

Talking About Multiple Myeloma



A Guide for Talking With Your Healthcare Team



Being diagnosed with multiple myeloma can be overwhelming. This guide can help you feel more prepared, confident, and informed when talking with your healthcare team.

This guide includes:



An overview of multiple myeloma and treatment options



Tips for you to take an active role in your care



Key questions to ask your care team



Reliable resources for information and support

Use this guide to get the answers you need and make decisions that feel right for you.



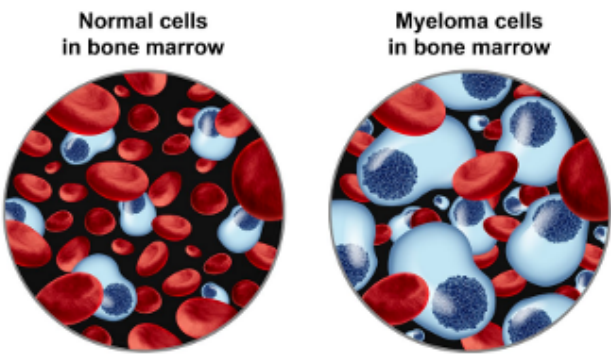
To learn more about multiple myeloma, visit:
www.CancerSupportCommunity.org/Multiple-Myeloma



WHAT IS MULTIPLE MYELOMA?

Multiple myeloma is a rare blood cancer. It starts in plasma cells, which are a type of white blood cell found in the bone marrow. Bone marrow is the soft, spongy tissue inside bones where blood cells are made.

Healthy plasma cells help your body fight infections and other diseases. Multiple myeloma happens when normal plasma cells turn into abnormal/ mutated cells, multiply, and grow out of control. These myeloma (cancer) cells build up in the bone marrow and crowd out healthy blood cells. The myeloma cells keep trying to make antibodies — or tiny proteins in the blood that your body makes to help fight infections. But the antibodies myeloma cells make don't work properly. Instead, these abnormal proteins (called M proteins) cause problems, such as damage to the kidneys, blood cells, bones, and immune system.



Adapted from: National Comprehensive Cancer Network

Some people may not have symptoms at first. Others may experience CRAB symptoms. **These include:**

"CRAB" SYMPTOMS FOR ACTIVE MYELOMA	
C = high calcium	High levels of C alcium in your blood: This can cause extreme thirst, peeing a lot, dehydration, constipation, belly pain, loss of appetite, weight loss, and brain fog or confusion.
R = renal (kidney) problems	R enal (kidney) problems: Your kidneys may not work as well or may start to fail. This can make you feel weak or very sleepy, short of breath, itchy, or cause swelling in your legs.
A = anemia	A nemia (low red blood cells): This can make you feel weak, tired, dizzy, and short of breath.
B = bone problems	B one problems: This can include bone pain, weak or broken bones.

Multiple myeloma can be difficult to diagnose. It may take time and several tests to get a complete diagnosis. Being involved in your care can help. Ask questions, share your concerns, and tell your care team about any changes you notice.



Doctors may use several tests to diagnose multiple myeloma, understand how advanced it is, and help choose the best treatment. These may include:

- Blood tests
- Urine tests
- Imaging tests, like X-rays, CT scans, MRI scans, PET scans
- Bone marrow biopsy
- Biomarker testing

TREATMENT FOR MULTIPLE MYELOMA

Treatment for multiple myeloma depends on:

- The stage of your disease
- Your symptoms
- Your overall health
- Your personal goals and preferences

Multiple myeloma is often treated like a chronic illness, meaning treatment may be needed on and off over time. Treatments may include:

Active surveillance: This is also called watch and wait, watchful waiting, or observation. It is used for patients with MGUS or smoldering multiple myeloma. These are early or slow growing forms of myeloma. Some patients do not need treatment right away. Instead, the healthcare team watches the disease closely with regular checkups and tests. Treatment may start if symptoms appear or the disease begins to get worse.

Targeted therapy: Targeted therapy is a type of treatment that uses special drugs to attack multiple myeloma cells. The type of targeted therapy you receive depends on the results of biomarker testing. These drugs block certain genes or proteins that cancer cells need to grow, divide, and spread. Because they target cancer cells more precisely, they may cause less damage to healthy cells. There are different types of targeted therapy to treat multiple myeloma:

- Immunomodulatory drugs (IMiDs)
- Cereblon E3 ligase modulatory drugs (CELMoDs)
- Proteasome inhibitor therapy (PIs)
- Selective inhibitors of nuclear export (SINE)

Chemotherapy (chemo): Chemo uses drugs to kill or damage cancer cells. These drugs are given through a vein or pill/tablet. It is a systemic (whole body) treatment. Other newer targeted therapy drugs are now commonly used for multiple myeloma. Chemotherapy may still be part of treatment in some situations:

- Before a stem cell transplant and a CAR T-cell infusion
- After a transplant or treatment
- To relieve symptoms
- If the multiple myeloma returns or stops responding to earlier treatments

Immunotherapy: Immunotherapy uses the body's natural defenses (the immune system) to find, attack, and kill cancer cells. There are a few different kinds of immunotherapy used for multiple myeloma:

- CAR T-cell therapy
- Monoclonal antibody therapy (mAbs)
- Antibody-drug conjugates (ADCs)
- Bispecific T-cell engagers (BiTEs)

Stem cell transplant (SCT): In a SCT, patients get an infusion of healthy blood-forming cells (stem cells). The most common type used in multiple myeloma is an autologous stem cell transplant, which uses the patient's own stem cells.

Corticosteroids (steroids): Steroids are often used in combination with other treatments. They are used to kill myeloma cells and reduce inflammation and nausea.

Radiation therapy: This therapy uses high-energy rays to kill or damage cancer cells. In multiple myeloma, it is often used to relieve bone pain or treat plasmacytomas (a single lump of myeloma cells).

Surgery: Surgery is not commonly used for multiple myeloma. It may be used to help stabilize weakened bones or remove plasmacytomas.

Clinical trials: Clinical trials provide patients access to new therapies. They are research studies to test new treatments or learn how to use current treatments better. There are several therapies and drugs being tested for multiple myeloma. Clinical trials are often recommended if your multiple myeloma stops responding to treatment. However, they may be an option at any stage of your disease or treatment.

Supportive care: Multiple myeloma can make your bones weak. It can raise the risk of bone pain, fractures, and high calcium levels in your blood. Supportive treatments can help strengthen the bones, lower the chance of fractures, and reduce pain. Some patients may also receive radiation therapy or procedures to stabilize weak bones when needed.



PALLIATIVE CARE

Palliative care is support that helps you feel better during and after cancer treatment. It focuses on relieving symptoms like pain, tiredness, or stress. A palliative care specialist can help you manage side effects and stay as comfortable as possible. Palliative care is not the same as hospice. It can start at any time, and it is available regardless of your type of multiple myeloma. The goal of palliative care is to help you live as well as possible throughout your cancer experience.



To learn more about palliative care and other treatment options, visit www.CancerSupportCommunity.org/Treatment-Options-Cancer



WORKING WITH YOUR CARE TEAM

Cancer care can be complex and is always changing. You deserve a care team you trust. This team may include doctors, nurses, social workers, and other experts who work together. This is called multidisciplinary care.

The members of your care team may vary at different points throughout your care. These members may include:

Hematologist-oncologist

This is the main doctor leading your care. They specialize in blood cancers like multiple myeloma and help create your treatment plan.

Bone marrow transplant specialist

If you are having a stem cell transplant, this doctor and the transplant team will help manage that treatment.

Radiation oncologist

This doctor specializes in radiation treatment. They may help treat bone pain or areas where myeloma is causing problems.

Interventional radiologist

This doctor uses imaging tests (X-rays and scans) to help with bone marrow biopsies and spine kyphoplasty (small surgery to fix broken bones).

Nurse practitioner (NP) or physician assistant (PA)

These healthcare providers work closely with your doctor. They help manage your care, check on your symptoms, answer questions, and provide treatments.

Oncology nurse

A nurse who specializes in cancer care. They give treatments, help manage side effects, and provide support throughout your care.

Because multiple myeloma can affect many parts of the body, other specialists may also be part of your care team:

- **Nephrologist** – Helps treat kidney problems that can happen with multiple myeloma.
- **Orthopedic surgeon** – Treats broken or weakened bones caused by multiple myeloma.
- **Radiologist** – Reviews imaging tests, such as X-rays, CT scans, MRIs, or PET scans, to help your healthcare team understand your disease.
- **Pathologist** – Examines blood, bone marrow, and other tissue samples to help diagnose multiple myeloma and guide treatment.



You may also work with other healthcare professionals who can support your overall health and well-being:

- **Oncology social worker and therapist/counselor** – Helps you and your caregiver find resources to cope with cancer and its treatment side effects. This includes emotional and mental support, financial resources, transportation, and other services you may need.
- **Registered dietitian** – Helps you eat well, manage treatment side effects, and stay as healthy and strong as possible.
- **Physical therapist** – Helps you stay active, improve your strength and balance, and manage pain or weakness.
- **Psychologist/psychiatrist** – Mental health specialists who can help you and your family understand, manage, and cope with feelings, thoughts, worries, and behaviors. Psychiatrists can prescribe medication.

To learn about care team members, visit
www.CancerSupportCommunity.org/Article/Your-Cancer-Care-Team





BE YOUR OWN ADVOCATE

You are an important part of your care team. It is important to ask questions, share concerns, and speak up before, during, and after treatment. Your needs and preferences help guide your care and help you feel more in control.

If your concerns are not being heard, you have the right to advocate for yourself. Even when you feel tired or unwell, it is important to get the support you need. You know your body best, so reach out for care when you notice new symptoms or side effects.

TIPS FOR APPOINTMENTS

- **Write down your questions** before each doctor's visit. Bring a notebook to take notes or use this resource guide to track your progress over time.
- **Ask your doctor to explain anything you don't understand** when they are talking about your cancer. Ask if they can provide any printed material to help you and your caregiver(s) understand. You can contact your care team at any time if you want more information.
- **Bring someone with you to appointments**, for support and an extra set of eyes and ears. If you attend alone, take notes or ask if you can record the conversation — always check with your doctor first to make sure recording is allowed.
- **Consider getting a second opinion.** A second opinion can confirm the diagnosis and treatment plan, offer other options, and provide different perspectives. Do not worry about hurting anyone's feelings. It is important to feel comfortable with your treatment plan, diagnosis, and care team. But remember, cancer treatment should not be delayed when deciding whether to seek more than one opinion.

Read more about seeking a second opinion at
www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion



MANAGING COSTS

Before you start treatment, talk with your care team or a financial navigator about any financial concerns. They can help you understand what costs to expect, explore ways to manage expenses, and find resources that may reduce your financial stress. This support lets you focus on your care and recovery.



For more information, visit
www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment



TAKING CARE OF YOURSELF

Before you start treatment, talk with your care team or a financial navigator about any financial concerns. They can help you understand what costs to expect, explore ways to manage expenses, and find resources that may reduce your financial stress. This support lets you focus on your care and recovery.



Control what you can:

- If you smoke, get help to stop.
- Stay active and exercise regularly, as long as it is approved by your care team.
- Stay hydrated and eat healthy foods.
- Avoid cured meats, alcohol, sugar, fried foods, and other processed foods high in fat, starches, or sugars.



If you feel anxious or stressed:

- Get the help you need. Your care team can refer you to a support group, one-on-one counseling, behavioral health specialist (psychologist/ psychiatrist), or organizations that specialize in multiple myeloma. They can also connect you with a mentor or another patient who's "been there" and may be a friend.
- Learn relaxation techniques, like deep breathing and meditation.



Consider your priorities and ask yourself:

- How can I gain meaning in my life?
- Can I do things that give me a sense of peace or belonging?
- Can I spend time doing things that I enjoy and are important to me?

For more information, visit

www.CancerSupportCommunity.org/Resource/10-Tips-Eating-Well-Multiple-Myeloma-0



QUESTIONS TO ASK YOUR CARE TEAM

Diagnosis

- *What stage is my multiple myeloma, and what does that mean?*
- *Do I have high risk mutations in my myeloma cells?*

Treatments

- *What are my treatment options? What are the pros and cons of each treatment?*
- *How often will I need treatment and for how long? How long will each session take?*
- *Where will I receive treatments?*
- *How will we monitor how well I'm responding to treatment, and how often?*
- *Are there any new treatments or clinical trials that might be appropriate for me?*

Side effects

- *What side effects should I look out for once I start treatment? What can we do to manage them?*
- *How will treatment affect my daily life? What type of help will I need from a caregiver?*
- *How can I prevent infections with a compromised immune system?*
- *How can I manage pain?*
- *What long-term side effects are possible? What kind of follow-up care will I need?*

Support

- *Who can I reach out to for support? Are there support groups or counseling options that are available to me and my partner/caregiver?*
- *Is there a palliative care specialist to help me manage my quality of life?*
- *What is the contact information for when I have questions? Is there a patient portal that would make communication easier?*
- *How can I manage the costs of treatment? Is there a financial navigator or social worker I can talk with about expenses or insurance questions?*
- *Should my family be tested for genetic risk factors?*

MANAGING SIDE EFFECTS

Everyone's experience with treatment is different. Side effects depend on the type of therapy you receive. It helps to learn about possible side effects before treatment starts. This way, you know what to expect and can work with your care team to manage them.

Below are some of the treatment side effects patients with multiple myeloma may experience. Think about how often you experience each one. Share this with your care team during your next visit. They can talk with you about how to best manage them.



PHYSICAL SIDE EFFECTS	Rarely	Sometimes	Often
Feeling very tired or weak			
Pain (general or in specific area)			
Shortness of breath or trouble breathing			
Frequent infections or getting sick often			
Bruising or bleeding easily			
Nausea, vomiting, or loss of appetite			
Changes in taste, mouth sores			
Diarrhea or constipation			
Weight loss or gain			
Swelling (lymphedema)			
Tingling or numbness			
Darkening of the skin and nails			
Hair loss			
Sleeping problems (unable to fall asleep or stay asleep)			
Other:			

For more information about how to manage treatment side effects, visit:

www.CancerSupportCommunity.org/Managing-Side-Effects

www.CancerSupportCommunity.org/Article/Bone-Health



EMOTIONAL AND MENTAL HEALTH SIDE EFFECTS	Rarely	Sometimes	Often
Fear of disease progression, treatments, or upcoming appointments			
Feeling sad or depressed			
Feeling nervous, anxious, overwhelmed, or afraid			
Difficulty thinking clearly or remembering (brain fog or “chemo brain”)			
Experiencing stigma			
Infertility-related concerns			
Intimacy concerns			
Financial concerns			
Other:			

For more information about how to manage emotional and mental health side effects, visit:

www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns



GETTING SUPPORT

It helps to have emotional support, both during and after cancer treatment. Talking with people who understand your experience can help you cope and feel in control. A good support system can also help you with practical things. Talk with your care team about resources for social, emotional, and practical support. Ask if they can connect you to a support group for people with multiple myeloma. A social worker can be a great resource for mental health, financial, and transportation support. They may also connect you with other healthcare providers about managing side effects of treatment.

Below is a list of trusted organizations. Cancer Support Community and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others impacted by multiple myeloma.

MULTIPLE MYELOMA RESOURCES

Cancer Support Community

888-867-5309 | www.CancerSupportCommunity.org/Multiple-Myeloma

American Cancer Society

800-227-2345 | www.Cancer.Net/Cancer-Types/Multiple-Myeloma

Blood Cancer United

800-955-4572 | BloodCancerUnited.org/Blood-Cancer/Myeloma

Health Tree Foundation

800-709-1113 | www.HealthTree.org/Myeloma

International Myeloma Foundation

800-452-2873 | www.Myeloma.org

Multiple Myeloma Research Foundation

1-888-841-6673 | www.TheMMRF.org

National Cancer Institute

www.Cancer.gov/Types/Myeloma

National Comprehensive Cancer Network (NCCN)

www.NCCN.org/PatientResources/Patient-Resources/Guidelines-For-Patients/Guidelines-For-Patients-Details?PatientGuidelineId=24

NCI Clinical Trials

www.Cancer.gov/ClinicalTrials

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline at CSC-867-5309 (or outside the U.S., toll-free 888-793-9355), available in 200 languages.

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 CSC-867-5309 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 over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more
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 secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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**.

This publication is available to download and print yourself at
www.CancerSupportCommunity.org/Multiple-Myeloma

For print copies of this publication or other information about coping with cancer, visit
Orders.CancerSupportCommunity.org.

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other healthcare professionals to answer questions and learn more.

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