# FRANKLY SPEAKING ABOUT CANCER

# When Cancer Spreads to the Bone



Cancer occurs when cells in your body start growing and dividing faster than normal. At first, these cells may form into small clumps or tumors. But they can also spread to other parts of the body. When cancer spreads, it is said to have "metastasized."

It is possible for many types of cancer to spread to the bones. People with cancer can live for years after they have been told their cancer has spread to their bones. This booklet explains:

- Why bone metastases occur
- How they are treated
- What patients with bone metastases can do to prevent broken bones and fractures





# What is Bone?

Many people don't spend much time thinking about their bones. But there's a lot going on inside them. Bone is living, growing tissue, made up of proteins and minerals. Your bones have two layers. The outer layer called cortical bone— is very thick. The inner layer—the trabecular (*truh-BEH-kyoo-ler*) bone—is very spongy. Inside the spongy bone is your bone marrow. It contains stem cells that can develop into white blood cells, red blood cells, and platelets.

The cells that make up the bones are always changing. There are three types of cells that are found only in bone:

- Osteoclasts (OS-tee-oh-klast), which break down the bone
- Osteoblasts (OS-tee-oh-blast), which form new bone
- Osteocytes (OS-tee-oh-site), the cells inside the bone (these cells start out as osteoblasts)

Your body's hormones control how fast osteoclasts and osteoblasts work.

# BONE ANATOMY



# What are Bone Metastases?

If you are told you have "metastases," "metastatic cancer," or "stage 4 (IV)" cancer, it means cancer cells have left the place the cancer started and have spread to other parts of your body. The word "advanced" also may be used to describe these cancers.

#### **IS THIS BOOK FOR YOU?**

This booklet is **not** for people with cancer that started in the bones or bone marrow (primary bone cancer) — just for people whose cancer **spread** to their bones from another part of their body.

Learn more about cancer that starts in the bone or bone marrow on the CSC website at www.CancerSupportCommunity.org/bone-cancer and www.CancerSupportCommunity.org/multiple-myeloma.

Cancer can spread to other organs. When it spreads to the bone, it's called "bone metastases," or "bone mets." This doesn't mean you now have bone cancer—you still have the same type of cancer you started with. Once cancer cells get inside your bones, they can keep new, healthy bone from forming. This can cause your bones to become thin and weak and increase your risk for bone breaks.

Some cancers are more likely to spread to the bone than others. These include:

- breast cancer
- bladder cancer
- kidney cancer
- lung cancer
- melanoma
- prostate cancer
- thyroid cancer

When cancers spread, they can show up almost anywhere in the body. The most common sites for bone metastases are:

- hip bone (pelvis)
- skull, ribs, and spine
- upper leg bone (femur)
- upper arm bone (humerus)

### **Diagnosing Bone Metastasis**

Your doctor can find out if you have bone metastases through tests like bone scans,

blood tests, X-rays, CT scans, PET scans, and MRIs. These tests are painless. Your doctor may suggest you get these tests regularly or in response to specific pain or soreness.

#### THINGS YOU CAN DO

People with cancer can live for years after their cancer has spread to their bones. This is one of the most common and treatable places for cancer to spread. If you have bone metastases, it is important to:

- Tell your doctor if you have any bone or joint pain. Be you own advocate and let them know all your concerns.
- Strengthen your bones with medication, a balanced diet, supplements, and exercise.
- Take steps to reduce your risk of falls and bone breaks. (See page 9.)

### Testing for Bone Density

Your doctor may have you get a bone density scan—called a DEXA scan. The test uses low levels of X-rays to measure how much calcium and minerals are in the bones in your hip, wrist, and spine. The test is painless and is most often done every two years. The test results show if you have:

- Osteopenia (OS-tee-oh-PEE-nee-uh)—bone that is thinner than normal
- Osteoporosis (OS-tee-oh-puh-ROH-sis) bone that has become so thin you are at higher risk of bone breaks

The DEXA scan test gives your bone density a "score." Here is what the score means:

- 0: bone mineral density is equal to that of a 30-year-old adult
- Between +1 or -1: bone mineral density is normal
- Between -1 and -2.5: bone mineral density is low (osteopenia)
- -2.5 or lower: bone mineral density is significantly low (osteoporosis)

You may also get a Fracture Risk Assessment Tool (FRAX) score when you get your DEXA bone density score. Your FRAX score is an estimate of how likely you are to break a bone in the next 10 years. Your score is based on your age, weight, gender, smoking history, alcohol use, and whether you have already had one or more broken bones. Your doctor will use the scores from these two tests to decide whether to recommend that you take a bone-building drug.

### Treating Bone Metastases

There are many different treatments for bone metastases. The treatments your doctor will recommend will be based on:

- Your symptoms
- Where the metastases are located
- What other cancer treatments you are currently receiving
- What treatments you have received previously



## Types of Treatments

Treatments for bone metastases include:

**CHEMOTHERAPY:** Chemotherapy is used to kill cancer cells that may be anywhere in your body, including in your bone.

HORMONE THERAPY: If you have prostate cancer or breast cancer that is estrogen and/ or progesterone receptor positive (ER+/ PR+), you may be treated with a hormone therapy drug. These therapies, taken as pills or injections, can help stop cancer cell growth in the bones and other parts of your body. The hormone therapies used to treat breast cancer block estrogen. The treatments used for prostate cancer block testosterone.

**BONE-BUILDING DRUGS:** These drugs help strengthen bone, slow bone metastases, and help reduce pain caused by bone metastases. Often given by IV (into the vein) or as injections under the skin, they include:

• **Bisphosphonates:** There are different types of bisphosphonates *(bis-FOS-fob-nayts)* available. The two bisphosphonates most commonly used to treat bone metastases are zoledronate (Zometa<sup>®</sup>) and pamidronate (Aredia<sup>®</sup>).

The most common side effects are headache and muscle aches for up to three days after the injection. In rare cases, after more than five years of use, patients have developed a crack in the middle of their thigh bone. Another rare side effect is osteonecrosis (bone death) of the jaw after having a tooth pulled. For this reason, you should have a dental exam before starting on a bisphosphonate.

• Denosumab (Xgeva<sup>®</sup>): Cancer cells can send messages to the osteoclasts (bone cells), telling them to break down bone more quickly. Xgeva, which is given as an injection under the skin, works by keeping the bone cells from getting these messages.

The most common side effects are shortness of breath, tiredness, weakness,

### ALREADY ON A BISPHOSPHONATE?

You are likely to already be taking a bone-building drug if you were diagnosed with osteoporosis before you were diagnosed with cancer. Your previous cancer treatments may also have included a bone-building drug.

Once you learn you have bone metastases, your doctor may keep you on the same drug but change the dosage or frequency of treatments. Or, your doctor may recommend that you switch to another type of bone-building drug. nausea, diarrhea, low blood counts, back pain, swelling of the lower legs or hands, upper respiratory tract infection, pneumonia, rash, and headache. Like the bisphosphonates, in rare cases, Xgeva can cause a crack in the thigh bone or osteonecrosis (bone death) of the jaw.

**INTRAVENOUS RADIATION** (also called radiopharmaceuticals or radionuclide therapy): These treatments use low levels of radioactive material that have a strong attraction to bones. They include:

- Radium-223 (Xofigo<sup>®</sup>): Used to treat men with prostate cancer that has spread to the bone. It may also help reduce pain caused by bone metastases. Side effects can include damage to the bone marrow, which can lead to low blood cell counts.
- Strontium-89 Chloride Injection (Metastron<sup>®</sup>): Used to reduce bone pain caused by bone metastases.
- Samarium sm 153 lexidronam (Quadramet<sup>®</sup>): Used to treat certain types of severe bone pain in patients with prostate, breast, or lung cancers that have spread to the bone.

**RADIATION:** Radiation therapy can be directed to the specific site of your bone metastases to slow cancer cell growth. It is also sometimes used to relieve pain.

**SURGERY:** Your doctor may recommend surgery—possibly followed by radiation—if you have a bone that is weak or has broken. Surgery may include:

- Orthopedic fixation. Using metal plates, screws, and nails to stabilize bones that have become weak or are at risk of breaking.
- Bone cement to stabilize bones. The cement is injected into a bone that is broken or has been damaged by the bone metastases. This procedure can also help reduce pain.
- **Repairing broken bone** with metal plates, screws, and nails.
- Joint replacement to repair a broken bone or to reduce bone/joint pain.

#### TREATMENT WITHIN A CLINICAL TRIAL:

Clinical trials are research studies with patients. Their goal is to find better ways to treat cancers. Often, the most promising treatments are only available through trials.

Many people with bone metastasis decide to participate in a clinical trial.

# Managing Bone Pain

Bone metastases can be very painful. Your treatment may help to reduce your pain, but it may not get rid of it completely. You may also need other medicine or treatments for the pain itself. If you have bone pain, tell your health care team. You can ask about:

- Getting a referral to a pain specialist or a palliative (PA-lee-uh-tiv) care specialist. Palliative (or supportive) care is used to treat pain or other symptoms caused by cancer and its treatments. Palliative care is not the same thing as hospice care, which is end-of-life care. You can ask for a referral to a palliative care specialist at any point during your cancer treatment.
- Taking pain medicines. Over-thecounter medication, like acetaminophen (Tylenol<sup>®</sup>) or ibuprofen (Advil<sup>®</sup> or Motrin<sup>®</sup>), may be all you need. Talk to your doctor to be sure you are taking the right

### **KEY THINGS TO KNOW ABOUT CLINICAL TRIALS**

- People who receive their treatment through a clinical trial receive high quality care.
- No one receives a placebo or "sugar pill" in place of appropriate treatment.
- People who join clinical trials can leave at any time, and for any reason.
- There are laws to protect the safety of people who participate.
- Some clinical trials may require travel, others may be close by. They are NOT only available at major cancer centers.
- Not all costs may be covered in a clinical trial, so it's important to learn about costs and insurance coverage.

Be sure to ask your doctor about clinical trials. Keep in mind that clinical trials aren't available for everyone. There are rules about who can join each one. To learn more about active clinical trials, visit **ClinicalTrials.gov**.

dose. Even though they don't need a prescription, they can still cause harmful side effects. If these don't help your pain, talk to your doctor about other types of pain medicines

- **Steroids** to decrease swelling that makes the pain worse.
- **Radiation** to treat specific sites of bone pain.

# Spinal Cord Compression

One of the most common places for bone metastases to develop is the spine. It is important for your doctor to watch spine metastases closely. If they grow too big, they can crush (or compress) your spinal cord, which can paralyze you and keep you from walking. Call your oncologist immediately or go to the emergency room if you have these symptoms:

- Back pain that gets worse
- Back pain and leg pain at the same time
- Numbness or tingling in your arms, legs, or belly
- Problems standing due to leg weakness
- Problems moving your legs
- Problems holding or keeping objects in your hands, due to arm weakness
- Loss of control over when you urinate (pee) or defecate (poop)

Treatment for spinal cord compression may include steroids, radiation, surgery, and/or physical therapy after surgery.

#### **HYPERCALCEMIA**

Cancer cells affect how your body builds bone. This can cause your bones to get thinner or cause calcium to seep from the bones into your blood. If the calcium levels in your blood get too high, you can develop hypercalcemia (*HY-per-kal-SEE-mee-uh*). Be sure to let your doctor know if you:

- Are constipated.
- Need to urinate (pee) more often than usual.
- Feel tired often.
- Are always thirsty and drinking more fluids than usual.

If the hypercalcemia gets worse and you become more dehydrated, you may also have muscle weakness or pain in your muscles and joints. Hypercalcemia can be dangerous if it is not treated. It can lead to confusion, a coma, or kidney failure.

To prevent hypercalcemia, you can:

- Drink the right amount of fluids.
- Get enough salt in your diet.
- Control nausea and vomiting.
- Stay active by walking.
- Control fever.
- Stop taking drugs that can cause hypercalcemia or affect its treatment, when possible. Your health care team can tell you what drugs you may need to stop taking.

Hypercalcemia causes the body to absorb less calcium from food. However, changing the diet to decrease calcium will not lower the amount of calcium in the blood.



#### **DIANA'S STORY**

Diana was diagnosed with stage II breast cancer at age 40. Two years later, on a routine checkup, her radiation oncologist felt a lump on her chest. A PET scan showed she had cancer cells in the lymph nodes near her collarbone. The cancer had also spread to her ribs, pelvis, lower back, and skull.

She's been treated with hormone therapy, chemotherapy, and radiation. "But," she says, "I've never been NED—no evidence of disease." And she's never sure what to expect. One afternoon, she felt a sudden burst of intense pain in her back. Scans showed a tumor pressing against her spinal cord. She wasn't allowed to lift anything over 20 pounds and could only sit in chairs with back support. With radiation therapy, "slowly I was in less pain," she says, "and then the pain was gone."

After her tumor was stabilized, she married her boyfriend, with whom she sings in a Led Zeppelin tribute band. A year later, more pain led to more scans, which showed a large tumor on her pelvic bone. There was a spot on her liver, too. She had radiation therapy again.

These experiences can make it hard to plan ahead. But Diana says she tries to make the most of every day.

# What You Can Do To Keep Your Bones Healthy

Even if you are being treated for bone metastases, there are things you can do to help maintain bone density. Some changes that can make a difference include:

- Not smoking—smoking makes bone loss happen faster
- Limiting alcohol to one drink a day (for women) or two (for men)
  - Alcohol affects the cells that build new bone
  - Also, drinking increases the risk of falling
- Eating a diet rich in calcium and vitamin D
- Exercising (such as weight bearing exercises)
- Preventing falls

Try to get your daily recommended levels of calcium and vitamin D from the food you eat. Good sources of calcium include:

- Low-fat dairy products, like yogurt
- Kale and other dark green, leafy vegetables

- Broccoli, acorn squash, butternut squash, and okra
- Canned salmon or sardines with bones
- Calcium-fortified foods and drinks (orange juice, soy milk, almond milk, and some cereals and breads, are often fortified with calcium and vitamin D)

Talk to your health care provider about whether calcium and vitamin D supplements are right for you.

#### EXERCISE FOR HEALTHY BONES

Exercise is a key part of a healthy lifestyle that helps maintain bone density. Exercise also improves balance, which makes you less likely to fall. This, in turn, lowers your risk of breaking a bone.

You may not have as much energy or flexibility as you had before you developed bone metastases. Even so, you should try to move as much as you can. Whether you are starting to exercise for the first time or hoping to pick up where you left off, talk to your doctor about what types of exercises are okay or what you may need to change. For

DAILY RECOMMENDATIONS	CALCIUM	VITAMIN D
Women ages 19 to 50	1,000 mg/day	600 IU
Men ages 19 to 70	1,000 mg/day	600 IU
Women ages 51 to 70	1,200 mg/day	600 IU
Women and Men 70+	1,200 mg/day	800 IU

#### EATING FOR HEALTHY BONES

example, depending on where your bone metastases are, there may be limits on how much weight you should lift.

Here are some tips that can help you get started:

- Try to build up to exercising 30 minutes each day.
- Find things that feel good and safe to you—walking with friends, gardening, swimming, or gentle yoga. It doesn't have to be strenuous to be exercise.
- Try to add in some resistance exercises. These exercises build muscle strength, which helps support your bones. They can also help with balance, which can help prevent falls. Examples include lifting weights and stretching with exercise bands.
- When you feel sick, exercise only as much or as strenuously as you feel comfortable.
- Allow yourself to exercise gently, slowly, and for short amounts of time.
- If you are extremely tired but want the energy benefits exercise can provide, try gentle, slow, and brief movements that are comfortable for you. You can always do more on a day when you are not so tired.
- If you have trouble sleeping, exercise during the day to help you sleep better at night.

### Living with Bone Metastases

Bone metastases is one of the most common types of metastases. It is also one of the most treatable. Eating a healthy diet, exercising, preventing falls, and taking the proper medicine can help you keep your bones as strong as possible, decrease pain, reduce your risk of broken bones, and improve your quality of life.

You can find more information about living with cancer on the Cancer Support Community website **www.CancerSupportCommunity.org** and on the next page.

# **PREVENT FALLS**

Thin bones are more likely to break if you fall. To prevent falls, you can:

- Wear low-heeled shoes that fit well.
- Get shoes with nonslip soles.
- Check your house—move anything that could cause you to trip (electrical cords) or slip (rugs).
- Keep rooms brightly lit.
- Put grab bars inside and outside your bath or shower (and ask for rooms that have them when you are staying at a hotel).
- Lower your mattress if it's hard for you to get out of bed.
- Consider buying a pair of walking sticks, especially if walking or hiking is your favorite type of exercise.
- Talk to your doctor about whether you should start a strength-training program. This could be a pool exercise program or involve using resistance from weights or bands.

#### AMANDA'S STORY

Four years after completing treatment for early-stage breast cancer, Amanda learned her cancer had returned and spread to her liver, ovaries, spine, and pelvis.

She started on chemotherapy to shrink the tumors in her organs and had radiation therapy to treat the metastasis on her spine. She also started taking Zometa<sup>®</sup> to strengthen her bones. Slowly the tumors shrank.

Every year, she says something new pops up. But that hasn't kept Amanda from being active. She runs a CSC affiliate, and appreciates the opportunity to helps others.





#### PROSTATE CANCER IS ONE OF THE MOST COMMON CANCERS TO SPREAD TO THE BONE.

- About 12 of every 100 men will be diagnosed with prostate cancer at some point in their lives.
- Out of 100 men diagnosed with prostate cancer, about 5 will be told at diagnosis that it has spread to the bones and about 20 more will be diagnosed with bone mets in the next 5 years.

The most common symptoms felt by men with prostate cancer that has spread to the bone are fatigue, pain, or aches.

Your health care team can do a lot to relieve pain. However, men with bone metastases may not tell their health care team about their pain. Be sure to regularly tell your care team about your level of pain, especially if it keeps you from doing normal activities, makes it hard to sleep, or causes you anxiety or stress.

# Bone Metastasis Information & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/BoneMets

Living Beyond Breast Cancer • 888-753- 5222 • www.lbbc.org/bone-metastases

LUNGevity • 844-360-5864 • www.lungevity.org

Us TOO Prostate Cancer Education & Support • 800-808-7866 • www.ustoo.org

Young Survival Coalition • 877.972.1011 • www.youngsurvival.org

## Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit **www.CancerSupportCommunity.org** for more info.

**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 9am - 9pm ET.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**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. Sign up at **www.MyLifeLine.org**.

**Open to Options**<sup>®</sup> — Need help making a cancer treatment decision? 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.

**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.

**Cancer Experience Registry**<sup>®</sup> — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.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**.

#### FRANKLY SPEAKING ABOUT CANCER: BONE HEALTH PROGRAM PARTNERS:







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