

**Breast Cancer
inFocus:**
Breast Cancer
in Men



**LIVING BEYOND
BREAST CANCER™**

**Connecting you
to trusted breast cancer information
and a community of support**

“I didn’t know men could get breast cancer.”

If you haven’t heard it yet, you probably will. You may have said it yourself the first time you were told that you might have breast cancer. Maybe one of your doctors even said it to you.

Being a man diagnosed with what is usually considered a “woman’s disease” can be lonely and sometimes feel embarrassing.

While you can’t turn around most days without seeing a pink ribbon, or a charity walk or a magazine cover focused on women with breast cancer, information and support for men with breast cancer is much more difficult to find.

Yet while breast cancer is much less common in men than in women, there are still about 2,350 men who will be diagnosed with breast cancer in the United States each year. That’s about the same number of men who will play in the NFL this season.

That these numbers seem low may not make you feel better as a man diagnosed with breast cancer. But know that while you may not be part of a very large community, you are not alone in your journey. Your feelings and emotions as a man with breast cancer are shared by thousands of others.

At Living Beyond Breast Cancer, we recognize the unique issues faced by men diagnosed with breast cancer. This guide is meant to serve as a resource to help you cope with your diagnosis and to prepare you for the specific issues you may face in the coming months and years.

SECTION 1

Coping With the News: A Man With a ‘Woman’s Disease’

Dealing with any cancer diagnosis is difficult. You likely know people, both men and women, who have dealt with cancer over the years. Maybe it’s been a parent, spouse, partner or child who has needed your help and support. Most people are overwhelmed and amazed at how supportive their network of loved ones can be in times of need.

But as a man diagnosed with breast cancer, it may be trickier. Maybe you feel embarrassed or ashamed. Perhaps you feel overwhelmed and isolated.

Every man deals with the initial shock of learning that he has breast cancer in his own way. Not only is there the question of the right approach to treatment, but there is also the worry of, “How am I going to tell people?”

Telling Family, Friends and Colleagues

Ask any man who has been diagnosed with breast cancer about his initial reaction to

the news and he’ll almost always tell you the same thing — “shock.”

While it is possible that you may have known another man with breast cancer before, you likely never thought you would be one of them.

It may take time for you to come to grips with your diagnosis. You may not want to tell many people, or anyone at all, for a few days or weeks, and that’s OK. But once you get over the initial shock, it’s going to be important to build a support network to help you along the way. Your network may be a personal one comprised of friends and relatives, co-workers, or church or other community members, or it may be a professional one of doctors, social workers and therapists. It might be a combination of both.

Because there is so little public awareness of male breast cancer, you are probably going to be met with surprised looks by many of the people you tell. It may be a little bit uncomfortable speaking about things at first and explaining that “Yes, men can get breast cancer, too,” but it will get easier as time passes.

Think about what you want to tell certain people and how much you want to explain. You may want to share more details about your diagnosis and how you are feeling with people you are closer to. Or you may wish to keep much of the information private. While some people may not respond the way you expect, others may surprise you with their support and concern.

My Story

EDWARD, 62, was working full-time as an IT professional when he was diagnosed with stage I breast cancer in early 2012. Telling his family, and even some of his friends, was the easy part. Telling his work colleagues? Not so much.

“The initial reaction was that they were stupefied,” Edward says.

“They kept looking at me like I had said the wrong thing. Most of them had never heard of or met a man with breast cancer before,” says Edward. “I had to explain to them that ‘Yes, men can get breast cancer’ and ‘No, it’s not really all that different than women who get breast cancer.’”



Edward says he was fortunate that his employer was flexible with his work schedule. Because of his responsibilities, it would have been a burden if Edward took a long leave of absence. He worked with his colleagues to find a schedule that made sense.

“As I was going through chemotherapy, I utilized a combination of sick days, personal days and working at home to stay in the work loop. Some days I was so worn down and would need to leave early if I was feeling too tired. Once everyone understood that I wasn’t going to be back to full strength right away, they were pretty accommodating,” he says.



“[My co-workers] kept looking at me like I had said the wrong thing. Most of them had never heard of or met a man with breast cancer before.”

Male Breast Cancer by the Numbers

2,350

The approximate number of men in the United States newly diagnosed with breast cancer in 2014, according to the American Cancer Society.

92

The approximate percentage of breast cancers in men that are hormone receptor-positive, meaning they grow in the presence of estrogen, progesterone, or both. This helps explain why most men will be given hormonal therapies such as tamoxifen.

68

The approximate average age of men newly diagnosed with breast cancer. This is slightly older than the average age for women.

50

The odds that children of someone with a *BRCA1* or *BRCA2* gene mutation will have the mutation themselves, making genetic testing crucial for all men diagnosed with breast cancer who have children, especially daughters (see page 21).

33

The approximate percentage of breast cancer-related clinical trials that are open to men. While rules of some clinical trials prevent men from being able to participate, there are still many studies open to men with breast cancer.

10

The approximate percentage of men with breast cancer that has a genetic link, with *BRCA2* being the most common gene mutation.

3rd

The week of October that has been dedicated to male breast cancer awareness. Several states recognize this week, including Pennsylvania, Florida, New Jersey, Massachusetts and Michigan.



How Is Male Breast Cancer Different Than Female Breast Cancer?

1. **Men tend to develop breast cancer at an older age than women** — Men are newly diagnosed with breast cancer at an average age of 68 compared to 61 in women. This may be in part because men often delay reporting symptoms.
2. **Men are diagnosed at later stages of disease than women** — About half of all affected men are diagnosed with stage II, III or IV cancer. This again may be tied to delays in reporting symptoms and lack of screening.

SECTION 2

What You Need to Know Today

Many people learn about breast cancer from the news and events that are geared toward getting us closer to “the cure.” But in reality, researchers are looking for many different treatments and therapies, because breast cancer is not a single disease but rather a group of diseases.

Breast cancer occurs when normal breast cells grow and reproduce out of control, turning into cancerous, or **malignant**, cells. These malignant cells grow to fill the **ducts** (ductal cancer) or **lobules** (lobular cancer) of the breast. Ductal cancers tend to grow together in a mass, making them somewhat easier to find. Lobular cancers tend to grow in more than one area in the breast. Unlike women, men usually don’t have lobules in their breasts, so lobular cancer is very uncommon, accounting for about 1–2 percent of all cases of male breast cancer.

When cancer cells stay inside and fill the walls of the ducts, it is called **in situ** breast cancer or **ductal carcinoma in situ (DCIS)**. Approximately 5–11 percent of men diagnosed with

breast cancer will be diagnosed with DCIS. When cells escape through the walls of the ducts and lobules, it is called **invasive** or **infiltrating** cancer. This type of cancer is found in 85–95 percent of all men diagnosed with breast cancer.

At the time of diagnosis, you will likely have little information about the cancer, its behavior, and whether it has traveled beyond your breast. Additional tests may be needed over the next few weeks to learn more.

How You Will Learn More About the Type of Breast Cancer You Have

Before you and your doctor consider a treatment plan, more tests will need to be run. You may already know whether the cancer is noninvasive (DCIS) or invasive, based on your biopsy. Now you’ll need to learn about the cancer’s size and where it is located — whether it is only in the breast or in other parts of the body, too. The information these tests collect will be summarized for you in your **pathology report**.

One of the most common options to learn more involves a **sentinel lymph node biopsy**, surgery to check for cancer in several lymph nodes in your armpit. A blood test, chest x-ray,

3. **Men have a higher rate of hormone receptor-positive cancer than women** — More than 90 percent of all male breast cancers are HR-positive: either estrogen or progesterone receptor-positive, or both. This compares to about two-thirds of all female breast cancers. HR-positive disease responds well to hormonal therapy, and some men can avoid other types of treatment.

Note: Both men and women naturally make some estrogen and progesterone in their bodies. The natural estrogen found in a man is not unhealthy or unusual.



Questions You May Want to Ask Your Doctor at Diagnosis

- In general terms, how would you assess my condition?
- Are my test results unclear? Will I need to have anything retested?
- What are my treatment options? What are the pros and cons of each?
- How will you check for signs of cancer spread?
- What is your experience with male breast cancer? Have you treated male breast cancer before?

CAT scan, MRI, bone scan or PET scan may also be ordered. Taken together, the results of these tests create a profile of the cancer that may help determine next steps.

Learn more about these tests at LBBC.ORG.

Staging the Cancer

Breast cancer has five stages. In general, the higher the stage, the larger the amount of cancer in the body. Doctors use these stages as one piece of information to predict your chances of survival. It is important to remember that the statistics you'll hear and read about are **averages** for a large group of people. Don't be discouraged by these percentages — everyone is different, and what is average for the group may not reflect your experience.

Stage 0 breast cancer is noninvasive, or DCIS. It is confined to the ducts of the breast. Between 5–11 percent of men with breast cancer have stage 0 disease at diagnosis.

Stage I breast cancers are invasive cancers. They involve small tumors of 2 centimeters or less in your breast, with no cancer in the

lymph nodes. Approximately 35–40 percent of men with breast cancer have stage I disease at diagnosis.

Stage II breast cancers are invasive cancers. At this stage, the breast cancer is growing, but is still contained in the breast or has only traveled to the nearby lymph nodes. Approximately 40–45 percent of men with breast cancer have stage II disease at diagnosis.

Stage III breast cancers are invasive cancers. This stage includes large tumors or tumors with growth into nearby skin or muscle, and cancers that spread to more lymph nodes under the arm or in the chest wall. Approximately 10 percent of men with breast cancer have stage III disease at diagnosis.

Stage IV breast cancers, or **metastatic** cancers, are invasive cancers that have spread beyond the breast and nearby lymph nodes to other parts of the body. Breast cancer most commonly spreads to the bones, liver, lungs and brain, but it can affect any organ and tissue. Approximately 5 percent of men with breast cancer have stage IV disease at diagnosis.

- Do you know a local doctor with expertise in male breast cancer?
- How many male breasts have you operated on?
- Will you be doing the surgery or will someone else be assisting you?
- What are the differences between operating on a female breast compared to a male breast?
- Would you be willing to consult with a doctor who has treated male breast cancer in the past?



Breast cancer has five stages, ranging from stage 0 to stage IV. Doctors use these stages to describe the extent of cancer in your body. This helps with predicting long-term survival and deciding on best treatments.

SECTION 3

Treatment Basics

There are two parts to breast cancer treatment: local therapy and systemic therapy.

Local therapy is used to treat the disease in the breast and nearby lymph nodes.

Systemic therapy is used to attack cancer cells throughout the body that may have traveled outside the breast to other sites.

Options for local therapy include surgery (**mastectomy** or **lumpectomy**) and **radiation therapy**. These are sometimes offered together, although surgery alone is sometimes enough. Each case is unique, and your treatment plan will depend on your specific symptoms and your comfort with each option.

Systemic therapy includes **chemotherapy**, **hormonal therapy** and **targeted therapy**. Your systemic therapy options depend on the type of breast cancer you have and the likelihood it will come back, or **recur**, in the breast or somewhere else.





What Is Different About Treating Breast Cancer in Men?

Because men get breast cancer far less often than women, most of what we know about the treatment of this disease comes from clinical trials that involved mostly or only women. This is both good and bad — good because tens of thousands of people before you have taken part in studies, and bad because there are little data specific to men.

Should I Consider Reconstructive Surgery?

Some women choose breast reconstruction after a mastectomy. This is also an option for men.

If you are concerned about your appearance, talk to your doctor about it. After mastectomy or lumpectomy, you may be hesitant to remove your shirt at the beach or in the gym locker room, and you may consider reconstructive surgery. There are other options as well — some men get a simple tattoo of a nipple to make them feel less self-conscious.

A Word on Clinical Trials

Clinical trials are important for progress to be made in medicine, and they may be valuable for you. **Clinical trials** are studies that test how well new therapies, medicines or treatments work, and whether they are safe and effective. Some of these new options may be better than what is now available, or they may be equally effective with fewer side effects.

While only about one-third of all open clinical trials in breast cancer include men, this still leaves a large number of options for

you to consider. You can learn more about clinical trials by talking with your doctor, and visiting LBBC.ORG or ClinicalTrials.gov.

Male-only clinical trials in breast cancer continue to be rare, but researchers are taking steps to change that. One international group of experts is working on a 3-part study to better understand the disease and how it should be treated. The group's goal is to take what they learn in the first two parts of the study to design a clinical trial exclusively for, and about, men with breast cancer.

Should I Get a Second Opinion?

Getting a second opinion on your diagnosis and treatment options may give you peace of mind that you are making the right decisions. You may find that one doctor has a very different opinion than the other, and you may have to make the final decision about which treatment course to pursue. It is helpful to think about your medical and emotional needs when making any decision.

You may want to bring someone with you to your appointments to get a second perspective. That person may hear or interpret something differently than you do.

Some experts feel the lack of data specific to men is not important because male breast cancer seems well managed by the therapies used for female breast cancer.

Still, there are some differences in how men with breast cancer are treated:

1. Because men typically have less breast tissue than women, mastectomies are more common — Most men diagnosed with breast cancer will have a mastectomy, surgery to remove the whole breast. Experts believe that less than 14 percent of men have lumpectomy, surgery to remove only the tumor and a small amount of tissue around it.

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2. Men are more likely to receive hormonal therapy — This is tied to the higher rate of hormone receptor-positive breast cancer in men. Between 75–95 percent of men will receive either tamoxifen or an aromatase inhibitor as part of treatment.

It is important that you don't feel "stuck" with your doctor. Not many doctors have seen or treated more than a handful of men with breast cancer, so they may not be able to answer all your questions. It is important to find a doctor you feel comfortable with for the long-term.

SCOTT is the son of a surgeon. Still, when he was told by his doctors at age 44 that he had breast cancer, he was at a loss for words.

"I was by myself with an internist, and he had a very concerned look on his face when he came into the room with the results of my biopsy," Scott says. "That's when the freaking out time started. The only question I could come up with was about the treatment for breast cancer. I wasn't in a position to ask any good questions, especially since I was all alone. It wasn't until I was able to sit down with an oncologist that I was able to ask better questions."

My Story



During his initial treatment, which included a mastectomy and chemotherapy, Scott didn't do much independent research about the chances of a recurrence. He relied instead on the advice and guidance of his oncologist. When he learned about 5 years later that his cancer had spread to his lungs, that all changed.

"That's when I became compulsive about learning everything that I could to increase my longevity and quality of life," Scott says.

"Initially, I was just trying to get my life back to normal as quickly as I could. But once I was diagnosed with metastatic disease, I knew I needed to take things a lot more seriously."

So what would Scott have done differently?

"I definitely would have gotten a second opinion to either confirm the first one or even to give me another set of options," Scott says. "I would also have gotten a second opinion during the follow-up care after my mastectomy and chemotherapy."



"I wasn't in a position to ask any good questions, especially since I was all alone. It wasn't until I was able to sit down with an oncologist that I was able to ask better questions."



Questions You May Want to Ask Your Doctor Before Surgery

- Should I stop any other medicines I take before surgery? Are there risks if I choose not to?
- Is a lumpectomy an option for me?
- What are the risks and possible complications of surgery?
- Is there anything I need to do to prepare for surgery?
- How long is the operation likely to take?
- How will you manage any pain I have after surgery?

“I would have enlisted the help of an excellent internist at the very beginning of my treatment. I discovered that chemotherapy can cause side effects that are best diagnosed and treated by an internist, including, in my case, hypertension and hypothyroidism.

“It can be a lot of work to remain positive as you are going through treatment, especially when you have metastatic disease, so it’s important to try not to isolate yourself. I was told by one woman I met who ran a breast cancer support group that they weren’t interested in having men, which unfortunately happens, but there are people and channels that will welcome you.”

Some Specifics About Surgery

Most men with breast cancer have surgery of some type. In a **modified radical mastectomy**, which is the most common breast cancer surgery for men, all your breast tissue and most lymph nodes under your arm will be removed. About 70 percent of all men with breast cancer have this kind of surgery.

Since the male breast is generally smaller than the female breast and has less tissue

below the nipple, cancer often spreads more easily to the nipple or skin. This requires a greater amount of surgery.

Still, some men will only need a **simple mastectomy**, which does not remove underarm lymph nodes or muscle tissue from beneath the breast, or a **lumpectomy**, where only part of the breast is removed. Others may need a **radical mastectomy**, a more extensive operation that removes the entire breast, underarm lymph nodes, and the chest wall muscles under the breast.

In addition to post-surgical pain and temporary swelling, the most common side effects of surgery include bleeding and infection at the site of the surgery, a buildup of blood in the wound, called a **hematoma**, or a buildup of clear fluid in the wound, called a **seroma**.

You should discuss your options with your doctors to decide which surgery will be best for you, as well as whether you need radiation therapy afterward.

- What will my recovery period be like?
- Am I going to need physical therapy after my surgery?
- What are some common post-surgical side effects I might have? Which are short-term and which may be longer term?
- When will I know the results of my surgery?
- What will my scar look like? Am I at risk of developing lymphedema?

SECTION 4

Sexuality and Fertility Issues

A diagnosis of breast cancer doesn't mean the end of a healthy sex life. But you may experience side effects from hormonal therapy that impact your sexual performance. Many men being treated for breast cancer report difficulty maintaining an erection or reaching orgasm, or simply reduced overall sexual desire.

Medicines for erectile dysfunction such as sildenafil citrate (Viagra) or tadalafil (Cialis) may help and are often prescribed for men with breast cancer.

If you are interested in having future children, you may want to consider sperm banking before starting chemotherapy. Sperm samples can be frozen and stored for years after collection. You can look online to find a sperm bank near you.

A talk therapist, especially one who specializes in couples' issues, may be helpful if you or your partner has specific issues or concerns.

SECTION 5

Genetics and Family Risk

About 10 percent of men diagnosed with breast cancer have a breast cancer-related genetic mutation, most commonly in the *BRCA1* or *BRCA2* gene. Though everyone has the *BRCA1* and *BRCA2* genes, errors in the genes, called **mutations**, are linked to hereditary breast cancer. In all people, only a small percentage of diagnosed breast cancers are related to gene mutations.

About 5–10 percent of all men with the *BRCA2* mutation and up to 5 percent with the *BRCA1* mutation will be diagnosed with breast cancer. Rates of risk are significantly higher among women with these mutations.

Genetic counseling is recommended for all men with breast cancer, and is vital for those with children, especially daughters. If you test positive for a *BRCA1* or *BRCA2* mutation, you should encourage your adult children and siblings to consider genetic counseling and testing.

There are important factors that need to be weighed if you or any of your children test positive for *BRCA1*, *BRCA2* or another gene



mutation that has been linked to breast or ovarian cancer. For more information, read our *Guide to Understanding Genetics and Family Risk* at LBBC.ORG.



age 70. The risk of developing ovarian cancer is also greater among women with one or both of these mutations.

“That was actually my biggest source of anxiety,” Bob says. “As difficult as it was being diagnosed with breast cancer myself, I was even more concerned that I might have a mutation that I passed on to my daughters.”

Bob said that there was no decision to be made about getting a genetic test, even if insurance decided not to cover it (it did). He simply had to know. He tested negative for each BRCA mutation and could reassure his daughters that they could breathe easier.

My Story

*As an Ashkenazi Jew with two adult daughters, one of the most significant concerns for **BOB**, 70, after he was diagnosed with breast cancer was whether he would test positive for a BRCA1 or BRCA2 gene mutation.*

Ashkenazi Jews trace their ancestral roots to Central or Eastern Europe. They have been shown in studies to have a higher prevalence of BRCA mutations than the average population (the same holds true for people of Icelandic, Norwegian and Dutch descent).

Children of people with a BRCA1 or BRCA2 mutation have a 50 percent chance of inheriting the mutation themselves. Having this information is very important for women whose fathers have a mutation, as 55–65 percent of women who inherit a BRCA1 mutation and 45 percent of women who inherit a BRCA2 mutation develop breast cancer by



“As difficult as it was being diagnosed with breast cancer myself, I was even more concerned that I might have a mutation that I passed on to my daughters.”

SECTION 6

Feeling Blue in a World of Pink

The emotional and psychological toll of being a man diagnosed with breast cancer may be the most difficult hurdle to overcome. Women with breast cancer are highly visible and the spotlight is always going to be mostly focused on them.

Still, there are growing efforts to make the public aware that men can also get breast cancer. Online and in-person support communities are much more visible than they were even 5 years ago. So although you may come across breast cancer groups that aren't interested in having men join their "circle of sisters," there are options if you'd like to talk to other men with breast cancer or cancer in general. Your doctor or a social worker at your treatment center may be able to connect you with someone to speak to. There are also support communities attached to many of the websites focused on male breast cancer included in the Resources insert of this guide.

Becoming a Public Advocate

Many media outlets have written or filmed recent human interest stories focusing on men. There are several documentaries being filmed that trace the lives of men with breast cancer. If you are interested in spreading the word about male breast cancer, get in touch with your local media outlets. It can be beneficial to share your story and feel like you are helping others.

My Story

*From the outside, **GERRY**, 68, doesn't stand out when he's sitting in a restaurant booth with six other men during their semi-regular meetings of the Man-to-Man breast cancer support group outside San Francisco. His specific issues, though, are quite unique.*



While the others share stories of providing support to their spouses undergoing treatment for breast cancer, Gerry is the one talking about his journey as a person with breast cancer.



“Everyone needs someone to support them, whether that’s a family member or someone else. Otherwise, it’s very easy to let everything get you down, which simply isn’t healthy.”

“I initially tried to contact several other men who had been diagnosed with breast cancer, but they all wanted to be left alone,” Gerry says. “Maybe it was because they were ashamed to have a ‘woman’s disease’ — I don’t really know.”

“But after I couldn’t find a local support group of male breast cancer patients, this group popped up. I contacted the guy in charge and he told me that I was welcome to stop by. It’s just been a nice way to talk about it to other people.”

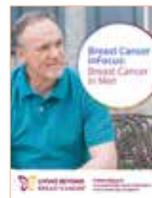
Since then, Gerry has served as a resource for a handful of other men in his area who have been newly diagnosed with breast cancer.

“You can’t hide from it and pretend that this isn’t happening,” says Gerry. “Everyone needs someone to support them, whether that’s a family member or someone else. Otherwise, it’s very easy to let everything get you down, which simply isn’t healthy.”

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Thank you

for helping Living Beyond Breast Cancer improve our programs and services.

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We dedicate this guide to the memory of Scott Cotlar, who died in November 2015 after living 7 years with metastatic breast cancer. LBBC is proud to honor Scott's dedication to helping others through his contributions to this brochure. Read more about Scott on page 16.

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This brochure is designed for educational and informational purposes only, as a resource to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

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- Managing Stress and Anxiety
- Treatment Options for Today and Tomorrow
- Understanding Palliative Care
- Understanding Symptoms and Treatment Side Effects

Information is current as of February 2016 but may change.

General Resources About Breast Cancer

- American Cancer Society — acs.org
- Susan G. Komen — komen.org

Sites Specific to Male Breast Cancer

- Dana Farber Cancer Institute Male Breast Cancer Program — dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Breast-Cancer-Treatment-Center/Male-Breast-Cancer-Program.aspx
- HIS Breast Cancer Awareness Foundation, Inc. — hisbreastcancer.org
- John W. Nick Foundation — malebreastcancer.org
- Male Breast Cancer Coalition: malebreastcancercoalition.org
- MaleBC (part of the Association of Cancer Resources Online) — acor.org/listservs/join/86
- Malecare — malecare.org
- National Cancer Institute male breast cancer treatment PDQ: cancer.gov/types/breast/patient/male-breast-treatment-pdq

The background is a solid blue color with several overlapping, semi-transparent circular and arc-like shapes in various shades of blue, creating a layered, geometric pattern.

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