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The Triple Negative Breast Cancer Foundation funds groundbreaking research and provides support services and resources for patients, including:

• A TNBC Telephone Helpline staffed by oncology social workers
• Annual patient conferences, teleconferences, webinars, and online support groups
• Free fact sheets and educational materials for you and your caregivers
• Online discussion forums for 24/7 peer support
• A TNBC-specific Clinical Trials Matching Service

Learn more by visiting tnbcfoundation.org.

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I'm just so thankful that I had doctors who listened to me when I knew something wasn't right. If I hadn't pushed, I might not be here today. ~ Misty Smith

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Breast cancer is the most common cancer in American women after skin cancer. About 15 or 20 percent of breast cancers are triple-negative breast cancer. Most people are familiar with breast cancer, but many have not heard of triple-negative breast cancer.

**Development and classification**

Breast cancer starts from one abnormal cell that grows out of control and forms a mass of abnormal cells called a tumor. There are different kinds of breast cancers, and they behave in different ways. Some breast cancers are estrogen-receptor positive (ER+), which means they need the hormone estrogen to grow. Breast cancers may also be progesterone-receptor positive (PR+), which means the hormone progesterone helps them grow. In addition to hormones, proteins can help breast cancers grow. If a breast cancer is HER2-positive (HER2+), the protein HER2 helps it grow. Breast cancers that are positive for estrogen receptors, progesterone receptors or HER2 can be treated with hormones or drugs that target HER2.

Triple-negative breast cancers test negative for estrogen receptors, progesterone receptors and HER2. They do not need estrogen, progesterone or HER2 to grow, which means they cannot be treated with hormones or drugs used for ER+, PR+ or HER2+ breast cancers. However, many other treatment options are available for triple-negative breast cancer.

The most common subtype of triple-negative breast cancer is called “basal-like.” 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 refer to triple-negative breast cancer as a basal tumor, basal breast cancer or basal-like disease. People with basal-like triple-negative breast cancer have the same treatment options as others with triple-negative breast cancer.

**Why triple-negative is unique**

Triple-negative breast cancer affects a unique population. Compared with other breast cancers, it is more common in young women, in African Americans and Latinas, and in women with the BRCA1 mutation. Ask your doctor about genetic testing, which can show if you have the BRCA1 mutation. Genetic testing can help identify treatments that will be most successful for you. Gene mutations also are associated with a family risk of breast and ovarian cancers. It is recommended that all patients with triple-negative breast cancer under age 60 be tested for BRCA1 and BRCA2.

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**MYTH vs FACT**

**MYTH** | Women with triple-negative breast cancer have all of the same treatment options as women with other types of breast cancers.
---|---
**FACT** | There are many treatment options for TNBC. They include surgery, radiation and chemotherapy. TNBC does not respond to hormone therapies or to HER2-targeted therapies. Scientists are working to identify other targeted therapies that will be effective in treating TNBC. Studies also indicate that some women with TNBC may respond well to immunotherapy.

**MYTH** | Triple-negative breast cancer always comes back or metastasizes.
---|---
**FACT** | TNBC does not always come back or metastasize. Many women with early-stage disease are treated effectively with no recurrence. TNBC can have a higher rate of recurrence than other types of breast cancer. This is why it is often treated more aggressively when it is diagnosed.

**MYTH** | Triple-negative breast cancers are hard to treat.
---|---
**FACT** | Your prognosis depends on a number of factors in addition to the triple-negative status, including the tumor size and whether it has spread to nearby lymph nodes. This type does tend to be more aggressive; however, effective treatment options are available. Research has shown that hormone-negative breast cancers, which include triple-negative breast cancer, may actually respond better to chemotherapy than other types of breast cancer. Talk to your treatment team about the treatment regimen that is right for you.

**MYTH** | Triple-negative breast cancer means I must have a mastectomy.
---|---
**FACT** | In many cases, a lumpectomy and mastectomy will be associated with the same prognosis, but a lumpectomy is less invasive. Talk to your doctor about which surgical option is recommended for your diagnosis. Know all of your options and weigh both the physical and emotional effects of each treatment type. This will help you make the best treatment decision for you.

**MYTH** | Triple-negative breast cancer affects only African-American women.
---|---
**FACT** | In the United States, approximately 15 percent of breast cancers in white women are triple-negative compared with nearly 30 percent of breast cancers in African-American women. Even though African-American women are more likely to have triple negative disease, this type of breast cancer affects women of all ethnicities.

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**ADDITIONAL RESOURCES**

- **Triple Negative Breast Cancer Foundation:** www.tnbcfoundation.org
- **American Cancer Society:** www.cancer.org/Breast_Cancer
- **Living Beyond Breast Cancer:** www.lbbc.org/Diagnosed_with_Triple-Negative_Breast_Cancer
You know what your body should feel like so if you think something is wrong, push your doctors to investigate further. If I hadn’t done that during my run with breast cancer, things may have turned out very differently.

Back in 2011, I’d had a head cold for a couple of weeks and was having some pain around my breast. I thought I’d just pulled a muscle, but one night I decided I wanted to have it checked out anyway. While I was taking a shower the next morning, I felt a lump and knew I needed to accelerate my appointment.

My family doctor got me in right away. After a quick exam, she referred me to a nearby hospital for a mammogram and an ultrasound. The test results revealed what the doctors thought was a fluid-filled cyst, and they immediately drained it with a needle aspiration. Three days later, the lump was back. A second ultrasound the following week confirmed that the cyst had returned and that it was already the same size as it had been before it was drained.

At that point, I asked for a referral to a surgeon. He did yet another ultrasound and another needle aspiration. And just like the time before, the lump returned only a few days later. I’d had enough, so I told my surgeon I wanted it out. He respected my wishes and removed the cyst on Nov. 18. Four days later on Nov. 22 — a date I’ll never forget — my surgeon called me to say that what we’d thought was a cyst was actually cancer. I had Stage II triple-negative breast cancer — specifically, invasive (infiltrating) ductal carcinoma — at age 35.

I was shocked. My first thought was not about myself but how my girls would get through this. I have two daughters; one was in high school and one in preschool at the time. We were supposed to travel for Thanksgiving the next day, but we stayed put. Six or seven of my close friends were at my house within 30 minutes after my surgeon called. I was so blessed to have them help me through that first night.

I soon began eight rounds of chemotherapy, four with doxorubicin (Doxil) and cyclophosphamide (Cytoxan) and four with paclitaxel (Taxol). The side effects were tough, and after the third and fourth rounds I was actually hospitalized for about a week because of dehydration and extreme nausea. Emotionally I had a difficult time, too, but I knew I had to fight with everything I had to be there for my girls.

After chemotherapy, my doctors ordered a few routine follow-up scans. Not expecting anything big, I brought my mother and one of my daughters to the appointment with me — but the results hit me like a ton of bricks. They showed spots in my lungs, liver and under my arms. It looked as if my cancer had spread and advanced to Stage IV. My daughter lost it, and I lost it. I just felt numb.

To find out exactly what was going on, my oncologist ordered a mediastinoscopy to obtain a biopsy. After three excruciating weeks of scans, appointments with specialists and waiting, we got the results. To everyone’s surprise and relief, they showed a granulomatous inflammation, not metastasized cancer.

As it turned out, the chemotherapy had suppressed my immune system and caused me to develop an autoimmune disease called sarcoidosis, which was what showed up on the scans. Treatment involves high doses of steroids, which I took and will continue to take each time the disease flares up. After confirming that I didn’t have Stage IV cancer, I underwent radiation therapy 33 times to round out my initial treatment plan, finishing in August 2012.

I wouldn’t have made it through all of this without my family and friends. I had someone with me for every chemo session, and having them there was just amazing. It made treatment go faster and took my mind off what I was there for. I also received a lot of support from the school district where I work as a fourth-grade teacher, and my sister-in-law even put on a benefit in my honor.

Now I go to the oncologist every three months to check for tumor markers. I still take steroids for my sarcoidosis and am doing great. This journey has taught me that I’m truly blessed and that life is never guaranteed — none of us are promised tomorrow. I spend every second I can with my children, and it meant the world to me to see my little girl start kindergarten and my oldest start college. I’m much stronger physically, mentally and emotionally than I ever thought I was, and I’m just so thankful that I had doctors who listened to me when I knew something wasn’t right. If I hadn’t pushed, I might not be here today.
Once breast cancer is diagnosed, the disease must be staged according to the extent of cancer, including how much is in the body, where it’s located, and whether or how far it has metastasized (spread). Staging helps the doctor plan a course of treatment.

Clinical staging, which is done by the managing physician, is based on the tumor’s characteristics as assessed through a physical exam, X-rays, scans and/or other imaging studies and laboratory results. Pathologic staging is done by a pathologist, who examines tissue specimens removed during surgery or biopsy.

The staging system used for most cancers, called TNM staging, was developed by the American Joint Committee on Cancer (AJCC). This tumor (T), node (N) and metastasis (M) classification (see Table 1) is then used as the foundation for the overall stage of breast cancer.

The T (tumor) classification is the same for both clinical and pathologic staging. This category provides information on the size and extent of the tumor within the breast. Clinical staging for the N (node) category describes which lymph nodes have evidence of breast cancer cells. The anatomic location of the involved lymph nodes is important because it shows the extent the disease has spread. The pathologic N (node) category (sometimes denoted as pN) shows how many lymph nodes are involved and the amount of tumor cells actually found in the nodes.

The M (metastasis) category indicates whether there’s evidence of distant metastasis (spread of cancer to another part of the body beyond the breast and local lymph nodes). Staging for the M category is primarily clinical, although a new M subcategory is based on the presence of tumor cells that can be detected only by microscopic examination or with molecular testing. The most common sites of distant metastasis in breast cancer are the bones, lungs, liver and brain.

After the breast cancer has been classified according to this system, an overall stage is assigned (see Table 2).

A pathologist will also assign a grade to your breast cancer, which is based on the microscopic features of tumor cell growth rate and aggressiveness. Knowing the grade helps determine how fast a cancer is likely to grow and how likely it is to spread. Triple-negative breast cancers are often diagnosed as Grade 3, meaning they tend to grow quickly and spread. Higher grade cancers may be more aggressive, but they are still treatable.

In addition to staging breast cancer, the AJCC recommends tissue testing to better determine which treatments are likely to be most effective. Breast cancer tumors are tested for estrogen and progesterone receptors (ER/PR) and human epidermal growth factor receptor-2 (HER2).
**STAGES OF BREAST CANCER**

**Stage IA**
- Tumor is 2 cm or smaller
- Lymph nodes
- Micrometastases in lymph nodes

**Stage IB**
- Tumor is 2 cm or smaller
- Lymph nodes
- Micrometastases in lymph nodes

**Stage II A**
- Tumor is up to 5 cm in greatest dimension
- Possible lymph node metastasis in one to three lymph nodes

**Stage IIB**
- Tumor is 2 to 5 cm (T2) or larger than 5 cm (T3) in greatest dimension
- Possible lymph node metastasis in one to three lymph nodes

**Stage IIC**
- The tumor may be any size but has not spread to distant parts of the body
- Multiple lymph node metastasis

**Stage IIIA**
- Tumor may be any size
- Multiple lymph node metastasis

**Stage IIIB**
- Tumor has spread to the chest wall or caused swelling or ulceration of the breast
- Possible multiple lymph node metastasis

**Stage IVA**
- Tumor may be any size and spread to other parts of the body
- Possible multiple lymph node metastasis

**Stage IV**
- Metastases
- Brain
- Bone
- Lung
- Liver

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**GENETIC TESTING**

**Triple-negative breast cancer** is associated with mutations in the *BRCA1* and *BRCA2* genes. Knowing whether you have a mutation in one of these genes is valuable for two reasons: choosing treatment and assessing your family's cancer risk.

**GENETIC PROFILING FOR TREATMENT**

Experts recommend that people with TNBC under age 60 be tested for *BRCA* mutations. If you have a *BRCA* mutation, some treatments may be more effective for you. Your health care team will work closely with you to determine the best treatment plan for your TNBC. Additionally, a *BRCA* mutation puts you at a higher risk for cancer in the other breast and ovarian cancer. If you have a *BRCA* mutation, you can learn about ways to lower your risk for those cancers. Research is being done to find better ways to detect, treat and prevent cancer in people with *BRCA* mutations.

**GENETIC TESTING FOR YOUR FAMILY’S RISK**

If you have a *BRCA* mutation, your family members may also carry the mutation. A genetic counselor can discuss the risks and benefits of genetic testing to help you and your family decide if it is appropriate for your family members. A genetic counselor can also explain the results of genetic testing, which can sometimes be complicated.

Most experts recommend against testing children under 18 for *BRCA* mutations because no safe, effective therapies to prevent breast cancer in children currently exist. Moreover, children are not old enough to decide whether they want to know about their cancer risk.

**Ask your doctor about genetic testing, and visit the following websites to learn more:**

- **Triple Negative Breast Cancer Foundation:** www.tnbcfoundation.org/guide-to-understanding-triple-negative-breast-cancer
- **Facing Our Risk of Cancer Empowered:** www.facingourrisk.org
- **National Society of Genetic Counselors:** www.nsgc.org

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Each breast cancer is unique, and so is each person’s response to treatment. After learning more about your triple-negative breast cancer from your pathology report and other test results, your doctor will determine the best treatment plan for you based on the following:

- Features of your tumor, including its size and location
- Lymph node involvement
- Tumor grade
- Genetic testing results

TREATMENT OPTIONS

Triple-negative breast cancer is typically treated with a combination of surgery, radiation therapy and/or chemotherapy. Clinical trials also offer access to cutting-edge treatments that are being studied. In addition to educating yourself about the options available to you, talking with other survivors of triple-negative breast cancer can be helpful in making treatment decisions.

Surgery

For most breast cancers, surgery is the primary treatment. A lumpectomy is a surgery known as “breast-conserving treatment” because most of the breast is left intact. The surgeon removes only the tumor (lump) and a small amount of healthy tissue around the lump (see Figure 1). Lumpectomy can be done for most small tumors.

A mastectomy, surgery to remove the entire breast, is often done for large tumors (Figure 2). Some people with a small tumor may choose a mastectomy to ease their worry about monitoring the breast for recurrence, and some choose this option as a way to potentially avoid radiation therapy. Your doctor may recommend a mastectomy if you have a large tumor, multiple tumors in the breast, cancer that involves the nipple or has spread to the skin or if you’ve already had breast cancer in the same breast.

During either surgery, the surgeon may also remove lymph nodes under the arm. A pathologist will examine the nodes for cancer cells. This step is called lymph node staging and helps doctors determine the stage of the breast cancer. To remove as few lymph nodes as possible when suspicious nodes are not felt on physical examination, surgeons use a procedure called sentinel lymph node biopsy, which helps determine if and where cancer has spread. If cancer cells are found in the sentinel lymph node (the closest node to which the cancer has most likely spread), nearby lymph nodes are usually removed. If no cancer cells are found in the sentinel node, it’s unlikely that cancer cells have spread to farther lymph nodes. After a mastectomy, you have many options for reconstructive surgery. This is usually done by a plastic surgeon who rebuilds the breast to make it look as much as possible like it did before surgery.

Other types of surgery may be appropriate, especially for women in whom hereditary breast cancer has been identified. These women have a higher-than-average risk for cancer in the contralateral (opposite) breast, ovaries or fallopian tubes and may choose to have prophylactic (preventive) removal of the ovaries and fallopian tubes or of the opposite breast as a precaution against future cancer. Removal of the ovaries has substantial side effects, such as infertility (the inability to have children), potential risks to bone and heart health, early menopause and negative body image. Talk to your doctor about all of these risks before deciding if surgery is right for you.

Radiation therapy

External-beam radiation therapy is the most common type of radiation therapy for triple-negative breast cancer. With this type of therapy, radiation is delivered from an external machine. Internal radiation, or brachytherapy, may be used either alone or in combination with external-beam radiation. Brachytherapy involves placing radioactive seeds through a catheter in the breast to deliver radiation directly to the area where the tumor was removed.

Radiation therapy is almost always done after lumpectomy to destroy any cancer cells that may remain. Research shows that women with a small tumor who have radiation therapy after a lumpectomy live as long as those who have a mastectomy. Radiation therapy may also be done after a mastectomy and is typically recommended for women at high risk for cancer recurrence. If the breast cancer has metastasized (spread), radiation therapy may be used to treat symptoms of metastasis.

Chemotherapy

Chemotherapy is typically the most effective treatment for triple-negative breast cancer. Research has shown that triple-negative breast cancer may respond better to chemotherapy than other types of breast cancer. Several chemotherapy drugs are available and may be given as a combination of drugs, either together or one after the other (sequentially) over a specific period (usually...
three to six months).

Chemotherapy may be given before surgery, known as neoadjuvant chemotherapy, or after surgery, known as adjuvant chemotherapy. Neoadjuvant chemotherapy may be used to shrink a tumor so that it can be surgically removed or to shrink a large breast tumor to allow for lumpectomy rather than a mastectomy. Chemotherapy may also be used as the primary treatment for triple-negative breast cancer that has spread beyond the breast and nearby nodes, in which case the regimen and schedule will depend on how the cancer responds and the side effects of treatment.

Adjuvant chemotherapy is given to destroy cancer cells that may remain after surgery, some of which may be too small to detect with laboratory testing or imaging studies. It is typically recommended for patients with a high risk of recurrence, such as those with cancer in the lymph nodes.

Disease responds differently to chemotherapy in every patient, and certain drugs may be more effective for you. If your disease doesn’t respond as expected to one chemotherapy drug, your doctor may recommend another. Researchers continue to study various chemotherapy combinations and the genetic makeup of tumors to determine which regimens work best against the specific characteristics of different tumor types.

Chemotherapy often causes side effects such as nausea, hair loss and increased risk of infection, but many patients can continue most of their usual activities. Discuss the advantages and disadvantages of chemotherapy drugs with your medical team so you can make an informed decision.

Clinical trials

The cancer treatments in use today are the result of clinical trials, research studies that explore whether a medical strategy, treatment or device is safe and effective. Triple-negative breast cancer is an ongoing focus of cancer research. New treatment options are being studied, with much of the development in targeted therapy and immunotherapy.

When you volunteer to participate, you will receive specific instructions. Ask questions about anything you don’t fully understand. This is the ideal time to talk with your medical team about misconceptions about clinical trials. For example, although there is fear to the contrary, participants are guaranteed to receive at minimum the current standard of care during the trial.

All enrolled patients in a clinical trial are treated exactly the same. Whether you’re at a small rural hospital or a large facility in a metropolitan area, your medical team must diligently follow all the safety measures for your treatment plan. You will be carefully monitored throughout the clinical trial. Even after treatment ends, you will be in close contact with the medical team.

Immunotherapy

The immune system naturally protects the body by attacking germs, but cancer cells have a unique ability to withstand those attacks and to inhibit the immune system. Immunotherapy uses drugs to activate the immune system to block the cancer cells’ immune-inhibiting mechanisms, which stops or slows the growth of cancer. Something that separates immunotherapy from traditional treatments is its “memory,” the ability to remain effective long after treatment ends.

Successes in treating melanoma and lung cancer with immunotherapy have encouraged scientists to continue studying ways to treat triple-negative breast cancer with immunotherapy.

Targeted Therapy

Targeted therapy is treatment with drugs or other substances that block the growth and progression of cancer by interfering with specific molecules on or in the cancer cell. There are currently no approved targeted therapies for triple-negative breast cancer, but promising treatments in clinical trials include poly (ADP-ribose) polymerase (PARP) inhibitors, VEGF (vascular endothelial growth factor) inhibitors, androgen receptor blockade, PI3 kinase inhibitors, EGFR (epidermal growth factor receptor) inhibitors and combination therapies that include chemotherapy.

Clinical trials offer access to treatments that could work for you. You also might consider volunteering for quality-of-life trials, which study ways to improve the quality of life for people with cancer and survivors who experience cancer- and treatment-related symptoms. You may be a candidate for prevention, screening and diagnostic trials, which assess ways to reduce the chance of getting a second cancer or having a recurrence.

If you are interested, ask your medical team or search for trials online (see below).

Additional Resources

- Triple Negative Breast Cancer Foundation: www.tnbcfoundation.org
- Guide to Understanding Triple-Negative Breast Cancer
- National Cancer Institute: www.cancer.gov
- Triple Negative Breast Cancer
- National Comprehensive Cancer Network: www.nccn.org
- NCCN Guidelines for Patients: Breast Cancer

SEARCH FOR CLINICAL TRIALS

You can learn more about clinical trials and search for triple-negative breast cancer clinical trials at the following sites:

- TNBC Foundation Clinical Trials Matching Service: www.tnbcfoundation.org/clinical-trials
- BreastCancerTrials.org: www.breastcancertrials.org
- CISCRP: www.searchclinicaltrials.org
- ClinicalTrials.gov: http://clinicaltrials.gov
- Coalition of Cancer Cooperative Groups: www.cancertrialshelp.com
- My Clinical Trial Locator: http://myclinicaltriallocator.com
- National Cancer Institute: www.cancer.gov/clinicaltrials
A metastatic triple-negative breast cancer diagnosis can be overwhelming and brings with it concerns about treatment options, finances and more. Still, progress is being made every day in triple-negative breast cancer research. You are not alone.

Metastatic breast cancer is also referred to as advanced or Stage IV breast cancer. When breast cancer spreads, or metastasizes, it typically lands in the liver, lungs, brain or bones. Some patients are diagnosed with metastatic disease during follow-up appointments or during evaluation of symptoms in those organs such as persistent cough, shortness of breath or bone pain. Others with triple-negative breast cancer are diagnosed with advanced disease from the beginning.

When breast cancer spreads to another part of the body, it is still considered breast cancer. For example, triple-negative breast cancer that has metastasized to the lung is still breast cancer, not lung cancer, and will be treated with the breast cancer therapy you decide on with your medical team.

A cure is not yet available for Stage IV breast cancer. As a result, the goal of treatment is to control the growth of the cancer while providing the highest quality of life possible. Your doctor will work closely with you to identify the treatment that works best for you. Ongoing advances in research are resulting in treatments that let many people with metastatic breast cancer live longer, with a good quality of life.

Monitoring your cancer

Tracking your disease’s response to treatment is an important part of your overall care plan. To monitor your cancer, you will undergo routine testing. If that testing shows that your treatment is not slowing or stopping the growth of your cancer, you and your health care team will consider alternative treatment options.

Several types of tests can help monitor the cancer’s response to treatment. These tests include imaging studies, tumor marker testing and a blood test that measures a special type of tumor cell in the blood. Often, more than one test is needed to determine how well treatment is working. To have a baseline for comparison with later studies, your doctor will perform one or more of these studies before starting treatment.

You will probably have routine visits with your doctor during treatment. Use these visits to tell your doctor about any new or changing symptoms. Pain relief, easier breathing or increased energy could be signs that the cancer is responding to treatment. Depending on the sites of metastasis, your doctor may be able to tell if treatment is working by doing a physical exam. For example, if a lymph node is a site of metastasis, your doctor may be able to feel that the node has gotten smaller, which means that the metastasis has shrunk.

Together, your input and the results of ongoing, specific testing can tell you and your doctor how well your treatment is working.

Shifting your treatment course

Your treatment may need to be adjusted depending on how your body responds and the progression of the disease. If you feel like you need a break from treatment, talk with your medical team. Your doctor may suggest a different treatment or a different dosage of your current treatment. Weigh the pros and cons, and consider how the corresponding side effects fit into your idea of a good quality of life before you make a decision. Changing your chemotherapy dosage or managing your side effects differently could improve how you feel.

If you have tried multiple treatment options that are no longer working, you may reach a time when you choose to stop treatment altogether. Talk with your doctor about your feelings. You likely will receive input from others on your medical team as well as family members and friends, but the decisions are yours to make.

If you make that difficult decision, you are strongly encouraged to investigate hospice care, where efforts are focused on managing symptoms and supporting the patient and family, but not using cancer therapies. Hospice care can take place at home or in a hospice center and offers physical, emotional and spiritual support for you and your loved ones.

Exploring clinical trials

Clinical trials are a valuable, potentially life-saving treatment option to consider. Through clinical trials, researchers and doctors are learning more about triple-negative breast cancers and how they respond to treatment. If you qualify for a clinical trial, you will have access to leading-edge treatments, such as immunotherapy and targeted therapy, that aren’t yet available to the public.

There are many reasons to consider participating in a clinical trial:

- As someone living with TNBC, you have a unique cancer and could benefit from these leading-edge treatment options.
- Your current treatment may not be working as well as expected.
- A clinical trial may significantly improve your quality of life. Discuss your personal situation with your medical team, so they understand your expectations for side effects.
- By simply participating, you play an integral role in helping refine and improve the way millions of people with cancer are treated.

Successes from other clinical trial participants may inspire you to volunteer. Keep in mind that not everyone responds to treatments in the same way, so you cannot expect an identical experience in response to treatment or side effects.

You can research clinical trials at any time during your treatment. Regardless of when you enroll in a trial, participating will not jeopardize your guarantee to receive the standard of care.

Ask your doctor if you are a candidate for a clinical trial, or search online for available clinical trials starting with the two below.

- TNBC Foundation Clinical Trials Matching Service: www.tnbcfoundation.org/clinical-trials
- Metastatic Trial Search: www.breastcancertrials.org
After you complete treatment for triple-negative breast cancer, your medical team will set up a follow-up care plan. This is an important step in your cancer care to monitor your recovery, manage any remaining side or late effects from treatment and to watch for any signs of recurrence or metastasis. To develop a personalized plan, talk to your medical team about your follow-up schedule, which physicians you will continue to see and what screening is necessary.

Your screening schedule will depend on several factors, including your specific diagnosis, the treatments you received and your age and overall health. Generally, the following screening tests are recommended after breast cancer treatment:

- **Physical exams every three to six months** for the first three years after the first treatment, every six to twelve months for the next two years, and then once each year thereafter.
- **A mammogram one year after the first mammogram that led to your diagnosis.** If you received radiation therapy, it is advised to wait six months after your last treatment. A mammogram is then recommended at least once per year. Additionally, perform monthly breast self-examinations.

**Survivor Story | Roxanne Martinez**

I was pregnant with my first child at the time of my diagnosis. My treatment plan entailed an immediate mastectomy, followed by chemotherapy starting in my second trimester. I based my treatment decisions on research and the advice of my oncologist and other medical experts and decided on a course that would allow me to continue with my pregnancy while also fighting for my own life.

Because I needed to undergo treatment while pregnant, I was forced to balance prenatal check-ups and treatment. With chemo every other week, it was a rough pregnancy. On the day of my last scheduled chemo appointment, I instead went into early labor. Despite being born premature, my baby girl was born perfectly healthy. She’s my miracle. After her birth, I underwent additional surgery, which brought with it many challenges for a new mom.

My diagnosis brought on a rollercoaster of emotions. I faced many dark moments during my battle with breast cancer, but there were also many overwhelming moments of joy. Fighting cancer takes a huge toll on you emotionally, and one thing I learned was that it doesn’t get easier just because you finished treatment. As a survivor, you’re often still faced with depression, anxiety and other emotions. And fear of recurrence can consume you. After treatment, I started seeing a psychotherapist and tried yoga and meditation to reduce anxiety. About 4 years after my diagnosis, I made the conscious decision to completely let go of my fear that the cancer would return. At first, it took a daily effort to not focus on breast cancer, but it has gotten easier as time goes on.

It’s important not to focus on the negative. You can survive triple-negative breast cancer. Seek out the support you need and know that it may come from unexpected sources. Connect with other triple-negative survivors through groups like the Triple Negative Breast Cancer Foundation. You are not alone in this fight.

**Genetic counseling** if you have not considered it already.

In addition to following screening guidelines, patients recovering from triple-negative breast cancer are encouraged to maintain a healthy lifestyle, including reaching and maintaining a healthy weight, eating a balanced diet and exercising.

**Recurrent disease**

One of the biggest fears patients with cancer face is the possibility the cancer will come back, or recur. A triple-negative breast cancer recurrence is when the breast cancer comes back in the same or opposite breast or chest wall. If the cancer comes back outside of the breast, it is called metastatic recurrence. Both are considered advanced disease and a diagnosis of either can be overwhelming. It is important to remember that you are not alone and that there are treatment options available to you.

If your cancer recurs, be sure to talk to your medical team about re-evaluating the tumor for hormone-receptor and HER2 status because it may be different than your original diagnosis.

**Recognizing your fear**

As a patient with triple-negative breast cancer, your fear of recurrence may be compounded by the knowledge that long-term treatment is not an option for you. Once your treatment ends, you may feel as if you are not doing all you can to protect yourself against recurrence. Additionally, certain events such as holidays, family gatherings and medical appointments may make you emotional and more susceptible to worry.

All of those feelings and fears are valid, but they don’t have to control your life. You can help manage your fear of recurrence in the following ways:

- Listen to your body. Not every symptom means a recurrence, but you can only be sure if you communicate openly with your medical team.
- Create a follow-up plan, also called a survivorship plan, which addresses long-term side effects, support resources, nutrition, finances and more.
- If you have metastatic cancer, monitor your condition with scheduled periodic testing as suggested by your medical team.
- Embrace life by engaging in activities you enjoy.

If your fears become overwhelming, it’s time to seek the advice of a professional. See the resources in this guide, and reach out to your medical team.
Women with triple-negative breast cancer may worry about the side effects of their treatment. Medication and simple lifestyle changes may help prevent or manage these side effects. Each woman responds to treatment differently, so you may not experience all these side effects. Tell your doctor about your side effects so he or she can recommend a remedy. Side effects differ according to the type of treatment you receive. Knowing which side effects to anticipate and how to manage them prepares you as you begin treatment.

**Cognitive dysfunction ("Chemo Brain")**

Many women who receive chemotherapy for triple-negative breast cancer have trouble remembering words or directions, or concentrating, and may experience memory lapses in the middle of tasks. This can leave you feeling like you are in a mental fog. These memory and thinking problems are collectively referred to as chemo brain. The science behind this is still not well-developed, but many of the side effects of chemotherapy improve or resolve over time.

Try keeping a record of the problems you have and when they happen, and tell your health care team about them.

**Fatigue**

Everyone knows what exhaustion feels like, but the fatigue caused by cancer and its treatment is different. It's stronger and often lasts longer, even with enough sleep. Fatigue often occurs with chemotherapy and radiation therapy.

**Hair loss (Alopecia)**

Hair loss can be one of the most emotionally difficult side effects of treatment for triple-negative breast cancer. You may lose your eyebrows, eyelashes and other body hair in addition to the hair on your head. Chemotherapy can cause hair loss, and radiation therapy may cause hair loss in the treated area.

**Lymphedema**

Your lymphatic system carries white blood cells throughout the body to help fight infections. When lymph nodes are removed as part of your treatment, the lymphatic fluid can build up. This can cause swelling in the area where the lymph nodes were removed, most often in an arm or leg. Patients with breast cancers typically experience lymphedema immediately after surgery or radiation therapy. However, it can also become an issue months or even years after treatment ends.

**Nausea and vomiting**

Nausea is feeling sick to your stomach and may come with an urge to vomit. Nausea and vomiting are most often caused by chemotherapy but can be caused by other treatments too. Your doctor may be able to prescribe medicines to prevent or reduce nausea before or during your treatment.

**Neuropathy**

Neuropathy is pain or discomfort caused by damage to the nerves that control movement and feeling in the arms and legs. Symptoms of neuropathy are numbness, pain, burning, tingling or loss of feeling in the hands or feet. If you have these symptoms, keep a journal of when they happen, what they are, how long they last and how intense they are and share this information with your health care team. Chemotherapy can cause neuropathy, but not everyone who receives chemotherapy will experience neuropathy.

If your treatment causes neuropathy, your doctor may switch to a different chemotherapy drug or change how your chemotherapy is given. He or she may also prescribe pain medicines, steroids or numbing creams or lotions.

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**TIPS FOR MANAGING SIDE EFFECTS**

- During treatment for triple-negative breast cancer, simple changes may help you prevent or manage some of the most common side effects.

**COGNITIVE DYSFUNCTION ("CHEMO BRAIN")**

- Use a daily planner or calendar to keep track of "to do" lists and events.
- Focus on the task at hand. It’s okay not to multitask.
- Organize your home and work spaces and keep important items, such as keys, in a specific place.
- Tell your friends and family you’re having trouble so they can help you remember important information.

**FATIGUE**

- Accept help from others who want to help lighten your load.
- Regular moderate exercise, especially walking, decreases fatigue so try to stay active.
- Nap when you can, but not too much. Try to keep naps to about 30 minutes and get eight hours of sleep per night when possible. Set a routine for sleeping and waking.
- Conserve energy by setting priorities and planning to do the most important things when you have the most energy.

**HAIR LOSS (ALOPECIA)**

- If you choose to use a wig, buy it before treatment begins to help you match it to your own hair. Also consider turbans, scarves and hats.
- Your health insurance may cover wigs. If so, ask your doctor to use “cranial prosthesis” on the prescription rather than “wig.”
- Use a mild shampoo and a soft brush or wide-toothed comb and avoid using elastic hair bands, which can cause breakage.
- Sleep on a satin pillowcase.
- Ask your doctor if using a cooling cap during treatment would be appropriate for you.

**LYMPHEDEMA**

- Use a compression garment or tight bandages to apply pressure to the area.
- Elevate the swollen limb to encourage drainage of the lymphatic system.
- Talk to your doctor about manual lymphatic drainage (MLD), a gentle skin massage that helps drain lymphatic fluid into the bloodstream, reducing swelling.

**NAUSEA AND VOMITING**

- Eat smaller, more frequent meals throughout the day.
- Eat at the times of day you feel best.
- Avoid spicy, citric and fatty food. Bland foods, such as bananas and crackers, are easier to digest.
- Foods and drinks that include ginger, such as ginger ale or ginger tea, can be soothing. Peppermint can also relieve nausea.
- Drink plenty of fluids.

**NEUROPATHY**

- Avoid tight-fitting clothes and wear comfortable shoes.
- Keep your hands and feet warm.
- Avoid standing or walking for long amounts of time.
Managing Emotionally

A diagnosis of any kind of cancer is upsetting. Triple-negative breast cancer can be especially difficult to hear because people do not always understand that it is different from other breast cancers. Feeling a range of emotions is normal as you learn about your diagnosis, begin treatment and explain your diagnosis to friends and family. Even if you feel alone during this time, remember that you are not. Many other women with triple-negative breast cancer have gone through similar experiences. Below are some of the common emotional responses you may have and helpful ways to cope with them.

Feelings of isolation

Some women with triple-negative breast cancer feel isolated, even from women with other breast cancer diagnoses. It can be hard to hear about people who have treatment options you don’t have. Likewise, well-meaning friends may ask insensitive questions or suggest options that just aren’t available to you. Having to explain how your diagnosis is different from other breast cancers or needing to correct misconceptions can also be frustrating.

Seeking out other patients with triple-negative breast cancer may help you cope with feeling isolated.

Anxiety and depression

Feeling sad, worried or overwhelmed during your treatment is normal. You may find that these feelings are worse at some times than others. If these negative feelings don’t go away or get worse, you may have anxiety or depression. Anxiety and depression are considered medical conditions and can be managed.

If your anxiety grows beyond normal worry, you may have an anxiety disorder. Common symptoms of an anxiety disorder include:

- Feeling in a constant state of tension or worry
- Feeling “on edge” or irritable
- Becoming tired easily or having trouble sleeping
- Having trouble concentrating

If your sadness interferes with your daily life, you might have depression. If you experience at least five of these symptoms every day for at least two weeks talk to your doctor about depression:

- Persistent sad, anxious or “numb” feelings
- Loss of interest or pleasure in hobbies and activities
- Feelings of hopelessness
- Feelings of guilt, worthlessness or helplessness

Women with mild anxiety or depression may benefit from counseling. Counseling can help you improve your communication with family members and friends, as well as ease fears about your cancer. Cancer support groups may also be helpful.

Other women may find a combination of counseling and medication (antidepressants) effective. Many antidepressants are available and each one has different side effects, so talk to your doctor about which antidepressants may work best for you with the fewest side effects. Cognitive behavioral therapy may also be an option and involves changing your negative thoughts and behavior with the help of a mental health professional.

Fear

Fear is common during treatment and may remain prevalent even after treatment ends because of the risk of recurrence associated with triple-negative breast cancer. Feeling fear is completely normal. These suggestions may help you manage the fear you feel during or after treatment:

- Focus on what you love. Activities you enjoy can help you feel better and live in the present.
- Avoid unnecessary stress by staying away from people who make you feel negative and say no to taking on extra responsibilities.
- Get support. Talk to your family and friends about your feelings and fear of recurrence. Talking to a mental health provider or attending a support group may also be helpful.

Survivor Story

I was diagnosed with Stage IIIA triple-negative breast cancer at the age of 55 and was treated with a double mastectomy, radiation therapy and chemotherapy. I’ve spent the last five years working diligently to raise awareness of TNBC, especially among young African-American women, who are far more likely than other groups to have this type of breast cancer. I always tell the women I talk with to check the breasts you love and be cognizant of your body. This type of breast cancer is unique because, unlike most others, there is no maintenance therapy to help prevent recurrence. And although I’ve been tested and do not have the BRCA mutation, I feel very strongly that when my daughters reach their mid-30s they should consider prophylactic surgery.

The best advice I received early in my treatment was to remove stress from my life. I worked really hard and made some very drastic changes to get rid of my stress. I filed for divorce from my husband of 30 years, sold my house and moved to the beach where I grew up. I can’t prove it, but I know that focusing on my happiness had a significant effect on my cancer. And the support that I received was critical. Family and friends took care of me, and I was never alone for the entire first year.

It can be difficult to deal with a triple-negative diagnosis, but I decided early on that I was going to be triplepositive because I am a walking blessing and so grateful for every moment. I was saved to do something with my life, and I’ve found my purpose in advocacy work. Find your happy place, figure out what is going to give you peace and get stress out of your life. Channel your fear into faith so that you can celebrate every day because every day is a blessing.

Additional Resources

- American Cancer Society: www.cancer.org Caring for the Patient With Cancer at Home
- American Society of Clinical Oncology: www.cancer.net Managing Emotions
- CancerCare: www.cancercare.org Triple Negative Breast Cancer
Many women diagnosed with triple-negative breast cancer are younger than most breast cancer patients. Although a breast cancer diagnosis can be shocking at any age, it can be especially difficult when you are in the middle of starting or raising a family and/or career. The drastic shift in focus to treatment and recovery often presents unique issues, such as how to preserve your fertility or needing to talk to your kids about cancer. Know that you are not alone. Talking to other triple-negative breast cancer survivors can help you to better cope with the adjustment you may have to make before, during and after treatment.

Fertility

Millions of women undergo cancer treatments that will successfully save their lives but can also leave them permanently unable to get pregnant. This can be a major concern for women of childbearing age who were diagnosed with this disease before they were able to start or finish creating their families. If you’ve been diagnosed with cancer but are not ready to rule out the possibility of becoming a parent, consult with a fertility expert before committing to any treatment options that may leave you unable to have children. Fortunately, there are ways to preserve your fertility, and your medical team can help you better understand your options.

Talking to your kids about cancer

Kids are perceptive and often know when something is wrong so you should consider talking to your kids about cancer as soon after the diagnosis as possible. If you’re having trouble starting the conversation, it may be helpful to include another family member or a professional who can help answer questions. Also keep the following in mind:

• When talking about it, don’t avoid the word “cancer” as this may unintentionally cause confusion and misunderstanding.
• Provide age-appropriate information to help ensure kids aren’t drawing their own conclusions, which can sometimes be scarier than the facts.
• Be realistic. Making your kids believe you’re going to be just fine may confuse or scare them even more if you get sicker. Instead, let them know that you and the doctors are doing all you can to fight the cancer.
• Try to help your child understand the treatments and side effects you may have.

Re-entering the work force

Many people diagnosed with cancer are forced to make choices that affect their career, and younger patients may find that they have to put it on hold altogether. If you took time off during cancer treatment, re-entering the work force can be a difficult transition, whether you are returning full-time, part-time or starting a new job. It can be a confusing clutter of feelings, but mixed emotions are normal so give yourself plenty of time to work through them. Setting career goals, understanding disclosure obligations and determining any necessary modifications you’ll need beforehand can all help you clear your head and ease the transition.

SURVIVOR VOICE | Roxanne, Stage II B

“I was terminated from my full-time job during treatment but my cancer diagnosis ultimately led me to start my own business as a marketing consultant. Overall, losing my job was a blessing in disguise.”

GLOSSARY TERMS

Use these definitions to help familiarize yourself with some of the terms your medical team may use.

Breast reconstruction – Surgery to recreate the breast’s shape after a natural breast has been removed. Procedures may involve the use of implants or natural tissues.

Estrogen – A female hormone produced by the ovaries and adrenal glands. It is important for reproduction and may stimulate some cancers to grow.

Estrogen receptors – Specific proteins in breast cancer cells to which estrogen hormones attach. A high number of estrogen receptors often means the cancer cell needs estrogen to grow.

Lumpectomy – Also called breast-conserving surgery, this procedure removes only the part of the breast containing and closely surrounding the cancerous tumor.

Lymph nodes – Tissues in the lymphatic system that filter lymph fluid and help the immune system fight disease.

Lymphatic system – The network of lymph nodes and vessels in the body.

Mastectomy – Surgical removal of the breast. The exact procedure (simple, total, radical) depends on the diagnosis.

Metastasis – Spread of cancer to other organs through the lymphatic and/or circulatory system.

Mutation – A mistake or alteration of the information contained in a gene.

Progesterone – A hormone made by the body that is important in menstrual cycles and pregnancy.

Progesterone receptor – Specific proteins on breast cells that progesterone hormones attach to. A high number of progesterone receptors often means that a cancer cell needs progesterone to grow.

Prognosis – The expected or probable outcome or course of a disease; the chance of recovery.

Prophylactic surgery – Preventive surgery in order to keep cancer from developing.

Sentinel lymph node – The lymph node in the underarm area nearest to the breast tumor that filters lymph fluid from the tumor site.

Tumor markers/biomarkers – A substance made by cancer cells and sometimes normal cells that may be useful in developing a treatment plan, monitoring response to treatment or when looking for cancer that has come back (recurred).
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