

Taking Care

**A caregiver's guide to supporting
someone with multiple myeloma**







Caring for a loved one with multiple myeloma

If you provide support to someone with an illness, you may be referred to as a “caregiver.” You may provide emotional support, physical support, or both. Your role may change over time, as your loved one’s multiple myeloma changes over time.

Inside this brochure you’ll learn how multiple myeloma can affect your loved one and how you can best care for them—and yourself.



What is multiple myeloma?

Multiple myeloma (MM) is a type of blood cancer; specifically, it's a cancer of the **plasma cells** in your **bone marrow**. When your plasma cells are healthy, they work as part of your immune system to fight infections and diseases. With MM, these plasma cells become abnormal and start to push out your healthy cells.

This can cause:



Bone damage:

Pain, weakness, and broken bones



Low red blood cell count (anemia):

Weakness, shortness of breath, and dizziness



Low white blood cell count (leukopenia):

Lowered ability to fight infection



Excess calcium in the blood:

A frequent result of MM cell activity; can put extra strain on the kidneys










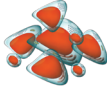
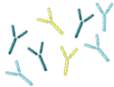

Kidney problems:

Damage and failure

Treatment is important. There is no cure for MM, but a long-term treatment strategy can help manage it.

How does multiple myeloma develop?

Scientists still don't know the exact cause of MM. But they do know how MM works. The graphic below explains the difference between what typically happens in the body and what happens with MM.

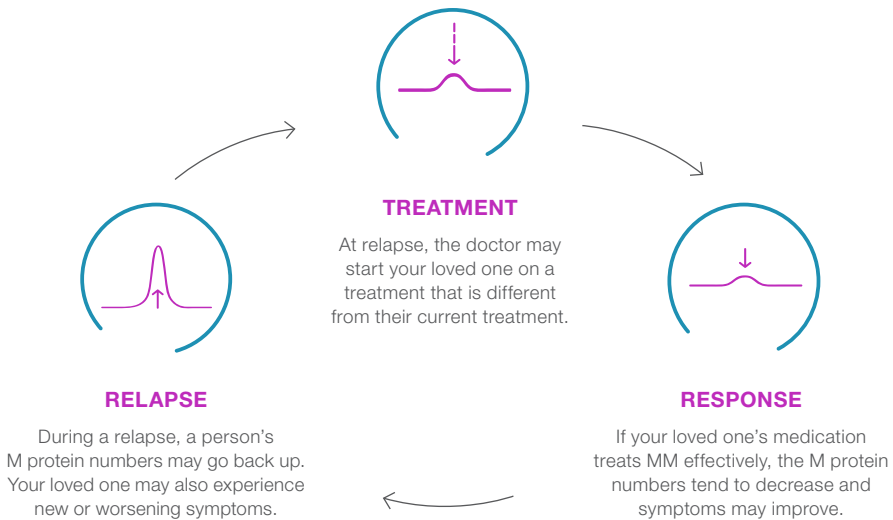
WHAT TYPICALLY HAPPENS	WHAT HAPPENS WITH MM
 <p>Stem cells Live in the bone marrow and divide to become different types of cells, like white blood cells</p>	 <p>Stem cells Begin to form into white blood cells but undergo a genetic change. DNA damage occurs</p>
 <p>White blood cells Can become plasma cells</p>	 <p>Damaged white blood cells DNA damage causes white blood cells to make abnormal plasma cells</p>
 <p>Plasma cells Make antibodies that help the body fight infection</p>	 <p>Abnormal plasma cells Turn into cancerous myeloma cells</p>
 <p>No myeloma cells Your immune system functions normally as your plasma cells remain normal</p>	 <p>Myeloma cells Can multiply quickly, then hide among and crowd out normal cells, so the immune system can't see them</p>
 <p>Normal antibodies Guard against infection and disease</p>	 <p>M proteins Instead of making normal antibodies, myeloma cells make M proteins that can't fight infection</p>

Why does multiple myeloma keep coming back?

Currently, there is no cure for MM. Treatment can help reduce the number of myeloma cells in your body. However, these cells often stop responding to medication and can begin to grow uncontrollably again—and the cycle of MM restarts.

RELAPSING MM IS PROGRESSIVE AND CYCLIC

It's common for someone with MM to go through periods of response to treatment and periods of relapse.



It's important for patients to stay on their MM treatment, so make sure that your loved one discusses any side effects with their doctor.

Dealing with a multiple myeloma diagnosis and providing care

A diagnosis of MM can be difficult for your loved one and you—emotionally, physically, and logistically. Your loved one faces new challenges, and you must take on greater responsibilities. On top of that, your loved one may have to make major life changes, such as:

- Taking multiple medicines
- Visiting a healthcare professional regularly
- Getting routine blood work and other testing
- Managing MM symptoms or treatment side effects

Common responsibilities of a caregiver

From advocate to driver to nurse and beyond, a caregiver may provide important support, such as:

- Helping with daily activities
- Giving emotional support
- Working with your loved one's healthcare team
- Managing medication, insurance, and medical expenses
- Driving to doctor visits and managing appointments
- Assisting with cooking, cleaning, personal care, or childcare

Whether you've been a caregiver in the past or are just starting out, the tips on the following pages can help you provide the best care for your loved one.

Speaking up for someone with multiple myeloma

At times, patients with MM may be too overwhelmed to pay attention or to grasp what the doctor is telling them. That's where you can step in—by going to doctor visits, asking questions, and being their advocate.

If you are unsure about something the doctor or nurse is saying, don't be afraid to ask for more information or to have them explain it again. Make sure that you understand everything before you leave the office. You may want to bring a notebook to take notes.

If you have any specific questions for the healthcare team, you should write them down before each visit. It may be helpful to prioritize them ahead of time. Some topics you might want to discuss openly with a doctor or nurse are:

- Your loved one's diagnosis
- A change in your loved one's health
- Concerns about a new symptom your loved one has
- A new medication or changing medication
- Possible side effects
- The results of lab tests

Practical tips for caregivers

There is no “one way” to be a caregiver, but these tips can guide you as you navigate the challenges and opportunities.

PRACTICE PATIENCE WITH YOUR LOVED ONE

MM may be stressful for patients, and they may not know how to talk about it. When they are ready to talk, let your loved one set the tone and topic of the conversation. One of the best ways to support them during this time is to stay positive, be there to listen, and keep an open mind.

OTHERS WANT TO HELP—LET THEM

It's important to know that you are not alone on this journey. There are things others can do to help. When asking others for help, first ask if they would like to share in some of the caregiving tasks. Then clearly explain the task needed and what would be most helpful to you and your loved one.

Your family and friends may even volunteer to do certain tasks you haven't considered. Let them know how much this is appreciated. As the day of the task draws nearer, remind them that they are needed and ensure that they are available to help.

KNOW WHEN TO STEP BACK

Completing tasks and taking care of oneself can provide a sense of dignity and independence, something your loved one may want to keep for as long as possible. Don't assume that you need to take over right away. Pay attention to how they are feeling; you may need to step in more when they are feeling poorly.

CARING FOR YOURSELF IS IMPORTANT, TOO

It's just as important to care for yourself as for your loved one. It's easy to become focused on your loved one's needs and forget about your own. It can be helpful to:

- Make time to focus on yourself and activities you enjoy
- Share your feelings either with a friend, an MM support group, or a professional counselor
- Be kind to yourself. Know that it's natural to have a wide range of feelings during this process
- Understand your employer's policies regarding paid and unpaid leave
- Monitor your own health, particularly if you have your own medical issues
- Be sure to visit your doctor for routine checkups
- Keep an eye on stress and take time to exercise, even if it's just going for walks
- Don't put too much on your plate—be honest with yourself about how much you can do

Helpful resources for caregivers

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National Alliance for Caregiving	caregiving.org	301-718-8444
Well Spouse Association	wellspouse.org	800-838-0879
Multiple Myeloma Research Foundation (MMRF)	themmrf.org	203-229-0464
Cancer Hope Network	cancerhopenetwork.org	877-HOPENET
Caring Bridge	caringbridge.org	651-452-7940
National Comprehensive Cancer Network	nccn.org	215-690-0300
Cancer Support Community	cancersupportcommunity.org	888-793-9355
International Myeloma Foundation	myeloma.org	800-452-CURE
The Myeloma Beacon	myelomabeacon.org	
Myeloma Crowd	myelomacrowd.org	
Lotsa Helping Hands	lotsahelpinghands.com	



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