

Insights on

Metastatic Breast Cancer

WINTER 2014/2015

WHEN DISTRESS PERSISTS:

Depression and Metastatic Breast Cancer

BY ANNA SHAFFER



Kathryn Davis

Kathryn Davis felt victorious after undergoing treatment for stage III breast cancer. By 2013, 2 years after her diagnosis, the 38-year-old mother was working as a real estate agent and paralegal while going to school for a bachelor's degree in law.

"My doctor was so sure it was gone. I had no traces in my body," says the Riverside, California, resident. So when a routine PET scan showed the cancer had *metastasized*, or spread, to her pelvis, she felt "crushed, devastated and shocked."

"I was so angry. I called my mom sobbing and texted my husband that I had bad news. We didn't tell the kids for a long time," she says.

A month later, Kathryn's feelings of distress had not gone away. She decided to seek professional help. "I wanted to sleep. I withdrew within myself," she says. "I talked to my primary doctor. I said, 'I can't live like this.'"

Studies show people with metastatic disease often experience distress that can lead to depression. The key is to recognize the symptoms and take steps to get the help and support you need.

What Causes Depression?

A metastatic breast cancer diagnosis can be very emotionally difficult. You may feel distressed from uncertainty or feelings of loss. You may have fears about survival and disease progression, or worry about the impact on family and friends. Stress caused by these emotions can trigger depression.

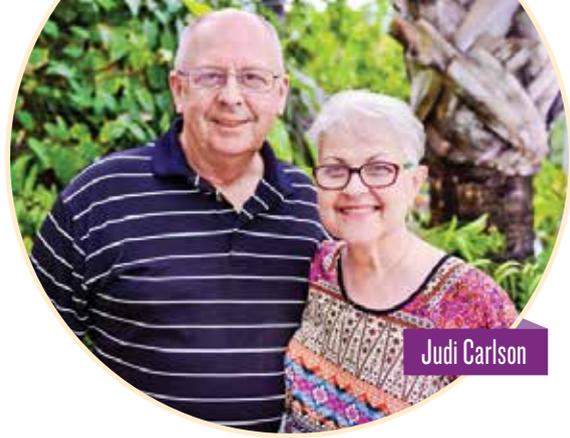
"Depression hit me when I was done with surgery and healing—I crashed and burned," says **Sharon Robbins**, 54, of Arden, North Carolina, who was diagnosed with metastatic breast cancer in November 2013. Uncertainty about how long the cancer would stay in check caused her to fear how long she would live.

"After I was diagnosed, I felt mostly scared, and there was a huge sadness at the time," says **Judi Carlson**, 63, of Holyoke, Minnesota. "Then I remember getting on the 'fight, fight, fight' bandwagon with my husband. We were so busy going to doctors and tests...[there was] the feeling of deserving to live. Something told me to keep going."

Once Judi finished her first treatments, she started a monthly plan, which meant she didn't see the doctor as often. "I started thinking it's so bad there is nothing more to do, and this is how it's going to be. I was thinking too much," she says. "I had a couple meltdowns in the last 3 months and decided it was time to find help."

Symptoms of metastatic breast cancer and side effects from medical treatments can also cause depression. Some may directly affect your emotions, while others may cause fatigue, loss of appetite, pain and other physical side effects that can affect your mood.

"I had to stop work because of the severe side effects related to ongoing treatment, and I went from 60 to 0 mph. I felt lonely and lost," Sharon says.



“I’ve noticed that there isn’t an area of my body that isn’t different,” Judi says. In addition to fingernail, hair and skin changes, her eyesight has been affected. “I’m an artist, so that’s very painful.”

The cause of depression can determine how it is treated, says **Jesse R. Fann, MD, MPH**, professor of psychiatry and behavioral sciences at the University of Washington and director of psychiatry and psychology at the Seattle Cancer Care Alliance. “For example if a particular medicine or combination of medicines is contributing to the depression, the medicines may be adjusted,” he says.

Several factors increase risk of depression, including a personal or family history of depression or other mental health issues, substance abuse, certain medicines, lack of social support and physical symptoms and side effects. It is important to address these other concerns.

“Depression and anxiety often go hand in hand. If someone has problems with depression, it’s likely that anxiety is also present. It’s essential to identify and treat both problems,” Dr. Fann says.

Recognizing Symptoms

It’s normal to feel a range of emotions, including sadness, loneliness and anxiety, over a metastatic breast cancer diagnosis. You may have trouble sleeping or find yourself sleeping too much. In your day-to-day life, you might be irritable, impatient or slow to react to emotional situations.

Often, the hardest time is between getting the news and starting or changing treatment. Anticipating treatment can create anxiety, but for most people their mood improves after treatment starts, says **Gregory D. Garber MSW, LCSW**, supervising social worker at the Kimmel Cancer Center at Thomas Jefferson University Hospital in Philadelphia.

“Adjustment reactions ... resolve pretty much on their own over several weeks. Symptoms that persist beyond a few weeks and begin to interfere with daily life—when you are not getting out of bed, feeling blue most days and not enjoying activities that were previously enjoyable, for example—those are red flag symptoms.”

In addition to lingering, intense feelings of sadness, despair, loss of energy and difficulty dealing with daily life, symptoms of depression may include:

- loss of pleasure in activities that you once enjoyed
- feelings of worthlessness and hopelessness
- changes in eating or sleeping habits
- poor energy or concentration
- thoughts of ending your life or hurting yourself in some way

“In an oncology population, we rely on mood symptoms more than physical symptoms to diagnose depression, because physical symptoms like loss of appetite and sleep disturbances are influenced by treatment like chemotherapy and hormonal therapy,” Mr. Garber says.

It is important to recognize when your feelings may be symptoms of a more serious medical condition. Your oncology team or primary care doctor can help you sort out whether you have depression or just fatigue or sadness.

Types of Depression

There are several types of depression:

- An *adjustment disorder or reaction* happens when you aren’t able to cope with, or adjust to, a source of stress, such as a metastatic breast cancer diagnosis. These usually occur within 3 months of the trigger, can last for a few months and usually go away once you have adapted.
- *Dysthymic disorder* involves feelings of moderate depression that occur most days for at least 2 years.
- *Major depression*, also called *clinical depression*, involves symptoms that interfere with your ability to function and enjoy life. These include feelings of continued sadness, hopelessness and despair and a loss of interest or pleasure in relationships and favorite activities. If these symptoms have been present every day for at least 2 weeks, you may have major depression. Other symptoms may include fatigue or lack of energy almost every day; feeling guilty or worthless almost every day; trouble getting motivated; significant weight loss or gain; problems with concentration; or recurring thoughts of death or suicide.

Although depression can go away on its own, most people who have it need treatment to get better, Dr. Fann says. Without treatment, depression can become chronic and develop into a *persistent depressive disorder*.

“Depression impacts every aspect of your health. It is something we have very good treatments for, and treating it can be associated with higher survival,” Mr. Garber says. “No one should be expected to ‘tolerate’ depression as a ‘side effect’ of a metastatic breast cancer diagnosis. Treating depression is just as important, if not more so, than treating nausea or pain or fatigue.”

Finding Help and Support

Feeling sad or anxious doesn’t mean you are weak or coping poorly. Seeking help is a sign of strength and self-respect, shows commitment to self-care and is important to the healing process. In addition to your oncology team or primary care doctor, a social worker or oncology nurse can connect you to treatment, resources and support.

“It’s never a bad time to talk to a mental health professional, especially if you are persistently sad, depressed or feeling isolated,” Mr. Garber says. “When distress is persistent and impacts your functioning, it is time to seek support. There are many ways to help relieve distress, but reaching out for help is

the first step. Talking to your oncologist, nurse, social worker or primary care provider can be a good place to start.”

Talk therapy can help you feel supported and allow you to talk about what is bothering you. Sharon sees a counselor at the cancer center where she receives treatment. “Being able to talk through my feelings is really helpful,” she says. “We talk about nutrition, exercise and other things I can do that are positive and creative.”

Integrating depression care with oncology care can be beneficial, Dr. Fann says. If you do, a nurse, social worker or other professional serves as a liaison between your mental health provider and oncologist.

Your oncologist or psychiatrist might suggest an antidepressant or other medicine to help ease sadness and help you feel better. “Medication with psychotherapy can often be an effective approach to treating depression,” Dr. Fann says.

Some medicines take time to start working, so continue taking them as recommended, even if you don’t feel better right away. Which medicines your providers recommend will depend on other medicines you take and your unique needs. Some antidepressants may reduce the effectiveness of tamoxifen, a treatment for hormone-sensitive breast cancer. Be sure to talk with your doctor if you are taking tamoxifen, before you start any new medicines or stop taking others.

Having a support system helps Kathryn cope. “I started going to a cancer support group at my church. We talk about our fears and feelings that nobody else can understand,” she says.

Judi meditates and listens to guided imagery podcasts to “quiet the brain” so she can sleep. She takes walks outside and continues to create art when she can. “It brings me out of a lot of stuff when I sew, draw, paint or create,” she says. “Having spiritual beliefs is important—some days I don’t want to take a step before asking if I am going the right direction.”

Sharon practices self-care by eating well, exercising and taking medicine to manage pain. She has also delved into bible study. “With the tools, resources, attitude and outlook I now have, I have established a ‘new normal’ that, in my opinion, is sweeter and richer than my old life,” she says.

Kathryn also tries to give back as much as possible. She founded Thrive Cancer Support Ministry to help others with cancer. “I have to use my cancer for good, otherwise I will go crazy,” she says. “We have to be stronger than our cancer, and that means depression, too.”

If you feel depressed, tell your healthcare team right away. They will be able to do a thorough assessment or refer you to a mental health professional at your cancer center or in your community.

*If you feel hopeless, reckless or trapped, or you think you are in danger of hurting yourself, we strongly encourage you to call the **National Suicide Prevention Lifeline at (800) 273-8255**. This free hotline, a service of Mental Health America, is staffed with trained counselors day and night.*



Sharon Robbins

WHEN METASTATIC BREAST CANCER TURNS INTO A CALLING **Q&A With Sarah Merchant**

BY ERIN ROWLEY



Sarah Merchant

Sarah Merchant was 28 years old when she was diagnosed with metastatic breast cancer about 5 years ago. Living in Salem, Massachusetts, and working in Boston while raising her son, getting breast cancer was the last thing on her mind. “My diagnosis came as a shock to everyone,” Sarah says, especially since she has no family history of the disease.

Sarah dove headfirst into the breast cancer community, taking part in programs offered by Living Beyond Breast Cancer and other groups. Because she found that there were few resources for women like her, who were young and living with metastatic disease, she also started a blog to share her experience, and a nonprofit to spread awareness of metastatic breast cancer.

ERIN

What did you know about breast cancer before you were diagnosed?

SARAH

Before I was diagnosed with breast cancer I did not know much about the disease. I believed it was a disease that affected older women or women with a family history. I never would have thought that I would be susceptible to a diagnosis myself.

ERIN

In what ways have you taken part in breast cancer-related activism and charity work since being diagnosed?

SARAH

Since my diagnosis I submersed myself in the advocate community through training programs like LBBC's Young Women's Initiative and the National Breast Cancer Coalition's Project LEAD. I wanted to learn as much as I could about breast cancer and the science behind cancer. I started a blog, [InsertBoobsHere.com](#), when I was diagnosed, to document my journey and keep family members up to date.

After receiving my training in breast cancer advocacy I wanted to start fundraising for the cause. I started a small grassroots, volunteer-run nonprofit to raise funds for other nonprofits. My goal when creating Beyond Stage 4 was to spread awareness about metastatic breast cancer as well as the large number of women who are diagnosed with breast cancer before they are in their 40s.

Beyond Stage 4 has run several successful fundraising campaigns. Our most popular campaign is Bikers 4 Boobies, which is a pink tent set up in Laconia, New Hampshire's annual Motorcycle Week, in June. We raise funds by selling merchandise we design, as well as from donations. At Bikers 4 Boobies we also provide an array of educational materials to inform the public.

ERIN

Not everyone who goes through breast cancer becomes so active in the breast cancer community. Why is volunteering important to you?

SARAH

Volunteering became important to me because there were not a lot of nonprofits out there that concentrated on metastatic breast cancer in young women. I had the marketing background and once I was too sick to work full time I knew that I needed to do something. I couldn't just sit back and not participate.

Helping others became a way for me to not get so consumed in my own disease. It allowed me to keep myself busy and feel as though I was making a difference instead of just being another victim. Volunteering and fundraising gave me a purpose, a reason to get out of bed every morning. I think that I also felt that if I kept myself busy enough that I would have no time to be sick myself.

ERIN

What misconceptions do people have about metastatic breast cancer? What do you want them to know?

SARAH

I think the biggest misconception about metastatic breast cancer is that once breast cancer spreads to another organ, a lot of people think that it is a new cancer, like liver cancer or bone cancer. I think that a lot of people think because breast cancer fundraising is so popular, that we get enough funding and do not need more. Most people do not know that less than 5 percent of breast cancer research dollars actually go toward finding a cure for metastatic breast cancer. As an advocate I try to work against these misconceptions and let the public know that we need more research to save the lives of metastatic survivors. We are not a lost cause because our disease has spread.

There has been a lot of work in prevention and breast cancer awareness. Breast cancer is no secret—we all know someone who has been diagnosed with breast cancer. The current screening tools we have are not enough for those diagnosed before they are old enough for yearly mammograms. There is still a lot of work to be done in the metastatic community and I am more than happy to take on the challenge.

For more information about metastatic breast cancer, visit lbcc.org/Audiences/Metastatic-Breast-Cancer.

“Helping others became a way for me to not get so consumed in my own disease. It allowed me to keep myself busy and feel as though I was making a difference instead of just being another victim.”