

Metastatic Breast Cancer

LISTEN TO YOUR BODY

Staying Physically Active After a Metastatic Breast Cancer Diagnosis

BY CLAIRE NIXON, FOR LBBC



Christine Hodgdon

Christine Hodgdon, of Baltimore, was training for a triathlon in 2015 when she was diagnosed with de novo metastatic breast cancer in her lung at age 34. “I was an avid runner before my diagnosis and ran eight half-marathons,” she says. “I had to give up the training when I entered into treatment.”

Kristina Logsdon, 43, of Shoreline, Washington, was an active hiker and runner before she was diagnosed with de novo metastatic breast cancer in her spine in 2015. That year, she was planning to run her first half-marathon. Instead, she had chemotherapy, a double mastectomy (surgery to remove both breasts), radiation and targeted therapy.

If exercise was a big part of your life before a metastatic breast cancer diagnosis, having to stop an activity can feel like a major loss. Treatment side effects can make exercise a challenge: fatigue can reduce your available energy; neuropathy — a burning, numbness or tingling in the hands or feet caused by damage to the nervous system that is a side effect of some treatments — can be painful and affect balance and coordination. The cancer itself may spread to areas of the body that make it harder to stay active. For example, metastases in the bones of the hips and legs may create fragile areas that make running unsafe; a lung metastasis in an airway or fluid building up around the lungs requires medical attention before exercise can be considered.

Still, you can keep exercising after a metastatic breast cancer diagnosis. You may need to make adjustments or

take a break. Exercise and activity have benefits for people with early-stage breast cancer. And early research shows that in people with metastatic breast cancer, exercise may ease pain, fatigue and anxiety. Better fitness can make it easier to do daily chores and activities.

Adjusting Activity for Cancer

Research on metastatic breast cancer remains just that — early. “Clinical trials want a nice clean group,” says **Sami Mansfield**, cancer exercise specialist and founder of Cancer Wellness for Life, an exercise, nutrition and emotional consulting organization based out of Kansas City, Kansas. “In metastatic breast cancer, there are so many differences: age, hormone receptor status, and the area or amount of metastases, which make it difficult to create studies.”

“We are never, ever going to have all of the evidence,” says **Kathryn Schmitz, PhD, MPH**, president of the American College of Sports Medicine. Dr. Schmitz studies exercise in people living with cancer at Penn State Cancer Institute. Since data is lacking, she says, it’s important to start low and progress low.

The American College of Sports Medicine, with the American Cancer Society, recommends 150 minutes of moderate-intensity exercise a week, but is that what your goal should be? “Not necessarily,” says Ms. Mansfield. “I’d rather someone do 5 minutes per day every day than go out



With you, for you.

one day, do an hour, and then they're done for 4 to 5 days because they're so wiped out. Consistent daily activity is much more important than just trying to hit a number."

The location of metastasis may also affect your ability to do some activities, according to **Pallav K. Mehta, MD**, a breast cancer oncologist and director of integrative oncology at MD Anderson Cancer Center at Cooper in Camden, New Jersey. Bones that don't carry much weight are not likely to break during exercise even if they have metastases, but it's important to work with your doctor if there are lesions in your leg bones, hips or lower spine.

Research shows that cancer treatment can cause loss of muscle tissue, making resistance training, exercise that uses weights or resistance to build muscles and strength, important. Lifting weights is safe for people with bone metastasis, Ms. Mansfield says. "Weightlifting is subjective — it could be 2 to 3 pounds or 150 pounds." Talk with your doctor about any precautions, such as weight restrictions or treatment-related side effects to watch for, such as blood clots.

Kristina no longer carries a 25-pound backpack, but she does more day hikes. Earlier this year, she hiked 12 days from the base of Mont Blanc in France to the base of Zermatt in Switzerland. "I built up my strength and stamina slowly through regular exercise, starting just a few miles at first, and always with friends to accompany me and keep it fun."

Another area of metastasis that can affect exercise is the brain. Brain metastases can impact stability, balance and coordination. Small metastases may not require activity limits. But with multiple brain lesions and extensive treatment, falling is a risk, particularly if you've had surgery or radiation treatment.

Adjusting for Common Side Effects

In addition to the cancer itself, treatment side effects can also interfere with exercise.

Fatigue, a common side effect, is often due to loss of lean muscle, Ms. Mansfield says. Loss of lean muscle happens due to inactivity, such as times when you're not feeling well or you're recovering from surgeries or treatments. It's something you can improve through muscle-building exercise, she says.

With mild neuropathy — some numbness and tingling — you may not need any adjustments but may choose to try different types of activity, such as pool exercise, to take pressure off your feet. Higher grades of neuropathy that cause pain or balance challenges need to be addressed with your doctor.

Eileen Schild, 71, of Commack, New York, loved to do Zumba when, in 2014, she was diagnosed with metastatic breast cancer. She developed painful foot neuropathy from treatment. Her dermatologist recommended lidocaine patches, bandage-like strips lined with lidocaine to numb an area of the body. She says they help relieve foot pain during indoor cycling classes.



Kristina Logsdon

Eileen also developed hand-foot syndrome, a skin condition caused by some treatments, while taking the chemotherapy capecitabine (Xeloda). She had to quit Zumba because of the foot pain. To make up for it, she does more stationary bike and elliptical workouts.

If you exercised daily before diagnosis, having to cut down can bring feelings of frustration or sadness. Talk to your physician, a cancer trainer, hospital social worker or someone else with breast cancer for help with difficult feelings and finding alternative activities with similar benefits. For Christine, being outdoors is important. Although she cut back on running, she discovered yoga, biking and kayaking, which still allow her to be out in nature.

"This is hard stuff," Dr. Mehta says of pausing certain activities. "But because you have muscle density and muscle memory, you're going to recover more quickly from chemo."

Getting Started Again

Before returning to exercise, Dr. Mehta recommends that in some cases, such as metastases in weight-bearing bones or multiple brain metastases, it's important to see a physical therapist for a safety assessment.

Depending on your history of exercise and how you feel, Ms. Mansfield says, you can start at home with chair-based strength exercise, which engages your core muscles to support your lower back and improve your posture. She suggests starting with body weight only first, then adding extra resistance as you complete more repetitions with ease.

If you want a trainer, ask your doctor to refer you to a qualified exercise specialist with some knowledge about cancer and cancer treatment. Look for a trainer with a cancer training certification. If there are no trainers with cancer experience in your area, look for one who works with older adults, or who has advanced certifications in diabetes prevention, cardiac rehabilitation or disabilities. The National Strength and Conditioning Association, ACE Fitness, and the American College of Sports Medicine are some resources Dr. Schmitz recommends for finding a trainer.

As you start a new routine, pay attention to how your body feels, says Ms. Mansfield. For example, it's normal to feel a little out of breath during exercise due to heart-rate

elevation, but if you feel out of breath during more gentle activities such as yoga or daily tasks, it's important to tell your doctor. Notice any pain you feel when you're not moving or pain that is more severe and does not go away within a few days of an intense workout.

It's important to understand the difference between being tired — when you can and should push yourself a little bit — and being debilitated, when you should stop and rest, Dr. Mehta says.

"Listen to your body and do what you can," says Eileen. "For me, in my first bout, I came home and took a nap and then I went to the gym. Do what you have to do, and do as much as your body lets you."

Kristina recently hiked up to 10,500 feet on Mt. Adams, Washington. "Hiking makes me feel like I have more control over what is happening in my body," she says. "It's the physical manifestation of my persistence and determination and my strength. It gives this perspective of time — how long it's taken for the mountains to be built up, valleys to be carved — and from that perspective, it reminds me that the world doesn't revolve around me. It's going to keep going. And with the short time that I have, how do I use it wisely?" 🍌

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Eileen Schild

MISLEADING HEALTH NEWS:

A Q&A With Susan Jacobson, PhD

BY MADISON HUGHES



Susan Jacobson, PhD

In May 2015 **Susan Jacobson, PhD**, had just moved to Miami when she was diagnosed with metastatic HER2-positive breast cancer.

In the first few months after diagnosis, Dr. Jacobson looked for information online. What she found was overwhelming, misleading and scary. Eventually she found reliable information and support. She went on to help found a Facebook group for women with metastatic HER2-positive breast cancer where they discuss treatments and how to deal with side effects.

Dr. Jacobson, a professor of journalism at Florida International University, had researched social media and politics before breast cancer. After her experience trying to find good medical information online, she saw how harmful misleading medical news could be. Since then, she has been working with her colleague, **Weirui Wang, PhD**, on research about fake and misleading health news online.

Dr. Jacobson spoke with LBBC's content coordinator, **Madison Hughes**, about her experiences and research.

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Why is misleading health news created? What is it made up of?

DR. JACOBSON

There are different players with different motivations that [spread] fake health news. Usually, the motivation is financial. On one hand, you have researchers, medical centers, drug companies doing research on new things. When they get results, they want to spin them in the most positive way possible. On the other side, there are small [web]sites. They're not real publications, they're internet fiction. Their main motivation is to get clicks. They can take a perfectly reasonable press release and it becomes distorted. One example: the University of Windsor in Canada discovered some cancer-fighting properties of dandelion root. And they said, "We're going to do some investigation into dandelion root." And they put out a press release. And then [a website] gets ahold of it and the headline becomes, "Dandelion root more effective than chemotherapy, kills cancer in two days." And that's very common.

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How is it harmful to people with breast cancer?

DR. JACOBSON

There have been a few news stories about women who were diagnosed with breast cancer who chose to forgo traditional treatment for natural cures, then died or became metastatic as a result. Part of that is a culture that wants to believe that there's something out there other than chemo. Another [thing is that research shows] people who are first diagnosed remember about 20 percent of what they are told. These people are vulnerable to misleading information.

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How is this misleading information spread?

DR. JACOBSON

One of the things [misleading news sites] do is borrow on the name of a legit news organization. And if they go through the trouble of mimicking a real news organization's website, sometimes they'll take some care with the proofreading. They have all these pieces of whispers and conspiracies, these semi-true and maybe-not-true things, and they layer it together into this very suggestive story. It's the layering that makes it sophisticated. We don't have very strong health journalism, so that can make [people] susceptible to sharing misleading information.

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If it's so easy to be misled, how can the average person spot it?

DR. JACOBSON

I think we need more awareness. People have to know that health news and health information can be misleading [or] can be partially true. People don't know that. People need to know there are places they can go to get more accurate information. Some sources are better [than others].

MADISON

With the national discussion happening about misinformation and fake news, why is your focus on fake medical news so important right now?

DR. JACOBSON

Misleading health information is often more pervasive. If you're a Democrat and you see something terrible about President Trump, even if it's from a squirrely news source, you might be inclined to believe it. Or if you're a Republican and see the same story, you're inclined to disbelieve it. Meanwhile in health news, people see something like, "Drink lemon every morning!" and they don't have the same critical tools to approach that.

MADISON

How has your experience with breast cancer inspired and influenced your work on this project?

DR. JACOBSON

Before I was diagnosed I had never been sick. I didn't know what stage IV meant, I just didn't know what it was. I went on the internet first thing and the information on there is overwhelming. I was in this fog. And while I was trying to find my way I found the right [Facebook] groups. I started to see that there was value in talking to other women about what's going on because there's all kinds of crazy [stuff] out there. Then the 2016 election happened, and the story of how different parties with different interests were creating misleading information on the internet. I could see some of that coming through the cancer groups. That's when I decided, "Let's take a look at fake news." 🙄