

Triple-Negative Breast Cancer



What to expect... today, tomorrow and beyond

Steps for coping with the medical, emotional and practical concerns of breast cancer



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CANCER®

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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 call **LBBC's Survivors' Helpline at (888) 753-LBBC (5222)** or **TNBCF's Helpline at (877) 880-TNBC (8622)**.

Warmly,



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*All women pictured in this brochure
are LBBC volunteers whose lives have
been affected by breast cancer.*

*We thank them for sharing themselves
and their experiences.*

Understanding Triple-Negative Breast Cancer

What is triple-negative breast cancer? About 10 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 three **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, treatments prevent, slow or stop cancer growth with medicines that target those receptors. But **triple-negative breast cancers** 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 you see 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 cell pattern**. This term means the cells look like the basal 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 basal status of the cancer does not factor into treatment decisions, but your doctor may tell you if the cancer is basal-like because the term appears in breast cancer resources and information.

"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

MYTH

Women with triple-negative breast cancer can have the same treatments as all other women with breast cancer.

FACT

Many people do not understand that there are different kinds of breast cancer. Even some women 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. Women you meet may have taken a hormonal treatment pill for five years to protect them from **recurrence** (a return of the cancer), or they may know someone who has. These women 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 women with other types of breast cancer.

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 in your armpit 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.

MYTH

Only African-American women get triple-negative breast cancer.

FACT

Triple-negative breast cancers affect women 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 women 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. However, less than 10 percent of people with breast cancer are born with a **mutation**, or abnormality, 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 11).

Age, Race or Ethnicity

Several studies suggest that being premenopausal, African-American, Latina or Caribbean 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.

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.

“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

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, call the [LBBC Survivors’ Helpline at \(888\) 753-LBCC \(5222\)](#) or the [Triple Negative Breast Cancer Foundation Helpline at \(877\) 880-TNBC \(8622\)](#). LBBC and TNBCF can match you with someone in a similar situation. The websites of Young Survival Coalition at [youngsurvival.org](#) or [LIVESTRONG](#) at [livestrong.org/fertilehope](#) have information to help you.



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 the lymph nodes near your breast, 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 recommend some type of surgery, with the goal of removing the cancer from your breast. The two types of surgery for breast cancer are lumpectomy and

mastectomy. 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 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 recurrence? If you're interested, explore your breast reconstruction options. Consider talking it over with someone on our Survivors' Helpline who has made the same decision.

If you have a BRCA mutation, you may discuss with your doctors the option of removing both breasts. 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 women 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?
- 4 What side effects might I have? Are there ways to prevent or lessen side effects?
- 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 7)?
- 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?

Find more detailed questions at tnbcfoundation.org.

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

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.

Chemotherapy is the most effective 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 women 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 (Cytosan), also known as AC chemotherapy. Adriamycin belongs to a family of medicines called anthracyclines, which work by stopping cancer cell growth and repair. Cytosan is in the family of alkylating agents that halt fast-growing cells.

FEC AND FAC (OR CAF)

Some doctors give another medicine, fluorouracil (5FU), in addition to AC, and the regimen is called FAC or CAF. Sometimes a medicine called epirubicin (Elevance) 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. Your doctor may also suggest other combinations of medicines to treat triple-negative cancer.

Radiation

Radiation is a **local therapy** that kills any 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 under-arm 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 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 lbcc.org to order LBCC's *Guide for the Newly Diagnosed*.

Considering Clinical Trials

“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 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.

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. Your participation could make a difference in your life and in the lives of many women 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 open to women with metastatic, or stage IV, cancers.
- **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 women 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 women 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 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 other women 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 downloading a copy of LBBC's *Guide to Understanding Breast Cancer Treatment Research Studies* at lbbc.org.

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 our Survivors' Helpline or the Triple Negative Breast Cancer Foundation for help thinking through your decision.

*As of 2014, the Health Care and Education Reconciliation Act (enacted March 30, 2010) requires individual and group insurance plans to cover routine costs to people who take part in clinical trials.



Dealing with Myths

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 women diagnosed with other types of breast cancer in doctor's 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.

"I have learned as others do that there are survivors out there, long-time survivors. 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 women who have all types of breast cancer. On the other hand, you may feel you cannot relate to women 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 women 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 women with triple-negative breast cancer. The message boards of the Triple Negative Breast Cancer Foundation serve as a forum for you to meet other women with the disease. You also may use the message boards to find news about promising studies and new treatments relevant to you. If you call LBBC's Survivors' Helpline, we can match you with a woman who has been treated for triple-negative breast cancer so you can share your feelings and fears. Journaling and volunteering are avenues you can use to tell your story and get support.

Remember, though, that other women 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



If you just started treatment, we suggest you hold off reading the next few sections until you feel ready to think about what happens when your treatment ends. These sections cover fear of recurrence, emotional concerns, follow-up care and lifestyle changes. You'll also learn about research in the pipeline and ways to move forward with your life. Come back to this booklet any time you have questions.

When Treatment Ends

"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

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.

Fears of Recurrence

With triple-negative breast cancer, the risk of a metastatic recurrence, the breast cancer coming back outside the breast, is strongest in the first five 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 five 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

doctor's appointments and mammograms to find any new breast cancer.

Most women with triple-negative breast cancer never 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

"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

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.

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 lbcc.org.

Follow-up Care

“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

After treatment ends, you will see your oncologist every three to six months for the first one to two years; then every six to 12 months for the next three to four years; and then once a year. If you had a lumpectomy, you will get a mammogram or MRI on the remaining breast or breasts.

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.

“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 health-care 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.

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 more recurrences through physical exams and good health histories than through testing.

If you have a very high risk of new breast cancers, studies show that digital mammography and MRI may be used together to help your doctor detect breast changes. Unfortunately, breast MRI also detects abnormalities that turn out not to be 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 cancer in both breasts or if you have a BRCA1 or BRCA2 mutation. Genetic testing 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 to 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.

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 about these questions.

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.

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

—Suzanne

Try to get your vitamin D and other nutrients from foods like oily fish, milk, fortified cereals and cheese. Getting sunlight for short periods also boosts vitamin D. Ask your doctor whether you need a blood test to check your vitamin D level. If you do not have enough vitamin D in your body, you may need to take a supplement.

If you are considering diet changes, 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. The government recommends at least 150 minutes of physical activity each week. Exercise during treatment if you can, but don't force yourself to do more than you can handle.

The Nurses' Health Study suggested that three to five hours of walking or similar exercise per week may reduce the risk of death after a breast cancer diagnosis. Walking does not cost money. And 150 minutes is only about 20 to 25 minutes each day, or 30 minutes five 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.

If you can, 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.

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, but your doctor or physical therapist should guide you. Aim for moderate exercise 30 minutes a day, five days a week, and eight to 10 strength-training exercises with eight to 12 repetitions of each exercise twice a week.

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. Visit lbbc.org to learn more about these kinds of exercises.

“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. 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 a healthy way. 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 how PARP inhibitors work in triple-negative breast cancers. Consider asking about PARP inhibitors in clinical trials (page 7). To learn more about these medicines, please visit lbcc.org.

DNA Damaging Agents

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

Anti-angiogenic Agents

Anti-angiogenic medicines prevent the growth of blood vessels that cancer cells need to thrive. They block the **vascular endothelial growth factor receptor** (VEGFR), which cells make to grow new blood vessels that connect a tumor to the tissues around it.

Several trials suggest that there may be a benefit from anti-angiogenic therapies against triple-negative metastatic breast cancers and local recurrences, cancers that come back in the area where they were originally found. Researchers hope these medicines may work in early breast cancer as well.



Moving Forward

Researchers are working hard to learn more about triple-negative breast cancers. Every day we 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 Survivors’ Helpline** at **(888) 753-LBBC (5222)** 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.

“My inner life has changed quite a bit and that shows up in my relationships, my work, my life in general. I have, of course, been changed forever.”

—Cheryl



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More Resources

Visit lbcc.org or call (610) 645-4567 to order our other *Understanding* publications:

- Guide for the Newly Diagnosed**
- Fear of Recurrence
- Hormonal Therapy
- Intimacy and Sexuality
- Lymphedema
- Treatment Decisions
- Yoga and Breast Cancer
- Your Emotions

Guides in our Metastatic Breast Cancer Series:

- Guide for the Newly Diagnosed**
- Managing Stress and Anxiety
- Understanding Palliative Care

Tell us what you think of the Guide to Understanding Triple-Negative Breast Cancer.

Fill out our online survey today for a chance to win a **\$25 gift card!**

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<https://www.surveymonkey.com/s/2013LBBC>

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