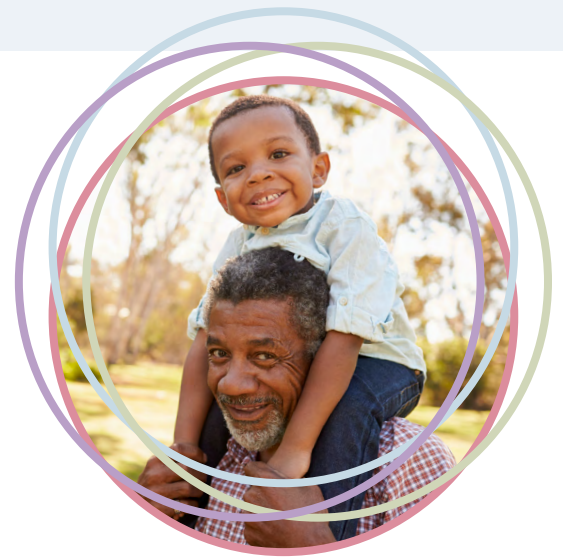


## Multiple Myeloma in Black and African American Communities



Multiple myeloma is the 2<sup>nd</sup> most common blood cancer in the United States. About 131,390 people in the U.S. are currently living with multiple myeloma. Because of new treatments, many more people are living with multiple myeloma as a chronic, or life-long, condition than 15 years ago.

Members of the Black and African American community are diagnosed with multiple myeloma more than twice as often as other groups. They also have symptoms at much younger ages, often by age 50 rather than age 65.

Learning what multiple myeloma is and what the signs and symptoms are can help you and your care team catch the disease early, when it is easier to treat. Asking about the latest treatments and clinical trials can also help you have more options.

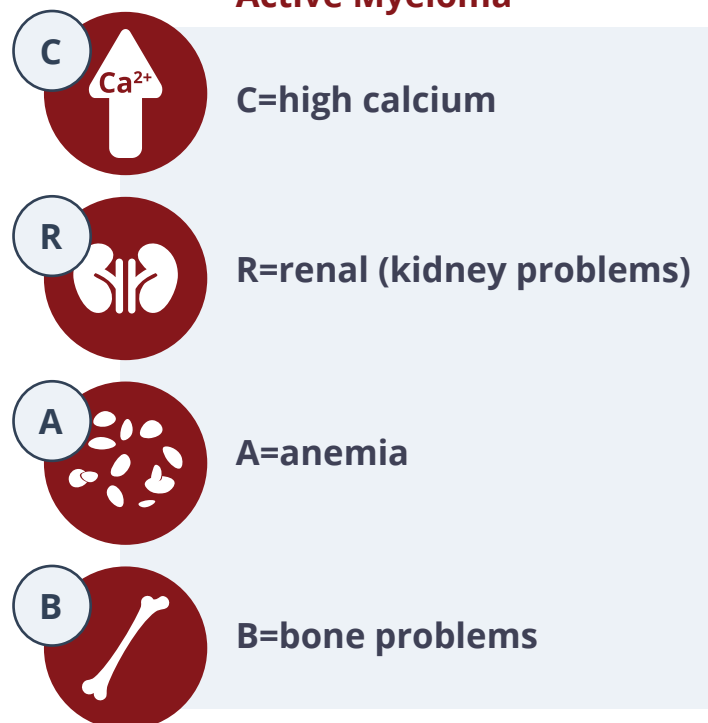
### WHAT IS MULTIPLE MYELOMA?

Multiple myeloma starts when white blood cells, called plasma cells, grow out of control. When myeloma cells grow in bone marrow, they weaken the immune system. Problems develop, like:

- High levels of a protein called M protein and/or other markers in blood or urine
- Tiredness and foggy thinking from high calcium in the blood or urine
- Kidney (renal) problems
- Anemia (low red blood counts)
- Infection and illness
- Weak or broken bones

These problems are often called CRAB symptoms.

### “CRAB” Symptom for Active Myeloma



## WHY ARE AFRICAN AMERICANS AT RISK FOR MULTIPLE MYELOMA?

It's not clear why African Americans are more than twice as likely to develop multiple myeloma. Or, get it at younger ages.

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 protein.

Though we don't know the reason why, it is still important to know that differences for African Americans with multiple myeloma do exist.

An important risk factor is access to health care. Not having health insurance or having high co-pays make people less likely to go to a health care provider for non-emergency needs. Not having a multiple myeloma specialist on your care team leads to worse outcomes. So it's important to see one as you think about treatment options or to ask your doctor to consult with one on your care. Learning about the latest treatments also may help you feel comfortable asking your health care team about stem cell transplants, clinical trials, and other treatment options.

When choosing your health care team, it is important that you can have honest and open conversations. During appointments, make sure you share all of your concerns and feel like you are being heard.

At any point in your care, you can get a second opinion.

Black and African American people are underrepresented in clinical trials when compared with many groups. When people from all backgrounds aren't included in research, the results do not show how treatments will work for everyone. Talk to your health care team about whether there is a clinical trial that is right for you. Clinical trials often test the most cutting-edge treatments and give you a high level of care.



## WHAT CAN HELP?

Early diagnosis helps. The earlier someone is diagnosed, the more options you have for treatment and overall cancer care. Multiple myeloma is not like other cancers. It involves several periods of illness, recovery, relapse (illness again), and remission (health). It is key to also learn about new treatment options.

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**M Proteins=Abnormal Protein**

All patients have better health outcomes when better treatment is available. Currently, research in clinical trials is finding better treatments. Some may even lead to a cure. Yet, only about 4.5% of clinical trial participants are African American (while 20% of patients with multiple myeloma are African American). Generally, African Americans would benefit from accessing the newest treatments through clinical trials. Information on which treatments are best for people with different genetics can only

be found through clinical trials. Information on which treatments are best for people with different genetics can only be found if people from diverse backgrounds take part in clinical trials

Learn more about multiple myeloma at [www.CancerSupportCommunity.org/Multiple-Myeloma](http://www.CancerSupportCommunity.org/Multiple-Myeloma).

### **TERMS YOU MAY HEAR AFTER DIAGNOSIS**

- **MGUS:** Monoclonal Gammopathy of Undetermined Significance. This means abnormal plasma cells (M protein) are in the blood, but not many. (M protein is less than 3 g/dL). This is very common. Patients with MGUS progress to multiple myeloma at a rate of 1% each year. There are no symptoms. Black and African American people seem to be more likely to have MGUS. Having MGUS is a risk factor for multiple myeloma.
- **Smoldering Myeloma:** This means M protein levels in the blood are over 3 g/dL and 10-60% of bone marrow has abnormal plasma cells. There are no symptoms. Patients progress to active multiple myeloma at a rate of 10% each year.
- **Active Multiple Myeloma:** For this diagnosis, M protein and cancerous plasma cell levels are high. Bone lesions (holes in bones) are found. These patients have at least one CRAB symptom or a 90% chance to develop CRAB symptoms.

- **Active Surveillance:** If you don't have active multiple myeloma, your health care team may recommend active surveillance, also called "watch and wait." This means you and your health care team will watch for symptoms and schedule regular tests. But you won't have any other type of treatment.

## WHAT TESTS ARE DONE TO CONFIRM, TRACK, AND FOLLOW UP ON MULTIPLE MYELOMA?

The earlier multiple myeloma is diagnosed, the easier it is to manage. Talk to your health care team about any unusual or ongoing symptoms. For example, if you feel tired, urinate a lot, and get confused easily, talk to your doctor about getting tested for multiple myeloma. Here are some tests your health care team may order if they are looking for multiple myeloma:



|   |   |
|---|---|
| <b>BLOOD &amp; URINE TESTS</b>          | <ul style="list-style-type: none"> <li>• Anemia, electrolytes, and kidney function</li> <li>• M protein amounts</li> <li>• Bone loss</li> <li>• Staging</li> </ul>    |
| <b>KIDNEY TESTS</b>                     | <ul style="list-style-type: none"> <li>• Kidney damage and overall kidney function</li> </ul>   |
| <b>SCANS: X-RAY, MRI, CT, OR PET</b>    | <ul style="list-style-type: none"> <li>• Broken bones</li> <li>• Lytic (bone) lesions</li> </ul>  |
| <b>BONE MARROW BIOPSY</b>               | <ul style="list-style-type: none"> <li>• Myeloma cells in bone marrow</li> </ul>  |
| <b>BIOMARKER TESTING OF BONE MARROW</b> | <ul style="list-style-type: none"> <li>• Mutations in the DNA of myeloma cells: Fluorescence in situ hybridization (FISH), karyotyping, and DNA sequencing</li> </ul> |



## WHAT SHOULD YOU KNOW?

Hematologist oncologists are the doctors who know the most about multiple myeloma. They hope to treat people as soon as possible, based on test results and staging. The goal is to reduce the rate of M proteins and limit or manage symptoms over time. You may have periods when you need treatment, and others when you don't. Better treatment plans help multiple myeloma patients live longer and healthier lives.

Talk to your care team about clinical trials. Clinical trials are safe and appropriate for everyone at any stage of multiple myeloma. New antibody therapies combined with standard treatments, immunotherapies, and new types of drugs show promise. They may even lead to a cure.

Talk with a doctor who's experienced in treating multiple myeloma. They should also know a lot about new treatment options. Ask for a second opinion if your doctor is not aware of clinical trials available to you. A second opinion does not mean you have to leave your doctor. It's just getting more people on your care team.

Throughout treatment, patients with multiple myeloma will work with both their hematologist oncologist and primary care physician to manage their care. Make sure that your primary care physician is aware of your multiple myeloma diagnosis. If possible, connect your primary care physician and oncology team to work together to help you achieve your health care goals.

## TALK TO YOUR COMMUNITY

Talk to friends, family, and your community about how you have been affected by multiple myeloma. Remember that you are not alone. It can be helpful to talk to people who have similar experiences to feel supported. Your care team may be able to share local support groups for people with multiple myeloma and their caregivers. Support may also be found in your religious organizations, workplaces, and other communities. Sharing your story may help others with their own multiple myeloma experience.



## 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](http://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](http://www.CancerSupportCommunity.org/FindLocation).

**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](http://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](http://www.CancerSupportCommunity.org/become-advocate).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

Frankly Speaking About Cancer:  
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