



# Support for the Caregiver

Multiple myeloma (MM) is a chronic (or long-lasting) and progressive (worsening over time) disease. As MM changes, so can the needs of the person for whom you're caring. This article can help you understand what you're facing—and how best to help someone with MM at each stage of his or her journey.

## WHY IT'S HELPFUL

It's important to understand the responsibilities you have as a caregiver when it comes to caring for your loved one and for yourself. The more informed and prepared you are, the more effective you can be at caring for your loved one through the ups and downs that come with MM.

## KEY POINTS

1. The needs of people with MM change over time—and that means your role as caregiver may change too
2. Staying organized and planning ahead for doctor visits can help make your responsibilities easier to manage
3. You are an important part of the healthcare team
4. There are many ways to provide both emotional—and practical—support to someone with MM
5. To be an effective caregiver, you need to take care of yourself too

## CARING FOR SOMEONE THROUGHOUT THE CYCLE OF MM

Because MM is a chronic (or long-lasting) disease that is also progressive (meaning that it worsens over time), people living with MM may have times when they feel better and times when symptoms return. When symptoms worsen, the doctor may change the person's treatment.

It is common for someone with MM to go through several of these cycles. The time between receiving medicine, response, and relapse—as well as the number of cycles—can vary from person to person.

As the symptoms and needs of the person you're caring for change, your role as a caregiver may also change. But there are some things you can do consistently to help, no matter where in the cycle the person's MM may be:

- **UNDERSTAND HOW THE DISEASE CAN IMPACT THE PERSON WITH MM PHYSICALLY.**

Below are the most common medical issues associated with MM and the medicines for it. If the person you're caring for experiences any of these symptoms, contact his or her healthcare team.



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Common Issues	Cause	Symptoms
High calcium levels (hypercalcemia)	Breakdown of bone	<ul style="list-style-type: none"><li>• Dehydration</li><li>• Constipation</li><li>• Fatigue</li><li>• Confusion</li></ul>
Kidney disease (renal failure)	Too much calcium and/or M-protein in the blood	<ul style="list-style-type: none"><li>• Frequent urination</li><li>• Swelling</li><li>• Fatigue</li><li>• Confusion</li></ul>
Anemia	Low number of red blood cells	<ul style="list-style-type: none"><li>• Fatigue</li><li>• Weakness</li></ul>
Bone damage	Myeloma cells crowd out normal bone cells	<ul style="list-style-type: none"><li>• Fractures</li><li>• Bone pain</li></ul>
Reduced immune function	Myeloma cells block the production of normal antibodies, which fight infection	<ul style="list-style-type: none"><li>• Frequent infections</li><li>• Delayed recovery from infections</li></ul>
Peripheral neuropathy	Certain MM medications, too much M-protein	<ul style="list-style-type: none"><li>• Tingling sensation in the feet and hands</li></ul>

- **KEEP TRACK OF ALL THE MEDICINES THE PERSON WITH MM IS TAKING.** Medicines used to treat MM can also cause changes to the person's health.
- **KEEP AN OPEN DIALOGUE WITH THE PERSON WITH MM.** Make sure the person is comfortable talking with you about how he or she is feeling.
- **KEEP A RUNNING LIST OF CHANGES IN HEALTH AND OTHER ISSUES.** Bring this list to each doctor appointment to discuss anything of concern. It's important to be open and honest about any changes the person is going through, so the healthcare team can provide the best care and medicine for MM. You can read more about staying organized and working with the healthcare team below.
- **TALK WITH THE PERSON'S HEALTHCARE TEAM ABOUT THE OPTIONS AVAILABLE AT EACH STAGE IN THE JOURNEY.** That way, you can stay informed and educated about his or her care and become an active participant in making decisions. You can read more about working with the healthcare team below.



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- **HELP THE PERSON WITH MM STAY AS HEALTHY AS POSSIBLE.** It's important to encourage people with MM to eat and drink right, rest, and reduce physical activity. To reduce the risk of infection, people with MM should limit contact with sick people and maintain personal hygiene. As MM progresses, you will also likely need to help with more everyday tasks. You can read more about how to help below.

### STAYING ORGANIZED

Caregivers often play many roles; balancing doctor appointments, medication schedules, and household responsibilities can feel like a full-time job. Staying organized and planning ahead may help make things easier. Writing detailed notes and reminders in a notebook, planner, or calendar can help you keep track of all you need to do.

Attending medical visits will help support the person with MM and enable you to gain a full understanding of his or her treatment plan. To make the most of those visits, it's helpful to plan ahead.

### HERE'S WHAT YOU SHOULD BRING TO EACH VISIT:

- Contact information for all physicians, specialists, and therapists on the person's healthcare team
- Insurance information and any financial issues
- List of allergies
- Notes on how the person with MM is feeling or changes in how he or she feels
- Schedules of other appointments
- List of other medicines, dosing schedule, and side effects
- List of questions

Any time the appointment is with a new doctor or hospital, you should also bring previous records, test results, and a list of other medicines. Be sure to tell any new healthcare professional—including primary care doctors, dentists, and other specialists—that the person you're caring for has MM. It may have an impact on other medical decisions.

### WORKING WITH THE HEALTHCARE TEAM

Medical visits are a regular part of life for someone with MM. His or her healthcare team may involve many different people—doctors, nurses, physician assistants, nurse practitioners, social workers, and others. In fact, nurses are great sources of information and may be the people you have the closest relationships with at the doctor's office.

As a caregiver, you are also an important part of the healthcare team. At times, the person with MM may be too overwhelmed to pay attention or grasp what the doctor is telling him or her. That's where you can step in, by going to doctor visits, asking questions, and being his or her advocate.



## HERE ARE SOME QUESTIONS YOU MAY WANT TO ASK WHEN STARTING WITH A NEW HEALTHCARE PRACTICE:

- When is the office open?
- Who do you contact after office hours, or is there an emergency number?
- When is the best time and what is the best way to contact the office (phone, fax, or e-mail)?
- Who can you go to with questions when the doctor is not available?

## HERE ARE SOME TIPS TO MAKE SURE YOU REMEMBER EVERYTHING YOU NEED TO DO:

- **WRITE DOWN QUESTIONS 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:
  - The diagnosis of MM and the prognosis (or outlook) for the person for whom you're caring
  - A new medication or changing medication and what to expect
  - Any changes in health
  - Possible side effects of medicines
  - Any concerns about new symptoms
  - The results of lab tests
- **ASK FOR MORE EXPLANATION.** 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.
- **RECORD THE CONVERSATION.** Ask your doctor if you can bring a recording device to each visit so that you can replay the healthcare team's explanations later. Or you can bring a notebook in which to take notes.

## PROVIDING EMOTIONAL SUPPORT

Being diagnosed with MM or finding out that MM has come back again can be very stressful. The person you're caring for may not know how to talk about it. And you may not know exactly what kind of emotional support he or she needs. Staying positive, having patience, and keeping an open mind can help.

## HERE ARE SOME TIPS THAT MAY HELP YOU PROVIDE EMOTIONAL SUPPORT:

- Be practical about what your loved one can deal with
- Be understanding when he or she is no longer able to do something
- Provide encouragement and be there to listen
- Make sure the person with MM knows how important he or she is to you
- Let him or her set the tone and topic of conversation when talking about MM
- Help locate a local patient support group
- Help the person you're caring for stay positive



## HELPING WITH EVERYDAY TASKS

A caregiver plays many roles in the journey of someone with MM. And that role can change from one day to the next. At times you might feel like a chauffeur, nurse, cheering section, administrative assistant, or counselor. There might be several people to fill these different roles, or you may be the only one.

Each time MM comes back, the person you're caring for may be less able and have less energy to go about his or her daily life. Therefore, helping him or her with everyday tasks becomes even more important.

## SOME ACTIVITIES YOU—OR OTHERS—MAY BE ABLE TO HELP WITH INCLUDE:

- Driving to doctor visits and errands like grocery shopping
- Managing schedules and appointments
- Helping with personal care, such as dressing, bathing, and feeding
- Assisting with at-home tasks, such as preparing meals, cleaning, and doing yard work
- Understanding insurance coverage and paying medical expenses
- Performing medical care at home, like giving medications and watching for side effects

## MAKING TIME TO FOCUS ON YOURSELF

This article has discussed many ways you can help support a person with MM. And it's natural for caregivers to be so focused on caring for someone else that they sometimes forget about their own needs.

Being an effective caregiver also means taking care of yourself. And staying healthy and positive will help you carry out your caregiving tasks.

## HERE ARE SOME WAYS YOU CAN TAKE CARE OF YOURSELF:

- **ALLOW TIME FOR YOURSELF.** Take breaks to walk outside, watch TV, read, or take part in a hobby. And make time to relax and clear your mind so you can re-energize yourself to care for the person with MM.
- **BALANCE YOUR SCHEDULE WITH THAT OF THE PERSON WITH MM.** Keep a planner or a calendar to make a list of tasks you need to do each day.
- **EXPRESS YOURSELF.** Try not to feel guilty if you become overwhelmed, because feeling scared, sad, or lonely is normal. Be open and honest with others about your emotions. Consider joining a caregiver support group or talking with a professional counselor.



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- **STAY HEALTHY.** Monitor your own health, particularly if you have your own medical issues. Be sure to visit your doctor for routine check-ups. Watch for stress-related symptoms, such as depression, headaches, upset stomach, difficulty sleeping, irritability, or lack of focus. And do your best to maintain a balanced diet, exercise regularly, and get enough sleep each night.
- **REACH OUT TO OTHERS FOR HELP.** Remember, you don't have to do all of these things yourself. A caregiver's job is to support—but you can ask for support from others as well.

### REACHING OUT TO OTHERS FOR HELP

If you're the only caregiver—or the primary caregiver—you may feel like you are handling everything yourself. But especially when MM comes back, there may be more to do than you can handle on your own. Asking others to help can benefit you and the person you're caring for. So don't be afraid to reach out—even to people who haven't asked what they can do. Sometimes others may want to help but may not know how to offer.

### HERE ARE SOME TIPS TO HELP YOU SHARE CAREGIVING ACTIVITIES:

- Be realistic about what you can do and learn how to pass on responsibilities
- If someone does offer to help, be willing to accept it, no matter how much or how little the offer is
- Let people know what they can do, as they might not know what is involved in caregiving
- Make a plan with friends and family of what needs to get done now or later
- Let go of tasks that aren't important at the time, because you can always pick them up again
- Get to know the skills and availability of others before charging them with specific caregiving tasks. Talk about exactly how they can help you—and clearly explain the tasks needed

### HERE ARE SOME SPECIFIC TASKS THAT OTHERS CAN HELP YOU WITH:

- Chores like cooking, cleaning, shopping, yard work, and childcare
- Talking with you and listening to your feelings
- Driving to doctor visits and running errands
- Researching information about MM
- Reaching out to others to give them updates on the well-being of the person with MM

You can also find support from patient advocacy groups, as well as websites and groups that offer support and guidance for caregivers. Visit the other tiles found in the Patient–Caregiver Support section for more on these groups.

Visit [MyelomaCentral.com](http://MyelomaCentral.com)

