MULTIPLE MYELOMA
Research Foundation

MULTIPLE MYELOMA
CAREGIVER GUIDE

themmrf.org

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ABOUT THE **MMRF**

The Multiple Myeloma Research Foundation® (MMRF®) is the largest nonprofit in the world solely focused on accelerating a cure for each and every multiple myeloma patient. We drive the development and delivery of next-generation therapies, leverage data to identify optimal and more personalized treatment approaches, and empower myeloma patients and the broader community with information and resources to extend their lives.

Central to our mission is our commitment to advancing access for all so that every myeloma patient can benefit from the scientific and clinical advances we pursue. Since our inception, the MMRF has raised over $600 million for research, opened over 100 clinical trials, and helped bring more than 15 FDA-approved therapies to market, which have tripled the life expectancy of myeloma patients.

To learn more about the MMRF, visit **themmrf.org**.

To speak to a patient navigator at the Patient Navigation Center, call **1-888-841-6673** or email **patientnavigator@themmrf.org**.

Accredited by:

INTRODUCTION

Caregivers (partners, family members, and close friends) play a vital role in helping multiple myeloma patients manage their disease, navigate treatment options, and achieve the best possible outcome. Having a second person at office visits can be helpful, as there is often a lot of new information to process.

Caregivers can:

- Accompany the patient on office visits
- Take notes and ask questions
- Record discussions with the care team, if permitted (be sure to ask before recording)
- Help patients report symptoms and side effects

Taking care of a myeloma patient typically involves supporting healthy eating and exercise habits, helping them manage symptoms and side effects, providing emotional support, and coordinating health care needs and visits. For caregivers, this may require a time commitment that could last many years. It can take an emotional, physical, psychosocial, and financial toll.

At the MMRF, we recognize that the need to support caregivers is paramount. We know that myeloma patients and their caregivers are interested in learning about therapies, benefits and risks of treatment, and disease prognosis. Greater knowledge in these areas will help alleviate fears, anxiety, and uncertainty, as well as empower caregivers to advocate for the best treatment options for the myeloma patient in their lives.

The information in this booklet is not intended to replace the services or advice of trained health care professionals. Please consult with a care provider regarding specific questions about myeloma diagnosis or treatment.

For more information about multiple myeloma and its treatment, refer to the other booklets in our Patient Toolkit, as well as the MMRF website, **themmrf.org**.

ABOUT MULTIPLE MYELOMA

Multiple myeloma is a blood cancer that develops in the bone marrow. In myeloma, plasma cells, which under normal circumstances are healthy antibody-producing cells, transform into cancerous myeloma cells. Myeloma cells produce large amounts of abnormal antibodies called M proteins and also crowd out and block the production of normal blood cells in the bone marrow. Multiple myeloma can affect the bones, blood, and kidneys.

Multiple myeloma is different in every patient in terms of genomic features, clinical features (that is, symptoms and disease course), and prognosis.

Following The Right Track—the MMRF's framework for helping myeloma patients achieve the best possible outcome—is key to managing multiple myeloma.

The Right Track includes three components:

- Finding the right doctor or treatment center
- Getting the right tests
- Working with the doctor to determine the right treatment plan

Key steps for the best possible care for myeloma patients.

THE RIGHT TRACK

Right Team

Access experts and centers that have extensive experience treating multiple myeloma

Right Tests

Get the information, tests, and precise diagnoses to make the right treatment decisions

Right Treatment

Work with your team to decide on the best treatment plan and identify clinical trials that are right for you

THE RIGHT TEAM

For diseases like multiple myeloma that are rare or complex, finding a doctor who specializes in that disease is essential.

There are several options when it comes to finding a doctor:

- A hematologist-oncologist who focuses on multiple myeloma (that is, a myeloma specialist) is the best option, as these doctors are most likely to be aware of the latest research and newest treatment options
- If seeing a myeloma specialist regularly is not possible, a patient can see a general hematologist-oncologist or medical oncologist

Often, myeloma specialists work out of specialized cancer treatment centers. Myeloma patients treated at specialized centers have been shown to have better outcomes, including longer overall survival.

If the patient isn't able to see a myeloma specialist regularly, it's a good idea for them to consult with one at particularly important points of the journey, such as diagnosis, key treatment decision points, or relapse.

If care is overseen by a hematologist-oncologist or medical oncologist, they may consult with a myeloma specialist to help the patient receive the best care possible.

An increasingly important part of establishing a myeloma diagnosis is getting a second opinion from a myeloma specialist. Getting a second set of eyes can be crucial to confirming a myeloma diagnosis and helping you, the patient, and the patient's care team move with confidence toward the management plan that will yield the best results.

When looking for doctors, be sure to ask about their experience treating multiple myeloma and how many multiple myeloma patients are under their care.

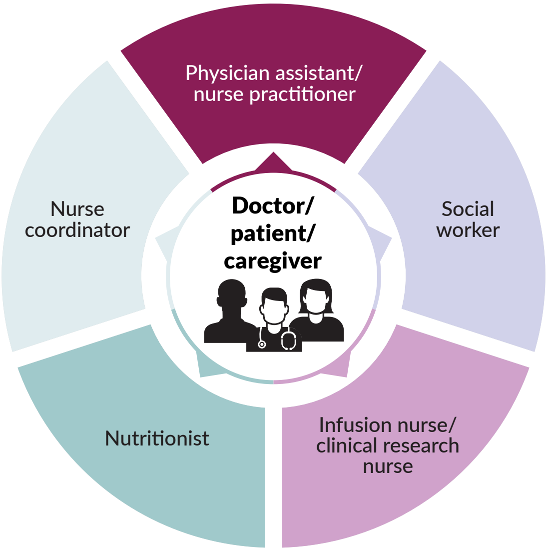
For pointers on how to talk to the care team, see the ***How to Talk to Your Care Team* High-Impact Topic** video.

bit.ly/TalkToCareTeam_HIT

There are several members of the care team that will be involved in providing care and can offer support to the patient—and to you as their caregiver:

- A doctor takes the lead in making decisions based on the patient's treatment goals and preferences. The doctor may be a myeloma specialist, hematologist-oncologist, or medical oncologist. If they are not a myeloma specialist, they may consult with a myeloma specialist regarding treatment decisions
- A physician assistant and/or nurse practitioner may meet with you and the patient during office visits and can answer questions
- A social worker connects you and the patient with extra support
- An infusion nurse and/or clinical research nurse administers the treatment
- A certified dietitian/nutritionist helps plan the patient's diet and answers questions about dietary issues that arise during treatment and recovery
- A nurse coordinator relays concerns to the care team and treats symptoms and treatment side effects

The myeloma care team.



As a caregiver, it's important to educate yourself about myeloma. You can take part in discussions with the care team about which treatments to consider, as well as the patient's results.

Many clinics and hospitals have patient portals that allow patients and caregivers to review results before patient appointments. To make the most of the patient's visits with their care team, it's helpful to bring a list of questions and concerns about their treatment, results, and any side effects to the appointments. Be sure to talk with the patient before office visits about what they want to discuss with the care team.

The MMRF offers many sources of information, including the MMRF Patient Navigation Center. MMRF patient navigators can share information and resources, help patients find a myeloma specialist, identify questions or concerns to bring up with the care team, provide perspective on treatments, and offer general support.

THE RIGHT TESTS

At diagnosis and throughout disease management, the patient will undergo several tests that allow the care team to monitor the disease and guide treatment:

- Blood tests
    - Measure M protein and assess kidney function, blood cell levels, and other markers of myeloma activity
- Bone marrow tests
    - Measure how many myeloma cells are present and sometimes determine their genetic makeup, which helps the care team determine the patient's likely prognosis and whether they have standard- or high-risk disease
- Imaging tests
    - Find areas of bone damage or plasmacytomas (solid masses of myeloma)

These tests are repeated regularly to check how well treatment is working and to watch for changes in the disease.

It's important for patients to have all the appropriate tests done, as the results will help the doctor choose the best treatment options and determine the patient's prognosis.

THE RIGHT TREATMENT

The treatment options for myeloma patients, regardless of stage or disease subtype, are more plentiful and varied than ever before. With many different treatment options available, the right treatment will be tailored for the patient.

Goals of myeloma therapy.

Reduce disease burden as low as possible with the aim of reducing the number of myeloma cells to undetectable levels.

Improve quality of life with as few treatment side effects as possible.

Provide the longest possible period of response before relapse.

Prolong overall survival.

The choice of initial treatment depends on many factors, including the features of the myeloma, the risk of side effects, and the patient's treatment goals.

The patient and the caregiver should discuss treatment goals with the care team. As the caregiver, you can support the patient by making sure that you're familiar with all of the treatment options at every stage of the disease. Be aware of what the standards of care are for myeloma.

For more information about multiple myeloma treatment, refer to the ***Multiple Myeloma Treatment Overview*** booklet in our Patient Toolkit, as well as the MMRF website, **themmrf.org**.

GETTING THROUGH THERAPY

As part of the care team, caregivers play many crucial roles in the treatment process:

- Make sure that the patient attends appointments, providing transportation if necessary
- Serve as another set of ears for information relayed to the patient and take notes during and/or record each visit, if permitted
- Learn about myeloma so you know what to expect and so you can help the patient make decisions about his or her care
- Ask questions about treatment options and side effects
- Note and report symptoms and side effects to the care team
- Remind the patient to take any prescribed medications in the correct dosages at the appropriate time
- Help the patient with personal care, sleep, and exercise
- Help with meal preparation
- Provide emotional support and encourage the patient to maintain other sources of support
- Develop questions to ask at the patient’s next appointment
- Advocate for the patient in appointments, especially when the patient isn’t able or comfortable doing so
- Talk with the patient about topics and questions they’d like to discuss with the care team

Key questions to ask the care team.

- What are the treatment choices?
- What are the risks and benefits of each?
- What can I do to prepare the patient for treatment?
- How will treatment affect the patient’s normal routine?
- What are the side effects and how can I help the patient minimize the risk of side effects?
- What resources are available to the patient and his or her family?
- What is the best way to get in touch with you for questions or emergencies?

DAY-TO-DAY CAREGIVING

Caring for someone with myeloma may include:

- Keeping a clear medication schedule
- Helping manage pills and treatments
- Watching for side effects like fatigue, pain, infection, or mood changes so they can be quickly shared with the care team

Many tools are available to help with these tasks:

- Pill boxes, phone alarms, or written charts can help you manage medication schedules
- A notebook or phone app can help you track side effects and symptoms so patterns are easy to spot
- Grab bars and shower chairs, and making sure the patient knows how to properly use canes or walkers, can help you provide mobility support to the patient
- Planning rest breaks and limiting heavy lifting or stairs can help the patient reduce the risk of bone fractures

Daily life may also involve driving to visits, helping with meals and household tasks, and gently adjusting the level of help based on how tired or unsteady the person feels that day.

When the patient feels well, encourage them to do things on their own to help them maintain independence.

COPING AND SUPPORT FOR MYELOMA CAREGIVERS

Serving as a caregiver is not easy. You'll be doing it out of love, but it can be demanding and is often stressful.

As a caregiver, you may find it hard to take breaks from your caregiving responsibilities. This can be because you feel the patient's needs are too great. And, sometimes, you may just feel guilty taking time for yourself. But taking that time is essential, for both you and the patient: your ability to be a good caregiver is only as strong as your own health and well-being.

It's important to have strategies, coping mechanisms, and support systems in place to help you take care of your own health and well-being.

Support strategies for myeloma caregivers.

1 Look into support groups where you can meet and speak with others who are caregiving or where the patient can talk to others facing multiple myeloma.

2 Establish and maintain a strong support system for yourself.

3 Share caregiving responsibilities with others. Maintain a strong support system for yourself—be specific about the help you need. Friends and family are vital.

4 Provide care for yourself: nutrition, exercise, sleep, spirituality. See your own health care provider, too.

5 Maintain some normalcy (work, relationships, travel, social activities). Keep to a normal routine as much as possible.

Caregiver coping mechanisms.

Concerns

- Fear of disease recurrence
- How to resume a "new normal" life
- Child care issues
- Managing work schedule and responsibilities
- Managing your response (anxiety, depression, shock, fear, confusion, frustration)
- Helping the patient manage loss of control and independence

Coping mechanisms

- Exercise
- Take short breaks, even if it's only to take a walk or run an errand
- Arrange a backup caregiver (respite care) to relieve you
- Minimize stress
- Humor
- Individual or family counseling
- Optimism
- Yoga/meditation/Reiki
- Faith/prayer
- Journal
- Music/art

The MMRF Patient Navigation Center also supports myeloma patient caregivers! Talk to a patient navigator at ***888.841.6673***.

FINANCIAL AND WORKPLACE CONSIDERATIONS

Caregivers may face their own financial and workplace challenges, and it's important to know about options and strategies that can help:

- The Family and Medical Leave Act (FMLA; **www.dol.gov/agencies/whd/fmla**) allows eligible employees to take up to 12 weeks of unpaid, job-protected leave to care for a seriously ill family member while keeping their health insurance
- Workplace accommodations such as flexible hours, remote work, or reduced schedules may be available to balance caregiving duties and work
- Planning finances ahead, understanding insurance coverage, and exploring assistance programs can help manage costs and reduce stress; many cancer centers have social workers who specialize in helping in these situations

PREPAREDNESS

As a caregiver for someone with myeloma, you may find it helpful to prepare for problems that may arise.

Familiarizing yourself with the possible side effects of the patient's myeloma treatment can help you be ready and able to spot problems early.

Create a list that includes information about the patient:

- All current medicines (names, doses, and when they are taken)
- Allergies
- Phone numbers for their myeloma doctor, clinic, and trusted family or friends
- Copy of health insurance cards
- A brief medical history, including major diagnoses, surgeries, and recent treatments

Keep this list in an easy-to-reach place and bring it to all appointments and any emergency room visit so providers have easy access to the patient's health history, which will help them treat the patient more safely and efficiently.

Call the doctor's office for new or worsening symptoms that are not severe, such as:

- Mild fever
- New or increasing pain
- Nausea or vomiting
- Constipation or diarrhea
- Increased tiredness or weakness

Go to the emergency room or call 911 right away for serious warning signs, such as:

- Trouble breathing
- Chest pain or pressure
- Confusion or sudden change in behavior
- Sudden trouble walking or moving a part of the body
- Not being able to stay awake
- Heavy bleeding or vomiting blood
- High fever (for example, 100.4°F or higher)

The MMRF would like to thank Joshua Richter, MD, Associate Professor of Medicine, Hematology and Oncology, in the Myeloma Division at the Tisch Cancer Institute at the Icahn School of Medicine at Mount Sinai and Director of Myeloma at the Blavatnik Family Chelsea Medical Center at Mount Sinai and myeloma caregiver Karen Strauss of Norwalk, Connecticut, for their contributions to this booklet.

MMRF PATIENT SUPPORT AND RESOURCES

The MMRF supports the myeloma community by providing a broad range of resources for myeloma patients and their family members and caregivers. The MMRF is available to help guide you through your multiple myeloma journey every step of the way.

YOUR QUESTIONS ANSWERED

The Patient Navigation Center is available to answer your questions about disease management and treatments, help you find clinical trials, and connect you with financial and other resources.

Telephone: 1-888-841-6673
Monday—Friday, 9:00 AM to 7:00 PM ET
Email: **patientnavigator@themmrf.org**

themmrf.org/support/patient-navigation-center

CONNECT WITH AN MMRF MYELOMA MENTOR

Connect one-on-one with a trained patient and/or caregiver mentor that can share their patient journeys and experiences.

themmrf.org/support/myeloma-mentors

FIND A CLINICAL TRIAL

The MMRF Clinical Trial Finder lets you search for a clinical trial in your area.

themmrf.org/diagnosis-and-treatment/clinical-trials-and-emerging-therapies/clinical-trial-finder/

VIEW PAST PROGRAMS ON DEMAND

Access our archive of recorded Patient Summits and webcasts. Hear expert perspectives on key clinical research and the rapidly evolving myeloma treatment landscape. All available online, and free.

themmrf.org/educational-resources

SUPPORT THE MMRF

Help support the MMRF's efforts to accelerate research and find a cure! Participate in an event or donate today.

Telephone: 1-203-229-0464
Donate now/Take action: **themmrf.org/get-involved**

ATTEND A MULTIPLE MYELOMA PATIENT SUMMIT

Available in-person and virtually, MMRF Patient Summits discuss new treatments, promising clinical trials, and all the information you need to make well-informed decisions about your treatment and care.

themmrf.org/educational-resources

Don’t miss out on the latest myeloma updates!
Sign up today to receive news updates and notice of educational programs.

Name:

Address:

City: State: ZIP:

Telephone: Mobile:

Email:

Or sign up at **themmrf.org**

I AM A:

- ☐ Myeloma Patient
- ☐ Myeloma Patient Caregiver
- ☐ Myeloma Patient Family Member (non-caregiver)
- ☐ Family/Friend of Deceased Myeloma Patient
- ☐ Healthcare Professional or Researcher
- ☐ Biopharma, Medical Device, or Healthcare Technology Industry Professional
- ☐ None of the Above

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Contact one of our patient navigators at the Patient Navigation Center **1-888-841-6673**

Hours: **Mon–Fri, 9 AM–7 PM ET**
Email: **patientnavigator@themmrf.org**

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