INSIGHTS ON

SUMMER 2017

Metastatic Breast Cancer

COPING WITH LOSS:

An Ongoing Process

BY ERIN ROWLEY

Caitlin and Kyle on their wedding day

Caitlin Kennedy-Masterson and her husband, Kyle, married this spring. They've faced more loss in the decade they've known each other than many couples face in a lifetime. They were together when Caitlin was diagnosed with early-stage breast cancer, in 2010, at age 26, and when she was diagnosed with metastatic breast cancer in 2013, at age 29.

Doctors originally found metastases in the pleura, a lining around the lungs. Since then, the cancer has spread to her lungs, liver, bones and, in the fall of 2016, her brain.

Metastatic breast cancer forced Caitlin to consider her mortality while planning her wedding, and the rest of her future. She and Kyle did in vitro fertilization years ago, and still pay to store the embryos. But they don't know whether they'll ever use them. (Caitlin would be unable to carry a child herself.)

"Everybody my age is planning their futures, and I can't really plan much in my future," she says.

Different Types of Loss

Metastatic cancer causes grief from the moment of diagnosis, says **Kelly Grosklags, LICSW, BCD**, an oncology psychotherapist with a fellowship in grief counseling. Though the word "grief" is associated with death, it can refer to deep sadness caused by any loss. Metastatic breast cancer may cause you to feel anticipatory grief — sadness about things you expect to lose in the future, like your energy, your independence, your job, your financial stability, and ultimately, your life. Uncertainty about whether you'll marry, have kids, enjoy retirement or meet your grandchildren can also cause grief.

There isn't a beginning, middle and an end to grief, Ms. Grosklags says. It's an ongoing process. You may feel it more strongly or less strongly as time goes by, but it isn't likely to go away entirely. So it's important to learn to live as well as possible *with* the grief.

"Grief is something that is meant to be felt. It's something you can run and hide from, but hiding from grief long-term is difficult. It finds us," she says.

JOB AND MONEY

Even if you have insurance, it's expensive to have metastatic cancer. Paying for cancer treatment may cause you to lose out on goals you and your family had, like traveling or saving for a child's college tuition.

If cancer forces you to stop working or work less, making ends meet can get even harder. And not working may leave you with more time to worry about your health. You may also experience strong feelings of loss if you find work fulfilling and think of it as a big part of who you are. If that's the case, talk to your current or former employers, or other organizations whose work interests you, and ask if you can work part-time or on a freelance basis. You could also consider volunteering for an organization you're passionate about.

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If you're in or near retirement, your savings may suddenly not be enough for the retirement you wanted. **Carol Miele**, 72, from Davenport, Florida, was diagnosed with metastatic breast cancer in 2010, just months into retirement after 45 years as a registered nurse. Her husband was already retired, and they were looking forward to travel and freedom from schedules or deadlines. Her diagnosis of de novo metastatic breast cancer, meaning it was metastatic from the start, brought them "crashing down," she says.

For financial help, talk to an oncology social worker, a financial adviser, or both. They can help you find grants from nonprofit organizations or use resources like medical leave and disability insurance.

RELATIONSHIPS WITH LOVED ONES

Ideally, many people you love have offered you support since your metastatic diagnosis. But maybe there are others you thought would be there for you, who haven't been. Unfortunately, this is common. Try not to dwell on people who disappoint you. Instead, focus on those who lift you up.

Two friends of Carol's stopped talking to her after she told them about her diagnosis. But other family and friends came through for her. She also gets support from social media groups made up of people with metastatic breast cancer. Whenever someone tells her they're praying for her, it strengthens her, she says.

SEX, INTIMACY AND BODY IMAGE

A metastatic breast cancer diagnosis doesn't stop sex and intimacy from being important parts of life. But it can create challenges. Pain, fatigue, hair loss, weight gain, menopausal symptoms or other changes in the way you look and feel may affect your sex drive or make you self-conscious. And a partner may assume you aren't interested in sex, or be afraid of causing you pain.

That's why it's important to talk about how metastatic breast cancer is affecting your sex life. Your doctor may be able to prescribe medicine or suggest strategies to deal with sexual symptoms or side effects. And you and your partner should talk about what sexual or intimate activities you both feel comfortable with. Your sex life may never be the same, but if you are understanding and patient with each other and make an effort to share your wants and needs, intimacy doesn't have to be something you lose.

ENERGY AND INDEPENDENCE

Deep, ongoing fatigue is common among people with metastatic breast cancer. Many different things can cause it, including the disease itself, its treatments, stress and anxiety. It's also common to feel weak and less able to do everyday activities. An important part of treatment for stage IV breast cancer is helping you live as well as possible with the disease. So talk to your doctor about medicines or lifestyle changes that could increase your energy. Still, you may have to accept that you can't be as energetic or independent as you once were.

Carol Miele

You may have to stop cleaning, cooking, driving or doing other common tasks, or start sharing some of the load with others. Try to be realistic about what you can do and what you need help with, and share that information with your family members and friends. Asking for help isn't a sign of weakness; it is a sign of strength.

Make it a priority to save your energy for things that are most important to you, like visiting with friends, going to a grandchild's birthday party or doing a hobby that makes you happy. Plan naps beforehand so you can fully enjoy those activities and if you're tired afterward, allow yourself to get the rest you need.

Keep track of when you feel most and least energetic throughout the day, and plan activities and down time accordingly. Focus on what you can do, not on what you can't.

FAMILY MILESTONES

Missing milestones in their loved one's lives — and whether, or how, their loved ones will remember them — are some of Ms. Grosklags' clients' biggest worries. She encourages taking actions to help deal with this anticipatory grief now and leave a legacy.

She suggests people write cards congratulating loved ones on different life milestones, like retirement, buying a house, getting married — even graduation from kindergarten.

"What I always say to people is, 'It'll be really cool if you can hand them this card yourself, but if not, then we want you to be represented at these things,'" she says.

She encourages her clients to hand-write messages, rather than type them, or create voice messages or videos. That way, loved ones can later see your handwriting or hear your voice.

To clients who worry they may never meet their grandchildren, she recommends they record themselves reading one of their favorite children's books. That recording can be played in the future, giving the client a way to be present in the future child's life.

"Often they'll pick one they liked reading to their children," she says. "It's for the grandchild, but it's really sweet for the children too, who have their parent's voice on a recorder."

Some people buy gifts to be given in the future. Ms. Grosklags had a client who collected angel figurines. So the woman bought angels for future children-in-law whom her sons had not even met yet. She included a note with each angel, thanking the recipient for loving her son.

"As a grief therapist, I will tell you that [things like that] are priceless," Ms. Grosklags says.

> *"Life doesn't stop happening because cancer has struck."*

Getting Help

You're likely dealing with more than one loss related to metastatic breast cancer, and maybe other losses unrelated to cancer. All our griefs are connected, so multiple griefs can pile up, Ms. Grosklags says. And past feelings of loss can reappear when new losses occur.

"Life doesn't stop happening because cancer has struck," she says. "There's a lot of complicated grieving and multiple losses that happen that have to be dealt with."

There are subtle but important differences between grief, which is a normal response to losses associated with a life-changing situation like cancer, and clinical depression, a mood disorder, Ms. Grosklags says. But it's possible to experience both at the same time. She recommends you let a trained professional help you figure out whether you're experiencing grief, depression, or both.

Carol takes antidepressants, which she says help her handle difficult emotions, as well as menopausal symptoms caused by her treatment. Doing things she enjoys — like painting, drawing and gardening — also helps her cope with the many losses she's experienced. She also likes to write about what she's been through. She's published two books (*Metastatic Madness* and *Kicking Cancer to the Curb*) and has written articles for the *Huffington Post*.

Caitlin finds that exercising, and using her body in ways that people who don't have cancer do, helps her cope. So does reading, meditating, talking to loved ones and seeing a therapist. She and Kyle travel, go to concerts, see movies, and try to enjoy every day they have together.

"I'm learning how to accept that I can't change this," Caitlin says. "That's pretty hard."

INCREASING IBC AWARENESS:

Mary Jennings Smith

BY ERIN ROWLEY

Mary Jennings Smith (right), with her daughter, Shannon Mumenthaler

Mary Jennings Smith, 68, of San Marcos, California, was diagnosed with stage IIIB inflammatory breast cancer (IBC) in 2005 and metastatic breast cancer in 2008.

She is a long-time volunteer with LBBC's Breast Cancer Helpline and a recipient of one of this year's volunteer awards (see page 6).

Mary volunteers with other organizations, too, and is passionate about increasing people's understanding of inflammatory breast cancer. She answered questions about that passion from Living Beyond Breast Cancer's writer and content coordinator, **Erin Rowley**.

Erin

What was your experience of being diagnosed with breast cancer?

Mary

I had been taught that if I had cancer, it would be round. That wasn't the case for me. I had felt something hard and flat [in my breast], but I wasn't too concerned because the doctor said it was probably an infection. I had a mammogram, which showed nothing, and an ultrasound, which I assume also showed nothing.

I went back 4 months later and told the surgeon that I thought whatever it was had grown. He sort of poo-pooed my concern, but did send me for another ultrasound. The radiologist came in and told me the bad news. She made an appointment for me to see an oncologist within 2 days. By the time I saw him, my breast had started to enlarge. Within 2 weeks of scans, appointments to have skin biopsies, and meeting with a different surgeon, my breast had grown to twice its normal size. It was turning red and the nipple was being pulled inward. I freaked over what was happening to my body, and the only way I knew how to deal with it was to throw myself into my work as a faculty director of many programs at the local community college. Everyone deals with their cancer diagnoses differently, and for me I think I just walked through my diagnosis and treatments in a daze.

Erin

What did you know about inflammatory breast cancer before you were diagnosed with it?

Mary

I had never heard of IBC, and it took my breath away when I looked it up on the internet. This was in 2005 and there wasn't much research about this form of breast cancer, but the recurrence and death rate within 5 years [of diagnosis] was pretty high. I wanted to learn more, especially when my cancer metastasized 2 years later. So, I attended an MD Anderson Inflammatory Breast Cancer Clinic conference and realized that although this cancer was considered rare and aggressive, there were many women around the world who were diagnosed with this disease. At the conference I met a nurse, Ginny Mason, who told me about the IBC Research Foundation.

Erin

Why did you want to get involved with that foundation and other advocacy and volunteer efforts, including LBBC?

Mary

I wanted to educate other people about this type of breast cancer that not only I didn't know about, but it seemed like the medical community didn't know much about either. I thought I would be an advocate, but I needed to learn more about how breast cancer works. So I signed up for a National Breast Cancer Coalition training program. I took the initial weekend course first and loved it. A few years later, I signed up for the week-long program. I also sent a video on IBC to all my colleagues at the college as well as other colleagues at other educational institutions.

Many people had never heard of IBC, which is why so many women were dying from it — especially African-American women, who seemed to be affected at higher rates than women of other racial populations. And people thought you had to have a lump to have breast cancer and didn't know that IBC often can't be detected with a mammogram. Many doctors had never seen a patient with IBC so initial diagnoses were often wrong. I wanted to help spread the word, so I started working with the IBC Research Foundation. I have done this by locally giving speeches about my personal story and being supportive to women who were referred by medical personnel or the IBC Research Foundation staff.

I also have had a couple of match calls from LBBC's Helpline with women who have either been diagnosed with IBC or think they have it.

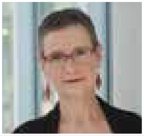
> *"It is very rewarding to know that my story with IBC has helped give others hope."*

Erin

How does it make you feel to take those calls and help those people learn more about the condition? What do you hope they take away from those calls?

Mary

It is very rewarding to know that my story with IBC has helped give others hope. Most women are super surprised that I have had metastatic breast cancer for 10 years and that I take chemo and now a targeted therapy. Callers' "thank you so much" makes me feel that they will sleep better that night and that puts a smile on my face!



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