

someday is today

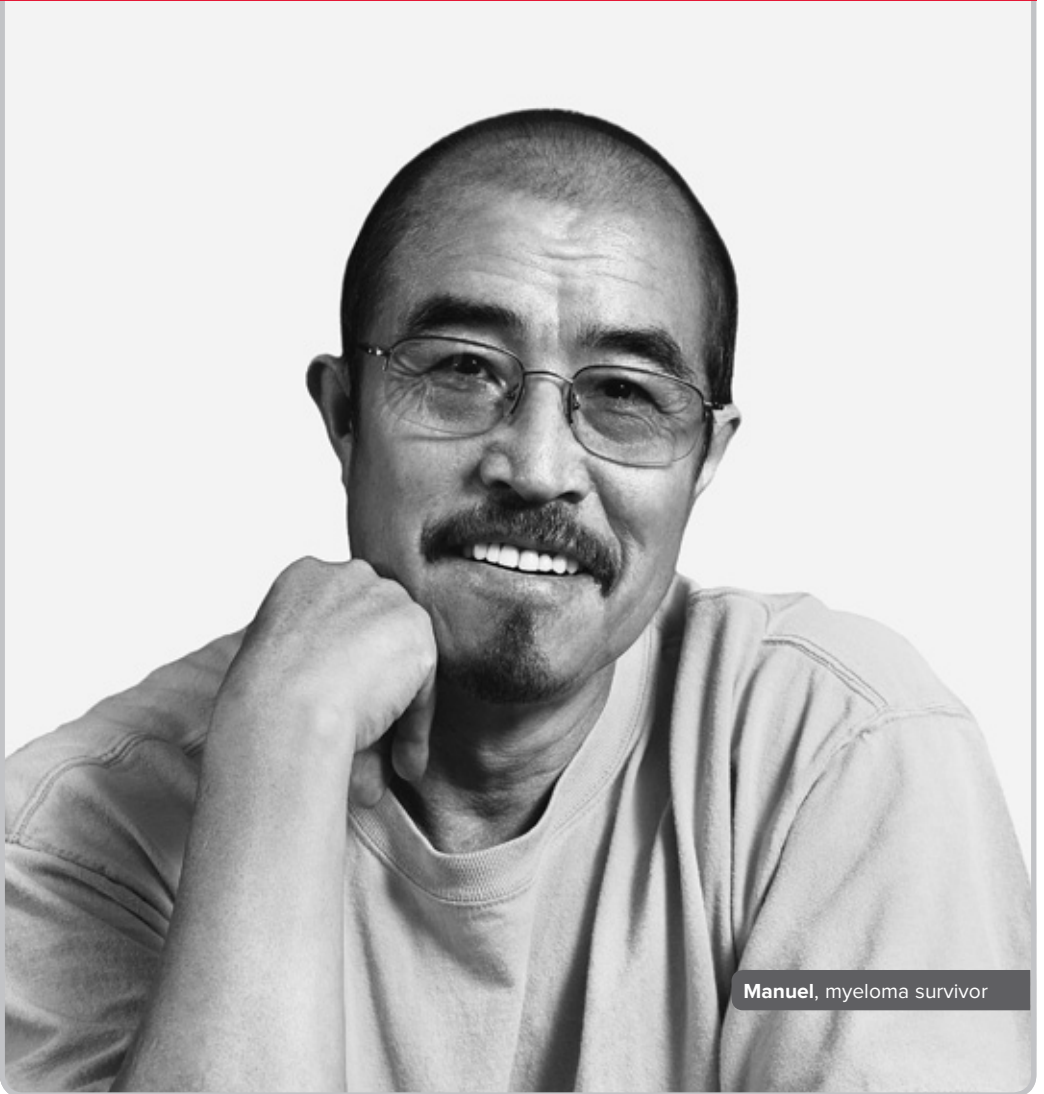


LEUKEMIA &
LYMPHOMA
SOCIETY®

fighting blood cancers

The Myeloma Guide

Information for Patients and Caregivers



Manuel, myeloma survivor

This publication was
supported in part by a grant from



Revised 2013

A Message From John Walter

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) wants to bring you the most up-to-date blood cancer information. We know how important it is for you to understand your treatment and support options. With this knowledge, you can work with members of your healthcare team to move forward with the hope of remission and recovery.

Our vision is that one day most people who have been diagnosed with myeloma will be cured or they will be able to manage their disease with good quality of life. We hope that the information in this *Guide* will help you along your journey.

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, advocacy and patient services. Since its first funding in 1954, LLS has invested more than \$875 million in research specifically targeting blood cancers. We will continue to invest in research for cures and in programs and services that improve the quality of life of people who have myeloma and their families.

We wish you well.

A handwritten signature in black ink, appearing to read 'J. Walter', with a large, stylized initial 'J'.

John Walter

President and CEO

Inside This Guide

- 2 Introduction**
- 3 Here to Help**
- 7 Part 1—Understanding Myeloma**
 - About Marrow, Blood and Blood Cells
 - About Myeloma
 - Signs and Symptoms
 - Diagnosis
 - Tracking Your Myeloma Tests
- 14 Part 2—Treatment**
 - Choosing a Specialist
 - Ask Your Doctor
 - Goals of Treatment
 - Treatment Planning and Staging
 - Drugs to Treat Myeloma
 - Stem Cell Transplantation
 - Maintenance Therapy
 - Radiation Therapy
 - Measuring Treatment Response
- 23 Part 3—About Clinical Trials**
- 24 Part 4—Side Effects and Follow-Up Care**
 - Side Effects of Myeloma Treatment
 - Follow-Up Care
- 26 Take Care of Yourself**
- 27 Medical Terms**

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

Survival in people with myeloma is much improved since the 1960s. About 81,089 people in the United States are living with, or in remission from, myeloma.

The Myeloma Guide is for people who have myeloma and others who want basic information. Many people find that it helps to know the questions to ask about choosing a specialist and about treatment. The *Guide* includes suggested questions to ask your healthcare providers (see the inside back cover). For a list of other healthcare question guides you can print, go to www.LLS.org/whattoask. Or, contact our Information Specialists for a copy.

Some words in the *Guide* may be new to you. Check *Medical Terms* beginning on page 27. Or, call our Information Specialists at (800) 955-4572.

Want more information?



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

Here to Help

The information in this *Guide* will help you when you talk to your doctor about tests and treatment. Members of your healthcare team will answer your questions and give support and any needed referrals. Let your doctor know if you want a professional healthcare interpreter who speaks your native language or uses sign language. Many times, this is a free service.

The news that you have myeloma may be a shock to you and your loved ones. You may feel sad, depressed or afraid. Keep in mind that

- The number of patients who have gone into remission is increasing each year.
- New treatments are being studied in clinical trials for patients of all ages and in all stages of treatment.

LLS Has Ways to Help. Treatment for myeloma will affect your daily life for a period of time. You may want to ask friends or family members to help you

- Get information
- Take care of chores.

We want you to know that LLS offers free information and patient services for individuals and families touched by blood cancers.

Information Specialists. Our Information Specialists are master's level professionals. They provide up-to-date blood cancer information. You can call to speak with an Information Specialist Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can also email infocenter@LLS.org or chat online at www.LLS.org.

Clinical Trials. Our Information Specialists help patients work with their doctors to find out about specific clinical trials. You can also use our online clinical-trial search service supported by LLS. It offers

patients and caregivers immediate access to listings of blood cancer clinical trials. You can reach this online service by visiting www.LLS.org/clinicaltrials.

Advocacy and Public Policy. The LLS Office of Public Policy (OPP) enlists volunteers to help advocate for policies and laws to speed the development of new treatments and improve access to quality medical care. Visit www.LLS.org/advocacy to find out more or get involved.

Co-pay Assistance Program. This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check www.LLS.org/copay or call (877) 557-2672 to speak to a *Co-Pay Assistance Program* specialist for more eligibility information.

Language Services. Free language services are available for calls with our Information Specialists.

Free Materials and Información en Español. LLS has free patient education and support booklets in English and Spanish. You can order these materials by phone at (800) 955-4572. You can also read or print the booklets, or order free print versions, at www.LLS.org/resourcecenter.

Chapter Programs and Services. LLS chapter offices around the United States and Canada offer support and education. Your chapter can arrange for you to speak to another person living with myeloma through the *Patti Robinson Kaufmann First Connection Program*. The *Patient Financial Aid* program offers a limited amount of financial aid for qualified patients. Find your chapter by calling (800) 955-4572 or by visiting www.LLS.org.

Other Helpful Organizations. Our website, www.LLS.org/resourcedirectory, offers an extensive list of resources for patients and families about financial assistance, counseling, transportation, summer camps and other needs.

Telephone/Web Education Programs. LLS provides free telephone and web education programs presented by experts for patients and caregivers. For more information contact our Information Specialists.

Reach Out. You and your loved ones can reach out to others for support. For example:

- LLS offers online Blood Cancer Discussion Boards and live online chats at www.LLS.org/getinfo.
- Local or Internet support groups and blogs can give support.
- You may get to know other people living with cancer. These friendships provide support.

Suggestions From Other People Living With Cancer

- Get information about choosing a cancer specialist or treatment center.
- Talk with family and friends about how you feel and how they can help you.
- Find out what your insurance covers.
- Find out if financial assistance is available.
- Learn about the most current tests and treatments for myeloma.
- Talk openly with your doctor about your fears or concerns.
- Tell your doctor if you have any side effects of treatment.
- Contact your doctor if you have fatigue, fever, pain or sleep problems.
- Get medical advice if you have changes in mood or feelings of sadness or depression.

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. For more information call the Department of Veterans Affairs at (800) 749-8387 or visit www.publichealth.va.gov/exposures/agentorange.

Information for World Trade Center Responders and Survivors.

Responders, workers, and volunteers who helped with rescue, recovery, and cleanup at the World Trade Center and related sites in New York City; survivors who were in the New York City disaster area, lived, worked, or were in school in the area; and responders to the Pentagon and the Shanksville, PA crash who have been diagnosed with a blood cancer may be able to get help from the World Trade Center Health Program. For more information, call the World Trade Center Health Program at (888) 982-4748 or visit www.cdc.gov/wtc.

We'd Like to Hear From You. We hope this *Guide* helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on **LLS Disease & Treatment Publications—Survey for Patients, Family and Friends**.

Understanding Myeloma

About Marrow, Blood and Blood Cells

The information in this section about normal blood and marrow may help you understand the myeloma information in the rest of the *Guide*.

Marrow is the spongy center inside of bones where blood cells are made.

Blood cells are made in the marrow. They begin as stem cells. Stem cells become red cells, white cells and platelets in the marrow. Then the red cells, white cells and platelets enter the blood.

Platelets form plugs that help stop bleeding at the site of an injury.

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

White cells fight infection in the body. There are two major types of white cells: germ-eating cells (neutrophils and monocytes) and infection-fighting **lymphocytes** (B cells, T cells and natural killer [NK] cells).

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

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

- 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 type of cancer that begins in the bone marrow. It is a cancer of plasma cells.

Plasma cells are part of the body's immune system. Plasma cells make antibodies that help fight infection. Myeloma cells cannot help the body fight infection.

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.

African Americans get myeloma about twice as often as Americans of European descent. People of Asian and Hispanic descent have lower rates of myeloma. The reason for these different rates is not yet known.

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 the 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. A plasmacytoma that is outside of the marrow is called an **extramedullary plasmacytoma**.

A single plasmacytoma is not common. It is a “myeloma-related” condition. Patients who have treatment for a single plasmacytoma may not develop any other sites of myeloma.

Myeloma starts with a change to a single B cell. As the myeloma cells grow in the marrow, they crowd out the normal plasma cells. They also crowd out normal white cells and red cells.

Normally, some B cells become plasma cells that fight infection.

With myeloma, the change in the B cell causes it to become a myeloma cell instead of a normal plasma cell.

Signs and Symptoms

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 patients have no symptoms of myeloma. These patients may find out they have myeloma after a regular medical checkup which showed changes in the blood and/or urine.

More often, patients have bone pain, or bone fractures with no known cause, or many infections.

Doctors sometimes refer to 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 due to a decrease in blood-flow to the kidneys)

A—Anemia (low red blood cell counts)

B—Bone abnormalities (lesions)

Diagnosis

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 tests are done to see if there are myeloma cells in the patient's 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. Some patients are awake during the procedure. They get medication first to numb the part of the body that will be used to get the sample of cells. This is usually the patient's hip bone. Some patients are sedated (asleep) during the procedure.

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 together.

Lab 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 (amount) of the myeloma.

For a blood test, usually a small sample of blood is removed through a needle that has been placed into a blood vessel in the patient’s arm. The blood is collected in tubes and sent to a lab.

Other proteins called **light chains** can be found in the myeloma patient’s urine. This is also called **Bence Jones protein**.

There is a newer, special test to check for light chains. The test is called **serum-free light chain test**.

Other tests to find myeloma are called “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, breaks or thinning in the bones. MRIs and PET scans look for changes to marrow and pockets of myeloma cells.

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

Lab and imaging tests are also done to measure the extent of myeloma. These are listed on page 16.

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 binder. Organize the reports in date order.
- 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/resourcecenter to learn more about lab tests and what to expect. Or, you can contact our Information Specialists for a copy.

Myeloma patients may have problems with

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

Bone pain. Myeloma may cause bone pain. Drugs called **bisphosphonates** (Aredia® or Zometa®) may help. Bisphosphonates work by blocking the myeloma cells from making the bones weak.

Kidney problems. Myeloma patients have a protein called light chains or Bence Jones protein. Myeloma patients may also have high levels of calcium in their blood. Each 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.

Treatment

Choosing a Specialist

Choose a doctor who specializes in treating myeloma and knows about the most up-to-date treatments. This type of specialist is usually called a **hematologist/oncologist**. Or your local cancer specialist can work with a myeloma specialist.

Ways to Find a Myeloma Specialist

- Ask your primary care doctor.
- Contact your community cancer center.
- Call your local medical society.
- Reach out to doctor and/or health plan referral services.
- Call our Information Specialists.
- Use online doctor-finder resources, such as
 - The American Medical Association’s (AMA) “DoctorFinder”
 - The American Society of Hematology’s (ASH) “Find a Hematologist.”

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/resourcecenter. Or, you can 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 to be actively involved in your care and to make decisions. This *Guide* includes questions to ask your doctor about myeloma treatment (see the inside back cover).

It may be helpful to write down the answers to your questions and review them later. You may want to have a caregiver, a family member or friend with you when you talk to the doctor. This person can listen, take notes and offer support. Some people like to record information from the doctor and then listen to the recording later on.

People with myeloma who are unsure about their treatment options are encouraged to get a second opinion.

Want more information?



For a list of healthcare question guides about treatment, second opinions and other topics that you can print, go to www.LLS.org/whattoask. Or, you can contact our Information Specialists for copies.

Goals of Treatment

The goals of myeloma treatment are to

- Slow the growth of the myeloma cells
- Help patients to 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 extent of the patient's myeloma. This is called **staging**.

The doctor checks

- Blood counts of red and white cells. These may be lower than normal with myeloma.
- The amount of M protein found in the blood and urine. M protein is made by the myeloma cells.
- The calcium level in the blood. This may be higher than normal with myeloma.
- The beta₂-microglobulin level in the blood. This level may be higher than normal with myeloma.
- The albumin level in the blood. This level may be lower than normal with myeloma.
- How many parts of the bones the myeloma has affected.

Treatments for myeloma 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)
- Treatment in a clinical trial.

For some patients, those who have myeloma that grows slowly, **watchful waiting** may be a better option than early treatment. Watchful waiting is when doctors check on a patient with examinations and imaging tests. In most cases, these patients will eventually need treatment.

Drugs 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 transplant.” More information about transplants begins on page 20. Some of the drugs used to treat myeloma are

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

Bortezomib (Velcade®) is given intravenously (IV) or subcutaneously (sub-q). It is used to treat some myeloma patients. Velcade is also being studied in clinical trials in combination with other drugs such as Revlimid.

Thalidomide (Thalomid®) is given by mouth. Thalidomide is used with dexamethasone and another agent, such as Velcade 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 have already had at least one other type of treatment.

Aranesp® (darbepoetin alfa) and **Procrit®** (epoetin alfa) are drugs that can increase the number of red cells and may help with 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.

Velcade and **liposomal doxorubicin** (Doxil®) are drugs approved to treat myeloma patients who have relapsed or who have not responded to at least one other treatment.

Bisphosphonates include drugs such as pamidronate (Aredia®) and zoledronic acid (Zometa®) and can help lessen the effects of bone disease in patients with myeloma by decreasing pain and decreasing 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.

Carfilzomib (Kyprolis™) is given intravenously (IV). It is used to treat myeloma patients who have received at least two other treatments (including Velcade and a drug such as thalidomide or Revlimid) and the myeloma progressed soon after the last treatment.

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

Some Drugs Used to Treat Myeloma*

Generic Name	Brand Name
Bortezomib	Velcade®
Carfilzomib	Kryopolis®
Carmustine	BiCNU®
Cyclophosphamide	Cytosan®
Dexamethasone	(Many brands)
Doxorubicin	Adriamycin®
Lenalidomide	Revlimid®
Melphalan	Alkeran®
Pamidronate	Aredia®
Liposomal doxorubicin	Doxil®
Pomalidomide	Pomalyst®
Prednisone	(Many brands)
Thalidomide	Thalomid®
Vincristine	Oncovin®
Zoledronic acid	Zometa®

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

Some Drug Combinations for Myeloma Treatment

Revlimid, dexamethasone
Revlimid, dexamethasone, Velcade
Revlimid, melphalan and prednisone
Revlimid, Velcade
Thalomid, dexamethasone
Thalomid, dexamethasone, melphalan, Velcade
Thalomid, melphalan, prednisone
Thalomid, Velcade
Velcade, Doxil

Most patients get two or more drugs that are used together.

Stem Cell Transplantation

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

- The patient’s own stem cells are collected from the patient’s blood or marrow and stored after the first cycles of drug therapy are completed.
- The patient is then given high-dose chemotherapy to kill the myeloma cells. This treatment also kills normal stem cells in the marrow.
- The last step is to infuse the stem cells back into the patient through a central line.

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

- What other good treatment choices the patient has
- 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 transplant.

Allogeneic Stem Cell Transplantation. An “allogeneic stem cell transplant” is a treatment used to treat some diseases. With this type of transplant, stem cells from a donor are used. The donor can be a brother or sister. Or the donor can be another person with stem cells that “match” the patient’s. It may be a good treatment for younger patients who are not doing well with other treatments. An allogeneic stem cell transplant is a high-risk procedure.

Doctors are working to make allogeneic stem cell transplants safer. A “reduced-intensity transplant” (also known as a **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/resourcecenter. Or, you can contact our Information Specialists for a copy.

Maintenance Therapy

Some patients may be given a low-dose of Revlimid after transplant as a maintenance therapy. More information is needed about the effects on overall survival as well as the risk of second cancers with this treatment. Other ongoing studies are looking at treatment with Velcade and thalidomide, Velcade and Revlimid or Velcade alone.

Radiation Therapy

Radiation therapy (treatment with x-rays or other high-energy rays) may be used to treat patients with a single area 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.

Measuring Treatment Response

Your doctor does tests to see if treatment is working. The test results help the doctor to 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, breaks or thinning in 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” (or complete response) or “partial remission” (or partial response) are sometimes used.

Complete remission or response. No sign of M protein in the blood and urine; normal percentage of plasma cells or no sign of myeloma cells in the marrow

Partial remission or response. More than a 50 percent decrease in the amount of M protein in the blood

Near complete response. No sign of myeloma cells in the marrow by using the findings of very sensitive tests.

Minimal response. Less than a 50 percent decrease in the amount of M protein in the blood

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.

About Clinical Trials

There are new treatments under study for myeloma patients of all ages. New treatments are studied in clinical trials. Clinical trials are also used to study new uses for approved drugs or treatments. For example, changing the amount of the drug or giving the 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 do not get 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 now listed in *Some Drugs Used To Treat Myeloma* on page 19. You can also call our Information Specialists for information about clinical trials, or use our free clinical-trial service at www.LLS.org/clinicaltrials.

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/resourcecenter. Or, you can contact our Information Specialists for copies.

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 myeloma cell death. 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 cell count (anemia)
- Low white cell count (neutropenia)
- Low platelet count (thrombocytopenia)
- Achy feeling
- Numb feeling in arms, hands, legs or feet.

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/resourcecenter. Or, you can 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 to see if more treatment is needed.

Adults who have been treated for myeloma should see their primary care doctor and an 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 to have the tests. It is important to get a record of the cancer treatment you received so that your doctor can follow up on specific long-term effects that may be associated with your treatment.

Want more information?



Learn about managing fatigue, anxiety, depression, and pain through the experiences of two survivors, with insights from their healthcare professionals. You can watch this free LLS web video *Paths To Recovery—Stories From Two Blood Cancer Survivors* at www.LLS.org/webcasts.

Take Care of Yourself

- Keep all appointments with the doctor.
- Discuss 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 foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screening. 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 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.

Medical Terms

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

Antibodies. Proteins made by plasma cells. Antibodies help to 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 extent of the patient's myeloma. A very low level is better than a very high level.

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

Bone marrow biopsy. A procedure to remove and examine 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 goal of clinical trials for blood cancers is 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 in the body, outside of the marrow.

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 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 blood cell diseases.

Immune response. The reaction of the body to foreign material. Examples of foreign material are an infection-causing microorganism, a vaccine or the cells of another person used for an allogeneic stem cell transplant.

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 is found in patients who have myeloma.

Lymphocyte. A type of white cell. Some lymphocytes become plasma cells. Plasma cells make antibodies to fight infection. Myeloma is a cancer of plasma 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. It is used to estimate the extent of the myeloma.

Oncologist. A doctor who treats 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.

Platelet. A type of blood cell that helps prevent bleeding. Platelets cause plugs to form in the blood vessels at the site of an injury.

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 be disease that is getting worse or staying the same.

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

Remission. No sign of the disease 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 makes red cells, white cells and platelets.

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



REACH OUT TO OUR **INFORMATION SPECIALISTS**

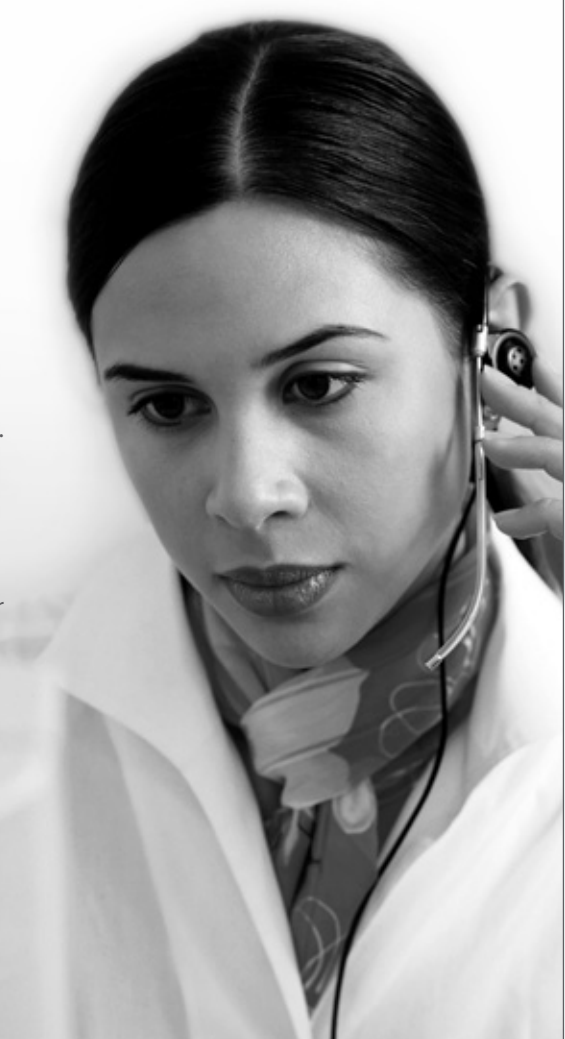
The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology professionals who are available by phone Monday through Friday, 9 am to 6 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.

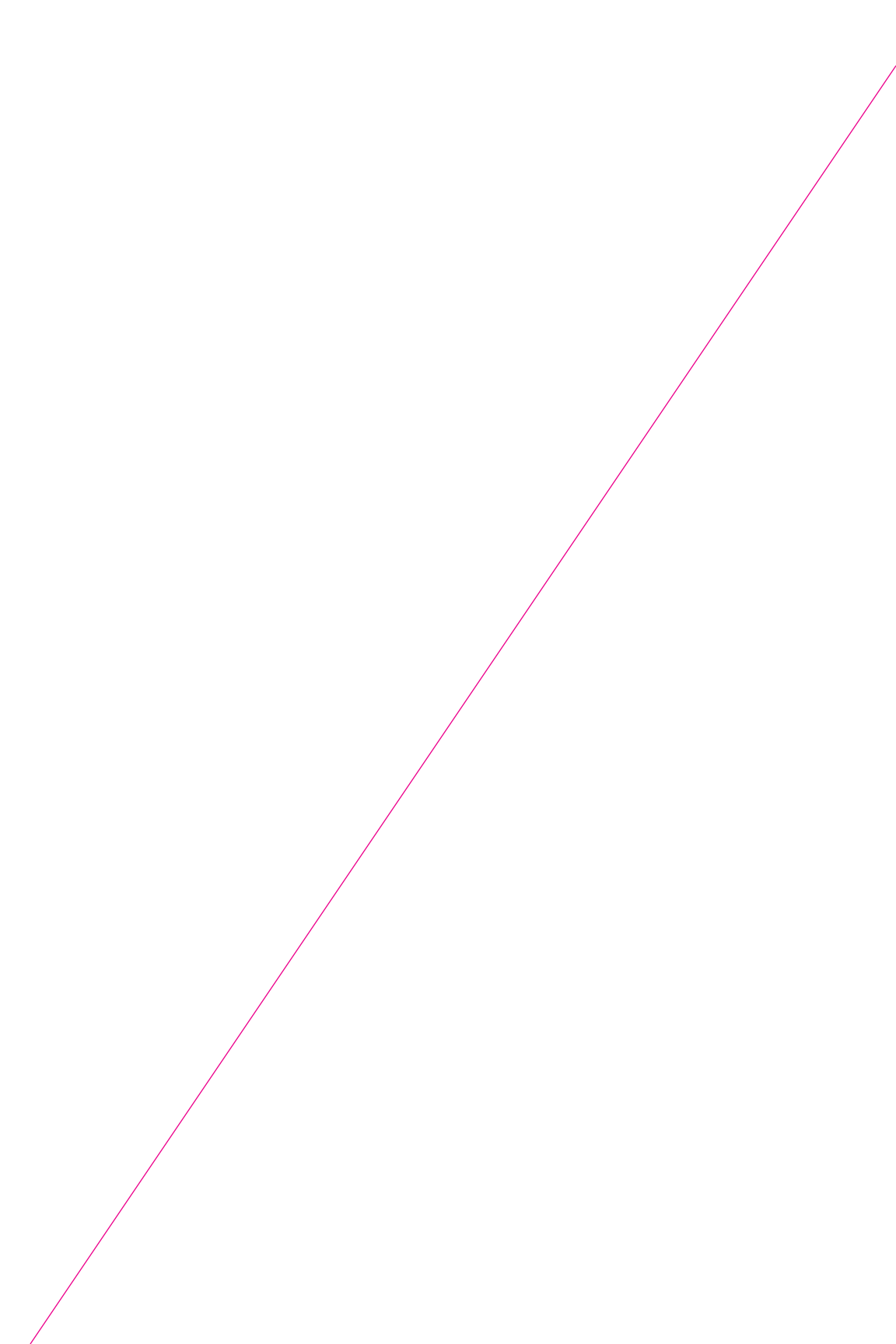
For more information,
call **877.557.2672** or
visit **www.LLS.org/copay**.



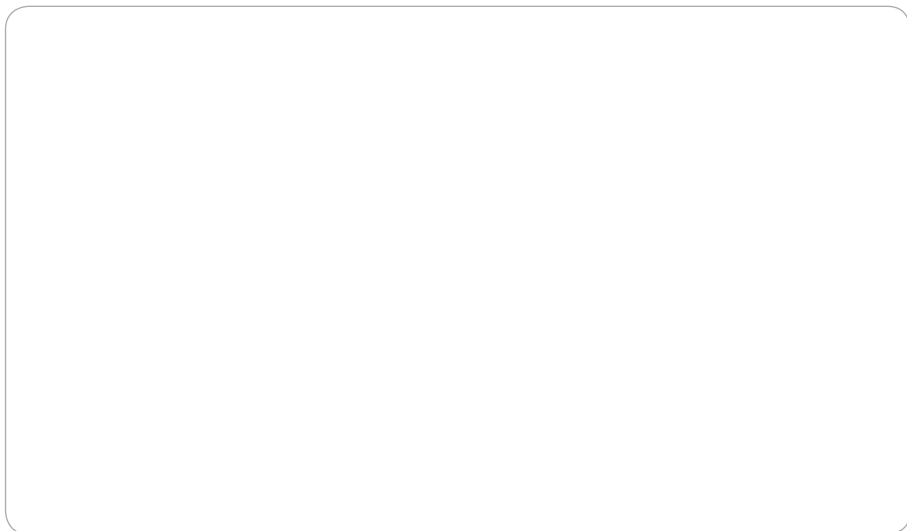
For a complete directory of our patient services programs, contact us at

800.955.4572 or **www.LLS.org**

(Callers may request a language interpreter.)



For more information, please contact:



or:

National Office

1311 Mamaroneck Avenue, Suite 310, White Plains, NY 10605

Contact our Information Specialists **800.955.4572** (*Language interpreters available upon request*)

www.LLS.org

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.



FSC
LOGO