

# The realities of living with premenopausal metastatic breast cancer

Receiving a breast cancer diagnosis is difficult, but these young women faced an especially challenging diagnosis: stage IV metastatic breast cancer.

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## Helga: shifting passions to help others following diagnosis

At age 35, Helga was diagnosed with early-stage breast cancer. She thought, “OK, I’m going to get cured and move on.” As she was finishing her treatment, Helga’s doctor told her in passing that there was a chance that her breast cancer could come back – but that was the end of the discussion. She recalls being told to not spend too much time on the internet because the information she might find about recurrence and metastatic breast cancer (MBC) could be “terrifying.”

Nearly 30% of women initially diagnosed with early-stage disease will ultimately develop metastatic breast cancer.

Looking back, she wishes she understood what a recurrence could look like, because 18 months after her initial diagnosis, her breast cancer came back as metastatic disease (when cancer cells spread to new parts of the body, such as the lungs, liver and bones). Helga remembers needing to wrap herself mentally and emotionally around the recurrence. Like most women in their 30s, she was focused on her career, relationship and starting a family; to receive the news that her illness was incurable was devastating.



Helga is not alone. In the US, premenopausal metastatic breast cancer in women is growing in prevalence. Nearly 1 in 7 of the individuals living with metastatic breast cancer is younger than 50 years old, and younger

patients typically face unique challenges associated with the disease.

“Younger women tend to have a whole different host of challenges that are very different from postmenopausal women,” says Dr. Nikita C. Shah, medical oncology team leader at Orlando UF Health Center\*. “[The younger patient] is probably trying to work full-time, take care of her kids, and deal with metastatic disease. It’s a whole different ballgame for younger patients with the same disease compared to an older patient with metastatic breast cancer.”

At 39 years old and after living with breast cancer for four years, Helga made the difficult decision to retire from her career of 16 years as a highway engineer to focus on her health. “This disease comes and takes over your life,” Helga says about her lifestyle changes. “You have to think of things that people typically [think about] later in life.”

When interacting with the metastatic breast cancer community as a patient advocate, especially with those who are newly diagnosed, she hopes that others will be able to learn from her story. She encourages others to “learn as much as you can. It doesn’t matter if you’re stage 0 or stage IV – learn as much as you can about your disease. That way you can be a very active member in your care.” As no two people are alike, no two metastatic breast cancer experiences are either.

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**Helga**, living with metastatic breast cancer

## **April: a new mother coping with a metastatic breast cancer diagnosis**

Similar to Helga, April learned that her breast cancer had recurred and spread to her bones during a five-year checkup. She was only 36, and the diagnosis blindsided her. Like many others, she didn’t know that her breast cancer could recur as metastatic disease in other places in her body, especially at such a young age. “My immediate thought was: I have bone cancer now?” she says.



In the five years between diagnoses, April had what she refers to as “a little miracle” with the birth of her son, Colin. She had been told after her first breast cancer diagnosis that she would never have kids, despite all of her efforts to get pregnant in the years prior. “I wasn’t ready to not be a mom, and as luck would have it, as soon as I finished chemo, I was pregnant three months later.”

April had to learn how to be a parent while managing her disease. Her son is now 7 years old – and given her advocacy work, treatments and full-time job, “spare time” is not in April’s vocabulary. She says she is dedicated to making sure her son has all that he deserves, even though the only life he knows is with his mom living with metastatic disease.

I’ve always gone into it with the idea that my son is still entitled to his childhood, and he’s still entitled to a mother who gives him everything that she possibly can. So I really try to not let [cancer] impact his life, even though he’s having to deal with it just as much as I am.

#### **April, living with metastatic breast cancer**

While she’s committed to making time for activities like riding bikes and visiting Walt Disney World with her son, she’s also committed to others within the breast cancer community. She attends conferences and she spent fourteen months as the editor-in-chief of *The Underbelly*, an online magazine for breast cancer patients that focuses on building a breast cancer community spanning all disease stages and delivering information through an authentic voice.

April encourages others living with the disease to become their own advocate, to find their voice and to speak up. “Don’t be afraid to say what you need. Don’t be afraid to say what you’re feeling. There are going to be days where you’re going to feel awful, or you’re going to be moody or you’re cranky or you’re angry.”

Breast cancer has often been referred to as a “disease of aging,” typically associated with older women. For nearly 20 years, the majority of scientific research into metastatic breast cancer has studied postmenopausal women typically older than 50 years old.

What’s more, younger people often experience unique medical, social and psychological challenges, such as making the difficult decision to retire young and learning how to talk to young children about the disease.

# Hear more from Helga, April and others on how they are living with metastatic breast cancer

Every person is different, and every experience with metastatic breast cancer is distinct. Hear from Helga, April and other young women about the realities of being diagnosed with this disease.

## Additional Resources:

- For more information on the stages of breast cancer, visit [www.advancedbreastcancercommunity.org](http://www.advancedbreastcancercommunity.org).
- For more information on how to make your dialogue count when talking to your doctor or loved ones about metastatic breast cancer, visit [www.makeyourdialoguecount.com](http://www.makeyourdialoguecount.com).

## References:

- Breast Cancer Research Foundation. Breast Cancer in the Elderly: How BCRF Researchers are Treating this Growing Patient Population. Available at: <https://www.bcrf.org/blog/breast-cancer-elderly-how-bcrf-researchers-are...> Accessed August 2, 2018.
- Mariotto, Angela B., et al. "Estimation of the Number of Women Living with Metastatic Breast Cancer in the United States." *Cancer Epidemiology and Prevention Biomarkers* 26.6 (2017): 809-815

There is a need for #metastaticBC research and resources, especially for young women living w/ MBC. Hear more: [bit.ly/2CY12b9](http://bit.ly/2CY12b9)

## Rethinking who metastatic breast cancer affects

Metastatic breast cancer isn't always recognized as a disease that can affect anyone. But in the US alone, nearly 1 in 7 women living with the disease is under 50. It's important to understand the unique challenges these patients face as they deal with a terminal illness during what is arguably one of the busiest times of their lives.

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