



CANCERcare®
Connect™

Bone Health for People Living With Multiple Myeloma

Presented by

James R. Berenson, MD

The Institute for Myeloma and Bone Cancer Research

E. Willis Partington, MSSW, MDiv

CancerCare

Find out about:

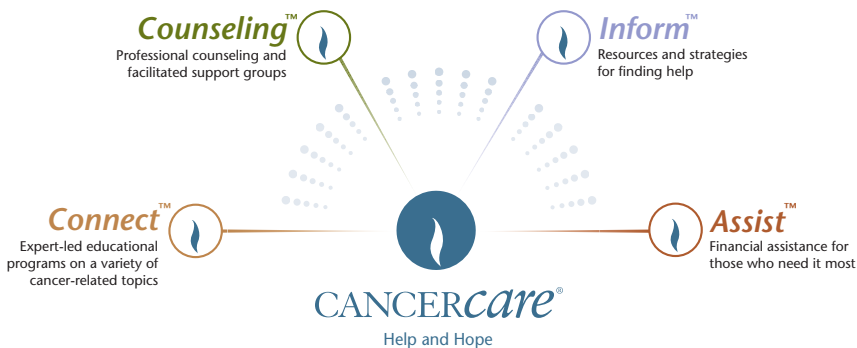
- Treating multiple myeloma
- Managing bone pain
- Improving quality of life
- The importance of a support network



CANCERcare®

Help and Hope

The **CANCERcare**[®] Constellation of Services



CancerCare's services are provided
free of charge to anyone affected by cancer

1-800-813-HOPE (4673) • www.cancercare.org

CancerCare is a national non-profit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling, education, financial assistance, and practical help—are provided by trained oncology social workers and are completely free of charge. Founded in 1944, CancerCare now provides individual help to more than 90,000 people each year, in addition to the more than 1.4 million people who gain information and resources from its website.

Contacting CancerCare

National Office

CancerCare
275 Seventh Avenue
New York, NY 10001
E-mail: teled@cancercare.org

Administration

Tel: 212.712.8400
Fax: 212.712.8495
E-mail: info@cancercare.org
Website: www.cancercare.org

Services

Tel: 212.712.8080
1.800.813.HOPE (4673)

Health care professionals interested in ordering bulk quantities of this booklet for their patients should contact publications@cancercare.org for more information.

Bone Health for People Living With Multiple Myeloma

Presented by

James R. Berenson, MD

Medical and Scientific Director

The Institute for Myeloma and Bone Cancer Research
West Hollywood, California

E. Willis Partington, MSSW, MDiv

Oncology Social Worker

CancerCare

The information in this booklet is based on an April 2005 Telephone Education Workshop conducted by CancerCare in partnership with the Association of Oncology Social Work, The Institute for Myeloma and Bone Cancer Research, Multinational Association of Supportive Care in Cancer, Multiple Myeloma Research Foundation, and Research Advocacy Network.

INTRODUCTION

page 2

- **TREATING MULTIPLE MYELOMA**, page 3
- **DEALING WITH BONE PAIN**, page 5
- **DIET AND EXERCISE**, page 8
- **CLINICAL TRIALS**, page 11
- **YOUR SUPPORT TEAM**, page 11

FREQUENTLY ASKED QUESTIONS

page 13

GLOSSARY (definitions of blue boldfaced words in the text)

page 15

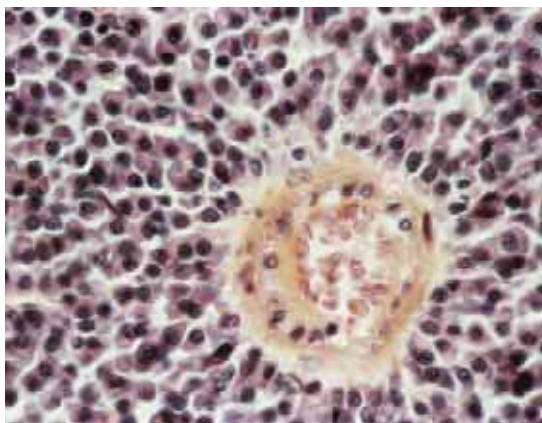
RESOURCES

page 16

This patient booklet was made possible by an educational grant from Novartis Oncology.

New techniques and new drugs can now deal better with bone pain.

Each year, an estimated 16,000 adults in the United States will be diagnosed with multiple myeloma. It is a cancer of the **plasma cells** in the bone marrow, the spongy tissue inside of bones. When plasma cells mutate (change abnormally), they can grow out of control and form tumors called **plasmacytomas**.



In this photo taken through a microscope, cancerous plasma cells (purple, darker staining) have replaced most of the healthy tissue in the bone marrow, leaving a patch of dying normal blood cells (pink).

The disease is often called *multiple myeloma* because usually by the time it is diagnosed, tumors are found in many bones in the body. Most patients with multiple myeloma are 65 or older. The disease is slightly more common in men and twice as common in blacks as in whites, although experts don't know why.

The rapid growth of plasma cells in the bone marrow can crowd out normal healthy blood cells and lead to a number of conditions. A shortage of red blood cells can result in **anemia**; a shortage of **platelets** can lead to excessive bleeding; and a shortage of white blood cells can reduce the body's ability to fight infection.

Myeloma Signs and Symptoms

Sometimes, people with multiple myeloma do not show any symptoms. But patients in more advanced stages of the disease may experience:

- Bone pain
- Fatigue, muscle weakness, mental confusion
- Kidney damage or failure
- Weight loss
- Nausea, constipation
- Thirst
- Blood clots, nosebleeds, bleeding gums, bruising
- Infections, especially of the urinary tract and lungs

Treating Multiple Myeloma

Although multiple myeloma cannot be cured, treatments are available that can control tumor growth, reduce pain, and allow people with the cancer to live normally and actively, with a good quality of life. In the past several years, the number of treatment options has increased significantly.

People with early stage myeloma and no symptoms may need only close monitoring by their doctors. The same is true for patients who have **MGUS**, an early form of the disease in which the blood level of M protein made by plasma cells is slightly elevated, but no other symptoms are present. About 20 percent of people diagnosed with MGUS will eventually—over a 20-year period—develop myeloma. Several new drugs to stop MGUS from turning into myeloma are being studied now.

Patients whose myeloma has caused symptoms may be treated with radiation to shrink the tumors. The decision to use radiation must be made carefully. In many cases, pain caused by the cancer—especially back pain—is due

to bone damage. Radiation treatment will not ease such pain and may affect the body's ability to respond to chemotherapy.

Bone marrow transplants are considered standard therapy for myeloma. Several different types of transplants may be used, depending upon a person's particular case.

Because multiple myeloma is usually widespread and scattered, **surgery is usually not an option.**

Doctors use a number of medications—chemotherapy and other types of drugs—to treat myeloma. In the past several years, researchers have found that some of the newer drugs not only kill tumor cells, they also make the disease more sensitive to chemotherapy. And when the drugs are combined, they allow doctors to offer more effective treatments. For instance:



- **Bortezomib (Velcade)** is now used to boost the effects of an old standard, a drug called **melphalan (Alkeran)**. By combining these drugs, doctors can prescribe lower doses of each. This has led to fewer side effects and longer lasting results. Bortezomib and a newer form of doxorubicin called **Doxil** have also led to a high rate of response in people with myeloma.
- **Thalidomide (Thalomid)** alone works well for about one third of patients; when combined with cortisone-like steroids, it can help two thirds of people with myeloma.
- **Lenalidomide (Revlimid)**, a newer version of thalidomide, combined with steroids has shown promise in a study now under way. The combination appears to prolong **remission**, although there is some concern that it may also

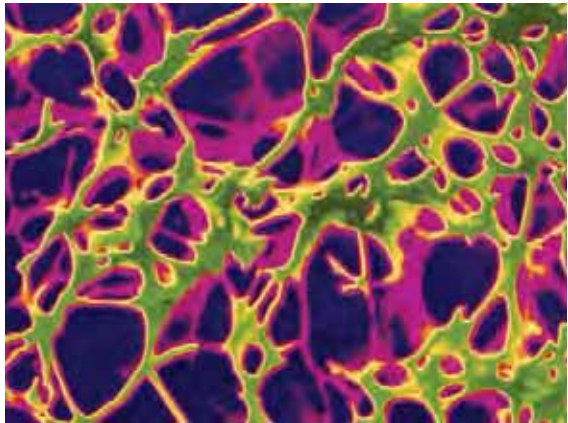
increase the chance of blood clots unless aspirin tablets are taken daily.

- It may seem unusual, but scientists have found that when used with **vitamin C** and low doses of **melphalan**, the compound **arsenic (Trisenox)** shows great promise in treating myeloma.

Dealing With Bone Pain

One of the most difficult aspects of multiple myeloma is its effect on bones. Pain in the bones is common, especially in the ribs and spine. This pain is caused by damage to the bone brought on by tumors. These tumors can lead to **osteoporosis** (thinning of the bone), and even bone loss.

Bones that are thinner or more porous (full of holes) are more likely to break. Up to one out of four people with multiple myeloma can develop **fractures** (bone breaks) that require radiation treatment. Doctors prefer to give



The porous, weakened bone of osteoporosis

as little radiation as possible, since it can affect the bone marrow—already affected by myeloma—and its ability to maintain a healthy immune system. Other types of treatments for bone pain are used as well.

SURGERY

If cancer is in the spine, one or more of the **vertebrae** can collapse, press on the spinal cord, and cause nerve pain. A new

technique to treat this pain is now being studied in people with myeloma. It's called "balloon kyphoplasty" and was designed



to reverse the collapse of vertebrae. The procedure, originally developed to reduce back pain in women with osteoporosis, has been greatly successful in improving myeloma patients' quality of life, allowing them to become more mobile.

Briefly, balloon kyphoplasty works like this:

- Using a special type of needle, the surgeon carefully inserts a tiny balloon into the narrow space between two collapsed vertebrae in the spine.
- The balloon is then gently inflated to widen the space between the vertebrae and relieve pressure on the spinal cord.
- The balloon is removed, and a special type of bone cement is inserted into the expanded space. The cement stabilizes the fractured area, much like an internal cast.

More studies are needed to ensure that this technique, which requires only a brief hospital stay, can help people with myeloma who have back pain due to spinal collapse. If you are experiencing this problem, you may wish to talk with your doctor about entering a clinical trial in which you can receive this treatment.

MEDICATIONS

Over the past 15 years, doctors have focused on treating bone pain in cancer patients with a class of drugs known as **bisphosphonates**. Most myeloma patients receive monthly **intravenous (IV) infusions** of bisphosphonates to help

prevent bone disease. These medications stop cells in the skeleton known as osteoclasts from breaking down bone.

When **pamidronate (Aredia)** was introduced in the mid-1990s, it was the first bisphosphonate that could reduce the bone complications of myeloma. Laboratory studies also showed that it could reduce the number of tumors. But in higher doses it can lead to kidney problems. Now, a newer bisphosphonate is available—**zoledronic acid (Zometa)**—which studies show is more potent against bone loss.

If you are taking a bisphosphonate, your doctor will monitor your kidney function with frequent blood tests.

Of course, kidney problems can be the result of a number of factors, such as high blood pressure, diabetes, and certain types of medications you may be taking. These medications include:

- **Over-the-counter and prescription pain relievers**, such as ibuprofen (Motrin and others) or naproxen sodium (Aleve, Naprosyn, and others)
- **COX-2 inhibitors** such as celecoxib (Celebrex), used mainly for arthritis pain
- **Statins** such as lovastatin (Mevacor), atorvastatin (Lipitor), or simvastatin (Zocor), used to lower cholesterol levels.

Bisphosphonate Side Effects

Other side effects of bisphosphonates include:

- Flu-like symptoms: fevers, muscle aches, and bone aches. In 10 to 20 percent of cases, these side effects can occur the day after the first or second dose. But by the third to fifth dose, such side effects tend to stop.
- In rare cases, inflammation in the eye or eyelid
- Anemia
- Osteonecrosis of the jaw (ONJ)—damage to the jawbone

If you and your doctor believe that the bisphosphonate you are taking is the root of the problem, you can switch to a different bisphosphonate. Slowing down the rate at which you receive bisphosphonates during treatment also can reduce kidney damage.

DEALING WITH JAWBONE DAMAGE

Although it has not been proven that bisphosphonates cause damage to the jawbone—known as osteonecrosis of the jaw or ONJ—a rising number of cases suggest that there may be a link between the two. If you are a myeloma patient with jaw problems, whether you should stop taking this medication is a decision to be made with your doctor and dentist. If jaw damage progresses, it can sometimes cause great difficulty in chewing and eating. The damage may require antibiotics to fight infections, and even surgical repair. **That is why it is so important to practice good oral hygiene if you are taking bisphosphonates.**

The mouth is the site of many bacteria, so patients need to make every effort to keep their teeth and gums clean and



healthy. Your dentist is an important member of your health care team who can help you do this. **Ideally, you should visit your dentist for a complete oral exam before using bisphosphonates.**

Even after treatment begins, it is still important to see your dentist and consult him or her regularly throughout your cancer treatment.

Diet and Exercise

Strong bones need calcium and vitamin D. Be sure to talk with your doctor about your individual needs.

Your Daily Intake

Calcium

Eat plenty of:

- Dairy foods such as milk or cheese (choose skim or low-fat)
- Dark leafy greens
- Beans

Consider vitamin/mineral supplements: doctors recommend 1,500 milligrams (mg) of calcium per day. Citrates and chewable calcium are the most easily absorbed.

Vitamin D

Eat or drink plenty of:

- Vitamin D-fortified milk and cereal
- Fatty fish such as salmon, tuna, sardines, herring, mackerel, or swordfish

Get some sun—but not too much:

If you live north of the line connecting San Francisco to Philadelphia, you probably don't get enough vitamin D. A 15-minute walk in the sun at least three times a week with the skin exposed helps the body make vitamin D naturally. Although sunscreens prevent vitamin D from forming, doctors still recommend you use a sunblock for prolonged sun exposure. Sunscreens reduce the risk of skin cancer and skin damage.

Consider vitamin supplements; doctors recommend 800 International Units (IU) of vitamin D daily.

Also important: Drink plenty of water to flush the kidneys and help them filter impurities from the blood.

Light exercise, when you are able, should be part of your regular routine. Exercise maintains bone strength and reduces the loss of calcium in your bones. Walking, dancing, stair-climbing, or light weightlifting are all “weight-bearing” activities. They encourage the bones to strengthen by stressing them in the way nature intended. Each type of exercise stresses

The Importance of Clinical Trials

There's no question that clinical trials have led to advances in cancer treatment, creating a brighter future for all people with cancer. Clinical trials are the gold standard by which we measure the worth of new treatments and quality of life as patients go through those treatments. For this reason, doctors and scientists urge patients to take part.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things you should know:

- The first patients to gain access to and benefit from new treatments are those who take part in clinical trials.
- Before you participate in a trial, you will be fully informed as to the risks and benefits of the trial.
- No patient receives a placebo or “dummy pill” if there is a standard treatment available for the disease. Most trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any benefit.
- You can stop taking part in a clinical trial at any time for any reason.

different bones, so it's best to engage in a variety of activities if you can.

Although swimming is a useful form of exercise for the heart, water supports the bones rather than putting stress on them, so it's not considered a good weight-bearing exercise for building bone strength.

Exercise also increases muscle strength and coordination. With greater muscle strength, you can often avoid falls and injuries that cause bones—especially those weakened by cancer—to break. T'ai chi is a gentle strengthening exercise that's excellent for improving balance.

Clinical Trials

Researchers are finding out that bisphosphonates not only ease bone pain, they can also treat myeloma. There are a number of ongoing studies in this area. Your doctor can tell you about clinical trials for which you may be eligible. You can also go online for more information. See our list of resources on page 16.

Your Support Team

Being diagnosed with a cancer such as multiple myeloma can be overwhelming and disorienting. You're faced with a series of choices that will have a major effect on your life, and perhaps you don't know where to turn. But help is available. Of course, your most important resources are your health care team, your family members, and friends. It is very important to develop good communication with them. You can also turn to these resources:

Oncology social workers and nurse practitioners are specially trained to help you find out more about your treatment options, learn how to navigate the health care system, and get the best care possible. Often, when people are dealing with cancer, they need someone to talk with who can help them and their families sort through the complex emotions and issues that arise. These health care professionals can provide emotional support, help you deal with treatment and its side effects, and guide you to resources. CancerCare offers free counseling from professional oncology social workers on staff.



Support groups can reduce the sense of isolation and loss—of mobility, your old energy, the life you had before cancer—and the feeling that you are going through cancer alone. Support groups focus on adapting to a diagnosis of cancer and living with it. These groups provide reassurance, suggestions, insight—a safe harbor where you can share similar concerns with your peers in a supportive environment. At *CancerCare*, people with cancer and their families can take part in support groups in person, online, or on the telephone.

Financial help is offered by a number of organizations, including *CancerCare*, to cover the cost of transportation to treatment, child care, or help needed around the home. *CancerCare* can also refer you to other resources in your community.

Frequently Asked Questions

Q I have been in **remission** for the past few years. I know myeloma can weaken bones, but in my case, do I need to keep taking bisphosphonates?

A There is a lot of debate on this question; scientists just don't have enough information yet. Someone in your situation is most likely still at risk for bone problems, especially if you stop taking medication for it. We base that assumption on the experience of older women with **osteoporosis**. We know that women who continue taking **bisphosphonates** have better bone health than those who stop taking them. Also, several studies suggest bisphosphonates actually prevent myeloma from growing—another reason to continue taking this medication.

Q I don't have any tumors in my bones, but I do have osteoporosis, and my myeloma is in the "smoldering" inactive stage. Are bisphosphonates right for me?

A People in your situation should receive bisphosphonates monthly. It is certainly worth taking them to reduce your risk for fracture and all the complications that go along with bone breaks.

Q I'm a little concerned that weight-bearing exercises could hurt my bones rather than help them. What should I do?

A Talk with the members of your health care team, especially a physical therapist or bone surgeon. They know your particular

case and can advise you on which types of exercises are best for you and the safest way to do them. Light weightlifting and other types of weight-bearing exercises, such as walking, dancing, or stair-climbing, are important to your health. Not only do they help you build bone strength, they also strengthen muscles and improve coordination to prevent falls and fractures. And as we outlined on page 9, diet is also a vital part of maintaining bone health.

Q I don't like to complain or take more pills than necessary, so I've been tolerating my bone pain. Besides, can't you become addicted to painkillers?

A Many patients fear “addiction” to powerful pain-relieving drugs, but the chances of that happening are *very* small. The fact is, *not* treating pain can have an undesirable effect on your health. Pain causes stress, depression, and fatigue. It ruins quality of life and slows progress toward better health—or at least toward feeling more comfortable. Pain medication is an important tool for controlling pain and not something to be shunned or feared. Talk with your doctor about working with pain specialists. They can offer many options to people with myeloma and bone pain.

Glossary

anemia A condition that can cause disabling fatigue, shortness of breath, and other symptoms due to low levels of red blood cells.

bisphosphonates A family of drugs that stops cells in the skeleton known as osteoclasts from breaking down bone.

fractures Bone breaks. Myeloma can weaken bones, leading to fractures or compression of the spine and bone pain.

intravenous (IV) infusion A method for delivering drugs and fluids through a needle placed in a blood vein.

MGUS Monoclonal Gammopathy of Unknown Significance, an early form of myeloma in which the blood level of M protein produced by plasma cells is slightly elevated, but no other symptoms are present.

osteoporosis A condition in which the bones thin out and can collapse or break; sometimes referred to as “porous bones.”

plasma cells A part of the body’s immune system that helps the body fight infection. Multiple myeloma is a cancer of the plasma cells.

plasmacytomas The tumors of multiple myeloma that form when plasma cells mutate (change abnormally) and grow uncontrollably.

platelets Blood cells that help stop bleeding by plugging leaks or tears in the blood vessels.

remission When cancer responds to treatment or is under control. In a complete remission, all the signs and symptoms of the disease disappear. In a partial remission, the cancer shrinks but does not completely disappear. Remissions can last anywhere from several weeks to many years.

vertebrae The bones of the spine (singular = vertebra).

Resources

CancerCare

Services: 1.800.813.HOPE (4673)

E-mail: teled@cancerca.org

Website: www.cancerca.org

American Cancer Society

Support line: 1.800.ACS.2345

Website: www.cancer.org

American Society of Clinical Oncology

People Living With Cancer

Website: www.plwc.org

International Myeloma Foundation

1.800.452.2873

Website: www.myeloma.org

Multiple Myeloma Research Foundation

1.203.972.1250

E-mail: info@themmrf.org

Website: www.multiplemyeloma.org

National Cancer Institute

Cancer Information Service

Support line: 1.800.4.CANCER (422.6237)

Website: www.cancer.gov

To find out about clinical trials:

Coalition of National Cancer Cooperative Groups

www.CancerTrialsHelp.org

National Cancer Institute

www.cancer.gov/clinicaltrials



CANCER*care*[®]

The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

Microphotograph of myeloma on page 2 © CNRI/Photo Researchers, Inc.
Computer artwork of osteoporosis on page 5 © A. Pasieka/Photo Researchers, Inc.

© 2005 CancerCare, Inc. All rights reserved.



From the moment of diagnosis, let the hope begin.

When Fran was diagnosed with cancer, she knew that she and her daughter, Rachel, would need support. Both found help and hope with *CancerCare*.

Since 1944, our professional oncology social workers have provided **free** counseling, education and practical help for anyone touched by cancer. *CancerCare* is with you every step of the way.

If we can help you and your family, please call us at 1-800-813-HOPE (4673) or visit www.cancercares.org.



CANCERcare[®]
Help and Hope

1-800-813-HOPE (4673)
www.cancercares.org

©CancerCare 2005