

Caring for Someone with Multiple Myeloma



A caregiver is anyone who provides unpaid help or arranges to support someone with an illness. Caregivers provide a range of help, from physical

and emotional support to financial or planning assistance. A caregiver may feel a lot of pressure in this role, and caregiving can get harder over time.

Caring for a Loved One with Multiple Myeloma

As you prepare to take on this role, consider these helpful tips:

- 1. Learn about the diagnosis.** This includes treatment options, possible side effects and expectations for recovery. Focus on credible websites like those in this fact sheet. Try to get a second or third opinion, ideally from highly experienced local medical centers and experts. Ask about the full range of services and treatment options in clinical trials.
- 2. Weigh the pros and cons of each treatment with your loved one.** Consider things like time, cost, where treatment will be given, possible side effects, and balancing your loved one's goals for treatment with what's available.
- 3. Ask about financial assistance.** Some pharmaceutical companies, support organizations, and clinical trials offer co-pay support when asked. Your loved one may be eligible for other discounts, too. Always ask.
- 4. Create a “to do” list with your loved one.** Include immediate and long-term needs. Decide what your loved one can do on their own, and what you or someone else can do.
- 5. Recognize and respect the wishes, capabilities, and roles of everyone involved.** Each stage of care will require different levels of support, and roles will change over time. Openly talk about what you and others can reasonably provide, what your loved one can do, what outside organizations can help with, and what must adjust along the way.
- 6. Organize a care-plan calendar.** Include who is doing what, and when. This can help reduce a patient's stress and bring needed relief. www.MyLifeLine.org offers a way to keep track of tasks that everyone can help with.
- 7. Set your own limits.** Offer help in reasonable ways. If you can't help with something (which is fine), look for other ways to get your loved one the help they need.
- 8. Gain permission to get copies of medical records when needed.** Legal “Power of Attorney” will allow you or someone else to help with follow-up care plans and future medical or financial needs.
- 9. Tap into support services.** An oncology social worker or financial navigator can be very helpful for you. Look at websites from organizations like Cancer Support Community, the Multiple Myeloma Research Foundation, CancerCare, or the Leukemia & Lymphoma Society. Other MM caregivers (who understand what you're going through) can also be very helpful.
- 10. Take care of yourself.** When you take care of yourself, you can do a better job of helping others. If you need a “break,” ask about respite care. Respite care offers short-term, temporary relief for caregivers. It brings a professional caregiver to the patient's home for intensive care and is available for short periods of time. The patient's health care team and insurance company can tell you more about these services.

Try to find humor and pleasure in life so you can enjoy special moments together.

OTHER TYPES OF CARE ASSISTANCE MAY BE AVAILABLE, DEPENDING ON YOUR LOVED ONE'S NEED OR STAGE OF ILLNESS:

- **Palliative care** offers home care and relief to a patient for a range of pain and other problems. It is available at any stage of illness.
- **Hospice care** offers a full range of care to a patient and their family within the last 6 months of a patient's life. It is offered in a hospice care setting or in the patient's home.

For more tips and caregiver resources, visit www.CancerSupportCommunity.org/caregivers.



Multiple Myeloma Information & Support

American Society of Clinical Oncology • 888-282-2552 • www.asco.org

CancerCare • 800-813-4673 • www.cancercares.org

National Institute of Health's Clinical Trial Search • ClinicalTrials.gov

International Myeloma Foundation • 800-452-2873 • www.myeloma.org

The Leukemia & Lymphoma Society • 800-955-4572 • www.LLS.org/myeloma

For clinical trials: www.LLS.org/clinicaltrials

Multiple Myeloma Research Foundations • 866-603-6628 • www.themmr.org

For clinical trials: www.themmr.org/treatment-options/clinical-trials

NCCN Guidelines for Patients: Multiple Myeloma • www.nccn.org/patientresources/patient-resources/

Myeloma Central • www.myelomacentral.com/

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

National Cancer Institute • 800-422-6237 • www.cancer.gov

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am–9 pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with other Multiple Myeloma patients by joining the Managing Multiple Myeloma online discussion board. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

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This book is available to download and print yourself at www.CancerSupportCommunity.org/Multiple-Myeloma. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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