

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 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 if you are a caregiver, 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 informational support directly related to their diagnosis and treatment. Here are specific types of 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. Your loved one's health care team can provide additional information on potential side effects, based on the specific drug or drugs used in treatment.

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 their health care team, including doctors, nurse practitioners, physician assistants, nurses, 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 (either on paper or in a digital format) will allow your loved one to keep all of their health information in one place. It should include the names and contact information of the members of their health care team and details of their treatment plan. The journal can also be used as a diary to capture their 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.
- **If you can, accompany your loved one to medical appointments or be present during telehealth sessions.** Even if they have a journal and a prepared list of questions or concerns, it's always helpful for them to have support at appointments. You may think of additional questions to ask, or remember details about their symptoms, treatment, or overall quality of life that they may have forgotten. If you can't be there in person for whatever reason, see if you can arrange to provide support via the phone or your mobile device.

- **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.

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 multiple myeloma treatment may need help with a number of activities they would normally handle themselves, such as bathing or dressing. Ask your loved one to let you know if they want help with these activities. Some people may want help, but would prefer that it is provided by a paid helper, rather than a spouse, significant other 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 changing bandages. If you need help with these health care needs, 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. There are also free medication reminder apps available for use on a smart phone or tablet.

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.

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.

Support your loved one's treatment decisions. While you may be in a position to share decision making, ultimately it is your loved one who bears the impact of their multiple myeloma and its treatment.

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. You may also have questions about how to transition away from being a caregiver, so getting support during this transition can be helpful.

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. 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 My Cancer Circle™ (mycancercircle.net) to organize help from friends and family. My Cancer Circle is a free, private, and customizable online tool that enables people facing cancer to organize and coordinate a circle of family members and friends to provide practical and emotional support. This tool provides caregivers of people facing cancer a simple, effective answer to a question they are constantly asked, "What can we do to help?" In addition to family, friends and neighbors, 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 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 per night for adults. Also, take naps during the day if you need them.

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 to help you cope:



- **Take a break.** Take some time for yourself regularly. Even if it's just for a few minutes, doing something you like can help you recharge.
- **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. And 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. 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.

Multiple Myeloma Treatment Options

Multiple myeloma that is not causing symptoms (also known as smoldering multiple myeloma) may not initially need to be treated. The person’s condition is regularly monitored through blood and urine tests to determine if the disease is progressing and if treatment is needed.

If treatment is recommended, approaches are discussed based on the person’s individual circumstances. Research arising from clinical trials has shown that administering a combination of drugs is usually more effective than a single drug given alone. However, the benefit of such an approach must be weighed against the potentially higher risk of side effects.

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. 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 their own stem cells, the procedure is called an “autologous” stem cell transplant. The procedure is known as an “allogeneic” stem cell transplant if the stem cells are from a donor (either a close relative, such as a brother or sister, or a donor from a registry).

A stem cell transplant is an intensive treatment. To determine if stem cell transplant 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.

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) was approved in 2013 for the treatment of relapsed disease.

Targeted Therapy

Targeted therapy focuses on specific molecules and cell mechanisms thought to be important for cancer cell survival and growth, taking advantage of what researchers have learned in recent years about how cancer cells grow.

Three proteasome inhibitors, a type of targeted therapy, are approved by the FDA for 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.

- **Bortezomib (Velcade)** was approved as a single agent (a drug used alone) in 2008 and is now often given in combination with lenalidomide and dexamethasone as first-line therapy for multiple myeloma. It is typically given as a shot subcutaneously (under the skin).
- **Carfilzomib (Kyprolis)** was approved as a single agent in 2012. In 2016, its approval was expanded for use in combination with the immunomodulatory drug lenalidomide and dexamethasone, a type of corticosteroid. Carfilzomib is given intravenously (through a needle into a vein).
- **Ixazomib (Ninlaro)** was approved in 2015 to be taken in combination with lenalidomide and dexamethasone. Given in pill form, this combination is usually given after other drugs have been tried.

Immunotherapy

The purpose of immunotherapy in the treatment of cancer is to modify the immune system to recognize that the cancer is foreign to the body, and needs to be attacked. There are three immunotherapy drugs approved by the FDA to treat multiple myeloma:

- **Elotuzumab (Empliciti)** was approved in 2018, in combination with pomalidomide and dexamethasone, for the treatment of relapsed or refractory myeloma in people who have received at least two prior therapies, including lenalidomide and a proteasome inhibitor. Elotuzumab had previously been approved in combination with lenalidomide and dexamethasone to treat people with multiple myeloma who have received one to three prior therapies.
- **Daratumumab (Darzalex)** was initially approved for people who have received at least three prior treatments for multiple myeloma, and whose cancer has become resistant to those treatments or has progressed within a short period of time after treatment. It was subsequently approved in combination with lenalidomide plus dexamethasone (or bortezomib plus dexamethasone) in people whose cancer has returned after one prior treatment type. In June 2019, the FDA approved daratumumab in combination with lenalidomide and dexamethasone for the treatment of newly diagnosed multiple myeloma in people who are not candidates for a stem cell transplant.
- **Isatuximab-irfc (Sarclisa)** was approved in March 2020, in combination with pomalidomide and dexamethasone, for the treatment of people with multiple myeloma who have received at least two prior therapies, including lenalidomide and a proteasome inhibitor.

These three drugs are monoclonal antibodies, lab-generated molecules that target specific antigens (foreign substances that trigger an immune response) on the surface of the myeloma cell.

Other Treatment Options for Multiple Myeloma

Corticosteroids, such as prednisone and dexamethasone, control inflammation in the body and can also fight myeloma cells. Corticosteroids can be taken in pill form or given intravenously. In combination with other drugs, corticosteroids are often used throughout the course of multiple myeloma treatment.



Chemotherapy drugs, given intravenously or in pill form, can destroy myeloma cells. The types of chemotherapy most often given to treat multiple myeloma are:

- **Melphalan (Alkeran)**. Given in high doses, melphalan is used in association with a stem cell transplant.
- **Cyclophosphamide (Cytoxan)**. Cyclophosphamide is frequently given as a high-dose monotherapy (treatment given alone) or in combination with other types of treatments.
- **Panobinostat (Farydak)**. Panobinostat is approved, in combination with bortezomib and dexamethasone, for people who have received at least two prior multiple myeloma treatments. It is used less often than melphalan and cyclophosphamide.

Antibody drug conjugates (ADCs) work by combining (linking) a chemotherapy with a monoclonal antibody. The ADC belantamab mafodotin-blmf (Blenrep) was approved by the FDA in August 2020 as therapy for relapsed or refractory multiple myeloma that was treated with at least four prior therapies, including an anti-CD38 monoclonal antibody, a proteasome inhibitor and an immunomodulatory agent.

Selective Inhibitor of Nuclear Export (SINE) compounds work by inhibiting the action of proteins involved in cancer cell growth. Selinexor (XPOVIO), a type of SINE called an XPO1 inhibitor, was approved in 2019 for people with relapsed (returned) or refractory (not responding to treatment) multiple myeloma who have received at least four prior therapies. Approved for use in combination with the immunomodulatory drug dexamethasone, it is often combined with proteasome inhibitors for the treatment of multiple myeloma.

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 bone tumor). 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 their 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, they 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 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 fatigue and digestive tract symptoms such as diarrhea and loss of appetite. 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 the health care team if there is any open skin or painful area, 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 can help, call us at 800-813-HOPE (4673) or visit www.cancercares.org.



Frequently Asked Questions

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?

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.in an on-line journal such as CaringBridge (www.caringbridge.org).

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.

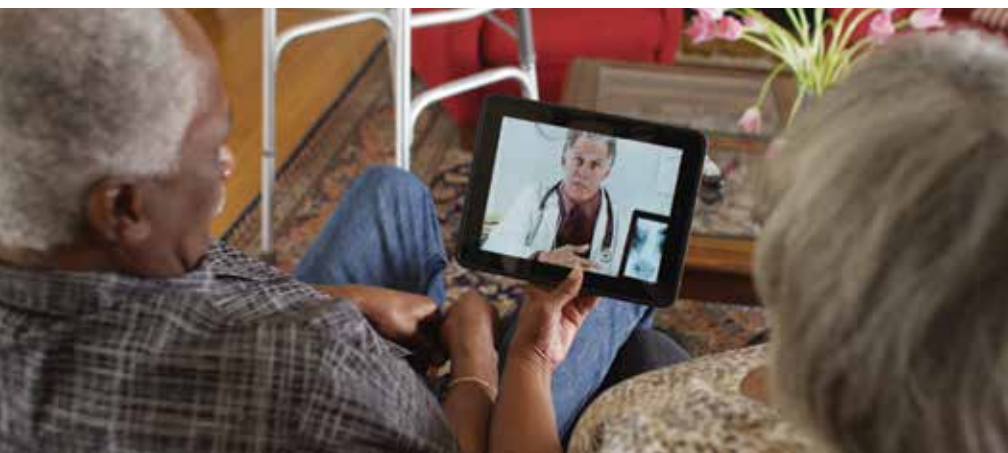
Should a fracture of the vertebrae occur, there are minimally invasive surgical procedures available:

- **Vertebroplasty** is a procedure in which a special cement is injected into a fractured vertebra, to relieve spinal pain and restore mobility.
- **Kyphoplasty** is similar to vertebroplasty, with the additional step of creating space for the special cement by using a balloon-like device.

There are also lifestyle choices that your loved one can make to improve the health (density) of bones:

- **A diet high in calcium and vitamin D.** Foods that are high in calcium include dairy products, spinach, kale, okra and certain fish (sardines, salmon, perch and rainbow trout). Foods that provide Vitamin D include fatty fish (tuna, mackerel and salmon), cheese, egg yolks and beef liver. Some other foods come in versions fortified with calcium and/or Vitamin D.
- **Exercise.** Although high-impact exercise should be avoided, some forms of exercise can be beneficial for bone health, including flexibility, endurance, aerobic and strengthening exercises. Importantly, exercise is also known to have a positive impact on physical function, mood, sleep and overall quality of life.
- **Eliminate smoking.** Even minimal smoking has a negative effect on bone density.
- **Avoid or reduce alcohol consumption.** Alcohol intake has been shown to decrease bone density.

It's important that your loved one consult a member of their health care team before making any changes to their diet or exercise routine.



Resources

CancerCare®

800-813-HOPE (800-813-4673)
www.cancercares.org

American Cancer Society

800-227-2345
www.cancer.org

Cancer.Net

Patient information from
the American Society of
Clinical Oncology
888-651-3038
www.cancer.net

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

National Cancer Institute

800-422-6237
www.cancer.gov

Be The Match

800-627-7692
www.bethematch.org

BMT InfoNet

888-597-7674
www.bmtinfonet.org

CLINICAL TRIALS WEBSITES

EmergingMed

www.emergingmed.com

National Cancer Institute

www.cancer.gov

International Myeloma Foundation

800-452-2873
www.myeloma.org

The Leukemia & Lymphoma Society

800-955-4572
www.lls.org

Lymphoma Research Foundation

800-500-9976
www.lymphoma.org

Multiple Myeloma Research Foundation

www.themmr.org

National Bone Marrow Transplant Link

800-546-5268
www.nbmtlink.org

Medicine Assistance Tool

888-477-2669
www.medicineassistancetool.org

CAREGIVER RESOURCES

Family Caregiver Alliance

888-445-8106
www.caregiver.org

My Cancer Circle

www.mycancercircle.net

Well Spouse Association

800-838-0879
www.wellspouse.org

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