Information and resources for African Americans living with multiple myeloma and their caregivers

Pictures do not depict actual patients
Standing in the Gap:
An initiative created to help bridge the gaps in care for African Americans living with multiple myeloma.

The essence of the phrase “Standing in the Gap” is: *I am there for you, I have your back, I will provide the bridge to help you achieve your goals.*

Celgene has created the “Standing in the Gap for African Americans with Multiple Myeloma” initiative to help spread the word about how multiple myeloma affects African Americans differently, in order to improve the quality of the care they receive.
Multiple myeloma is the second most common form of blood cancer in the United States, and the most common blood cancer among African Americans, yet it is still relatively rare. It affected almost 96,000 Americans, including almost 20,000 African Americans, in 2013. The good news is that some studies suggest that compared to white Americans, African Americans tend to have less aggressive forms of multiple myeloma and may have a better prognosis when receiving the proper care. This means that when African Americans get the care they need, they may be able to live longer with the disease. However, data suggest that African Americans with multiple myeloma aren’t always getting the appropriate care they need.

Join us in Standing in the Gaap. The Standing in the Gaap initiative offers information and resources to help you feel more confident and involved in your care. Get informed, find out about support available to you, and work with your doctors and nurses to get the best care possible.
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About Multiple Myeloma
What is multiple myeloma?

Multiple myeloma is a rare cancer that affects your blood and bones. Multiple myeloma is a type of cancer that develops in the soft, spongy tissue at the center of your bones, called bone marrow. Multiple myeloma causes cancer cells to accumulate, where they crowd out healthy blood cells and can prevent your immune system from working properly.

Multiple myeloma is a long-lasting disease. Work with your doctors and nurses to learn more about how it may affect you.
What is multiple myeloma?

Healthy white blood cells help your body fight infection and disease. Multiple myeloma affects a certain kind of white blood cell called plasma cells. These plasma cells are made in your bone marrow.

White blood cells
- Help the body fight infection and other diseases.

Plasma cells
- A type of white blood cell that helps the body fight infection and other diseases.

Red blood cells
- Carry oxygen from the lungs to all parts of the body.

Platelets
- Help form blood clots to slow or stop bleeding and to help wounds heal.

Healthy blood cells in the bone marrow
In people with multiple myeloma, plasma cells develop abnormally. These cells are called myeloma cells. They grow and spread in the bone, leaving no room for healthy cells to grow. This condition is called multiple myeloma.

Myeloma cells can also stop healthy plasma cells from working. When healthy plasma cells can’t grow, they can’t fight off diseases. This means even more myeloma cells can grow. This cycle can go on and on and can cause multiple myeloma to get worse over time.
How can **multiple myeloma** affect you?

CRAB is an acronym used to describe the most common symptoms of multiple myeloma. It stands for Calcium, Renal, Anemia, and Bone. It may also be accompanied by infection caused by a weakened immune system.

<table>
<thead>
<tr>
<th>Sometimes multiple myeloma can cause</th>
<th>It might make you feel</th>
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</thead>
<tbody>
<tr>
<td><strong>Calcium</strong></td>
<td>Very tired - Confused</td>
</tr>
<tr>
<td>Too much calcium in your blood</td>
<td>Nauseated, you may even vomit</td>
</tr>
<tr>
<td></td>
<td>You may lose your appetite</td>
</tr>
<tr>
<td></td>
<td>You may urinate more often</td>
</tr>
</tbody>
</table>

| **Renal**                             | Very tired - Confused  |
| Kidney problems                       | Nauseated, you may even vomit |
| sometimes called renal problems       | You may lose your appetite |
|                                      | You may urinate more often |
|                                      | You may have high blood pressure |
For African Americans living with Multiple Myeloma

Don’t be shy. **Always talk to your doctors and nurses** if you’re feeling any **pain or discomfort**.

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<td>Very tired - Dizzy</td>
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<td>Too few oxygen-carrying cells in your blood</td>
<td>You may have headaches</td>
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**Anemia**
- Too few oxygen-carrying cells in your blood
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- You may have headaches
- Out of breath
- You might feel cold

**Bone**
- Bone problems
- Bone pain, which may be a sign of bone fractures
How is multiple myeloma treated?

Although there is no cure for multiple myeloma, it’s still important to treat it. Many new medicines have been approved in recent years. People diagnosed today are now living longer than they would have if they were diagnosed 10 years ago.

If you are diagnosed with multiple myeloma, your primary physician will send you to get treated by an oncologist, a type of doctor who specializes in treating cancer, or a hematologist, a doctor specializing in treating blood disorders. Your oncologist or hematologist might talk with you about many different treatment options, including:

**Chemotherapy and other drugs**
Treatment with drugs that are meant to destroy or control cancer cells. Chemotherapy may harm healthy surrounding cells.

**Targeted therapies**
Treatments that precisely identify and attack cancer cells. Targeted therapy may have different and less severe side effects.
Stem cell transplant
A medical procedure that may be used as a treatment for multiple myeloma. It replaces stem cells in the body after bone marrow has been destroyed.

Radiation
Radiation therapy is the use of high-energy particles or rays to damage cancer cells and prevent them from growing. Other names for radiation therapy include radiotherapy, x-ray therapy, and irradiation.

Talk to your healthcare provider to learn more.

Bring someone along with you for your office visits, such as a friend or family member.
Multiple Myeloma in African Americans
What’s different about multiple myeloma for African Americans?

It’s more common

Multiple myeloma is a rare cancer, yet African Americans are twice as likely to be diagnosed with multiple myeloma than white Americans. The reason for this is not completely understood.

Yet it remains a rare cancer. About 6000 African-American patients were estimated to have been newly diagnosed with multiple myeloma in 2016.
What’s different about multiple myeloma for African Americans?

African Americans make up a significant number of Americans living with multiple myeloma.

TODAY

African Americans currently represent about 20% or 1 out of 5 patients living with multiple myeloma.

The US African-American population is expected to grow much more quickly than the white population. Because of this, African Americans will make up even more of those living with multiple myeloma in the future.
It’s usually diagnosed at a younger age

African Americans are diagnosed with multiple myeloma at a younger age.

71 years
Average age at diagnosis for white Americans

66 years
Average age at diagnosis for African Americans

Some studies suggest that the type of multiple myeloma that affects African Americans tends to be less aggressive with a better prognosis. However, it's still important that you seek the proper care.
What’s different about multiple myeloma for African Americans?

African Americans are less likely to have access to appropriate care

African Americans with multiple myeloma have benefited less from survival improvements in recent years. This might be because African Americans may not have had the same access to treatments.

However, when treated for multiple myeloma, African Americans do just as well as, and sometimes even better than, white Americans.

You deserve it. Talk to your doctor about how you can get the best treatment for you.
Stem cell transplant is a standard of care in multiple myeloma

An **autologous stem cell transplant**, which is the most common type of transplant in multiple myeloma, is a procedure in which the patient donates his or her own **stem cells** and does not require someone else to donate the cells to the patient. Stem cells are collected from the patient and preserved, then transplanted at a later time.

To learn more about stem cell transplants, visit [www.myelomacentral.com](http://www.myelomacentral.com).

According to a study: African Americans are more than 40% less likely to have a stem cell transplant vs white Americans.

**Ask your doctor** if you are a candidate for a **stem cell transplant**.
What should I know about clinical trials?

Joining a clinical trial should be considered as another treatment option for multiple myeloma.

**Clinical trials** are necessary for new medicines to be approved by the US Food and Drug Administration (FDA). They have played a major role in advancing the treatment of multiple myeloma, and without these trials and the patients who voluntarily participated in them, we would not have the treatment options we have today.

When you participate in a clinical trial, you add to the knowledge about cancer and help improve cancer care. It is through clinical trials that researchers can determine whether new treatments are safe and effective and work better than current treatments.

Why does it matter who joins a clinical trial?

African Americans make up almost a quarter of people living with multiple myeloma today. Yet only 8% of patients in cancer clinical trials are African Americans. Therefore, it is important that they are represented in clinical trials to better understand and address the needs of African Americans.
What should I know about joining a clinical trial?

• There are both benefits and risks to clinical trial participation. You can talk to your doctor to learn more.
• People who participate in clinical trials for a cancer drug will always receive at least a current standard treatment or the new drug being studied.
• You are free to quit the trial at any time if you experience unwanted side effects, if the treatment is not working for you, or for any reason at all.
• If early results show that one group being studied is seeing a clear, significant benefit over the other group, the researchers will stop the study so that all volunteers can receive the better treatment.

To learn more about clinical trials and how they work, watch the Understanding Clinical Trials video presented by Dr. Craig Cole, available at www.MyelomaCentral.com.

To search for multiple myeloma clinical trials, visit www.clinicaltrials.gov.
It’s important to be open and honest with your doctors and nurses. Always tell them how you’re feeling at every visit. Feel free to ask questions about your health and your treatment. It may be helpful to bring a list of questions to each appointment.

Here are some examples of questions you may want to ask your doctor or nurse:

**Questions about diagnosis**

- How is multiple myeloma different from other cancers, like breast or lung cancer?
- How would you describe my risk level?
- What is my *prognosis* (outlook)?
- What doctors will be involved in my care?
- Will there be one doctor or nurse coordinating my care?
Talking with your doctor

Questions about testing

• What should I expect when I go for testing?
• What types of tests will I undergo, and how often?
• What will I need to do to prepare for these tests?
• Where will I go for these tests?
• When and how will I get the results of my tests?
• Can you explain what my results mean after each test?

Questions about treatment

• What types of treatments are available for multiple myeloma?
• What are the benefits and risks of each treatment?
• What treatment do you recommend, and why?
• What other options do I have?
• Will I be able to continue my normal work schedule with this treatment?
• Do I need chemotherapy as part of my multiple myeloma treatment?
• Could a stem cell transplant be an option for me?
• Could a clinical trial be an option for me?
• What are your thoughts on visiting a multiple myeloma specialist? Is there a multiple myeloma specialist you would recommend and would coordinate with?
Questions about paying for treatment

- Can I get help paying for treatment and related expenses?
- Is this treatment covered by my insurance?
- Are there patient assistance programs?
- Is there a financial counselor or someone in the office I can speak with about affording treatment?
Get Support
Foundations can offer support for people living with multiple myeloma. Pharmaceutical companies also offer assistance and education.

It’s okay to ask for help. There are lots of organizations dedicated to helping patients just like you.
Where can I go for help?
Learn more and find support

BlackDoctor.org
Black health news and information on fitness, nutrition, and weight loss.

www.blackdoctor.org

Cancer Support Community
A social and emotional support network for people impacted by cancer.

www.cancersupportcommunity.org | Phone: 202-659-9709 | Toll Free: 888-793-9355

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For African Americans living with Multiple Myeloma

International Myeloma Foundation

Multiple myeloma research, clinical trial information, events, fundraising information, and newsletters.

www.myeloma.org  I  Phone: 800-452-cure (2873) or 818-487-7455

Leukemia and Lymphoma Society

The largest voluntary health organization dedicated to funding research, finding cures, and ensuring access to treatments for patients with blood cancer.

www.ills.org  I  Phone: 914-949-5213

Information about independent organizations is provided as an additional resource for obtaining information related to multiple myeloma. It does not indicate endorsement by Celgene Corporation of an organization or its communications. Your healthcare team is your best source of information.
Where can I go for help?
Learn more and find support

Multiple Myeloma Research Foundation
A nonprofit research foundation whose mission is to accelerate next-generation multiple myeloma treatments to extend patients’ lives in pursuit of a cure.

www.themmrf.org | Phone: 203-229-0464

The Myeloma Beacon
Multiple myeloma news, resources, and online forums for patients, medical professionals, and others interested in multiple myeloma.

www.myelomabeacon.com

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More resources for you and your loved ones

How can I find support within my own community?

You are not alone. There are resources and community members who will help you with daily activities.

- Ask your doctor or nurse about a local multiple myeloma support group near you.
- Church groups may offer support, transportation, or meals.
- Local elderly assistance groups may also offer meals and transportation, as well as housecleaning services.

Find comfort in your community. Look for local organizations that may be able to help you and your loved ones.
Caregiver support

Caregivers must remember to care for themselves too. Seeking help and accepting help when it is offered will enable you to better care for yourself and your loved one with multiple myeloma.
Glossary
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anemia</td>
<td>A condition in which the number of red blood cells is below normal.</td>
</tr>
<tr>
<td>Autologous stem cell transplant</td>
<td>A type of stem cell transplant in which the patient is a self-donor. Stem cells are collected from the patient and preserved, then transplanted at a later time. Autologous transplants are the most common type of transplants for multiple myeloma.</td>
</tr>
<tr>
<td>Blood cancer</td>
<td>Cancer that begins in blood-forming tissue, such as the bone marrow, or in the cells of the immune system. Examples of blood cancer are leukemia, lymphoma, and multiple myeloma.</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>The soft, sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.</td>
</tr>
<tr>
<td>Calcium</td>
<td>A mineral needed for healthy teeth, bones, and other body tissues. It is the most common mineral in the body.</td>
</tr>
<tr>
<td>Cancer</td>
<td>A term for diseases in which abnormal cells divide without control and can invade nearby tissues.</td>
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<tr>
<td>Chemotherapy</td>
<td>Treatment with drugs that are meant to destroy or control cancer cells. Chemotherapy may harm healthy surrounding cells.</td>
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<td><strong>Clinical trial</strong></td>
<td>A type of research study that tests how well new medicines work in people. Also called clinical study.</td>
</tr>
<tr>
<td><strong>Hematologist</strong></td>
<td>A doctor who specializes in treating blood disorders.</td>
</tr>
<tr>
<td><strong>Immune system</strong></td>
<td>A complex network of cells, tissues, organs, and the substances they make that helps the body fight infections and other diseases.</td>
</tr>
<tr>
<td><strong>Multiple myeloma</strong></td>
<td>A type of cancer that begins in white blood cells. As the number of multiple myeloma cells increases, the body can’t make enough healthy blood cells. Multiple myeloma cells also damage and weaken the bone.</td>
</tr>
<tr>
<td><strong>Myeloma cells</strong></td>
<td>Abnormal white blood cells that build up in the bone marrow.</td>
</tr>
<tr>
<td><strong>Oncologist</strong></td>
<td>A doctor who specializes in treating cancer.</td>
</tr>
<tr>
<td><strong>Placebo</strong></td>
<td>An inactive substance that looks the same as, and is given the same way as, the medicine or drug being tested. Sometimes called a sugar pill.</td>
</tr>
<tr>
<td><strong>Plasma</strong></td>
<td>The fluid part of the blood that carries the blood cells.</td>
</tr>
<tr>
<td><strong>Plasma cells</strong></td>
<td>A type of white blood cell that helps the body fight infection and other diseases.</td>
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<td><strong>Platelets</strong></td>
<td>Platelets are found in the blood. They help form blood clots to slow or stop bleeding and to help wounds heal.</td>
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<tr>
<td><strong>Prognosis</strong></td>
<td>The likely outcome of a disease or the chance of recovery or recurrence.</td>
</tr>
<tr>
<td><strong>Radiation</strong></td>
<td>X-rays that reach and destroy cancer cells.</td>
</tr>
<tr>
<td><strong>Red blood cells</strong></td>
<td>A type of blood cell that is made in the bone marrow and found in the blood. Red blood cells carry oxygen from the lungs to all parts of the body.</td>
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<td><strong>Stem cell transplant</strong></td>
<td>A method of replacing blood-making cells in the bone marrow.</td>
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<td><strong>Stem cells</strong></td>
<td>A cell from which other types of cells grow. For example, blood cells grow from blood-forming stem cells.</td>
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<td><strong>Targeted therapy</strong></td>
<td>A treatment that precisely identifies and attacks cancer cells. Targeted therapy may have different and less severe side effects.</td>
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<td><strong>White blood cells</strong></td>
<td>A type of blood cell that is made in the bone marrow and found in the blood. White blood cells help the body fight infection and other diseases.</td>
</tr>
<tr>
<td><strong>X-ray</strong></td>
<td>A type of radiation used to detect and treat diseases. In large amounts, x-rays are used to treat cancer.</td>
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