

# Taking Care

A caregiver's guide to  
supporting patients 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 him or her—and yourself.

## What is multiple myeloma?

Multiple myeloma (MM) is a chronic cancer of **plasma cells** that live in the **bone marrow**. Healthy plasma cells are a critical part of the immune system and play an important role in fighting infection. In MM, cancerous plasma cells build up and cause damage, including:



**Bone damage** can cause bone pain and weakened or broken bones



**Low red blood cell counts (anemia)** can cause weakness, shortness of breath, and dizziness



**Excess calcium in the blood**, a frequent result of myeloma cell activity, can put extra strain on the kidneys



**Kidney problems** can cause weakness and leg swelling



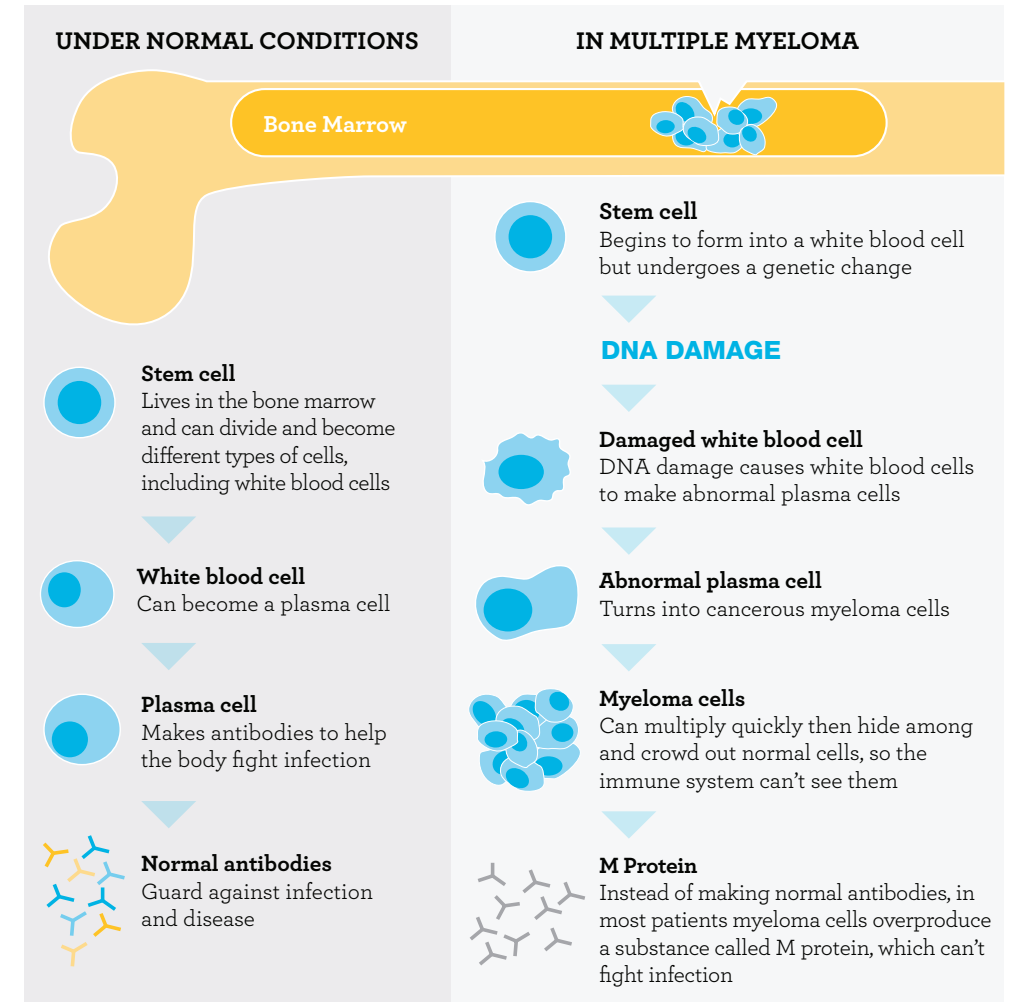
**Low white blood cell count (leukopenia)** can make it harder to fight infections

### Treatment is important

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

## How multiple myeloma develops

The bone marrow makes different types of immune cells, including plasma cells. In multiple myeloma, plasma cells become cancerous—or myeloma—cells. These cells can disguise themselves to look harmless. They go undetected and multiply, crowding out healthy cells in the marrow. Myeloma cells also release chemical messengers that can stop healthy immune cells from working.



## Why does multiple myeloma keep coming back?

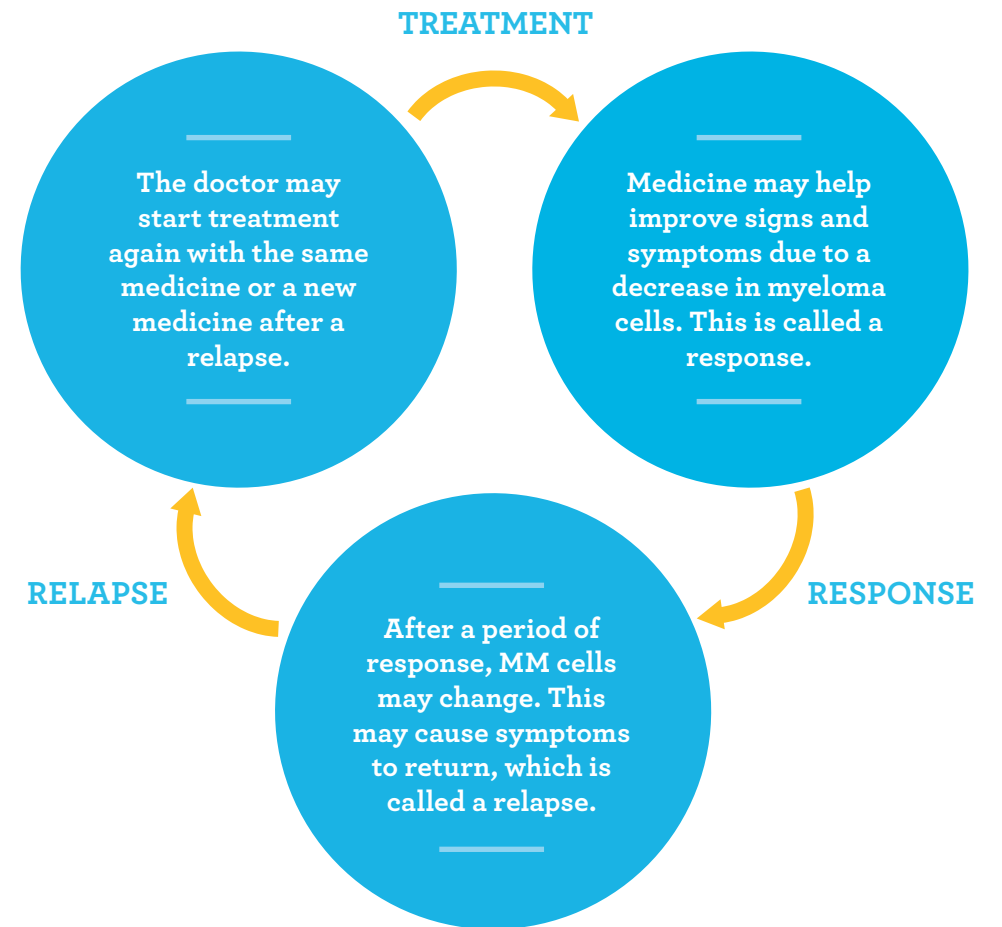
Multiple myeloma (MM) is currently an incurable disease. Treatment can significantly reduce the number of myeloma cells. But these cells can stop responding to treatment, which allows them to multiply uncontrollably and your loved one to relapse. This starts the cycle of MM once more.

It is common for someone with MM to go through several of these cycles.

Your loved one's doctor will likely change the treatment plan to try to control your loved one's MM again.

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

## Understanding the cycle of multiple myeloma



## Dealing with a multiple myeloma diagnosis and providing care

A diagnosis of multiple myeloma (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 roles of a caregiver

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

- Helping with daily activities
- Providing 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 are some ideas that can help you provide the best care for your loved one.

## Speaking up for someone with multiple myeloma

At times, patients with multiple myeloma may be too overwhelmed to pay attention or grasp what the doctor is telling them. That's where you can step in, by going to doctor visits, asking questions, and being his or her 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 him or her 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
- A concern about a new symptom your loved one has
- A new medication or changing medication
- Possible side effects
- The results of lab tests



Caring for  
a loved one  
includes  
taking care  
of yourself

## 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

Multiple myeloma may be stressful for patients, and they may not know how to talk about it. When he or she is 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 in 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, what would be most helpful to you, and what’s most helpful to 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 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, a multiple myeloma 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 check-ups
- 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 really do

## Helpful resources for caregivers

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



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