Standing in the Gaap

For **African Americans** living with **multiple myeloma**

Actual patients living with multiple myeloma

Let's **stand together** for change

The essence of the phrase
"Standing in the gap" is:

I am there for you,

I have your back,

I will support you however I can.

Standing in the Gaap
For African Americans
Living with Multiple Myeloma

Why we are
Standing in the Gaap

- **Multiple myeloma** is considered a rare form of cancer
- Even though it is relatively rare, it is the most common form of **blood cancer** among African Americans
- According to data, African Americans with multiple myeloma aren't always getting **appropriate care**
- Learning about current treatments and access to clinical trials can help you **advocate for yourself**
- The Standing in the Gaap initiative was created to help **raise awareness** of these issues, and help improve the quality of care for African Americans living with multiple myeloma

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 create a care plan to treat your multiple myeloma.

Visit our website and join us on Facebook:
StandingintheGaap.com
@StandingInTheGaap

“The more information you have, the more power you have and that helps you make a decision.”

Gwendolyn
An actual patient living
with multiple myeloma

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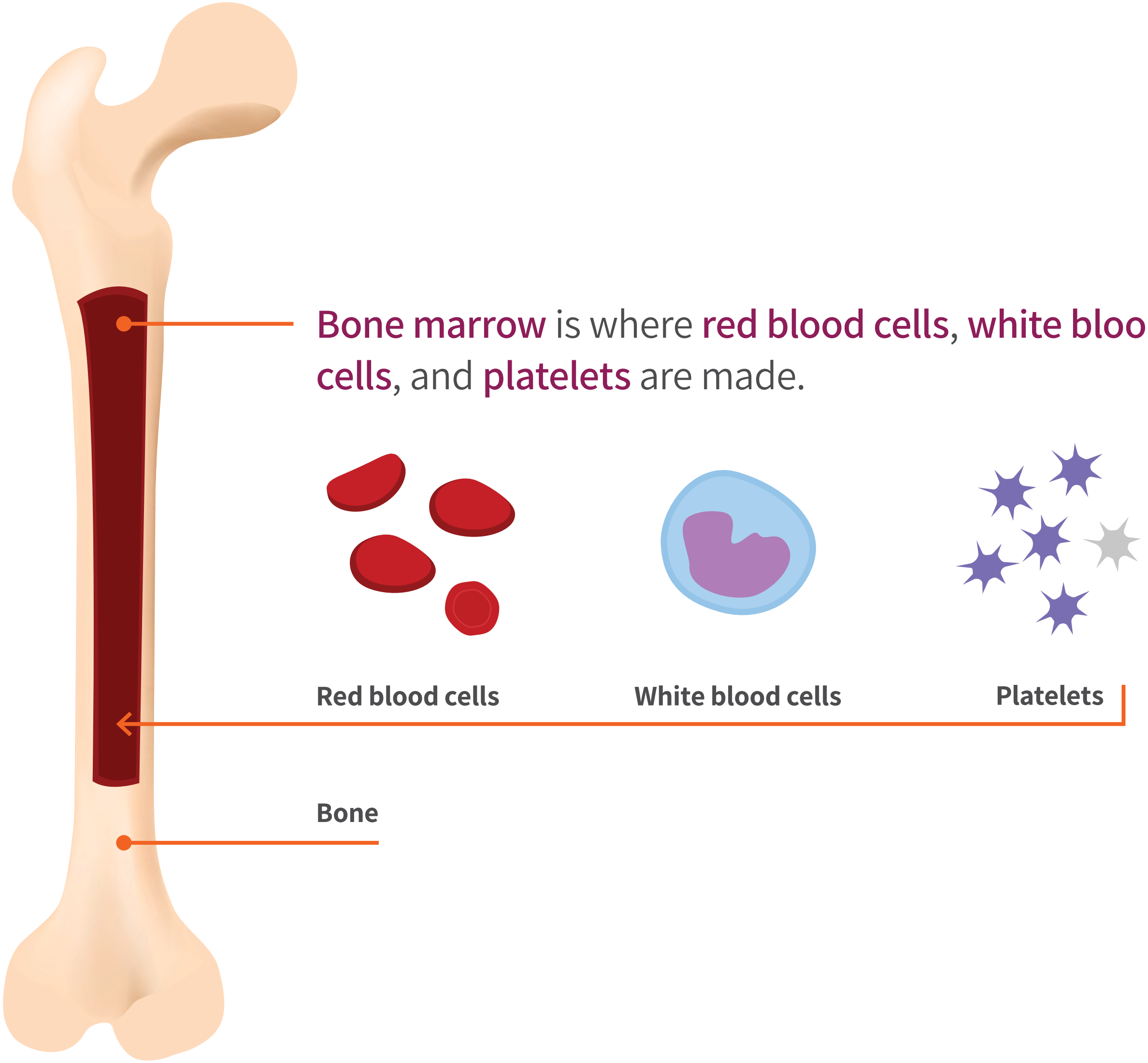
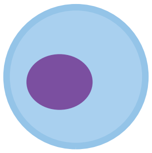
What is **multiple myeloma?**

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.

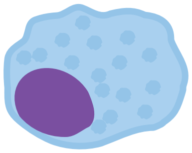


Bone marrow is where **red blood cells**, **white blood cells**, and **platelets** are made.

Healthy white blood cells help your body fight infection and disease. **Multiple myeloma affects a certain kind of white blood cell called a plasma cell.**

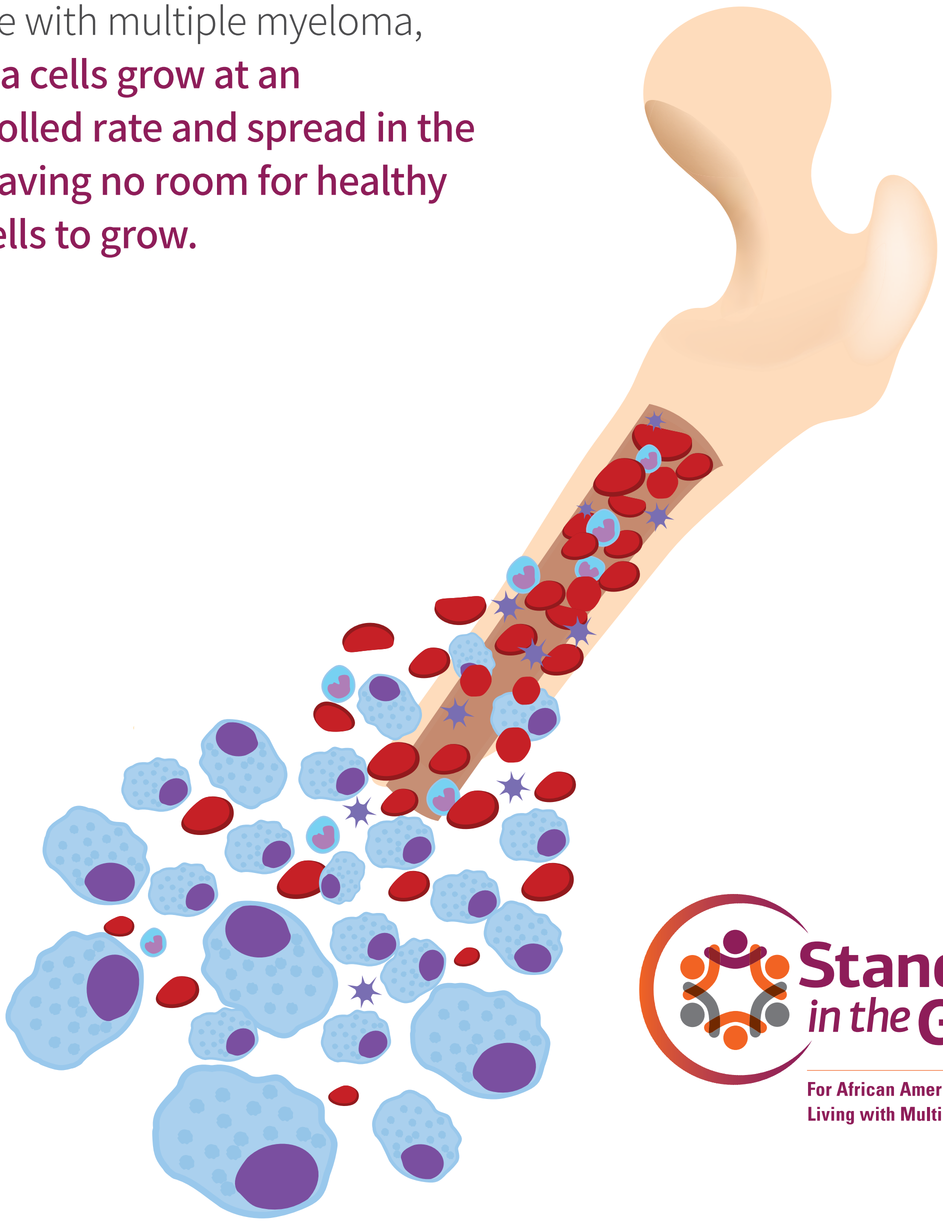


Normal plasma cell



Myeloma cell

In people with multiple myeloma, **myeloma cells grow at an uncontrolled rate and spread in the bone, leaving no room for healthy blood cells to grow.**



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How can **multiple myeloma** affect you?

CRAB is an acronym used to describe the most common symptoms of multiple myeloma. It may also be accompanied by infection caused by a weakened immune system.

	C	R
It stands for	Calcium	Renal
Sometimes multiple myeloma can cause	Too much calcium in your blood	Kidney problems, sometimes called renal problems
It might make you feel	Very tired Confused Constipated You may lose your appetite You may urinate more often	Very tired Confused Nauseated You may feel itchy Your legs might swell

Multiple myeloma affects every person differently. This is not a complete list of all possible symptoms. Your doctor might also mention guidelines used by medical organizations for the diagnosis. Always talk to your doctors and nurses if you have any questions or if you're feeling any pain or discomfort.

A	B
Anemia	**Bone**
Too few oxygen-carrying cells in your blood	Bone problems
Very tired Dizzy You may have headaches Out of breath You might feel cold	Bone pain, which may be a sign of bone fractures

What treatment is **right for me**?

Everyone's myeloma is different, so everyone does not receive the same treatment. When recommending treatment, your care team will be considering many factors, including the stage of your cancer.

When you're diagnosed with a rare condition like multiple myeloma, you may want to get a second opinion by talking to more than one doctor, including a multiple myeloma specialist in your area.

Over time, it's common for a person with multiple myeloma to go through periods of response to treatment and periods of **relapse**. Relapse means the body has stopped responding to treatment. After a relapse, your doctor may consider a different treatment. Thankfully, there are many treatment options available for people with relapsed or **refractory** disease.

How will I receive treatment?

- Medications for multiple myeloma may be given to you in different ways
- Some medicines are pills that you take orally. Other medicines may be injected under your skin, or injected or infused directly into your bloodstream

Will I need more than one treatment?

- With multiple myeloma, it is very common for treatments to be combined or given at the same time. In fact, medications are combined so often, that there are even terms for these combinations: doublets, triplets, and quadruplets
- If one treatment stops working, there may be other options to try

With ongoing research, **more treatment options are becoming available** as approved medications. Additionally, you can consider being part of a clinical trial studying potential new treatment options. Talk with your doctor about your options.

Multiple myeloma treatment options explained

There are many treatment options available for myeloma. Sometimes there are multiple rounds of treatment. This means you will receive more than 1 course of the same treatment.

Multiple myeloma is usually managed with a combination of treatments. The goal is to help the body find and attack cancer cells. Types of treatment for multiple myeloma include:

Stem cell transplant is a procedure that replaces the damaged bone marrow with healthy bone marrow. Intensive chemotherapy is given before the transplant

Immunomodulatory agents trigger an immune system response that helps the body fight cancer. These drugs are pills that you take orally on a schedule provided by your doctor

Proteasome inhibitors are a type of targeted therapy that causes proteins to build up in myeloma cells. This creates an environment where cancer cells die off. The treatment can be given as a pill, an injection, or through an infusion

Antibody therapy targets one or more proteins in order to help the immune system kill cancer cells. This treatment is given through an infusion or injection

CAR T cell therapy is a type of immunotherapy that can find and fight cancer. It is given as a one-time infusion*

Chemotherapy is a treatment that kills fast-growing cells, including myeloma cells

Steroids help relieve inflammation in the body. Higher doses of steroids also kill myeloma cells

CAR, chimeric antigen receptor.

*The treatment process includes blood collection, CAR T cell creation, administration, and adverse event monitoring.

Stem cell transplants explained

A **stem cell transplant** is a procedure that replaces damaged or diseased stem cells with healthy stem cells. For many people with multiple myeloma, a stem cell transplant is an important part of treatment.

?

What are stem cells?

- A stem cell is a type of young blood cell found in the bone marrow and blood
- These stem cells can mature into all types of blood cells, including red blood cells, white blood cells, and platelets
- Once mature, blood cells have many jobs and help the body function properly

?

How does a stem cell transplant help in multiple myeloma?

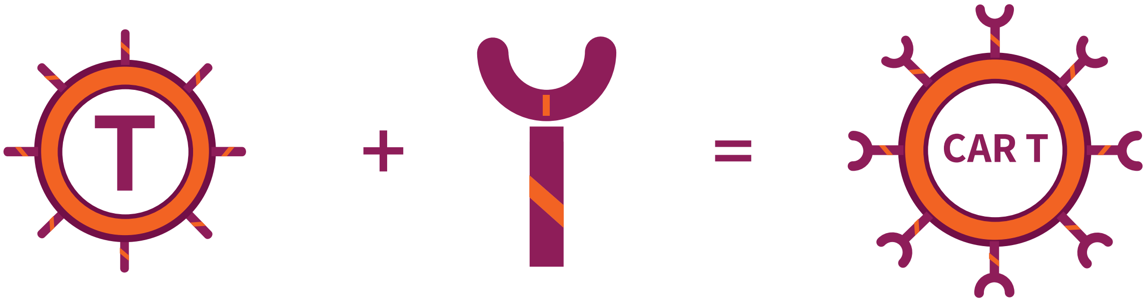
- Doctors use high doses of chemotherapy to kill as many myeloma cells as possible. These high doses can also damage or kill stem cells, which we need to live
- A stem cell transplant replaces damaged stem cells with healthy stem cells. In most cases, stem cells are collected from your own body, saved, and transplanted at a later time

Some of the steps for CAR T cell therapy may seem similar to the steps for stem cell transplant, but they are different types of treatment.

CAR T cell therapy explained

CAR T cell therapy is a type of immunotherapy that uses your body's own immune cells to fight your cancer. **It is a one-time infusion.**

The process for CAR T cell therapy includes several steps, including blood collection, CAR T cell creation, administration, and side effect monitoring.



T Cell
A key fighter in the immune system

CAR
A specific receptor (or hook) that is added to the T cell

CAR T Cell
A T cell with the CAR added is now called a CAR T cell

CAR T cell therapy may be considered after other treatments.

- CAR T cells may help find and fight specific targeted cells, which include both cancer and healthy cells
- After the infusion, you will be closely monitored by a trained healthcare team for possible side effects, which can be severe or even fatal. You will need to stay near the CAR T cell therapy treatment center for at least 4 weeks after the infusion

For a video on the step-by-step process, please scan the QR code with your smartphone.

“There are many ways that you can continue along this journey.”

Gail
An actual patient living
with multiple myeloma

What's different about **multiple myeloma** for **African Americans?**

It's more common

Multiple myeloma is considered a rare cancer, yet African Americans are more than twice as likely to be diagnosed vs White Americans. The reason for this is not completely understood.

>2X African Americans are **more than twice** as likely to be diagnosed vs White Americans

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

It’s usually diagnosed at a younger age

African Americans may show signs associated with multiple myeloma 5 to 10 years earlier than White Americans. Typically, African Americans are diagnosed with multiple myeloma at a younger age than White Americans.

70 years
Average age at diagnosis for White Americans

66 years
Average age at diagnosis for African Americans

It might be less aggressive

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 appropriate care.

Ask your doctor if stem cell transplant, immunotherapies, **or treatments with a combination of medications** might be an option for you.

Getting **appropriate treatment**

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.

According to a

2016 study

African Americans

are less likely to get certain combination treatments

According to a different study of patients diagnosed between 2000 and 2011:

African Americans are

37% less

likely to have a stem cell transplant vs White Americans

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

What should I know about **clinical trials?**

Many doctors think of clinical trials as another option for multiple myeloma.

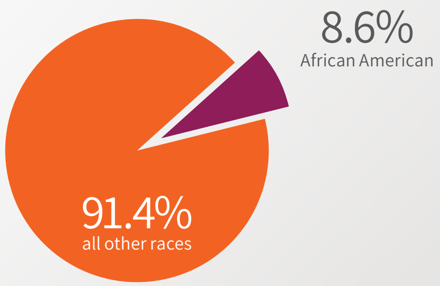
Clinical trials are necessary for new medicines to be approved by the US Food and Drug Administration (FDA). They have played a major role in advancing the treatment of multiple myeloma, and without these trials and the patients who voluntarily participated in them, we would not have the treatment options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

It is through clinical trials that researchers can determine whether new treatments are safe and effective.

Why does it matter who joins a clinical trial?

African Americans make up **1 out of every 5** people living with multiple myeloma today. Yet only 8.6% of patients in multiple myeloma clinical trials are African Americans, according to studies from 2000-2016. Therefore, it is **important that African Americans are represented** in clinical trials to better understand how they may be affected differently by multiple myeloma.

Participation in US Multiple Myeloma Clinical Trials



What should I know about joining a clinical trial?

- There are both benefits and risks to clinical trial participation. Talk to your doctor to learn more
- People who participate in clinical trials for a cancer drug will typically receive a current standard treatment or the new drug being studied
  - **Placebos, sometimes known as "sugar pills," are not used alone in clinical trials for multiple myeloma.** If used, placebos are given in combination with the current standard treatment
- You are free to quit the trial at any time, for any reason at all, including unwanted side effects of the treatment
- 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

Tips for visiting the doctor

It can be hard to remember all of the things your doctor tells you, especially if you're feeling anxious or afraid. Even if your doctor carefully explains things, you may not hear or remember everything said during your visit.

Here are some ways to help you remember everything your doctor tells you:

- It can be helpful to take notes during your doctor visits
- Take a family member or friend with you. They can help remind you of questions to ask and take notes for you
- If you have questions between doctor visits, write them down as they come up. Keep a notebook to help you stay organized

Here are some tips to help you prepare for your visits:

- Bring a list of important information your doctor may need to know. This includes your other medical conditions, any new symptoms you may be experiencing, and any medications you are taking
- Think about some of the questions your doctor may ask you during the visit, so you are prepared to answer. This can include questions about how well you're staying organized with your treatment, any side effects or symptoms you may be experiencing, and questions about changes in your appetite and bodily functions

How much do you want to know?

Have you ever thought about how much information you want from your doctor? Some people feel more in control when they fully understand their disease, treatments, and what they can expect. Other people prefer small pieces of information and only want to know what's necessary. Don't be afraid to tell your doctor how much or how little you want to learn.

"You're strong enough to do the process."

Robert
An actual patient living
with multiple myeloma

Talking with **your doctor**

It's important to be open and honest with your doctors and nurses. You should feel free to ask questions about your health and your treatment. Here are some examples of questions to help you get the conversation started:

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?

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?

For more information about blood tests, visit the Understanding Your Blood Tests page on Myeloma Central.

"It's important that we be an advocate for ourselves or have someone be our advocate if we're unable to."

Evelyn
An actual patient living
with multiple myeloma

Questions about treatment

- What types of treatments are available for multiple myeloma?
- Could a stem cell transplant be an option for me?
- Could immunotherapies be an option for me?
- Do I need chemotherapy as part of my multiple myeloma treatment?
- What are the risks and benefits of each treatment?
- What treatment do you recommend, and why?
- Will I be able to continue my normal work schedule with this treatment?
- 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

- 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

Affording **multiple myeloma** care

Financial concerns are common among people living with cancer. There are many resources that can help you understand insurance, plan for cancer costs, and assist you in paying your medical bills. Talk to your insurance company, healthcare team, or the financial specialist at your doctor's office about your insurance coverage and eligibility.

Visit **www.myelomacentral.com** for resources and information about the financial side of multiple myeloma.

Where can I go **for help?**

Learn more and find support

Below are some of the organizations that provide resources and information for people living with cancer.

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

M-Power

A project from the International Myeloma Foundation engaging with healthcare and community organizations to help educate about multiple myeloma, specifically in African Americans.
mpower.myeloma.org

Leukemia & Lymphoma Society

The largest voluntary health organization dedicated to funding research, finding cures, and ensuring access to treatments for patients with blood cancer.
www.lls.org I Phone: 800-955-4572

Myeloma Link

A national outreach and education initiative from The Leukemia & Lymphoma Society that directly connects Black patients and caregivers to trusted, free myeloma information and support and enhances access to care and the latest treatments.
www.lls.org/myelomalink I Phone: 1-844-955-LINK

Multiple Myeloma Research Foundation

The largest nonprofit in the world solely focused on accelerating a cure for each and every multiple myeloma patient.
www.themmrf.org I Phone: 203-229-0464

HealthTree Foundation for Multiple Myeloma

HealthTree Foundation for Multiple Myeloma uses cutting-edge technology to drive lifesaving breakthroughs by providing personalized, lifetime support and education, meaningful patient-to-patient connections and a powerful patient data portal.
www.healthtree.org/myeloma I Phone: 1-800-709-1113

Black Myeloma Health

An initiative from HealthTree Foundation to support myeloma patients and caregivers in the African American community.
www.blackmyelomahealth.org

The Balm In Gilead, Inc.

An organization that supports faith communities by providing education, training programs, and support services to help eliminate health disparities for African American and African communities.
www.balmingilead.org I Phone: 804-644-2256

Lazarex Cancer Foundation

An organization striving to improve cancer health outcomes, FDA cancer clinical trial diversity and enrollment, and patient access to care by providing assistance with clinical trial navigation, reimbursing trial-related travel costs, and partnering with at-risk communities to mobilize resources.
lazarex.org I Phone: 877-866-9523

Bristol Myers Squibb–sponsored pages:

Myeloma Central

Offers disease education and helpful resources for patients with multiple myeloma and their caregivers.
www.myelomacentral.com

Standing in the Gaap Facebook Page

The largest online community of African American patients with multiple myeloma.
www.facebook.com/StandingInTheGaap

Explore CAR T Therapy

Provides information, including downloadable resources, about CAR T cell therapy for patients and caregivers.
www.explorecarttherapy.com

Information about independent organizations is provided as an additional resource for obtaining information related to multiple myeloma. It does not indicate endorsement by Bristol-Myers Squibb Company of an organization or its communications. Your healthcare team is your best source of information.

Find support in your community.

Look for local organizations that may be able to help you and your loved ones.

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 multiple myeloma support group near you

Church and other religious groups may offer support, transportation, or meals

Local non-profit groups may also offer meals and transportation, as well as housecleaning

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

Anemia
A condition in which the number of red blood cells is below normal.

Autologous stem cell transplant
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.

Blood cancer
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.

Bone marrow
The soft, sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.

Calcium
A mineral needed for healthy teeth, bones, and other body tissues. It is the most common mineral in the body.

Cancer
A term for diseases in which abnormal cells divide without control and can invade nearby tissues.

CAR T cell therapy
A multistep treatment where T cells are removed from the body, modified, and then returned to help fight cancer cells.

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

Clinical trial
A type of research study that tests how well new medicines work in people. Also called clinical study.

Hematologist
A doctor who specializes in treating blood disorders.

Immunotherapy
A type of treatment that uses the body’s immune cells to fight cancer cells.

Immune system
A complex network of cells, tissues, organs, and the substances they make that helps the body fight infections and other diseases.

Multiple myeloma
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.

Myeloma cells
Abnormal white blood cells that build up in the bone marrow.

Oncologist
A doctor who specializes in treating cancer.

Placebo
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.

Plasma
The fluid part of the blood that carries the blood cells.

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

Platelets
Platelets are found in the blood. They help form blood clots to slow or stop bleeding and to help wounds heal.

Prognosis
The likely outcome of a disease or the chance of recovery or recurrence.

Radiation
X-rays that reach and destroy cancer cells.

Red blood cells
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.

Refractory
Disease that does not respond to usual therapies. Some patients may respond to treatment soon after (within 60 days of) their last therapy.

Relapse
The return of a disease or the signs and symptoms of a disease after a patient has experienced improvement.

Standard of care
A treatment that is accepted by medical experts as an appropriate treatment for a certain type of disease, and one widely used by healthcare professionals.

Stem cell transplant
A method of replacing blood-making cells in the bone marrow.

Stem cells
A cell from which other types of cells grow. For example, blood cells grow from blood-forming stem cells.

Targeted therapy
A treatment that precisely identifies and attacks cancer cells. Targeted therapy may have different and less severe side effects.

White blood cells
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.

X-ray
A type of radiation used to detect and treat diseases. In large amounts, x-rays are used to treat cancer.

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