What You Need to Know About Breast Cancer Recurrence

As Told By

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NATIONAL
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A NOTE FROM THE EDITOR

NBCF recently conducted a survey of breast cancer survivors and found that the #1 topic of interest for these women is risk of recurrence.

We understand that most people who want to know more about this topic are breast cancer survivors who ultimately want to know their odds of facing cancer again.

There is great medical content online about recurrence, but we wanted to get a fresh, candid perspective from someone who sees women dealing with breast cancer every day and has also experienced it firsthand.

To create this eBook, we are delighted to have collaborated with Lillie Shockney, former Director of the Johns Hopkins Breast Center.

The topics addressed here can be heavy. They reflect frequently asked questions about breast cancer recurrence and are answered in a conversational yet informational tone to give the effect as if you were talking to Lillie herself.

We hope this information is helpful, comforting, and most of all, empowering.

Note: All information shared in this eBook reflects Lillie Shockney's personal and professional experience. If you have concerns or want to learn more about something addressed in this eBook, consult with your healthcare team.

ABOUT LILLIE

"There's power in information. Information helps people be able to decipher: How much should I worry? Everybody kind of worries the same amount, which is at the max, when the majority don't have to."

– Lillie Shockney

Lillie was the Director of the Johns Hopkins Breast Center from 1997 until she retired in 2018. A two-time breast cancer survivor, Lillie has worked tirelessly to improve the care of breast cancer patients around the world. She is a registered nurse, and was named Johnson & Johnson's "Amazing Nurse of the Year". She has worked at Johns Hopkins since 1983, and is also certified as an oncology nurse navigator. In 2011, Lillie accepted the inaugural role as Director of the Johns Hopkins Cancer Survivorship Programs for the Kimmel Cancer Center at Johns Hopkins. She is a Professor of Surgery and Oncology in the Johns Hopkins University School of Medicine, and was appointed to a distinguished service physician chair as well. Lillie is a published author and nationally recognized public speaker on the subject of breast cancer. She has written 15 books and more than 250 articles on this subject. (1)

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What is Recurrence?

To understand recurrence, we must first define it.

Recurrence: Cancer that has recurred, usually after a period of time during which the cancer could not be detected. The cancer may be in the same place as the original tumor or in another place in the body.

Recurrence can be divided into two categories:

LOCAL RECURRENCE

Local recurrence happens when breast cancer is found in the remaining breast tissue, commonly reappearing at or near the original area of the breast where it was before.

If the patient had a lumpectomy, she has a lot of breast tissue left. If she had a mastectomy, she still has about 2% of breast tissue left. It's impossible to remove every single breast cell.

From a mortality perspective, the patient's mortality is still equal to what it was before the local recurrence in the breast tissue.

DISTANT RECURRENCE

Distant recurrence is metastatic disease. The cancer has shown up in another organ site, most commonly bone, lung, liver, or brain.

Distant recurrence is more worrisome to women than local recurrence. However, having a local recurrence does not increase the risk of a distant recurrence happening.

It's often a myth that women think, "Well, if the cancer comes back here in a residual breast cell, that means it's already gone someplace else." In reality, that's not what this means at all.

The risks of distant recurrence happening are dependent on a few things:

- The stage of the breast cancer
- The size of the invasive tumor
- The number of lymph nodes that contain the cancer
- The patient's prognostic factors, most specifically estrogen (ER), progesterone (PR), HER-2, and grade of the cells

> "Some patients say they were told they were cured. We should never use the word 'cured'. We should be saying, 'We believe you are cancer-free' instead of 'You are cured.' We believe you are cancer-free, just like I believe I am cancer-free 26 years out."
>
> *– Lillie Shockney*

Follow-Up Care

Follow-up care is incredibly important, especially when it comes to minimizing the risk of recurrence and arming yourself with knowledge to combat the fear of recurrence.

For early stage breast cancer (Stages 0, 1, and early Stage 2), the patient is usually only followed by surgical oncology and medical oncology for one to two years.

If the patient is on hormonal therapy, however, she may be followed by medical oncology specialists for five to ten years, based on the length of time she is to be taking this medication. She would be seen usually by a nurse practitioner alternating with the medical oncologist every six months. These are typically short visits – about 20 minutes. They are just to make sure the patient is taking her hormonal therapy and addressing any side effects from the medicine. Otherwise, she is back in the arms of her primary care physician.

Gone are the days of oncologists being able to say to a patient, "You and I are going to have a long-term relationship. You and I are going to see each other for the rest of our lives."

REMEMBER: Patients thinking they have the best oncologist in the world is great, but the primary care physician is just as important.

Ideally the patient would never disengage with her primary care physician. It really is best to have a shared care model with the primary care physician still involved with the patient's care while she's getting her breast cancer treatment.

> "They've got to work as a team. The primary care physician and the oncologist…they've got to be a team with this."
>
> *– Lillie Shockney*

If the patient has a patient navigator, some topics to address together include:

- Overview of what to expect with each phase of treatment
- How decisions about treatments will be made
- How to participate in decisions about care
- Understanding stage and prognostic factors
- Identifying barriers to care and providing solutions to those barriers, such as financial support or transportation needs during treatment
- Timeline of transitioning from oncologist to primary care physician

If the patient does not have a patient navigator, these are great topics to discuss with her oncologist or nurse practitioner.

REMEMBER: It's important not to be afraid to ask clarifying questions about what's to come along the journey. It is crucial the patient understands and is on board at every step.

Side Effects vs. Symptoms

Once treatments (surgery, chemotherapy, and/or radiation) are completed, it is essential to educate patients about how to distinguish between a side effect from treatment or a late effect from treatment, and a symptom of metastatic disease.

> "Unfortunately, the patient commonly thinks any ache or pain she has is associated with her breast cancer, which is not usually true. Everybody looks at the exception and considers it the rule."
>
> *– Lillie Shockney*

Example:

A patient goes to the doctor and says, "I have severe lower back pain that's radiating down my right leg. It started three days ago. It's very intense. I must have breast cancer now in my spine."

The first question a doctor may ask is: "Have you done anything in the last 10 days that is different than what you normally would be doing?" Or: "Have you picked up heavy furniture? Have you been laying new carpet? Have you been moving your daughter into her new dormitory at college, possibly carrying books up steps?"

Any of those things may trigger sciatica, which is what the patient is describing. These are classic symptoms of sciatica that are not caused by breast cancer.

However, she may say: "No, nothing at all has happened, and this has been coming on gradually for about two months. Now it's really intense." Now it sounds like a symptom of metastatic disease and doctors may need to take an x-ray to see if there is evidence of a metastatic lesion in the spine.

Staying in close contact with the team of doctors is important so they can help the patient understand the difference between side effects of treatments, symptoms of metastatic disease, and entirely separate issues.

There are some late effects of treatment that doctors don't even know about yet, which is problematic. It is important for doctors to remember: When did the patient have these treatments? What might be problematic for her?

It's also beneficial for the patient to keep a journal of how she is feeling. This can be used to see if there was a correlation between the symptom and any activity experienced recently. Sometimes a patient can just forget about her activity. After facing cancer it's easy to panic and think symptoms must be something horrific.

REMEMBER: While symptoms may not end up being breast cancer, they may be another illness or disorder, so it's always good to get checked out.

Example:

A patient starts developing numbness and tingling in her feet and hands. She might assume, "I've got lesions in my spine." However, she might be developing diabetes and experiencing neuropathy.

Hormonal Therapy

Hormonal therapy may be the most important treatment patients have. It can reduce a patient's risk of recurrence **by as much as 50%.**

> "Hormonal therapy is worth the headache.
> I did it. I put in my five-year tour of duty.
> I hated it, but I focused on its purpose."
>
> – *Lillie Shockney*

Hormonal therapy carries side effects that are very unpleasant. It can be difficult to get a patient to want to adhere to taking that pill every day. Yet, this is currently the only real way, other than chemotherapy, we know to reduce risk effectively.

We know from research, unfortunately, that between 40% and 60% of breast cancer survivors do not take their hormonal therapy as prescribed. Oftentimes, the reason they aren't taking it is because of the side effects.

Patients need to speak up and tell their doctors, "These are the side effects that are driving me crazy and causing me to not want to take this medicine." There are solutions to some of these side effects, but the doctors aren't going to know to offer solutions if they don't know what the patient is experiencing.

REMEMBER: It is crucial to take the hormonal therapy medicine *as prescribed.*

Example:

If the doctor asks, "Are you taking your medicine?" the patient will say, "Yes". He doesn't necessarily ask, "... as prescribed?"

She may be taking it every other day so now she has half of the hot flashes and the night sweats. But we've never done any research to know if the medicine does anything for patients if they're taking it every other day. We only know that it helps taking it **every day**.

Another problem is that doctors see their patients regularly during surgery, chemotherapy, and radiation. Now the patient goes back to the medical oncologist, who may even say, "Congratulations. Your treatment is done." Well, it's not done yet. She is going to be handed a prescription for hormonal therapy.

If the doctors say, "Now it's done," that sends the wrong message.

Then they say, "I want you to get this prescription filled. You're going to take it every day. You're going to be on it for 5-10 years. I'll see you back here in six months."

How important is this pill? The oncologist isn't seeing her again for six months, the conversation took 15 minutes, and she goes home, starts taking this pill, and begins feeling terrible.

Her spouse or partner may ask, "What's wrong with you?"

She says, "Well, it's because I'm taking this pill now."

Her spouse or partner asks, "How long do you have to take that pill?"

"Well, a long time."

"Why?"

"I think it's so that the cancer won't come back, but *I'm not exactly sure.*"

The importance of hormonal therapy cannot be understated. If the patient is unclear about why it's needed or what it will do, she should talk to her oncologist.

> "While on my hormonal therapy, I kept reminding myself, 'I don't want to revisit this again. I want to be here for my little girl. Whatever I've got to do, I'm going to do.'"
>
> *– Lillie Shockney*

Hormonal therapy also carries side effects that may affect intimacy.

Patients need to speak up and not be shy about discussing intimacy with their doctor. If the patient is looking at her doctor and thinking, "I really cannot discuss my sex life with a male doctor" then she needs to say, "Can I talk to a female doctor or nurse practitioner? There's something confidential I'd like to discuss that I'm just not comfortable discussing with a male."

The patient's partner needs to understand these things, too. He/She may consider their partner to be done, expecting her to be back at work and resuming all other activities, with everything back to normal. But partners need to understand that hormonal therapy is not going to make their loved one feel normal.

Patients need to feel empowered to bring their partner with them to their appointments so they can hear from the doctor the real truth and importance of hormonal therapy.

REMEMBER: 70% of patients are going to be on hormonal therapy. Today, many of them are going to be on it for 10 years. Patients should find others who are going through the same thing and rely on them for support. (2)

Coping with the Fear of Recurrence

After a patient has completed her acute treatment (surgery, chemo, radiation) she may feel like she has fallen off a cliff and say, **"This is a life-altering experience."** This feeling takes over rather than feeling like she wants to celebrate, which she thought she would want to do. Many patients don't want to celebrate – they think they're going to jinx themselves.

To cope with this fear of recurrence, it's important for the patient to know the things she has control over in helping to reduce the risk of recurrence:

- **Diet:** Maintain a low-fat diet, with 30 grams of fat or less per day.
- **Exercise:** Exercise for 30 minutes every day, at least five days a week. Power walking is a good place to start.
- **Tobacco:** No smoking or tobacco use.
- **Alcohol:** No alcohol. It used to be recommended to limit alcohol, but recent research now says no alcohol. It also doesn't matter what kind of alcohol.
- **Hormonal Therapy:** The patient must take her hormonal therapy prescription as prescribed. This can reduce her risk of recurrence by 50%. If the patient experiences unpleasant side effects, she should talk to her doctor or nurse practitioner.

- **Research:** Stay in touch with the latest research results from evidence-based research.

  The Johns Hopkins Breast Center has a website, Artemis, with a free subscription to monthly abstracts that show the latest, cutting-edge research that has been published about breast cancer. It's another way to keep patients and survivors empowered so they know the facts, and can start undoing the myths. (3)

- **Attitude:** If the patient is waiting for the cancer to raise its ugly head again, she is allowing the cancer to control her. Patients should surround themselves with positivity and live each day to the fullest.

> "I'm a believer in staying away from people who are Eeyores, and only hanging out with Tiggers."
>
> *– Lillie Shockney*

- **Limiting Stress:** Chronic stress taxes our immune system. When our immune system isn't working properly, cancer cells are allowed to grow.

  Our body produces cancer cells every day, and we have T-cells that go in and kill them. When we're under a lot of stress, that affects our T-cell production.

  It's also important to note the difference between acute stress and chronic stress.

Example:

Acute stress is the time during the holiday season where life can get wild. That's just stress, but it's for a finite period of time. It was expected.

> Chronic stress would be if your mother has been diagnosed with Alzheimer’s and is now living with you. You’re still trying to work full time and take care of her, and it stretches your budget as well because you may need to have a caregiver with her when you’re not there. You’re very upset that now she’s at the point where she doesn’t even know who you are. That’s chronic stress.

Chronic stress is what will affect a person's T-cell production. In general, it’s important to manage stress levels or implement methods to help reduce your stress.

- **Vitamin D3:** Low Vitamin D3 has become a new risk factor. Vitamin D3 levels needs to be 30 or above. The majority of women diagnosed with breast cancer are in the single digits.

  Primary care physicians rarely ever do a blood test for Vitamin D3. Now, we’re encouraging women to speak up and say, “I don’t think I’ve ever had my Vitamin D3 checked. Would you please check it?”

> “I didn’t have my Vitamin D3 tested until research was done on this. Mine was tested 15 years ago. It was 4.”
>
> *– Lillie Shockney*

  Low Vitamin D3 is an easy thing to solve. Sunshine is a great way to get it as long as the patient isn't being foolish with their exposure to the sun. The other way is to take Vitamin D3 as a supplement. Women who have a low level, particularly if it’s in the single digits, may receive a prescription from a doctor for a stronger dose.

The thing that needs to be understood by patients, though it can be scary, is that when doctors say, “Your cancer has recurred”, that implies it has suddenly started growing in the patient’s bones, liver, lungs, etc. as if it came to her from outside of your body, and now landed there. However, these cancer cells were in that organ all along – from the time of her diagnosis to now.

The adjuvant therapy the patient received didn’t kill those cancer cells. Even if she had numerous additional scans, doctors would not have seen those cells. It takes many, many cells to see a dot of a tumor growing somewhere in a patient’s body.

What has happened is these cancer cells were dormant and something woke them up. The medical community is now trying to figure out what can wake them up.

Risk of Metastatic Recurrence

The risk of metastatic recurrence happening is dependent on many factors. The patient's team of doctors can explain her risk based on stage, tumor size, number of lymph nodes that contain cancer, and prognostic factors.

Below are a few scenarios to better understand how recurrence risk changes based on different factors:

- **If someone has early stage breast cancer,** a small tumor (less than two centimeters) and no lymph nodes involved, that’s good news. Her risk of recurrence is going to be quite low, usually around 10% or less.
- **If someone has late stage inflammatory breast cancer**, that person unfortunately is going to carry about a 60% to 70% risk of the cancer showing up in one of her distant organs because it's such an aggressive and fast-growing form of breast cancer.

There’s a big difference between those two scenarios, a 10% and 70% chance of recurrence. Every scenario is different, which is why it’s important for the patient to understand her risk factors and stay educated.

Prognostic factors are characteristics of a patient that can be used to estimate the chance of the cancer recurring. Prognostic factors play an important role in treatment and also help determine risk factors.

- Being estrogen receptor positive (ER+) is good news. Being HER-2 negative is good news.
- The patients who have a higher risk have the opposite factors. It's estrogen receptor negative (ER-) **and** it's HER-2 positive.
- Triple negative patients (ER-, PR-, HER-2 negative) also have a higher risk. These patients aren't able to receive adjuvant hormonal therapy, which can help prevent distant recurrence from happening. They will however receive chemotherapy for prevention.
    - » Triple negative disease, if it were to return in the form of distant recurrence (metastatic disease), usually does so within two years of completion of the acute treatment (surgery, chemo, and radiation).
- Patients who are estrogen receptor positive (ER+) **and** HER-2 negative could see distant recurrence occur beyond five years, if it were to return. The larger the tumor and the number of lymph nodes that contained cancer are factors that influence how much risk there is.

There are women 10 years post-treatment, 15 years, even 20 years out of the blue, diagnosed with metastatic disease. It's heartbreaking and scares other survivors. Though unusual to see someone who is that far out from completion of treatment present with metastatic disease, it does happen.

Outcomes with Recurrence

Patients living in fear of recurrence and wanting to know odds is common. Does everybody who has Stage 4 breast cancer die? Well, they eventually do, but not necessarily right away. More and more women are living for years.

It's important to know that research isn't going to stop until there's true prevention of getting Stage 4 breast cancer because if breast cancer never left the breast, no one would ever die from it.

If distant recurrence occurs, the outcomes are different depending on type and prognostic factors.

Below are a few scenarios to better understand how outcomes can change based on different factors:

- **If patients are estrogen receptor positive (ER+)** and distant recurrence occurs, these women may go 20 years or more living in harmony with their disease.
- **Triple negative patients,** who only have chemotherapy as a treatment option, are the patients who are more likely to have a couple years if distant recurrence occurs. As painful as it is, it's important to be honest about it. Care providers need to work with patients regarding their future, and help them fulfill their life goals in other ways. (4) It's important to note that research is very promising with newer drugs being developed specifically for triple negative metastatic disease.

For patients who will see good longevity and can live in harmony with their cancer recurrence, they absolutely, positively must continue to be seen by their primary care physician.

> "It's a scary thing to think about developing distant recurrence and having metastatic disease, but we have more to offer today than we've ever been able to offer before."
>
> *– Lillie Shockney*

Appendix

(1) Learn more about Lillie Shockney's background

(2) Beyond The Shock: Beyond The Shock is an online community where patients, survivors, and loved ones can learn more about breast cancer and ask questions to those who've been in similar situations.

(3) Artemis: Free subscription to monthly abstracts about breast cancer from Johns Hopkins Breast Center

(4) Metastatic Retreats: NBCF, in partnership with Lillie Shockney & Johns Hopkins, hosts Metastatic Retreats across the country for Stage 4 breast cancer patients to work through their unique set of challenges and emotions, in hopes of leaving with a renewed sense of hope, increased knowledge, and the reminder that they are not alone.

Ask an Expert: Johns Hopkins Breast Cancer Center: Have a question for an expert at the Johns Hopkins Breast Center? Ask it in this forum and read other questions and answers.

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