

MULTIPLE MYELOMA **CAREGIVER GUIDE**



MULTIPLE MYELOMA
Research Foundation

themmrf.org

ABOUT THE MULTIPLE MYELOMA RESEARCH FOUNDATION

The Multiple Myeloma Research Foundation (MMRF) was established in 1998 by identical twin sisters Kathy Giusti and Karen Andrews shortly after Kathy's diagnosis with multiple myeloma. Kathy and Karen soon learned that little progress against this disease had been made in decades and that myeloma patients had few treatment options. They decided that it was time to accelerate change. Their mission was to ensure more access to better treatments and bring the promise of a cure for every myeloma patient.

Since its founding, the MMRF has remained steadfast in the pursuit of its mission. It is now the leading cancer research organization focused on the development and delivery of more precise therapies, and it is aggressively pursuing a world without myeloma. Working with its partners in industry, research, government, and academia, the MMRF has helped launch 15 new drugs in the past 18 years, an achievement that has almost tripled the life expectancy for myeloma patients. The MMRF is a patient-focused organization that stands with the entire myeloma community and is speeding the discovery of cures through precision medicine. Driven by data and innovative research, the MMRF is committed to empowering every patient with precisely what he or she needs to prevent or defeat multiple myeloma.

As the multiple myeloma community's most trusted source of information, the MMRF supports patients from the time of diagnosis throughout the course of the disease. All information on the MMRF website (www.themmr.org) is organized by disease stage, so patients can get the information they need, when they need it.

To learn more about the MMRF, visit www.themmr.org.

To speak to a Patient Navigator at the Patient Navigation Center, call **1-888-841-MMRF (6673)** or email patientnavigator@themmr.org.

Updates to and distribution of this booklet were supported by Adaptive Biotechnologies, Amgen, Bristol Myers Squibb, CURE Magazine, Genentech, GlaxoSmithKline, Karyopharm Therapeutics, Oncopeptides, and Takeda Oncology.

Accredited by:



GUIDESTAR®



INTRODUCTION

Caregivers (partners, family members, and close friends) play a vital role in helping multiple myeloma patients manage their disease and navigate treatment options. The surge in the number of new drugs that have become available (15 new myeloma drugs approved in the last 18 years!) has made multiple myeloma management an exciting but confusing arena. As a result, caregivers may not be confident in their knowledge of current standards of care, how drugs are used, what to expect while patients receive therapy, and—perhaps most importantly—how they can best help the myeloma patients in their daily living. Additionally, as optimal multiple myeloma management may involve participation in a clinical trial, it is beneficial for caregivers to be aware of myeloma clinical trials in their area.

Providing care to a patient with multiple myeloma encompasses supporting dietary needs, daily activities and exercise, managing symptoms, providing emotional support, and coordinating health care. For caregivers, this may require a considerable personal sacrifice, potentially involving a commitment of many years, and it may exact an emotional, physical, psychosocial, and financial toll. A recent study revealed that caregivers have more stress and anxiety than patients, which may be due to their fears regarding declines in patients' health, the risk of disease recurrence, and feelings about death and dying.

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 their loved ones.

For more information about multiple myeloma and its treatment, please refer to the companion booklets *Multiple Myeloma Disease Overview*, *Multiple Myeloma Treatment Overview*, *Autologous Stem Cell Transplantation*, *The Path to Precision Medicine in Multiple Myeloma*, and *Multiple Myeloma Immunotherapy*—as well as the MMRF website, www.themmr.org.

ABOUT MULTIPLE MYELOMA

Multiple myeloma is a blood cancer that develops in the bone marrow. In myeloma, plasma cells, which are normal 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 affects the bone, the blood, and the kidneys.

Multiple myeloma is a highly diverse disease, meaning that it 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 a number of steps to be taken once a diagnosis is made, including finding the right doctor or treatment center, getting the right tests, working with the doctor to determine the right treatment plan, and sharing data with registries to help advance myeloma clinical research. 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 assistance from the MMRF's Patient Navigation Center will help patients obtain 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

Get on the Right Track

THE RIGHT TEAM

For diseases that are rare or particularly complicated, such as multiple myeloma, specialized medical understanding is especially important. When considering potential doctors, don't be afraid to ask about their experience treating multiple myeloma. Ideally, a hematologist who focuses on multiple myeloma will be aware of the latest research and up-and-coming treatment options. If seeing a hematologist is not possible, the patient can be treated by another specialist, such as a medical oncologist, who may consult with a hematologist.

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

You may not live close enough for a specialist at a cancer center to be the myeloma patient's source of treatment. Nevertheless, consulting with a specialist at important times and obtaining specific types of care at a specialized center may help ensure that the patient for whom you are providing care receives the best medical care possible.

The MMRF also strongly encourages everyone diagnosed with multiple myeloma to get a second opinion from a multiple myeloma specialist at the start of treatment and when making changes to the treatment plan—even if the doctor the patient has been seeing is a specialist.

During treatment, several members of the health care team will be involved in the patient's care. As a myeloma specialist, the doctor is considered the quarterback of the health care team. 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 myeloma specialist; one or more of these individuals may meet with the patient during office visits, and any of them can answer patient and caregiver questions. A clinical research nurse or an infusion nurse usually administers the prescribed treatment, and a nurse coordinator relays patient or caregiver concerns to the team and can also treat some disease symptoms or treatment side effects.

The social worker is an excellent resource and can help connect the patient and caregiver with extra social 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.

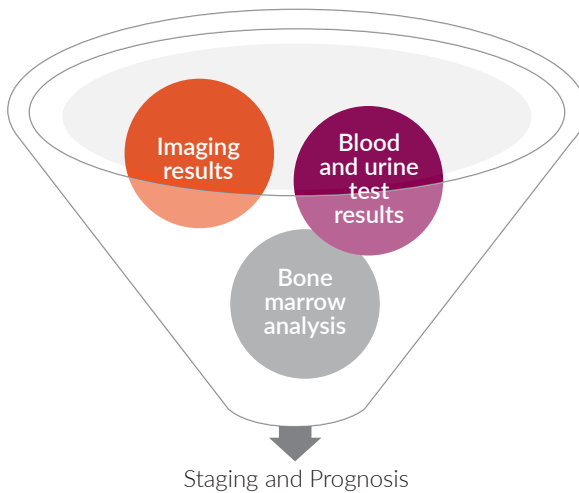
The myeloma treatment team.



THE RIGHT TESTS

Blood and urine tests, as well as bone marrow biopsy, are performed to confirm a diagnosis of myeloma, to assess the extent of the disease, and to monitor progress once treatment is started. Genomic tests are conducted by analyzing the DNA from the myeloma cells taken from a small amount of bone marrow. Tests are conducted as part of the initial diagnosis and may be repeated periodically. Additionally, imaging tests that could include x-rays, magnetic resonance imaging (MRI) scans, computed tomography (CT) scans, and positron emission tomography (PET) scans may be ordered. Minimal (measurable) residual disease testing can also be helpful to inform whether treatment is working. It is important for patients to have all the appropriate tests done, as the results will help the doctor better determine treatment options and prognosis.

Lab tests.

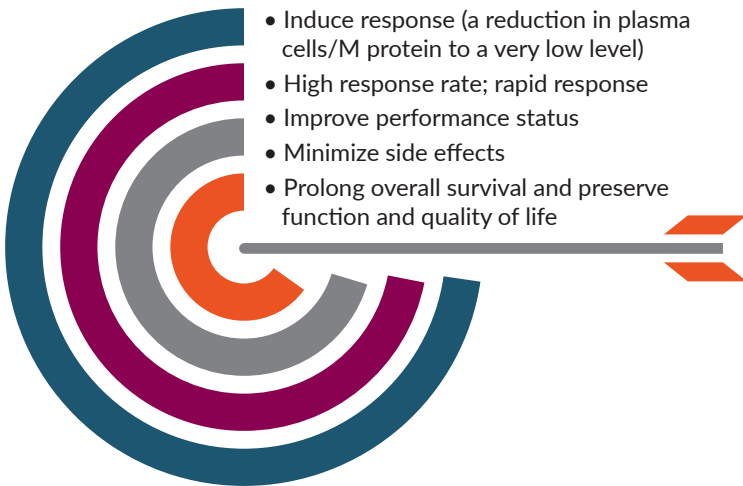


THE RIGHT TREATMENT

The treatment options for patients with multiple myeloma—at all stages and in all forms of the disease—are more plentiful and varied than ever before.

The goal of therapy is to induce a response (a reduction in plasma cells/M protein to a very low level) and to achieve that response as quickly as possible to minimize the risk of organ damage, improve quality of life (reduce pain, lessen fatigue), and minimize the occurrence and/or severity of side effects.

Goals of myeloma therapy.

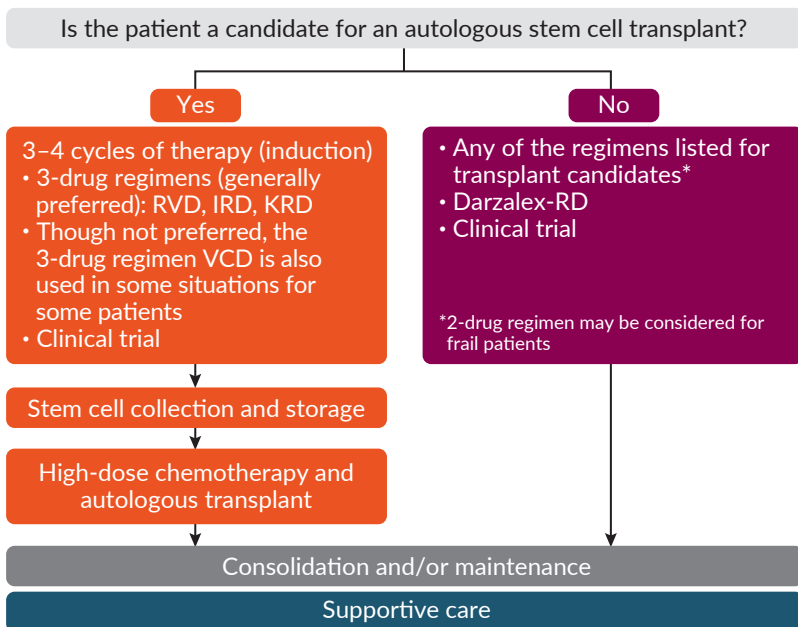


The choice of a patient's initial treatment depends on many factors, including the features of the myeloma, the risk of potential side effects, and the patient's treatment goals. Initial treatment options are similar regardless of whether patients undergo stem cell transplantation. A stem cell transplant is a procedure in which blood-forming cells are collected from the patient or a donor, 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 are candidates for transplant may choose to receive high-dose chemotherapy followed by a stem cell transplant after three or four rounds (cycles) of initial therapy (that is, the first treatment a patient receives after the myeloma diagnosis is confirmed; it's also known as induction therapy). Or they may decide to continue their initial therapy and consider transplant later. Maintenance therapy (treatment given when a patient achieved a response to initial therapy to help prevent a relapse) may be considered following transplantation.

Discuss treatment goals with your health care team and be sure 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.



C, cyclophosphamide; D, dexamethasone; I, Ninlaro; K, Kyprolis; R, Revlimid; V, Velcade

SHARE YOUR DATA AT EVERY STEP

All patients and caregivers should discuss with their myeloma specialist the option of sharing the patient's data. This data—which is invaluable to ongoing efforts to develop new myeloma treatments—can be shared via clinical studies such as the MMRF CureCloud®, which help researchers identify trends, learn about the most effective treatments, and work toward bringing new therapies to patients. Sharing data benefits every myeloma patient.

The MMRF created **CureCloud**, a centralized data hub that generates, aggregates, and visualizes data. To learn more about how patients can contribute their own data to this registry, please visit www.mmrfcurecloud.org.

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 for treatment?
- How will treatment affect my normal routine?
- What are the side effects and how can I minimize the risk of side effects?
- What resources are available for me and my family?
- What is the best way to get in touch with you for questions or emergencies?



SEEKING AND RECEIVING SUPPORT

As a caregiver, it is 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 your loved one 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 your loved one can talk to others facing multiple myeloma.
- 4 Establish and maintain a strong support system for yourself.
- 5 Encourage your loved one 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 and your loved ones about multiple myeloma so that you and those around 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 both with and without loved one).

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** or join the MMRF Facebook Community Group for myeloma caregivers (www.facebook.com/groups/393909578064580/about/).

The MMRF would like to thank Jesus G. Berdeja, MD, Director of Multiple Myeloma Research and Senior Investigator, Hematologic Malignancies at the Sarah Cannon Research Institute in Nashville, Tennessee, and Faith E. Davies, MBBCh, MRCP, MD, FRCPath, Director of the Clinical Myeloma Program at the Perlmutter Cancer Center at New York University Langone Health in New York, New York, and our patient advocates Allan and Deb Osborne of Millis, Massachusetts, and Cindy Chmielewski of Lawrenceville, New Jersey, for their contributions to this booklet.

RESOURCES

At the MMRF, we are dedicated to supporting the myeloma community by providing a broad range of resources for those living with myeloma, as well as their caregivers. We are here to help guide you through your multiple myeloma journey every step of the way.

MMRF Resources



Information & resources



Expert advice



Support



Patient Navigation Center

- Speak to an MMRF Patient Navigator from 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
- Connect with an MMRF Myeloma Mentor™:
themmrf.org/resources/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.
- Get the latest myeloma updates on the MMRF website and follow the MMRF on Facebook and Twitter

-
- Tap into educational resources, from reading materials to virtual meetings, by following this link: themmrf.org/resources/education-programs
 - The MMRF *Your Myeloma Journey Guide* downloadable toolkit provides information about the basics of myeloma and treatment options
 - MMRF *Patient Webinars* occur every month on specific topics
 - MMRF *Patient Summits* and *Expert Sessions* are held virtually or in multiple cities across the US every year
 - View slides and videos from past events
 - Find an MMRF Support Group at themmrf.org/resources/find-a-support-group
 - Search for a clinical trial in your area or let MMRF Patient Navigators guide you through the process: themmrf.org/resources/clinical-trial-finder

Financial Support

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



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 Summit symposia 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 all of our educational programming and myeloma news!

Name: _____

Address: _____

City: _____ State: _____ ZIP: _____

Telephone: _____ Mobile: _____

Email: _____

Or sign up at themmrf.org

I AM A: (CHECK BOX)

- Patient
- Patient Spouse
- Patient Family
- Patient Friend
- Healthcare Professional
- MMRF Supporter

**Please tear off reply card and tape all three sides before mailing.*

Fold here



MULTIPLE MYELOMA
Research Foundation

themmrf.org



MULTIPLE MYELOMA
Research Foundation

Place
stamp
here

Multiple Myeloma Research Foundation
383 Main Avenue, 5th Floor
Norwalk, CT 06851

Contact one of our
Patient Navigators at the
Patient Navigation Center
1-888-841-MMRF (6673)

Hours: *Mon–Fri, 9 AM–7 PM ET*

Email: patientnavigator@themmrf.org



MULTIPLE MYELOMA
Research Foundation

383 Main Avenue, 5th Floor, Norwalk, CT 06851

Email: info@themmrf.org

www.themmrf.org