

8 Common Myths About Metastatic Breast Cancer

There's no cure, but you can take steps to live longer and better.

By Barbara Brody Sep 11, 2018



If you don't already know somebody with breast cancer, you probably will. About 1 in 8 women will be diagnosed in their lifetime, according to the [Centers for Disease Control and Prevention](#), a fact that might not surprise you thanks to the massive pink-themed awareness campaigns that have been going strong since the '80s. But what sometimes gets lost in the push for early detection and fundraising is that the prognosis is not equally rosy for all patients.



About 1 in 8 women will be diagnosed with breast cancer in their lifetime.

While the five-year survival rate for someone with early stage (stage 0 or 1) breast cancer is nearly 100%, it's only 22% for women with metastatic (stage 4) breast cancer, according to data from the National Cancer Institute.

Here's what else is often misunderstood about this type of diagnosis.

1. Treatment may be grueling, but then you'll be fine.

By definition, metastatic breast cancer (MBC) is not curable. If you have stage 4 breast cancer it means that it's spread far beyond the breast and nearby tissue; it's likely infiltrated the brain, bones, liver, or lungs.

"There's a misconception that breast cancer always gets cured," says Josh Newby, community project coordinator at the Lester and Sue Smith Breast Center at Baylor College of Medicine. "It's a terminal disease, though people aren't always comfortable acknowledging that," adds Newby, who is also the founder and executive director of Theresa's Research Foundation, an organization dedicated to funding research for metastatic breast cancer.

2. Your days are numbered.

While it's true that metastatic breast cancer will eventually be fatal, most patients who find out they have it end up living with the disease for years. The average life expectancy is about three to five years from the time of diagnosis, says Newby. But, as research is advancing, so are the odds: "We're seeing some patients live five, 10, 15 years," he says.

3. There are no good treatment options for metastatic patients.

"We try to encourage women to think of it as a chronic disease," says Paula Klein, MD, associate professor of hematology and oncology at Mount Sinai in New York.



As with any chronic condition, you should expect to be getting some type of treatment for the rest of your life. How harsh that treatment is varies widely: If the cancer has receptors for estrogen or progesterone (ER/PR positive), then at first you might only need endocrine therapy (oral medication). "Women in this subset might not need chemotherapy right away, so their quality of life can be very good," says Dr. Klein, who serves on the executive committee of the New York Metropolitan Breast Cancer Group.

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4. Joining a clinical trial is too risky.

Patients are often hesitant to participate in research, but it's a good way to access a new therapy — which could help more than what's currently on the market. "If there's a clinical trial that's appropriate for a specific patient, that's always our first recommendation," says Dr. Klein. "There's no way to see anything brand new in breast cancer without joining a clinical trial."

In case you were wondering, there's no chance of being given a placebo if you have stage 4 cancer. If you're in a drug trial and you don't end up in the experimental medication group, then you'll be offered whatever the standard treatment is.

5. You did something wrong to let it get this far.

While screening mammograms often detect breast cancer early, they're not foolproof. What's more, what starts out as early stage cancer doesn't always stay that way, says Dr. Klein. That's true even if someone initially makes it beyond the five-year survival mark: "It's nice to celebrate at five years, but 50% of women [with early stage cancer] who are ER or PR positive will have a recurrence after five years," she says.

There's nothing you can do to prevent metastases.

It's also worth noting that while healthy lifestyle habits may help keep you healthy, there are few guarantees when it comes to cancer. "Some patients think it's their fault — 'I



shouldn't have had that extra cookie or glass of wine' — but you can't prevent metastases," says Newby.

6. Your doctor always knows best.

While it's generally wise to trust medical professionals — especially over Dr. Google — the stakes here are too high not to get a second opinion, says Newby. "People are so afraid to offend their oncologist, but this is your life. Even if the second expert says the same thing, that's helpful because it can be reassuring."

While you're at it, seek out an expert who specializes in metastatic cancer. Although all oncologists can treat advanced disease, those who focus on it generally have more in-depth knowledge and resources, adds Newby.

7. All metastatic patients look sick.

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Some do, but others might appear to be thriving. That often surprises well-meaning loved ones, who might question whether you're really as sick as your diagnosis implies.

"Metastatic breast cancer patients on endocrine therapy or even on gentle chemotherapy can look as good as their family and friends," says Dr. Klein.

Women getting antibodies for HER2 metastatic cancer (targeted to treat a protein) also often look "healthy," despite having a very serious disease. "Oftentimes they look fine until the very end," says Dr. Klein.

8. You should steer clear of someone who's dying.

You hopefully know that breast cancer is not contagious, but some people become incredibly uncomfortable around those with a terminal illness, so they decide it's best to stay away. Although it's always a good idea to ask the patient whether she wants visitors



many people with metastatic cancer crave support and companionship — yet they fail to receive it.

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"When my mom was first diagnosed with early stage breast cancer, the amount of people at the door to help and support her was unreal," says Newby. "When she was diagnosed with metastatic cancer, you couldn't get anyone to come around."

Newby acknowledges that supporting someone who's dying isn't always easy, but it's worth the effort.

Not sure what to say? When in doubt, just sit with them and wait for them to do the talking if they're in the mood. And don't ask the patient to tell you if they need anything: "Bring them food, gift cards, or offer transportation to treatment — just do it," he advises.

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