

Triple-Negative Breast Cancer



**LIVING BEYOND
BREAST CANCER™**

This brochure was created
in partnership with



**TRIPLE NEGATIVE
BREAST CANCER
FOUNDATION**
The Breast Cancer Breakthrough Foundation

Fill out our online survey today for a chance to

win a \$25 gift card!

VISIT: surveymonkey.com/s/2015LBBC



Tell us what you think of the *Guide to Understanding Triple-Negative 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 triple-negative breast cancer, you may be searching for information or overwhelmed with emotions. Whether you're newly diagnosed, in the midst of treatment or moving on with your life, chances are you have questions. We hope this guide will answer many of them and empower you to make decisions about your care.

Created by [Living Beyond Breast Cancer](#) in partnership with the [Triple Negative Breast Cancer Foundation](#), this booklet will guide you through treatment and beyond. If you've recently been diagnosed, use the first four sections to learn about triple-negative basics, risk factors, common treatments and ways to cope with your emotions and fears. If you have finished treatment, sections five through seven will help you face common post-treatment concerns, including follow-up testing and managing fears of recurrence. We hope when you finish reading this guide, you'll feel ready to move forward with your treatment and your life.

Living Beyond Breast Cancer and the Triple Negative Breast Cancer Foundation are here to help when you're ready to talk about your questions and emotions. We encourage you to contact [LBBC's Breast Cancer Helpline](#), toll-free at **(888) 753-LBBC (5222)** or via online chat at lbbc.org/helpline, or [TNBCF's Helpline](#) at **(877) 880-TNBC (8622)**.

Warmly,

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

Jean A. Sachs, MSS, MLSP
Chief Executive Officer
Living Beyond Breast Cancer

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

Hayley Dinerman
Executive Director
Triple Negative Breast Cancer Foundation



**LIVING BEYOND
BREAST CANCER™**

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

Triple Negative
Breast Cancer Foundation
Helpline
(877) 880-TNBC (8622)

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 Triple-Negative Breast Cancer 4
 Understanding the ‘Basal-like’ Subtype 7
 Three Myths About Triple-Negative Breast Cancer 8

SECTION 2

Triple-Negative Breast Cancer Risk Factors 10
 Breast Cancer Gene Mutations 11
 Age, Race or Ethnicity 12

SECTION 3

Common Treatments for Triple-Negative Breast Cancer 14
 Surgery 15
 Chemotherapy 19
 Radiation 22
 Considering Clinical Trials 23

SECTION 4

Emotions During Treatment 26
 ‘Fitting In’ 28

SECTION 5

Post-Treatment Issues 30
 Fears of Recurrence 31
 Dealing With Uncertainty 32
 Follow-Up Care 34
 Genetic Testing 36
 Lifestyle Changes 37

SECTION 6

Research in the Pipeline 40
 PARP Inhibitors 41
 Platinums 42
 Immunotherapy 42

SECTION 7

Moving Forward 44

SECTION 8

Resources 46
 Words to Know 47

Understanding Triple-Negative Breast Cancer

What is triple-negative breast cancer? About 15 to 20 percent of breast cancers are triple-negative, but you may never have heard of triple-negative breast cancer before you received your test results. Hearing new words and not understanding what they mean may make you feel scared and overwhelmed.

Knowing breast cancer basics can help you understand how triple-negative breast cancer is different from other types of breast cancer. To find out what type of breast cancer you have, your doctors search for the presence or absence of **receptors**, proteins that live inside or on the surface of a cell and bind to something in the body to cause the cell to react. You may have heard of the estrogen receptor (ER), progesterone receptor (PR) and human epidermal growth factor receptor 2 (HER2).

In estrogen receptor-positive breast cancer, progesterone receptor-positive breast cancer and HER2-positive breast cancer, treatment includes medicines that prevent, slow or stop cancer growth by targeting those receptors. But **triple-negative breast cancers** (TNBC) need different types of treatments because they are estrogen receptor-negative, progesterone receptor-negative and HER2-negative. Medicines like tamoxifen, which targets the estrogen receptor, and trastuzumab (Herceptin), which targets HER2, are not helpful in treating triple-negative breast cancer. Instead, chemotherapy has been shown to be the most effective treatment for triple-negative breast cancer.

LEARN MORE

Find out more about the terms in your pathology report by ordering a free copy of LBBC's *Guide to Understanding Treatment Decisions* at LBBC.ORG.

Researchers are working to improve their understanding of the biology of triple-negative breast cancers, how these types of cancers behave and what puts people at risk for them. Their goals are to find out the best ways to use treatments that already exist and to develop new ones.

“My initial reaction was shock, bordering on depression. Every step I have taken to become educated about cancer and what I can do to change the environment that the cancer was originally able to grow in has empowered me.”

—LORI



Understanding the ‘Basal-like’ Subtype

Most triple-negative breast cancers have a **basal-like genetic pattern**. This term means that the breast cancer cells look somewhat like the cells that line the breast **ducts**, the tubes in the breast where milk travels. You might have heard your doctor call triple-negative breast cancer a basal tumor, basal breast cancer or basal-like disease.

Basal-like breast cancers tend to **overexpress**, or make too much of, certain genes that encourage cancer growth. Not all triple-negative breast cancers are basal-like, and not all basal-like breast cancers are triple-negative. About 70 to 90 percent of triple-negative breast cancers are basal-like.

Doctors choose treatments because the cancer is triple-negative, not because it is basal-like. The term basal-like appears in breast cancer resources and information. Today, the basal-like status does not factor into treatment decisions. In the future, we may find that knowledge of the genetic makeup of triple-negative tumors (basal-like or non-basal-like) may allow for more individualized treatment options, but today these are research questions.

“After I found out about my triple-negative status, I hit the Internet. My heart sank. A long-time survivor at the Triple Negative Breast Cancer Foundation helped to make the transition smoother. Her words of encouragement and knowledge and her motherly demeanor gave me hope.”

—RAYMON

Three Myths About Triple-Negative Breast Cancer

1

MYTH

People with triple-negative breast cancer can have the same treatments as all other people with breast cancer.

FACT

Many people do not understand that there are different kinds of breast cancer. Even some people who have had breast cancer do not understand the differences between triple-negative breast cancers and breast cancers that are hormone receptor-positive or HER2-positive. People you meet may have taken a hormonal treatment pill for 5 to 10 years to lower their risk of **recurrence** (a return of the cancer), or they may know someone who has. These people may not understand that this option does not exist for you. Having to explain the differences between triple-negative and other breast cancers can be frustrating, especially if you are just learning about this diagnosis yourself. On the other hand, you may take some of the same chemotherapy medicines as people with other types of breast cancer.

2

MYTH

Triple-negative breast cancers are always hard to treat.

FACT

Your doctor may tell you triple-negative breast cancer is harder to treat than other types of breast cancer. While many triple-negative cancers are aggressive, your doctor's prediction of how well your treatment will work depends on

the tumor size and whether the cancer has traveled to the **lymph nodes**, tissues near the breast, just as much as it does on its triple-negative status. There are some very effective treatments for triple-negative breast cancer. Your doctor will work with you to find the treatment that is right for you.

3

MYTH

Only African-Americans get triple-negative breast cancer.

FACT

Triple-negative breast cancers affect people of all races. Breast cancers in African-American women are more likely to be triple-negative than those in white women.



The most frustrating thing about this diagnosis is everyone thinks I should respond to the same treatments and have the same side effects as Jane Doe. I just want people to understand that every form of breast cancer is different and none of us have the same side effects.”

—RAYMON

Triple-Negative Breast Cancer Risk Factors

Researchers are still learning why some people are more likely than others to develop triple-negative breast cancer. Research supports a relationship between risk and your genes, age, race and ethnicity.

Breast Cancer Gene Mutations

Everyone has *BRCA1* and *BRCA2* genes, which we get from our mother and father. When they work properly, these genes prevent the development of cancers. But only a small percentage of people with breast cancer are born with a **mutation**, a change in DNA, in *BRCA1* or *BRCA2*.

“The second time I was diagnosed, I realized that with our family history, there might be something wrong. A few weeks later, I learned I was positive, as were both my daughters, for a *BRCA1* mutation.”

—PAM

If you are born with a *BRCA1* or *BRCA2* gene mutation, you are at increased risk for developing breast, ovarian and other cancers throughout your life. The *BRCA1* mutation puts you at higher risk for developing a basal-like breast cancer. Scientists are still trying to find out why *BRCA1* mutations increase the risk of developing triple-negative breast cancer. Keep in mind,

not all breast cancers from BRCA mutations are triple-negative. In fact, *BRCA2* mutations are more likely to be present in estrogen receptor-positive breast cancer.

If you have a family history of breast cancer, you and your relatives could carry a *BRCA1* or *BRCA2* mutation. You could also be the first person in your family known to develop breast cancer because of a BRCA mutation. Knowing your BRCA status can help you and your doctors discuss an effective treatment plan and learn ways to reduce your risk for recurrence. A genetic counselor can talk with you about genetic testing (page 36).

Age, Race or Ethnicity

Several studies suggest that being premenopausal or of African ancestry increases your risk of developing basal-like or triple-negative breast cancer. Among African-American women who develop breast cancer, there is an estimated 20 to 40 percent chance of the breast cancer being triple-negative.

Researchers do not yet understand why premenopausal women and women in some ethnic groups have higher rates of triple-negative breast cancer than other groups of women.

“At the time of my diagnosis, I had returned to work full-time after having my baby. I was still adjusting to juggling work and motherhood. I decided to focus on my healing process and keep my baby as a priority. Working part-time allowed me to have more time with the baby and for yoga, meditation and reiki, which I believe helped me do well through chemo.”

—NATALIA, AGE 32

FOR YOUNG WOMEN

No matter what type of breast cancer you have, a diagnosis can be overwhelming, especially when you are young. It can be upsetting and disruptive when you are looking for a job or starting your career; taking classes; single, dating or newly married; struggling with finances or raising small children.

Balancing your daily responsibilities with your treatment can be very challenging. You may wonder, “How am I going to make it through financially?” Your friends might not be able to relate to what you are going through, and at times you could feel you lack support.

If you want children, you may worry about how treatments could affect your fertility. To learn about your options, talk with your doctor before treatment begins. Try to visit a fertility specialist with experience treating people with cancer.

For ways to cope, contact Living Beyond Breast Cancer’s **Breast Cancer Helpline**, toll-free at **(888) 753-LBCC (5222)** or via online chat at **lbbc.org/helpline**, or the **Triple Negative Breast Cancer Foundation Helpline** at **(877) 880-TNBC (8622)**. You can also find helpful information at the websites of Young Survival Coalition, at youngsurvival.org, or **LIVESTRONG**, at livestrong.org/we-can-help/fertility-services.

Common Treatments for Triple-Negative Breast Cancer

Doctors use the same tests and surgeries to figure out treatments for triple-negative breast cancers as they do for other kinds of breast cancer. Your treatment will be based on whether the cancer has traveled to your lymph nodes, the size of the main tumor and details of pathology tests such as the **tumor grade**, which shows how quickly the cancer cells are dividing. With early-stage disease, you are likely to have some type of surgery and chemotherapy. You also may have radiation.

Surgery

Your doctor will likely recommend some type of surgery, with the goal of removing the cancer from your breast. In **lumpectomy**, also called breast-conserving surgery, the surgeon removes the tumor plus a small rim of normal tissue around the tumor, called a **margin**.

Radiation therapy (see page 22) usually is given after lumpectomy. Sometimes radiation is needed after mastectomy.

“My surgeon said he was scheduling me immediately for a lumpectomy. I mentioned mastectomy. He replied that for me the prognosis would be the same with either procedure, and the lumpectomy is not as invasive.”

—SUZANNE

Your doctor may recommend **mastectomy**, or removal of the entire breast, if:

- You have multiple tumors in the breast
- The cancer is in your skin
- The tumor is in the nipple area
- You had cancer before in the same breast
- You have a large tumor
- You have **calcifications** (calcium deposits) or other abnormal cells over a large area of your breast

You do not have to have a mastectomy just because you have triple-negative breast cancer. Your surgeon should explain which surgery you need and the reasons why. In many cases, lumpectomy and mastectomy work equally well. If you have a choice, know that studies show lumpectomy followed by radiation therapy works as well as mastectomy in treating breast cancers similar to yours.

I spoke to a lady who had a double mastectomy. She showed me her scars and reconstructed breasts. This helped me see that I could have a normal body after a mastectomy.”

—NATALIA

As you consider your options, think about how this decision will impact your emotions, lifestyle and practical needs. Ask yourself if you can accept losing your breast or if you can manage weeks of radiation after surgery if you keep your breast. Will keeping your breast impact your fear of the cancer returning? If you're interested, explore your options for **breast reconstruction**, surgery used to rebuild the breast or breasts. Consider talking it over with someone on LBBC's **Breast Cancer Helpline**, toll-free at

(888) 753-LBBC (5222) or via online chat at lbbc.org/helpline, who has made the same decision.

If you are at high risk for breast cancer, especially if you have a BRCA mutation, you may discuss with your doctors the option of removing both breasts. This is called a **double mastectomy**, also known as a prophylactic or preventive mastectomy. Depending on where you are in your life and whether you want to have biological children, you also may consider removing your ovaries to reduce your risk of ovarian cancer. Your doctor can help you understand how these decisions impact your treatment and quality of life.



10 QUESTIONS TO ASK YOUR DOCTOR OR NURSE

- 1 Have you treated other people with triple-negative breast cancer?
- 2 Is the cancer invasive or noninvasive? What is the cancer stage? What is the cancer grade? How will these features impact treatment decisions?
- 3 What treatments do I need? What side effects might I have? Are there ways to prevent or lessen side effects?
- 4 Where can I find resources about triple-negative breast cancer? Are they available online or in print?
- 5 Are there long-term effects of treatment? How do those risks compare to the benefits of therapy?
- 6 Am I able to get treatment through a clinical trial (page 23)?
- 7 Should I take steps to preserve my fertility now if I want to have children after treatment? What are my options?
- 8 Could you connect me to someone else who has been treated for triple-negative breast cancer? Do you know of support groups?
- 9 What can I do to protect myself from recurrence?
- 10 Should I speak with a genetic counselor about genetic testing (page 36)?

Find more detailed questions at tnbcfoundation.org.

Chemotherapy

You are likely to receive **chemotherapy**, medicine that kills cancer cells everywhere in your body. This type of treatment is called **systemic**, or whole-body, therapy, and it may be given by vein or in some cases by pill. The goal of chemotherapy is to prevent **metastasis**, when breast cancer comes back and spreads to other parts of the body. A **metastatic recurrence** occurs when cancer cells travel away from the breast and start growing in other organs such as the bones, liver, lungs or brain.

Chemotherapy may be given before or after surgery. If you have a tumor that is very large or you have a sizable tumor and want a lumpectomy, your doctor may recommend chemotherapy before surgery, also called **neoadjuvant therapy**. This therapy shrinks the tumor and helps your doctor learn how sensitive the tumor is to chemotherapy.

I had read that chemotherapy provides the best chance of a cure for triple-negative breast cancer, so no one had to convince me that I needed it.”

—SUZANNE

Chemotherapy is the most effective systemic treatment for triple-negative breast cancer. The reason is that chemotherapy works better than other treatments at killing cancer cells that divide quickly, which is very common in triple-negative disease. When triple-negative breast cancers are found early, response rates to chemotherapy are high. Doctors try to lessen the chance of a metastatic recurrence by treating the whole body, including any areas where very tiny cancer cells may have traveled.

Often, the chemotherapy that you receive will be the same type given to people with hormone receptor-positive or HER2-positive breast cancer. Studies show chemotherapy works better against triple-negative cancers than hormone receptor-positive breast cancers. There are many types of chemotherapy, and you and your doctor will choose the best one for you.

“The oncologists and surgeons I saw told me that chemotherapy was crucial in lessening the chances of recurrence. One of the oncologists actually showed me statistics that illustrated how chemotherapy greatly improved my chances of survival.”

—NATALIA

In rare cases, you might not receive chemotherapy; for example, if you have a very low-grade tumor (the cancer cells are not dividing quickly), if the tumor is very small, or if the risks of chemotherapy outweigh the benefits. Because chemotherapy is a common treatment for triple-negative breast cancer, always ask your doctor to explain the reasons why you would not receive it.



COMMON CHEMOTHERAPIES FOR EARLY-STAGE, TRIPLE-NEGATIVE BREAST CANCER

AC

One common treatment for triple-negative breast cancer is doxorubicin (Adriamycin) with cyclophosphamide (Cytoxan), also known as **AC** chemotherapy. Adriamycin belongs to a family of medicines called anthracyclines, which work by stopping cancer cell growth and repair. Cyclophosphamide is in the family of alkylating agents that halt fast-growing cells.

FEC AND FAC (OR CAF)

Some doctors give another medicine, fluorouracil (5-FU), in addition to AC, and the regimen is called **FAC** or CAF. Sometimes a medicine called epirubicin (Ellence) is given in place of doxorubicin. Similar regimens with epirubicin are called **FEC**, CEF or EC. These combinations work by stopping the function of cancer cells and limiting cell division and growth.

TAXANES

Often, taxanes are given alongside or after AC or FEC. **Taxanes** work by blocking cell division and stopping the advance and growth of cancer cells, and they include paclitaxel (Taxol) and docetaxel (Taxotere). When Taxol or Taxotere is added to AC, the regimen may be called **AC-T**, AC-D or TAC. When Taxotere is added to FEC, the regimen is called **FEC-T**. When Taxotere is added to cyclophosphamide alone (without any other chemotherapy medicines), the regimen is called **TC**. Your doctor may also suggest other combinations of medicines to treat triple-negative cancer.

Radiation

Radiation is a **local therapy** that kills cancer cells left after surgery in the area where the breast cancer was found. It helps protect you from a **local recurrence**, cancer coming back in the same place.

Radiation usually is given from outside your body by an external beam. It can be given inside the body in some circumstances.

If you have a lumpectomy, you will need radiation to kill any cancer cells left in the breast and sometimes in the underarm area. Radiation also may be given after mastectomy if your surgeon found cancer close to your chest wall or in your lymph nodes. Ask a member of your healthcare team to explain the reasons why you need the treatment.

FINDING A DOCTOR WHO UNDERSTANDS TRIPLE-NEGATIVE BREAST CANCER

When selecting your healthcare team, choose providers with experience treating triple-negative breast cancer. Look online for oncologists and surgeons who say they specialize in breast cancer.

Search your region for clinical trials (page 23) on triple-negative breast cancer, and find the names of doctors coordinating the studies. If you do not live near a health center with a doctor specializing in triple-negative breast cancer, consider traveling outside your area for a second opinion on your treatment plan.

To learn more about who is on your healthcare team, visit LBBC.ORG to order LBBC's *Guide for the Newly Diagnosed*.



Considering Clinical Trials

Clinical trials are research studies in humans that test how well new therapies, medicines or treatments work and whether they are safe and effective. These new therapies or combinations may or may not work better than the standard treatment or may work as well but have fewer side effects. If you take part in a clinical trial, it is very likely you will get at least the best known standard treatment.

“One reason I chose to participate in a clinical trial was to help women with triple-negative breast cancer. It is thanks to women who have enrolled in clinical trials that we have the treatments that give us hope.”

—NATALIA

Clinical trials are very important in triple-negative breast cancers because researchers and doctors have a lot to learn about them. Consider asking your doctor about clinical trials as soon as possible, even if you have not yet had surgery. Looking into trials earlier in your treatment may mean that you are more likely to qualify. Your participation could make a difference in your life and in the lives of many others with triple-negative breast cancer.

CLINICAL TRIAL BASICS

Doctors hold clinical trials in four **phases**, or steps. Each phase has specific goals:

- Phase I trials study how a new medicine or treatment should be given (by mouth, by vein, etc.), how often and at what dose. The goal is to find out what dose of treatment may be given safely. These small trials are usually only open to people with metastatic, or stage IV, cancers but can be considered at any point in stage IV treatment. Some phase I trials are adding new medicines into known regimens.
- Phase II trials, which may include up to several hundred people, look further at the safety of a treatment and begin to test whether it is effective. These studies may involve people with early-stage or metastatic cancers.
- Phase III trials have several hundred to several thousand participants and compare a new treatment to a standard treatment. These trials involve people with all stages of cancer. By the time a medicine makes it to a phase III trial, researchers know it is safe and effective. The U.S. Food and Drug Administration (FDA) approves most medicines after they succeed in phase III trials.
- Phase IV trials evaluate the long-term side effects of a treatment that the FDA already approved.

Clinical trials do not always test medicines. Some look at the long-term effects of treatment or the impact of diet, nutrition and exercise on the return of breast cancer. Others study how changing your lifestyle could lower your risk for developing breast cancer.

Some benefits of clinical trials are:

- You may receive a new and better treatment than you would have gotten outside of a clinical trial.
- You can help others who share your diagnosis.

- Some trials involve extra tests and scans, so participating will give your doctors even more information about how the breast cancer behaves.
- A trial could help your doctors learn if your treatments are working.

Some unknowns of clinical trials are:

- You could take part in a **randomized trial**, a trial in which you do not know which treatment you are receiving.
- Your insurance company may or may not cover the study tests and medicines. Call before you enroll to find out.
- You may have other concerns about participating.

Ask your doctor about how to find clinical trials or research studies. Look at clinicaltrials.gov or the National Cancer Institute website at cancer.gov/clinicaltrials. The Triple Negative Breast Cancer Foundation offers a clinical trials matching service at emergingmed.com/networks/tnbcf.

LEARN MORE

Find out more about clinical trials by visiting clinicaltrials.gov.

The decision to participate in a clinical trial is a personal one. Your goals and lifestyle will help you make your choice. Talk with your healthcare team, family and trusted friends, or call LBBC's **Breast Cancer Helpline** toll-free at (888) 753-LBBC (5222) or via online chat at lbcc.org/helpline for help thinking through your decision.

Emotions During Treatment

Many people do not understand triple-negative breast cancer, and having to explain it can feel overwhelming. It's likely you will spend a lot of time with people diagnosed with other types of breast cancer in doctors' offices, treatment facilities or at events. Your family and friends may have heard misleading information from the Internet or other people. These misunderstandings can happen with any breast cancer diagnosis.

Because triple-negative breast cancer can be aggressive, some people will be concerned about or feel sorry for you. They may believe falsely that you have metastatic breast cancer or that triple-negative breast cancer always becomes metastatic.

Hearing negative comments may be frustrating or distressing. After all, you are focused on staying strong and getting well. If people make comments like these, gently explain that chemotherapy is very effective for triple-negative breast cancers. If someone insists on saying discouraging things, be direct. Say, "Thank you for your concern, but you are not helping me right now."

“Every time I share my diagnosis, I am the one who ends up comforting the person as opposed to receiving emotional support.”

—RAYMON

Help your family and friends understand how to support you. They might not know what to do or how to talk with you about your diagnosis. Ask if they can help out with meals, take care of your kids or run errands. Remember, you have control over who you tell and how many details you give. Consider giving more details to those who are supportive. Share less, or nothing, with others. Empower yourself by ignoring myths and focusing on your recovery.

We are all different individuals, our genetic makeup, our pathology, how we react to treatments — so it is important to remember that what you read will not apply to everyone.”

—PAM

‘Fitting In’

You may connect with people who have all types of breast cancer. On the other hand, you may feel you cannot relate to those with other diagnoses. Or you could be somewhere in the middle, knowing that you are coping with breast cancer along with everyone else but that the nature of your diagnosis is different.

Sometimes it can feel hard to relate to people who have different treatment options than you do. You may hear news that a new study shows huge benefits for women with breast cancer but find the information doesn’t apply to you. Or while your friends with hormone-sensitive breast cancer find comfort in taking hormonal therapy, you can’t relate because those treatments are not available to you. Your fear of recurrence may seem intense.

One way to cope with these feelings is to connect with others who share your diagnosis. Your local hospital, clinic or cancer center may have support groups for people with triple-negative breast cancer. The message

boards of the Triple Negative Breast Cancer Foundation serve as a forum for you to meet other people with the disease. They can be found at forum.tnbcfoundation.org. You also may use the message boards to find news about promising studies and new treatments relevant to you. If you contact LBBC’s **Breast Cancer Helpline**, toll-free at **(888) 753-LBBC (5222)** or via online chat at lbcc.org/helpline, we can match you with someone who has been treated for triple-negative breast cancer so you can share your feelings and fears. Journaling, blogging and volunteering are avenues you can use to tell your story and get support.

Remember, though, that other people may have different, easier or more difficult times than you have had. Resist the temptation to compare your experiences to those of others.

I have two friends who had hormone receptor-positive breast cancer and one who had a HER2-positive diagnosis, and I felt completely bonded with them and their experiences. I came to know that each woman’s journey is unique.”

—CHERYL



Post-Treatment Issues

You've finished your treatment. Now what? This question can be very challenging. Since there's no long-term treatment for you, you may worry you aren't doing anything to protect yourself. Questions about cancer coming back or becoming metastatic may distract you.

“The medical community cannot, at this time, offer ongoing treatments to help prevent recurrence. This information makes the emotional/mental aspect of the disease even more difficult to overcome.”

—LORI

Fears of Recurrence

With triple-negative breast cancer, the risk of the breast cancer coming back outside the breast is strongest in the first 5 years after your diagnosis. Aggressive cancer cells may travel from the breast to other parts of the body. These cells move through the bloodstream and the pathways that carry fluid away from the breast to the lymph nodes, called the **lymphatic channels**. The goal of chemotherapy is to kill these stray cells and lower your risk of recurrence.

“I am frightened of it coming back. Walking out of the doctor's office the last treatment day is like walking off a cliff.”

—PAM

After 5 years, your risk of recurrence goes down. In fact, as time goes on, your risk for recurrence may be lower than that of someone treated for estrogen receptor-positive breast cancer.

If you still have breast tissue after surgery, the risk for developing a new breast cancer in the same or opposite breast does not decrease over time. Keep up with regular doctors' appointments and mammograms.

Most people with triple-negative breast cancer do not have a metastatic recurrence or a new cancer. But you may be overwhelmed by worries about breast cancer returning. Birthdays, anniversaries and holidays can bring these emotions to the surface, as can news about a friend, family member or a famous person's diagnosis. Your fears may be stronger before you go for follow-up appointments and when you wait for test results. To lower your anxiety, share your fears with a trusted friend. Try yoga, meditation or other activities you enjoy.

Dealing With Uncertainty

After treatment ends, you will see your doctor less often, and you may worry more about every new ache or pain. Feeling unsure about whether your treatment worked can make you feel helpless and vulnerable. But you have control over your health. Protect yourself by paying attention to your body, being a good advocate for yourself, going to regular follow-up visits with your doctor, exercising and eating well.

The emotional impact of triple-negative breast cancer is enormous, and information on emotions is really lacking in most treatment facilities as well as in the literature.”

—CHERYL

Despite everything you do to protect yourself, you may struggle with your emotions. You have a right to your feelings. You have been through a distressing life event, and you are dealing with the possibility that cancer could return.

Talking with your healthcare team goes a long way toward helping you cope better both during and after treatment. If you have a new pain that persists and lasts longer than a week or two, bring it to your doctor's attention. If your doctors don't listen, get a second opinion.

Consider seeking emotional support through counseling, a support group or other programs. It is perfectly normal to seek help to cope with the emotional challenges of a cancer diagnosis. Talking with someone who understands can help a great deal in reducing your distress.

LEARN MORE

If worries begin to take over your everyday life, you could be developing anxiety or depression. Find out more about these and other concerns in our *Guide to Understanding Your Emotions*. To explore worries that the cancer could come back, read our *Guide to Understanding Fear of Recurrence*. Order or download these free guides at LBBC.ORG.





“I asked whether a PET scan would be done after treatment was over and my nurse said no. I felt like I had been dropped off at the airport after a long, treacherous flight with no one to pick me up or to tell me where to go.”

—RAYMON

You can take control of your follow-up care. Get a treatment summary and create a plan of action for your post-treatment care, also called a survivorship care plan, with your healthcare team and primary care provider. A **survivorship care plan** should include information about potential long-term side effects of treatment, screening and prevention recommendations, emotional and financial issues, follow-up care referrals, support resources and ways to improve overall health.

Depending on your doctor and the breast cancer stage, you probably will not get more tests and scans after treatment unless you have new symptoms. Large clinical trials show that women with early-stage, triple-negative breast cancer who have routine CT scans and blood tests to check for cancer recurrences during the follow-up period do not do better or live longer than those who do not have the tests. Tests do not pick up most recurrences, and finding them sooner rather than later will not help you live longer. Regular testing can lead to extra tests and surgeries that cause anxiety and could create more medical problems. Extra tests do not help extend life in early-stage breast cancer, whether triple-negative or any other type.

Not having routine tests and scans after treatment ends may increase your fears. You have been through a lot, and you want to know whether the treatment worked. You may feel powerless, but there are things you can do.

Follow-Up Care

After treatment ends, you should see your doctor every 3 to 6 months for the first 3 years; then every 6 to 12 months during years 4 and 5; and then once a year after 6 years. If you still have breast tissue, you should get a yearly mammogram on the remaining breast or breasts.

“I keep track of the latest research on triple-negative breast cancer. I consider it part of my job as a patient to be well-informed. I often show up for appointments with the latest studies in hand.”

—SUZANNE

When you see your doctor, bring your questions. Make sure to tell your oncologist about any new headaches, pains or problems that are out of the ordinary, more severe or last longer than before.

Pay attention to your body. Your doctor will give you thorough exams, and you should share your medical history at that time. Do not hesitate to tell your doctor if you aren't feeling well. You know your body better than anyone, so you are the key to helping your doctor do what is best for you. Doctors find recurrences mostly through physical exams and good health histories.

If you have a very high risk of new breast cancers, digital mammography and MRI may be used together to help your doctor detect breast changes — but not all changes are cancer. You may have to go through extra biopsies to find out.

Genetic Testing

You may be at high risk for developing cancer again if you have a strong family history of breast or ovarian cancer, of either cancer at young ages or if you have a *BRCA1*, *BRCA2*, or other known genetic mutation in your family. **Genetic testing**, looking at a person's DNA to learn if he or she has an inherited risk, may help reduce your fears of recurrence and guide your decisions about further preventive treatment.

“Having genetic testing and counseling reassured me that I made the right choices. I am thankful to know my risks in order to be able to take steps to reduce them.”

—NATALIA

If you do not know whether you have a *BRCA1* or *BRCA2* mutation, talking with a **genetic counselor** can help you figure out whether genetic testing is right for you. This provider can help you understand how the results could impact your follow-up tests and treatment, family and relationships, insurance coverage and more. You can find genetic counselors at most major medical centers.

A *BRCA1* or *BRCA2* positive result may help you think further about ways to lower your risk for another cancer. Your doctor may want to do more tests if your *BRCA* test is positive.

LEARN MORE

Learn more about genetics and genetic testing in our *Guide to Understanding Genetics and Family Risk*.

Lifestyle Changes

NUTRITION AND SUPPLEMENTS

Nutrition is a tool you can use to improve your overall health and quality of life. Although much more research is needed, some studies suggest that eating a low-fat diet may lower the risk for recurrence after a diagnosis of triple-negative breast cancer. Other early studies associate low vitamin D levels at diagnosis with a higher risk for recurrence. Further research will help us learn more.

“To support my overall health, I avoid red meat and alcohol, review labels for fat content and focus on fresh fruits and vegetables.”

—SUZANNE

Even though we are not sure how lifestyle changes affect breast cancer outcome, we do know that being active, eating a healthy diet and getting vitamins from food supports overall good health. Eating well is empowering.

If you are considering changes in your diet, consult a nutritionist or registered dietitian to outline goals for healthy eating. Look for someone at your local facility with experience treating people with cancer, or ask your doctor for a referral.

Physical Activity

No matter what your diagnosis, it can be challenging to get enough physical activity. Sometimes you feel too tired or too busy. But exercise is a great way to take care of yourself after treatment and throughout your life. Try to make it a priority in your daily routine, but don't force yourself to do more than you can handle.

AEROBIC EXERCISE

Aerobic exercise can improve your well-being and your social life. The gym is a great place to meet friends. If you prefer to exercise outdoors, call a neighbor and chat while taking a walk or jog.

Walking, running, aerobics and swimming are generally safe as soon as you feel up to doing them (and some of them are free!), but your doctor or physical therapist should guide you. The Nurses' Health Study suggested that 3 to 5 hours of walking or similar exercise per week may reduce the risk of death after a breast cancer diagnosis.

The government recommends at least 150 minutes of moderate aerobic activity each week. That's only about 20 to 25 minutes each day, or 30 minutes 5 days a week. Think of ways to make it easy on yourself and your schedule so you don't feel frustrated.

WEIGHT LIFTING

Building muscle can help you feel stronger and more empowered. Weight lifting helps you keep lean muscle mass, which promotes weight loss and maintenance. Aim for 8 to 10 strength-training exercises with 8 to 12 repetitions of each exercise twice a week. If you can, it may be a good idea to work with a trainer or physical therapist before you start. A physical therapist can watch your risk for developing **lymphedema**, when lymph fluid builds up in a part of the body, causing swelling.



LEARN MORE

Find out more about lymphedema by ordering a free copy of LBBC's *Guide to Understanding Lymphedema* at LBBC.ORG.

BODY AND MIND

Yoga, tai chi and reiki are good for stretching your body, especially if you aren't quite ready for other exercise. They also help you relax your mind and body.

LEARN MORE

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

I feel emotionally strong because I am pursuing the best health possible through diet and lifestyle changes.”

—LORI

Research in the Pipeline

Researchers are working to find targets for triple-negative breast cancers. We know that not all triple-negative breast cancers are the same. It is possible, and maybe very likely, that targeted therapy will differ from tumor to tumor. Understanding what drives their growth will help us develop effective treatments. Finding targets that are common in triple-negative breast cancer cells but not in other cells in the body will help scientists identify treatments with fewer side effects.

Before new medicines become available, clinical trials must show they are safe and effective. Several new treatments show promise for triple-negative breast cancer. Here are a few in early testing. These medicines are not yet FDA approved for early-stage breast cancer.

“I turned myself into a researcher of triple-negative breast cancer. That made a big difference because I knew the newest and best treatments to take.”

—PAM

PARP Inhibitors

PARP stands for poly (ADP-ribose) polymerase. **PARP** repairs damaged DNA to help cells grow. In some cells, PARP is too active. Some cancers may use PARP repair to promote cancer cell growth.

Medicines that stop the activity of PARP, called **PARP inhibitors**, may prevent cancer cells from repairing themselves. This process makes chemotherapy and radiation work better without harming normal cells.

Research is needed to find out if PARP inhibitors work in triple-negative breast cancers. Consider asking about PARP inhibitors in clinical trials (page 23). To learn more about these medicines, please visit LBBC.ORG.

Platinums

Platinum-based medicines may be effective against basal-like triple-negative breast cancers. These medicines disrupt the building blocks of DNA and destroy cancer cells.

Early studies show that these medicines may shrink tumors that are associated with BRCA mutations. Because BRCA-associated cancers are often basal-like, researchers think that basal-like tumors that are not BRCA positive also may respond to platinum-based medicines. Researchers are doing clinical trials to find out whether these tumors are more sensitive to chemotherapy in general or to platinum-based medicines, which are a type of chemotherapy.

Immunotherapy

Immunotherapy, also called biologic therapy or biotherapy, uses the body's own defenses to treat cancer. Recent studies suggest that the presence and activity of immune cells in and around the tumor may affect how a person responds to treatments and their long-term survival.

Immunotherapies are not likely to change practice in breast cancer in the near future, but they are an exciting area of research that could have an impact on treatment down the road.



Moving Forward

Researchers are working hard to learn more about triple-negative breast cancers. We continue to find out new things about what medicines we can use to treat them.

While you are waiting for new therapies to become available to you, be comforted in knowing that you have many tools at your disposal to protect yourself and improve the quality of your life. By completing your treatment, attending regular follow-up visits and keeping a healthy lifestyle, you can be sure that you have done everything you can to protect yourself from recurrence.

“I learned to develop a voice and to use it, and I learned to manage stress through yoga, meditation and spirituality. I feel better physically and emotionally now than I did in the years before being diagnosed.”

—LORI

If you need emotional support or just want to talk with someone who has been there, the volunteers on LBBC's **Breast Cancer Helpline**, toll-free at **(888) 753-LBCC (5222)** or via online chat at **lbcc.org/helpline**, are here for you. You can ask to be matched with a woman who has gone through treatment for triple-negative breast cancer. Our Helpline volunteers provide support and guidance about dealing with the impact of breast cancer, whether you have just been diagnosed or are decades beyond treatment. Your needs come first, and we want to be there for you.

Resources

Words to Know

AC. A common chemotherapy treatment for triple-negative breast cancer. Contains doxorubicin (Adriamycin) and cyclophosphamide (Cytoxan).

AC-T. A common chemotherapy treatment for triple-negative breast cancer. Contains an AC regimen and the taxane paclitaxel (Taxol) or docetaxel (Taxotere). Sometimes called AC-D or TAC.

Basal-like genetic pattern. About 70 to 90 percent of triple-negative breast cancers have a basal-like genetic pattern. This means the cancer cells look somewhat like the cells that line the breast ducts.

BRCA1/BRCA2. Mutations in these genes make a person more likely to develop breast, ovarian and other cancers. The *BRCA1* mutation increases the risk of developing triple-negative breast cancer.

Breast reconstruction. Surgery used to rebuild the breast or breasts.

Calcifications. Calcium deposits. If a large number of these or other abnormal cells are found inside your breast, your surgeon may be more likely to recommend you have a mastectomy.

Chemotherapy. Medicine that can destroy cancer cells throughout the body. Chemotherapy is the most effective full-body treatment for triple-negative breast cancer.



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

Ducts. The tubes in the breast where milk travels. Triple-negative breast cancers are often basal-like, which means they look somewhat like the cells that line the breast ducts.

FAC. A common chemotherapy treatment for triple-negative breast cancer. Contains the doxorubicin (Adriamycin) and cyclophosphamide (Cytoxan) used in AC chemotherapy, and another medicine, fluorouracil (5-FU). Sometimes called CAF.

FEC. A common chemotherapy treatment for triple-negative breast cancer. Similar to FAC chemotherapy, but with epirubicin (Ellence) instead of doxorubicin (Adriamycin). Sometimes called CEF or EC.

FEC-T. A common chemotherapy treatment for triple-negative breast cancer. Contains an FEC regimen and docetaxel (Taxotere).

Genetic counselor. This provider can help you understand how the results of genetic testing could impact your follow-up tests and treatments, family and relationships, insurance coverage and more.

Genetic testing. May be able to tell if a person has an inherited risk of developing breast cancer.

Immunotherapy. Also called biologic therapy or biotherapy, it uses the body's own defenses to treat cancer. Immunotherapy may be especially promising in treating triple-negative breast cancer.

Local recurrence. Cancer coming back in the same place.



Local therapy. Used after surgery to destroy remaining cancer cells in the area where the breast cancer was found.

Lumpectomy. Breast-conserving surgery that removes the tumor and the margin, but leaves the rest of the breast.

Lymphatic channels. Pathways that carry fluid away from the breast to the lymph nodes.

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.

Lymph nodes. Nearby tissues to which breast cancer may spread.

Margin. The rim of healthy tissue that surrounds a tumor. Along with the tumor, the margin is removed during a lumpectomy.

Mastectomy. Surgery that removes the entire breast.

Metastasis. Breast cancer that has spread to other parts of the body.

Metastatic recurrence. When cancer cells travel away from the breast and start growing in other organs such as the bones, liver, lungs or brain.

Mutation. A change in DNA that can make developing breast cancer more likely.

Neoadjuvant therapy. Breast cancer treatment, such as chemotherapy, given before surgery.

Overexpress. To make too much. Breast cancers with a basal-like genetic pattern tend to overexpress certain genes that encourage cancer growth.

PARP. Stands for poly (ADP-ribose) polymerase. PARP repairs damaged DNA to help cells grow. In some cells, PARP is too active. Some cancers may use PARP repair to promote cancer cell growth.

PARP inhibitors. Medicines that stop the activity of PARP. They may prevent cancer cells from repairing themselves.

Phases. Steps. Clinical trials go through four phases.

Platinum-based medicines. May be effective against basal-like triple-negative breast cancers. These medicines disrupt the building blocks of DNA and destroy cancer cells.

Radiation. A treatment used to destroy breast cancer cells and shrink tumors in the area where the cancer was originally found. It is often used after breast cancer surgery to lessen the risk of the cancer returning.

Randomized trial. A trial in which you do not know which treatment you are receiving.

Receptors. Proteins that live inside or on the surface of a cell and bind to something in the body to cause the cell to react. This can cause cancer. Today, triple-negative breast cancers are not linked to the estrogen, progesterone or HER2 receptors.

Recurrence. When breast cancer returns.

Survivorship care plan. Contains information about the cancer and the treatments you received, as well as information about potential long-term side effects of treatment, screening and prevention recommendations, emotional and financial issues, follow-up care referrals, support resources and ways to improve overall health. Your healthcare providers should help you create this plan.

Systemic. Treatment, such as chemotherapy, that can affect the whole body.

Taxanes. These chemotherapy medicines work by blocking cell division and stopping the advance and growth of cancer cells.

TC. A common chemotherapy treatment for triple-negative breast cancer. Contains cyclophosphamide (Cytoxan) and docetaxel (Taxotere).

Triple-negative breast cancer (TNBC). A type of breast cancer that doesn't grow because of estrogen, progesterone, or HER2 receptors. It is not known what causes TNBC to grow.

Tumor grade. Measurement of how quickly the cancer cells are dividing.

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

AUTHOR

Mary Alice Hartsock

LEAD MEDICAL REVIEWER

Lisa A. Carey, MD

UNC Breast Center, University of North Carolina—
Lineberger Comprehensive Cancer Center
Chapel Hill, North Carolina

LIVING BEYOND BREAST CANCER REVIEWERS

Amy B. Grillo

Janine E. Guglielmino, MA

Jean A. Sachs, MSS, MLSP

TRIPLE NEGATIVE BREAST CANCER FOUNDATION REVIEWERS

Allison Axenrod

Hayley Dinerman

HEALTHCARE PROFESSIONAL ADVISORY COMMITTEE REVIEWERS

Advocacy

Lisa Black, Bryn Mawr, Pennsylvania

Elizabeth S. Frank, EdM

Dana-Farber Cancer Institute
Harvard Cancer Center, Boston, Massachusetts

Elyse Spatz Caplan, MA, Morristown, New Jersey

Elizabeth Woolfe, MPH, New York, New York

Medical Oncology

Edith P. Mitchell, MD, FACP

Sidney Kimmel Cancer Center
at Thomas Jefferson University
Philadelphia, Pennsylvania

Kathryn J. Ruddy, MD, MPH

Mayo Clinic
Rochester, Minnesota

Oncology Nursing

Anna Kate Owens, MSN, RN, FNP

UNC Breast Center, University of North Carolina—
Lineberger Comprehensive Cancer Center
Chapel Hill, North Carolina

Social Work/Counseling

Gregory D. Garber, MSW, LCSW

Sidney Kimmel Cancer Center
at Thomas Jefferson University
Philadelphia, Pennsylvania

CONSUMER ADVISORY COMMITTEE REVIEWERS

Raymon Bessix, Petersburg, Virginia

Suzanne Carlson, Fairfield, California

Lori Crownover, Hollidaysburg, Pennsylvania

Cheryl Krauter-Leonard, El Cerrito, California

Natalia Muñoz, Miami, Florida

Pam Tinney, Stringtown, Oklahoma

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
- HER2-Positive Breast Cancer
- Hormonal Therapy
- Intimacy and Sexuality
- Lymphedema
- Treatment Decisions
- 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



This brochure is designed for education 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, 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.

© 2010, 2012, 2013, 2015 Living Beyond Breast Cancer, 4th Edition.





**LIVING BEYOND
BREAST CANCER™**

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

(855) 807-6386 • LBBC.ORG

This brochure was supported by the Grant or Cooperative Agreement Number 1 U58 DP005403, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.