

Get the facts

about multiple myeloma
in African Americans



Actual patients
living with multiple
myeloma



Standing
in the **Gaap**

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 support you however I can.

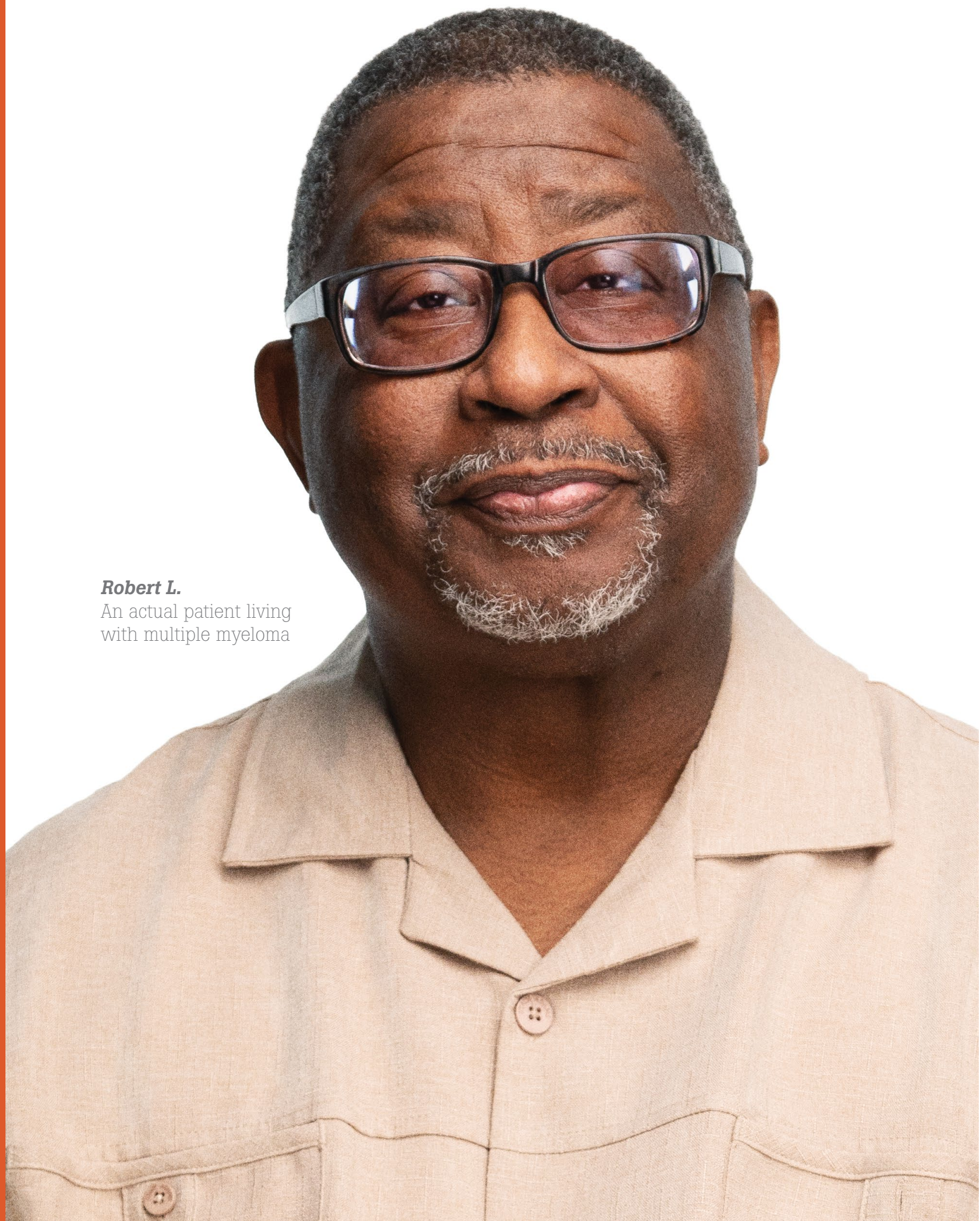


Why we are **Standing in the Gaap**

- **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**
- 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.



Robert L.

An actual patient living
with multiple myeloma

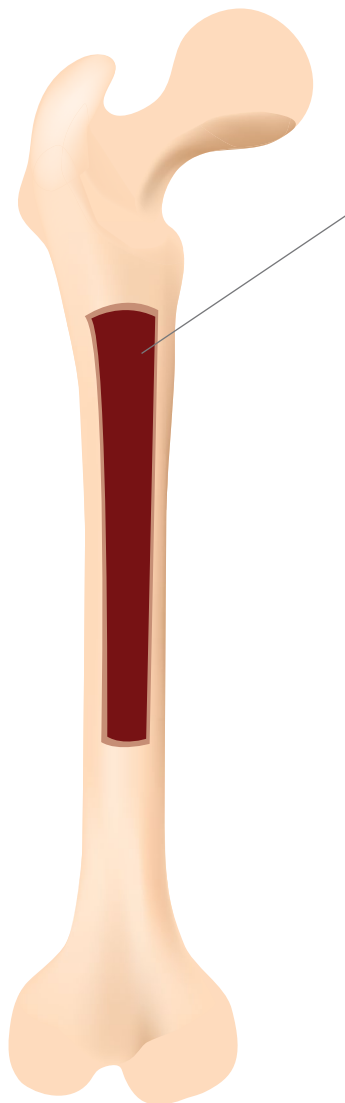
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What is multiple myeloma?

Multiple myeloma is a rare cancer that affects your blood and bones.

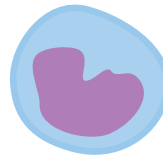
Multiple myeloma is a type of cancer that develops in the soft, spongy tissue at the center of your bones, called bone marrow. Multiple myeloma causes cancer cells to accumulate, where they crowd out healthy blood cells and can prevent your **immune system** from working properly.



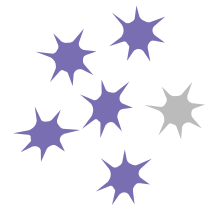
Bone marrow is where white blood cells, red blood cells, and platelets are made.



Red blood cells



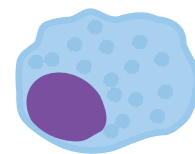
White blood cells



Platelets

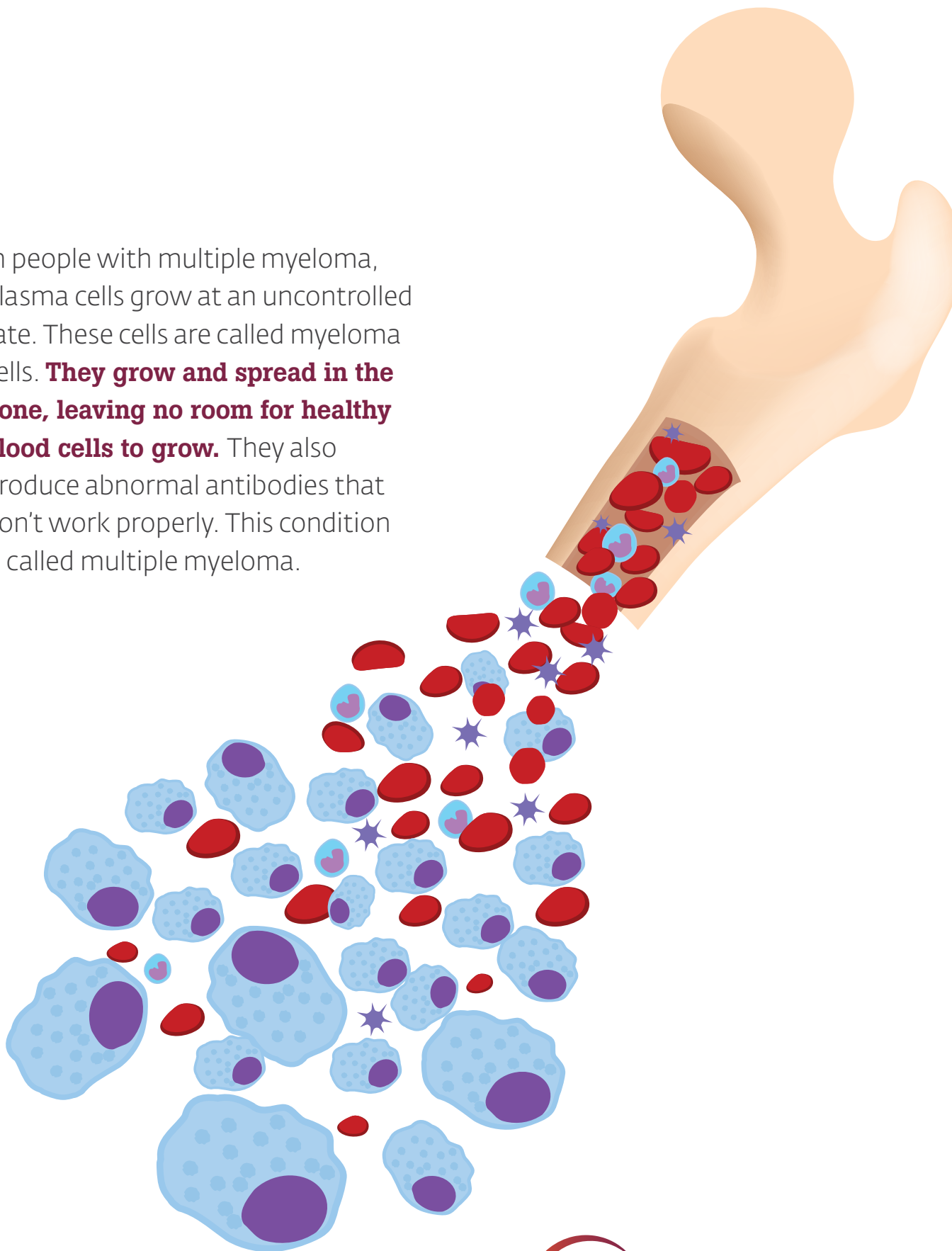
Healthy white blood cells help your body fight infection and disease.

Multiple myeloma affects a certain kind of white blood cell called a plasma cell.



Myeloma cell

In people with multiple myeloma, plasma cells grow at an uncontrolled rate. These cells are called myeloma cells. **They grow and spread in the bone, leaving no room for healthy blood cells to grow.** They also produce abnormal antibodies that don't work properly. This condition is called multiple myeloma.



About Multiple Myeloma

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.

<div>C</div> <div>R</div>		
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

Anemia

Too few oxygen-carrying cells in your blood

Very tired

Dizzy

You may have headaches

Out of breath

You might feel cold

B

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 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 will talk with you about treatment options, which may include:



Targeted therapies

Treatments that focus on specific features that are present on cancer cells and attack them. In many cases, these treatments are used together with other medications.



Steroids

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



Stem cell transplant

A medical procedure that may be used as a treatment for multiple myeloma. It replaces unhealthy **stem cells** with healthy stem cells in the body after bone marrow has been destroyed.



Chemotherapy and other drugs

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



Care for symptoms and side effects

Multiple myeloma can cause many symptoms and treatment can cause uncomfortable side effects. Your healthcare team may recommend different ways to help relieve these symptoms and side effects.

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**. Getting a second opinion is common. You may want to ask your doctor about **multiple myeloma specialists** in your area.

About Multiple Myeloma

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.

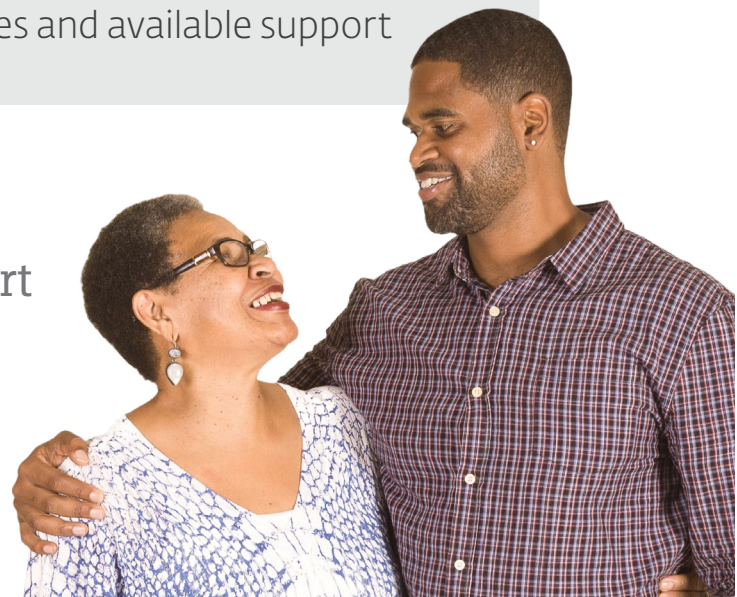
Stem cell transplants, for eligible patients, are known as a standard of care in multiple myeloma. A standard of care is a treatment that is accepted by medical experts as an appropriate treatment for a certain type of disease, and one widely used by healthcare professionals. However, like any other treatment, there are benefits and risks. You and your doctor will decide on the most appropriate treatment course.

?

Is it a good option for me?

- Your doctor will work with you to decide whether a stem cell transplant may be right for you
- The decision will be based on a number of factors which include your age, how well you've responded to multiple myeloma treatment, any other medical conditions you may have, and your own desires and available support

Consider **taking a friend or family member** to help support you during your next office visit.






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 treatment 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

A portrait of Gail, a Black woman with short, curly dark hair, wearing black-rimmed glasses and a pink top. She is smiling slightly and looking towards the camera. The background is white.

***"There are many
ways that you
can continue
along this journey."***

Gail

An actual patient living
with multiple myeloma

Multiple Myeloma in African Americans

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.

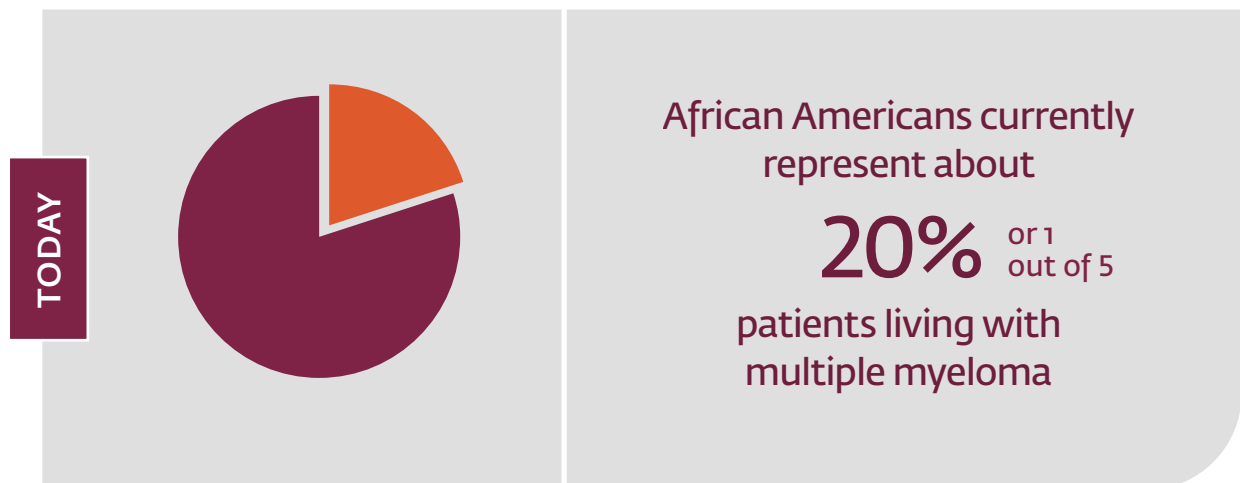
African Americans are
more than twice
as likely to be diagnosed
vs white Americans



Multiple Myeloma in African Americans

What's different about multiple myeloma for African Americans?

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



The **African-American population is expected to grow much more quickly than the white population.** Because of this, the number of African Americans living with multiple myeloma is likely to increase.



It's usually diagnosed at a younger age

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
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 treatment option for multiple myeloma.

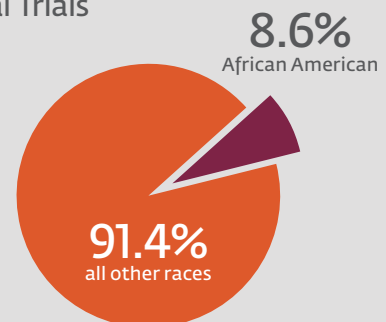
Clinical trials are necessary for new medicines to be approved by the US Food and Drug Administration (FDA). They have played a major role in advancing the treatment of multiple myeloma, and without these trials and the patients who voluntarily participated in them, we would not have the treatment options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

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 almost a quarter of 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
- 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

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.





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?

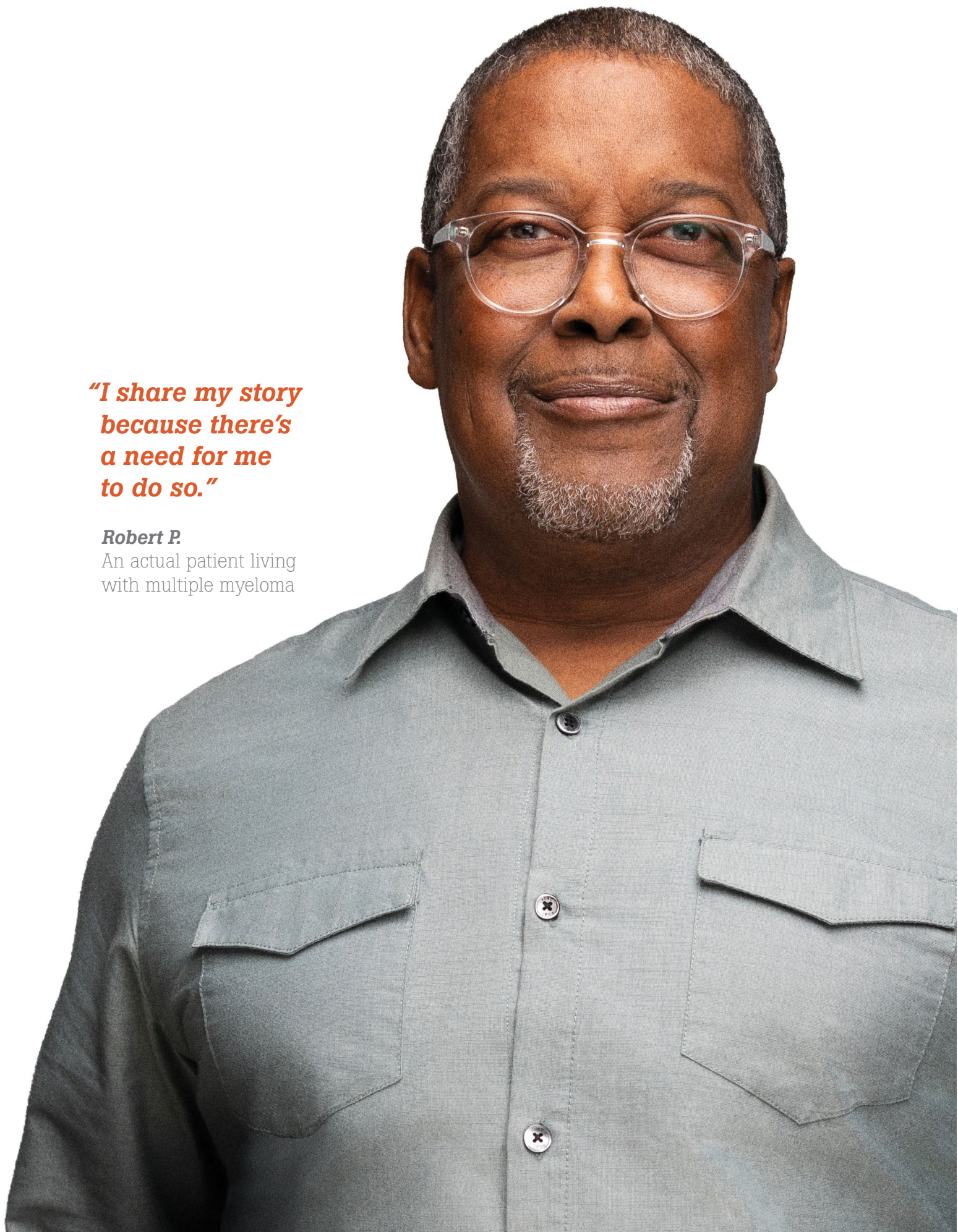
Have you ever thought about how much information you want from your doctor? Some people feel more in control when they fully understand their disease, treatments, and what they can expect. Other people prefer small pieces of information and only want to know what's necessary. They feel overwhelmed by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



***"I share my story
because there's
a need for me
to do so."***

Robert P.

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?



Questions about treatment

- What types of treatments are available for multiple myeloma?
- Could a stem cell transplant 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.



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



International Myeloma Foundation

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

www.myeloma.org | 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.lls.org | Phone: 914-949-5213



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.themmr.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



Standing in the Gaap Facebook Page

This Celgene-sponsored page is the largest online community of African-American patients with multiple myeloma.

www.facebook.com/StandingInTheGaap



Myeloma Central

A Celgene-sponsored website offering disease education and helpful resources for patients with multiple myeloma and their caregivers.

www.myelomacentral.com



Myeloma Crowd

<https://www.myelomacrowd.org/>

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.

Want more multiple myeloma resources? Be a part of Myeloma Central



When you sign up, you'll receive a Welcome Kit and complimentary copy of *The American Cancer Society's Healthy Eating Cookbook*, along with a letter of encouragement from real patients with multiple myeloma.

Limit one per person. While supplies last. Celgene reserves the right to discontinue this program at any time without notice. Healthcare professionals are not eligible to receive the book.

E-mail address:

Are you a:

- ☐ Patient with multiple myeloma
- ☐ Caregiver of someone with multiple myeloma
- ☐ Healthcare provider
- ☐ None of the above—I'm looking for more information

Your age:

- ☐ 18-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-64 years
- ☐ 65-74 years
- ☐ 75+ years
- ☐ Prefer not to answer

Are you:

- ☐ Male
- ☐ Female
- ☐ Prefer not to answer

What are you interested in learning about?

- ☐ Basic information about multiple myeloma
- ☐ Information about relapsed multiple myeloma

Tell us where to mail your Welcome Kit:

First Name:..... Last Name:.....

Street Address:

Street Address 2:

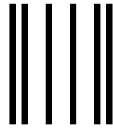
City: State:..... ZIP Code:

Please check the box below before returning this card:

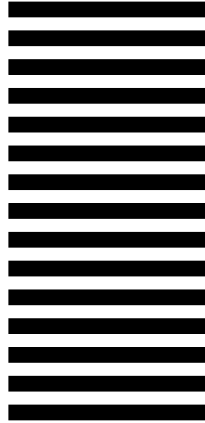
- ☐ I am interested in Celgene, its affiliates and its agents sending me information about multiple myeloma. I understand that these communications may offer the ability to opt in to marketing programs concerning Celgene products. Must be 18 years or older to sign up.

Celgene values your privacy. Celgene, its affiliates, and its agents will not sell or rent your personal information. The information that you provide here will only be used to fulfill your request to learn more about Myeloma Central and/or receive disease-state education and information.

For more information on Celgene's use and disclosure of personal information and your privacy rights, please read Celgene's Privacy Policy, available at www.Celgene.com.



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

Get Support

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.

Robert L. and his wife, Sharon

An actual patient living 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.

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.

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.

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.

