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The Real Deal on Young Women and Breast Cancer

The advice just isn't the same when you're under 40. Let doctors, advocates, and some very brave survivors enlighten you. *By Rebecca Webber*

When I was 34 I found a lump in my breast, and all I heard was a chorus of “Don’t worry!” First from myself: As a health reporter who had covered the topic of breast cancer for this very magazine, I knew that the majority of lumps in women my age were benign. Next from the nurse at my gynecologist’s office: “I’m sure it’s not cancerous.” Then from my boyfriend: “You don’t have a family history!” My friends: “It’s probably nothing!” And even from a top-notch breast surgeon: “This doesn’t feel like cancer to me.”

But it was.

And in part because of all that back patting and wait-and-seeing, it took a full 15 months for my lump to be diagnosed, by which time it was Stage 2B, having commandeered a lymph node in my armpit (my ticket for eight rounds of chemother-

apy). I now have a nearly 20 percent chance of dying from the disease in the next 10 years—becoming one of the 2,300-plus U.S. women under 45 whose lives are cut short by breast cancer annually. Even three years later, thinking about those 15 months when I now know that cancer was inside me—growing...*spreading?*—still makes me hyperventilate.

Some experts might say that waiting is prudent, that in general we tend to over-, not underscreen, women for cancer. But if you’re a young woman with a lump, you don’t care about statistics; you care about your health. After all, every year, for 11,000 American women under 40, that thing that’s “probably nothing” turns out to be something.

How can we move forward feeling empowered, not afraid? With facts. Here are eight of the most important ones that every young woman should know. *Continued on next page ▶*

1. Breast cancer isn't common in young women—but it's deadlier than you think.

The odds you'll get breast cancer by age 40: one in 173. This means you're more likely to receive the diagnosis than win the lottery, but less likely to get breast cancer than die in a motor vehicle accident. (The disease is more common in older women; the lifetime odds are one in eight.) Yet when young women *do* get cancer, they often get nasty cases. Five-year survival rates for women under 30 with cancer are about 82 percent, compared with 90 percent for those older than 40. Some reasons for the disparity: Young women's breast cancers tend to be the hereditary and/or more aggressive types.

2. It's also harder to spot cancer in young women's breasts.

"We don't have a good way to pick needles out of haystacks when it comes to younger women's breasts," says Ann Partridge, M.D., director of the Program for Young Women with Breast Cancer at the Dana-Farber Cancer Institute in Boston. For women 40 and over, the American Cancer Society recommends annual mammograms because breast cancer begins to be more common around that age and because X-rays can better reveal tumors in older women's breasts. But mammograms don't work as well for young women, who have denser breasts, says former breast surgeon Susan Love, M.D., author of *Dr. Susan Love's Breast Book*: "On a mammogram, dense breast tissue is white, and breast cancer is white. It's like looking for a polar bear in the snow."

In fact, "in women with the densest breasts, mammograms miss over 60 percent of cancers," adds Thomas Kolb, M.D., a diagnostic radiologist in New York City. But ultrasound scans, a.k.a. sonograms, *do* find the vast majority of those tumors, he says. What you can do: Pay attention to breast discharge, skin changes, or lumps that persist or grow. If your doctor is uncertain about a lump seen on a mammogram, demand an ultrasound or other diagnostic tests. And get clinical breast exams every one to three years before age 40, and every year after that.

3. Pregnancy can both raise and lower your risk.

You may have heard that having kids and breast-feeding lessens the risk of breast cancer. Actually, once you give birth to your first child, you have a slightly increased risk for developing breast cancer over the next five to 10 years. "One hypothesis is that the hormones that turn your breasts into milk factories may also stimulate dormant cancer cells to grow," explains Dr. Love.

After that 10-year window, though, the cancer-protective benefits of having had a baby can kick in. "Breast cells don't mature until you go through pregnancy and start breast-feeding," says Marc Hurlbert, Ph.D., executive director of the Avon Breast Cancer Crusade. Mature cells are better able to copy DNA accurately, so there's less chance for a cancer-causing mutation to occur. "Even when a woman is 90, if she never had children, her breast cells will still be immature, which makes them more susceptible to carcinogens," he says.

"What I Wish I'd Known About Breast Cancer"

These women have all reached the critical five-year survival mark—and they're sharing



"Don't blame yourself.

In my social circle, a lot of people talk about 'The Secret'—the idea that you create your own reality. Some even implied that I was the cause of my cancer! That blame-the-victim mentality is destructive."
—Mimi Ferraro, 37



"No one is invincible.

I was 21 and returning from studying abroad. I had so many plans for the future, none of which involved breast cancer. Everyone said being young kept me healthy, but it made me ignore the risks young women face."
—Liz Stower, 26



"Get your checkups.

My gynecologist found my lump at a regular exam. If I'd skipped the appointment, the cancer would have gone undiscovered for some time. Be proactive about your health: You could save your life."
—LaToya Davis Parker, 38



"Know your dad's history.

People are still misinformed about the fact that BRCA gene mutations can be passed down from the father's side. If I had known that, I might have gotten some kind of imaging much sooner."
—Sara Nevares, 36

(That's why breast cancer was once called the nuns' disease. Seriously.) What all this means is that if you're pregnant or nursing, you shouldn't write off a change in your breast as just a pregnancy thing—tell your doctor.

4. There is an Angelina Effect.

From the moment Ms. Jolie published an op-ed in *The New York Times* this spring on her preventive double mastectomy, doctors and genetic counselors have been inundated. "Our number of calls nearly doubled," says Jennifer Ivanovich, a genetic counselor at the Washington University School of Medicine in St. Louis. "Overall it's been positive. If it gets people to ask more questions about their family history, I'm in favor of that." Peter Beitsch, M.D., president of the American Society of Breast Surgeons, saw a similar spike but notes that fewer than four women in 1,000 have a cancer-related BRCA gene mutation like Jolie did. "For some women the risk is really high," he says, "but for many, my role is to alleviate their fears."

Just how high is *your* risk? Some familial factors: If you have at least two first-degree relatives (mother, daughter, or sister) who were diagnosed with breast cancer when at least one of them was 50 or younger, or if a male relative had it, or if you have multiple relatives with breast or ovarian cancer, your BRCA mutation odds are elevated, and you should ask your doctor whether you're a candidate for genetic counseling.

The good news: Testing is about to become more affordable. The Supreme Court ruled this summer that companies can't patent naturally occurring genes, so while one company

"If the only way to prevent testicular cancer was to cut off men's testicles, I don't think society would be as blasé about that as they seem to be about mastectomies."

—Jen Cowell, a survivor who was diagnosed at 30 and ultimately opted for a lumpectomy

previously charged about \$4,000 for an analysis of BRCA1 and BRCA2 genes, you can now get other tests for hundreds of dollars less that cover a wider array of cancer-linked genes, including CDH1, STK11, and PTEN.

That's welcome news to U.S. Representative Debbie Wasserman Schultz (D-Fla.), 47, a breast cancer survivor and advocate for better funding and treatment options for women. "When I found out I had the BRCA2 mutation, my first question was, Can I get a second opinion? And they said no: There's only one company that has a patent on this gene and the test for it," recalls Wasserman Schultz, who has been cancer-free for five years. "So I had to make the decision to have a double mastectomy, my ovaries removed, and a total of seven surgeries based on the results of one single test because some company decided it was OK to patent genes that are in every human body." The recent court ruling against gene patenting means, she says, that "other women won't have to make the decisions I did."

their hard-won wisdom with you.



"Demand the best care."

After I found a lump, it took months to get a doctor to refer me for a mammogram. I finally realized we were talking about my *life*. Never settle for medical treatment that is less than you deserve."

—Jen Cowell, 35

"It's OK to get angry."

It's also OK to find humor in the situation. In one early appointment, the doctors were feeling my breasts; I started laughing because all I could think was that I hadn't been this awkwardly groped since high school."

—Aimée Bariteau, 37

5. Young women are getting more mastectomies than they used to—even when they don't need them.

One thing doctors are clear on: Don't assume Angelina's personal decision is right for you. "We've seen a dramatic increase in women under 40 getting mastectomies," says Deborah Axelrod, M.D., director of clinical breast programs and services at the New York University School of Medicine. One study found 56 percent of young women diagnosed with early-stage cancer remove the cancerous breast (versus 38 percent for all women). While it's true certain cancers in young women are aggressive, experts believe some women may also be swayed by fear. "The initial inclination is often 'Oh my gosh! Take my breasts off, take them both off!'" says Dr. Beitsch. The facts: Your odds of surviving breast cancer are often as good whether you're treated with a mastectomy or a lumpectomy with radiation.

For women with BRCA mutations, a bilateral mastectomy might be the best choice. But, says Dr. Love, "It's awful that the best prevention we can offer high-risk women is cutting off normal body parts." Jen Cowell, 35, who opted for a lumpectomy after she was diagnosed five years *Continued on next page* ▶

ago, agrees: "If the only way to prevent testicular cancer was to cut off men's testicles, I don't think society would be as blasé about that as they seem to be about mastectomies." Talk with your doctor about the pros and cons of each procedure, and consider getting a second opinion before making your choice.

6. We need more research on younger women (and you can help).

Imagine this: You ask your doctor how treatment will affect your sex life (or memory), and she shrugs and answers, "There isn't any research on that." Ridiculous, right? Happens all the time. Shockingly, the impediment to that research sometimes comes from the breast cancer community, says Wasserman Schultz. When she introduced the EARLY Act, legislation to fund research and education for breast cancer in young women, "some breast cancer organizations opposed the bill because they said it's unnecessary to focus on young women's unique challenges," she says. "I was stunned." (The bill passed in 2010.)

Research is critical. Scientists have made significant progress in treating other cancers when they've been able to conduct large-scale clinical trials; mortality rates for childhood leukemia dropped measurably in the past 40 years due in part to such work. If you're a breast cancer survivor, you can help by volunteering for clinical trials at clinicaltrials.gov or breastcancertrials.org. Even 100 percent healthy women can aid research through the Dr. Susan Love Research Foundation's website healthofwomenstudy.org.

Funding scientific work is a powerful way to help combat breast cancer, but be wary: "Some organizations put a young woman front and center to say, 'Hey, donate,' while on the back end, they don't contribute to research that directly helps this group," Ivanovich says. Sites like charitynavigator.org can tell you how your dollars are being spent.

7. Babies aren't off the table.

Many patients assume their fertility will be shot after chemo. But "while studies may vary, it seems less than 10 percent of 25-year-old chemo patients experience ovarian failure," says Dr. Beitsch. "At 35, it's about 25 to 35 percent." After that, the pendulum swings: "About three out of four 45-year-olds who go through chemo are pushed into menopause," he says. Fortunately, science is increasingly making it possible for cancer survivors to conceive. If you're diagnosed and want kids someday, do what I did and see fertility specialists to discuss freezing eggs *before* starting chemo.

8. Your lifestyle matters. Really.

It's easy to feel terrified at the prospect of breast cancer, and there's no one thing you can do to eliminate your risk. But there are small steps you can take: Doctors suggest a varied diet that keeps your body at a healthy weight, since putting on pounds between age 18 and menopause could increase your breast cancer risk as you get older. "You may improve your cancer-prevention odds if you eat healthfully," says Rachel Beller, R.D., a spokesperson for the American Cancer Society. Her

Pushing for change
Rep. Wasserman Schultz, a survivor and advocate



"Some breast cancer organizations opposed the bill because they said it's unnecessary to focus on young women's unique challenges. I was stunned."

—Rep. Debbie Wasserman Schultz on the EARLY Act, which promotes breast cancer research for young women

advice: Cover half your plate with vegetables at lunch and dinner, and eat fish four times a week in place of meat; get 30 to 35 grams of fiber daily; and keep alcohol to one drink a day, max. Next, start moving: Women who exercise are up to 30 percent less likely than couch potatoes to develop the most common types of breast cancer, research shows. Aim for at least 150 minutes of moderate exercise a week, divvied up however you like.

As for me, along with gym time and taking it easy at happy hour, I keep pushing for answers. I am a proud participant in six clinical trials (three on my genes, others on my tumor, fertility after chemo, and my implants). After two and a half more years of tamoxifen treatments to try to prevent a recurrence, my fiancé and I will retrieve our children-to-be from frozen storage and move forward with our family plans.

Still, research breakthroughs can't come fast enough for me or my sister, who was diagnosed 18 months after I was. For her, for me—for all of us—we need answers now. ■

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WASSERMAN SCHULTZ: MARCUS MAM