

# Caregiving for a Loved One with Multiple Myeloma

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# Caregiving for a Loved One with Multiple Myeloma

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*Each year in the United States, approximately 32,000 people—most over the age of 60—are diagnosed with multiple myeloma, a cancer of a type of white blood cell that lives in the bone marrow.*

This booklet provides information, guidance and resources for people helping to care for a loved one with multiple myeloma. Use this booklet in whatever way works best for you—read it straight through or refer to sections as you need them. Be sure to share the information you find most helpful with your loved one.

## The Role of the Caregiver

Caregivers provide important support for a person living with cancer. Often, caregivers are family members or friends. They may live with, nearby or far away from the person they support.

Please remember that you should not be alone as you provide support to your loved one. People in your personal network (family, friends, neighbors) will be eager to help, especially if you are specific in your requests. Take some time to think about the people in your life and how they are best suited to help you, and match your request to their strengths—ask a family member who loves to shop to pick up a few things at the store; ask a friend who's a good listener to come over for a chat with you and your loved one.

There are also professional resources available to you, including the oncology social workers at CancerCare, who are specially trained to help people and their caregivers cope with the emotional and practical challenges of cancer. Additional resources are listed at the end of this booklet.

## Guidance for Caregivers

The kind of support that a caregiver provides will be different for each person. In general, caregiving support falls into one of three areas: informational, practical and emotional. This booklet provides examples of how caregivers can help in each of these areas.



## Informational Support

A person diagnosed with multiple myeloma can feel overwhelmed, and may need support directly related to his or her diagnosis and treatment. Here are specific types of informational support caregivers can provide:

**Learn about your loved one's diagnosis and possible treatment options.** There is information in this booklet on current treatment approaches for multiple myeloma. You will also receive information from your loved one's health care team, and can ask a member of that team what additional resources they recommend.

**Understand the potential side effects of the chosen treatment approach.** In addition to information on treatment approaches, this booklet lists potential effects of multiple myeloma therapy. Some are specific to a certain type of therapy; some are more general side effects that are seen across a number of different therapies. Your loved one's health care team can provide additional information on potential side effects, based on their specific treatment approach.

**Help your loved one communicate with health care professionals.** As you help your loved one manage their multiple myeloma, it's important to remember that you are both consumers of health care. In addition to educating yourself about the diagnosis and treatment options, get to know the members of your loved one's health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators. Here are a few things you, as a caregiver, can do to ensure that communication with the extended health care team is as effective as it can be:

- **Help create a health care journal.** Having a health care journal or notebook will allow your loved one to keep all of his or her health information in one place. It should include the names and contact information of members of their health care team and details of their treatment plan, including dates of treatment and the schedule for taking treatment-related medication. The journal can also be used as a diary to capture his or her experiences while undergoing treatment, and your experiences as a caregiver.
- **Help prepare a list of questions for their next appointment.** This list should include your questions and concerns as well as those of your loved one. Because the doctor may have limited time, create the list in order of importance.
- **Accompany your loved one to medical appointments.** Even if he or she has a journal and a prepared list of questions and concerns, having additional support at appointments is always helpful. You may think of additional questions to ask, or remember details about your loved one's symptoms, treatment or overall quality of life that they may have forgotten.
- **Write down the doctor's answers.** Taking notes will help you and your loved one remember the doctor's responses, advice and instructions. If you have a mobile device, ask if you can use it to take notes or record the discussion, which will help you review the information later.

### **Important note about communicating with health care**

**professionals:** If you want to speak with the health care team without your loved one present, find out about the rules of the Health Insurance Portability and Accountability Act (HIPAA). This law gives patients greater access to their own medical records and more control over how their health information is used. Your loved one will need to give written permission, by signing a consent form, before doctors can share information with you about his or her medical treatment.

## Practical Support

There are many ways that caregivers can help with practical matters (the activities of daily living), including:

**Personal care.** Depending on how they are feeling, people going through treatment for multiple myeloma may need help with daily living activities such as bathing or dressing. Some people may want help, but would prefer that it is provided by a paid helper, rather than a spouse or friend. If that's the case with your loved one, ask a member of their health care team for recommendations on local home health agencies that can provide these services.

**Health care.** As a caregiver, you may be involved in some health care tasks that are more typically handled by a nurse, such as administering medication and monitoring vital signs. If you need help, ask the doctor, nurse or hospital social worker about local home health agencies that can send in-home nurses to provide these (and other) services.

**Organizing medications.** Keeping track of prescription and over-the-counter medications can be a challenge under any circumstances. An inexpensive pill organizer (available at most drugstores) allows for the sorting of medications by day of week and time of day, which will help your loved one take his or her medications on schedule. There are also free medication reminder apps available for smart phones or tablets.

**Household tasks and errands.** If you are a caregiver to a spouse or significant other, you may already be handling a large share of household tasks and errands. This would be a good time to take short-term responsibility for additional chores, if possible.



## Helping with financial issues:

- **Review your loved one's insurance policies or Medicare plan to understand what's covered.** If your loved one has private insurance, the company can assign a case manager to explain what services and treatments the plan covers and answer any questions you may have.
- **Understand what your loved one is entitled to.** There are government programs called entitlements that give financial and other aid to people in certain groups, such as those with cancer. A hospital or community social worker can direct you to the governmental agencies that oversee these programs.
- **Ask for help.** If you need help with hospital bills, speak to a financial counselor in the hospital's business office about setting up a payment plan. If your loved one is in financial difficulty, talk to his or her creditors, as often mutually-agreeable arrangements can be made. Reaching out for help early is the most effective approach.
- **Utilize available programs.** For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are many programs to help individuals get medications for free or at a low cost. For more information, contact the Medicine Assistance Tool, listed in the Resources section of this booklet.



## Emotional Support

It's hard to watch someone you care about go through the difficult emotions that may arise with a cancer diagnosis, which can range from denial to sadness to anger. There are things you, as a caregiver, can do to help both of you cope:

**Listen to your loved one.** It's important to listen without judging or "cheerleading." Simply listening to and validating what your loved one is expressing can be one of the most important contributions you make.

**Do what works.** Think about how you've helped each other feel better during difficult times in the past. Do whatever works for the both of you, but don't be afraid to try something new or to make modifications as needed.

**Support your loved one's treatment decisions.** While you may share decision making, ultimately it is your loved one who bears the impact of multiple myeloma and its treatment. It is important to support whatever decisions he or she makes.

**Get information about support groups.** Joining a support group gives your loved one a chance to talk with others coping with cancer, and learn what they do to manage difficult emotions. Ask a hospital social worker for a referral, or contact CancerCare. CancerCare offers free face-to-face, telephone and online support groups for people affected by cancer.

## **Continue your support when your loved one's treatment**

**is over.** The end of treatment means fewer meetings with the health care team, whose support you have likely relied on. Contact CancerCare or a member of your loved one's health care team for guidance on providing caregiving help during this transitional period.

## **Remember to Take Care of Yourself**

Taking care of a loved one can be a positive experience, but it can also feel like a full-time job and be very stressful. Caregiving can be even more challenging if you have other significant responsibilities, like working, raising children, or caring for your own health. Many caregivers tend to put their own needs and feelings aside; however, it's important for you to take good care of yourself. Here are some tips to help you do so:

**Ask for help.** Consider using MyCancerCircle.net™ (<https://mycancercircle.net>) to organize help from friends and family. MyCancerCircle is a free, private and customizable online tool that gives people facing cancer (and their caregivers) a way to organize and coordinate a circle of family members, friends and neighbors to provide practical and emotional support. The tool also allows you to look for professional or volunteer resources in your community.

**Stay active.** Experts recommend at least 150 minutes (2.5 hours) of moderate-intensity aerobic activity per week, preferably spread throughout the week. Aerobic activity includes the use of cardio machines, walking, running, hiking, swimming and dancing.

**Pay attention to what you're eating.** Keeping a balanced diet is an important part of taking care of yourself. Include fruits and vegetables in your meals. Nuts, yogurt and peanut butter are easy snacks with lots of protein that will keep your energy level up. Pack healthy snacks if you know you will be with your loved one at the doctor's office or the hospital for an extended period of time.

**Get enough sleep.** Caregiving can be emotionally and physically draining, and you should try to get enough sleep. The Centers for Disease Control and Prevention (CDC) recommends at least seven hours each night.

**Keep up with your own checkups, screenings and medications.** Your health is very valuable. Stay on top of your own medical appointments, and have a system for remembering to take any medicines you need to stay healthy.

**Get emotional support.** Caregiving is hard work that can affect your emotional well-being. Taking care of yourself includes coping with many of your own feelings that come up as you care for your loved one. Here are some tips:

- **Take a break.** Take some time for yourself regularly. Even if it's just for a few minutes, doing something you enjoy (e.g. taking a walk, listening to relaxing music, working on a favorite hobby) can help you recharge.
- **Be aware of your limits.** Remember that there are only so many hours in a day. Feel free to say "no" when people ask you to take on tasks (whether or not they are related to caregiving) that you don't have the time or energy to complete.
- **Keep a journal.** Writing often helps people organize their thoughts and come up with practical solutions. Writing about your thoughts, feelings and memories can also strengthen your spirit.

- **Open up to friends and family.** Ask friends or family members if they would be willing to be “on call” in times of stress. You can also plan a regular check-in time. Be sure to make time for socializing with friends or family, preferably outside of your home.
- **Talk to a professional about your feelings and concerns.** Many caregivers feel overwhelmed and alone. Speaking with a counselor or oncology social worker may help you cope with some of your feelings and worries. CancerCare’s oncology social workers are just a phone call away.
- **Join a support group for caregivers.** CancerCare offers free face-to-face, telephone and online support groups for caregivers. These groups provide a safe haven where you can share your concerns and learn from others who are going through a similar situation.
- **Be kind to yourself.** Sometimes, you may feel you could have done something differently or better. Don’t dwell on that; instead, focus on all the positive things you are doing for your loved one.



# Multiple Myeloma

## Treatment Options

Numerous treatment options are available to people living with multiple myeloma and more are on the horizon.

Multiple myeloma that is not causing symptoms (also known as smoldering multiple myeloma) may not initially need to be treated. Your loved one's doctor will regularly monitor his or her condition through blood and urine tests to determine if the disease is progressing and if treatment is needed.

### **Stem Cell Transplant**

A stem cell transplant (also known as a bone marrow transplant) is a procedure in which diseased bone marrow is replaced with healthy bone marrow after high dose chemotherapy. It is an important treatment option for some people with multiple myeloma.

In the procedure, stem cells are harvested (collected) from the patient or from a donor and then stored. The patient is given high doses of chemotherapy to destroy as many myeloma cells as possible. The stem cells are then “infused” (transplanted) into the body, where they travel to the bones and begin rebuilding bone marrow.

When a person with multiple myeloma receives his or her own stem cells, the procedure is called an “autologous” stem cell transplant. Autologous stem cell transplant is the most common type of stem cell transplant in multiple myeloma. Allogeneic stem cell transplants, in which stem cells are from a donor (either a close relative, such as a brother or sister, or a donor from a registry), are not commonly used in treating multiple myeloma.

A stem cell transplant is an intensive treatment. To determine if it is the right treatment approach, doctors weigh a number of factors, including the person's age and general physical health.

## **Immunomodulatory Options**

Through a complicated mechanism that was only recently discovered, immunomodulatory drugs lead to the degradation (reduction) of growth signals in myeloma cells. These medications are taken by mouth as capsules, typically in combination with corticosteroids like dexamethasone and frequently in combination with proteasome inhibitors (see the next section of this booklet) or other drugs.

Immunomodulatory drugs are an important option for treating multiple myeloma. Lenalidomide (Revlimid) was approved by the U.S. Food and Drug Administration (FDA) in 2006 for relapsed (recurring) multiple myeloma. It was approved for newly-diagnosed patients in 2015 and as a maintenance therapy (continued treatment designed to prevent relapse) in 2017. Pomalidomide (Pomalyst), another type of immunomodulatory drug, was approved in 2013 for the treatment of relapsed disease.

## **Proteasome Inhibitors**

Proteasome inhibitors are a type of therapy used in the treatment of multiple myeloma. The proteasome is a complex of proteins inside cells that breaks down proteins in healthy cells and cancer cells. Proteasome inhibitors interfere with this action, resulting in the death of myeloma cells.

The FDA has approved three proteasome inhibitors for the treatment of multiple myeloma: bortezomib (Velcade), carfilzomib (Kyprolis) and ixazomib (Ninlaro).

## Monoclonal Antibodies

Monoclonal antibodies are a type of therapy in which an antibody targets a specific protein on the surface of a cell. The two monoclonal antibodies approved by the FDA approved to treat multiple myeloma are elotuzumab (Empliciti) and daratumumab (Darzalex).

## Other Treatment Options for Multiple Myeloma

**Corticosteroids**, such as dexamethasone and prednisone, fight myeloma cells and also control inflammation in the body. Corticosteroids are typically used to increase the efficacy (effectiveness) of other therapies used in the treatment of multiple myeloma.

**Chemotherapy drugs**, given intravenously (through a needle into a vein) or in pill form, can destroy myeloma cells. The types of chemotherapy most often given to treat multiple myeloma include melphalan (Alkeran) and cyclophosphamide (Cytoxan).

**Radiation therapy** is often used to shrink myeloma cells in a specific area, such as a plasmacytoma (a collection of myeloma cells that create a tumor, most often starting in the bone). The course of treatment can last several weeks.



# The Importance of Clinical Trials

**Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.**

Here are a few things, as a caregiver to a person with multiple myeloma, that you should know:

- A member of his or her medical team can provide guidance as to whether a clinical trial is right for their specific circumstances. Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before your loved one participates in a clinical trial, he or she will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- Participation in a clinical trial is voluntary. Your loved one can stop taking part in a clinical trial at any time for any reason.

# Treatment Side Effects

All cancer treatments can cause side effects. It's important that side effects are reported right away so that your loved one's health care team can help him or her manage them. Not all people being treated for multiple myeloma experience all of these side effects, and people may experience side effects not listed here.

General side effects of multiple myeloma treatment include digestive tract symptoms (nausea, vomiting, diarrhea, loss of appetite) and fatigue. Your loved one's health care team can suggest ways to manage these side effects should they occur.

People with multiple myeloma have an increased risk of infection, both from the disease itself and its treatment. When white blood cells are abnormally low (a condition called neutropenia), an infection may progress rapidly and become serious. For this reason, it's important that people being treated for multiple myeloma immediately report fevers or other signs of infection to their health care team.



## Side Effects by Treatment Type

In addition to general side effects and an increased risk of infection, there are potential side effects associated with the specific therapy used to treat multiple myeloma.

Common side effects of immunomodulatory options include blood clots and rash. Proteasome inhibitors can result in peripheral neuropathy (numbness or tingling in hands and feet), an increased risk of shingles and an increased risk of cardiovascular disease or pulmonary side effects. Side effects that may be experienced with monoclonal antibodies include allergic reactions (such as hives or itching), skin rashes and low blood pressure.

The side effects of corticosteroids include an increase in blood sugar levels, fluid retention (leading to swelling in the feet and ankles), trouble sleeping and mood alterations.

The side effects of chemotherapy depend on the type and dose of drugs given and the length of time they are used, and can include hair loss, easy bruising or bleeding, changes in memory or thinking, peripheral neuropathy, edema (swelling) and mouth sores.

Radiation therapy can cause changes to the skin, including dryness, swelling, peeling, redness and blistering. It's especially important to contact your loved one's health care team if there is any open skin or painful areas, as this could indicate an infection. Infections can be treated with an oral antibiotic or topical antibiotic cream.

# CancerCare's Free Support Services and Programs

**Being a caregiver to a person living with multiple myeloma can be very difficult, and adjusting to the necessary changes in your life can be challenging.**

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).



## Frequently Asked Questions

**Q: My sister has multiple myeloma. I want to help with caregiving, but I live far away. What can I do?**

A: Even from a distance, you can provide ongoing emotional support to your sister and to her primary caregiver. It is sometimes easier for people to talk about difficult topics over the phone than in person, so be willing to have in-depth and serious conversations. You can also help coordinate medical appointments (and send reminders to your sister and her caregiver about those appointments), provide verbal updates to other family members, and share information on how your sister is feeling (if she agrees) in an on-line journal such as CaringBridge.

**Q: I know that multiple myeloma can cause bone damage and an increased risk of fracture. What can I do to help my loved one?**

A: As a caregiver, it's good for you to be aware of the medications that are available to minimize the impact of bone damage (also called bone lesions):

- **Bisphosphonates** include drugs such as zoledronic acid (Zometa) and pamidronate (Aredia). These drugs slow the process by which bone wears away and breaks down. Bisphosphonates belong to a class of drugs called osteoclast inhibitors, which are also used to treat osteoporosis.
- **RANK ligand inhibitors** block a factor in bone development known as RANK ligand, which stimulates cells that break down bone. By blocking RANK ligand, drugs such as denosumab (Xgeva, Prolia) increase bone density and strength.

There are also lifestyle choices that your loved one can make to improve the health (density) of bones, including choosing a diet high in calcium and vitamin D, regular exercise (flexibility, endurance, aerobic and/or strengthening), elimination of smoking, and reduction of alcohol consumption.

Your loved one should consult a member of his or her health care team before making any changes to their diet or exercise routine.

**Q: My husband was just diagnosed with multiple myeloma. What questions should he and I ask the oncologist about the recommended treatment approach?**

A: Here are some questions you should ask; others will likely arise in the course of your discussion.

- What are the goals of treatment?
- How long will treatment last?
- Do you have any written information about this treatment?
- What medical procedures and expenses does my insurance plan cover?
- What are the side effects of this treatment?
- Are there any ways to help manage side effects?
- How do we know if a side effect is severe enough to call you?
- Are there any other treatment options?
- Are there any clinical trials we should be aware of?
- What is the best way to let you know when we have questions about treatment?

# Resources

## **CancerCare®**

800-813-HOPE (800-813-4673)  
[www.cancercares.org](http://www.cancercares.org)

## **American Cancer Society**

800-227-2345  
[www.cancer.org](http://www.cancer.org)

## **Cancer.Net**

Patient information from  
the American Society of  
Clinical Oncology  
888-651-3038  
[www.cancer.net](http://www.cancer.net)

## **Cancer Support Community**

888-793-9355  
[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## **National Cancer Institute**

800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

## **Be The Match**

800-627-7692  
[www.bethematch.org](http://www.bethematch.org)

## **CLINICAL TRIALS WEBSITES**

### **EmergingMed**

[www.emergingmed.com](http://www.emergingmed.com)

### **National Cancer Institute**

[www.cancer.gov](http://www.cancer.gov)

## **BMT InfoNet**

888-597-7674  
[www.bmtinfonet.org](http://www.bmtinfonet.org)

## **International Myeloma Foundation**

800-452-2873  
[www.myeloma.org](http://www.myeloma.org)

## **Multiple Myeloma Research Foundation**

[www.themmr.org](http://www.themmr.org)

## **National Bone Marrow Transplant Link**

800-546-5268  
[www.nbmtlink.org](http://www.nbmtlink.org)

## **Medicine Assistance Tool**

888-477-2669  
[www.medicineassistancetool.org](http://www.medicineassistancetool.org)

## **CAREGIVER RESOURCES**

### **Family Caregiver Alliance**

888-445-8106  
[www.caregiver.org](http://www.caregiver.org)

### **My Cancer Circle**

<https://mycancercircle.net>

### **Well Spouse Association**

800-838-0879  
<https://wellspouse.org>

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