Leslie Robbert Marsh, 52, of New Orleans, has been living with metastatic breast cancer in her bones for the past seven years.

“When I got the phone call saying I had bone metastases, I was ready to just lie in bed for the rest of my life and never leave my house,” Leslie recalls. “But once I got information about all the treatment options, I acclimated and realized I could live with the cancer as a chronic disease.”

Breast cancer spreads to the bone in 70 to 80 percent of women with metastatic disease. The spine, pelvis, ribs and proximal long bones (long bones in the arms and legs) are most commonly affected. While in some cases metastatic breast cancer spreads to bones but not to other organs, in others it spreads to both.

**SYMPTOMS**

When breast cancer spreads into bones, it disrupts the bones’ normal growth, causing pain and a higher risk of fractures. If cancer spreads to the spine, it can also cause spinal cord compression, when fragments of bone break off and press on the spinal cord. This can be very painful and, in severe cases, even cause paralysis. Sometimes bone mets can also cause hypercalcemia, or high levels of calcium in the blood.

Fractures, compression and other physical effects of cancer in the bone are called skeletal-related events, or SREs. Treating SREs and delaying or preventing them is a main goal of treating bone metastasis.

**TREATMENTS**

Treatment for bone metastases depends to some extent on which type of breast cancer you have.

Hormonal therapy is one of the first treatment options considered for hormone receptor-positive disease. Trastuzumab (Herceptin) is an option for bone metastases that are HER2 positive. For triple-negative cancers there are many types of chemotherapy medicines and combinations.

For all types of breast cancer to the bone, there are treatments aimed at strengthening the bone, delaying the development of SREs, and slowing the growth or spread of cancer in the bone. These include medicines given by mouth or into a vein, local radiation treatment, and metal rods or glue-like substances inserted or injected into the bones. Pain treatment is a central aspect of controlling symptoms.
When you’re diagnosed with bone mets, your team of doctors may include a medical oncologist, radiation oncologist, orthopedic surgeon and palliative care, or pain management, specialist.

**Bone-Strengthening Medicines**

Bisphosphonates (pronounced bis-FOSS-fuh-nates) are a type of medicine that can strengthen bones, delay development of SREs and reduce bone pain. Bisphosphonates can also reduce the number of new bone mets that develop and lower high levels of calcium in the blood.

Zoledronic acid (Zometa), a bisphosphonate commonly given for bone mets, is taken by vein about once a month. Others include pamidronate disodium (Aredia), another IV treatment, and clodronate (Bonefos), given as a pill.

Denosumab (Xgeva) is a newer bone treatment given as an injection that has been shown to work a bit better than zoledronic acid in treating bone pain and delaying SREs. It may also help after zoledronic acid or another bisphosphonate stops working. But denosumab is still in clinical trials, and bisphosphonates remain the standard of care for bone metastasis.

Although you may start treatment with a bisphosphonate right after you are diagnosed with bone mets, your doctor might prefer to start with chemotherapy (for example, if you have metastases to other organs as well) or with hormonal therapy. Sometimes you get more than one type of treatment at the same time.

When you should start taking bisphosphonates, how long you should stay on them, and whether you should switch from one to another if the disease progresses are questions that you and your doctor will answer together based on your symptoms, type of cancer, disease progression, side effects and other factors.

For example, Elaine Manby, 57, of Battle Creek, Mich., was diagnosed with bone mets to two places in her breastbone and then developed metastases in both lungs. The cancer was triple-negative. Her doctor started her on capecitabine (Xeloda), an oral chemotherapy. After six cycles, she started zoledronic acid.

Carter Smith, 54, of Spartanburg, S.C., has hormone receptor-positive bone mets only, and she started her treatment with hormonal therapy and zoledronic acid at the same time.

“I personally tend to use more Xeloda with bone-only, ER-negative breast cancer, and we tend to use chemotherapy earlier and more often with cancer that has spread to other organs beyond the bone,” says Adam Brufsky, MD, PhD, professor of medicine and co-director of the Comprehensive Breast Cancer Center at the University of Pittsburgh. “But it’s important to consider all the treatment options on a case-by-case basis.”

Both bisphosphonates and denosumab have side effects including bone pain, fatigue and osteonecrosis of the jaw, when pieces of jaw bone break off and poke through the gums or palate, among other places, although denosumab seems to cause some of them less frequently.

**Radiation**

If bone mets are painful and limited to a few spots, radiation can help reduce the size of the cancer, relieve pain, strengthen bones and delay the development of SREs. Radiation can cause different side effects depending on where it’s directed and which organs it passes through.

Julie DuSablon, 53, of Columbus, Ohio, received radiation that relieved pain from mets in her bones in the lower back. “But at first I was sick as a dog,” she says. “The radiation passed through my stomach, and for a few weeks I had terrible nausea. The good news is that after the treatment, the pain in my bones was almost gone!”

**Physical Bone Support**

If a bone is weakened and at a serious risk of fracturing, an orthopedic surgeon may place a metal rod in the weak area. Other devices can be placed in bones if they have already broken. Another option is to inject a cement or glue-like substance that adds strength and limits the area where the cancer can grow in that bone.
MANAGING SYMPTOMS AND SIDE EFFECTS

Because more women are living longer with metastatic breast cancer, managing symptoms and side effects over the long term is more important than ever.

Pain

Because managing pain plays a central role in your quality of life, pain medication will likely be part of your treatment plan. The medicines, radiation and physical support used to treat your bones can reduce pain, although some medicines may actually cause bone pain.

"Pain from bone mets is very distinctive. A lot of meds will cause additional joint and muscle pain. You learn to tell difference between these two types of pain,” Julie says.

For Carter, controlling pain from the disease was key. “When I was first diagnosed, I couldn’t even walk,” she says. “But once the pain was controlled with pain meds, I went back to driving and back to work.”

Osteonecrosis of the Jaw

Osteonecrosis of the jaw, or “ONJ,” is a relatively rare side effect of bone-strengthening medicines. It affects more women with bone mets as they live longer.

“You can’t prevent ONJ,” says Julie, who has had several episodes of this side effect, “but you can minimize its negative impact.”

Before you start bisphosphonates or other bone-strengthening medicine, make sure you get any dental work you need. Oral hygiene is extremely important to reduce risk of dental problems.

QUALITY OF LIFE

The women interviewed for this article had two primary pieces of advice for those diagnosed with bone mets: Know your body, and work with a medical team you trust.

“You have to pay attention to your aches and pains, but at the same time not be paranoid,” Elaine says. “It’s very hard to find the balance, so you should err on the side of reporting more, rather than less, to your doctor.”

Leslie does relaxation and exercises like yoga and pilates to keep her body moving.

“My advice is to keep yourself centered and realize that you control your life; the cancer doesn’t control you,” she says. “Every now and then when a new spot develops in my bones, I allow myself a 48-hour pity party, and then I’m back to normal. You have to give yourself the chance to be sad and upset, and then move on.”

The Beauty of Life

BY JANIE TAYLOR, FOR LBBC

What a beautiful world, what a beautiful place, I see such a beauty in every face.

As they rush around and hurry by, They can’t take the time to catch my eye.

I want to grab and shake them hard, but they speed right by in their shiny cars.

I finally yell and scream out loud, STOP a moment and look around.

There is so much beauty and so much love, so many blessings from above.

But how can you see it when you go so fast, it instantly turns into your past.

Stop for a moment to see what's around, listen to all the wonderful sounds.

There is more to life than work and stress, You’re really missing the very best.

Take time for yourself to do what you love, after all, you are special, a gift from above.

Do you have a poem, drawing, painting or photograph you created in response to metastatic breast cancer? Submit it to us at editor@lbbc.org, and we may publish it in a future issue.
Don’t get me wrong—living with metastatic breast cancer isn’t easy. But since my diagnosis in 2007, I’ve been able to find ways to keep on living my life and loving my life.

After my first breast cancer diagnosis and treatment in 1999, I worked as a community program manager for Cancer Lifeline in Bellevue, Wash. I developed and facilitated support programs for cancer patients and survivors, including gentle yoga, nutrition, journaling and art workshops. My background as an arts administrator and art historian helped me design a successful drop-in art workshop where play and creativity were encouraged. Many who attended found the workshops to be fun support groups where the focus wasn’t entirely on the complexities of living with cancer. Usually, about halfway through the session, so much laughter filled the room that people in the next office complained!

One day, a woman joined the group in tears. We sat her down with some art supplies, and soon she was engaged in the project and interacting with others. By the close of the two-hour session, she stood up and announced to the group, “This is the first time in two years I haven’t been thinking about my cancer! Thank you!” Since then, she has continued to pursue art as a healing practice.

Her experience had a profound effect on me. While working as an arts administrator, I made it possible for others to pursue their passions. But I never had time to pursue my own. So after I was diagnosed with metastatic breast cancer, I resigned from my job to focus on my health and quality of life.

One of the first things I did was create a healing journal to help me process some of the difficult feelings associated with metastatic breast cancer. Writing my feelings down relieved much of my stress and mental anguish. Eventually I started making mixed media art as well. And like the woman in the Cancer Lifeline workshop, I found that making art somehow interrupted the pain and distress messages. It was totally absorbing. Even when I wasn’t working on art, I was thinking about it.

Then the most wonderful thing happened. A group of women from the Cancer Lifeline workshops started organizing potluck lunches and craft activities at their homes. Naturally, I joined them, and soon the events came to be known as “arty parties.” We still enjoy each other’s company, play a lot, and laugh a lot—and I mean, A LOT.

In addition to making art, in 2008 I started giving art lectures for the King County Library System. Sharing my passion for art with others has enriched my life and given it focus. The way I see it, I am still contributing something positive and living my life to the fullest. And when the cancer progresses, as it will in time, I will just make adjustments to my schedule.

The most important thing for me is not to identify too much with the cancer—to cope with it and get the best medical care, yes, but not let it define my life. When people say to someone living with cancer, “You’re so brave,” I think to myself, “Well, of course! What’s the alternative? To live in a state of fear? Who needs that?” Life is short no matter which way you look at it. And creating a good life is a choice we make, whether or not we have cancer.

I have my good days and my difficult days, but I count myself among the most fortunate. I have excellent health care, a loving husband, family and faith, and the most amazing friends. Each day I make some art, play with my dog, talk to a friend, hug my husband and make it the best day possible. In these wise words attributed to Abraham Lincoln, “And in the end, it is not the years in your life that count. It’s the life in your years.” Each and every day is a gift to be received, shared and celebrated.

The views expressed in this newsletter are those of the authors and do not necessarily reflect the views of Living Beyond Breast Cancer.