



FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



MULTIPLE MYELOMA



The Cancer Support Community has developed this book for people facing multiple myeloma with the support of its partner, the Multiple Myeloma Research Foundation. We had help from patients/survivors, caregivers, medical experts, mental health counselors, and patient advocates. We hope this book offers insight into understanding a diagnosis of multiple myeloma, making treatment decisions, and coping with the emotional and practical challenges you may face.

As you read this book, you will become part of a global cancer support community and find you are not alone—there is a whole community behind you.

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WHAT'S INSIDE?

This book was written with the help of medical experts as well as patients and caregivers who have “been there.” It has a lot of information about living with multiple myeloma.

It may be too much to take in all at once. Feel free to use this book as a guide, and refer to its content as you need it. Take a look at the Table of Contents or use the guide below to help you find the information you need right now.

If you...	Go to...
are newly diagnosed	Chapters with a ★ (star) icon.
want to learn the basics about Multiple Myeloma (MM) and MGUS	★ Chapter 1: What is Multiple Myeloma? (pgs. 8-13)
want to learn how MM is diagnosed and tracked over time	★ Chapter 2: How is Multiple Myeloma Diagnosed? (pgs. 14-19) Pgs. 14-18 for common tests and information on what test results mean Pg. 19 for questions to ask about diagnostic tests
want to learn how to gain control over your care	★ Chapter 3: Taking Control of Your Care (pgs. 20-27) Pgs. 20-21 for how you can be an active partner in your health care Pg. 22 to learn how to find a local MM expert Pg. 22 to learn why second opinions help Pgs. 26-27 for questions to ask as you seek the best medical team



If you...	Go to...
need treatment or want to plan for treatment	<p>Chapter 4: Treatments for Multiple Myeloma (pgs. 29-43)</p> <p>Pg. 29 to learn how your doctor decides which treatments are best for you</p> <p>Pg. 31 for tips on how to plan for treatment</p> <p>Pgs. 32-33 for questions to ask during treatment planning</p> <p>Pgs. 34-39 to learn about treatment options for MGUS, MM without symptoms, MM with symptoms, relapsed MM, maintenance therapy, and refractory MM</p> <p>Pg. 42 for questions to ask about your treatment</p> <p>Pg. 43 to learn about promising new treatments in clinical trials</p>
want to learn how to manage common problems caused by MM and its treatment	<p>Chapter 5: Managing Symptoms and Side Effects (pgs. 44-53)</p> <p>Pgs. 44-45 to learn how to manage pain and bone weakness, as well as treatments to strengthen bones</p> <p>Pg. 47 to learn how to manage blood problems like anemia, blood clots, amyloidosis, or calcium in the blood</p> <p>Pg. 48 for tips on preventing infections</p> <p>Pg. 49 for kidney care</p> <p>Pg. 50 for tips in coping with drug-related side effects</p> <p>Pgs. 52-53 for tips on nutrition and healthy eating</p>
want to learn what you can do to improve your quality of life today, and in the future	<p>Chapter 6: Coping and Moving Forward (pgs. 54-59)</p> <p>Pg. 55 for ideas on where to go for emotional support</p> <p>Pgs. 57-58 for tips on how to plan for the future</p> <p>Pg. 58 for the importance of finding hope</p>
care for someone with MM and want to learn how to help them, while caring for yourself	<p>Chapter 7: If You Are A Caregiver (pgs. 60-63)</p>
want to find good resources for more information and support	<p>Chapter 8: Resources (pgs. 64-66)</p>



HOW TO USE THIS BOOK

A diagnosis of multiple myeloma (MUL-tih-pul MY-eh-LOH-muh) also known as MM, can feel overwhelming. Fortunately, you will learn that there's a lot you can do. Thanks to advances in research, there are several new treatments. More than ever, people with multiple myeloma are living better and longer.

MM is not like other cancers. It's unique because it involves several periods of relapse (illness) and remission (health). Until a cure is found, your goal through this journey will be to stay as healthy as possible for as long as possible. You'll have to manage multiple myeloma throughout your life. It's important to learn as much as you can, starting now.

In this book, we offer information on available short- and long-term treatments, and how to find a medical team. We offer you tools to manage the physical, emotional, and practical impacts of MM. We show you that you can focus on your quality of life—to feel better on a daily basis—while finding hope.





"What helps me is my family. I want to be here and live, for them. I have so much more to experience. I plan to do everything I can to get rid of the myeloma." —Laura, MM Survivor

What is Multiple Myeloma?

About 18,130 men and 12,980 women (about 1 in 132 people in the U.S.) are diagnosed with MM every year. —American Cancer Society

Multiple Myeloma (MM) is a blood cancer that starts in the plasma cells of bone marrow. The bone marrow is the spongy material in the center of your bones. It serves as the factory to make blood cells. Here, stem cells mature into red blood cells, white blood cells, and platelets.

- **Red blood cells** carry oxygen to tissues throughout the body.
- **White blood cells** help fight infection. There are many types of white blood cells, but MM affects plasma cells.
- **Platelets** help form blood clots that control bleeding.

MULTIPLE MYELOMA (MM) IS DIVIDED INTO TWO MAIN GROUPS:

Asymptomatic (smoldering)

myeloma: This is when you have high M protein levels in blood and urine tests. There are no “CRAB” symptoms. (See pg. 10.) If multiple myeloma isn’t causing symptoms, then you may not need treatment. Active surveillance (regular tests to track the disease) will make sure it is addressed if it develops into active myeloma.

Plasma cells are a type of white blood cell that makes antibodies. Antibodies are proteins that help the immune system protect the body from disease. In patients with multiple myeloma, plasma cells have become abnormal. Too many are produced. These abnormal plasma cells make an abnormal protein, called monoclonal or **M proteins**.



M Proteins=Abnormal Proteins



Normal Versus Myeloma Cell Growth

The abnormal cells that grow out of control with myeloma don't die the way normal cells do. When there are too many abnormal cells, they crowd out healthy cells and can cause many problems, such as:

- Bone pain and fractures
- Anemia (low red blood cell count)
- Uncontrolled infections
- Kidney damage

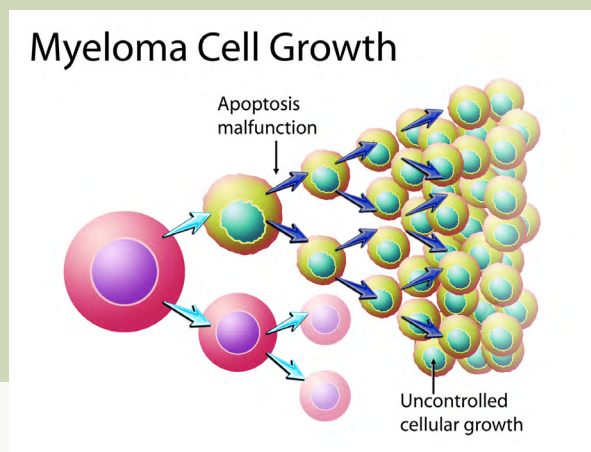
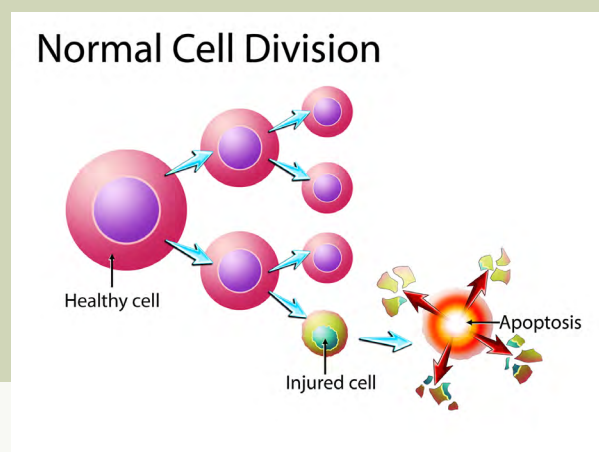


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Risks for getting multiple myeloma include:

- Age: Most patients are age 60 or older
- Gender: Occurs more among men than women
- Weight: Being obese
- Race: African Americans are twice as likely to get MM
- Genetics: People with a family history of MM
- Medical conditions: People with Monoclonal Gammopathy of Undetermined Significance

(MAH-noh-KLOH-nul ga-MAH-puh-thee of UN-deh-TER-mihnd sig-NIH-fih-kunts) or MGUS (sometimes pronounced EM-gus). If you have MGUS, you have abnormal M proteins in your blood but not enough to be called "blood cancer." MGUS can develop into blood cancer, including MM. (Only about 1 in 100 people with MGUS get MM each year. Most often, MGUS does not develop into a blood cancer and is harmless.)

Symptomatic (active) myeloma:

This is when high M protein levels are found in blood and urine tests. Also, at least 10% of the bone marrow biopsy contains plasma cells. One or more “CRAB” symptoms are present, as well. Even if you don’t “feel” very sick, you may have active myeloma. Once myeloma becomes active, it will remain active. Treatment is recommended and can help.

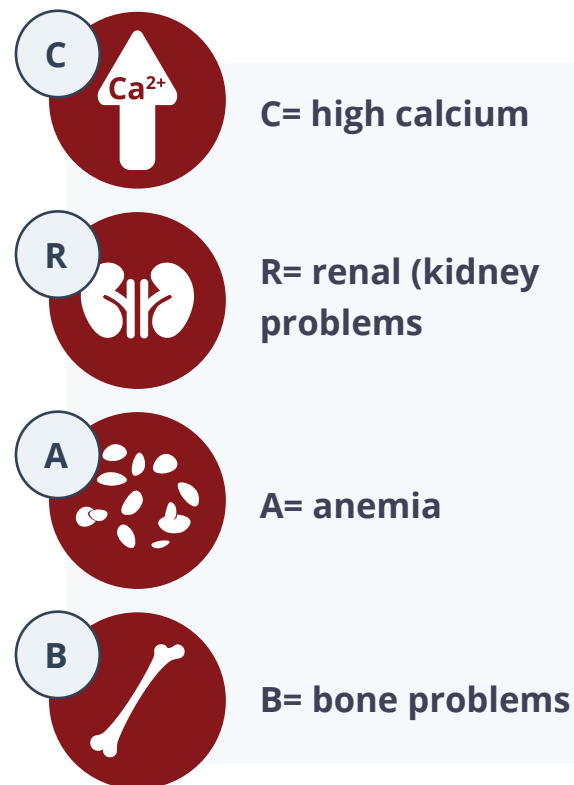
Sometimes a **plasmacytoma** (PLAZ-muh-sy-TOH-muh) is found in scans. This means that only one mass of abnormal plasma cells is seen. The mass can be in or outside the bone. Multiple Myeloma refers to many (multiple) masses of abnormal cells.

A doctor trained to treat blood cancers is called a hematologic-oncologist (HEE-muh-tuh-LAH-jik on-KAH-loh-jist). Try to find one who knows a lot about myeloma and sees a lot of MM patients. Aim to get a second opinion from another expert before choosing one to work with.

Successful care depends on the experience of your medical team. Success also depends on the biology of your disease, your general health, and how well your body responds to different treatments.

The good news is that treatments for MM are advancing quickly. Many exciting new options have been approved in the past 5 years. It is important to discuss these new options, as well as your goals for treatment with your care team. Research into new treatments brings hope to many patients and their families. (See chapter 4.)

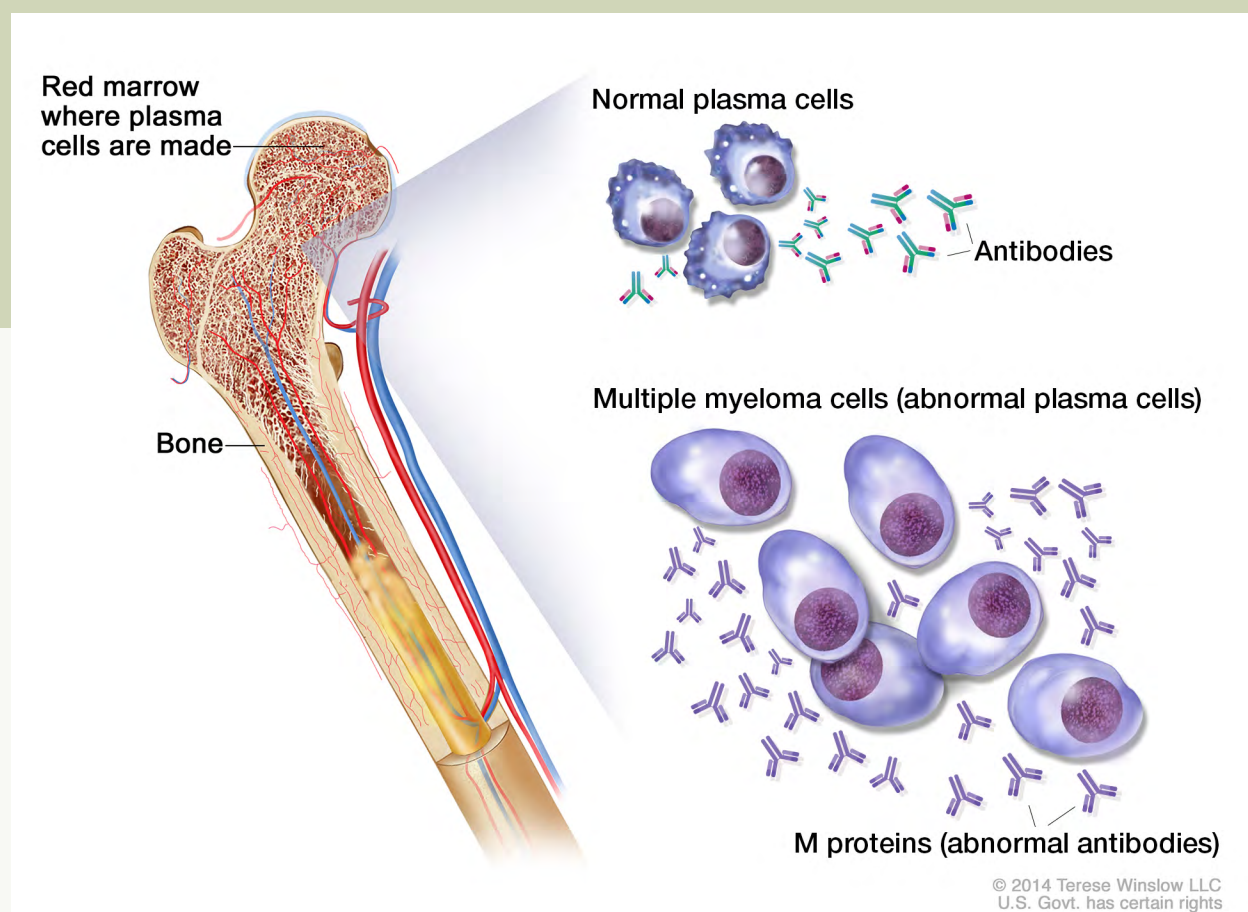
“CRAB” SYMPTOM FOR ACTIVE MYELOMA



Multiple Myeloma

Myeloma begins in blood cells made in bone marrow. It is not the same as:

- **Melanoma.** A cancer of the skin.
(They sound similar, but they're very different.)
- **Bone cancer.** This cancer, like osteosarcoma, begins in bone cells.
- **MGUS** (monoclonal gammopathy of undetermined significance). This is when you have abnormal M proteins in your blood but not enough to be called a blood cancer.



With improved diagnosis and treatment methods, Multiple Myeloma is treatable and can be managed like any other chronic illness.

SYMPTOMS AND COMPLICATIONS

Myeloma symptoms depend on the stage of your disease and your body's response to it.

Asymptomatic or smoldering myeloma often has no symptoms. Still, it must be watched. Tests to track this stage of MM are done every 6 months to every year.

Symptomatic or active multiple myeloma can lead to issues that need treatment such as:

Weakness, anemia-related fatigue, or difficulty breathing. You can feel very tired all the time. Even sleep won't help. This is because myeloma cells replace oxygen-carrying red blood cells. Anemia may make you look pale (this is hard to notice if you have darker skin). You may also feel short-of-breath from anemia.

Bone pain, damage, and fractures. The type of bone damage in multiple myeloma is called "lytic" or "osteolytic." It looks like your bones have holes. Bone pain is common and bones break easily. This is especially true in the spine, pelvis, ribs, and skull. A series of X-rays of your bones (skeletal survey) or full body CT scans are done on a regular basis to look for lytic lesions (LIH-tik LEE-zhuns).

Kidney (renal) failure. Kidneys can be damaged from high levels of the abnormal M protein and calcium in your blood. Calcium levels in your blood get high because the bones are being "broken down" by the MM. This makes the kidneys work harder to clean your blood. If they can't clean your blood (remove salts, minerals like calcium, and water), you can experience serious health problems.

Infection and illness. The immune system doesn't work the way it should with abnormal blood cells. Myeloma patients are much more likely to get infections and take longer to get better. Pneumonia is a common and serious infection in myeloma patients.

Loss of appetite and weight loss. High levels of calcium in your blood from bone damage can cause a lot of problems. You can feel very thirsty, nauseous, or constipated; can lose your appetite; and might even feel light-headed or confused.



Headaches, confusion, and blurred vision. When myeloma makes the blood thicken and flow poorly (hyperviscosity), you can feel light-headed or confused and get headaches or blurred vision.

Amyloidosis (A-muh-loi-DOH-sis). A small number of MM patients will get amyloidosis. This buildup of amyloid proteins can affect the way some organs work. Special treatment is needed.

Information on managing these and other symptoms are detailed in

Chapter 5, “Managing Symptoms and Side Effects.” The goal of MM treatment is to limit and manage your symptoms over the course of many years. You may have periods when you need treatment to manage symptoms and other periods when you don’t. Fortunately, MM patients can live longer and healthier lives now with better treatment options.



DISPARITIES IN MULTIPLE MYELOMA DIAGNOSIS

Cancer does not affect all people in the same way. These differences in diagnoses and outcomes are examples of health disparities. Multiple myeloma affects African American and Black communities more than other groups. In 2021, African Americans and Blacks were:

- twice as likely to be diagnosed with multiple myeloma
- diagnosed at a younger age
- twice as likely to die from this cancer

Doctors do not know why rates differ so much in these populations. Some reasons may be:

- access to health care
- differing rates of MGUS
- low awareness of multiple myeloma in the community
- and a history of other chronic conditions

Exposure to tobacco or alcohol does not explain these differences.



How is Multiple Myeloma Diagnosed?

Most people are surprised by their diagnosis of multiple myeloma (MM). They may have gone to the doctor for fatigue, sudden weight loss, urinary problems, infections, or a broken bone. They had no idea that the problem is really blood cancer. Then, a routine blood test or bone x-ray alerts their primary care provider to check for multiple myeloma. More tests must be done by a specialist to confirm the diagnosis.

With or without symptoms, several tests are needed to confirm a MM diagnosis. Not all MM is treated the same way. Results from the tests detailed on the next two pages will help your doctor decide on the right treatment for you. Results can inform doctors about the best actions to take for your treatment. Many of the same tests are repeated to track the disease over time and see how well your treatment works. Ask what each tests looks for and how to read your lab reports.

DIAGNOSTIC STEPS

At first you'll get a physical exam and the health care team will ask about your health history. Then blood and urine tests will be done. If abnormal results are found, a bone scan and a bone marrow biopsy or aspiration will be done. Other tests may be done to gather more information.

TESTS TO CONFIRM, TRACK, AND FOLLOW-UP ON TREATMENT

There are several tests done to confirm your diagnosis. Over time, some of the same tests will be used for treatment planning and to track how well you're doing.

Blood Tests

- The complete blood count (CBC) test counts the number and types of blood cells in a sample of your blood. It can show if the M protein (abnormal protein) is present. It also checks your hemoglobin. Low levels of hemoglobin mean you have anemia.
- The serum protein electrophoresis (SPEP) test finds and measures M proteins. A high M protein level may be the first sign for MGUS and MM.





KNOW YOUR M PROTEIN LEVEL

If the M protein level is:

Less than 3 g/dL – you may have MGUS, with a 1% risk per year for multiple myeloma or related conditions.

Greater than or equal to 3 g/dL – you may have asymptomatic myeloma, with a 10% risk per year for active myeloma.

Greater than or equal to 3 g/dL plus at least one “CRAB” issue (high calcium, renal problems, anemia, bone problems) – you may have active myeloma.

TALK TO A SPECIALIST IN MULTIPLE MYELOMA.

If your primary care provider finds something that makes them believe you have MGUS or multiple myeloma, you should talk to a hematologic-oncologist (blood cancer specialist). Ideally you can find one who specializes in MM.

Treatments change so quickly for MM that only a specialist will know about all of your options. To find a specialist, see pg. 22.



- Immunofixation or immunoelectrophoresis tests find the exact type of M protein. There are heavy and light chains in the M protein. Knowing the type of M protein you have can help your doctor decide what treatment options to offer you.
- The serum free light chain (SFLC) assay test looks for excess amounts of proteins called light chains. These are small fragments of immunoglobulins (antibodies) in your blood made by plasma cells, a type of white blood cell in the blood.
- The levels of these light chains are tested either in the blood with the serum free light chain assay or in the urine with a 24-hour urine collection.
- A blood calcium test. High levels of calcium in your blood mean that you have bone loss or bone lesions due to multiple myeloma.
- Beta 2-microglobulin (β 2M) level test finds how much β 2M is in your blood or urine. Higher β 2M levels can mean that more advanced disease is present.

Kidney Tests

- 24-hour urine test looks for high levels of the Bence Jones protein (parts of M protein) and other

abnormal immunoglobins. Results show if the kidneys are showing signs of damage by MM.

- A set of chemistry profile tests, also called metabolic panel tests, measure how well the kidneys and liver are functioning.

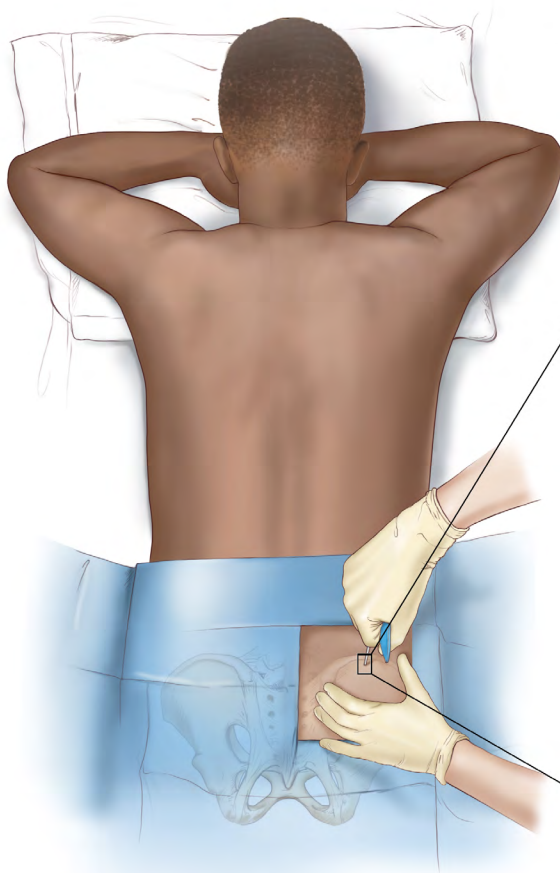
Scans

- Tests such as a skeletal survey, x-rays, MRI, CT, or PET scan look for thinned, broken, or damaged bones. These are called lytic lesions and may be found in any bone in the body.

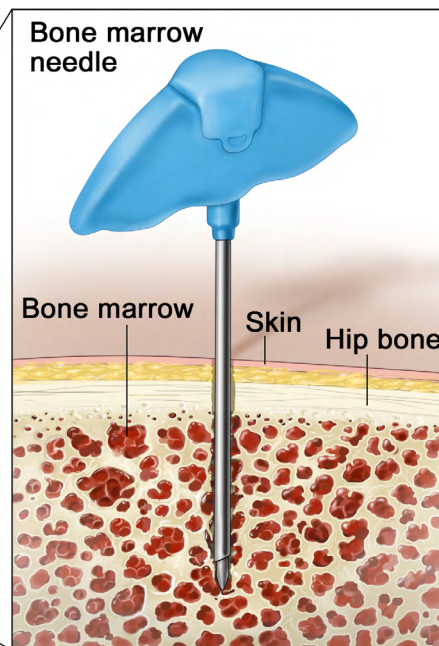
Bone Marrow Biopsy

- A bone marrow biopsy is done by a skilled doctor or nurse. It is done to look at the cells in bone marrow. It confirms if cancer cells are present, and what type. A special needle is used to remove liquid bone marrow (an aspirate) and a small piece of the bone with marrow (the biopsy) from the hip.
- A pathologist (puh-THAH-loh-jist) is the doctor who analyzes the bone and marrow samples under a microscope. They look for myeloma cells, count them, and look at their size, shape, and how they are arranged. The pathologist will make a clear diagnosis based on what they find in this and biomarker tests.





Bone Marrow Aspiration and Biopsy



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RAISING MULTIPLE MYELOMA AWARENESS

As you learn more about multiple myeloma, you may want to share information with others in your community. Here are some ideas:

- Let others know what the symptoms of multiple myeloma are. (See pg. 12.) They are often overlooked because they may not seem like a big deal and can be caused by other health problems.
- If your community center, health center, or house of worship has a speaker series, ask if they'd invite someone to talk about multiple myeloma.
- If you have access to a room with a screen and an internet connection, you may be able to stream a national event. See our list of resources for organizations that may host online events.



Biomarker Tests Done on Bone Marrow Samples

- Fluorescence in situ hybridization (FISH) looks for changes (mutations) to the DNA of myeloma cells.
- Immunohistochemistry and flow cytometry can identify and sort different myeloma (and other cancer) cells based on specific antibodies on the surface of the cell.
- Cytogenetics and karyotyping look for changes in myeloma cells' chromosomes (long strands of DNA). Finding these changes can help predict a person's prognosis (outlook).

- DNA sequencing uses a special instrument to find mutations in the genes of the cancer cells. This is mostly used in clinical trials.

STAGING MULTIPLE MYELOMA

If MM is diagnosed, a hematologic-oncologist will “stage” it and learn how far it has spread. This information will guide your treatment plan.

Multiple myeloma is not staged in the same way as other cancers. The main staging system for MM is the **International Staging System**. This is based on the results of lab tests. Stage 1 is least aggressive, and Stage 3 is most aggressive.



QUESTIONS TO ASK ABOUT DIAGNOSTIC TESTS:

What tests will I need, and what are they looking for?

Can you teach me how to read my lab reports and what everything means?

Will I need to repeat a blood or urine test before moving on to other tests?

If I need a biopsy, how should I prepare for it? Will it hurt?

What are the risks of having a biopsy?

How soon will I know the results?

If I have MGUS, asymptomatic MM, or amyloidosis, will I need more tests?
How often?

If cancer cells are found, will you ask another pathologist for a second opinion?

How accurate are test results?

Will my insurance cover these tests? How much will tests cost? Is there a financial counselor on staff who can help me?

How should I describe this diagnosis to my friends and family?

Can I have a copy of my test results for my own files?

Who should I talk with about next steps?

Taking Control of Your Care

“I’ve learned that I feel more powerful with positive thinking. I believe that if you truly want it, you will fight for it and win. I try to tell myself that this disease is not going to defeat me. I will win!”

—David, MM Survivor

When most people are told that they have multiple myeloma, they feel a rush of fear and strong emotions. **Remember:** there are actions patients can take to feel better and gain control.

There are no “instructions” on how to deal with cancer. There is no right or wrong way to go. Remember that you are the expert in knowing how you feel. You can take advantage of helpful resources, people, and services. After you feel informed, you can decide what’s best for you.

FINDING THE RIGHT DOCTOR AND CARE TEAM

A hematologic-oncologist specializes in cancers of the blood and related tissues. This is the main doctor who coordinates care for MM patients. Ideally, you will find one with a lot of experience, and who puts you at ease. Before you choose a specialist, make sure they accept your health insurance. You’ll be partnering with this doctor for a long time.

To find a MM expert in your area:

- Ask your primary care provider for a referral. They should know one or more hematologic-oncologists with expertise in MM.
- You can also ask your health insurance company for a list of hematologic-oncologists in your area. Find out which are covered under your insurance plan. Ask your primary care doctor to recommend one from the list.
- Or, search the websites of organizations such as:
 - American Society of Hematology www.hematology.org/education/patients/find-a-hematologist Search by city and state to find a specialist in your area.
 - American Society of Clinical Oncology at www.cancer.net/find-cancer-doctor Filter your search with the specialty “Multiple Myeloma” and your location.



- Multiple Myeloma Research Foundation at **www.themmrff.org/find-a-treatment-center/** Search by state to find some of the nation’s top cancer centers specializing in MM.
- National Cancer Institute (NCI) at **www.cancer.gov/cancer-centers** Click on “Find an NCI-Designated Cancer Center” to search by state for comprehensive cancer centers.

Your care team includes more than just a hematologic-oncologist. Depending on your treatment needs, your team may include a radiation oncologist and/or a stem cell transplant specialist.

Key members of your team can also be an oncology nurse practitioner, registered nurse, physical therapist, financial counselor, hospital navigator or social worker, and nutritionist. Each of these professionals can help guide you. You can ask to meet them all.

Because you will be working with many different people, it helps to keep a list of them with contact information handy. It also helps to make sure everyone is up-to-date on your care.



“You have to trust your doctor and have a positive relationship with them. You trust your life with your doctor.” — Frank, living with MGUS



THE POWER OF SECOND OR THIRD OPINIONS

It's always helpful to interview a few doctors and collect a few opinions about how to treat your disease. This will teach you about different paths you can take. The process will also show you different medical offices, hospitals, teams, and resources. Ask how many MM patients each doctor treats in a year to get a sense of their experience. (Try to pick someone who treats a lot of patients with MM.)

It also helps to ask if the specialist participates in MM clinical trials or knows about trials that may be right for you. At any stage of MM, a clinical trial can be a high-quality treatment option. Ideally, your doctor will let you know about local clinical trials that may help you.

There is no right or wrong time to ask for a second opinion. Often, it's best to do this before you start (or re-start) treatment. But you can ask for advice at any point. When you talk with several doctors, you will gain confidence about your plans.

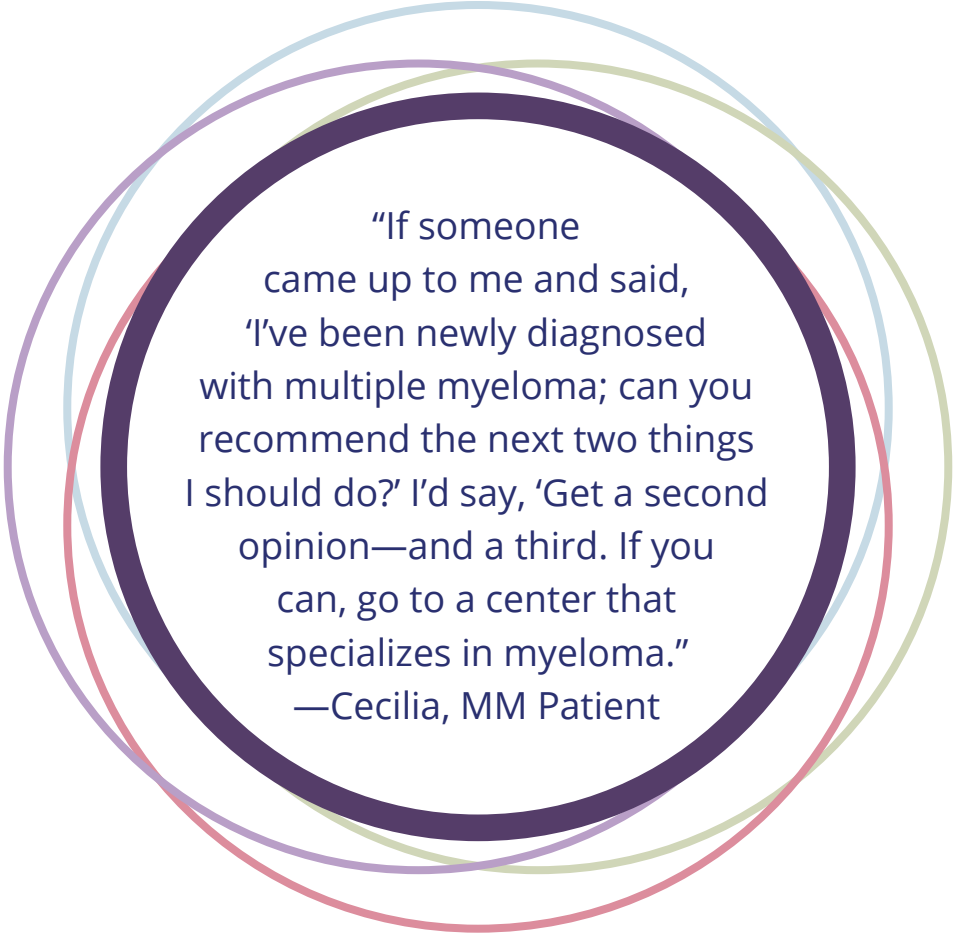
Many people feel shy about asking for a referral to another doctor. It's really okay. A doctor should expect to give this information and shouldn't give you any push back if you ask for it.

No matter whom you work with, it's important to talk openly with your treatment team. The more they know, the more they can help you.

THE BENEFITS OF A SECOND OPINION:

- To confirm your diagnosis
- To get more information about your treatment now and in the future
- To learn about possible clinical trials
- To help you choose the doctor and treatment team you want to work with
- To learn about different treatment locations (i.e. a community clinic, a local hospital, an academic medical center, or an NCI-designated cancer center)
- To learn about what services each treatment location can offer
- Some insurance companies require a second opinion





“If someone came up to me and said, ‘I’ve been newly diagnosed with multiple myeloma; can you recommend the next two things I should do?’ I’d say, ‘Get a second opinion—and a third. If you can, go to a center that specializes in myeloma.’”
—Cecilia, MM Patient

BUILDING YOUR CARE TEAM

After receiving a diagnosis of multiple myeloma, it is important to build your care team. Your care team should include a multiple myeloma specialist. They are a type of hematologic-oncologist, a doctor trained to treat blood cancers. They can help you learn about the latest treatments. Patients who have a multiple myeloma specialist on their care team have better outcomes. If you don’t have a multiple myeloma specialist near you and you aren’t able to travel to see one, ask your oncologist to consult with one.

Your care team may also include a nurse, social worker, nutritionist, physical therapist, and other specialists. This team works together to support you and your loved ones through diagnosis and treatment.

Remember, at any point you can ask another multiple myeloma expert for a second opinion.



10 ACTIONS YOU CAN TAKE

SEEK ACTIVITIES YOU ENJOY

Just because you have MM doesn't mean that you can't enjoy life! Find humor in your day. Do things that you enjoy and bring you comfort. Enjoy your alone time or spend quality time with the people you care about.

ACKNOWLEDGE AND ADDRESS YOUR FEELINGS

A diagnosis of multiple myeloma can trigger strong emotions. Find ways to address your feelings. Try journaling, exercise, or creative projects. Talking to a therapist may help, especially if you feel depressed or anxious.

TALK WITH OTHERS WHO LIVE WITH MULTIPLE MYELOMA

You can gain comfort and strength from other MM survivors. They can help you cope with this illness and talk about it. Consider a support group. Your doctor, nurse, or social worker can help you connect. Contact the organizations listed in the Resources section (Chapter 8).

LEARN TO BE MINDFUL AND RELAX

The goal is to feel peaceful and enjoy the moment. Yet, it is not always easy to feel calm. Start with things that help you relax such as: a walk, yoga, meditation, or cooking. There are also meditations, mindfulness, and hypnosis apps that can help.

MAINTAIN A SPIRIT OF HOPE

Even if your cancer is complex, you can still feel hopeful. Set small goals and enjoy daily pleasures. Hope can make each day a little better. Focus on the things that bring you happiness. Some days will be better than others, but you can continue to enjoy the small, special moments.

MAKE ACTIVE CHOICES IN YOUR TREATMENT

Partner with your doctors and caregivers by talking openly with them. Bring your list of questions and concerns with you. Learn where to go for information and support. Stay aware of how you feel, as well as your tests and results.

TALK OPENLY WITH YOUR FAMILY/FRIENDS

Be open about your diagnosis and your needs. Your health care team can teach you how to tell others. Many people in your life will want to help and support you. Determine who can be your primary caregiver and ask for their help.

MyLifeLine.org is one tool that can connect your friends and family with the kinds of help you need.

SEEK SECOND OR EVEN THIRD OPINIONS

Learn from different experts to help you feel informed and ready for next steps. Learn as much as you can about each specialist. Different medical facilities offer different services. Choose someone and somewhere that you like.

RETAIN AS MUCH CONTROL AS YOU CAN

Multiple myeloma is managed over many years. You can make a plan that gives you control. You can adjust treatments over time or consider clinical trials. Remember that your medical records are yours, so ask for them. Keep a folder with all of your lab reports. Also, keep track of and let your health care team know how you feel.

BUILD EXERCISE AND A HEALTHY DIET INTO YOUR DAILY LIFE

How much you exercise and what you eat are critical for strength, a healthy weight, and feeling happier. It also helps with side effects like neuropathy. Ask for physical therapy or a physical medicine doctor to learn how to protect your body. Build exercise into your daily routine. Even small changes can help you feel better physically and emotionally.

QUESTIONS TO ASK THE DOCTOR WHO WILL TREAT YOU:

Are you a board certified hematologist and/or oncologist?

How many patients with MM do you treat each year?

Do you participate in clinical trials for patients with MM?

How do you stay up-to-date with new treatments and trials for MM?

Do you have access to a stem cell transplant center?

Do you accept my insurance?

Who can I talk with about cost-of-care and financial questions?

Do you work with an oncology nurse or supportive care professional to help me with side effects?



How often and when can I contact you or a nurse with questions? Can I use email or phone, is there a patient portal, or do you prefer questions only at office visits?

Do you work with a social worker and support services for me and my family?

What other members of your team can I talk with as I go through treatment?

Can I have a copy of my test results for my own files?

Who should I talk with about next steps?





Treatments for Multiple Myeloma

The goal of treating multiple myeloma is to help you live as long and as comfortably as possible. MM is not like other cancers. It can be controlled with treatment for some time, but it will likely return. Most people with MM experience several periods of remission (when the signs of cancer are gone) and relapse (when the signs of cancer return).

The good news is that there are many treatments available to manage MM. Also, new research is offering the potential for a cure in clinical trials.

As you begin to explore treatments, tell your doctor about your needs and treatment goals. Discuss your choices now and in the future. Ask about different paths you can take. After you gather information, you can decide what to do.

EXPLORING TREATMENT OPTIONS

There are many different options for treating MM. Your doctors should recommend a treatment plan customized for you. People with asymptomatic myeloma may

be followed closely but not yet put on active treatment. People with active myeloma may begin with a combination of drug treatments, stem cell transplant, or a clinical trial. If you have symptoms, supportive care (like bone strengthening, surgery for bone repair, or kidney care) can also play a role. This chapter walks through the treatment options you may have, depending on your diagnosis.

HOW YOUR DOCTOR DECIDES ON THE BEST TREATMENT PATH TO TAKE

The main factors that help your doctor recommend a certain treatment path include:

- The results of biomarker tests and the stage of your MM
- Your values, goals, and preferences
- Your age
- Your health and symptoms (including whether or not you have kidney disease, heart disease, anemia, or other illnesses)
- Your medical history and what treatments you have already had for MM



TREATMENT PLANNING

Treatment planning is the process of working with your health care team and loved ones to think through short- and long-term treatment plans before you begin.

Before you make a decision about your next steps, try to get answers to all of your questions. (Throughout this book, we offer a lot of questions you can ask!) This will help you feel prepared and in control. Remember that you can always bring someone with you to appointments. They can help you sort through information, take notes, and ask more questions.

TREATMENT GOALS FOR MULTIPLE MYELOMA

- To stop and/or slow the growth of myeloma cells
- To provide long periods of remission (when there are no signs of myeloma)
- To help you feel better when you have pain, fatigue, or other symptoms
- To help you reach personal goals (such as being able to attend an important family event or being active enough to travel).

Let your health care team know what your goals are.

“I started off at a clinic where I didn’t care for the oncologist. I didn’t like his personality or his diagnosis. Quite frankly, I opted to get a second opinion. Since then I have had a wonderful experience. My new oncologist is very caring. The medical staff takes their time, they educate us, and they walk us through the steps.”

—Bill, MM survivor



TIPS FOR TREATMENT PLANNING:

- **Listen to answers.** Any questions you have about the cancer and its treatment are worth asking. Listen closely and keep asking questions until you understand what is being said. Ask for information in a different language or format (like a drawing) if you need to.
- **Bring a friend or relative to take notes or record the doctor** if they are ok with that.
- **Think about the pros and cons.** Your family, friends, current patients, and your health care team can help you think through your options before you pick a path.
- **Ask how likely it is for each treatment path to work for you.**
- **Ask about side effects.**
- **Ask about costs.** Is this treatment covered by your insurance? If not, can you get help paying for it? Are there programs that can help you with other costs (prescriptions, childcare, household costs) while you are in treatment?
- **Ask about your time commitment.** How often will you need to go to the clinic? How long will you be hospitalized? How much work will you miss? Will you need help with child or elder care?
- **Ask about travel.** Where will you go for treatment? How will you get there? Is transportation assistance an option?

NEED HELP MAKING TREATMENT DECISIONS?

Open to Options® is a free telephone or in-person counseling program provided by trained professionals at the Cancer Support Community. It helps you to:

- Talk about your concerns more clearly to your health care team
- Create a list of questions for your health care team that will help you address your specific needs
- Organize your questions for specialists to help you get the most helpful answers from the right people

Call 1-888-793-9355 to schedule an appointment or visit
www.CancerSupportCommunity.org/Cancer-Support-Helpline



QUESTIONS TO ASK DURING TREATMENT PLANNING:

What is the goal of this treatment? (To control the cancer or symptoms, or both?)

What are the chances this will work for me? Could you provide statistics?

Can you put me in touch with others who received the treatment that you recommend?

Can I complete normal activities during this treatment?
(i.e., driving, taking a walk, playing with my dog, etc.)

What are all the steps in my treatment? How will my treatment change over time?

Are there any clinical trials that I should look into?

What kind of side effects might I expect and for how long? When should I tell you about issues? Is it helpful if I write them down?



What can I do to prevent or manage side effects?

Should my diet change at all? (i.e. neutropenic diet)

What else can I do to prepare for treatment and stay healthy?

Can you connect me with a local MM support group?

What should my family and friends expect? Will I need their help?

Will this treatment limit my treatment choices in the future?

If this treatment doesn't control my cancer, what's next?

Who can I call or email if I have questions along the way?



TREATMENTS BY DIAGNOSIS

The choice of treatment(s) you start with depends on the current stage of your disease. It also depends on how far it has progressed and your overall health.

TREATMENT FOR MGUS

Monoclonal gammopathy of undetermined significance (MGUS) means that M proteins (abnormal proteins) are building up in your blood. It usually can't be reversed or cured.

Most often, MGUS causes no problems. MGUS alone requires no treatment. Sometimes, it can develop into blood cancer. Only about 1 in 100 people with MGUS get MM each year. Doctors cannot tell who will develop MM and who will have benign (non-cancerous) MGUS.

MGUS is used as a biomarker or early sign of multiple myeloma. That's why it's important to have regular checkups (the "active surveillance" approach). Checkups will likely be every 6 months to every year. You and your doctor will want to closely monitor the level of M protein in your blood.

If MGUS progresses, you can get treatment early. Most of the time, people with MGUS stay stable for many years or even decades. If you feel stressed and worried about this condition, it is a good idea to talk with your doctor or a counselor. Healthy exercise and diet habits are always helpful and may slow progression. (See Chapter 5 for more information on nutrition.)

TREATMENT FOR MULTIPLE MYELOMA WITHOUT SYMPTOMS (ASYMPTOMATIC OR SMOLDERING MYELOMA)

You may not need treatment right away. When your doctor watches your health closely but does not treat, it is called active surveillance. Treatment should start if or when you begin to have symptoms.

Active Surveillance

Active surveillance (regular testing only) can be used for many years. It is a common practice when cancer is growing slowly and not causing symptoms. Healthy exercise and diet habits are always helpful, and may slow progression. (See Chapter 5 for more information on nutrition.)



Until recently, doctors considered that “standard care” for asymptomatic MM was “active surveillance.” A new study raises questions about this. Ask your doctor to explain your level of risk of progression. You should discuss with your doctor other options or if you may be eligible for a clinical trial. You should discuss the pros and cons of each treatment option. You can learn more about active surveillance and tips on how to cope at www.CancerSupportCommunity.org/active-surveillance

TREATMENT FOR MULTIPLE MYELOMA WITH SYMPTOMS (SYMPTOMATIC OR ACTIVE MYELOMA)

Once you have symptoms like bone pain, infections, or kidney problems (when you’re first diagnosed or after active surveillance) you will need treatment. Most often, a combination or sequence of treatments are used. These can include anti-myeloma drugs, stem cell treatment, and supportive care to manage symptoms. These all can be offered through a clinical trial or as a standard treatment. You’ll likely use different treatments at different times over your lifetime.

Unlike with other cancers, with MM you can re-use a drug or drug combinations over time.

To learn more about approved treatments for multiple myeloma, visit: www.CancerSupportCommunity.org/multiple-myeloma



“When you learn about the tools in your cancer-treatment toolbox, and know that there are new tools coming, you can feel ready for whatever comes next. You’ll feel better that something out there may help you.” —Sheri, Caregiver



QUESTIONS TO ASK ABOUT ACTIVE SURVEILLANCE:

If I wait before starting treatment, will the cancer be harder to control later?

What tests will I need to see if the cancer has advanced? How often should I be tested?

Between appointments, what problems should I be aware of and report to you?

Are there clinical trials I should know about to delay symptoms?

What are you looking for to determine if and when I will need treatment?

SUPPORTIVE CARE DRUGS

Growth Factors to Increase Low Blood Counts

Growth factors treat myeloma by helping the bone marrow produce more blood cells.

- Growth hormones that stimulate red blood cell growth include epoetin alpha (Procrit®, Epogen®) and its biosimilars such as epoetin alpha-epbx (Retacrit®).
- Colony stimulating factors that encourage white blood cell growth include filgrastim (Neupogen®) and its biosimilars such as filgrastim-sndz (Zarxio®) and filgrastim-aafi (Nivestym™).

For information on ways to cope with low red blood counts (anemia) and prevent infections that can result from low white blood counts, see Chapter 5.

Drugs to Strengthen Your Bones

These are given to help prevent bone problems. They can keep myeloma from weakening your bones so you stay out of the hospital.

- Drugs to strengthen the bones include: pamidronate (Aredia®), and zoledronic acid (Zometa®), as well as denosumab (Xgeva®). They are often given with other drugs to increase bone and decrease pain. The first two are given by



IV. Xgeva is given as a monthly shot. Jaw problems are rare, but can be a serious side effect from these drugs. Have a dental checkup before you start. If you begin to have jaw pain or sores while on bone strengtheners, let your doctor know. For more information, see Chapter 5.

STEM CELL TRANSPLANT

Stem cell transplant is a common treatment for healthy patients with MM. This treatment can lead to cancer remission for a long time. For MM patients, it can even be done more than once (after relapse).

A stem cell transplant is an infusion of blood-forming cells (stem cells), not a surgery. A stem cell transplant allows your health care team to use higher-dose chemotherapy than would otherwise be safe to give. The process starts by collecting and freezing healthy blood-forming cells (stem cells) from the patient or a donor. A few rounds of high dose chemotherapy are then used to kill MM cells in the body. After this, the stem cells collected earlier are infused into the patient to replace the blood-forming cells that are killed off by the high dose chemotherapy.

Side effects from a stem cell transplant are mainly due to the chemotherapy. They can include nausea, vomiting, diarrhea, mucositis (painful mouth sores), and fatigue. Other problems include the risk of infection and organ damage to the lungs, liver, and kidneys.

“A stem cell transplant is not a walk in the park, but you do it because you think it will help. You have to be a candidate first of all, and a combination of things must fall into place, and then you hope for the best. It was 30 days in the hospital for me, but it really did help. I’m doing well.”

—Avi, MM Survivor

Two types of transplants are available for patients who qualify:

- Autologous (aw-TAH-luh-gus) or “auto” stem cell transplant is a transplant using your own stem cells. This is used most often for MM. Stem cells are collected from your blood. After this type of transplant, you recover in the hospital for about 10-21 days. New ways to deliver this treatment are allowing some patients to recover outside the hospital (as an outpatient). You can ask about this.



- **Allogeneic** (Ah-loh-jeh-NAY-ik) or “allo” transplant is a transplant using the healthy stem cells from a family member or matching donor. This type is considered riskier than an autologous stem cell transplant. It is rarely used for MM. An allogeneic transplant requires the patient (and donor) to be young and very healthy. Only patients with no other health issues are candidates. To reduce side effects, a mini-allogeneic transplant can be offered that uses lower doses of chemotherapy. Still, there are risks, including death. The hospital stay for this type will be longer. It can be a good option for patients who are likely to relapse. It can also be used for patients who don’t respond fully to other treatment or who relapse after successful treatments.

Navigating a Stem Cell Transplant

If you go through a major procedure like a stem cell transplant, there are many things to consider. Learn what to expect from the procedure, how to prepare for it, and how best to recover.

Only consider having a stem cell transplant at an accredited transplantation center. Make sure that the transplant center and teams are highly experienced at treating MM.

Tips for recovering from a stem cell transplant:

- Read all materials given to you by your health care team about what to expect.
- If you are in the hospital to recover, use technology to stay in touch with friends and family. Ask your doctor if visitors are allowed.
- Learn if you’ll need the help of a caregiver during your recovery period. Ask if there is a social worker or case manager who can help.
- Learn if you’ll need time off of work (and for how long).
- To rebuild energy after the transplant, take naps and be patient.
- Staying active is important. Start slowly with light exercises, build up to walks, then on to strength training as you can.
- Keep antibacterial soap handy for visitors and friends.
- Eat well-cooked foods until you are told that it’s ok to eat raw foods. Learn if you should follow the neutropenic diet. This diet recommends eating well cooked foods, pasteurized dairy products, and purified water while your white



blood cell counts are low. Vitamin D can be important, also.

For more information on stem cell transplant, visit www.CancerSupportCommunity.org/SCT.

RELAPSED MULTIPLE MYELOMA

Relapsed MM is when cancer returns after treatment. This can happen after a period of remission (no symptoms). This is very common for MM. A second period of remission after more treatment is also possible. If you need more treatment, it often helps to seek another opinion with a new MM specialist.

Most often, a combination of treatments are used. A clinical trial may also be a good option. The treatment offered after relapse depends on several things:

- Disease-related symptoms
- The risk of another relapse
- Your general health
- Past treatments
- How well past treatments worked

MAINTENANCE THERAPY TO KEEP MULTIPLE MYELOMA FROM RETURNING

Even when the cancer seems to have been destroyed, MM can return.

Maintenance Therapy is given to patients whose cancer responds well to treatment. It can help prevent the cancer from returning. You will have a schedule for regular blood tests and maybe x-rays to keep track of how you're doing. You will also have to manage treatment side effects, if there are any.

Report any health problems that you have between checkups to your health care team.

Promising immunotherapy-based maintenance therapy is being studied in clinical trials.

It is not helpful to dwell on a possible return of cancer, but it helps to stay aware of your health and find ways to feel your best.

REFRACTORY MULTIPLE MYELOMA (MM THAT DOES NOT GO AWAY WITH TREATMENT)

Refractory (reh-FRAK-tor-ee) myeloma is when myeloma does not respond to treatment. Often, if the first treatment regimen doesn't work, another entire treatment regimen will be tried. Many clinical trials in myeloma are focused on refractory disease. It is worth learning if you qualify for a clinical trial.



For all patients with refractory disease, supportive care and palliative care will help with discomfort and pain.

To learn more about approved treatments for multiple myeloma, visit www.CancerSupportCommunity.org/multiple-myeloma

CONSIDER CLINICAL TRIALS AT ANY POINT

There are two strategies to treat multiple myeloma:

- Standard care — the typical treatment path, understood as the “best available care”
- Care within a clinical trial — the chance to try a new type of treatment within a carefully controlled research setting

There are several treatments available for MM patients today that are effective for some time, but researchers are trying to find a cure. Some treatments in clinical trials are promising. Your health care team should tell you about current clinical trials that may be right for you at different points in your care.

The only way better treatments are found, are thanks to people who take part in clinical trials.

KEY THINGS TO KNOW ABOUT CLINICAL TRIALS

A clinical trial may be the only way to get some of the newest, most hopeful treatments.

Clinical trials aren’t available to everyone. Each trial has rules about who can join.

Not all treatment centers offer clinical trials. And not all centers offer the same clinical trials.

People who receive their treatment through a clinical trial receive high quality care. There are laws to protect the safety of people who participate.

No one receives a placebo or “sugar pill” in place of appropriate treatment. Patients are given either standard care or the new option being tested. If you join a clinical trial, you can leave at any time.

Most often, the trial pays the costs of the drug being studied. Then your health insurance and your copay cover “standard” treatment costs. Be sure to learn about costs and coverage before you begin.

To learn more about clinical trials, visit www.CancerSupportCommunity.org/ClinicalTrials or call 1-888-793-9355.



HOW TO LEARN MORE ABOUT CLINICAL TRIALS AND FIND CLINICAL TRIALS THAT ARE RIGHT FOR YOU:

Ask your health care team if there are any clinical trials that are right for you. To search listings of current clinical trials, visit: **www.cancer.gov/clinicaltrials**. Or see the multiple myeloma clinical trial resources listed in our Resource Section on pg. 64.



DIVERSITY IN CLINICAL TRIALS

Clinical trials are research studies that help patients access the latest treatment developments. Clinical trials rely on patient participation. It is important that people of diverse backgrounds take part in these studies.

If people from all groups enroll in clinical trials, results can better show how treatments work with all patients. Everyone can equally benefit from the newest treatments in clinical trials. Each person who has cancer should be told about clinical trials regardless of race, ethnicity, gender or age.

Studies show:

- People of color, underserved populations, women, and older people do not go on clinical trials as often as white men.
- In 2018, 5,157 patients took part in clinical trials that led to the approval of 17 new cancer drugs. 68% were white, 15% were Asian, 4% were African American, and 4% were Hispanic.
- African Americans make up 13% of the US population, but only 5% of clinical trial participants.
- Hispanics make up 16% of the US population, but only 1% of clinical trial participants.
- Ask your doctor if clinical trials are an option for you. Share any reasons you might be worried about going on a trial. Have a discussion with your care team and family.



QUESTIONS TO ASK ABOUT TREATMENT:

Which treatment(s) do you recommend and why? How does it work?

What are the goals of the proposed treatment(s)? Will it impact my quality of life?

What information do you have so I can learn more about the treatment plan you recommend?

When will treatment start? When will it end? How often and where?

Are there any clinical trials that would be right for me? How do I find out more about them?

Do you recommend a stem cell transplant? If so, tell me about all of the steps.

Do I need a caregiver during and after treatment? If so, for how long?

What are the risks of this treatment? What are the benefits?

What short or long term side effects should I plan for? Can I prevent or treat any of these side effects?

How much will this treatment cost? Will it be covered by my insurance? Is there a social worker or financial counselor I could meet with?

How will I know if my treatment is working?

How often will I need checkups after treatment?

What type of maintenance therapy will I be on?

Can I have MRD (minimum residual disease) testing after treatment?

Assuming my cancer returns, what are the next steps?



HOPE FOR THE FUTURE: NEW TREATMENTS IN CLINICAL TRIALS*

Every multiple myeloma treatment used today was first tested in a clinical trial. The ways multiple myeloma will be treated in the future are being tested now. Current clinical trials research is looking at:

- **Drug Combinations:** Combining approved drugs in new ways. In some cases, myeloma cells stop responding to anti-cancer drugs. This is called multidrug resistance. Doctors hope to avoid this by pairing drugs in different ways.
- **Immunotherapy:** Treatment that uses the body's immune system to identify, attack, and kill cancer cells. Doctors are studying these types of treatments for multiple myeloma. They work in 3 ways. They boost the immune system so it can better fight the cancer. They “mark” myeloma cells so that the immune system can see them better to find and destroy them. And they help deliver treatments directly to the cancer cells.
- **Palliative Care:** A type of treatment focused on managing symptoms and maintaining quality of life. Palliative care (also called

supportive care) is different from hospice or end-of-life treatment. You can have palliative care at the same time as treatment. It can be used at any stage of the illness. Several clinical trials focus on ways to relieve and treat symptoms and side effects. Their goal is to help multiple myeloma patients feel better and improve their quality of life.

- **Precision Medicine:** A new approach to finding the most effective treatment. It is based on each patient's cancer subtype. There are clinical trials studying precision medicine in the treatment of multiple myeloma. Doctors test for biomarkers, cell changes (mutations), or other targets found in the patient's DNA. The treatments “target” that information. Doctors expect “targeted” drugs to work better and give patients better treatment results, such as longer remissions.

Be sure to ask your health care team if clinical trials are an option for you. Find up-to-date information at www.cancer.net/cancer-types/multiple-myeloma/latest-research.

*As of September 2021



Managing Symptoms and Treatment Side Effects

Supportive care is needed to manage symptoms at any stage of the disease. Common problems from MM (like bone pain, fractures, anemia, or kidney damage) will need care right away.

You can keep track of how you feel in a journal or calendar. Take notes about your mental health and your physical health. Keeping notes can help you remember how you're doing over time. Report symptoms or side effects to your health care team, even if they come and go. Your team can use this information to manage your care.

PAIN

Pain can be caused by the myeloma itself, by nerve damage, or by a biopsy or treatment. Let your health care team know when you feel pain. Don't keep it to yourself. If you continue to feel pain, ask if you can talk with a pain management specialist. Pain in the spine and hips are often the first places people with MM feel bone pain.

Think of your pain in terms of a scale from 0 (no pain) to 10 (extreme pain). Track the location, the type of pain

(burning or stabbing, sharp or dull, neuropathy), and how often you feel it. Track what makes it change or feel better.

Bone Strengtheners and Support

Bone pain and weakness is common for people with MM. Tiny breaks or softening in the bone are called lytic or osteolytic lesions. They happen when too many abnormal plasma cells build up in the marrow. It weakens bone structure and leads to pain and weakness.

Vitamin D and calcium can be helpful to keep your bones strong. Also, good nutrition may help you build strength. Regular physical fitness, including daily walks, yoga, or more intense exercise can also keep bones strong. (Check with your doctor about good exercises for you.) Exercise can also help you feel better in general.

When diet and exercise are not enough, bone strengthening drugs, radiation, orthopedic supports, or surgery can help. (See nutrition tips offered later in this chapter.)







Treatments to Strengthen Your Bones

Drugs that strengthen your bones include:

- Bisphosphonates can slow the way MM cells weaken bones.
- Monoclonal antibodies can prevent the growth of cells known to break down bone.

Bone strengtheners may be helpful against active myeloma for a fixed period of time. They may also improve survival rates. The down side is that they can cause side effects, like kidney problems. Several others can cause major dental/jaw problems. Ask if you need a dental exam before starting use of bone strengtheners. If dental problems occur, your doctor may want you to stop this treatment.

Orthopedic (OR-thuh-PEE-dik)

Support—Physical therapy, splinting bones, or surgery to repair breaks may be needed. Treatment for spinal fractures may include painkillers, rest, and maybe exercise (like gentle water exercises).

Radiation Therapy—Radiation therapy uses high powered x-rays to stop the growth of tumors. It can shrink a tumor within a bone and relieve pain. External beam radiation therapy may be used to treat a single plasmacytoma (one tumor caused by MM). Or, it may be used with other treatments. Radiation may prevent paralysis (puh-RA-lih-sis), or loss of movement, if myeloma weakens the spine so it breaks down and/or pinches the nerves.

Spinal Injections—Vertebroplasty (VER-teh-broh-PLAS-tee) and kyphoplasty (KY-foh-PLAS-tee) are similar spinal procedures. For both, bone cement is injected through a small hole into fractures in the spine. It stabilizes the damaged bone and can help with back pain.

Complementary Medicine—Some people find relief from practices like Qi Gong (an ancient mind-body exercise) or acupuncture (needle-pressure therapy). Other tools, like



deep and slow breathing, meditation, or hypnosis can help relieve pain. If you'd like to try a complementary method, talk with your doctor. Some supplements (like St. John's Wort) may affect the drugs you take.

BLOOD PROBLEMS: ANEMIA, CLOTS, AMYLOIDOSIS, OR CALCIUM IN THE BLOOD

Anemia

Myeloma and its treatment can lead to some blood-related problems. Anemia needs treatment right away. Anemia is when your red blood cells do not carry enough oxygen through your body. This can make you feel tired and weak. Other symptoms can be: shortness of breath, a pounding heartbeat, feeling dizzy or faint, or having a hard time with focus.

Medicine (like growth factors, discussed on pg. 35) can help with anemia. If your red blood cell count is very low, a blood transfusion may be offered. Your health care team will check you with regular blood tests. Anemia will be treated when it is found.

Tips to manage anemia:

- Get plenty of rest.
- Eat iron-rich foods (shellfish,

spinach, beans, red meat, quinoa, etc.) and drink plenty of fluid (not alcohol or caffeine).

- Ask your doctor if medicine would help.
- Ask for help from friends or family when your energy is low.
- Stand slowly to avoid feeling dizzy after sitting or resting.

Blood Clots

Several myeloma drugs are known to increase the risk of a dangerous blood clot known as deep vein thrombosis (DVT). Patients taking immunomodulatory drugs (IMiDs) are often given blood thinners to prevent DVT. Aspirin is also recommended during treatment for most patients.

Amyloidosis (A-muh-loi-DOH-sis)

A small number of people with myeloma develop amyloidosis. Amyloid is an abnormal protein (made in the bone marrow) that can build up in tissues or organs. When this happens, it can cause organs to swell. Symptoms will depend on which organ is affected. In the heart, for example, it causes chest pain and swollen feet. Depending on the type of amyloidosis, medicine, chemotherapy, a stem-cell transplant, or other therapy may help.



Calcium in the Blood

When calcium leaves the bones and enters the bloodstream from myeloma, it can make you feel sick. You may lose your appetite or feel nauseated, restless, or confused. A high calcium level can make you very tired, weak, and thirsty. If you have a high level of calcium in your blood, then you will be asked to drink a lot of fluids. Drugs that lower calcium levels in your blood may also help.

INFECTIONS

When living with MM, you may have very low white blood cell counts from the disease and its treatment. Your risk for infections can be high. Even a small infection or cold may become serious. You should tell your health care team as soon as possible if you're feeling sick.

You may be asked to stay away from crowds and people with colds or other contagious diseases. With approval from your oncologist, you should keep up with your vaccines. Encourage friends and family to get theirs too, especially the flu vaccine. When the people around you are protected from infection, it helps keep you safe too (called herd immunity).

Tips to prevent infection:

- Wash your hands often and well (15 seconds — about as long as it takes to sing 1 verse of “Happy Birthday” — of scrubbing) before eating, after the bathroom, and after a sneeze or cough.
- Use hand sanitizer when soap and water are not close.
- Avoid things that may cause cuts. Use antiseptic right away if you get a cut.
- Keep your mouth clean with regular teeth brushing and mouthwash.
- Avoid uncooked meat, chicken, eggs, and seafood. Ask if you can talk to a registered dietician about a “neutropenic diet.”
- Avoid people with colds.
- Ask about vaccines for the flu or pneumonia. Remember that you should not receive any vaccines unless your oncologist approves.
- Ask about the medicine Neupogen and its biosimilars to increase your white blood cells.
- Learn the signs of infection so that you can tell your health care team early. This is not the time to “watch and wait.”



“I try to stay away from situations where there are a lot of germs, because my immune system isn’t very strong. I know that if you sneeze on me, then I’m down for the count, so I’m very careful with that.”

—Cathy, diagnosed with MM

KIDNEY PROBLEMS

The kidneys help clean the blood to remove waste (urine) and regulate the body’s water balance. Some people with MM develop kidney problems from the disease and/or its treatment.

When the kidneys can’t do their job well, extra fluid can build up in tissues (edema). You may notice swollen feet or ankles. If fluid builds in your lungs, you’ll feel short of breath. Talk to your nurse or doctor about eating, drinking, and other tips that can help you.

If kidney problems are severe, you may need dialysis. Dialysis is a treatment to remove waste and fluid from your blood. People with kidney failure on dialysis must keep track of their fluid levels.

There are two types of dialysis.

Hemodialysis (HEE-mo-dy-AL-uh-sis): the patient’s blood flows out of the body through a catheter and into a filter that cleans the blood. Then the cleaned blood returns to the body through the catheter.

Peritoneal dialysis (PAYR-ih-toh-NEE-ul dy-AL-uh-sis): a catheter fills a patient’s abdomen with a dialysis solution that draws wastes and extra fluids from the blood into the abdominal cavity. The wastes and fluids are then drained from the body.

Tips to protect your kidneys:

- Adjust your diet. Limit protein, excessive fluid, salt, phosphorus, and potassium.
- Keep hydrated based on specific daily amounts. Water, decaffeinated drinks, and juice are fine. Avoid alcohol and caffeine. Look for signs of over-hydration such as swollen ankles and problems breathing. If you’re thirsty but shouldn’t drink more, suck on a lemon or ice chips or chew gum.
- Exercise daily for at least 30 minutes. Walking is a great option. If you can, move for even 10 minutes at a time. Your health care team can help you find an exercise



plan that is safe and works for you.

- Keep a healthy blood pressure, cholesterol level, and blood-glucose level.
- Observe and keep a healthy body weight. Inform your doctor of any changes in your weight.
- Take the proper dose of all medicine prescribed. Learn why they may help.

DRUG-RELATED SIDE EFFECTS

All drugs have the potential to cause side effects. Ask your oncology nurse or doctor about the side effects your treatment may cause and what you can do about them. Ask about the best way to manage problems before they begin. This will help you feel prepared and avoid trouble. If you are part of a clinical trial, the research nurse will talk with you about side effects and possible next steps.

Tips to take care of yourself during and after drug treatment:

- Stay hydrated to protect your kidneys. Fluids also help you avoid dehydration, prevent constipation, and limit fatigue.
- Good nutrition is key (see pgs. 52-53). A dietician can help you target your diet. This will help your

energy level, your immune system, and can ease side effects.

- Try to do some form of exercise every day. Exercise fights fatigue, helps you sleep, and can improve your mood. Talk with your health care team about what exercises may help you.
- Wash your hands to prevent infection.
- Learn to relax. Techniques like yoga, meditation, and deep breathing can reduce stress and increase energy.
- Join a support group to connect with others facing cancer and reduce your stress.
- Empower yourself to ask questions, stay informed, and make decisions that feel right.

Frankly Speaking About Cancer: Coping with Side Effects

Download or order a free copy of CSC's *Frankly Speaking about Cancer: Coping with Side Effects* book or planner at **www.**

CancerSupportCommunity.org/cancer-treatment-side-effects.

The planner includes a printable journal to help you track how you feel physically and emotionally.



EMOTIONAL CARE

Most people dealing with a serious illness like myeloma experience periods of anxiety or depression. Because MM is a chronic condition, disease-related stress will come and go throughout your life. There are several ways to get help when you need it. You can find support from organizations that specialize in cancer and MM; from individual therapy; from in-person, telephone, or online support groups; or through other ways of connecting with others living with MM.

If you feel depressed, it's very important to seek help right away. Start by speaking with your doctor, nurse, or social worker.

"It's good to hear about resources I can pursue for some more information."
—Clarence, Caregiver

Unlike anyone else, people who have “been there” can:

- Talk with you about questions you can't easily ask your doctor or friends.
- Share information about where to go for support and services.
- Give you tips to help you stay on track with difficult appointments and treatment schedules.
- Help you learn about what others have done and what has helped.
- Help you feel less alone and more hopeful.

For more information on coping with myeloma, please see Chapter 6.



NUTRITION

Multiple myeloma and its treatments may cause side effects that affect your appetite. Problems can include nausea, constipation, diarrhea, pain, and fatigue. Many people experience weight loss and malnutrition, which can delay or interrupt your treatment. Paying attention to your diet and making important changes can help you feel much better. A healthy diet can even protect you.

Here, we offer healthy eating tips. For your personal needs, consider meeting with an experienced Registered Dietician (RD or RDN). Look for someone who knows about the nutritional needs of myeloma patients. To find a dietician near you, visit the Academy of Nutrition and Dietetics at www.eatright.org/find-an-expert (click “Search by expertise,” click “Cancer/Oncology Nutrition,” and then enter your zip code to locate an RD who works with cancer patients).

You can also get tips on eating well and dealing with eating problems like nausea, constipation, diarrhea, and fatigue at www.CancerSupportCommunity.org/EatingWell.

HEALTHY EATING TIPS

Great foods to eat in general

- Colorful vegetables: dark green, deep yellow, orange, red, or purple. Note: people on blood thinners should avoid kale and leafy greens during treatment.
- Lightly colored vegetables: cauliflower, mushrooms, onions, cucumber, lettuce
- Starchy vegetables: squash, potatoes, corn
- Fresh and dried fruits, avocado
- Nuts, seeds, whole grains
- Tofu and beans

Good sources of iron to manage anemia

- Green vegetables: spinach, bell peppers, broccoli, Brussels sprouts
- Sweet potatoes
- Tropical fruits: mango, papaya, pineapple, guava
- Legumes
- Shellfish
- Lean red meat, liver
- Quinoa



Foods high in fiber

- Whole grains: oatmeal, quinoa, brown rice
- Dried fruits: raisins, figs, apricots, prunes
- Fresh fruits: apples, pears, oranges, berries
- Nuts, beans, lentils
- Broccoli, carrots, artichokes

Stay hydrated

- Water
- Fruit juice
- Coconut, almond, rice milk
- Green tea and decaffeinated tea.
Large amounts of green tea may have protective benefits.
- Fruit smoothies

Foods to limit

- Cured meats, uncooked meats
- Alcohol
- Sugar-sweetened drinks
- “Fast foods” and other processed foods high in fat, starches, or sugars
- Fried foods

Some studies suggest that different supplements may help. For example, many patients talk about using curcumin for its protective benefits. Please talk with your doctor about using any supplement before you begin treatment. Your doctor will want to avoid any conflict with other treatments.

“I have to build my immune system. I went to a nutritionist [Registered Dietitian] and she gave me great information about supplements and how to keep up with good nutrition. It really helps me.” —Cathy, diagnosed with MM





Coping and Moving Forward

Because of the nature of MM, it may require changes in your routine and the way you rely on others in your life. It does not, however, define you. You are not your disease.

Many people feel anxious and unsure about their health through the course of this disease. This is especially true when you:

- Feel symptoms, even if it turns out to be a common cold (for example)
- Need to return to your doctor's office or the hospital for follow-up visits
- Are waiting for test results
- Reach a 5-, 10-, or 15-year anniversary of being diagnosed or in remission
- Feel worried about something—from caring for yourself and your family, to keeping your job and paying bills, to living life the way you're used to.

Since coping with MM can be hard, it's normal for everyone involved to feel a range of emotions. Learning how to cope is critical.

GETTING THE HELP YOU NEED

People you feel close with will want to help you. Think about what each of them can do based on their abilities and time. Keep communication open. Try to be patient with others (and yourself). When a close friend or family member can't help, think about where else to go for back-up support.

Where to go for support:

- Doctors, nurses, and other members of your health care team can answer many of your questions about treatment and life outside of treatment.
- Social workers, counselors, or clergy members can help you work through concerns. Often, social workers can tell you where to find services for financial aid, transportation, home care, and emotional support.
- Support groups are places where patients or their family members meet to share life lessons. Groups meet in person, over the phone, or online. People facing MM often gain a lot of comfort from others who've "been there." A member of your health care team may be able



to connect you with a group. Or, contact an organization listed in the resources section of this book.

- Organizations that specialize in support for people with MM can provide a lot of information and ideas. (See our Resources in Chapter 8 which begin on pg. 64.) Avoid generic health-related websites.

WHAT IS PALLIATIVE (SUPPORTIVE) CARE?

Palliative care focuses on providing relief from an illness like cancer.

Palliative care specialists are highly skilled in treating the symptoms and side effects of MM. Their goal is to help you feel better.

This extra layer of support is offered by a team of doctors, nurses, social workers, and specialists. Palliative

care is different from hospice or end-of-life treatment. You can have palliative care to manage symptoms at the same time as treatment. It can be used at any stage of your illness.

“The autologous transplant went well. Three years later, I take a chemo pill as maintenance therapy. The side effects are minimal — just some fatigue and mild stomach distress. I’m OK with it.” —Laura, MM Survivor

THE DIFFERENCE BETWEEN PALLIATIVE CARE AND HOSPICE

Some people confuse palliative care with hospice. While both palliative care and hospice focus on helping patients and their families feel better, they are different. Hospice focuses on end-of-life care. It is used when active treatment has stopped. Hospice provides comfort to the patient and the patient’s family. For more information on hospice, see pg. 63 of this book.



QUESTIONS TO ASK YOURSELF:

What type of help do I want? (Help at home? Help with driving? Help with insurance?)

Who would I like to talk with about my next steps? Or join me at medical appointments?

Who can help with practical support, such as work leave, family care, insurance, or driving?

Can a website scheduler (like www.MyLifeline.org) make it easy for friends and family to schedule times to help me?

Can a cancer support organization provide me with useful services or information?

Do I want to join a support group?

ADVANCE CARE PLANNING

It's wise to prepare for the future by having your affairs in order. The legal documents listed here can help you do that:

- A will is a legal document that selects who will receive your money and belongings and who will care for your children (if another parent can't). If there is no will in place, an agent of the state may make these decisions.
- A living will lets your doctor know what kind of medical care you want at the end of your life if you can't speak for yourself.
- A durable power of attorney is a person who can make health care decisions for you if you can't make them yourself.
- A power of attorney is a person responsible for making financial decisions if you can't. (Every financial institution and state has different rules, so it helps to learn yours.)
- A do not resuscitate (DNR) order tells your doctors that you would not like CPR if your heart stops beating or if you stop breathing.



These documents let everyone know that the decisions listed in them are yours. They can help the people closest to you feel clear about your wishes at an emotionally difficult time. You can work with an estate lawyer or (as a less expensive option) use free templates online. Share these documents with the people you trust.

“You have to face reality. It’s good to have your will and advanced directives done before anything happens, so the family doesn’t have to worry about anything.”
—Joyce, MM Survivor

POSITIVE LIFE CHANGES

Some people living with cancer talk about the “gifts of illness”—positive changes that occur after a trauma or crisis. Often, people living with MM say that different things are important to them now. Ordinary moments may become more meaningful. This experience may give you a chance to do things you’ve left undone.

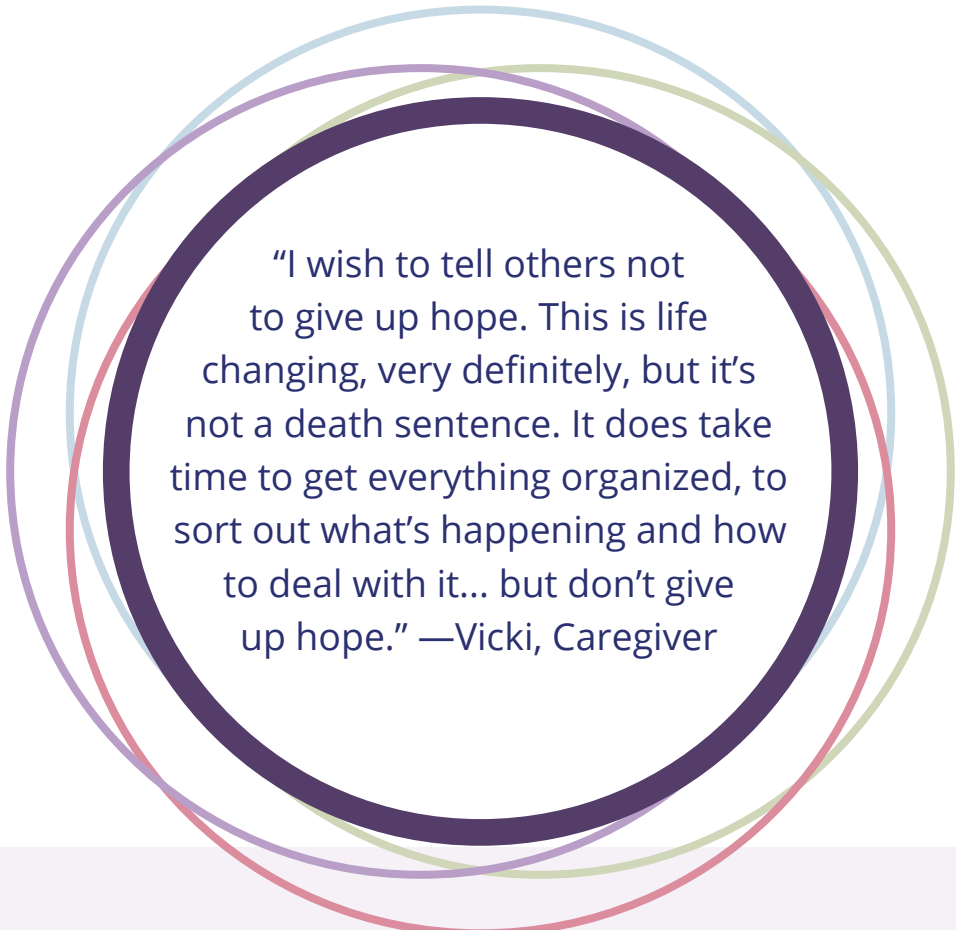
FINDING HOPE

People can hope for many things: for physical and emotional health, peace in relationships, and a way to come to terms with the illness. You can balance hope with a realistic understanding of what may be ahead. You can revise how you view your life, and feel strength in knowing that you are not alone.

CONSIDER YOUR PRIORITIES AND ASK YOURSELF:

1. How can I gain “meaning” in my life?
2. Do I have people that I can count on or should I find help elsewhere?
3. Can I make plans to do something I’ll look forward to?
4. Can I do things that give me a sense of peace or belonging?





“I wish to tell others not to give up hope. This is life changing, very definitely, but it’s not a death sentence. It does take time to get everything organized, to sort out what’s happening and how to deal with it... but don’t give up hope.” —Vicki, Caregiver

MAKING TREATMENT DECISIONS

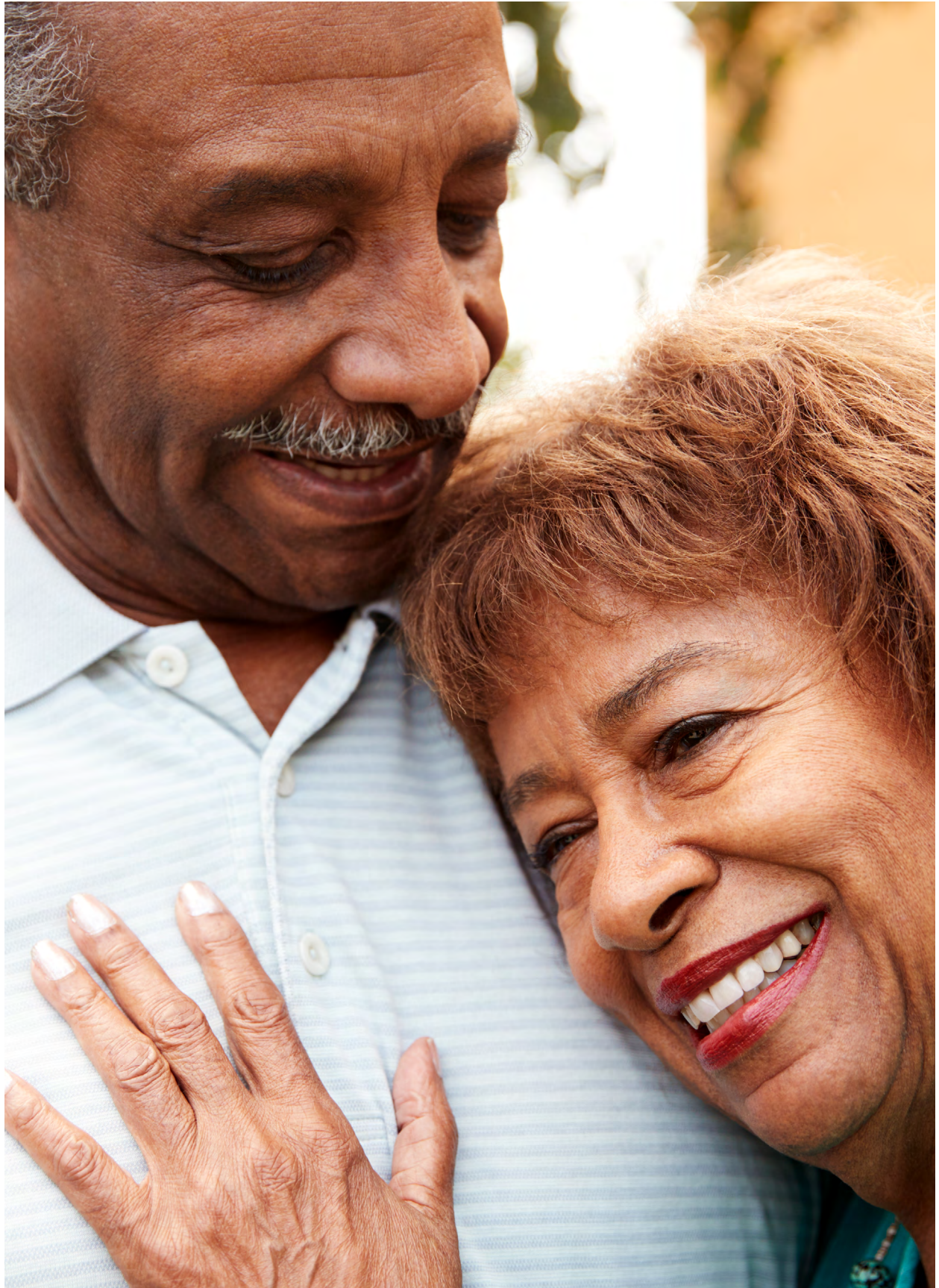
Making treatment decisions does not happen only once. Making treatment decisions is an ongoing process. You will make decisions with your family and care team throughout treatment. If the cancer progresses or returns, you will have more discussions about treatment options. Some questions may be the same as when you first received the diagnosis:

- **What are the treatment options?**
- **What are the goals of treatment?**
- **How can we manage symptoms and side effects?**

But now the answers may be different. Be open and honest with your family and care team about what is important to you.

Identify the support you need, whether that is emotional, logistic, medical, or financial. You may find a support group is helpful later in your cancer journey, even if you didn’t need one at the beginning.





If You are a Caregiver

“It helps to find a good support group. Share with them, and they’ll share back. It reminds you that you’re not in it by yourself. You’ll meet six-year survivors, two years, two months, whatever. Together you’ll see that ray of hope that this is not the end of the road, just a little wave in it.” —Vicki, Caregiver

A caregiver is anyone who provides unpaid help or arranges for help to support a loved one or friend with an illness. Caregivers may provide physical, emotional, spiritual, financial, or logistical help. A lot of pressure can be put upon a caregiver in this role. This gets harder as an illness gets worse.

TIPS FOR THE CAREGIVER

- Learn about the diagnosis. This includes treatment options, possible side effects, and expectations for recovery.
- Research information on credible websites like those listed at the end of this book.
- Ask your health care team if your loved one is eligible for financial assistance. Some pharmaceutical companies even offer drug co-pay support when asked.
- Try to find the best local medical centers and experts for a second opinion or additional services, as needed.
- Weigh the pros and cons of each treatment option with your loved one. Consider things like time, where treatment will be given, cost, and your loved one’s goals for treatment.
- Create a “to do” list with your loved one of immediate and long-term needs. Decide what your loved one can address and what you or someone else can do.
- Recognize and respect the wishes and capabilities of your loved one and the roles of others involved.
- Set your own limits. Define what you can and can’t reasonably do to help.



Organize a care-plan that includes lists of who is doing what and when.

This can help reduce the patient's stress and bring needed relief.

www.MyLifeLine.org can keep track of tasks other friends and family can help with.

- Remember that each stage of care requires different levels of support. Everyone's roles will change along the way.
- Gain permission to get copies of medical records when needed. Legal "Power of Attorney" will allow you or another loved one to help with follow-up care plans and future medical or financial needs.
- Tap into support services such as an oncology social worker or financial navigator. Look for resources from organizations like Cancer Support Community, CancerCare, the Leukemia & Lymphoma Society, or the Multiple Myeloma Research Foundation. They can also connect you with other MM caregivers who understand what you're going through.
- Take care of yourself. When you take care of yourself, you can do a better job of helping your loved one.

- Try to find humor and pleasure in life.
- Enjoy special moments together.

A "BREAK" FOR THE CAREGIVER

Respite Care

Respite care is a service that offers short-term, temporary relief for caregivers. Respite care providers offer intensive care in a patient's home. The health care team can help you get respite care, and address your own needs. If you use respite care, it helps to prepare your loved one. This way everyone feels comfortable with the temporary change in routine.

"My aunt was diagnosed with multiple myeloma 20 years ago. I started as a young adult caregiver. I truly understand the importance of caregivers in a cancer patient's life, recovery, and well-being."

—Stephani, Caregiver



END-OF-LIFE CARE FOR THE PATIENT AND FAMILY

Hospice Care

Hospice is a coordinated program that helps relieve symptoms and provide support when a patient has six months or less to live. Hospice involves care provided by doctors, nurses, social workers, chaplains, and volunteers. Care is delivered in a hospice setting or in the patient's

home. Learn about what hospice can offer you and your loved one before you need it. Most patients and their families do not get the full benefit of hospice, because they and their doctors don't ask for it soon enough.

For more information on caregiving, visit **www.**

CancerSupportCommunity.org/caregivers.



CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge.

To access any of these resources below call 1-888-793-9355 or visit www.CancerSupportCommunity.org

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET and Sat-Sun 9am - 5pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.



Multiple Myeloma Specific Information and Support

AMERICAN SOCIETY OF CLINICAL
ONCOLOGY'S CANCER.NET
[www.cancer.net/cancer-types/
multiple-myeloma](http://www.cancer.net/cancer-types/multiple-myeloma)

CANCER SUPPORT COMMUNITY
1-888-793-9355
[www.CancerSupportCommunity.org/
Multiple-Myeloma](http://www.CancerSupportCommunity.org/Multiple-Myeloma)

INTERNATIONAL MYELOMA
FOUNDATION
1- 800-452-2873
www.myeloma.org

THE LEUKEMIA & LYMPHOMA SOCIETY
800-955-4572
www.LLS.org/myeloma

MULTIPLE MYELOMA RESEARCH
FOUNDATION
866-603-6628
www.themmr.org

NCCN GUIDELINES FOR PATIENTS:
MULTIPLE MYELOMA
[www.nccn.org/patients/guidelines/
myeloma/index.html](http://www.nccn.org/patients/guidelines/myeloma/index.html)

Information About Pain Relief

"PAIN CONTROL" BY THE NATIONAL
CANCER INSTITUTE
[www.cancer.gov/cancertopics/coping/
paincontrol.pdf](http://www.cancer.gov/cancertopics/coping/paincontrol.pdf)

MYELOMA CENTRAL: RECOGNIZING
AND UNDERSTANDING PAIN
[www.myelomacentral.com/recognizing-
and-understanding-pain](http://www.myelomacentral.com/recognizing-and-understanding-pain)

General Cancer Information and Support

AMERICAN CANCER SOCIETY
800-227-2345
www.cancer.org

CANCERCARE
800-813-4673
www.cancercare.org

AMERICAN SOCIETY OF CLINICAL
ONCOLOGY'S CANCER.NET
888-651-3038
www.cancer.net

CANCER SUPPORT COMMUNITY
888-793-9355
www.CancerSupportCommunity.org

NATIONAL CANCER INSTITUTE
800-422-6237
www.cancer.gov

Financial, Insurance and Legal Help

CANCER AND CAREERS
646-929-8023
www.cancerandcareers.org/en

CANCER LEGAL RESOURCE CENTER
1-866-843-2572
www.disabilityrightslegalcenter.org



CO-PAY RELIEF PROGRAM
1-866-512-3861
www.copays.org

HEALTH INSURANCE MARKETPLACE
1-800-318-2596
www.healthcare.gov

NEEDYMEDS
1-800-503-6897
www.needymeds.org

PATIENT ACCESS NETWORK
FOUNDATION
1-866-316-7263
www.panfoundation.org

PATIENT ADVOCATE FOUNDATION
1-800-532-5274
www.patientadvocate.org

Clinical Trials

CANCER SUPPORT COMMUNITY
888-793-9355
www.CancerSupportCommunity.org/ClinicalTrials

THE LEUKEMIA & LYMPHOMA
SOCIETY'S CLINICAL TRIALS MATCHING
SERVICE
800-955-4572
www.LLS.org/clinicaltrials

MULTIPLE MYELOMA RESEARCH
FOUNDATION
866-603-6628
www.themmrf.org/treatment-options/clinical-trials

NATIONAL CANCER INSTITUTE
1-800-422-6237
www.cancer.gov

Caregivers and Self-Care Support

CAREGIVER ACTION NETWORK
202-454-3970
www.caregiveraction.org

HOPE LODGE
(ACS HOUSING SUPPORT)
www.cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge.html

MEALS ON WHEELS
888-998-6325
www.mealsonwheelsamerica.org

Complementary Medicine Information

NATIONAL CENTER FOR
COMPLEMENTARY AND ALTERNATIVE
MEDICINE
888-644-6226
www.nccam.nih.gov



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SO THAT NO ONE FACES CANCER ALONE®

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C., and across the nation.

**For more information, visit www.CancerSupportCommunity.org
or call the toll-free Cancer Support Helpline at 888-793-9355**



**Frankly Speaking About Cancer: Multiple
Myeloma PROGRAM PARTNER**



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Bluebird Bio
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Takeda