



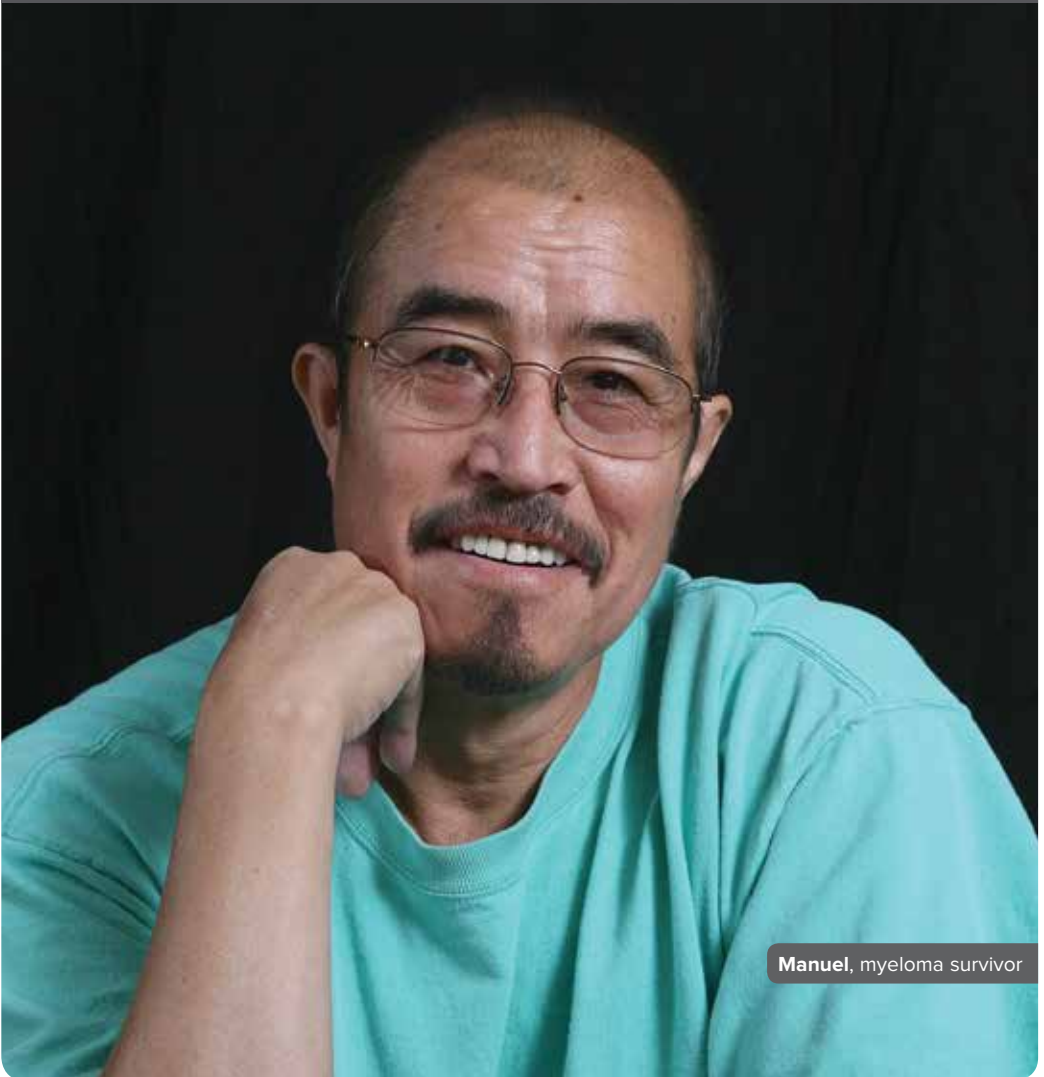
LEUKEMIA &
LYMPHOMA
SOCIETY®

fighting blood cancers

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is today®**

The Myeloma Guide

Information for Patients and Caregivers



Manuel, myeloma survivor

Support for this publication
provided by



Revised 2017

The Leukemia & Lymphoma Society wants you to have the most up-to-date information about blood cancer treatment. See below for important new information that was not available at the time this publication was printed.

- In January 2018, the Food and Drug Administration (FDA) approved denosumab (Xgeva®) for the prevention of skeletal-related events in patients with multiple myeloma.

For more information, contact an Information Specialist at (800) 955-4572 or infocenter@lls.org.

A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Since 1954, we have invested more than \$1 billion in research specifically targeting blood cancers to advance therapies and save lives. We will continue to invest in research for cures, programs and services to improve the quality of life for people with myeloma.

We know that understanding myeloma can be tough.

We are here to help and are committed to providing you with the most up-to-date information about myeloma, your treatment and your support options. We know how important it is for you to understand your health information and to use it with your healthcare team toward good health, remission and recovery.

Our vision is that one day all people with myeloma will be cured or be able to manage their disease with good quality of life.

Until then, we trust the information in this Guide will help you along your journey.

We wish you well.

A handwritten signature in black ink, appearing to read 'Louis J. DeGennaro', with a long horizontal flourish extending to the right.

Louis J. DeGennaro, PhD

*President and Chief Executive Officer
The Leukemia & Lymphoma Society*

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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. This is a hopeful time for people with myeloma. Progress toward a cure is under way. Many new myeloma drugs have been approved in the last few years. And other possible new treatments are being studied. With medical treatment, many patients live good-quality lives for years.

Survival rates in people with myeloma have improved a lot since the 1960s. About 110,345 people in the United States are living with, or in remission from, myeloma.

People who have myeloma need to see special blood cancer doctors, called hematologist-oncologists. Please use this *Guide* as a resource to help you

- Understand myeloma
- Find good doctors and other healthcare providers
- Understand complicated healthcare terms
- Access our Information Specialists, healthcare information, free information booklets and other resources

This *Guide* includes

- Information on how to contact our Information Specialists: call (800) 955-4572
- Internet links to important free LLS information about disease and treatment: www.LLS.org/booklets
- Information about myeloma, diagnosis, treatment and care
- Lists of suggested questions to ask your doctor (see pages 31 and 33)
- Definitions of health terms (see page 27)

We are here to help.

Want more information?



You can view, print or order the free LLS publication *Myeloma* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

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, from 9 am to 9 pm ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/informationsspecialists
- Visit: www.LLS.org/informationsspecialists

Free Information Booklets. LLS offers free education and support publications that can either be read online or ordered. For more information, please visit www.LLS.org/booklets.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/copay

Community Resources and Networking

LLS Community. This is a one-stop virtual shop for chatting with other patients and staying up-to-date on the latest diagnosis and treatment news. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. To join, visit www.LLS.org/community.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. For more information, please visit www.LLS.org/chat.

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

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. Resources can provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/resourcedirectory.

Clinical Trials (Research Studies). New treatments for patients are under way. Patients can learn about clinical trials and how to access them. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches. When appropriate, personalized clinical-trial navigation by trained nurses is also available.

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

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). For more information, please visit www.LLS.org/espanol.

Language Services. Let your doctor know if you need a language interpreter or other resource, such as a sign language interpreter. Often, these services are free.

Information for Veterans. Veterans with myeloma who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs (VA). For more information call the VA at (800) 749-8387 or visit 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

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 and enter “depression” in the search box

Feedback. To provide your opinion of this booklet, visit: www.LLS.org/publicationfeedback

Understanding Myeloma

About Blood

Blood is the red liquid that circulates in our bodies. It is created inside the bones, in a spongy place called the marrow.

Blood is made up of plasma and blood cells.

Plasma. This is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals. Blood plasma is not the same as plasma cells or plasma B cells, which are white blood cells.

Blood cells. Each blood cell starts as a stem cell. Then it turns into a specific kind of blood cell. There are three types of blood cells

- Platelets (allow blood to clot)
- White blood cells, including plasma cells (fight infection)
- Red blood cells (carry oxygen)

Normal Blood Cell Count Fast Facts

The ranges of blood cell counts below are for adults. These 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 (HCT) (the part of the blood made up of red cells)

- Men: 42% to 50% of the total volume of blood
- Women: 36% to 45% of the total volume of blood

Hemoglobin (Hgb) (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
- 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 their blood.

What Is Myeloma?

Myeloma is a type of cancer that begins in the bone marrow. It is a cancer of plasma cells, which are a type of white blood cell, also called plasma B cells. White blood cells are responsible for producing antibodies that fight infection.

Myeloma starts with a change to a single B cell. A change in one B cell can cause it to become a myeloma cell instead of a normal plasma cell. As myeloma cells multiply in the marrow, they crowd out the normal red cells and white cells, including normal plasma cells.

Plasma B cells and other white cells are an important part of the body's immune system because they make antibodies that help fight infection. Myeloma cells cannot help the body fight infection.

Some patients have myeloma that grows slowly, called **indolent myeloma**. This is sometimes called **smoldering myeloma**. Some patients with indolent myeloma do not need treatment right away. But treatment is needed at some point for most patients. Information about treatment begins on page 14.

Myeloma that is found in the marrow of many bones in a person's body is often called **multiple myeloma**. Most patients with myeloma have this form of the disease.

A mass of myeloma cells may be called a **plasmacytoma**. A plasmacytoma can form in the bone, skin, muscle, lungs or almost any other part of the body. If someone has only a single plasma cell mass, this is called an **isolated or solitary plasmacytoma**. A plasmacytoma that is outside of the marrow is called an **extramedullary plasmacytoma**.

A single plasmacytoma is not common. Patients who have treatment for a single plasmacytoma may not develop myeloma in any other place in the body.

Causes of Myeloma. Doctors do not know why some people get myeloma and others do not. There is no way to prevent it. You cannot catch myeloma from someone who has it.

Most people with myeloma are 50 years or older. It is not a common disease in people younger than 40 years.

Black Americans get myeloma more than twice as often as Americans of European descent. The reason for these different rates is not yet known.

Research suggests that people who are very overweight or obese are more likely to get myeloma.

Signs and Symptoms

People often get 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 lab test result.
- A symptom is a change in the body that a patient can see or feel.

Some people who have myeloma have no symptoms. These people may find out they have myeloma after a regular medical checkup that shows changes in the blood and/or urine.

More often, persons with myeloma do have symptoms which may include bone pain or bone fractures with no known cause, or many infections.

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

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

R—Renal insufficiency (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 symptoms listed above.

Diagnosing Myeloma

When a person has signs and symptoms of myeloma, the doctor does special tests to find out the cause.

Tests for Myeloma

- Bone marrow aspiration and biopsy
- Lab tests
 - Blood tests
 - Urine tests
- Imaging tests
 - X-ray (skeletal survey)
 - CT (computed tomography) scan
 - MRI (magnetic resonance imaging) scan
 - PET (positron emission tomography) scan

Bone Marrow Aspiration and Biopsy. These tests are done to see if there are myeloma cells in the patient's bone marrow. A bone marrow aspiration is done by removing a sample of cells from the marrow. A bone marrow biopsy is done by removing a very small amount of bone filled with marrow cells.

Both bone marrow tests are done with a special needle. First, patients get medication to numb the part of the body that will be used to collect the sample of cells. This is usually the back of the patient's hip bone (pelvic bone). Some patients are awake during the procedure. Some patients are sedated (asleep) during the procedure, and it will take a little more time to recover.

Blood and marrow tests may be done in the doctor's office or in a hospital. The aspiration alone usually causes minor temporary pain. A

biopsy may cause some pain in the biopsy area for a week or so. A bone marrow aspiration and biopsy are almost always done together.

Lab Tests. These 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 stage (severity) of the myeloma.

For a blood test, a small sample of blood is removed by needle through a blood vessel in the patient’s arm. The blood is collected in a tube and sent to a lab.

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**.

A test called **FISH and other similar tests** are used to see if there are changes to the chromosomes of the myeloma cells. FISH is short for “fluorescence in situ hybridization.”

Imaging Tests. These include x-rays of areas of bone pain, x-rays of the skull, spine and ribs (skeletal survey), CT scans, MRIs and PET scans. X-rays and CT scans are used to see if there are any holes or breaks in, or thinning of the bones. MRIs and PET scans look for changes in the bone marrow and pockets of myeloma cells.

Tracking Your Myeloma Tests

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

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports in a file folder or three-ring binder. Organize test reports in order 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 to learn more about lab tests and what to expect, or contact an Information Specialist for a copy.

Myeloma patients may have problems with

Infections. Myeloma patients may have more infections. This is because myeloma cells do not make the antibodies needed for the body to fight infection. Patients should follow the doctor's advice about how to reduce infection risk. The doctor may give antibiotics to treat infections.

Bone pain. Myeloma may cause bone pain due to thinning, weakening, and breaking of bones. Drugs called **bisphosphonates** (Aredia® or Zometa®) may help. Bisphosphonates work by making the bones stronger.

Kidney problems. Myeloma patients have a protein called **light chains**, also called **Bence Jones protein**. Myeloma patients may also have high levels of calcium in their blood. Both of these can damage the kidneys. The doctor will check the patient's kidney function.

Acute myeloid leukemia (AML). A small number of patients with myeloma develop AML.

Treating Myeloma

Finding the Right Doctor

Patients with myeloma are treated by doctors called **hematologist-oncologists**, who are specially trained in treatment of both blood disorders and cancer.

Finding the right doctor, one who you feel comfortable with, is important. Use these resources to help you find the right cancer specialist.

- Your primary care doctor
- The community cancer center
- Your health plan and its referral services
- Online doctor-finder resources, such as
 - The American Medical Association’s (AMA) “DoctorFinder”
 - The American Society of Hematology’s (ASH) “Find a Hematologist”
- LLS resources such as our Information Specialists, who can be reached from Monday to Friday from 9 am to 9 pm ET at (800) 955-4572

Once you find a doctor to treat myeloma, he or she will help you understand the disease and create a treatment plan. When you meet with your doctor

- Ask questions.
 - Use the question guides starting on pages 31 and 33 to help.
 - Read and print other LLS “What to Ask” questions guides at www.LLS.org/WhatToAsk.
- Take notes or bring an audio recorder to record your visits.

- Bring a friend or family member to help you understand the doctor and to take notes.
- Make sure you understand what the doctor is saying. If you don't, ask the doctor to explain so you can understand.
- If you need more information, consider getting another opinion (a second opinion from another qualified doctor).

Want more information?



You can view, print or order the free LLS publication *Choosing a Blood Cancer Specialist or Treatment Center* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Goals of Treatment

The goals of myeloma treatment are to

- Slow the growth of the myeloma cells
- Help patients feel better if they have bone pain, fatigue or other symptoms
- Provide long periods of remission (when there are no signs of myeloma and/or the myeloma is not causing health problems)

Treatment Planning and Staging

The treatment plan for a patient depends on

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

Lab and imaging tests are done to measure the severity of the patient's myeloma. This is called **staging**.

When staging myeloma, the doctor does lab tests and checks

- Blood counts of red and white cells, 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 beta₂ -microglobulin (protein produced by myeloma cells) level in the blood, which may be higher than normal
- The albumin level in the blood, which may be lower than normal
- What parts of the bones the myeloma has affected
- Presence of high-risk cytogenetic (chromosome) abnormalities
- Increased lactate dehydrogenase level (protein that helps produce energy in the body)

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 for Myeloma

There are a number of treatments for myeloma. These include

- Single or combination drug therapy
- Supportive care
- High-dose chemotherapy, with one of three types of stem cell transplantation
 - Autologous
 - Allogeneic
 - Reduced-intensity allogeneic
- Radiation therapy for patients who have only a single mass of myeloma cells (a plasmacytoma)
- New and emerging drug therapies (as a part of clinical trials)

For patients who have myeloma that grows slowly, **watch and wait** may be a better option than early treatment. Watch and wait is when doctors continuously check on a patient with examinations and imaging tests but do not treat with drug therapy. In most cases, these patients will eventually need treatment.

Drugs Used to Treat Myeloma. Drug therapy to kill myeloma cells is the main therapy for myeloma patients who need treatment. Some patients are also treated with an autologous stem cell transplantation. More information about transplants begins on page 20. The following lists some of the drugs used to treat myeloma.

Bortezomib (Velcade®) is given through a vein, intravenously (IV), or under the skin, subcutaneously (Sub-Q, or SC). It is used to treat some myeloma patients. Velcade is also used in combination with **doxorubicin liposome** (Doxil®) to treat patients with myeloma who have relapsed or who have not responded to at least one other treatment. Velcade is also being studied in clinical trials in combination with other drugs.

Thalidomide (Thalomid®) is given by mouth. Thalidomide is used with dexamethasone to treat newly diagnosed myeloma patients. The use of thalidomide in combination with other drugs is also being studied.

Lenalidomide (Revlimid®) is a drug like thalidomide and is given by mouth. It may be safer and work better for myeloma patients. Revlimid is used with dexamethasone to treat myeloma patients who are newly diagnosed or have already had at least one other type of treatment. This drug is often given in combination with other drugs. Revlimid is also used as a maintenance therapy following an autologous transplant.

Carfilzomib (Kyprolis®) is given intravenously (IV). It is used to treat people with myeloma in combination with dexamethasone or with Revlimid plus dexamethasone for patients who have received at least one to three other treatments. It can be given by itself for patients who have received one or more treatments.

Ixazomib (Ninlaro®) is given by mouth. It is used in combination with Revlimid and dexamethasone to treat people with myeloma who have received at least one other treatment. It is well tolerated by older patients.

Pomalidomide (Pomalyst®) is given by mouth. It is used with dexamethasone to treat myeloma patients who have received at least two treatments (like Revlimid and Velcade) and the myeloma progressed soon after the last treatment.

Panobinostat (Farydak®) is given by mouth. It is used to treat patients with myeloma who have received at least two prior standard therapies, including Velcade and an immunomodulatory agent. Farydak is to be used in combination with Velcade and dexamethasone.

Elotuzumab (Empliciti™) is given intravenously (IV). It is used to treat people with myeloma who have received one to three other treatments. It is used in combination with Revlimid and dexamethasone.

Daratumumab (Darzalex™) is given intravenously (IV). It is used to treat people with myeloma in combination with dexamethasone and either Revlimid or Velcade, who have received at least one prior therapy; in combination with Pomalyst and dexamethasone who have received at least two prior treatments; or as a single therapy for patients who have received at least three prior treatments.

Darbopoetin alfa (Aranesp®) and **epoetin alfa** (Procrit®) are drugs that can increase the number of red cells and may help lessen anemia. These drugs can decrease the need for blood transfusions. The benefit of these drugs to treat people who have different types of cancer is under study. Talk to your doctor about the benefits and risks.

Melphalan (Alkeran®) is a type of chemotherapy given by mouth and used to treat some myeloma patients. Melphalan may be combined with other drugs such as Velcade®, Thalomid® or Revlimid®.

Melphalan hydrochloride (Evomela™) is given by injection and is for patients who cannot take the oral melphalan. It is given to patients before an autologous stem cell transplantation. It is also used for palliative treatment.

Bisphosphonates include drugs such as **pamidronate disodium** (Aredia®) and **zoledronic acid** (Zometa®) and can help lessen the effects of bone disease in patients with myeloma by decreasing pain and lowering the likelihood of a fracture. It is important to know about the side effects of these drugs. Talk to your doctor about the benefits and risks.

Some Drugs Used to Treat Myeloma*

Generic Name

Bortezomib
Carfilzomib
Carmustine
Cyclophosphamide
Cytarabine

Daratumumab
Darbopoetin alfa
Dexamethasone
Doxorubicin
Doxorubicin liposome
Elotuzumab
Epoetin alfa
Ixazomib
Lenalidomide
Melphalan
Melphalan hydrochloride
Pamidronate
Panobinostat
Plerixafor
Pomalidomide
Prednisone
Thalidomide
Vincristine
Zoledronic acid

Brand Name

Velcade®
Kyprolis®
BiCNU®
Cytosan®
Cytosine arabinoside,
Ara-C, Cytosar-U®

Darzalex™
Aranesp®
(Many brands)
Adriamycin®
Doxil®
Empliciti™
Procrit®
Ninlaro®
Revlimid®
Alkeran®
Evomela™
Aredia®
Farydak®
Mozobil®
Pomalyst®
(Many brands)
Thalomid®
Oncovin®
Zometa®

*Some of these drugs are being studied in clinical trials.

Some Drug Combinations for Myeloma Treatment

Empliciti, Revlimid, dexamethasone
Kyprolis, Revlimid, dexamethasone
Kyprolis, cyclophosphamide, dexamethasone
Farydak, Velcade, dexamethasone
Farydak, Velcade
Ninlaro, Revlimid, dexamethasone
Pomalyst, dexamethasone
Revlimid, dexamethasone
Revlimid, dexamethasone, Velcade
Thalomid, dexamethasone
Thalomid, dexamethasone, Velcade
Thalomid, melphalan, prednisone
Velcade, dexamethasone
Velcade, melphalan, prednisone

Most patients get two or more drugs that are safe to use together.

Stem Cell Transplantation

Autologous Stem Cell Transplantation. Some patients with myeloma are treated with drug therapy and autologous stem cell transplantation. The goal of autologous stem cell transplantation is to help the body start a new supply of blood cells after high-dose chemotherapy. In an autologous transplant

- The patient's own stem cells are collected from his/her blood or marrow and stored. If needed, a doctor may use plerixafor (Mozobil) in combination with G-CSF to help mobilize stem cells. Mobilizing stem cells means helping to move them from the marrow to the blood so enough cells can be collected for a transplant.
- The patient is then given high-dose chemotherapy to kill the myeloma cells. This treatment also kills normal stem cells in the marrow.

- The patient's own stem cells which were stored before the high-dose chemotherapy are then infused back into the patient through a central line.

The decision to have an autologous transplant depends on a number of things, such as

- The patient's other treatment options
- The patient's physical ability to have a stem cell transplant

Autologous stem cell transplantation is not a cure. It can give patients longer disease-free periods than other standard myeloma therapies. This treatment is not a good choice for all myeloma patients. There are a growing number of treatment choices for older or sicker patients who may not have the physical ability to have a stem cell transplant.

Allogeneic Stem Cell Transplantation. An allogeneic stem cell transplant is another treatment option. With this type of transplant, 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.

Doctors are working to make allogeneic stem cell transplants safer. A "reduced-intensity transplant" (doctors may also use the term "nonmyeloablative transplant") uses lower doses of chemotherapy than a standard allogeneic stem cell transplant. Older and sicker patients may be helped by this treatment.

Some patients may benefit from having two stem cell transplants, such as an autologous transplant and a reduced-intensity allogeneic stem cell transplant.

Talk to your doctor to see if stem cell transplantation is an option for you.

Want more information?



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

Maintenance Therapy

Some patients may be given a low-dose of Revlimid® after a stem cell transplant. This is called “maintenance therapy.” Revlimid has been approved for myeloma patients. More information is needed about the effects of Revlimid on overall survival as well as the risk of second cancers with this treatment. Studies continue to look at different drug combinations to be used in maintenance therapy.

Radiation Therapy

Radiation therapy (treatment with x-rays or other high-energy rays) may be used to treat patients with a single mass of myeloma called a plasmacytoma.

A small number of patients have bone pain that is not helped by chemotherapy. These patients may receive radiation therapy.

Oral Adherence

Many new myeloma drugs are now taken orally (by mouth). “Adherence” means staying on a set plan or regimen; taking the medication as prescribed--on the right day and at the right time.

There are many benefits of taking a drug by mouth. These include better quality of life, ease of use and time. Unfortunately, when patients do not adhere to their medication, it can result in drug resistance, poor response to therapy, progression of disease, increased doctor visits, lab tests and hospitalizations and 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 or contact our Information Specialists for copies. You can view the video *Oral Therapies in Myeloma: Medication Adherence* at www.LLS.org/videos.

Measuring Treatment Response

Your doctor does tests to see if treatment is working. 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 marrow.

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

Responses to Treatment

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 M protein in the blood and urine.

Stringent complete response. Normal percentage of plasma cells or no sign of myeloma cells in the marrow.

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

Partial response. 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.

Minimal response. Less than a 50 percent decrease in the amount of M protein in the blood; between a 50 and 89 percent decrease in the amount of M protein in the urine in a 24-hour collection.

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

Stable disease. Not meeting criteria for complete response, very good partial response, partial response, minimal response or progressive disease.

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 becomes refractory, which means the cancer does not respond to treatment. In some instances, the drug or combination of drugs that the patient had a good response to initially may be repeated. Another option is to try a different drug or combination of drugs.

See *Drugs Used to Treat Myeloma* on pages 17-20 for options in treating relapsed or refractory myeloma.

Part 3

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, or to find new uses for approved drugs or treatments. For example, changing an amount or dose of a drug or giving a drug along with another type of treatment might be more effective. 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
- Patients who relapse after treatment
- Patients who continue treatment after remission (maintenance)

A carefully conducted clinical trial may provide the best available therapy. Ask your doctor if treatment in a clinical trial is right for you. Drugs being studied in clinical trials are listed in *Drugs Used to Treat Myeloma* on pages 17-20. You can also call our Information Specialists for information about clinical trials. When appropriate, personalized clinical trial navigation by trained nurses is also available.

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, or contact our Information Specialists for a copy.

Part 4

Side Effects and Follow-Up Care

Side Effects of Myeloma Treatment

Myeloma patients should talk with their doctors about side effects before they begin any type of treatment. The main goal of treatment for myeloma is to get rid of myeloma cells. The term **side effect** is used to describe how treatment affects healthy cells.

Patients react to treatments in different ways. Sometimes there are very mild side effects. Other side effects may be serious and last a long time.

Some side effects of myeloma treatment may include

- Upset stomach and vomiting
- Mouth sores
- Constipation
- 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)

Talk to your doctor about the possible side effects of your treatment. You can also call our Information Specialists.

Want more information?



You can view, print or order the free LLS publication *Understanding Side Effects of Drug Therapy* at www.LLS.org/booklets, or contact our Information Specialists for a copy.

Follow-Up Care

Medical follow-up is important for every myeloma patient. Follow-up care helps the doctor decide if more treatment is needed.

Adults who have been treated for myeloma should see a primary care doctor and a hematologist-oncologist (cancer specialist) for follow-up care. Patients should talk to the doctor about how often to have follow-up visits. They can ask what tests they will need and find out how often they will have the tests. It is important to keep a record of the cancer treatment you received so your doctor can follow up on specific long-term effects that may be associated with your treatment.

Ongoing Care

It is important that you take very good care of yourself. Review the following tips to keep yourself healthy.

- Keep all appointments with your doctor.
- Talk about how you feel with the doctor at each visit.
- Ask any questions you may have about side effects.
- People with myeloma may have more infections. Follow the doctor's advice for preventing infection.
- Eat healthy food each day. It is okay to eat four or five small meals instead of three large ones.
- Contact the doctor about tiredness, fever or any other symptoms.

- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest.
- Exercise, but first talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings for cancers other than myeloma.
- See your primary care doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. 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. For example, if you feel “down” or “blue” or don’t want to do anything every day for two weeks, 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.

Health Terms

Albumin. A protein in the blood that can be measured.

Antibodies. Proteins made by plasma cells. Antibodies help fight infection in the body.

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

Beta₂-microglobulin. A protein found on the surface of plasma cells and some other cells. It is measured and the level is used to estimate the seriousness of the patient’s myeloma. A low level is better than a high level.

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

Chemotherapy or drug therapy. Treatment with chemical agents to treat myeloma and other cancers.

Chromosomes. Any of the 23 pairs of certain basic structures in human cells. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. The number or shape of chromosomes may be changed in blood cancer cells.

Clinical trials. Careful studies 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 together to treat myeloma and other cancers.

Extramedullary. Outside the marrow. For example, **extramedullary plasmacytoma** is the name for a cluster of myeloma cells that are found outside of the bone marrow in tissues or organs of the body.

FDA. The initials that stand 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 to measure the presence of a specific chromosome or gene in cells. The results of this test can be used to plan treatment and to measure the results of treatment.

Hematologist. A doctor who treats diseases of the blood.

Immune response. The reaction of the body to foreign material. Examples of foreign material are viruses, bacteria, and other harmful substances that cause infection in the body.

Immune system. Cells and proteins in the body that defend it against infection.

Immunoglobulins. Proteins that fight infection.

Indolent myeloma. Slow-growing myeloma. Sometimes called **smoldering myeloma**.

Light chains. Parts of the monoclonal (M) protein that are 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.

Marrow. The spongy material in the center of bones where blood cells are made.

M protein. Monoclonal immunoglobulin, a protein made by myeloma cells. This protein, also called **M protein**, enters the blood. The amount of M protein in the blood can be measured. This measure is used to estimate the seriousness of the myeloma.

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

Pathologist. A doctor who identifies diseases by studying cells and tissues under a microscope.

Plasma. The liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals.

Blood plasma is not the same as plasma cells or plasma B cells, which are white blood cells.

Platelet. A type of blood cell that helps stop bleeding. Platelets gather at the site of an injury and cause the blood to clot.

Red 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 get worse or stay the same.

Relapsed myeloma. Myeloma that responded to treatment but then returns.

Remission. No sign of a disease after treatment and/or a period of time when the disease is not causing any health problems.

Stem cell. A type of cell found in marrow that becomes a red blood cell, a white blood cell or a platelet.

White cell. A type of blood cell that is part of the immune system that helps the body fight infection.



Asking questions will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What is your board certification and licensing? Are you a member of any professional societies?

- 2.** How much experience do you have treating patients who have my disease?

- 3.** Is your hospital, university, center or clinic accredited and experienced in treating blood cancers?

- 4.** How long would I usually have to wait for appointments or return of my phone calls?

5. Will there be nurses, social workers and case managers available to help me with support needs and quality-of-life concerns?

6. Do you know of other oncologists who specialize in treating blood cancers? Would you recommend that I speak to any of them?

7. What types of things should I call you about? What types of things should I call my family doctor about?

8. How should I contact you when I have questions?

9. How do I contact you at night? On weekends? On holidays?

To print additional copies of this question guide, or to print copies of question guides on other topics, go to www.LLS.org/whattoask. You may also request that copies be sent to you by contacting our Information Specialists at (800) 955-4572.



Asking your healthcare provider questions at any phase of your treatment will help you take an active role in managing your (or your child'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.

Doctor's name _____

Date of appointment or call _____

- 1.** What are my (my child's) treatment options? What is the goal of the treatment?

- 2.** What are the FDA-approved treatments, and are there treatments being studied in clinical trials (study treatments), for my (my child's) diagnosis?*

- 3.** What are the benefits and risks of the treatment(s) available to me (my child)?
What are the expected side effects?

4. Is there one treatment option (FDA-approved or study treatment) that you recommend over the others? Please explain.

5. If I (my child) enroll(s) in a clinical trial, who will be in charge of my (my child's) treatment?

6. When do you think I (my child) will need to begin treatment?

7. How long will I (my child) be treated and how many treatments will be needed?

8. Will I (my child) need to be hospitalized for all or part of the treatment?

9. What kind of testing will be done to monitor my (my child's) disease and treatment? How often will testing be needed?

10. If I am treated at an out-patient clinic or at the doctor's office, will I be able to drive/get myself home after treatments or will I need someone to assist me?

11. What are the risks if I don't (my child doesn't) get treatment?

12. How will I know if the treatment is effective? What options are available if the treatment is not effective?

13. How do I find out if my insurance will cover the costs of my (my child's) treatment or the study treatment? Who can help answer any medical questions my insurance company or health plan asks?

14. If I do not have insurance coverage, how can the healthcare team help me (my child) get treatment? Is there someone I need to speak to for assistance?

15. If I'm (my child is) getting a study treatment, will I be responsible for paying any treatment-related costs, such as tests, travel or the clinical trial drug(s)?

16. Will the healthcare team continue to check on me (my child) after the treatment is over? If so, for what period of time?

17. I (My child) would like to continue some type of lifelong follow-up care in order to be monitored for long-term and late effects of treatment. Can I (my child) follow up with you?

*For definitions of an FDA-approved treatment and a clinical trial (study treatment), visit www.LLS.org or contact an Information Specialist.

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REACH OUT TO OUR **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 am to 9 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

For more information,
call **877.557.2672** or
visit **www.LLS.org/copay**.



For a complete directory of our patient services programs, contact us at

800.955.4572 or **www.LLS.org**

(Callers may request a language interpreter.)



LEUKEMIA & LYMPHOMA SOCIETY®

fighting blood cancers

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



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Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.