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Myeloma: The Basics

A companion to the booklet Myeloma: In Detail

Revised **2025**

Formerly titled Myeloma Guide:
Information for Patients and Caregivers

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Inside This Guide

Question Guides

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INTRODUCTION

Myeloma is a blood cancer that begins in a type of white blood cell called a plasma cell. Plasma cells are mainly found in the bone marrow, the soft, spongy tissue in the center of bones where most blood cells are made. Because myeloma often occurs in many locations in the bone marrow, it is frequently called multiple myeloma.

Advances in the treatment of myeloma have resulted in improved remission rates, quality of life and survival. More work, however, needs to be done. Researchers continue to study and develop new therapies in clinical trials to treat myeloma.

The more you know about myeloma, the better you can take care of yourself—your body, your mind and your health. This booklet provides information about the diagnosis and treatment of myeloma. It also includes brief descriptions of blood and bone marrow as well as definitions of health terms related to myeloma.

We hope that you will keep this booklet handy and that, should you ever feel alone in confronting problems, you will turn to it for information and guidance to find the support and resources you need.

We are here to help.

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

WANT MORE INFORMATION?

For more information about myeloma, you can view, print or order the free LLS booklet *Myeloma: In Detail* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Feedback. Visit www.LLS.org/PublicationFeedback to make suggestions about this booklet.

PART 1 MYELOMA

Overview

- Most red blood cells, white blood cells and platelets are made in the bone marrow, the soft, spongy tissue in the center of bones.
- Plasma cells are a type of white blood cell that makes antibodies that help the body fight infection. Myeloma is a blood cancer that starts in a plasma cell in the bone marrow.
- Myeloma starts with a mutation (change) 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 booklet.

Bone marrow is the spongy tissue located inside the center of most bones. This is where most 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. A low white blood cell count may cause repeated infections and fever. There are two major types of white blood cells: lymphocytes and germ-eating cells.

- Lymphocytes are infection-fighting cells and include:
    - B cells
    - T cells
    - NK (natural killer) cells
- Germ-eating cells kill and ingest bacteria and include:
    - Neutrophils
    - Monocytes

Plasma cells are types of white blood cells that develop from B cells. When bacteria and viruses enter the body, some B cells mature and change into plasma cells that make antibodies to help fight infection.

Platelets help stop bleeding by clotting (clumping together) at the site of an injury. Low platelet counts may cause unexplained bruising and bleeding.

Plasma is the light yellow liquid that is 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)

- Measures the amount (percentage) of each of the different types of white blood cells
- Counts the types of white cells (neutrophils, lymphocytes, monocytes, eosinophils and basophils)
    - Normal adult white blood cell count: 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. Plasma cells develop from B cells, a type of white blood cell. Normally when bacteria or viruses enter the body, some B cells mature and change into plasma cells. Plasma cells then make antibodies (also called immunoglobulins) that help the body fight infection.

Myeloma happens when there is a mutation (change) to a single plasma cell, causing 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 build up in the bone marrow, they crowd out other types of healthy blood cells. As a result, the body may not have enough healthy red blood cells, white blood cells and platelets.

When myeloma cells build up in the bone marrow, they may form masses called plasmacytomas. These masses can weaken bones and cause pain. The myeloma cells also release substances that break down bones. This causes the bones to become weaker and increases the risk of fractures (breaks). When myeloma cells damage bones, calcium is released from the bones into the blood. If this happens too quickly, high blood calcium levels can occur. This can cause kidney failure, heart attack or coma.

While plasmacytomas are most commonly found in the bone marrow, they may build up in other parts of the body including the 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 often called multiple myeloma. Most people with myeloma have multiple myeloma.

Myeloma cells make large amounts of abnormal antibodies known as M proteins. Other common names for M protein are monoclonal protein, M spike and paraprotein. M proteins are made up of two large pieces called heavy chains and two small pieces called light chains. M proteins do not help fight infection like normal antibodies, and they can also damage the kidneys.

The term smoldering myeloma is an early form of myeloma. People with smoldering myeloma have low levels of myeloma cells or M protein. It is a precancerous condition that may turn into myeloma. People with smoldering myeloma usually have no symptoms but need to be checked often to see if their condition has changed to myeloma.

Causes and Risk Factors of Myeloma. Myeloma starts with a change to a single plasma cell in the bone marrow. Doctors do not know why some people get myeloma and others do not.

Although 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.
- Sex—More males than females develop myeloma.
- Race—Blacks are more likely to develop myeloma than whites.
- Environmental factors—Some studies are investigating a link between the development of myeloma and exposure to radiation or certain kinds of chemicals, such as pesticides, fertilizers and Agent Orange.
- Familial Risk/Germline Predisposition—Having a parent or sibling with myeloma increases the risk of developing the disease.
- Firefighting—Some studies indicate that firefighters are at a higher risk for many types of cancer, including myeloma.

Having a risk factor does not mean a person will develop the disease. Some people with several risk factors for myeloma never develop it, while other people with no known risk factors do. There is no way to prevent myeloma. You cannot catch myeloma from someone else.

WANT MORE INFORMATION?

You can view, print or order the free LLS awareness postcard *Firefighters and Cancer Risk* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy. For information on the World Trade Center (WTC) Health Program, see page 38.

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 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 are:

- Fatigue, severe tiredness
- Frequent infections, fever and/or chills
- Bone pain or bone fractures with no known cause

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

C—High levels of calcium in the blood, also known as hypercalcemia
R—Renal (kidney) failure
A—Anemia (low red blood cell count)
B—Bone lesions (damage)

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/or symptoms of myeloma, the doctor does 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 47-52 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 will I find out my test results?
3. How long does it take to get the results?
4. How often will testing be needed?
5. Where will the testing be done?

Blood and Urine Tests. Myeloma cells make too much of a protein called M protein. Tests can measure the amount of M protein in the blood and urine. Abnormal levels of M protein in the blood and urine may be a sign of myeloma.

A test called a complete blood count is used to count the number of red blood cells, white blood cells and platelets in a sample of blood. Many people with myeloma have low blood cell counts. The most common is a low red blood cell count.

Bone Marrow Tests. Myeloma usually starts in the bone marrow. When blood tests show low blood cell counts, or M proteins are found in the blood or urine, the doctor may recommend a test of the bone marrow to see whether the bone marrow is healthy and making normal amounts of blood cells. Bone marrow tests are done to help diagnose myeloma.

Bone marrow aspiration and bone marrow biopsy are different tests in which two small samples of bone marrow (liquid and bone) are removed from the back of the hip bone using special needles. The samples are then sent to the lab for examination. Additional tests will be done on the blood and bone marrow samples to gather more information about the cells.

How Are 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.

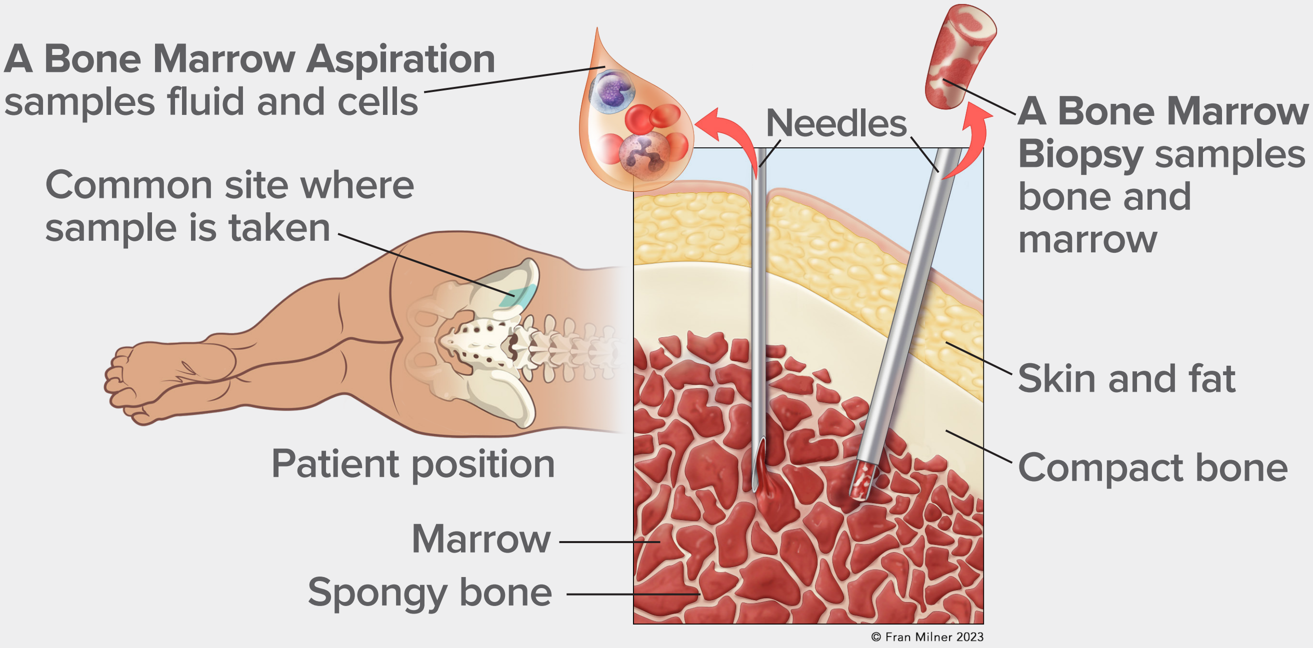
Bone Marrow Aspiration—A sample of fluid with cells from the bone marrow is removed.

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 where the needle is inserted 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 bone 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 hip bone where a bone marrow aspiration or biopsy is typically done. **Right:** One needle goes into the bone marrow to get a liquid sample for aspiration (the needle on the left) and the other needle goes inside the bone for a bone marrow biopsy (the needle on the right). The needle for the aspiration is thinner than the one for the biopsy.

Visit www.LLS.org/3D and click on "Bone Marrow Biopsy and Aspiration" to view an interactive 3D image which will help you visualize and better understand the bone marrow aspiration and biopsy procedures.

Fluorescence In Situ Hybridization (FISH). FISH is a laboratory test to see if there are changes to the chromosomes of the myeloma cells taken from the bone marrow. Chromosomes are the parts of a cell that contain 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 FISH test help your doctor plan your treatment.

Next-Generation Sequencing (NGS). This test looks for mutations in the genes of the myeloma cells. Next-generation sequencing is currently being done in research but may soon become part of routine practice.

Imaging Tests. Bone problems are common in people with myeloma. Imaging tests make images (pictures) of the inside of the body and can help show bone problems such as bone lesions, breaks or thinning of the bones. Because myeloma can be in any bone in the body, it is important to receive a whole body scan. Imaging tests are a very important part of the diagnosis, staging and management of myeloma. These tests include:

- **Whole Body Low-Dose Computed Tomography (CT) Scan.** CT scans take many pictures of areas inside the body from different angles using x-rays. A computer combines all the images to create a single, clear and detailed picture. The amount of radiation used in a low-dose CT scan is much lower than that used for standard CT scans.
- **Positron Emission Tomography (PET)-Computed Tomography (CT) Scan.** A PET-CT scanner combines the techniques of both PET and CT in one machine. A PET scan is a procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is taken up. Because cancer cells often take up more glucose than normal cells, the pictures can be used to find cancer cells in the body. A PET-CT scan provides a more detailed picture of where the cancer is located in the body than either test alone.
- **Magnetic Resonance Imaging (MRI).** This test is done in select cases. It uses radio waves, a powerful magnet and a computer to make a series of detailed pictures of areas inside the body.
- **Bone/Skeletal Survey.** X-rays of all the bones in the body are taken and examined. Bone surveys have mostly been replaced by low-dose CT scans, which show bone damage better than regular x-rays.

WANT MORE INFORMATION?

You can view or print the LLS booklets *Understanding Lab and Imaging Tests, Biomarker Testing for Cancer Treatment* and *Understanding Genetics*. Go to www.LLS.org/booklets or call our Information Specialists at (800) 955-4572 for copies.

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 test results with your doctor.
- Ask how to get copies of your lab reports. You can ask for copies of your test results at the doctor's office. Many hospitals and treatment centers now offer digital patient portals where you can view your medical records on line.
    - Keep test reports in a file folder or binder and organize by date.
- Find out if and when follow-up tests are needed.
- Mark upcoming appointments on your calendar.

PART 2 Treating Myeloma

Overview

- People with myeloma should choose a doctor who specializes in treating myeloma. This type of 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 question guides *My First Doctor's Visit* and *Treatment and Follow-Up Care* on pages 47-52.
- Treatment for myeloma focuses on fighting the cancer and relieving symptoms. Treatment often begins with multi-drug therapy.
- 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.

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 hemotologist-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.

A local or community-based oncologist may only see a few myeloma patients. In large medical centers, there are hematologist-oncologists who specialize in treating myeloma. These myeloma specialists see hundreds of myeloma patients, and they develop experience and expertise in diagnosing and treating myeloma.

If you are being treated at a local medical center that does not have a hematologist-oncologist, ask your local cancer specialist to consult with a hematologist-oncologist at another medical center. Always check to see if your health insurance covers the services of the doctors (and the hospitals associated with them), or the hospital you choose for your treatment.

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 insurance plan referral services.
○ Call our Information Specialists at (800) 955-4572.
○ Use online doctor-finder resources, such as
  ○ 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 47-52 for a full list of questions.

1. How many patients have you treated with 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 booklet *Choosing a Specialist or Treatment Center* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Ask Your Doctor

Talk with the doctor and ask questions about how they plan to treat your myeloma. This will help you become involved in making decisions about your care.

When you meet with your doctor

- ○ Ask questions. Below are a few questions to ask. See pages 47-52 at the end of this booklet for a full list of questions. Visit 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 I should begin treatment?
  - ○ 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 you can record the conversation (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 a second opinion (another 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 our Information Specialists at (800) 955-4572 to discuss a way that makes you comfortable. You should also check with your health insurance plan 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
- Lengthen survival while preserving quality of life

Treatment Staging and Planning

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 best to treat it.

Myeloma has three stages numbered from 1 to 3. Often doctors write the stage 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.

The stage tells your doctor how quickly your myeloma is growing. Stage 1 myeloma typically grows slowly. As the stages get higher, the myeloma typically grows more quickly. Knowing the stage can help your doctor predict your prognosis (likely outcome of the disease). Doctors use the results of blood, bone marrow and imaging tests to stage myeloma. These tests look at:

- Hemoglobin levels in the blood, 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-2 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 in the blood, which may be higher than normal

There are two staging systems that are commonly used in myeloma. One is called the Durie-Salmon Staging System, and the other is called the Revised International Staging System (R-ISS) for Multiple Myeloma.

Treatment Planning. You and your doctor will customize your treatment 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

About Myeloma Treatments

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

Before you begin treatment, you and your doctor will discuss your treatment options. One option may be a clinical trial. Like all treatment options, clinical trials have possible risks and benefits. You can take an active role in making treatment decisions by considering all of your options, including clinical trials.

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

- Combination drug therapy
- High-dose chemotherapy followed by stem cell transplantation
- Immunotherapy such as chimeric antigen receptor (CAR) T-cell therapy and bispecific antibodies
- Radiation therapy for patients with localized disease such as a solitary plasmacytoma (see page 23 for more information on radiation therapy)
- New and emerging drug therapies (given in clinical trials, see page 28)

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

Speak to your doctor to find the best treatment 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 47-52 for full list of questions.

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

Many patients will need supportive care to address some symptoms and complications of myeloma such as bone damage and bone pain, fatigue (extreme tiredness) and infections. For more information on supportive care, see *Complications, Side Effects and Follow-Up Care* on page 29.

Induction. Induction is the first treatment for myeloma. Induction typically consists of 4 (or sometimes 3) drugs given over 3 to 6 cycles. People who are unable to tolerate a 3-drug or 4-drug combination may start with 2 medications. Below is a list of some common drug combinations for people with newly diagnosed myeloma.

Some Drug Combinations for Newly Diagnosed Myeloma

- **Dara-VRd:** daratumumab, bortezomib, lenalidomide, dexamethasone
- **Isa-VRd:** isatuximab, bortezomib, lenalidomide, dexamethasone
- **Dara-KRd:** daratumumab, carfilzomib, lenalidomide, dexamethasone
- **Dara-CyBorD:** daratumumab, cyclophosphamide, bortezomib, dexamethasone
- **Dara-Rd:** daratumumab, lenalidomide, dexamethasone
- **VRd:** bortezomib, lenalidomide, dexamethasone
- **KRd:** carfilzomib, lenalidomide, dexamethasone

Treatment for myeloma may or may not include an autologous stem cell transplant. Patients who are not eligible for a transplant typically continue with the same drugs used during induction for another 2 to 4 cycles. The goal is to deepen the gains made with the initial cycles of therapy before starting maintenance therapy.

After induction, patients who are eligible for autologous stem cell transplant will have stem cells removed from their blood or bone marrow. When possible, enough stem cells should be collected for two transplants in case there is a second transplant at a later date. For more information on stem cell transplantation, see page 22.

Some Drugs Used in the Treatment of Myeloma

For more information, see the package insert and/or the full prescribing information for each medication (available on the internet).

Drug Types	Drug Names
Proteasome Inhibitors	○ Bortezomib (Velcade®, Boruzu™) ○ Carfilzomib (Kyprolis®) ○ Ixazomib (Ninlaro®)
Immunomodulatory Drugs (IMiDs)	○ Lenalidomide (Revlimid®) ○ Pomalidomide (Pomalyst®)
Monoclonal Antibodies	○ Daratumumab and hyaluronidase-fihj (Darzalex Faspro®) ○ Elotuzumab (Empliciti®) ○ Isatuximab-irfc (Sarclisa®)
Corticosteroids	○ Dexamethasone (Decadron®)
Bispecific Antibodies	○ Elranatamab (Elrexfio®) ○ Livoseltamab (REGN5458) ○ Talquetamab-tgvs (Talvey™) ○ Teclistamab-cqyv (Tecvayli™)
Chimeric Antigen Receptor (CAR) T-Cell Therapy	○ Ciltacabtagene autoleucel (Carvykti™) ○ Idecabtagene vicleucel (Abecma®)
Selective Inhibitors of Nuclear Export (SINE)	○ Selinexor (Xpovio®)
Chemotherapy	○ Cyclophosphamide (Cytoxan®) ○ Melphalan hydrochloride (Evomela®)
BCL-2 Inhibitor	○ Venetoclax (Venclexta®)

Stem Cell Transplantation. Some eligible patients may benefit from high-dose chemotherapy followed by 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 their own stem cells (autologous transplant), and one that uses replacement stem cells from a donor (allogeneic transplant). Allogeneic transplant is not commonly used to treat myeloma, but it may be a treatment option for patients participating in a clinical trial.

In myeloma treatment, an autologous tem cell transplant 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, which make red blood cells, white blood cells and platelets. This can lead to anemia, serious infections and uncontrolled bleeding. Stem cell transplantation replaces the stem cells destroyed by high-dose chemotherapy.

Not everyone can have a stem cell transplant. It is an intense treatment with high-dose chemotherapy that can cause life-threatening side effects in some patients. Doctors use a number of factors to determine if a patient is eligible for a stem cell transplant. These factors include the status of their myeloma, age and overall health.

Autologous Stem Cell Transplantation. The patient's own stem cells are collected for this type of stem cell transplantation. If needed, a doctor may use special medications to help mobilize stem cells and move them into the blood for collection. "Mobilizing" stem cells means stimulating them to move from the bone marrow into the bloodstream so that enough cells can be collected for an autologous transplant. 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.

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, or contact our Information Specialists at (800) 955-4572 for a copy.

Maintenance Therapy. After induction or induction with autologous stem cell transplantation, you doctor may recommend maintenance therapy. During maintenance therapy, medications are given at lower doses or less often. Maintenance therapy is not appropriate for every patient. Talk with your doctor about the risks and benefits of taking maintenance therapy.

For standard-risk patients, lenalidomide is the preferred medication after an autologous stem cell transplant. Based on recent clinical trials, your doctor may add daratumumab to lenalidomide.

In some circumstances maintenance therapy may also include bortezomib or carfilzomib. Your doctor may also discuss clinical trials that are studying the best type of maintenance therapy.

Maintenance therapy is intended to be continued over the long term. Studies continue to explore different drugs and 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 cells (called a plasmacytoma), or to treat a painful area of bone damage.

Oral Adherence

Many new myeloma drugs are taken orally (by mouth). Oral adherence means staying on a set plan of taking your medication 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 follow their medication plan, their irregular schedule can result in drug resistance, poor response to treatment, 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 publications *Oral Treatment Adherence Facts* and *A Medication Resource for Blood Cancer Patients* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

You can also view the video *Oral Therapies in Myeloma: Medication Adherence*. Go to www.LLS.org/EducationVideos and select myeloma videos.

Measuring Treatment Response

Your doctor will perform regular tests to see if treatment is working. These test results help 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 of myeloma cells in the bone marrow.

Imaging tests (low-dose whole body CT scans, MRIs and PET-CT scans) are used to look at the bones and bone marrow. These tests are used to see if treatment is reducing bone damage.

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 monoclonal protein (M protein) in the blood and urine.

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 over a 24-hour collection time period.

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 change therapies.

Treatment for Relapsed or Refractory Myeloma

Some patients with myeloma have refractory disease. Refractory myeloma is cancer that does not respond to treatment. After a time, almost all myeloma patients experience relapse, which means the cancer returns after a successful course of treatment.

Treatment for relapsed and refractory myeloma depends on a series of factors including:

- Previous therapy
- How quickly or slowly the myeloma is growing

- Patient health and comorbidities (other health conditions such as diabetes or heart disease)
- Genetic abnormalities in the myeloma cells that have developed over time

Treatment for relapsed or refractory myeloma may include a clinical trial, medications that have been used before, new medications, autologous stem cell transplantation, chimeric antigen receptor (CAR) T-cell therapy and bispecific antibodies.

Clinical Trial. Treatment in a clinical trial should be considered for patients with refractory or relapsed myeloma. LLS offers help for patients and caregivers in understanding, finding and accessing clinical trials. For more information see *Clinical Trials* on page 28.

New Drug Regimen. For many patients diagnosed with myeloma, treatments stop working. This is commonly known as drug resistance. When drug resistance happens, a different medication, or a different combination of medications can be tried. For example, in some patients, myeloma can become resistant to bortezomib. In that case, patients who received bortezomib, lenalidomide and dexamethasone may have their treatment changed to daratumumab, lenalidomide and dexamethasone.

Below are some treatments commonly used in the treatment of relapsed/refractory myeloma. Additionally, CAR T-cell therapy, bispecific antibodies, or a second autologous stem cell transplant can be used as well. See page 27 for more information on these therapies.

- **KPd:** carfilzomib, pomalidomide, dexamethasone
- **Dara-Kd:** daratumumab, carfilzomib, dexamethasone
- **Dara-Pd:** daratumumab, pomalidomide, dexamethasone
- **Elranatamab** (a bispecific antibody)
- **Elo-Pd:** Elotuzumab, pomalidomide, dexamethasone
- **Isa-Pd:** Isatuximab, pomalidomide, dexamethasone
- **Isa-Kd:** Isatuximab, carfilzomib, dexamethasone
- **Seli-Vd:** Selinexor, bortezomib, dexamethasone
- **Talquetamab** (a bispecific antibody)

- **Teclistamab** (a bispecific antibody)
- **Venetoclax:** This is used in certain cases that your doctor may discuss

Talk to your doctor about which drug regimens are available to you. Your doctor can explain the benefits of choosing a particular drug combination and the side effects that may occur.

Autologous Stem Cell Transplantation. The use of high-dose chemotherapy followed by autologous stem cell transplantation may also be an option for some patients with relapsed or refractory myeloma—those who have either not been treated with a transplant or who have had a good response with a prior transplant. See page 22 for more information on stem cell transplantation.

Chimeric Antigen Receptor (CAR) T-Cell Therapy. CAR T-cell therapy is a type of treatment that uses a person's own immune cells (T cells) to kill cancer cells. T cells are taken from a patient's blood and sent to a lab. There, the T cells are genetically modified to allow them to identify and attack myeloma cells. The T cells are then returned to the patient's blood.

Idecabtagene vicleucel and ciltacabtagene autoleucel are FDA approved for the treatment of adult patients with relapsed or refractory myeloma.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Chimeric Antigen Receptor (CAR) T-Cell Therapy* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Bispecific Antibodies. These drugs are similar in some ways to CAR-T therapy as discussed above because they also help T cells to attack myeloma cells. However, instead of genetically modifying a patient’s T cells in the lab, bispecific antibodies are infused directly into the patient, and they temporarily redirect normal T cells to attack myeloma cells. FDA-approved bispecific antibodies for myeloma include teclistamab, elranatamab and talquetamab.

About Clinical Trials

Your doctor may recommend that you join a clinical trial. Clinical trials are careful studies done by doctors to test new drugs or treatments. Clinical trials also may 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 clinical trial may provide the best available treatment.

Here are some questions you may want to ask your healthcare team.
See pages 47-52 for a full list of questions.

1. Is a clinical trial a treatment option for me?
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 our Information Specialists who can provide more information about clinical trials. Patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist throughout the entire clinical trial process. Visit the Clinical Trial Support Center at www.LLS.org/CTSC for more information.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

PART 4 Complications, Side Effects and Follow-Up Care

Overview

- Supportive care for myeloma helps patients manage the complications of the disease and the side effects of treatment.
- After you begin treatment, your healthcare team will regularly order blood, bone marrow and imaging tests to see how well treatment is working.
- People treated for myeloma should see both their primary care doctor and their cancer specialist regularly for follow-up care.

Complications, Side Effects and Supportive Care

Supportive care for myeloma helps patients manage the complications of myeloma and the side effects of the drugs used for treatment. The term side effect refers to the way 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 extreme tiredness and lack of energy that can interfere with your daily activities. Fatigue may make you feel weak, worn out, slow or run down. Fatigue is a common problem for people with myeloma. It can be caused by anemia (low red blood cell counts), treatment side effects, depression, stress or another medical problem. Talk with you doctor for help managing your fatigue.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Cancer-Related Fatigue* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Infection. Myeloma and certain myeloma treatments can increase your risk of infection. Infections are not just troublesome medical problems; they can also contribute to the risk of dying from myeloma.

You should follow your doctor's advice about how to reduce your risk of infection. Your doctor may also recommend:

- Intravenous (IV) immunoglobulin therapy, for patients with frequent and life-threatening infections
- Vaccinations for flu, pneumonia, shingles and COVID-19
- Treatment to prevent *Pneumocystis* pneumonia (PCP), herpes and fungal infections, for some patients who have received a high-dose drug regimen

WANT MORE INFORMATION?

You can view, print or order the free LLS booklet *Side Effect Management: Reducing Your Risk of Infection* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Bone Pain. Myeloma often weakens and destroys bones. This can lead to bone pain and fractures (broken bones). There are treatments to help strengthen bones and reduce pain. Bisphosphonates are a type of medication that can help slow the destruction of bone caused by meyloma cells and reduce pain. The bisphosphonates commonly used to treat myeloma are pamidronate (Aredia®) and zoledronic acid (Zometa®).

Denosumab (Xgeva®) is a monoclonal antibody approved by the FDA to prevent bone fractures in myeloma patients. This medication is recommended when bisphosphonates cannot be used due to potential damage to the kidneys.

Treatment of myeloma may relieve bone pain, but many patients still require pain medication. Nonsteroidal drugs such as ibuprofen should be avoided in myeloma patients given the increased risk of kidney failure. If your myeloma is causing pain, talk to your doctor to find the best way to manage it.

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Pain Management* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

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

Low Blood Cell Counts. Bone marrow is constantly producing new red blood cells, white blood cells and platelets. Myeloma and myeloma treatments often cause drops in blood cell counts. If not managed effectively, low blood cell counts can be life threatening and interfere with treatment and quality of life. Treatment for low blood cell counts may include blood transfusions and medications that help the bone marrow make more blood cells.

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Side Effect Management: Managing Low Blood Cell Counts* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

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

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Side Effect Management: Peripheral Neuropathy (Nerve Damage)* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Deep Vein Thrombosis and Embolism. The term "deep vein thrombosis" (abbreviated DVT) refers to a blood clot that forms in a deep vein of the body, usually in a leg. A DVT can block blood flow and cause pain and swelling. Some myeloma treatments can increase the risk of a DVT. Patients who receive these treatments are usually prescribed medication to reduce the chance of developing a DVT. It is important for you to discuss your risk of DVT with your doctor and ask what you can do to reduce your risk.

When a blood clot breaks away and travels through the bloodstream, it is called an embolus. An embolus can cause life-threatening conditions, depending on where it travels.

An embolus that travels to the lungs can block blood flow to the lungs. This is called a pulmonary embolism. Depending on the size and number of clots that reach the lungs, a patient may experience chest pain, shortness of breath and other potentially severe or even life-threatening symptoms. Your doctor may put you on aspirin or another blood thinner to lower your risk.

WANT MORE INFORMATION?

You can view, print or order the free LLS publication *Side Effect Management: Managing Blood Clots and Deep Vein Thrombosis (DVT)* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for a copy.

Other Cancers. Myeloma patients have an increased risk of developing other types of blood cancers including myelodysplastic syndromes (MDS) and acute myeloid leukemia (AML). This is rare and only occurs in a small number of patients.

WANT MORE INFORMATION?

For more information on myelodysplastic syndromes and acute myeloid leukemia, visit www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572.

Nutrition and Cancer

Eating well is important for blood cancer patients. Proper nutrition plays a key role in keeping the body strong, supporting the immune system and reducing the risk for diseases. Patients who eat well and maintain a healthy weight usually manage treatment and its side effects better. It is also important for patients with weakened immune systems to follow all food safety guidelines to reduce the risk of foodborne illness. Speak to your doctor about food and nutrition and for a referral to an oncology registered dietitian (RD) for specific nutrition advice and guidance.

LLS registered dietitians have expertise in oncology nutrition and provide patients, parents and caregivers with free nutrition consultations by phone. Call (877) 467-1936 or visit www.LLS.org/nutrition to schedule a consult.

WANT MORE INFORMATION?

You can view, print or order the free LLS booklets *Food and Nutrition During Cancer Treatment* and *Nutrition Handbook: Feeding your family from meal planning to mealtime* at www.LLS.org/booklets, or contact our Information Specialists at (800) 955-4572 for copies.

Financial Concerns

Myeloma patients are living longer primarily because of the development of new and effective drugs. While this progress is exciting, the financial costs associated with new treatments can become a major concern for many people who are living with myeloma. The high cost of cancer can lead to significant financial and emotional stress for both patients and their families.

Even if you have health insurance, cancer can still take a toll on your finances. You may have new expenses such as co-payments or travel for treatment. You may also have less income if you need to take time off from work.

Speak to your healthcare team if you have any concerns about being able to pay for your treatment. They 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 many resources available to help with prescription drug payment. In addition several major drug manufacturers currently provide patient assistance or prescription assistance programs. These programs can provide both insured and uninsured patients 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, or contact our Information Specialists at (800) 955-4572 for a copy or 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 decide how well your treatment is working and determine if different treatment is needed.

You should see your primary care doctor and your cancer specialist regularly for follow-up care. Follow-up care involves regular medical checkups, which may include a physical exam and blood tests. Sometimes bone marrow and imaging tests may also be needed.

Talk with your doctor about how often to have follow-up visits. You should ask your doctor which tests will be needed and find out how often you need to have these tests.

It is important to 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. Page 46 has a place to list your treatments.

Here are some questions you may want to ask your healthcare team.
See pages 47-52 for a full list of questions.

1. Who will I work with to ensure lifelong follow-up care?
2. Will I continue to see this healthcare team?
3. What information should I give to my primary doctor about my myeloma treatments?

Survivorship clinics provide services that can help cancer patients manage issues related to living with and surviving cancer. A survivorship clinic may help you deal with the lasting physical and emotional changes of cancer. To find a survivorship clinic, talk to your doctor or contact our Information Specialists.

WANT MORE INFORMATION?

For additional information about survivorship, visit www.LLS.org/SurvivorshipWorkbook to reach the children and adolescent, young adult and adult books called *Navigating Life During and After a Blood Cancer Diagnosis*. Or, call our Information Specialists at (800) 955-4572 for a copy.

Take Care of Yourself

- Keep all your doctor and lab appointments (specialists, primary care, testing).
- Talk with your 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 doctor'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.
- Keep a record of your cancer diagnosis, treatment and follow-up care needs. This is often called a survivorship care plan. Ask your doctor for a written survivorship care plan. Share this information with any new doctors you see. The plan should include the following information:
  - A list of all healthcare providers
  - Diagnosis summary with specifics such as subtype and/or genetic markers
  - Treatment summary with specifics such as the names, dates and dosages of drugs, surgery and/or transplant information, response to treatment and side effects
  - Maintenance treatment information, if applicable
  - List of possible late effects
  - Schedule for ongoing monitoring with recommended tests, frequency and coordinating provider
  - Health and wellness recommendations such as nutrition, exercise or other disease information
- Do not smoke. Patients who smoke should get help to quit.
- Contact your doctor about tiredness, fever or other symptoms.
- 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. 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.

Additional Resources

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, visit www.LLS.org/ResourceDirectory to view the directory.

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; to airborne hazards and burn pits while serving in Iraq, Afghanistan and other areas of Southwest Asia; to contaminated water at Camp Lejeune between 1953 and 1987; or to ionizing radiation during service 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: https://www.va.gov/disability/eligibility/hazardous-materials-exposure/

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. 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

Mental Health. Caring for your mental health has benefits if you are a cancer patient. Seek medical advice if you are struggling. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov

If you or your loved is experiencing a mental health crisis, call 988 to talk to a trained mental health professional. The 988 Suicide and Crisis Lifeline is free, confidential and always available. For the Crisis Text Line, text HOME to 741741.

Health Terms

Albumin. A protein in the blood. Low levels of albumin may be a sign of a faster-growing myeloma or another health problem.

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. Also called an immunoglobulin.

Beta-2 microglobulin. A protein found on the surface of plasma cells and some other cells. A high level of Beta-2 microglobulin in the blood 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. Treatment that stops the growth of cancer cells, either by killing the cancer cells or stopping them from dividing.

Chromosome. Part of the cell that contains genetic information. Chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. Human cells have 23 pairs of chromosomes. The number or shape of chromosomes may not be normal in 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.

FDA. The short name for the **US Food and Drug Administration.** Part of the FDA's job is to ensure 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.

Heavy chain. A longer protein made by a plasma cell. An immunoglobulin (antibody) is made up of two heavy chains linked to two light chains.

Hematologist-Oncologist. A doctor who has special training in the diagnosis and treatment of blood cancers.

Hemoglobin. A protein inside red blood cells that carries oxygen from the lungs to tissues and organs in the body.

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. Also called an antibody.

Lactate dehydrogenase. An enzyme (protein) found in the body that is involved in energy production of cells. An increased amount of lactate dehydrogenase in the blood may be a sign of tissue damage and some types of cancer.

Light chain. A protein made by plasma cell. An immunoglobulin (antibody) is made up of two heavy chains linked to two light chains.

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

Monoclonal (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.

Plasma. The liquid part of the blood. Blood plasma is not the same as plasma cells which are types of white blood cells.

Plasma cell. A type of white blood cell that makes large amounts of a specific antibody. Plasma cells develop from B cells that have been activated.

Plasmacytoma. A mass made up of abnormal plasma 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.

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: (800) 955-4572
Email and live chat: www.LLS.org/InformationSpecialists

HEMATOLOGIST-ONCOLOGIST NAME:

Address:

Phone number/Fax number:

Email address:

Website/Portal:

Additional information:

NURSE/NURSE PRACTITIONER NAME::

Address:

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:

MY LIST OF TREATMENTS

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

DATE: ____

Treatment: ____________________________________

____

DATE: ____

Treatment: ____________________________________

____

DATE: ____

Treatment: ____________________________________

____

DATE: ____

Treatment: ____________________________________

____

DATE: ____

Treatment: ____________________________________

____

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 them to explain it again in another way. The following are questions you may want to ask your healthcare team.

When you meet with the doctor, nurse and other members of your healthcare team, ask 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 patients may not be old enough or able to make their own decisions. A parent, relative or caregiver may be assisting or making the decisions.)

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:

____

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
or call (800) 955-4572.

QUESTION GUIDE: Treatment and Follow-Up Care

Talk with the doctor and ask questions about how they plan 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 patients may not be old enough or able to make their own decisions. 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:

____

____

____

Write down your stage of myeloma:

____

____

____

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 can 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 back?
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. Can I go to work or school during treatment?
   1b. Will someone need 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 my appearance or ability to work/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 clinical-trial drugs?
7. How can I (we) find out if 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 lifelong 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 I (we) have side effects later, how can the healthcare team be reached?
6. What information can be provided to a primary doctor about this treatment?

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

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, and optimism. Finding 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**

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

The Leukemia & Lymphoma Society Mail Center
1201 15th Street N.W., Suite 410, Washington, D.C. 20005

The mission of The Leukemia & Lymphoma Society (LLS) is to cure blood cancer and improve the quality of life of all patients and their families. Find out more at www.LLS.org.