 written as Stage II and stage 3 written as Stage III. In general, lower stages have better outcomes. Doctors use bone marrow exams and lab and imaging tests to stage myeloma. These tests look at:

- Blood counts of red blood cells, white blood cells and platelets, which may be lower than normal
- The amount of M protein found in the blood and urine (M protein is made by myeloma cells)
- The calcium level in the blood, which may be higher than normal
- The beta<sub>2</sub> microglobulin level in the blood, which may be higher than normal
- The albumin level in the blood, which may be lower than normal
- The bones, to see if there are any bone lesions
- The presence of high-risk cytogenetic (chromosome) abnormalities in the myeloma cells
- The lactate dehydrogenase level, which may be higher than normal

There are two staging systems. One is called the Durie-Salmon Staging System and the other is called the International Staging System (ISS) for Multiple Myeloma.

**Treatment Planning.** Once you are diagnosed with myeloma, your doctor will customize your treatment approach based on a number of factors including:

- The stage of your myeloma
- The characteristics of your myeloma, such as the presence of chromosomal abnormalities
- The rate of disease progression — whether the cancer continues to grow or spread
- The presence of other conditions such as heart or kidney disease, diabetes or neuropathy (a nerve problem that causes pain, numbness, or tingling, usually in the hands or feet)
- Your age
- Your overall health

Patients are advised to consult a doctor who specializes in myeloma treatment to discuss the most appropriate treatment option for their diagnosis. Most treatment plans include a combination of different therapies.

## About Myeloma Treatments

New treatments may have been approved since this book was printed. Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

A patient has two options for treatment: standard care or taking part in a clinical trial. It is important to talk to your doctor about the best treatment option.

There are a number of treatments for myeloma. These include:

- Combination drug therapy
- High-dose chemotherapy followed by stem cell transplantation
- Radiation therapy for patients with localized disease (for example, a solitary plasmacytoma)
- New and emerging drug therapies (given in clinical trials, see page 23)

A patient may receive drugs that are different from those described in this Guide. These drugs may still be considered proper treatment.

Speak to your doctor to find out what treatment is best for you.

Our Information Specialists can help you plan questions about treatment to ask your doctor.

**Here are some questions you may want to ask your healthcare team.** See pages 39-44 for full list of questions.

1. What stage is my cancer?
2. What are my treatment options, including clinical trials?
3. What is the goal of treatment?
4. What are the benefits and risks of these treatments?
5. Is there one treatment recommended over others?

For patients who have myeloma that grows slowly, an approach called “**watch and wait**” may be a better option than early treatment. In the watch-and-wait approach, treatment is delayed until there are signs that the disease is progressing. Frequent and careful observation by a doctor is required so that treatment can begin when the disease starts advancing. Patients with active myeloma, however, need immediate treatment.

Some patients will need supportive (palliative) care to address the symptoms and complications of myeloma such as anemia, high blood calcium levels, infection and bone damage (see *Complications, Side Effects and Follow-Up Care* on pages 24-27).

**Drugs Used to Treat Myeloma.** Systemic drug therapy (meaning treatment that travels through the bloodstream to kill myeloma cells) is the main treatment for myeloma. The initial therapy for myeloma usually includes a combination of targeted agents (these work by targeting specific types of cancer cells) and/or standard chemotherapy. This therapy is often followed by stem cell transplantation in patients who are eligible for this procedure. (See *Stem Cell Transplantation* on pages 19-20.)

The following is a list of drug options for myeloma patients.

### **Proteasome Inhibitors**

- **Bortezomib (Velcade®)** is given through a vein, intravenously (IV), or under the skin (subcutaneously, abbreviated SC) and is approved by the Food and Drug Administration (FDA) to treat myeloma. It can also be used for retreatment of patients with relapsed myeloma.
- **Carfilzomib (Kyprolis®)** is given intravenously (IV) and is FDA-approved for use in combination with dexamethasone, or with lenalidomide plus dexamethasone, for the treatment of patients with relapsed or refractory

myeloma who have received one to three prior therapies. It is also indicated as a single agent for the treatment of patients with relapsed or refractory myeloma who have received at least one or more prior therapies.

- **Ixazomib (Ninlaro®)** is given by mouth. It is used in combination with lenalidomide and dexamethasone for the treatment of myeloma patients who have received at least one prior therapy. It is a good option for patients who have difficulty going to the doctor's office for treatment injections.

### **Immunomodulatory Drugs**

- **Lenalidomide (Revlimid®)** is given by mouth. Lenalidomide is used with dexamethasone to treat myeloma patients. It is also used as a maintenance therapy following an autologous stem cell transplant.
- **Pomalidomide (Pomalyst®)** is given by mouth. It is used with dexamethasone to treat myeloma patients who have received at least two prior treatments including lenalidomide and a proteasome inhibitor, and have experienced disease progression either on or within 60 days of completion of the last therapy.
- **Thalidomide (Thalomid®)** is given by mouth. Thalidomide is used with dexamethasone to treat newly diagnosed myeloma patients.

### **Histone Deacetylase Inhibitors**

- **Panobinostat (Farydak®)** is given by mouth. It is FDA-approved for use in combination with bortezomib and dexamethasone for the treatment of patients with myeloma who have received at least two prior regimens including bortezomib and an immunomodulatory agent.

### **Monoclonal Antibodies**

- **Elotuzumab (Empliciti®)** is given intravenously (IV). This drug is FDA-approved for use in combination with lenalidomide and dexamethasone for the treatment of patients with myeloma who have received one to three prior therapies. It has also been approved in combination with pomalidomide and dexamethasone to treat adult myeloma patients who have received at least two prior therapies, including lenalidomide and a proteasome inhibitor.
- **Daratumumab (Darzalex®)** is given intravenously (IV). It has been approved for use:
  - In combination with lenalidomide and dexamethasone in newly diagnosed patients who are ineligible for autologous stem cell transplant, and in patients with relapsed or refractory myeloma who have received at least one prior therapy.
  - In combination with bortezomib, melphalan and prednisone for the treatment of patients with newly diagnosed myeloma who are ineligible for autologous stem cell transplant.

- In combination with bortezomib, thalidomide, and dexamethasone in newly diagnosed patients who are eligible for autologous stem cell transplant.
- In combination with bortezomib and dexamethasone for the treatment of patients with myeloma who have received at least one prior therapy.
- In combination with pomalidomide and dexamethasone for the treatment of patients with myeloma who have received at least two prior therapies including lenalidomide and a proteasome inhibitor.
- In patients with myeloma who have received at least three prior lines of therapy including a proteasome inhibitor and an immunomodulatory agent, or who are double-refractory to a proteasome inhibitor and an immunomodulatory agent.
- **Melphalan hydrochloride (Evomela®)** is given intravenously (IV) and is approved as a high-dose conditioning treatment before a stem cell transplantation. It is also used as a palliative treatment in patients for whom no oral therapy options are appropriate.
- **Denosumab (Xgeva®)** is given subcutaneously (under the skin) and is FDA-approved for the prevention of skeletal-related problems in myeloma patients.

### **Bisphosphonates**

- **Pamidronate disodium (Aredia®)** is given intravenously (IV). It alleviates the effects of bone disease by decreasing the pain, likelihood of bone fractures and high blood calcium levels associated with bone destruction.
- **Zoledronic acid (Zometa®)** is given intravenously (IV). It alleviates the effects of bone disease by decreasing the pain, likelihood of bone fractures and high blood calcium levels associated with bone destruction.

## Some Drugs Used in the Treatment of Myeloma

Generic Name	Brand Name
Bortezomib	Velcade®
Carfilzomib	Kyprolis®
Carmustine	BiCNU®
Cyclophosphamide	Cytoxan®
Cytarabine	Cytosine arabinoside, Ara-C, Cytosar-U®
Daratumumab	Darzalex®
Denosumab	Xgeva®
Dexamethasone	(many brands)
Doxorubicin	Adriamycin®
Elotuzumab	Empliciti®
Ixazomib	Ninlaro®
Lenalidomide	Revlimid®
Liposomal doxorubicin	Doxil®
Melphalan	Alkeran®
Melphalan hydrochloride	Evomela®
Pamidronate	Aredia®
Panobinostat	Farydak®
Pomalidomide	Pomalyst®
Prednisone	(many brands)
Selinexor	Xpovio™
Thalidomide	Thalomid®
Zoledronic acid	Zometa®

New treatments may have been approved since this book was printed.  
Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

## Some Drug Combinations for Myeloma Treatment

- |  |
|--|
| ○ <b>MP:</b> melphalan (Alkeran®), prednisone                                  |
| ○ <b>TD:</b> thalidomide (Thalomid®), dexamethasone                            |
| ○ <b>RD:</b> lenalidomide (Revlimid®), dexamethasone                           |
| ○ <b>Pom/Dex:</b> pomalidomide (Pomalyst®), dexamethasone                      |
| ○ <b>VD:</b> bortezomib (Velcade®), dexamethasone                              |
| ○ <b>MPT:</b> melphalan, prednisone, thalidomide                               |
| ○ <b>VMP:</b> bortezomib, melphalan, prednisone                                |
| ○ <b>VTD:</b> bortezomib, thalidomide, dexamethasone                           |
| ○ <b>VCD or CyBorD:</b> bortezomib, cyclophosphamide (Cytosan®), dexamethasone |
| ○ <b>VRD:</b> bortezomib, lenalidomide, dexamethasone                          |
| ○ <b>CCyD:</b> carfilzomib (Kyprolis®), cyclophosphamide, dexamethasone        |
| ○ <b>KRD:</b> carfilzomib, lenalidomide, dexamethasone                         |
| ○ bortezomib and liposomal doxorubicin (Doxil®)                                |
| ○ daratumumab (Darzalex®), bortezomib, melphalan, prednisone                   |
| ○ daratumumab, lenalidomide, dexamethasone                                     |
| ○ elotuzumab (Empliciti®), lenalidomide, dexamethasone                         |
| ○ panobinostat (Farydak®), bortezomib, dexamethasone                           |
| ○ ixazomib (Ninlaro®), lenalidomide, dexamethasone                             |

**Stem Cell Transplantation.** Some eligible patients may benefit from high-dose chemotherapy followed by a stem cell transplantation. Your doctor will talk with you about whether stem cell transplantation is a treatment option for you.

There are two types of stem cell transplantation, one that replaces the patient's stem cells with his or her own stem cells (**autologous transplant**), and one that uses replacement stem cells from a donor (**allogeneic transplant**).

Stem cell transplantation allows doctors to give higher doses of chemotherapy than can typically be given to a patient. Such high doses of chemotherapy can severely damage the stem cells in the bone marrow and result in anemia, serious infections and uncontrolled bleeding. Stem cell transplantation replaces the stem cells destroyed by high-dose chemotherapy.

When doctors are planning treatment, they use a number of factors to determine a patient's eligibility for stem cell transplantation. These factors may include: the individual's disease; if the patient is not doing well with other treatments; if the expected benefits of a transplant exceed the risks; if there is a stem cell donor; other treatment(s) received; and physical ability to have the transplant. Stem cell transplantation is not for every patient, but it can be helpful for some.

Additional information about different kinds of transplants available for some myeloma patients is below. Talk to your doctor about whether a stem cell transplant is a possible treatment for you.

**Autologous Stem Cell Transplantation.** The patient's own stem cells are collected for this type of stem cell transplantation. The patient is then treated with high doses of chemotherapy to kill the myeloma cells, but this treatment also kills stem cells in the patient's bone marrow. To replace the stem cells after chemotherapy, the patient's stem cells that have been collected and stored are returned to the patient's bloodstream by an IV infusion (similar to a blood transfusion).

Autologous stem cell transplantation is not a cure for myeloma. It can, however, give patients longer disease-free periods than other standard myeloma therapies. This treatment is not appropriate for all myeloma patients. Patients should discuss the benefits and risks of an autologous stem cell transplantation with their doctors. For patients who are not eligible for an autologous stem cell transplantation, a growing number of treatment choices are available for older or sicker patients who may not be physically able to have a stem cell transplant.

**Allogeneic Stem Cell Transplantation.** With allogeneic stem cell transplant, the stem cells are collected from a donor. The donor can be a brother or sister or another person whose stem cells "match" the patient's. An allogeneic stem cell transplant is a high-risk procedure and has a limited role in myeloma treatment. It should only be done in the context of a clinical trial. Doctors are working to make allogeneic stem cell transplants safer.

Another type of allogeneic stem cell transplant is called a "**reduced-intensity transplant**" (doctors may also use the term "nonmyeloablative transplant"). This uses lower doses of chemotherapy than a standard allogeneic stem cell transplant. Older and sicker patients may be helped by this treatment.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Blood and Marrow Stem Cell Transplantation Guide* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Maintenance Therapy.** Maintenance therapy is treatment that is given to help keep cancer cells suppressed after initial therapy. Maintenance therapy is also given after stem cell transplantation. Some patients may be given a low dose of lenalidomide (Revlimid®) after an autologous stem cell transplantation. Studies continue to explore different drug combinations to be used in maintenance therapy.

**Radiation Therapy.** Radiation therapy uses high-energy rays (x-rays) to kill cancer cells. It may be used to treat patients with a single mass of myeloma (called a **plasmacytoma**), or to treat carefully selected patients whose bone pain does not respond to chemotherapy.

## Oral Adherence

Many new myeloma drugs are taken orally (by mouth). “Adherence” means staying on a set plan or regimen by taking your medication in pill form as prescribed—on the right day and at the right time. It is important to make sure that you continue to take your medications at home as prescribed.

There are many benefits of taking a drug by mouth. These include better quality of life and convenience. Unfortunately, when patients do not adhere to their medication plan or regimen, that irregular schedule can result in drug resistance, poor response to therapy, progression of disease, increased doctor visits, more lab tests and hospitalizations, and even death.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Myeloma Oral Treatment Adherence Facts and A Medication Resource for Myeloma Patients* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies. You can also view the video *Oral Therapies in Myeloma: Medication Adherence* at [www.LLS.org/videos](http://www.LLS.org/videos).

## Measuring Treatment Response

Your doctor will do tests to see if treatment is working. These test results help the doctor decide if changes to treatment are needed.

Blood and urine tests are done to check blood cell counts, kidney function and growth of myeloma cells.

A bone marrow biopsy is used to look at the number and pattern of myeloma cells in the bone marrow.

Imaging tests (x-rays, CT scans, MRIs and PET scans) are used to look at patient's bones and bone marrow. X-rays and CT scans are used to see if bones have any holes or breaks, or if there is thinning of the bones. MRIs and PET scans look for changes to the bone marrow and for pockets of myeloma cells.

### Some Terms Used to Describe Myeloma Treatment Responses

The doctor may use these terms to talk about a patient's response to treatment.

**Remission.** No sign of disease; the terms "complete remission" (complete response) or "partial remission" (partial response) are sometimes used.

**Complete response.** No sign of the M protein in the blood and urine.

**Very good partial response.** A 90% or greater decrease in the amount of M protein in the blood.

**Partial response.** A more than a 50 percent decrease in the amount of M protein in the blood; more than a 90 percent decrease in the amount of M protein in the urine in a 24-hour collection.

**Stable disease.** Not meeting the criteria to be called a "complete response" or a "very good partial response," or even a "partial response"; but also not meeting criteria to be called "progressive disease."

**Progressive disease.** At least a 25 percent increase in the amount of M protein in the blood and urine, new areas of bone damage or a new mass of myeloma cells; progressive disease usually indicates the need to start therapy or change therapies.

### Treatment for Relapsed or Refractory Myeloma

After a time, almost all myeloma patients experience relapse, which means the cancer returns after a successful course of treatment. Or the disease may be refractory, which means the cancer does not respond to treatment. In some instances of relapse, the drug or combination of drugs that the patient had a good response to initially may be tried again. Another option for either relapsed or refractory disease is to try a different drug or combination of drugs.

The choice of a treatment regimen after relapse is dependent on a series of factors including:

- Previous therapy
- How quickly or slowly the myeloma is progressing
- Patient health and comorbidities (presence of other health conditions)
- Genetic abnormalities in the myeloma cells that have developed over time.

See *Drugs Used to Treat Myeloma* on pages 15-19 for options in treating relapsed or refractory myeloma.

## PART 3 Clinical Trials

### About Clinical Trials

Doctors may recommend that a patient join a clinical trial. Clinical trials are careful studies done by doctors to test new drugs or treatments. Clinical trials are also used to study new uses for approved drugs or treatments, such as changing the dose of the drug or giving the drug along with another type of treatment or drug. Some clinical trials combine drugs for myeloma in new sequences or dosages.

There are clinical trials for

- Newly diagnosed myeloma patients
- Patients who did not have a good response to treatment (refractory disease)
- Patients who relapse after treatment (relapsed disease)
- Patients who continue treatment after remission (maintenance therapy)

A carefully conducted clinical trial may provide the best available treatment.

**Here are some questions you may want to ask your healthcare team.** See pages 39-44 for a full list of questions.

1. Is a clinical trial a treatment option?
2. How can I find out if insurance covers the cost of the clinical-trial treatment and treatment-related costs such as testing?
3. Who pays for the travel costs to get to the clinical trial?

Ask your doctor if treatment in a clinical trial is right for you. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can provide more information about clinical trials and help search for a clinical trial for you. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Visit the Clinical Trial Support Center at [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

## PART 4 Complications, Side Effects and Follow-Up Care

### Overview of This Section

- Supportive (palliative) care for myeloma helps patients manage the complications of the disease and the side effects of treatment.
- After you begin treatment, your doctor will regularly order bone marrow tests, lab tests and imaging tests to see how well treatment is working.
- Myeloma patients should see their primary care doctor and a cancer specialist regularly for follow-up care.

### Complications of Myeloma Therapy

Supportive (palliative) care for myeloma helps patients manage the complications of the disease and the side effects of the drugs used for treatment. The term **side effect** refers to the way that treatment affects healthy cells, but also often describes the negative or undesirable effects of a treatment.

Some complications of myeloma and myeloma therapy include:

**Fatigue.** Fatigue is one of the most common complaints reported by myeloma patients. It may be caused by many factors including anemia caused by both the

myeloma and the side effects of treatment. Sometimes fatigue caused by anemia may be treated with **darbepoetin alfa (Aranesp®)** and **epoetin alfa (Procrit®)**, drugs that can increase the number of red blood cells, which may help lessen the severity of anemia.

**Infection.** Myeloma and certain myeloma treatments can increase the risk of infection. Infections are not just a troublesome medical problem; they can also contribute to the risk of dying from myeloma. Patients should follow their doctor's advice about how to reduce their risk of infection. The doctor may also recommend

- Intravenous (IV) immunoglobulin therapy, for patients with frequent and life-threatening infections
- Vaccinations for the flu, pneumonia and shingles

**Bone Pain.** Myeloma may cause bone pain due to thinning, weakening, and breaking of bones. Fractures of bones may also result in pain. Successful treatment of myeloma may relieve bone pain, but some patients may need medication for severe pain. Treatment options for bone pain include drugs called bisphosphonates (**pamidronate [Aredia®]** and **zoledronic acid [Zometa®]**) to help reduce bone pain and the risk of bone fractures. **Denosumab (Xgeva®)** is FDA-approved to prevent bone fractures in myeloma patients. Denosumab is administered through subcutaneous injection (under the skin). This medication is recommended when bisphosphonates cannot be prescribed due to potential damage to the kidneys.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Pain Management Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Kidney Problems.** Myeloma patients have large amounts of M protein in their urine. They may also have high levels of calcium in their blood. Both of these can damage the kidneys. Myeloma treatment can improve kidney function and, in most cases, even return it to normal.

**Myelosuppression.** A condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells and platelets. Myelosuppression is a side effect of some cancer treatments including chemotherapy agents such as **lenalidomide (Revlimid®)** and **bortezomib (Velcade®)**. If not managed correctly, myelosuppression can be life threatening and interfere with treatment planning and quality of life.

**Peripheral Neuropathy.** This is the term for damage to nerves that causes pain, numbness, tingling or swelling in the arms or legs. It can be caused by the

myeloma itself, or it can be caused by certain anticancer drugs. Patients who develop neuropathy while receiving chemotherapy should tell their doctors as soon as symptoms appear. Often, reducing the dosage of the drugs or stopping them altogether can alleviate the symptoms.

**Thrombosis (DVT).** The term “deep vein thrombosis” (abbreviated DVT) refers to a blood clot that forms in the deep veins of the body, usually in the legs. A DVT can cause blood flow obstruction, pain and swelling. Patients who receive myeloma treatments that are associated with DVT risk are usually prescribed medication to reduce the chance of developing DVT. It is important for patients to discuss this risk with their doctors and ask which of the options to reduce DVT risk is best for them.

Some doctors have observed that taking either thalidomide or lenalidomide and dexamethasone in combination with red blood cell growth factors, for example epoetin alpha (Procrit®) or darbepoetin alfa (Aranesp®), further increases a patient’s risk for DVT. Other factors that can increase the risk of DVT include the presence of a central line (central venous catheter), decreased mobility, recent surgery, pregnancy, smoking, a prior history of DVT or a family history of blood-clotting problems.

**Pulmonary Embolism.** Pulmonary embolism is similar to DVT but it happens in a different place; it is a sudden blockage in one of the arteries in the lungs. An embolism usually happens when a blood clot breaks loose, travels through the bloodstream and lodges in the arteries of the lungs. Depending on the size and number of clots that reach the pulmonary arteries, a patient may experience chest pain, shortness of breath and other potentially severe or even life-threatening effects. Certain drugs may increase the risk of developing an embolism. The treatments thalidomide (Thalomid®) and lenalidomide (Revlimid®) are associated with an increased incidence of both DVT and pulmonary embolism when they are used in combination with corticosteroids, such as **dexamethasone**, and in particular, when they are used in combination with **liposomal doxorubicin**.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Cancer-Related Fatigue Facts* and the *Side Effect Management Series* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for copies.

**Acute Myeloid Leukemia (AML).** Myeloma patients have an increased risk of developing second cancers including acute myeloid leukemia, especially after treatment with certain drugs. This rare complication occurs in a small number of patients.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *The AML Guide: Information for Patients and Caregivers* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Chemotherapy Side Effects.** Side effects from chemotherapy affect the parts of the body where new cells form quickly. This includes the inside of the mouth and bowel, and the skin and hair. The side effects listed below are common during chemotherapy:

- Upset stomach and vomiting
- Diarrhea
- Constipation
- Mouth sores
- Hair loss
- Extreme tiredness
- Infections
- Low red blood cell count (anemia)
- Low white blood cell count (neutropenia)
- Low platelet count (thrombocytopenia)
- Achy feeling
- Numb feeling in arms, hands, legs or feet (neuropathy)

Not all patients have these side effects. Treatment to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable. Talk to your doctor about the possible side effects of your treatment. You can also call our Information Specialists at (800) 955-4572.

### WANT MORE INFORMATION?



You can view, print or order the free LLS *Side Effects Management Series* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

## Financial Concerns

Myeloma patients are living longer primarily because of the development of new and effective drugs. However, there can be a financial impact because of the cost of these medications.

Speak to your doctor if you have any concerns about being able to pay for your medications. A member of your treatment team may be able to provide information and resources that can help. Health insurance plans may not cover all the costs of cancer care, but there are a number of resources, including organizations, foundations and prescription assistance programs, available to help patients manage and afford their prescriptions.

In addition, several major pharmaceutical manufacturers (the companies that develop the drugs) provide patient assistance or prescription assistance programs. These companies may be able to help by providing both insured and uninsured patients with either free or reduced-cost medications.

### WANT MORE INFORMATION?



You can view, print or order the free LLS booklet *Cancer and Your Finances* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy. You can also contact an LLS Information Specialist at (800) 955-4572 for information about the LLS Co-Pay Assistance Program and other financial assistance programs.

## Follow-Up Care

Medical follow-up is important for every myeloma patient. Follow-up care helps your doctor see how well your treatment is working, and to determine if different treatment is needed.

Patients should see their primary care doctors and their hematologist-oncologists (cancer specialists) regularly for follow-up care. Ask your healthcare team how often you will need to have follow-up visits. You should also ask the healthcare team what tests will be needed and find out how often you need to have these tests. It is important to get and keep a record of your cancer treatment, including the drugs you received and the time period you received them, so that your healthcare team can follow up on specific long-term effects that may be associated with your treatment. See page 45 for a place that you can list your treatments.

**Here are some questions you may want to ask your healthcare team.** See pages 39-44 for a full list of questions.

1. Who will I work with to ensure life-long follow-up care?
2. Will I continue to see this healthcare team?
3. What information can be given to my primary doctor about past treatment and what may be needed in the future?

Follow-up care may include physical exams, blood tests and urine tests. Sometimes bone marrow tests and imaging tests are also needed.

To find survivorship clinics (places that provide services to help cancer survivors live well after cancer treatment) and other resources, contact our Information Specialists at (800) 955-4572.

## Take Care of Yourself

- Keep all your doctor and lab appointments (specialists, primary care, testing).
- Talk with the doctor about how you feel at each visit.
- Ask any questions you may have about side effects.
- People with myeloma may have more infections. Follow your healthcare team's advice for preventing infection.
- Eat healthy food each day. It may help to eat 4 or 5 smaller meals instead of 3 larger ones.
- Contact your healthcare team if you feel tired, have a fever or experience other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Check with your healthcare team before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. See your primary care doctor to keep up with your healthcare needs.
- Talk with family and friends about how you feel and about your treatment. When family and friends know about myeloma and its treatment, they may worry less.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. If you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for myeloma. Treatment for depression has benefits for people living with cancer.

## Resources and Information

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date information about disease, treatment and support. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)
- Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)
- Visit: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire process. Visit our Clinical Trial Support Center at [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Free Information Booklets.** LLS offers free education and support booklets that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial support, including insurance premium and medication co-pay assistance, to eligible individuals with blood cancer. For more information, please

- Call: (877) 557-2672
- Visit: [www.LLS.org/Finances](http://www.LLS.org/Finances)

**LLS Health Manager App.** This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Visit [www.LLS.org/HealthManager](http://www.LLS.org/HealthManager) to download for free.

**One-on One Nutrition Consultations.** Access free one-on-one nutrition consultations provided by a registered dietitian with experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Podcast.** *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

## Community Resources and Networking

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**LLS Chapters.** LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups and other great resources. For more information about these programs or to contact your chapter, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/ChapterFind](http://www.LLS.org/ChapterFind)

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to obtain the directory.

**Advocacy.** The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/advocacy](http://www.LLS.org/advocacy)

## Additional Help for Specific Populations

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

**Information for Veterans.** Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: [www.publichealth.va.gov/exposures/AgentOrange](http://www.publichealth.va.gov/exposures/AgentOrange)

**World Trade Center Survivors.** People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: [www.cdc.gov/wtc/faq.html](http://www.cdc.gov/wtc/faq.html)

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

## Health Terms

**Albumin.** A protein in the blood.

**Anemia.** A condition in which a person has fewer red blood cells than normal.

**Antibody.** A protein made by plasma cells, a type of white blood cell, in response to foreign substances such as bacteria, viruses and fungi. Antibodies help fight infection in the body.

**Bence Jones protein.** An abnormal protein made by myeloma cells. It is found in the urine of most patients with myeloma. It is also called **light chains** protein.

**Beta<sub>2</sub> microglobulin.** A protein found on the surface of plasma cells and some other cells. A high level of Beta<sub>2</sub> microglobulin may be a sign of faster-growing myeloma.

**Bone lesion.** An area of bone damage or abnormal bone tissue.

**Bone marrow.** The spongy material in the center of bones where blood cells are made.

**Bone marrow aspiration.** A procedure to remove and examine bone marrow cells to see if they are normal. A liquid sample containing cells is taken from the bone marrow, and the cells are looked at under a microscope.

**Bone marrow biopsy.** A procedure to remove and examine bone marrow cells to see if they are normal. A very small amount of bone filled with bone marrow cells is taken from the body, and the cells are looked at under a microscope.

**Chemotherapy or drug therapy.** Treatment that stops the growth of cancer cells, either by killing the cancer cells or stopping them from dividing.

**Chromosomes.** Threadlike structures within cells that carry genes. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may be changed in blood cancer cells.

**Clinical trial.** A careful study done by doctors to test new drugs or treatments or new uses for approved drugs or treatments. The goals of clinical trials for blood cancers are to improve treatment and quality of life and to find cures.

**Combination chemotherapy or drug therapy.** The use of two or more drugs given together to treat myeloma and other cancers.

**FDA.** The short name for the **US Food and Drug Administration**. Part of the FDA's job is to assure the safety and security of drugs, medical devices and the US food supply.

**FISH.** The short name for **fluorescence in situ hybridization**, a test for studying abnormal genes and chromosomes in cells and tissues.

**Hematologist.** A doctor who specializes in treating blood diseases.

**Immune system.** A network of cells, tissues and organs in the body that defend the body against infection.

**Immunoglobulin.** A protein that is made by plasma cells to help fight infections.

**Light chain.** Part of the monoclonal (M) protein found in patients who have myeloma.

**Lymphocyte.** A type of white blood cell. Some lymphocytes become plasma B cells. Plasma B cells make antibodies to fight infection. Myeloma is a cancer of plasma B cells.

**M protein.** Short for monoclonal immunoglobulin, an abnormal protein made by myeloma cells. The amount of M protein in the blood can be measured. This measure is used to help estimate the seriousness of the myeloma.

**Oncologist.** A doctor specially trained to treat patients who have cancer.

**Palliative care.** Specialized medical care focused on providing relief from the symptoms and stress of a serious illness. The goal of palliative care is to improve quality of life for both the patient and the family.

**Plasma.** The liquid part of the blood. Blood plasma is not the same as plasma cells or plasma B cells, which are white blood cells.

**Plasmacytoma.** A mass made up of abnormal plasma B cells (myeloma cells).

**Platelet.** A type of blood cell that helps stop bleeding. Platelets cause plugs ("clotting") to form in the blood vessels at the site of an injury.

**Red blood cell.** A type of blood cell that carries oxygen to all parts of the

body. In healthy people, red cells make up almost half of the blood.

**Refractory myeloma.** Myeloma that has not responded to initial treatment. Refractory disease may be disease that is getting worse or staying the same (stable disease).

**Relapsed myeloma.** Myeloma that responded to treatment at first but then returns.

**Remission.** A state in which there is no sign of the disease and/or a period of time when the disease is not causing any health problems.

**Smoldering myeloma.** A very slow-growing type of myeloma.

**Stem cell.** A type of cell found in the bone marrow that matures into either a red blood cell, a white blood cell or platelet.

**White blood cell.** A type of blood cell that helps the body fight infection.

## My Healthcare Team Contact List

Use this list to remember names and contact information for members of your healthcare team.

CAREGIVER NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PRIMARY CARE DOCTOR NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PHARMACY NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Additional information: \_\_\_\_\_

### Information Specialists:

Phone: 1-800-955-4572

Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)

Website: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

HEMATOLOGIST-ONCOLOGIST NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Website/Portal: \_\_\_\_\_

Additional information: \_\_\_\_\_

NURSE/NURSE PRACTITIONER NAME:

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

SOCIAL WORKER NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

INSURANCE CASE MANAGER/  
CARE COORDINATOR NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Website or email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PHYSICIAN ASSISTANT NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email Address: \_\_\_\_\_

Additional information: \_\_\_\_\_

NURSE NAVIGATOR NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

OTHER:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

OTHER:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

## Question Guide: My First Doctor's Visit

Asking questions will help you take an active role in managing your (or your loved one's) care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and healthcare team, ask a few questions to get a better idea of the doctor's experience and to understand how the office works.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

### Questions for the Doctor

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

1. How many patients have you treated who have this disease?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it normally take to receive a return phone call?
4. How can you be contacted when there are questions?
5. How can you be contacted at night? On weekends? On holidays?
6. Who are the other members of the team that I should be aware of?
7. Is there a release form available so my family/caregiver can be given medical information?

## Questions for the Nurse

NURSE OR OTHER HEALTHCARE TEAM MEMBER'S NAME:

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1. How long would I (we) have to wait for appointments?
2. What problems or symptoms should be reported to the nurse or doctor right away?
3. How long does it usually take to receive a return phone call?
4. Will there be nurses, social workers and case managers available to help with support needs and quality-of-life concerns?
5. Does your office accept my (our) insurance? Is it considered in-network?

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.

## Question Guide: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how he or she plans to treat your (your loved one's) myeloma. This will help you and your loved one to be actively involved in making decisions about medical care. The following are questions you may want to ask your healthcare team.

(Note: The use of "I (we)" and "me (us)" in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

Write down your diagnosis:

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Write down your stage of myeloma:

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## Before Treatment Begins

1. Will this treatment affect the ability to have a child in the future?
2. If yes, are there other treatment options available?
3. What are the options for preserving fertility?
4. How much time do I (we) have to make decisions?
5. What is the stage?
6. What is the goal of treatment?
7. What are the treatment options?
8. Are there any clinical trials I could join?
9. When do you think treatment should begin?
10. How long will treatment last?
11. What are the benefits and risks of these treatments?
12. Is there one treatment recommended over the others?
13. How can potential side effects be prevented or managed?

## Testing

1. What kind of testing will be done to monitor the disease and treatment?
2. How long does it take to get the results?
3. How are the results communicated to me (us)?
4. How often will testing be needed?
5. Where will the testing be done?

## Treatment

1. Will this be an in-hospital or an outpatient treatment?
  - 1a. Is it alright to attend work or school during treatment?
  - 1b. Will someone be needed to drive me home after treatment?
2. What kind of testing will be done to monitor this disease and treatment? How often will testing be needed? Where is the testing done?
3. How will we know if the treatment is effective? What options are available if the treatment is not effective?
4. What is the likely outcome of the disease (prognosis)?

## Side Effects

1. What are the common side effects for this treatment?
2. What side effects should be reported to the healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?
5. How should I report side effects (phone call, at the office visit, etc)?

## **Social/Financial Concerns**

1. Are there any side effects that will affect appearance or ability to do a job/go to school?
2. What kind of financial and social support services are available to me and my family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study (clinical trial) treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone I (we) can speak to for assistance?
6. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical-trial drugs?
7. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs such as testing?

## **Follow-Up Care and Long-Term and Late Effects**

1. Who should I (we) work with to ensure life-long follow up?
2. Will I (we) continue to see this healthcare team?
3. How can I (we) be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If there are side effects later, how can the healthcare team be reached?
6. What information can be provided to a primary doctor about this treatment?

To print copies of other question guides, go to [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk) or call (800) 955-4572.

## My List of Treatments

Use this space to list your treatments and when you took them.

DATE: \_\_\_\_\_

Treatment: \_\_\_\_\_

\_\_\_\_\_









# Get support. Reach out to our **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches



Contact us at  
**800-955-4572** or  
**www.LLS.org/  
informationspecialists**

(Language interpreters can be requested)



For more information, please  
contact our Information Specialists  
**800.955.4572** (Language interpreters  
available upon request).

**BEATING  
CANCER  
IS IN  
OUR BLOOD.**

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**National Office** 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).