

HER2-Positive Breast Cancer



**LIVING BEYOND
BREAST CANCER™**

With you, for you.

Fill out our online survey today for a chance to

win a \$25 gift card!

VISIT: surveymonkey.com/r/2016LBBC



Tell us what you think of the *Guide to Understanding HER2-Positive Breast Cancer*.

Thank you

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

Everyone's journey is different.

If you have stage IV (metastatic) breast cancer, visit LBBC.ORG for resources created just for you.



Dear Friend:

After a diagnosis of HER2-positive breast cancer, you may have many different feelings and thoughts. You're hearing many new words and preparing yourself for a lot of new experiences, none of which you wanted to be part of your life story.

At Living Beyond Breast Cancer, we know you want information that's just for you. This guide aims to help you understand a HER2-positive diagnosis and your treatment options. We hope this information empowers you to ask questions and speak openly with your healthcare team so that you feel you have an active role in your breast cancer care.

This guide will help you talk to healthcare providers and loved ones. It also provides tips on working through difficult emotions and teaches you ways to live your best life during treatment, and beyond. Use it as a reference now and in the future.

Warmly,

A handwritten signature in blue ink that reads 'Jean'.

Jean A. Sachs, MSS, MLSP
Chief Executive Officer



LIVING BEYOND BREAST CANCER™

With you, for you.

Toll-Free Breast Cancer Helpline
(888) 753-LBBC (5222)
lbbc.org/helpline

All people pictured in this guide are LBBC volunteers whose lives have been affected by breast cancer. We thank them for sharing their experiences.

SECTION 1

Understanding HER2-Positive Breast Cancer	4
What Is HER2-Positive Breast Cancer?	5
Who Gets HER2-Positive Breast Cancer?	7
How Do We Test for HER2-Positive Breast Cancer?	7
When Breast Cancer Is Both HER2-Positive and Hormone Receptor-Positive	10

SECTION 2

Treatment Options	12
Local Treatments	13
Systemic Treatments	15
Managing Side Effects	22

SECTION 3

Ongoing Research	24
Why Consider a Clinical Trial?	25
Learn More	26
What's Being Studied Now	27

SECTION 4

Financial Concerns	30
Resources to Help You Pay for Your Treatment	32

SECTION 5

HER2-Positive Breast Cancer and Your Emotions	34
Talking to Friends and Family	35
Other Ways to Find Support	36

SECTION 6

When Treatment Ends	38
Follow-Up Care	40
Survivorship Care Plans	41
Fear of Recurrence	43

SECTION 7

Resources	46
Words to Know	47

Understanding HER2-Positive Breast Cancer

About 20 percent of breast cancers are HER2-positive, but you may never have heard of this type of breast cancer before. On top of coping with a diagnosis, you may be hearing a lot of new words. That can be overwhelming.

Understanding what is unique about **HER2-positive breast cancer**, sometimes called HER2-amplified breast cancer, can help. It may clear your mind and help you face what's happening so you can make the best treatment decisions for you.

What Is HER2-Positive Breast Cancer?

Breast cancer is not one disease. It's a group of many diseases of the breast that have different causes.

HER2-positive breast cancer gets its name from **human epidermal growth factor receptor 2**, or HER2. It is sometimes called HER2/neu. The HER2 gene makes HER2 proteins, which act as **receptors**. They live on the outside of breast cells and receive signals from the body. These signals can tell cells to grow, multiply or repair damage.

Both the HER2 gene and HER2 protein are part of normal cell growth. They are seen in the breast cells of people who do not have cancer. But sometimes **mutations**, mistakes in a cell's DNA, cause the body to make too

many HER2 proteins. This can cause breast cells to grow faster than they normally would, which can lead to breast cancer.

The gene mutations that cause HER2-positive breast cancer are **sporadic**, meaning they happen randomly. We don't know why these mutations happen in some people and not in others.

Having many copies of the HER2 gene is not something that is given to you by your parents or passed on to your children. But a history of any kind of breast cancer may put family members at a greater risk for the disease. If you are worried about what your diagnosis could mean for your family's risk, consider speaking with a **genetic counselor**, a medical professional who can talk to you about what your diagnosis may mean for your family.



Who Gets HER2-Positive Breast Cancer?

Anyone with breast tissue can get HER2-positive breast cancer. This type of breast cancer is like other types in that

- it is most often seen in women, but men can get it, too
- it is seen most in women older than 50, but people of any age can get it
- higher weight, younger age at first period and older age when first child was born puts a woman at higher risk. But breast cancer is seen in people of all walks of life. You didn't do anything to cause breast cancer.

Younger women with breast cancer are more likely to have a HER2-positive diagnosis than older women. No research suggests that being a certain race or ethnicity makes you more likely to get HER2-positive breast cancer.

How Do We Test for HER2-Positive Breast Cancer?

After you were diagnosed with breast cancer, you should have had a variety of tests to help your doctors learn more about the cancer. Knowing what causes the cancer to grow allows your doctors to give you treatments that will work best for you. You can find your test results in your **pathology report**.

One or more of those many tests checked the cancer's HER2 status. The tests are usually done on tissue taken during the **biopsy**, the procedure in which cells or tissues are removed so they can be examined. This helps make pre-surgery treatment an option (see page 16). But sometimes HER2 testing is not done until after breast surgery.

If you haven't already had surgery, ask your providers whether they test for HER2 status before or after. It's OK to ask them why they recommend one or the other.



Two tests that check for HER2 status have been approved by the U.S. Food and Drug Administration (FDA). Which test or tests you receive likely depends on what your treatment center prefers.

THE IHC TEST

The **immunohistochemistry (IHC)** test measures how many HER2 proteins are on the surface of breast cancer cells. It uses a scale of 0 to 3+.

- A score of 0 to 1+ suggests a normal amount of HER2 proteins. This means the cancer is HER2-negative.
- A score of 2+ suggests a somewhat high amount of HER2 proteins. Your doctor may call this result equivocal, or uncertain.
- A score of 3+ suggests a high number of HER2 proteins. This means the cancer is HER2-positive.

If the test comes back with a score of 2+, you may need another test that will help your doctors understand if medicine for HER2-positive breast cancer will be helpful to you. You can also consider sending your sample to another lab for a second opinion.

Learning one test only leads to yet another test may be stressful. It's hard to be patient, but these tests are essential for deciding how best to treat the cancer.

THE ISH TEST

Another common test for HER2 status is **in situ hybridization (ISH)**. There are two kinds of ISH tests: fluorescence and bright-field. Both tests look for extra copies of HER2 genes in cancer cells, but they use different kinds of microscopes to do so. An ISH-negative result means there is a normal amount of HER2 genes in the cells, and the breast cancer is HER2-negative. An ISH-positive result means there are more HER2 genes than normal, and the breast cancer is HER2-positive.

“After I was diagnosed, my stress level was so high — I could not sleep or accomplish anything.”

—ERLINDA

When Breast Cancer Is Both HER2-Positive and Hormone Receptor-Positive

It is possible to have both HER2-positive and **hormone receptor-positive breast cancer**. Breast cancer that grows because of the hormones estrogen, progesterone, or both, is hormone receptor-positive. Cancer that grows because of these hormones *and* HER2 is sometimes called **triple-positive breast cancer**.

When the cancer is tested for HER2 status, it should also be tested for hormone receptor status. If the breast cancer tests HER2-positive and hormone receptor-positive, your treatment will likely include medicines that target the HER2 receptors and medicines that target the hormone receptors.

LEARN MORE

For more information about medicines for hormone receptor-positive disease, read our *Guide to Understanding Hormonal Therapy*.



Treatment Options

You may have heard other people with breast cancer talk about their treatment. Their stories may have inspired you, or they might sound scary.

Try not to assume your treatment will be just like theirs, even if they too had HER2-positive disease. Just like there are many different kinds of people, there are many different kinds of treatment plans.

Your breast cancer care will likely include some of the treatments in this section. But talk to your doctors about what treatments they recommend for you.

There are two parts to breast cancer treatment. **Local treatment** kills cancer cells in and around the tumor. **Systemic treatment** kills cancer cells that may have traveled throughout the body.

Local Treatments

SURGERY

Breast cancer surgery is used to remove tumors in the breasts and, if needed, the nearby **lymph nodes** — small, round organs that store white blood cells and filter bacteria and waste. Almost everyone has some surgery after a breast cancer diagnosis. Two common types of surgery are

- **lumpectomy** (also called partial mastectomy, segmentectomy or breast conserving surgery), in which the surgeon removes the tumor, as well as the **margin**, a small rim of healthy tissue around the tumor
- **mastectomy**, in which the surgeon removes the entire breast



Surgery may mean having to stay over at the hospital and taking time off from work or other responsibilities. It can take a few weeks or longer to feel better after breast surgery. Talk to your doctor about guidelines to follow during your recovery.

RADIATION THERAPY

Radiation therapy uses high-energy x-rays to destroy breast cancer cells and shrink tumors. Radiation therapy is almost always given after lumpectomy and sometimes after mastectomy.

Common side effects include fatigue, as well as soreness, redness and swelling of the breast. Most side effects begin soon after the start of radiation treatment and go away shortly after you finish.

LEARN MORE

A possible long-term, serious side effect of both radiation and breast surgery is **lymphedema**. With this condition, extra lymph fluid builds up, causing swelling in tissues under the skin of the hand, arm, breast or torso, on the same side that breast cancer occurs. For more information, read our *Guide to Understanding Lymphedema*.



WHAT'S STAGE GOT TO DO WITH IT

If you have stage I or small stage II HER2-positive breast cancer with a small tumor and no cancer in the lymph nodes, it's possible you could receive surgery and radiation with no further systemic treatment. Breast cancer research doesn't often include women with small tumors. For this reason, little is known about the benefits of more treatment compared to the side effects those treatments might cause. Recent research shows treatment with trastuzumab (see below) and a single type of chemotherapy could reduce the risk of the cancer coming back in those with stage I breast cancer. Talk to your doctor about your options and about how cancer stage affects your treatment.

Systemic Treatments

These medicines can be given either before or after breast cancer surgery.

TARGETED THERAPIES FOR HER2-POSITIVE BREAST CANCER

A **targeted therapy** is a systemic treatment that finds and attacks cells that have a large number of certain cancer-causing receptors, such as the HER2 receptor.

TRASTUZUMAB (HERCEPTIN)

Doctors have come a long way in treating HER2-positive breast cancer. As recently as the 1990s, few treatment options existed. At the time, there was no targeted therapy for this subtype.

Trastuzumab (Herceptin) was the first HER2-positive targeted therapy. It is a **monoclonal antibody**, a medicine made in a lab that acts like a natural substance in

the body. Trastuzumab attaches to the HER2 proteins and blocks the signals that tell cells to multiply too quickly, causing cancer.

Trastuzumab was FDA approved for early-stage disease in the mid-2000s.

Research shows people with HER2-positive breast cancer who take trastuzumab with chemotherapy are likely to live longer than those who receive chemotherapy without trastuzumab. Adding trastuzumab to chemotherapy cuts the risk of **recurrence**, or return of the cancer, in half.

Trastuzumab is given by vein every 1 or 3 weeks. It is usually combined with chemotherapy. It can be given before surgery, after surgery, or both, for a total of 1 year.

NEOADJUVANT THERAPY

Surgery is often the first breast cancer treatment a person receives. This is not always the case, though. Sometimes pre-surgery treatment, called **neoadjuvant therapy**, is given. This is often done for people with large tumors.

Neoadjuvant therapy may shrink the tumor, which may allow for different surgery options. The cancer may even seem to disappear after neoadjuvant therapy. This is called a **pathologic complete response** (pCR). It happens when no cancer can be found when the tissue is removed during surgery.

Many researchers are studying neoadjuvant therapy for HER2-positive breast cancer. To learn more, see section 3, on page 24.

In general, trastuzumab does not cause serious side effects that are likely to make you stop treatment. Some people describe flu-like symptoms from trastuzumab. The most common side effects include:

- Fever or chills
- Muscle aches
- Nausea
- Skin reaction to injection, including redness and irritation
- Low white blood cell count, which can lead to infections
- Diarrhea

Heart problems are a rare but serious possible side effect. Research shows heart problems from trastuzumab are usually not permanent or long-term. Though it's unlikely you'll have serious heart problems while taking trastuzumab, it's important your doctors closely monitor your heart health during treatment.

You should have an **echocardiogram** (sometimes called an echo), a test that looks at your heart health, before your doctor puts you on trastuzumab and at other times throughout your treatment. If the first test finds you have heart problems, trastuzumab may not be right for you. Talk to your healthcare team about other options.

PERTUZUMAB (PERJETA)

In 2013 the FDA approved **pertuzumab** (Perjeta). This targeted therapy is used in early-stage HER2-positive disease when given at the same time as trastuzumab and the chemotherapy medicine docetaxel (Taxotere). It was the first breast cancer medicine to be approved by the FDA specifically as neoadjuvant therapy. Like trastuzumab, pertuzumab works by blocking signals that tell breast cancer cells to multiply. It is given for up to 18 weeks by vein, before surgery, typically on the same day as trastuzumab and docetaxel.

I was very sick during chemotherapy, so when my doctor told me that I would be on trastuzumab for a year, I panicked. I went into it thinking the worst and was surprised when I started feeling better. I had no side effects from it at all. My hair started to grow back and I started to feel like myself again.”

—NICKIE

Doctors recommend pertuzumab when there is a high risk of cancer returning or spreading outside the breast. You may be able to take pertuzumab if the cancer is

- larger than 2 centimeters across, or
- locally advanced**, meaning it has spread to nearby tissue or lymph nodes, or
- inflammatory breast cancer**, which exists in the skin of the breast and causes it to look red and swollen and feel warm to the touch

The most common side effects people have with pertuzumab when given with trastuzumab and chemotherapy are hair loss, diarrhea, nausea and low white blood cell count, which can lead to infections.

Studies show adding pertuzumab to trastuzumab does not increase the risk of heart problems associated with trastuzumab.

Although my side effects from trastuzumab were not as severe as the side effects I experienced from chemo, I did experience fatigue and high blood pressure. To manage these side effects, my doctor prescribed medicine and I changed my diet.”

—YVONNE

PORTS

Treatment with medicines given by vein can involve repeated needle pricks that may irritate your veins. To avoid these problems, you may get a **port**, sometimes called a mediport or port-a-cath. Ports are inserted under the skin during a surgery, usually in the upper chest area, to create easy access to veins. The port is removed when you are done with treatment.

Many people like the ease their port brings to treatment. But it is possible for ports to get infected. Some people also find them uncomfortable. If your doctor talks with you about getting a port, ask about possible side effects. After a port is placed, report any problems to your doctor.

CHEMOTHERAPY

The purpose of **chemotherapy** is to destroy cancer cells throughout the body. It is given by vein or as a pill, before or after surgery, or both. It's likely your treatment for HER2-positive breast cancer will include chemotherapy.

Chemotherapy affects both healthy and unhealthy cells, making side effects likely. For this reason, chemotherapy is more likely to cause side effects than targeted therapies. Common side effects include diarrhea or constipation, stopping of periods in premenopausal women, rash, fever, loss of appetite, hair loss and nausea.

After cancer treatment, some people report problems with thinking and short-term memory. This is sometimes called **chemobrain**, but it isn't only linked to chemotherapy. It may be caused by other treatments as well, or even by the cancer itself. For more information about chemobrain and other treatment side effects, visit LBBC.ORG.

FERTILITY

If you are young, you may be worried about how breast cancer could affect **fertility**, your ability to get pregnant.

Some types of anticancer treatments, including chemotherapy, can make future pregnancies difficult or impossible. They can cause menopause to happen earlier than usual. Early menopause can be temporary or permanent.

Very early research suggests trastuzumab does not impact fertility. More study is needed before we know for sure. Keep in mind that if you're taking chemotherapy with trastuzumab, though, chemotherapy could affect your fertility.

Talk to your doctor about fertility as early as possible, before you start treatment if you can. You may have options, but you may need to take action before you begin having treatments that could affect your fertility.

Even if you are able to, you should not become pregnant during breast cancer treatment because of health risks to the fetus. If you are sexually active, it is important to use a reliable and approved form of birth control during treatment. Hormone-based birth control, such as the birth control pill, patch, shot or implant, is not recommended for people who have had breast cancer. Ask your doctor for information about safe, effective, non-hormonal birth control options.

LEARN MORE

We know women diagnosed with breast cancer before age 45 have unique needs. Visit LBBC.ORG for more information specific to young women with breast cancer and to learn more about our Young Women's Initiative. To talk to other young women who have been in your shoes, contact LBBC's **Breast Cancer Helpline**, toll-free at **(888) 753-LBCC (5222)** or via online chat at lbcc.org/helpline.

I was HER2-positive and I was young. It was very isolating. It's good to have other young women to talk to."

—AMANDA



HORMONAL THERAPY

If you have breast cancer that is both HER2-positive and hormone receptor-positive (see page 10), you may also receive **hormonal therapy** at the same time as anti-HER2 targeted therapy. Hormonal therapy includes tamoxifen and aromatase inhibitors. It can also include the use of surgery, radiation or medicine to remove the ovaries or to stop them from making estrogen. This can be permanent or temporary, depending on which method is used.

LEARN MORE

For more information, read our *Guide to Understanding Hormonal Therapy*.

Managing Side Effects

Having HER2-positive breast cancer means you will likely take more than one type of treatment at a time. The combination can make it hard to know which treatment is causing which side effect.

Remember that you are not alone. Your healthcare team can work with you to make treatment manageable while still fighting the cancer.

Tell your doctors about any side effects you have. They may be able to give you medicines or share tips to help prevent, ease or end some side effects. Consider **complementary and integrative medicine (CIM)**, sometimes called complementary therapies. These are physical, mental and spiritual practices used during and after treatment in addition to standard medicine. Research shows they can lessen side effects like stress, anxiety and hot flashes. CIM includes massage, acupuncture, art therapy, yoga and meditation. Some complementary therapies may impact how well your anticancer medicine works, so talk to your doctor before trying them.

LEARN MORE

For more information, read our *Guide to Understanding Complementary Therapies* and our *Guide to Understanding Yoga & Breast Cancer*.

Know, too, that having no side effects does not mean the treatment is not working. You may or may not experience side effects. Everyone's body reacts differently.



Ongoing Research

Clinical trials are research studies that test how well new therapies, medicines or treatments work, and if they are safe. About 10,000 people participated in trastuzumab clinical trials before it became widely available. About 1.5 million people have now been treated with it.

Clinical trials have allowed breast cancer treatment to become more tailored to the subtype and to the individual person. They give doctors a better idea of what treatments will work best for you and your specific situation.

Clinical trials fall into one of four **phases**, or steps. As a person with HER2-positive early-stage breast cancer, you would likely be able to participate in phase II or phase III trials. Phase II trials study if the new treatment works against cancer. Phase III trials are used to learn how a new treatment works compared to a standard treatment. A successful phase III trial is usually needed for FDA approval, but sometimes medicines are approved earlier in the process.

Why Consider a Clinical Trial?

Though clinical trials may sound scary, you don't have to fear that taking part will turn you into a guinea pig.

Clinical trials are highly regulated to ensure you receive quality treatment. You may receive a new treatment, alone or with a standard therapy. Or, you may receive a standard treatment that a new treatment is being compared against. You will always receive treatment. You may be given a **placebo**, or inactive substance,

along with an active treatment, but you will never receive a placebo *instead of* an active breast cancer treatment.

“There are several advantages to participating in a clinical trial. In addition to the possible health benefits, there’s satisfaction in knowing that your involvement is helping move research forward.”

—BETH

With so many new, promising HER2-positive treatments under study (see page 27), it’s an exciting time to take part in a trial. You may get access to medicines that won’t be available to others for many years. Another benefit is that some costs may be covered by the trial.

Learn More

Talk with your providers about trials as soon as possible. Doing so may give you more options.

Deciding whether to participate in a clinical trial is personal. Consider your goals and lifestyle as you make your choice. Talk it through with your health-care team, as well as your family and friends, and consider contacting our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at **lbcc.org/helpline**, to connect to someone who has made the decision.

Search for open studies at ClinicalTrials.gov, cancer.gov/clinicaltrials or breastcancertrials.org. You can also read our *Guide to Understanding Clinical Trials* and our Clinical Trials Resource Center section on LBBC.ORG.

What’s Being Studied Now

Researchers continue to look for new medicines for HER2-positive breast cancer. Some are being studied in early-stage disease, while others are being studied only in **metastatic** disease for now. Breast cancer is metastatic when it has spread beyond the breast and nearby lymph nodes to other parts of the body. New medicines are usually studied in people with metastatic disease first, then in early-stage disease later.

As of April 2016, these medicines are under study in early-stage HER2-positive disease:

T-DM1 (KADCYLA)

T-DM1 (Kadcyla) is an **antibody drug conjugate**, a medicine that combines a targeted therapy, in this case trastuzumab, with chemotherapy. It is able to send the chemotherapy medicine straight to cancer cells. T-DM1 is FDA-approved for people with metastatic HER2-positive breast cancer.

T-DM1 is being studied in early-stage disease in phase II and phase III trials. Two trials, called KAITLIN and ATEMPT, are comparing T-DM1 to standard therapy in people with early-stage HER2-positive disease.

VACCINES

Vaccines are associated with diseases like the flu, but they are also being developed for cancer. Cancer vaccines are a type of **immunotherapy**, a treatment that helps the body’s natural defenses fight cancer.

The **GP2 vaccine** is made from the HER2 protein. It is designed to alert the body’s immune system to fight HER2-positive breast cancer. A phase II study in women with early-stage HER2-positive disease showed promising results, especially when the vaccine was taken after finishing trastuzumab. Future studies of this vaccine and others are planned.



NERATINIB

Neratinib blocks the signals that tell HER2-positive breast cancer cells to grow. It is being studied in phase III trials for early-stage breast cancer after showing promise in metastatic disease.

A NOTE ON LAPATINIB (TYKERB)

Lapatinib (Tykerb) is FDA-approved to treat metastatic HER2-positive breast cancer. It has also been studied in early-stage disease. It's possible you or someone you know with early-stage disease received it in a clinical trial. In 2014, the phase III ALTTO trial found adding lapatinib to trastuzumab wasn't better at stopping cancer from coming back than trastuzumab alone. Because adding a second medicine did not change outcomes but could increase side effects, doctors now have little interest in continuing to study lapatinib in early-stage disease.

Several medicines are being studied in metastatic HER2-positive breast cancer only. They include:

AFATINIB (GILOTRIF) AND ONT-380

These two medicines are similar to neratinib. They block the signals that tell HER2-positive breast cancer cells to grow. **Afatinib** (Gilotrif) is being studied in phase II and phase III trials. **ONT-380** is being studied in phase I trials. This type of trial is the first step when testing a new treatment in people. It is used to find the safest and most effective way to give a new treatment.

MM-302

MM-302 is a medicine that targets the HER2 protein. Through a phase I trial and the phase II HERMIONE trial, researchers are studying it in people who have HER2-positive metastatic breast cancer that grew during treatment with trastuzumab, pertuzumab or T-DM1. They want to see if adding MM-302 to trastuzumab will make trastuzumab work better.



Financial Concerns

When you feel anxious about your health, wondering how you will pay your medical bills and living expenses is probably the last thing you want to worry about. But all those appointments and treatments can have a lasting impact on your finances.

Treatment can be very costly for people with HER2-positive disease. Medicines like trastuzumab and pertuzumab are still fairly new, which means they are expensive. A full course of each treatment can cost many tens of thousands of dollars.

This may seem scary, but there are ways you can prepare.

If you have health insurance, review your policy. Insurance will likely pay for many of your medical bills, but not all of them. Understanding your policy can help you get the most coverage possible for the appointments, tests and treatments you need. This will help you avoid as many **out-of-pocket expenses**, costs you must take on when a treatment or service is not covered by insurance or covered only in part, as possible.

If you have health insurance through your employer, ask your human resources representative for information about your policy. You can also call your insurance company and ask for a case manager. This person can help you find providers whose services are covered by your insurance. Another option is asking for help from a member of your healthcare team, such as a **nurse navigator** or **oncology social worker**, professionals trained to help people with cancer and

their families navigate the healthcare system and find support services that address the emotional, physical and financial issues caused by cancer.

“When the side effects from the chemotherapy took away my ability to work, my finances suffered a major hit. Always enlist the help of an advocate who can help with decisions that will affect your financial stability during and beyond treatments.”

—YVONNE

If you are uninsured or underinsured, you can buy a plan through your state’s health insurance marketplace or exchange. You may also be eligible for government programs like **Medicare** and **Medicaid**. If you are unable to work, you may be able to get **disability insurance**. Ask a member of your healthcare team to help you look into these options.

Resources to Help You Pay for Your Treatment

Many companies that make medicines have patient assistance programs and copay assistance programs to help pay for the medicines you need or the copays associated with them. These programs can help if you have no insurance, your insurance won’t pay for your medicine, or you have high out-of-pocket expenses.

Genentech, the company that makes trastuzumab, pertuzumab and T-DM1, may be able to help you get your medicine through the Genentech Access Solutions program. More information can be found at (866) 422-2377 or genentech-access.com/patients.

Patient assistance programs may also exist for other medicines you need. Some medicines may be available as **generics**, which usually cost less than brand name medicines. Generic medicines are the same as the brand name medicine, and treat the cancer, or the side effects, just as well.

You can also ask if your treatment center has a financial assistance program. The center may also be able to write off or reduce your bills, or put you on a payment plan. Talk to your doctor about clinical trials (see section 3, on page 24). Some pay for part or all of the cost of treatment.

Don’t be afraid to ask for help from family and friends. If you feel uncomfortable asking for money, your loved ones may be able to help in other ways. If they do your grocery shopping for one week or drive you to appointments, that can make a big difference in your budget. Your religious community or another group you belong to may be willing to raise money for you, or you might consider holding a fundraiser yourself. You may be able to get help, including grants or credit counseling, from nonprofit or government groups, too.

LEARN MORE

For more information, read our *Guide to Understanding Financial Concerns*.



HER2-Positive Breast Cancer and Your Emotions

Breast cancer may bring out a variety of emotions, including fear, sadness, anger, guilt, embarrassment and regret.

Your emotions are your own. They are a reasonable reaction to being put in a situation you wish you were not in. But there are ways to cope so you can move forward with your life.

Talking to Friends and Family

Talk to friends or family members about how you feel and how they can help you. It can be helpful to let them know you don't expect them to solve your problems or make everything better, you just need someone to listen or to help you with day-to-day tasks. You may find some friends or family members are easier to talk to, or more willing to listen, than others.

Sometimes people are insensitive without meaning to be. They may not understand that breast cancer is not one disease, and may say things that don't apply to you. Even if they have heard of HER2-positive breast cancer, they might not know about advances that have made it more treatable.

If someone's comments are hurtful, let the person know. Try, "I know you mean well, but this is not helping me." You may want to limit your time with people who continue to say things that upset you.

“As treatment progressed, there were good days and bad. The emotional toll was very difficult to deal with.”

—NICKIE

A NOTE ON BODY IMAGE AND SELF ESTEEM

Breast cancer can have a big impact on the way you feel about your body. Surgery may have left you looking and feeling different than you did before cancer. Treatments can affect your hair, skin and nails and leave you too tired to care for your appearance the way you once did. Poor body image can also cause you to avoid intimacy with a partner.

Focus on what you love about your body, not on the things you see as flaws. Take care of yourself emotionally. If you have a partner, try to talk openly about any sexual side effects you're experiencing. You may also want to talk to a counselor who has experience in issues of sexuality and breast cancer. For more information, read our *Guide to Understanding Intimacy and Sexuality*.

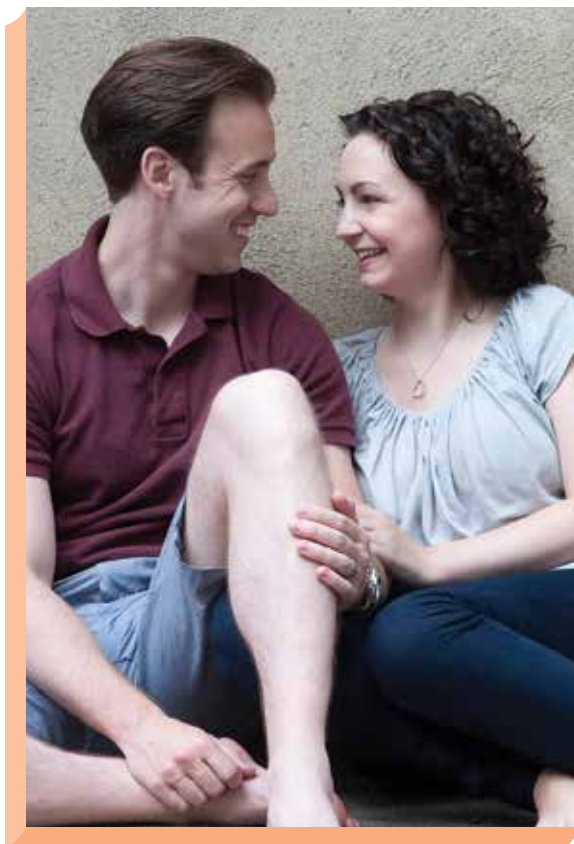
Other Ways to Find Support

You can also talk to a professional counselor who treats people with cancer. **Support groups**, where people in similar situations gather to share what they're going through, are a great source of strength for many people. Online communities accessed through websites and social media are also popular. You may prefer a group, such as HER2Support.org, that is HER2-specific.

Another source of support is LBBC's **Breast Cancer Helpline**, available toll-free at **(888) 753-LBBC (5222)** or via online chat at **lbcc.org/helpline**. The Helpline can connect you to another person who has been diagnosed with HER2-positive breast cancer and knows what you're going through.

LEARN MORE

For more information on the emotional effects of breast cancer, read our *Guide to Understanding Your Emotions*.



When Treatment Ends

Joining the more than 3 million Americans who have reached the end of active breast cancer treatment can be an emotional rollercoaster. While you were focused on getting better physically, you may not have processed what you were going through.

You may have shifted some responsibilities or stopped doing some things you enjoy. Now you may be unsure how to transition from life with cancer to life after cancer.

It's common to feel that you aren't getting the same emotional support you received during treatment. Your loved ones may not realize that even though you're done with treatment, you're not done working through the emotions that go along with it. Tell them what you need. One way to start is by asking how your being done with treatment makes them feel. Or say, "I know I look better, but I'm still hurting inside. Can we talk?"

If friends and family aren't open to hearing about your feelings, look to other sources. Talking to others who are finishing HER2-positive treatment may make it easier to cope and help you feel you're not alone. If you would like to connect with someone, please contact our **Breast Cancer Helpline** toll-free at **(888) 753-LBBC (5222)** or via online chat at lbbc.org/helpline. Talking to a mental health provider can also be helpful.

After treatment, you may feel inspired to help others. You could do this by talking to newly diagnosed people. Your story may show them what life beyond breast cancer looks like. You could also volunteer with a breast cancer or other nonprofit organization.

“Deciding to give back is a wonderful way for me to care for other women who sit where I once sat.”

— YVONNE

Follow-Up Care

Recommendations for breast cancer follow-up care released by the American Society of Clinical Oncology and the American Cancer Society include:

- Visiting your doctor every 3 to 6 months for the first 3 years after your first treatment, every 6 to 12 months for years 4 and 5, and once a year every year after that.
- If you still have breast tissue, getting a mammogram 1 year after the mammogram that led to your diagnosis. That mammogram should happen at least 6 months after your last radiation treatment, if you had radiation therapy. Going forward, get a mammogram every year.
- Maintaining good health by exercising, eating a diet rich in vegetables and fruit, limiting alcohol, not smoking and keeping a healthy weight.

Your healthcare team should tailor your follow-up care to you by age, breast cancer subtype and other factors. They may adjust this plan.

“I think being done with treatment is harder than being in treatment. You’re just released into the wild. There are a lot of unknowns and you feel kind of alone.”

—AMANDA

Survivorship Care Plans

As of 2015, healthcare facilities that want accreditation from the Commission on Cancer of the American College of Surgeons need to provide a **survivorship care plan** to people they treat for cancer.

A survivorship care plan is a guide for you as you move from active treatment to life beyond breast cancer. Its goal is to help you stay healthy, physically and emotionally. It can also help doctors who care for you in the future better understand your medical history. Survivorship care plans may feature:

A summary of your experience, including

- details of your diagnosis, such as HER2 status
- what treatments you received
- which doctors and facilities cared for you

A plan for follow-up care, including

- how often you should see your doctors
- what tests you should be given to look for a recurrence
- how to handle any long-term side effects
- lifestyle recommendations, such as exercising, eating healthy foods and not smoking



QUESTIONS TO ASK YOUR DOCTORS WHEN YOU FINISH TREATMENT

- 1 Do I keep seeing an oncologist or does my regular doctor handle all my care now?
- 2 How often should I visit a doctor to check on how I'm doing?
- 3 What tests will be used to monitor my health?
- 4 If I had side effects during treatment, will these problems continue, lessen or go away now?
- 5 How can I protect myself from recurrence?
- 6 Am I at higher risk for other illnesses because of cancer treatment? If so, which ones? What signs or symptoms should I look for?
- 7 Would a survivorship care plan help me? How do I create one?
- 8 Where can I go for emotional support?

Fear of Recurrence

For many people, being done with treatment doesn't mean being done with worries. Not seeing your doctors as often and receiving less or no treatment may make you feel you should be doing something more to stop the cancer from coming back. Try to remember that you and your healthcare team did everything you could to treat the cancer.

Because of advances in treatment, HER2-positive breast cancer is less likely to return now than it was years ago. Most people who receive treatment for early-stage HER2-positive breast cancer don't have a recurrence. Most cancers that do recur do so within 5 years of treatment ending. But every person's risk of recurrence is different. Talk to your doctor about your situation. Learning about it could make you feel less fearful.

If the cancer is also hormone receptor-positive, you may take hormonal therapy (see page 22) for 5 to 10 years after active treatment ends to lessen your risk of recurrence. Continuing treatment in this way may comfort you, make you feel anxious — or both.

There is no long-term medicine for you to take if you don't also have hormone receptor-positive breast cancer. That could make you feel relieved. Or, you may wish there was something you could take. Maybe you feel both ways. Asking doctors how and why your care changes after treatment may make you feel more confident that you're still getting the best quality care.

LEARN MORE

For more information, read our *Guide to Understanding Fear of Recurrence*.

“The fear of recurrence is never far away in my thoughts, but I don’t let it consume my life in a negative way. If I should have a recurrence, I will draw strength from the same place that keeps me going from day to day.”

—JUDITH

Once treatment is over, you might consider making nutrition and regular exercise a goal. These lifestyle changes can make it easier to maintain a healthy weight, may lower the chance of breast cancer returning and could increase long-term survival. They also just make you feel good.

LEARN MORE

For more information, read our *Guide to Understanding Complementary Therapies*.



Resources

Words to Know

Afatinib (Gilotrif). An experimental medicine that blocks the signals that tell HER2-positive breast cancer cells to grow.

Antibody drug conjugate. A medicine, such as T-DM1, that combines a targeted therapy with chemotherapy.

Biopsy. Procedure in which cells or tissues are removed so they can be examined.

Chemobrain. Problems with thinking and short-term memory after cancer treatment.

Chemotherapy. Treatment that destroys cancer cells throughout the body.

Clinical trials. Research studies that test how well new therapies, medicines or treatments work, and if they are safe.

Complementary and integrative medicine (CIM). Physical, mental and spiritual practices used during and after treatment, in addition to standard medicine, to ease the side effects of cancer treatment.

Disability insurance. Insurance used to replace some of the income that is lost when a medical condition prevents someone from working.

Echocardiogram. A test that measures heart health. Sometimes called an echo.

Fertility. A woman's ability to become pregnant.

Generics. Medicines that are sold under their chemical name, not a brand name. They are chemically the same as brand name versions, but are often less costly.

Genetic counselor. A medical professional who can talk to you about what your diagnosis may mean for your family.

GP2 vaccine. An experimental medicine that is made from the HER2 protein. It is designed to alert the body's immune system to fight HER2-positive breast cancer.

HER2-positive breast cancer. Breast cancer that grows because of too many HER2 receptors on breast cells. Sometimes called HER2-amplified breast cancer.

Hormonal therapy. Treatments for hormone receptor-positive breast cancer.

Hormone receptor-positive breast cancer. Breast cancer that grows because of the hormones estrogen, progesterone, or both.

Human epidermal growth factor receptor 2. A gene that makes HER2 proteins, which act as receptors on breast cells. A mutation can cause the body to make too many HER2 proteins, which can lead to breast cancer. Also called HER2 or HER2/neu.

Immunohistochemistry (IHC). A test that measures how many HER2 proteins are on the surface of the breast cancer cells. It is used to find out if breast cancer is HER2-positive.

Immunotherapy. A treatment that helps the body's natural defenses fight cancer.

In situ hybridization (ISH). A test that looks for extra copies of HER2 genes in cancer cells. It is used to find out if breast cancer is HER2-positive.

Inflammatory breast cancer. A type of breast cancer in the skin of the breast that causes it to look red and swollen and feel warm to the touch.

Local treatment. Treatments that kill cancer cells in and around the tumors.

Locally advanced. Breast cancer that has spread to nearby tissue or lymph nodes.

Lumpectomy. Surgery in which the tumor is removed, along with a small rim of healthy tissue around it. Also called partial mastectomy, segmentectomy or breast conserving surgery.

Lymph nodes. Small, round organs that store white blood cells and filter bacteria and waste.

Lymphedema. A condition in which extra lymph fluid builds up, causing swelling in tissues under the skin of the hand, arm, breast or torso, on the same side that breast cancer occurs.

Margin. A small rim of healthy tissue around a tumor. It is removed during a lumpectomy.

Mastectomy. Surgery in which the surgeon removes the entire breast.

Medicaid. A government health insurance program for low-income people.

Medicare. A government health insurance program for people aged 65 years or older and people with certain disabilities.

Metastatic. Refers to breast cancer that has spread beyond the breast and nearby lymph nodes to other parts of the body.

MM-302. An experimental medicine that targets the HER2 protein.

Monoclonal antibody. A type of medicine that is made in a lab but acts like a natural substance in the body. Trastuzumab is a monoclonal antibody.

Mutations. Mistakes in a cell's DNA that can cause cancer.

Neoadjuvant therapy. Treatment given before surgery.

Neratinib. Experimental medicine that blocks the signals that tell HER2-positive breast cancer cells to grow. It is being studied in metastatic and early-stage HER2-positive breast cancer.

Nurse navigator. Nurse who guides you and your caregivers through the healthcare system so you can get the care you need to make informed decisions about treatment.

Oncology social worker. A professional trained to talk to you and your family about your emotional needs and help you find support services.

ONT-380. An experimental medicine that blocks the signals that tell HER2-positive breast cancer cells to grow. It is being studied in metastatic HER2-positive disease.

Out-of-pocket expenses. Costs you must take on when a treatment or service is not covered by insurance or covered only in part.

Pathologic complete response (pCR). When cancer seems to disappear after pre-surgery treatment, with no cancer found in the tissue removed during surgery.

Pathology report. Report that describes the cells and tissues of a cancer, based on looking at them through a microscope.

Pertuzumab (Perjeta). A targeted therapy used to treat early-stage HER2-positive disease. It blocks signals that tell breast cancer cells to multiply.

Phases. The steps of a clinical trial.

Placebo. An inactive substance. In breast cancer trials, placebos may be given alongside an active treatment, but will never be given instead of an active treatment.

Port. Device that is surgically inserted under the skin, usually in the upper chest area, to create easy access to veins. Sometimes called a mediport or port-a-cath.

Radiation therapy. The use of high-energy x-rays to destroy breast cancer cells and shrink tumors.

Receptors. Proteins that live on the outside of breast cells and receive signals from the body. These signals can tell cells to grow, multiply or repair damage. Too many HER2 receptors can lead to HER2-positive breast cancer.

Recurrence. Return of cancer.

Sporadic. Describes cancer-causing gene mutations that are not inherited, but happen randomly.

Support groups. Groups in which people in similar situations, such as those who have breast cancer, gather to share what they're going through.

Survivorship care plan. A post-treatment plan meant to help you stay healthy, physically and emotionally. It can also help doctors who care for you in the future better understand your medical history.

Systemic treatment. Treatment that kills cancer cells that have traveled throughout the body.

T-DM1 (Kadcyla). A medicine that combines trastuzumab with chemotherapy. It is able to send the chemotherapy medicine straight to cancer cells. It is FDA-approved for people with HER2-positive breast cancer that is metastatic.

Targeted therapy. A systemic treatment that finds and attacks cells that have a large number of certain cancer-causing receptors, such as the HER2 receptor.

Trastuzumab (Herceptin). The first HER2-positive targeted therapy. It can attach to HER2 proteins and block the signals that tell cells to multiply too quickly, causing cancer.

Triple-positive breast cancer. Breast cancer that grows because of the hormones estrogen or progesterone, as well as HER2.



Many thanks to these individuals who volunteered their time and expertise for this guide:

AUTHOR

Erin Rowley

EDITOR

Nicole Katze, MA

LIVING BEYOND BREAST CANCER REVIEWERS

Josh Fernandez

Amy Grillo

Janine E. Guglielmino, MA

Arin Ahlum Hanson, MPH, CHES

LEAD MEDICAL REVIEWER

Sara M. Tolaney, MD, MPH

Dana-Farber Cancer Institute
Boston, Massachusetts

MEDICAL ADVISORY COMMITTEE REVIEWERS

Medical Oncology

Jennifer Litton, MD

University of Texas MD Anderson Cancer Center
Houston, Texas

Oncology Social Work

Betsy G. Clark, LCSW, OSW-C

Carolinas HealthCare System Levine Cancer Institute
Concord, North Carolina

Surgical Oncology

Steve R. Martinez, MD, MAS, FACS

The Everett Clinic
Everett, Washington

CONSUMER ADVISORY COMMITTEE REVIEWERS

Judith Anthony, Birmingham, Alabama

Beth Chernoff, Clearwater, Florida

Colleen Fernandez, Aston, Pennsylvania

Christina Ihfe, Windsor, Colorado

Thelma D. Jones, Washington, DC

Erlinda Mariano, Spencerport, New York

Yvonne McLean Florence, Lansdowne, Pennsylvania

Amanda Rainieri, Erie, Colorado

Nickie Slackway, Reading, Pennsylvania

Stacy Vivino, Philadelphia, Pennsylvania

CREATIVE DEVELOPMENT

BECK Photography

Masters Group Design

More Resources

Visit LBBC.ORG or call (855) 807-6386 to order our other *Understanding* publications:

- Guide for the Newly Diagnosed**
 - Clinical Trials
 - Complementary Therapies
 - Fear of Recurrence
 - Financial Concerns
 - Genetics and Family Risk
 - Hormonal Therapy
 - Intimacy and Sexuality
 - Lymphedema
 - Treatment Decisions
 - Triple-Negative Breast Cancer
 - Yoga & Breast Cancer
 - Your Emotions
-

Guides in our *Metastatic Breast Cancer Series*:

- Guide for the Newly Diagnosed**
 - Managing Stress and Anxiety
 - Treatment Options for Today and Tomorrow
 - Understanding Palliative Care
 - Understanding Symptoms and Treatment Side Effects
-

Guides in our *Breast Cancer InFocus Series*:

- Breast Cancer During Pregnancy
- Breast Cancer in Men
- Getting the Care You Need as a Lesbian, Gay or Bisexual Person



With you, for you.

This brochure is designed for educational and informational purposes only, as a reference to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, 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.

©2016 Living Beyond Breast Cancer, 1st Edition.



**LIVING BEYOND
BREAST CANCER™**

With you, for you.

(855) 807-6386 • LBBC.ORG

Supported by a grant from:

Genentech