



MULTIPLE MYELOMA
Research Foundation

MULTIPLE MYELOMA CAREGIVER GUIDE

themmrf.org





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 health equity so that all myeloma patients can benefit from the scientific and clinical advances we pursue. Since our inception, the MMRF has raised over \$600 million for research, opened nearly 100 clinical trials, and helped bring 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.

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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. Caregivers can accompany the patient on office visits, take notes, and (if permitted) record discussions with the health care team. Having a second person present at office visits can be helpful, as there is often a lot of new information to process. Caregivers can also report on the patient's symptoms and side effects.

Taking care of a patient with multiple myeloma typically involves supporting healthy eating and exercise habits, helping with management of 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 to alleviate fears, anxiety, and uncertainty and empower caregivers to advocate for the treatment options that are most likely to yield the best outcome 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 health 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 monoclonal (M) proteins. Myeloma cells also crowd out and block the production of normal blood cells in the bone marrow. Multiple myeloma can affect the bone, the blood, and the kidneys.

Multiple myeloma is different in every patient. There are at least eight different forms, or subtypes, of myeloma. Each subtype differs in terms of its genomic features, clinical features (that is, its symptoms and disease course), and prognosis.

To ensure the best possible outcome for multiple myeloma patients, there are steps to take after a diagnosis. These include finding the right doctor or treatment center, getting the right tests, and working with the doctor to determine the right treatment plan. This process, developed by the MMRF in collaboration with four cancer research organizations using data from patients, is called The Right Track. Following The Right Track with support from the MMRF's Patient Navigation Center will help patients get the best treatment and outcomes for their specific type of myeloma.

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. When looking for doctors, don't be afraid to ask about their experience treating multiple myeloma. A hematologist-oncologist who focuses on multiple myeloma (myeloma specialist) is the doctor most likely to be aware of the latest research and newest treatment options.

If seeing a myeloma specialist regularly is not possible, the patient can be treated by another specialist, such as a general hematologist-oncologist or medical oncologist, who may consult with a myeloma specialist to help manage the patient's care.

Often, myeloma specialists work out of specialized cancer treatment centers. Treatment centers that frequently see myeloma patients have been shown to produce better outcomes than those that see fewer myeloma patients.

Some myeloma patients may not live close enough to a myeloma specialist to see him or her frequently. Nevertheless, consulting with a specialist at important times, such as diagnosis or relapse, may help ensure that the patient receives the best care possible.

During treatment, several members of the health care team will be involved in the patient's care. The hematologist-oncologist or myeloma specialist takes the lead in making treatment decisions. However, treatment decisions are ultimately based not only on this doctor's recommendations but on the patient's treatment goals and preferences.

A nurse practitioner and/or a physician assistant may serve as an extension of the doctor; one or more of these individuals may meet with the patient during office visits, and any of them can answer patient and caregiver questions.

An infusion nurse (or possibly a clinical research nurse for patients in a clinical trial) usually administers the treatment, and a nurse coordinator relays patient or caregiver concerns to the team and can also treat some disease symptoms or treatment side effects.

A social worker is an excellent resource and can help connect the patient and caregiver with extra support. For example, a social worker can provide information about caring for young children at home, dealing with aging

parents, housing and transportation needs during treatment, or accessing financial support to cover the costs of treatment.

One of the important ways that caregivers can help is to make sure the patient follows recommendations from the dietitian or nutritionist. The patient may experience dietary issues during treatment and recovery. A certified dietitian or nutritionist can help plan their diet and answer questions regarding decreased appetite, weight loss/gain, dry/sore mouth, or nausea or vomiting.

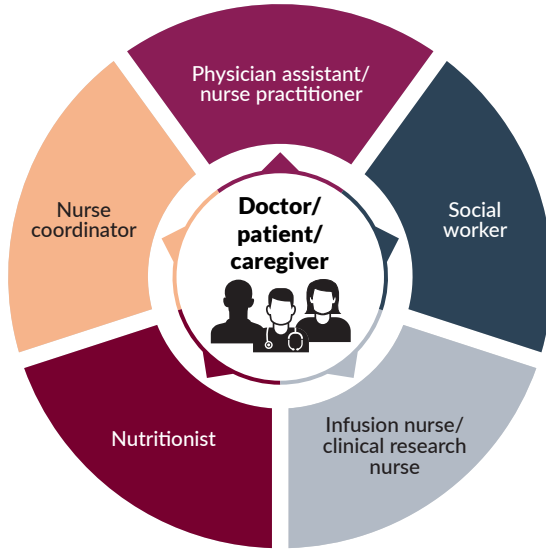
Even if the doctor who manages the patient's myeloma is a specialist, the MMRF strongly encourages everyone with a myeloma diagnosis to get a second opinion from a different myeloma specialist at the start of treatment and when making changes to their treatment plan.

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

Many sources of information are available, including the MMRF website and the MMRF Patient Navigation Center. The Patient Navigation Center is a resource where patients and caregivers can connect (by phone, email, or online) with patient navigators who can share information and resources, help with finding a myeloma specialist, provide perspective on treatments, and offer support.

Many clinics and hospitals have patient portals that allow patients or 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.

The myeloma care team.



THE RIGHT TESTS

The patient will undergo blood and urine tests, including a complete blood count, comprehensive metabolic panel, lactate dehydrogenase (LDH), beta-2 microglobulin ($\beta 2M$), quantitative immunoglobulins, serum protein electrophoresis, immunofixation electrophoresis, and serum free light chain assay.

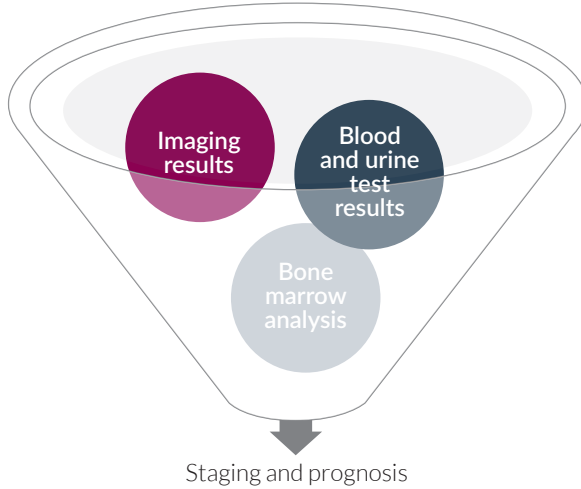
Imaging tests may be done to assess changes in the patient's bones, including bone (skeletal) survey, x-ray, magnetic resonance imaging (MRI), computed tomography (CT), and positron emission tomography (PET).

In addition, a bone marrow biopsy will be done to confirm the myeloma diagnosis, assess the extent of the disease, and monitor progress once he or she starts treatment.

Genomic tests are conducted by analyzing the DNA from myeloma cells taken from bone marrow during the patient's biopsy. As with other testing, genomic tests are conducted as part of the initial diagnosis and may be repeated periodically.

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.

Lab and imaging tests.







THE RIGHT TREATMENT

The treatment options for patients with multiple myeloma, regardless of stage or form of the disease, are more plentiful and varied than ever before.

The goal of therapy is to induce a remission as quickly as possible to minimize the risk of organ damage, maintain that remission for as long as possible, improve quality of life (reduce pain, lessen fatigue), and minimize the occurrence and/or severity of side effects.

Goals of myeloma therapy.

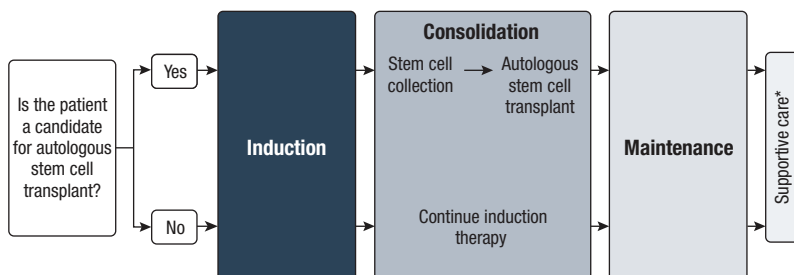
-  Reduce disease burden as low as possible with the aim of reducing the number of myeloma cells to undetectable levels.
-  Improve quality of life with as few treatment side effects as possible.
-  Provide the longest possible period of response before relapse.
-  Prolong overall survival.

The choice of a patient's initial treatment depends on many factors, including the features of the myeloma, the risk of side effects, and the patient's treatment goals. Initial treatment options are similar regardless of whether the patient undergoes stem cell transplantation. A stem cell transplant is a procedure in which blood-forming cells are collected from the patient, stored while the patient receives high-dose chemotherapy to eliminate the myeloma cells in his or her blood and bone marrow, then re-administered to the patient. Because high-dose chemotherapy can also reduce the normal cells in the bone marrow, a stem cell transplant can help to replenish the bone marrow.

Patients who opt for transplant receive high-dose chemotherapy followed by a stem cell transplant after induction therapy (that is, the first treatment a patient receives after the myeloma diagnosis is confirmed). Induction therapy typically consists of three-drug (triplets) or four-drug (quadruplets) regimens given over three to six cycles, each of which typically lasts 3 or 4 weeks. Some patients may decide to continue their initial therapy and consider transplant later. Maintenance therapy (treatment given once a patient has achieved a response to initial therapy to help prolong remission) may be considered following transplantation.

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

Myeloma treatment plan.



*Supportive care (care for the prevention and management of treatment side effects) is given throughout treatment.

GETTING THROUGH THERAPY

Caregivers, as part of the health care team, play a crucial role in the treatment process. They ensure that the patient attends appointments, serve as another set of ears for information relayed to the patient, and take detailed notes or record each visit. They also note symptoms and side effects and are able to report them to the health care team. Additionally, caregivers can ensure that the patient takes any prescribed medications in the correct dosages and at the appropriate time. Above all, the caregiver helps the patient optimize nutrition, self-care, sleep, and exercise, all while providing love and support!

Key questions to ask the health 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 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?



SEEKING AND RECEIVING SUPPORT

As a caregiver, it's possible that you may ignore your well-being while focusing on the needs of the patient in your care. However, caring for yourself is important: it recharges you and enables you to provide steady, strong support to the patient you care for. Below are some strategies to cope with physical and emotional stresses you may experience.

Coping and support for myeloma caregivers.

- 1 Learn enough about multiple myeloma to help the patient make decisions about his or her care.
- 2 Ask questions about treatment options and side effects.
- 3 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.
- 4 Establish and maintain a strong support system for yourself.
- 5 Encourage the patient to establish and maintain support, as well.
- 6 Friends and family are vital. Enlist help so you can share the responsibilities. Be specific about the help you need.
- 7 Educate yourself about multiple myeloma so that you know what to expect.
- 8 Provide care for yourself: nutrition, exercise, sleep, spirituality. See your own health care provider, too.
- 9 Maintain some normalcy (work, relationships, travel, social activities).

Concerns of the caregiver and coping mechanisms.



Concerns

- Fear of disease recurrence
- How to resume a “new normal” life
- Child care issues
- Work issues/disability
- Anxiety
- Depression
- Shock
- Fear
- Confusion
- Loss of control/independence
- Frustration

Coping mechanisms

- Seek information
- Share/talk with others
- Minimize stress
- Humor
- Individual or family counseling
- Optimism
- Yoga/meditation/Reiki
- Faith/prayer
- Journal
- Music/art

Speak to an MMRF patient navigator from the Patient Navigation Center at **888.841.6673**.

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 Annamarie Kealy of Norwalk, Connecticut, for their contributions to this booklet.

MMRF SUPPORT AND RESOURCES

The MMRF is dedicated to supporting 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

Speak to an MMRF patient navigator at the Patient Navigation Center for answers to your questions about disease management, treatments, clinical trials, and assistance with finding financial and other available resources.

Telephone: 1-888-841-6673

Monday–Friday, 9:00 AM to 7:00 PM ET

Email: patientnavigator@themmrf.org

Online: themmrf.org/support/patient-navigation-center

Connect with an MMRF Myeloma Mentor:

themmrf.org/support/myeloma-mentors

This is a phone-based program offering the opportunity for patients and/or caregivers to connect one-on-one with a trained patient and/or caregiver mentor to share their patient journeys and experiences.

FINANCIAL SUPPORT

For information on reimbursement-assistance programs for myeloma drugs, please go to themmrf.org/resources/financial-assistance.

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: Visit themmrf.org/get-involved

NOTES



MMRF RESOURCES IN PERSON OR ONLINE



Attend a Multiple Myeloma Patient Summit

Learn about standard and emerging therapies, including stem cell transplants, promising clinical trials, and more for optimal disease management. Attend a complimentary symposium for all the information you need to make well-informed decisions about your treatment and care.

To register or to view the complete calendar, visit:
themmrf.org/resources/education-programs



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, at:
themmrf.org/resources/education-programs



Find a Clinical Trial Near You

Clinical trials are critically important to developing new myeloma treatments and better understanding the biology of the disease. The more people who enroll, the faster we can find answers. Patients who enroll in clinical trials have the opportunity to be among the first to receive the newest drugs or drug combinations in development and receive close monitoring.

To find a clinical trial near you, visit:
themmrf.org/resources/clinical-trial-finder

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)
- Health Care Professional or Researcher
- Biopharma, Medical Device, or Health Care Technology Industry Professional

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383 Main Avenue, 7th Floor
Norwalk, CT 06851

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**



383 Main Avenue, 7th Floor, Norwalk, CT 06851
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