

# TRIPLE NEGATIVE BREAST CANCER GUIDEBOOK

Educating, advocating, empowering and supporting young women - before, during and after breast cancer



This guidebook is provided through the generous support of Merck.

# DEAR YOUNG WARRIOR:

Getting diagnosed with breast cancer is a lot to handle. You have some important decisions to make! Learning that you have triple negative breast cancer (TNBC) adds an additional layer of questions about your treatment plan and survivorship.

As a newly diagnosed young woman, this guidebook will help you understand what TNBC is; risk factors; treatment options; and empower you to use your voice to engage your healthcare team. Thank you for trusting us on this journey. We look forward to helping you navigate your diagnosis, and to become even stronger, more empowered and live an even more fearless life going forward. If you'd like to share your thoughts about this guidebook or for more information, email [info@tigerlilyfoundation.org](mailto:info@tigerlilyfoundation.org) or visit [www.tigerlilyfoundation.org](http://www.tigerlilyfoundation.org). You can also reach us at (888) 580-6253.

Blessings, hope and with much love,

**Maimah S. Karmo**

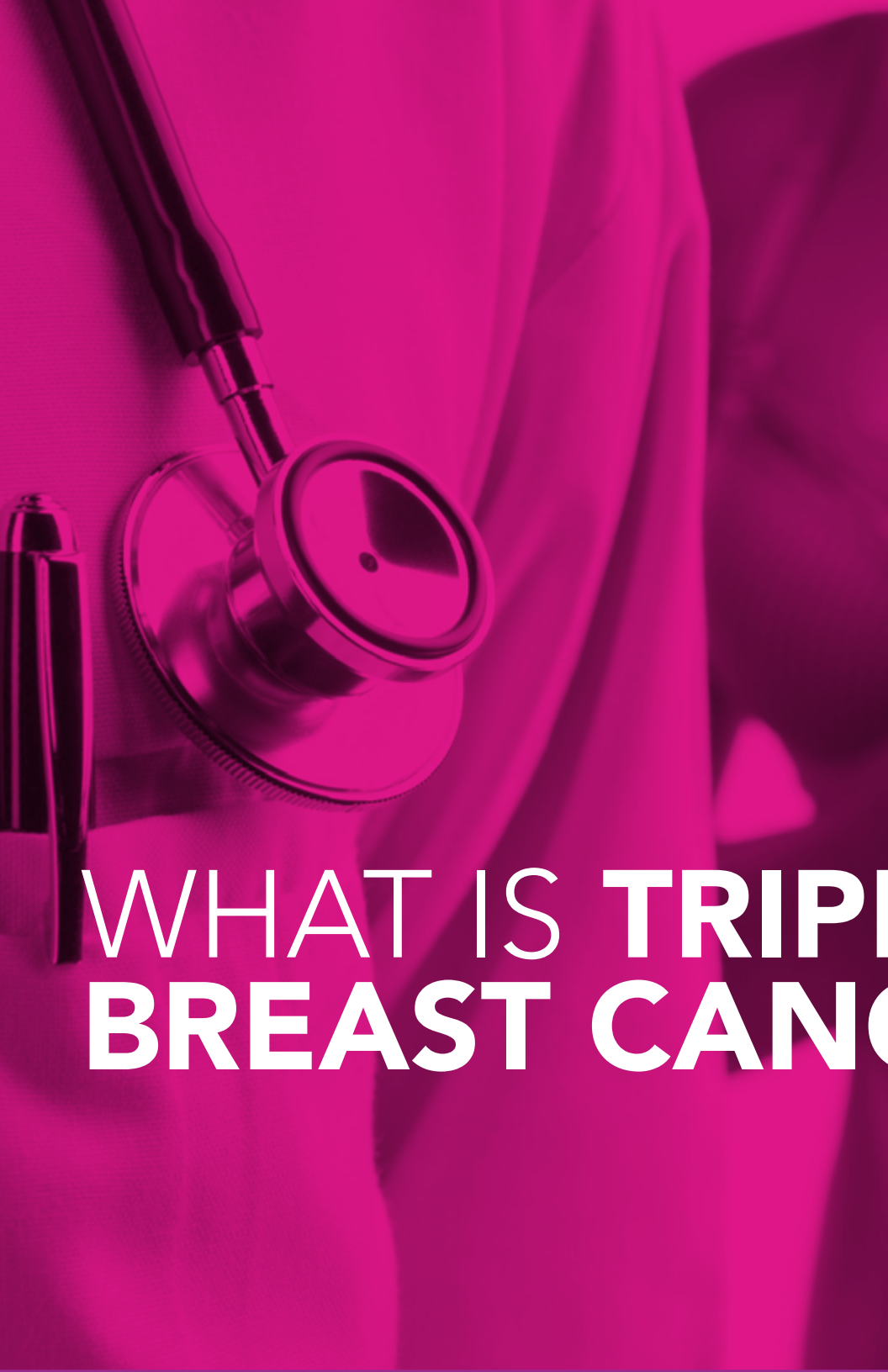
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## TABLE OF CONTENTS

<b>WHAT IS TRIPLE NEGATIVE BREAST CANCER? 4</b>	New and Emerging Treatment <b>12</b>	Tips for Fear and Anxiety <b>19</b>	Managing Survivorship <b>25</b>
Symptoms and Diagnosis <b>8</b>	Working With Your Healthcare Provider <b>14</b>	<b>BE EMPOWERED 20</b>	<b>TNBC Resources 26</b>
Prognosis <b>9</b>	Managing Side Effects <b>14</b>	Family <b>21</b>	<b>BE YOUR BEST ADVOCATE 27</b>
Prevalence <b>9</b>	Communicating with Your Medical Team <b>15</b>	Dating <b>21</b>	Know your rights <b>28</b>
Risk Factors <b>9</b>	Genetic Testing <b>17</b>	Managing Spiritual, Emotional Self <b>21</b>	Disability <b>28</b>
Reccurence <b>10</b>	Managing Your Medical Records And Health Information <b>17</b>	Creating a support network <b>22</b>	Fincances and Insurance <b>28</b>
Survival <b>10</b>	Living with TNBC <b>18</b>	Celebrating life <b>22</b>	Work <b>29</b>
Treatment <b>11</b>		Staying Fit <b>22</b>	<b>TNBC Facts 29</b>
		Nutriition <b>24</b>	<b>Glossary Terms 30</b>





# WHAT IS TRIPLE BREAST CANCER



**LE NEGATIVE  
CER?**

# WHAT IS TRIPLE NEGATIVE BREAST CANCER?

**T**riple Negative Breast Cancer (TNBC) is a type of breast cancer that is diagnosed in two U.S. women every hour, adding up to over 17,000 U.S. women per year. TNBC develops in the breast because of the presence of abnormal or cancer cells that look and behave differently from the normal cells in the breast.

TNBC is “triple negative” because these cancer cells lack three types of proteins that are known to help other cancer cells grow. These proteins are called receptors, and they are usually located on the surface of or inside of cells: estrogen receptor (ER), progesterone receptor (PR) and human epidermal growth factor receptor 2 (HER2). There are several drugs that are targeted to block ER, PR and HER2 so that the cancer cells won’t grow. Since TNBC cells do not have any of the receptors, these types of treatment do not work. However, if caught early, TNBC can often be treated successfully with the common treatments of chemotherapy, radiation and/or surgery.





Researchers are continuing to learn more about TNBC. It is known that 10-20% of breast cancers are TNBC, and that there are 6 subtypes of TNBC. These subtypes are basal-like 1, basal-like 2, mesenchymal-like, mesen-



**TIP:**

Knowing as much as possible about your diagnosis puts you in the driver's seat and enables you to make informed choices.

chymal stem-like, immunomodulatory and luminal androgen-receptor expressing. TNBC tends to grow faster than other types of breast cancer, and patients with TNBC have 16% percent less chance of surviving for 5 years after diagnosis, when compared to other types of breast cancer. Furthermore, TNBC tends to occur more commonly in women under 40 years old, and in African American and Hispanic women. But, it is not currently

known what puts certain people at risk for developing TNBC. As we learn more about how TNBC behaves, we will be able to develop targeted drugs to cure this disease. Among the new treatments that are being developed and tested to treat TNBC, poly ADP-ribose polymerase (PARP) inhibitors, are showing promise. These are drugs that block PARP, an enzyme that cells use to repair damaged DNA.

## SYMPTOMS AND DIAGNOSIS

The symptoms of TNBC are similar to the other types of breast cancer. These include a lump in the breast, dimpling or other changes in the breast, a large or hard lymph node under your arm or near the clavicle, a nipple that turns inwards, and discharge from the nipple.

For your diagnosis, your doctor will describe the breast cancer in 3 ways:

- **Stage:** This covers the size



of the tumor (the group of cancer cells) and how much it has spread to other parts of your body. The stages rank from 0 to IV, with the higher stage representing more advanced cancer.

- **Grade:** This tells how much difference there is between normal cells and the cancer cells. A higher grade means that the cancer cells look very abnormal, and that they are fast-growing.
- **Receptor Status:** This tells if the tumor has receptors that are known to help cancer cells grow. For each receptor, it is present, it is “receptor positive” and if absent, it is “receptor negative.”

## PROGNOSIS

When thinking about TNBC, one of the most common questions is about prognosis – the expected outcome or course of the disease, and the likelihood of recovery. Some characteristics make the cancer more aggressive than others, leading to a poorer prognosis. However, many TNBC cases are treated successfully.

## PREVALENCE

Of the estimated 1 million patients worldwide who are diagnosed annually with breast cancer, approximately 170,000 have TNBC.

The prevalence of TNBC is highest in premenopausal African American. Among all African American premenopausal women with breast cancer, 39% have TNBC. The prevalence of TNBC in non-African American women is 15%. Further, after adjusting for

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# 77%

The percentage of women with TNBC who have survived for at least 5 years.

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age and stage at diagnosis, African American women were almost 3-fold more likely than white women to have TNBC.

## RISK FACTORS

It is currently unknown why some women are more likely to develop TNBC. However, there is an association between developing TNBC and age, ethnicity and gene mutations. Being in one or more of these risk categories does not mean that you will get TNBC, as the overall risk is still small.

- Young women have a higher risk of being diagnosed with TNBC, whereas other breast cancer types typically occur in older women.
- African American and Hispanic women are the most common ethnic groups who are diagnosed with TNBC. In particular, premenopausal African American women have a much higher risk



of being diagnosed with TNBC than white women. Some studies suggest that this difference may be due in part to lifestyle. The risk of developing TNBC may be higher in women with lower rates of breastfeeding, women with high fertility and women with excess weight in the abdomen area – these characteristics are typically higher in African American women compared to other women.

- People with a BRCA1 and BRCA2 gene mutations have a high risk of developing breast cancer, and if it occurs before age 50, it is usually TNBC. In fact, most BRCA1-related breast cancers and some BRCA2-related breast cancers are triple negative.

In addition, while women who have at least one child have a lower risk of breast cancer, women with TNBC

may not have the protective benefit of childbearing. In other studies, being overweight has been shown to be associated with an increase in the risk of both premenopausal and postmenopausal TNBC.

## RECURRENCE

TNBC are more likely to recur than other types of breast cancer. TNBC tend to occur within a few years, and when they recur, the prognosis is usually poor. Recurrence of TNBC often involves metastasis, typically spreading from the breast to the brain or lungs.

## SURVIVAL

Among women with TNBC, 77% have survived for at least 5 years. In comparison, 93% of women with other

types of breast cancer survived for at least 5 years. It is also important to note that women with TNBC have a higher risk of death within 5 years of diagnosis, but not after that time period. Further, TNBC is likely to recur or come back after its been treatment, especially in the few years after treatment.

These numbers are an average of a group of women with TNBC who were studied. However, factors such as the grade and stage of the breast cancer will influence your prognosis. Based on the stage of your TNBC, your age and overall health, your doctor will give you a more precise outlook on your disease. How well you respond to treatment will also affect your prognosis.

## TREATMENT

TNBC is typically treated with a combination of surgery, radiation therapy and chemotherapy. Your doctor determines the best treatment option or combination treatment plan. If you follow the treatment plan that is best for your specific situation, while doing your best to make healthy lifestyle choices such as eating a healthy diet, exercising regularly, and limiting alcohol, you're doing everything you can to treat the cancer.

- Chemotherapy is the most common treatment for TNBC, and it can be given either before the surgery to shrink the tumor, or after the surgery to keep the cancer cells from spreading. Most TNBC cases are effectively treated with chemotherapy.
- Surgery may be done to

remove only the tumor, part of the breast, or all of the breast.

- Radiation therapy kills cancer cells using high-energy rays.

TNBC responds well to chemotherapy because it kills the cells that are dividing quickly throughout the body. When chemotherapy is done before surgery, it is called neoadjuvant therapy. In a small study of women with



locally advanced TNBC, two thirds of the women treated with chemotherapy medications before surgery showed no living cancer cells in the tumor when the tumor was removed. In another study, treatment of TNBC with chemotherapy before surgery resulted in the disappearance of all evidence of the disease.

If the tumor has spread or become metastatic, it is usually treated with chemotherapy. Research is needed to determine the best combination of chemotherapy for these cases.

Other treatment options for TNBC include (i) mastectomy, which is the removal of the entire breast and (ii) lumpectomy, which is the removal of a tumor and a bit of normal tissue.

what is the safe dose of a drug. It also tests the best way a medicine should be given – such as by mouth or by vein. Phase I trials are usually small, and they are open to women with cancer that has spread from the breast.

- **Phase II trials:** These studies look further into the safety of the drug. They also test whether the

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## IF THE TUMOR HAS SPREAD OR BECOME METASTATIC, IT IS USUALLY TREATED WITH CHEMOTHERAPY.

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Sometimes chemotherapy is given before surgery. This is called neoadjuvant chemotherapy, which can shrink tumors so the patient is able to have a lumpectomy.

### NEW AND EMERGING TREATMENT

Clinical trials are research studies where new medicines are tested in humans to determine how well they work, and if they are safe and effective. In addition to medicines, clinical trials can also test the impact of diet, nutrition or exercise on the return of breast cancer, or if changing your lifestyle could lower your risk for developing breast cancer.

**Clinical trials are divided into four types:**

- **Phase I trials:** The goal of this type of study is to find out

drug is effective. These studies involve up to several hundred people, and are open to women with either early stage or late stage cancer.

- **Phase III trials:** The goal of this type of cancer is to compare a new treatment to the standard treatment to see if the new treatment is better. These trials have several hundred to several thousand participants. If a drug passes this phase, it is very likely to be approved by the U.S. Food and Drug Administration (FDA).

- **Phase IV trials:** These studies test the long-term side effects of a treatment that the FDA already approved.

There are several treatments that are being developed and tested to treat TNBC.



- **BET Bromodomain Inhibitors** are drugs that block cell growth by dislodging the BRD4 and other bromodomain proteins from sections of chromosomes.

- **Immunotherapy Agents** such as pembrolizumab and avelumab are drugs that help the immune system to fight cancer by targeting PD-L1, a protein that is more common in TNBC than in other breast cancers. When PD-L1 binds with another protein on the immune system cells, it causes the cell to shut off its ability to attack cancer cells. Thus, drugs are being developed to bind to PD-L1 and allow the immune cells to function normally.

- **Poly (ADP-ribose) polymerase (PARP) Inhibitors** such as olaparib are drugs that block PARP, an enzyme that cells use to repair damaged DNA. Cancer cells have

damaged DNA, and these cells tend to have very active PARP. To kill the cancer cells, researchers are developing and testing PARP inhibitors, which prevent PARP from working. Since cancer cells can become resistant to chemotherapy, PARP inhibitors may help to lower the chance of resistance and increase the effectiveness of the chemotherapy.

- **DNA Damaging Agents** are drugs that disrupt the building blocks of DNA and kill cancer cells. These types of drugs are being developed and tested in the basal-like subtype of TNBC.

- **Anti-angiogenic Agents** prevent the growth of blood vessels, which is what cancer cells need in order to survive. Specifically, these agents block vascular endothelial growth factor receptor (VEGFR), which cells use to make new



blood vessels that connect the tumor to the surrounding tissues. Examples of VEGF inhibitors include Avastin (bevacizumab) and Sutent (sunitinib).

Ask your doctor about clinical trials for TNBC, and if you are suitable to participate in any of them. You can also look at [www.clinicaltrials.gov](http://www.clinicaltrials.gov), a website that lists all clinical trials, and at [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials), which is part of the National Cancer Institute. [There is also a site called [breastcancertrials.org](http://breastcancertrials.org) but I am not sure if it is recognized as a reliable resource.]

## MANAGING SIDE EFFECTS

With your cancer treatment, you may experience side effects such as nausea, vomiting, pain, fatigue and hair loss. These effects may be short-term while others last for a longer time. It is very important that you speak with your health care team

about which side effects you might experience from your treatment. You will be prescribed medications to manage your side effects, but you have to remember to keep your dosing consistent and timely. In addition to medications to manage your side effects, it is also recommended that you eat healthy, exercise and rest well.

## WORKING WITH YOUR HEALTHCARE PROVIDER

Choosing an excellent healthcare provider is one of the most important decisions you'll make. The best way to have confidence in your treatment choices is to learn about the history of the provider, their experience, ratings, referrals, and the quality of your communication with him/her. When choosing your physician, ask yourself: "Is he/she easy to talk to?" "How long is the wait to make appointments or talk to someone?" "Am I confident about the path they suggest I go

on?" The better your relationship with your healthcare provider, the easier it will be to communicate through your treatment journey.

Also, take note of the percentage of their practice dedicated to breast cancer, whether they accept your health plan, their care guidelines for patients, and the treatment environment.

When talking to your healthcare providers, don't be shy! And don't assume that because they are a doctor, you don't have a say. Remember, it's a partnership. Share your experiences, thoughts, interests, and concerns. Give feedback as they talk with you. Ask questions, despite how trivial they may seem. And remember, although your doctor will make recommendations for your treatment, the decision

cations and any side effects you might have. You can also record your doctor visits on your phone or other recording device. Also, consider asking a friend to be your advocate, who you can share everything with and also who can communicate on your behalf with your healthcare team.

## COMMUNICATING WITH YOUR MEDICAL TEAM

Being diagnosed with TNBC can be overwhelming. Your health care team, which may include your primary care doctor, a cancer specialist, nurses and social workers, can help you with your concerns. To communicate well with your team:

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## CHOOSING AN EXCELLENT HEALTHCARE PROVIDER IS ONE OF THE MOST IMPORTANT DECISIONS YOU'LL MAKE.

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is ultimately yours. No one knows your body or your needs better than you do! Before appointments, make a list of questions you want to ask and come prepared to collaborate with your medical team.

During appointments with your healthcare team, take a journal and keep track of your symptoms, challenges, concerns. Consider asking a friend to go to your appointments with you to take notes as well. Write everything down - which doctor you met with, referrals, how to take medi-

1. Write down questions as you think about them. Some examples of questions that you can ask your medical team include:

- Have you treated other patients with TNBC?
- What is the cancer stage, grade, and how do they impact my treatment options?
- What side effects might I





have, and how can I prevent or lessen them?

- Are there long-term effects of the treatment, and how do the risks of the therapy compare to the benefits?
- Am I eligible for a clinical trial?
- Should I speak with a professional about genetic testing?

2. Take notes during your appointments. Ask someone to accompany you to your appointments and have them write down the names and locations of professionals that you are referred to. Also, make notes on all medications that you are prescribed.

## GENETIC TESTING

Your chances of developing breast cancer again may be high if you have a family history of breast cancer in both breasts, or if you have a BRCA1 or BRCA2 mutation. Genetic testing may guide your decisions about preventative treatment. Speak to a genetic counselor to find out if genetic testing is right for you. The health care professional can help you understand how your test results can impact several important areas including your follow-up tests, treatment, relationships and insurance coverage.

## MANAGING YOUR MEDICAL RECORDS AND HEALTH INFORMATION

Each of the medical professionals who are caring for you will keep a record of your care. However, it is a very good idea for you to keep your own records with information about your medications, surgeries, treatments, treatment schedules, imaging reports, pathology reports, and other details of



your care. This way, you will have your complete health history all together. At your hospital appointments, it may be a good idea to record the sessions using a recorder or a phone. You can store your records and the recorded information on computer flash drives or hard drives, in a 3-ring binder or a file folder. You can also consider keeping your health information in a secure online



area such as Google Docs, Dropbox so that those whom you trust can access them easily. Choose a system that you think will be easiest for you and your caregivers to keep all of your information in one place and up to date.

## LIVING WITH TNBC

To help you cope while you're living with TNBC, you can get emotional support through several ways:

- Join a support group. Support groups connect you with other people who are coping with similar situations. They are led by professional cancer social workers who specialize in helping people with cancer. You can participate in the support groups in person, on

the telephone, or online.

Ask for help. Often times, people with cancer do not ask their family and friends for help because they worry that are a burden. Don't worry, someone will be there for you. Make a list of the things you need help with, for example, grocery shopping, household chores, and/or transportation.

- Maintain a positive outlook. There is an association between how well patients manage stress and how well they do during their diagnosis and treatment. Connect with your sources of strength, whether it is prayer, meditation, walking or reading. You can also relax your mind and body through breathing and relaxation techniques.

# 10

## TIPS FOR DEALING WITH FEAR AND ANXIETY

Being diagnosed with breast cancer is scary, but know that you're not alone. Also, what you're feeling is totally normal, and there are ways to cope.

# 1



Begin keeping a journal, talk to someone you trust or join a support group.

# 2

Get to know your medical team. They are here to help you, so the closer you are to them, the better you'll work together.

# 3

Learn more about your treatments and tests. Knowing what to expect will help eliminate your fear of the unknown.

# 4



Find ways to manage and lower your stress. Even though you have breast cancer, as much as possible, do some of the "normal" things you did before. Also, rally the troops to help! Spend time with friends and family, exercise, do yoga, meditate, and breathe. Also, "buddy up" with other survivors for peer support.

# 5

Surround yourself with people who make you feel better. Everyone's journey has its own outcome. Being educated, empowered and work towards being healthy again.

# 6

Ask for help. You don't have to go it alone. Sometimes anxiety, depression, lack of sleep and treatment side effects take their toll. Your doctor can recommend therapy or medications to help.



# 7

Get a change of scenery. If approved by your doctor, take a quick trip to the beach, take a staycation or take a weekend getaway.

# 8



Become an advocate. Share your experience with others, get involved with a breast cancer group and use your story to help others in a positive way.

# 9



Now would be a good time to pick up a hobby you didn't have time for before - it'll bring you joy, help distract you from the fears of cancer, and you'll learn something new!

# 10

Decide what kind of life you'll live after breast cancer. Use this opportunity to create life as you want it to be going forward; and as much as possible - start today.



BE  
**EMPOWERED**

# BE EMPOWERED



## FAMILY

Think about how you want to tell family members about your diagnosis. Will you share the news in person, on the phone, via FaceTime or Skype? Would you prefer to send a group text or a group email to all family members,



### TIP:

To keep everyone updated, choose a communication method that can provide updates to everyone at once, or designate one person to post updates for you regularly.

and then follow up with individuals at a later time? You may also not be ready to share your diagnosis yet, and that is OK too.

When people hear your news, they may ask you what they can do to help. Make a list of tasks that your family

members could do (meal preparation, household chores, transportation for you or other family members). Perhaps a family member could coordinate a web page on a site such as CaringBridge.org to provide family and friends with updates; you may find it draining to continually provide updates to concerned family and friends.

Sometimes family members and friends may not understand a cancer diagnosis no matter how many times you explain it, and this can be frustrating. Visit online or in person support groups to get ideas on how to formulate responses or if you just need to vent.



## DATING

Being single and dating can be challenging even without having breast cancer. When you tell someone you're dating that you have breast cancer or metastatic breast cancer is up to you. In the end, honesty is often the best policy; consider sharing information about your diagnosis, treatment, and side effects with your partner once you're ready to do so.

Something to keep in mind if you're single is this – finding the right type of partner for yourself, if you so choose to do so, will play an important role in your emotional health. It is important to make sure your partner is someone who supports you, your choices and the realities of your diagnosis. Your new partner will become a member of your support group and care team, lifting you up, accompanying you on your journey and nurturing your emotional, mental and physical well-being. Remember that many have found love, and even marriage, after a stage IV diagnosis.



## MANAGING YOUR EMOTIONAL, SPIRITUAL, MENTAL SELF

Learning that you have triple negative breast cancer can be over-

whelming at first. Eventually you will find “a new normal”. Make the time to nurture your emotional, spiritual self. Depending on your practices, connect or re-connect with a religious congregation. Try meditation or daily yoga. Consider prayer. Start a new hobby or take up an old favorite, like crocheting or knitting, reading, drawing or painting. Join a support group or social network. Take a class at your local community college. Make a vision board and map out your life – this is the time that you can purposefully design life – just as you want it to be.



### **CREATING A SUPPORT NETWORK**

Who are the people who lift you up when you are down? Family members, friends, neighbors, classmates, coworkers and others can work together to support you. Your support network can also include clergy, therapists, nurses, and other members of your medical team. Let them know what you need. Create a Google doc or set up daily, weekly or monthly outings, calls or in-home get togethers. Make sure you let them know how you really feel – and let them know when you want heart to heart about the things that worry your mind or if you want to get out and have a good time. You might just want to have someone sit with you and not talk. Whatever it is, make sure you have a core group that you can depend on.



### **CELEBRATING LIFE**

It is challenging not to brood about the past or worry about the future, but as much as possible, try to be present and live in the moment. Consider keeping a gratitude journal and taking time to savor the “little” things in life, like a beautiful sunrise, the ritual of brewing tea, and the changing colors of the seasons. Make time for favorite hobbies and visits with cherished family and friends. Enjoy every breath. Put your hand on your heart – hold it there and “feel” your heart beat. Take in every sight and sound. Enjoy the touch – of heat and cold, hugs, kisses, textures – take it all in. Above all, say all that needs to be said. Laugh. Do it all. Live.



### **STAYING FIT**

It's important to stay fit during treatment. So doctors encourage patients to remain active throughout their treatment stages. Instead of letting the fatigue get the best of you, continue your normal workout regimen - it can increase your energy and strengthen your body. If you don't have a fitness routine, create one with the help of your doctor and a fitness professional at your gym. Beyond managing weight and



boosting energy, exercising also produces endorphins, known as the happy hormones, and it keeps your muscles and bones engaged, preventing them from becoming weak due to a lack of activity. In other words, you'll look better and feel better!

do arm exercises as you walk - or you can do them at home.

If you want to take it a step further, try running! Remember to take it slow in the beginning. Run for one minute, and then walk the next minute. Keep this up for the duration of your work-

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## THIRTY MINUTES OF PHYSICAL ACTIVITY PER DAY IS RECOMMENDED TO MAINTAIN A HEALTHY LIFESTYLE.

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Thirty minutes of physical activity per day is recommended to maintain a healthy lifestyle. When getting started, listen to your body. Only do how much it allows. Pump up the intensity as much as you can tolerate it, but be sure to lower it when necessary. If you prefer less strenuous workouts, try taking a brisk walk through the park. If you want to challenge yourself, bring a couple of light weights with you and

out, and eventually, you'll be able to run the entire time without stopping!

If you're not fond of walking or running, consider other options, such as weight training or yoga. Visit a local fitness facility and ask about their group classes, which can be a fun alternative to working out alone. It will also allow you to learn the proper techniques for staying fit.



## NUTRITION AND YOU

It's important to maintain a balanced diet. When paired with exercising, eating properly has many added benefits, including giving your body healing, building nutrients, and increasing energy.

### WHAT DOES A BALANCED DIET CONSIST OF?

Lots of raw fruits and vegetables! It's important that you're consuming a fair amount of fats, carbohydrates, vitamins and protein. Nutritionists recommend enjoying a wide variety of foods, but the key is to avoid foods that are high in fat and sugar - although it's okay to have them in moderation. Incorporate fruits, vegetables, and lean meat into your diet. If you don't eat meat, opt for other protein filled alternatives such as fish or eggs.

**Here's a list of power foods, along with their added benefits:**



#### **Spinach**

Spinach is filled with an immense amount of vitamins! This leafy green can be put into a super smoothie or eaten in raw form as a salad tossed with fruit and paired with tangy vinaigrette.



#### **Salmon**

Coined as one of the world's healthiest foods, salmon contains high levels of vitamin D and Omega-3.



#### **Nuts**

For snacking on the go, grab a handful. Nuts contain healthy fats and vitamins and have been known to lower cholesterol.



#### **Eggs**

This power food is a great source of vitamin D and an even better breakfast option.



#### **Whole Grains**

For protein, fiber, and B vitamins, check out the whole grains family. From rice to pasta to cereals, this food group gives you plenty of options to choose from.

Stock up on healthy foods. It does the body good!





## MANAGING SURVIVORSHIP

Whether you have been declared no evidence of disease or are living with metastatic breast cancer, you are a survivor, thriver and a warrior! One of the challenges is that while you're in it, you focus all you have on getting through treatment. Then, once you're done with active treatment, the question becomes, "Now what?" Sometimes survivors find that while they are happy treatment is over, they don't have any direction in terms of "survivorship" or living a diagnosis. Many survivors must deal with managing family life, emotional stresses, fatigue and insomnia, early menopause, body image, sexuality and more.

### Dealing with Family Members

— Tell family that although treatment might be over, you're still healing from the experience - emotionally and physically, and that you may still need help or feel sad at times. If you're metastatic, communicate with your family honestly about your feelings and what you need. Also, family members may be concerned with having an increased risk of getting breast cancer. Suggest they get tested for genetic mutations. Educate them about risk factors, and encourage a healthy lifestyle.

**Fear of Recurrence** — Fears of recurrence is normal. Allow yourself to feel what you feel, but, don't dwell there. Deal with the fearful thoughts by combating them with positive ones.

You may not be able to control circumstances, but you are in control of your perspective on them. It may also be beneficial to speak with a counselor or join a support group. Also, advocacy is a powerful tool - helping others can help you!

**Fatigue and Insomnia** — Your body has gone through so much, and now it wants to rest and recover! It's going to take some time for your energy levels to increase. Don't fight it; embrace it. Take care of yourself, and if you haven't already, start engaging in regular exercise to reduce fatigue and increase energy.

**Early Menopause** — Though you've probably heard about it, nothing can really prepare you for when it actually happens. Common issues include vaginal dryness and hot flashes. Both can be medically treated via prescriptions from your healthcare provider, or you can opt for over the counter solutions.

**After the Mastectomy** -- Many women opt for breast implants or breast reconstruction surgery after a mastectomy for a more natural look. Though preference totally depends on you, your body has changed and it takes some time to get used to how it looks.

**Medical Follow-ups** — Continue to see your healthcare provider on a regular basis, to monitor for signs of cancer or side effects of treatment, discuss healthy behaviors, and post-treatment concerns.

# TRIPLE NEGATIVE BREAST CANCER RESOURCES

Below is a list of additional resources that provide information about diagnosis/treatment, complementary and alternative medicine, clinical trials, financial assistance, transportation and other resources.



## DIAGNOSIS/ TREATMENT

### **Breastcancer.org**

[www.breastcancer.org](http://www.breastcancer.org)  
610-642-6550

### **Living Beyond Breast Cancer**

[www.lbbc.org](http://www.lbbc.org)  
855-807-6386

### **Triple Negative Breast Cancer Foundation**

[www.tnbcfoundation.org](http://www.tnbcfoundation.org)  
877-880-8622

### **National Breast Cancer Foundation, Inc.**

[www.nationalbreastcancer.org](http://www.nationalbreastcancer.org)

### **Triple Step Toward The Cure**

[www.triplestep-towardthecure.org](http://www.triplestep-towardthecure.org)  
424-258-0313  
and 510-562-1889

### **Susan G. Komen**

[www5.komen.org](http://www5.komen.org)  
877-465-6636



## CLINICAL TRIALS

### **Clinicaltrials.gov**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### **Cancer.gov**

[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)  
800-422-6237



## FINANCIAL ASSISTANCE

### **Cancer Care**

[www.cancercare.org](http://www.cancercare.org);  
800-813-4673

### **Cancer Financial Assistance Coalition (CFAC)**

[www.cancerfac.org](http://www.cancerfac.org)

### **Cancer.Net**

[www.cancer.net](http://www.cancer.net)  
571-483-1780  
and 888-651-3038

### **Tigerlily Foundation**

<http://tigerlilyfoundation.org/>  
888-580-6253

A woman with dark, curly hair is shown from the chest up, leaning over a desk. She is wearing a light-colored, long-sleeved top and is focused on writing in an open notebook with a pen. To her right, there is a stack of several books. The entire image is overlaid with a semi-transparent magenta filter. The text "BE YOUR OWN BEST ADVOCATE" is written in large, white, sans-serif capital letters across the center of the image.

BE YOUR  
OWN BEST  
**ADVOCATE**

# BE YOUR OWN BEST ADVOCATE



## KNOW WHAT YOUR RIGHTS ARE

Learn about employment and labor rights, so that you can communicate with your supervisor, your team and human resource department. Become educated about discrimination, leave, insurance, discrimination, legal and privacy rights.



## DISABILITY

You may want to take a leave of absence from your job during part or all of your breast cancer treatment. If you have worked full-time at a company that has 50 or more employees for at least one year, you are covered by the federal Family and Medical Leave Act (FMLA) for up to 12 weeks of unpaid medical leave, with no loss of job or benefits. Contact your employer's Human Resources department to find out more about short-term (often 3-6 months) disability policies, which pay a percentage of your paycheck even if you are not able to work, such as during an illness. Long-term disability (longer than 6 months) may be right for you if you want to take a long-term leave of absence from work and focus on your treatment and recovery, however, you may not receive your paycheck or benefits during this time. You may want to look into social security disability as well.



## FINANCES AND INSURANCE

If you have health insurance, your policy will probably cover many of the expenses associated with your tests, diagnosis, and treatment. Make

sure that you know what policy you have and what is covered. You can look this up on your company's Human Resources website or call your health insurance company and ask them to send you a summary of your benefits. It's a good idea to keep insurance paperwork, receipts, copies of claims that you have submitted, bills, and other paperwork related to your healthcare costs in a 3-ring binder or folder.



## WORK

Talk to your medical team if you'd like to keep working during your treatment. It may be possible to schedule tests and treatments around your work schedule. Start an electronic or paper calendar with work projects and deadlines and your treatment dates so that you have all of this information in one place. It's important to stay flexible—you may experience side effects and might need to work less hours than usual during treatment. Having a backup plan, such as being able to work from home and/or delegate essential tasks to coworkers, is a good idea.

## TRIPLE NEGATIVE BREAST CANCER FACTS

✗ **Myth:** Women with TNBC can have the same treatments as other women with breast cancer

✓ **Fact:** TNBC cannot be treated with hormone-targeted treatments because they do not have those receptors.

✗ **Myth:** Only African American women get TNBC.

✓ **Fact:** TNBC affects all women, but it is occurs more commonly in African American women.

✗ **Myth:** Triple negative breast cancers are hard to treat.

✓ **Fact:** Triple negative breast can be harder to treat than the other types of breast cancer. Your doctor will predict how well your treatment will work based on the tumor size and how far it has spread.

✗ **Myth:** Since TNBC is generally more aggressive than other types of breast cancer, TNBC should be treated with a more aggressive plan.

✓ **Fact:** While TNBC is a more aggressive form of breast cancer, each case of TNBC is different. Your doctor will determine your best treatment plan. In some cases this may mean higher doses of chemotherapy drugs or a specific different combination of chemotherapy and surgery or chemotherapy and radiation. In other cases, you doctor may recommend a mastectomy or lumpectomy.

✗ **Myth:** TNBC is like other breast cancers.

✓ **Fact:** TNBC is quite different from other breast cancers. For one, it's less likely to be found on a mammogram than other types of breast cancer. It also grows faster. It can be treated, but it may recur and spread to other parts of the body. The challenge with TNBC is a lack of targeted treatments. TNBC has a poorer outcome for at least the first five years after diagnosis than estrogen receptor-positive (ER+) tumors. If breast cancer does not recur within five years, the chance of survival is higher than for ER+ tumors.

# **GLOSSARY** OF TERMS

# A

## **Ablation**

Focused destruction of tissue to reduce/remove or impair its function. Various methods include radiofrequency/heat, chemical, or other.

## **Absolute Risk**

A person's chance of developing a certain disease over a certain time period. The absolute risk of a disease is estimated by looking at a large group of people similar in some way (in terms of age, for example) and counting the number of people in this group who develop the disease over the specified time period. For example, if we followed 100,000 women between the ages of 30 and 34 for one year, about 25 would develop breast cancer. This means the one-year absolute risk of breast cancer for a 30- to 34-year-old woman is 25 per 100,000 women (1 per 4,000 women).

## **Access Port**

A small device implanted under the skin that allows access to your veins; sometimes called a port-a-cath.

## **Adjunct Therapy**

Treatment used in conjunction with primary treatment, to assist the primary treatment. It is also called adjunctive therapy.

## **Acupuncture**

Use of very thin needles inserted at precise points on the body that may help control pain and other side effects of treatment or breast cancer itself. It is a type of integrative or complementary

## **Adjuvant Therapy**

Treatment to lower the risk of cancer recurrence. It is often used after primary treatments, such as radiation or surgery. May also be used before the primary treatment and is then referred to as neoadjuvant treatment.

## **Advanced Cancer**

Cancer that has spread to other places in the body.

## **Alopecia**

Hair loss.

## **Alternative Therapy**

Any therapy used instead of standard medical treatments such as surgery, chemotherapy and hormone therapy. Alternative therapies are

different from integrative and complementary therapies, which are used in addition to standard treatments. Alternative therapies have not been shown to be effective in treating breast cancer, so it is not safe to use them.

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## **Amenorrhea**

The absence or stopping of menstrual periods.

## **Anesthesia**

Loss of feeling or sensation that keeps a person from feeling pain during surgery or other medical procedures. Local or regional anesthesia may be used for a specific part of the body, such as the breast, by injection of a drug into that area. General anesthesia

numbs the entire body and puts a person to sleep with drugs that are injected into a vein or inhaled.

**Aneuploid (DNA Ploidy)**

The presence of an abnormal number of chromosomes in cancer cells.

**Angiogenesis**

Blood vessel formation. Tumor angiogenesis is growth of new blood vessels that tumors need to grow, caused by the release of chemicals from the tumor.

**Antibody**

A protein made by white blood cells that is part of the body's immune system. Each antibody binds to a certain antigen (foreign substance, such as bacteria) and helps the body fight the antigen.

**Antibody Therapy**

A drug containing an antibody that is specially made to target certain cancer cells. See Antibody.

**Anti-carcinogen**

An agent that counteracts carcinogens (cancer causing agents).

**Antiemetic**

A medicine that prevents or relieves nausea and vomiting.

**Antigen**

A substance that causes the body to make an immune response. This immune response often involves making antibodies.

**Antioxidant**

A substance that protects the body from damage by oxidizing agents. Oxidizing agents are always present in the body and are often beneficial. However, when large amounts of oxidants are present in cells, they can cause damage, especially to DNA. This can lead to abnormal cell growth. Antioxidants include beta-carotene and vitamins A, C and E.

**Apoptosis**

Programmed cell death—the normal process in which molecular steps lead to cell death. This is how the body gets rid of unneeded or abnormal cells. The process of apoptosis may be blocked in cancer cells.

**Areola**

The darkly shaded circle of skin surrounding the nipple.

**Aromatase Inhibitors**

Hormone therapy drugs that lower estrogen levels in the body by blocking aromatase, an enzyme that converts other hormones into estrogen. Aromatase inhibitors are used to treat postmenopausal women with hormone-receptor positive breast cancer.

**Ascites**

In some cases of cancer, there may be tumor cells in the ascites. Ascites can also occur in benign liver disease.

**Aspirate**

To remove fluid and a small number of cells.

**Atrophic Vaginitis** (see Vaginal Atrophy)

**Atypical Hyperplasia**

A benign (not cancer) breast condition where breast cells are growing rapidly (proliferating). The proliferating cells look abnormal under a microscope. Although atypical hyperplasia is not breast cancer, it increases the risk of breast cancer.

**Autologous**

A blood donation or tissue graft from a person's own body rather than from a donor. For



example, autologous breast reconstruction techniques use skin and tissue flaps (grafts) from a person's own body.

### **Axilla**

The underarm area.

### **Axillary Dissection**

(Axillary Sampling)

Surgical procedure to remove some or all of the lymph nodes from the underarm area so that the nodes can be examined under a microscope to check whether or not cancer cells are present.

### **Axillary Lymph Nodes**

The lymph nodes in the underarm area.

### **Ayurveda**

An integrative or complementary medical system from India that involves diet, exercise, meditation and massage. Ayurveda means "life-knowledge."

## **B**

### **Benign**

Not harmful.

### **Benign Breast**

**Conditions** (Benign

Breast Disease)

Noncancerous conditions of the breast that can result in lumps or

other abnormalities.

Examples include cysts and fibroadenomas.

### **Benign Phyllodes Tumor**

A rare benign (not cancer) breast condition similar to a fibroadenoma. A lump may be felt, but is usually painless.

### **Bilateral Prophylactic Mastectomy**

Surgery where both breasts are removed to prevent breast cancer from developing.

### **Biobank**

(Tissue Repository)

A large collection of tissue samples and medical data that is used for research studies.

### **Bioimpedance**

(Bioelectrical Impedance Analysis)

A method of measuring the amount of fluid in body tissues.

### **Biological Therapy**

Treatment to boost/restore ability of the immune system to fight cancer, infections, and other diseases. It is also used to lessen certain side effects that may be caused by some cancer treatments. Agents used in biological therapy include monoclonal an-

tibodies, growth factors, and vaccines. These agents may also have a direct antitumor effect.

Also called biological response modifier therapy, biotherapy, BRM therapy, and immunotherapy.

### **Biomarkers**

There are various types of biomarkers. A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease.

### **Biopsy**

Removal of tissue to be tested for cancer cells.

### **Biphosphonates**

A drug/substance used to treat hypercalcemia (abnormally high blood calcium) and bone pain caused by some cancers. Forms of bisphosphonates are also used to treat osteoporosis and for bone imaging. Bisphosphonates inhibit a type of bone cell that breaks down bone. Also called diphosphonate.

### **Blood-brain Barrier**

A network of blood vessels with closely

spaced cells that makes it difficult for potentially toxic substances (such as anticancer drugs) to penetrate the blood vessel walls and enter the brain.

### **Body Mass Index (BMI)**

A measure used to estimate body fat. BMI takes into account a person's height and weight. Calculate your BMI.

### **Bone Scan**

A radiology exam that creates images of the bones. A small amount of radiotracer material is injected into a blood vessel and travels through the bloodstream; it collects in the bones and is detected by a scanner to form the diagnostic images.

### **Boost**

Additional dose of radiation to the part of the breast that had the tumor.

### **BRCA1 and BRCA2**

Abnormal changes (mutations) in these genes are associated with higher chance of developing breast and ovarian cancers. These genetic mutations can be inherited, meaning passed from generation to generation in a family.

### **Brachytherapy**

A procedure that uses targeted radiation therapy from inside the tumor bed.

### **Breast Cancer**

An uncontrolled growth of abnormal breast cells.

### **Breast Cancer Advocacy**

Influencing targeted audiences to promote the support of breast cancer issues.

### **Breast Cancer Survivor**

(see Survivor)

### **Breast Conserving Surgery**

(see Lumpectomy)

### **Breast Density**

A measure used to describe the relative amounts of fat and tissue in the breasts as seen on a mammogram.

**Breast-Specific Gamma Imaging** (see Nuclear Medicine Imaging of the Breast)

### **Breast Imaging Reporting and Data System (BI-RADS®)**

A system developed by the American College of Radiology to provide a standard way to describe the findings on a mammogram.

### **Breast Reconstruction**

Surgery to restore the look and feel of the breast after mastectomy.

### **Breast Self-Examination (BSE)**

A method that may help women become familiar with the normal look and feel of their breasts. BSE is not recommended as a breast cancer screening tool because it has not been shown to decrease breast cancer death.

### **Breast Tomosynthesis**

(3D Digital Mammography, Digital Tomosynthesis)

A tool that uses a digital mammography machine to take multiple two dimensional (2D) X-ray images of the breast. Computer software combines the multiple 2D images into a three dimensional image. Breast tomosynthesis is not a standard breast cancer screening tool at this time.

## **C**

**CAM** (Complementary and Alternative Medicine)

Nonconventional or nontraditional therapies that are used in addition

to (complementary) or instead of (alternative) more traditional treatments.

**Cachexia**

Loss of appetite and weight.

**Calcifications**

Deposits of calcium in the breast that appear as bright, white spots on a mammogram. Most calcifications are not cancer. However, tight clusters or lines of tiny calcifications (called microcalcifications) can be a sign of breast cancer.

**Cancer**

General name for over 100 diseases with uncontrolled cell growth.

**Cancer Staging** (see Staging)

**Carcinoma in Situ** (in Situ Carcinoma)

Condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. In situ means “in place.” See ductal carcinoma in situ and lobular carcinoma in situ.

**Case-Control Study**

An observational study that looks at two groups—one with people

who already have the outcome of interest (cases), and one with people who do not (controls). For example, the cases may be women with breast cancer and the controls may be cancer-free women. The two groups are then compared to see if any characteristic was more common in the past history of one group compared to the other.

**Case Series**

A health care provider’s observations of a group of patients who are given a certain type of treatment.

**Catheter**

A small tube used to deliver fluids to (or remove them from) the body.

**Centigray** (Centigrays)

One centigray describes the amount of radiation absorbed by the body and is equivalent to 1 RAD (radiation absorbed dose).

**Chemoprevention**

A drug or combination of drugs used to lower the risk of breast cancer in cancer-free women at higher risk.

**Chemotherapy**

Systemic treatment with

drugs that kill cancer cells.

**Chronic condition**

A disease process that occurs or can exist over a long period of time. Common chronic medical conditions include diabetes and high blood pressure (hypertension). For some types of cancers, metastatic cancer has become a chronic medical condition with which someone can live years with maintenance therapy.

**Clinical Trials**

Research done in humans to test a medicine or new treatment to determine safety and how well it works on people.

**Cognitive** (function)

Mental processes related to understanding, such as reasoning and problem-solving.

**Cohort Study**

A study that follows a large group of people (a cohort) over time.

**Co-Insurance** (see Co-Payment)

**Complementary medicine**

See CAM above.

Non-medical treatments or therapies used in

addition to medical treatment.

**Complementary Therapies** (Integrative Therapies)

Therapies (such as acupuncture or massage) used in addition to standard medical treatments. Complementary therapies are not used to treat cancer, but they may help improve quality of life and relieve some side effects of treatment or the cancer itself. When complementary therapies are combined with standard medical care, they are often called integrative therapies.

**Computerized Axial Tomography (CAT) Scan** (see CT Scan)

**95% Confidence Interval** (95% CI)

A statistical concept that shows there is a 95 percent probability the 'true' measure is found within a range of measures computed from a single study. For example, if the 95% confidence interval for a survival rate is 75 to 90 percent, there is a 95 percent chance the true survival rate falls between 75 and 90 percent.

**Co-Payment**

(Co-Insurance)

In an insurance plan, the portion of medical costs a person must pay (the portion not covered by his/her insurance policy).

**Core Needle Biopsy**

A needle biopsy that uses a hollow needle to remove samples of tissue from an abnormal area in the breast.

**Co-Survivor**

A person who lends support to someone diagnosed with breast cancer, from the time of diagnosis through treatment and beyond. Co-survivors may include family members, spouses or partners, friends, health care providers and colleagues.

**CT Scan** (Computerized Tomography)

A radiology imaging test that uses x-rays to create detailed pictures of the body using different projections. Also called CAT scan, computed tomography scan, computerized axial tomography scan. Depending on the reason for the test, contrast dye injected through the arm vein may be used.

**Cumulative Risk**

The sum of a person's chances of developing a disease (like breast cancer) over the course of a lifetime (usually defined as birth up to age 85). For example, the cumulative (lifetime) risk of breast cancer for women is about 1 in 8 (or about 12 percent). This means for every 8 women, one will be diagnosed with breast cancer during her lifetime (up to age 85).

**Cyst**

A fluid-filled sac.

**Cytopathologist**

A pathologist who specializes in looking at individual cells. A cytopathologist is needed to interpret the results of fine needle aspiration.

**Cytotoxic**

Toxic, or deadly, to cells (cell killing). Often used to describe chemotherapy.

**D**

**Deductible** (Insurance Deductible)

The pre-set amount of medical costs a person must pay before insurance payments begin.

**Definitive Surgery**

All of the known tumor is removed and no follow-up surgery is needed.

### **Diabetic Mastopathy**

A rare benign (not cancer) breast condition that consists of small hard masses in the breast. It occurs most often in women with insulin-dependent (type 1) diabetes.

### **Diagnosis**

Identification of a disease from its signs and symptoms.

### **Diagnostic Mammogram**

A mammogram used to check symptoms of breast cancer (such as a lump) or an abnormal finding noted on a screening mammogram or clinical breast exam. It involves two or more X-ray views of the breast.

### **Diagnostic Radiologist (Radiologist)**

A health care provider who specializes in the diagnosis of diseases using X-rays.

### **Diploid (DNA Ploidy)**

The presence of a normal number of chromosomes in cancer cells.

### **Disease-free survival**

The length of time after treatment for a specific disease during which a patient survives with no evidence of the disease. Disease-free survival may be used in a clinical study or trial to help measure how well a new treatment works. Also called DFS and disease-free survival time.

### **Distant Recurrence (see Metastases)**

### **DNA (Deoxyribonucleic Acid)**

The information contained in a gene.

### **Dose-Dense Therapy**

Chemotherapy given over a shorter (more condensed) time period compared to standard therapy. The frequency of treatment sessions is increased, so the length of the treatment period is shortened.

### **Down-Staging**

Lowering the stage of a cancer from its original stage (or the stage it was thought to be). Down-staging occurs most often after a good response to neoadjuvant therapy. Neoadjuvant therapy is chemotherapy or hormone therapy used as a first treatment (before surgery) for

some large or advanced breast cancers. Neoadjuvant therapy can shrink a tumor such that it lowers the stage of the breast cancer and a lumpectomy, instead of a mastectomy, can be done.

### **Duct**

Part of the breast anatomy. The passageways that carry milk from the lobules to the nipple when a woman is lactating.

### **Ductal Cancer**

A type of breast cancer of the ductal cells that arises in the ductal system. If the cancer is still contained in the milk ducts, it is called ductal carcinoma in situ (DCIS) and does not usually appear as a mass. If the cancer has broken through the wall of the milk ducts, then it is called invasive or infiltrating cancer.

### **Ductal Carcinoma in Situ (DCIS, Intraductal Carcinoma)**

A non-invasive breast cancer that begins in the milk ducts of the breast, but has not invaded nearby breast tissue. Also called stage 0 or pre-invasive breast carcinoma.

### **Ductal Papilloma (see**

Intraductal Papilloma)

## E

### Early Breast Cancer

Cancer that is contained in the breast or has only spread to lymph nodes in the underarm area. This term often describes stage I and stage II breast cancer.

### Edema

Excess fluid in body tissues that causes swelling.

### Effusion

An abnormal collection of fluid in hollow spaces/ between tissues of the body. For example, a pleural effusion is fluid that has collected in the lung cavity, where the lungs are housed.

**Endocrine Manipulation** (see Hormone Therapy)

### Endometrial Cancer

Cancer of the endometrium (the lining of the uterus).

### Enzyme

A protein that speeds up biologic reactions in the body.

### Epidemiology

The study of the causes

and prevention of disease.

### Estradiol

The most biologically active, naturally occurring estrogen in women.

### Estrogen

A hormone made in females by the ovaries that has effects on reproduction. Some breast cancer cells may grow in response to estrogen.

### Estrogen Receptors

Specific proteins in cells that estrogen hormones attach to. A high number of estrogen receptors on a breast cancer cell often means the cancer cell needs estrogen to grow.

### Etiology

The cause(s) of a disease.

### Excisional Biopsy

Surgical procedure that removes the entire abnormal area (plus some surrounding normal tissue) from the breast.

**External Beam Radiation Therapy** (see Radiation Therapy)

## F

### False Negative

A test result that incorrectly reports a person is disease-free when she/he actually has the disease.

### False Positive

A test result that incorrectly reports a person has a disease when she/he does not have the disease.

**Family History** (Family Medical History)

A record of the current and past health conditions of a person's biological (blood-related) family members that may help show a pattern of certain diseases within a family.

### Fat Necrosis

A benign (not cancer) breast change in which the breast responds to trauma with a firm, irregular mass, often years after the event. The mass is the result of fatty tissue dying, after either surgery or blunt trauma to the breast. This breast change does not increase risk of breast cancer.

### Fibroadenoma

A benign (not cancer) fibrous tumor that may

occur at any age, but is more common in young adulthood.

### **Fibrocystic Condition**

(Fibrocystic Changes)

A general term used to describe a benign (not cancer) breast condition that may cause painful cysts or lumpy breasts.

### **Fine Needle Aspiration**

(FNA, Fine Needle Biopsy) A biopsy procedure that uses a thin, hollow needle to remove a sample of cells from the abnormal area of the breast.

### **First-Degree Relative**

(Immediate Family Member) A person's mother, father, sister, brother or child.

### **First-Line Therapy**

The initial (first) therapy used in a person's cancer treatment.

### **Flow Cytometry**

A laboratory test done on tumor tissue to measure the growth rate of the cancer cells and to check if the cells have too much DNA.

### **Fluorescence In Situ Hybridization (FISH)**

A laboratory test done on breast tumor tissue to find out the number

of copies of the HER2/neu gene contained in the cancer cells.

### **Frozen Section**

Process where a portion of tissue from a surgical biopsy is frozen so a thin slice can be studied to check for cancer. Frozen section results are only preliminary and always need to be confirmed by other methods.

## **G**

### **Gail Model** (Breast

Cancer Risk Assessment Tool) A tool that uses personal and family history to estimate a woman's risk of invasive breast cancer.

### **Galactocele**

A milk-filled cyst.

### **Gene**

Coded information within cells in the body that contain instructions for cell growth and other processes

### **Genetics Counselor**

A medical professional who specializes in talking with patients and their families about their risks for developing diseases caused by changes in genes

### **Gene Expression**

Process in which a gene gets turned on in a cell to make RNA and proteins.

### **Gene Expression Profiling** (see Tumor Profiling)

### **Gene Mutation**

Any change in the DNA (the information contained in a gene) of a cell. Gene mutations can be harmful, beneficial or have no effect.

### **Gene Variant of Uncertain Significance**

A gene mutation not currently known to increase breast cancer risk.

### **General Practitioner**

(Internist, Physician) The personal or family physician who may first find a suspicious area in the breast through a clinical breast exam or mammogram.

### **Generic**

The chemical name of a drug, not the brand name. The chemical formulations of a generic drug and the brand name drug are the same.

### **Genetic** (Hereditary)

Related to genes. The information in a person's

genes can be passed on (inherited) from either parent.

### **Genetic Susceptibility**

(Genetic Predisposition)

An increased likelihood or chance of developing a disease due to specific changes in a person's genes passed on from either parent.

### **Genetic Testing**

Analyzing DNA to look for a gene mutation that may show an increased risk for developing a specific disease.

### **Genome**

The total genetic information of an organism.

### **Genomics**

The study of genes and their functions.

**Glandular Tissue** (in the breast) The tissue in the breast that includes the milk ducts and lobules.

**Grade** (see Tumor Grade)

### **Growth factors**

A substance made by the body that functions to regulate cell division and cell survival. Some growth factors are also produced in the laboratory and used in biological therapy.

### **Guaranteed Renewable Insurance**

A health insurance policy that requires the insurance company to renew your policy for a certain amount of time, even if your health condition changes

## **H**

### **Hand-foot Syndrome**

A condition marked by pain, swelling, numbness, tingling, or redness of the hands or feet. It sometimes occurs as a side effect of certain anticancer drugs. Also called palmar-plantar erythrodysesthesia.

**H&E** (Hematoxylin and Eosin) Staining

A laboratory test that gives color to cells so cell structures can be identified.

### **HER2/Neu**

A protein involved in normal cell growth. HER2/neu is a type of receptor tyrosine kinase. Also called c-erbB-2, human EGF receptor 2, and human epidermal growth factor receptor 2. This can be found as "overexpressed" in some cancers. Cancer cells removed from the body may be tested for

the presence of HER2/neu to help decide the best type of treatment. If found, Herceptin may be used as part of the therapy.

**Herceptin** (see Trastuzumab)

**Hereditary** (see Genetic)

### **Homeopathy** (Homeopathic Medicine)

A medical system based on a belief that "like cures like." Natural substances are specially prepared in small amounts to restore health. These substances cause symptoms similar to the condition they are meant to treat in healthy people. There are limited data on the safety of these substances.

### **Hormone**

A chemical that is made and released by a gland in the body that affects cells or organs in another part of the body.

### **Hormone Receptors**

Specific proteins on cells that hormones attach to. A high number of hormone receptors on a breast cancer cell often means the cancer cell needs the hormone to grow.



## **Hormone Receptor Status**

Shows whether or not a breast cancer needs hormones to grow. A hormone receptor-positive (estrogen and/or progesterone receptor-positive) cancer needs hormones to grow. A hormone receptor-negative (estrogen and/or progesterone receptor-negative) cancer does not need hormones to grow. See Hormone Receptor.

**Hormone Replacement Therapy**  
(see Menopausal Hormone Therapy)

**Hormone Therapy**  
Medicines that stop the action or production of hormones

**Hormone Treatment**  
Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to

remove the gland that makes a certain hormone. Also called endocrine therapy, hormonal therapy, and hormone therapy.

## **Hospice Care**

Caring for the whole person at the end of their lives by supporting their emotional, physical, social, and spiritual needs.

**Hyperplasia** (Usual and Atypical Hyperplasia)  
A benign (not cancer) breast condition where breast cells are growing rapidly (proliferating). Although hyperplasia is not breast cancer, it increases the risk of breast cancer. In usual hyperplasia, the proliferating cells look normal under a microscope. In atypical hyperplasia, the proliferating cells look abnormal.



**Immediate Family Member** (First-Degree Relative)

A person's mother, father, sister, brother or child.

## **Immunotherapy**

Therapies that use the immune system to fight

cancer. These therapies target something specific to the biology of the cancer cell, as opposed to chemotherapy, which attacks all rapidly dividing cells. See Biological Therapy.

## **Immunohistochemistry (IHC)**

A laboratory test done on tumor tissue to detect the amount of HER2/neu protein on the surface of the cancer cells.

**Implant** (Breast Implant)  
An "envelope" containing silicone, saline or both, that is used to restore the breast form after a mastectomy (or for other cosmetic reasons).

## **Incidence**

The number of new cases of a disease that develop in a specific time period.

## **Incisional Biopsy**

Surgical biopsy that removes only part of the tumor.

## **Indemnity Policy**

A prepayment insurance plan that gives services or a cash payment for medical care needed in times of illness or disability.

## **Induction**

**Chemotherapy** (see Neoadjuvant Chemotherapy)

## **Inflammatory Breast Cancer (IBC)**

A rare and aggressive form of invasive breast cancer. Its main symptoms are swelling (inflammation) and redness of the breast. The skin on the breast may look dimpled, like the skin of an orange, and may be warm to the touch.

## **Infiltrating/Invasive Breast Cancer**

See also ductal cancer above. This term usually refers to ductal cancer type and refers to cancer that has invaded through the wall of the milk duct and infiltrated into the surrounding breast tissue. At this point, the cancer can spread locally in the same breast, to nearby regional nodes, and further beyond the affected breast.

## **Informed Consent**

The process through which a person learns about the possible benefits and side effects of a treatment plan and then accepts or declines the treatment. The person is usually asked to sign

a consent form, but may stop the treatment at any time and get other medical care.

## **Infraclavicular Lymph Nodes**

The lymph nodes below the clavicle (collarbone). See Lymph Nodes.

## **In-Network Provider**

The health care providers and medical centers (hospitals and other treatment centers) that are part of a particular group health plan or health maintenance organization (HMO).

## **In situ cancer**

See also ductal cancer above. Cancer that has not invaded the walls of the ducts or acinus. It is also called stage 0, or non-invasive, cancer.

## **Insurance Payment Cap**

A maximum amount an insurance company will pay out in a given time period.

## **Insurance Premium (Premium)**

The cost of insurance coverage for a certain period of time.

## **Integrative Therapies (see Complementary Therapies)**

## **Intraductal**

Within the milk duct. Intraductal can describe a benign (not cancerous) or malignant (cancerous) process.

## **Intraductal Hyperplasia**

An excess of cells growing within the milk ducts of the breast.

## **Intraductal Papilloma (Ductal Papilloma)**

Small, benign (not cancer) growths that begin in the ducts of the breast and usually cannot be felt. Symptoms include a bloody or clear nipple discharge.

## **Intravenous or IV**

Being within or entering the body through the veins.

## **Invasive Breast Cancer**

Cancer that has spread from the original location (milk ducts or lobules) into the surrounding breast tissue and possibly into the lymph nodes and other parts of the body. Invasive ductal cancer begins in the milk ducts. Invasive lobular cancer begins in the lobules of the breast.

## **Investigational New Drug (New Experimental Treatment)**

A chemical or biological drug that has been

approved for use by researchers in studies, but is not yet available outside of a clinical trial.

## K

### **Ki-67 Rate**

A common way to measure proliferation rate. The more cells the Ki-67 antibody attaches to on a tissue sample, the more likely the tumor cells are to grow and divide rapidly.

## L

### **Lactation**

The process of producing milk and breastfeeding a child.

### **Large Veins** (Deep Veins)

The large veins deep inside the legs that carry blood from the legs back to the heart.

### **Late-Stage Cancer**

(see Metastatic Breast Cancer)

### **Lesion**

Area of abnormal tissue.

### **Lifetime Risk**

The chance of developing a disease (like breast cancer) over the course of a lifetime (usually defined as birth up to

age 85). For example, the lifetime risk of breast cancer for women is 1 in 8 (or about 12 percent). This means for every 8 women, one will be diagnosed with breast cancer during her lifetime (up to age 85).

### **Linear Accelerator**

The device used during radiation therapy to direct X-rays into the body.

### **Liver Scan**

An image of the liver that can show the presence or absence of a tumor.

### **Lobular Cancer**

Also a type of cancer but differentiated from and much less common than ductal type. Like ductal type, lobular carcinoma can also form mass and distortion. However, it can also be much more subtle on imaging, and therefore harder to detect.

### **Lobular Carcinoma in Situ** (LCIS, Lobular Neoplasia in Situ)

A condition where abnormal cells grow in the lobules of the breast. LCIS increases the risk of breast cancer.

### **Lobular Neoplasia in**

**Situ** (see Lobular Carcinoma in Situ)

### **Lobule**

Part of the breast anatomy where milk is made before it travels down the milk ducts to the nipple.

### **Local Anesthetic**

Anesthesia that only numbs the tissue in a certain area. See Anesthesia.

### **Local Therapy**

Treatments that are directly targeted to and affect cells in and around tumors.

### **Local Treatment**

Treatment that focuses on getting rid of the cancer from a certain (local) area. In breast cancer, the local area includes the breast, the chest wall and lymph nodes in the underarm area (axillary nodes). Local treatment for breast cancer includes surgery with or without radiation therapy.

### **Localized Breast Cancer**

Cancer that is contained in the breast and has not spread to nearby tissue, lymph nodes or other organs.

### **Locally Advanced Breast Cancer** (Stage III Breast Cancer)

Cancer that has spread beyond the breast to the skin or chest wall, but not to distant organs like the lungs or liver. It also refers to a tumor that is larger than five centimeters (about two inches) in size.

### **Local Recurrence**

(Recurrence)

The return of cancer to the same breast or to the same side chest wall.

### **Lump**

Any mass in the breast or elsewhere in the body.

### **Lumpectomy** (Breast Conserving Surgery)

Surgery that removes only part of the breast—the part containing and closely surrounding the tumor.

### **Lymph Nodes** (Lymph Glands)

Small groups of immune cells that act as filters for the lymphatic system. Clusters of lymph nodes are found in the underarms, groin, neck, chest and abdomen.

### **Lymph Node Status**

Shows whether or not cancer has spread to the lymph nodes. Lymph

node-positive means that cancer has spread to the lymph nodes.

Lymph node-negative means that cancer has not spread to the lymph nodes. See Lymph Nodes.

### **Lymphatic System**

The network of lymph nodes and vessels in the body.

### **Lymphedema**

Swelling due to poor draining of lymph fluid that can occur after surgery to remove lymph nodes or after radiation therapy to the area. Most often occurs in the upper limbs (arm, hands or fingers), but can occur in other parts of the body.

## **M**

### **Macrobiotics**

(Macrobiotic Diet)

Integrative or complementary dietary therapy that includes a mostly vegetarian, organic food diet with certain methods of food preparation.

### **Magnetic Resonance Imaging** (see MRI)

### **Malignant**

By strict definition, cancerous.

### **Mammary Duct** (see Duct)

### **Mammary Duct Ectasia**

A benign (not cancer) breast condition resulting from inflammation (swelling) and enlargement of the ducts behind the nipple. Often there are no symptoms, but calcifications seen on a mammogram may point to its presence. No treatment is needed if the woman is not having symptoms (burning, pain or itching in the nipple area).

### **Mammary Glands**

The breast glands that produce milk.

### **Mammogram**

An X-ray image of the breast.

### **Margins**

The rim of normal tissue surrounding a tumor that has been surgically removed. A margin is clean (also known as uninvolved, negative or clear) if there is only normal tissue (and no cancer cells) at the edges. Clean margins show the entire tumor was removed. With involved (also known as positive) margins, normal tissue does not completely surround the tumor. This

means the entire tumor was not removed and more surgery is needed to get clean margins.

### **Mastectomy**

Surgical removal of the breast. The exact procedure depends on the diagnosis. See Total Mastectomy and Modified Radical Mastectomy.

### **Mastitis**

An inflammation (swelling) of the breast usually occurring during breastfeeding. Symptoms include pain, nipple discharge, fever, redness and hardness over an area of the breast.

### **Medical Oncologist**

is in here twice. The first occurrence can be removed.

### **Median Survival Time**

The time from diagnosis or treatment at which half of the patients with a disease are found to be, or expected to be alive. In a clinical trial, median survival time is one way to measure how effective a treatment is. Also called median overall survival and median survival.

### **Mean**

The average of a group of numbers.

### **Mean Survival Time**

The average time from the start of treatment (or diagnosis) that people in a study stay alive.

### **Median**

The middle value (50th percentile) of a group of numbers.

### **Medical Oncologist**

A physician specializing in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy. The medical oncologist may also be the main treating physician, and can also provide and/or coordinate the treatments given by other specialists.

### **Melatonin**

Hormone made by the pineal gland in the brain. It is an important part of the body's internal timing system.

### **Menarche**

The first menstrual period.

### **Menopausal Hormone Therapy**

(Postmenopausal Hormone Use, Hormone Replacement Therapy) The use of hormone pills containing estrogen (with or without proges-

tin) to ease symptoms of menopause.

### **Menopause**

By definition, natural age-related menopause starts 12 months after the last menstrual period. It usually begins in the 40s or 50s.

### **Meta-Analysis**

A method for taking the results reported in a group of studies and averaging them to come up with a single, summary result.

### **Metabolized**

The chemical process whereby drugs and food are broken down by the body.

### **Metastasis**

Spread beyond the primary cancer site in the breast. Metastasis means spread to regional nearby nodes and beyond, or nearby lymph nodes to distant areas of the body.

### **Metastatic**

Cancer that has spread beyond the original location to other parts of the body.

### **Microcalcifications**

Small, clustered deposits of calcium in the breast that may be seen on a

mammogram. These may or may not be related to breast cancer.

### **Microvascular Surgery**

Surgery that involves connecting small blood vessels.

### **Modified Radical Mastectomy**

Surgical removal of the breast, the lining of the chest muscles and some of the lymph nodes in the underarm area. Used to treat early and locally advanced breast cancer.

### **Molecular Breast**

Imaging (see Nuclear Medicine Imaging of the Breast)

### **Monoclonal antibodies**

A protein made in the laboratory that can locate and bind to substances in the body, including tumor cells. Each monoclonal antibody is made to find one substance. Monoclonal antibodies are being used to treat some types of cancer and are being studied in the treatment of other types. They can be used alone or to carry drugs, toxins, or radioactive materials directly to a tumor.

### **Mortality Rate**

Number of deaths in a given group of people over a certain period of time.

### **MRI (Magnetic Resonance Imaging)**

An advanced form of radiology imaging exam using no radiation to create detailed images of the body.

### **mTOR (Mammalian Target of Rapamycin) Inhibitors**

A class of targeted therapy drugs that may increase the benefit of hormone therapy. Everolimus (Afinitor) is an example of an mTOR inhibitor.

### **Multifocal Tumors**

(Multicentric Tumors)  
One or more tumors that develop from the original breast tumor.

### **Multimodality Therapy**

Use of two or more treatment methods (such as surgery, radiation therapy, chemotherapy, hormone therapy and targeted therapy) in combination or one after the other to get the best results.

### **Mutation**

(Gene Mutation)  
Any change in the DNA

(the information contained in a gene) of a cell. Gene mutations can be harmful, beneficial or have no effect.

## **N**

### **Naturopathy**

(Naturopathic Medicine)  
A medical system based on a belief in using natural elements to maintain health and to help the body heal itself. It includes therapies such as nutrition and massage.

### **Needle Localization**

(see Wire Localization)

### **NED**

A period where tests show no evidence of disease.

### **Neoadjuvant Chemotherapy**

(Induction Chemotherapy, Primary Chemotherapy, Preoperative Chemotherapy)  
Chemotherapy used as a first treatment. Often used for large or locally-advanced cancers to shrink tumors before surgery.

### **Neoadjuvant Hormone Therapy**

Hormone therapy used as a first treatment. Often used for large or

locally-advanced cancers to shrink tumors before surgery.

### **Neoadjuvant Therapy**

(Preoperative Therapy)

Chemotherapy or hormone therapy used as a first treatment. Often used for large or locally-advanced cancers to shrink tumors before surgery.

### **Neoplasia**

Abnormal growth.

### **Neoplasm**

Excess number of cells in a mass that can be either benign (not cancerous) or malignant (cancerous).

### **Nested Case-Control Study**

A case-control study done within a prospective cohort study. The major advantage of a nested case-control study over a regular case-control study is the exposure of interest (for example, diet or alcohol use) is measured before any of the participants have disease, making it less subject to bias.

### **Neuropathy**

A nerve problem that may cause causes pain, numbness, tingling, swelling, or muscle

weakness in different parts of the body. It usually begins in the hands or feet and can worsen or improve over time.

### **Nipple-Sparing Mastectomy**

A breast reconstruction procedure that removes the tumor and margins as well as the fat and other tissue in the breast, but leaves the nipple and areola intact.

### **Node-Negative**

(Lymph Node-Negative)  
Cancer that has not spread to the lymph nodes. See Lymph Node Status.

### **Node-Positive**

(Lymph Node-Positive)  
Cancer that has spread to the lymph nodes. See Lymph Node Status.

### **Non-invasive**

Cancer that stays within the ducts or lobules of the breast. Also called in situ or stage 0 cancer

### **Nonpalpable**

Describes a breast lump or abnormal area that cannot be felt but can be seen on an imaging test (such as a mammogram).

### **Normal Tissue**

Cells that are can-

cer-free.

.  
**NSAID** (nonsteroidal anti-inflammatory drug)

A drug that decreases fever, swelling, pain, and redness.

### **Nuclear Medicine Imaging of the Breast**

(Molecular Breast Imaging)

A technique under study for use in the early detection of breast cancer. Nuclear medicine imaging uses short-term radioactive agents given through an IV. Cancer cells absorb these agents and can be imaged with a special camera. Nuclear medicine imaging is not a standard breast cancer screening tool. Breast-specific gamma imaging and scintimammography are types of nuclear medicine imaging.

### **Nucleus**

The part a cell that contains the genetic material DNA. Nuclei is the plural of nucleus.



### **Observational Study**

A research study where participants live their daily lives as usual and

report their activities to researchers.

### **Odds Ratio**

A measure reported in case-control studies that describes the increase (or decrease) in disease risk related to a risk factor. An odds ratio is interpreted in the same way as a relative risk, though it is calculated differently.

### **Oncologist**

The physician in charge of planning and overseeing cancer treatment.

### **ONJ** (Osteonecrosis of the Jaw)

Cancer patients taking certain bone drugs called bisphosphonates may develop bone damage in the jaw, which disrupts the blood supply to the bone, causing tiny breaks that can eventually lead to bone collapse.

### **Oophorectomy**

Surgery to remove one or both ovaries.

### **Opiate**

A drug that contains opium or a substance made from opium and is used to treat pain.

### **Opioid**

A substance used to

treat moderate to severe pain. Opioids are like opiates, such as morphine and codeine, but are not made from opium. Opioids bind to opioid receptors in the central nervous system. Opioids used to be called narcotics. An opioid is a type of alkaloid.

### **Osteoblastic/Osteolytic Bone Metastases**

Metastatic bone lesions are also known as osteolytic, osteoblastic and mixed, and are most common where the destructive processes outstrip the laying down of new bone. Osteoblastic lesions result from new bone growth stimulated by the tumor.

### **Osteoporosis**

A condition marked by a loss of bone mass and density that causes bones to become fragile.

### **Out-of-Network Provider**

Any health care provider or medical center (hospital or other treatment center) that is not part of a particular group health plan or health maintenance organization (HMO).

### **Ovarian Ablation**

Surgery, radiation therapy,

or a drug treatment to stop the functioning of the ovaries. Also called ovarian suppression.

### **Over-Diagnosis**

Diagnosis that occurs when a mammogram finds ductal carcinoma in situ (DCIS) or a small, invasive breast cancer that would have never caused symptoms or problems if left untreated. These breast cancers may never grow or a person may die from another cause before the breast cancer becomes a problem.

### **Over-Treatment**

Treatment for ductal carcinoma in situ (DCIS) or a small, invasive breast cancer that would have never caused symptoms or problems if left untreated.

### **Overall Survival**

(Overall Survival Rate, Survival)

The percentage of people alive for a certain period of time after diagnosis with a disease (such as breast cancer) or treatment for a disease.



# P

## **Paget Disease of the Breast** (Paget Disease of the Nipple)

A rare cancer in the skin of the nipple or in the skin closely surrounding the nipple that is usually, but not always, found with an underlying breast cancer (ductal in situ carcinoma or invasive breast cancer). In these cases, the tumor grows from underneath the nipple and breaks out onto the surface of the nipple.

## **Palliative Care**

Medical care given to reduce pain and maintain the best quality of life.

## **Palpable**

Describes a breast lump or abnormal area that can be felt during a clinical breast exam.

## **Palpation**

To examine, using the hands and fingers.

## **PARP Inhibitor**

A substance that blocks an enzyme involved in functions of the cell, including repair of DNA damage, which could have been caused by normal cell actions, UV light, some anticancer

drugs, and radiation used to treat cancer. This is a type of targeted therapy, that may cause cancer cells to die. Also called poly (ADP-ribose) polymerase inhibitor.

## **Partial Mastectomy** (see Lumpectomy)

## **Pathologic Response**

A measure describing how much of the tumor is left in the breast and lymph nodes after neoadjuvant (before surgery) therapy. The pathologic response gives some information about prognosis. A complete pathologic response means there is no invasive cancer in the tissue removed during breast surgery.

## **Pathologist**

The physician who uses a microscope to study the breast tissue and lymph nodes removed during biopsy or surgery and determines whether or not the cells contain cancer.

## **Pathology report**

A profile of your test results that helps doctors figure out treatment plan.

## **Peri-menopausal**

The period of time before a woman begins menopause, but experience some of its symptoms.

## **Peripherally Inserted Central Catheter** (PICC)

A small tube used to deliver medicine to the body through a vein. Instead of being reinserted for each use, a PICC is left in place to allow access for a long period of time (weeks to months).

## **Permanent Section**

A method used in diagnosis. Thin slices of tissue are processed and put on a slide so that a pathologist can study them under a microscope. These sections are of better quality than frozen sections.

## **Perometer**

A device that uses infrared light beams to measure limb volume.

## **Personalized Medicine**

Using information about a person's genes, the tumor's genes, molecular characteristics of the tumor and the environment to prevent, diagnose and treat disease (such as the use of targeted therapies). This may also be known as

precision medicine.

**PET** (Positron Emission Tomography)

A procedure where a short-term radioactive sugar is given through an IV so that a scanner can show which parts of the body are consuming more sugar. Cancer cells tend to consume more sugar than normal cells do. PET is sometimes used as part of breast cancer diagnosis or treatment, but is not used for breast cancer screening.

**PET Scan**

A radiology imaging exam using small injection of radioactive material (usually with glucose) to create images of the body.

**Pharmacogenomics** (Pharmacogenetics)

The study of the way genes affect a person's response to drugs to help predict which drugs may offer him/her the most benefit.

**Phenotype**

A characteristic in a person that results from the interaction between his/her genes and his/her environment.

**Phyllodes Tumor**

A rare sarcoma (cancer of the soft tissue) in the breast.

**PICC Line**

A thin, flexible tube inserted into a vein in the arm and extends into a larger vein in the body, used to administer chemotherapy treatment.

**Pituitary Gland**

A part of the brain that controls growth and other glands in the body, such as the ovaries.

**Placebo**

An inactive medicine sometime used to have a comparison to a new drug in a clinical study. May be called a "sugar pill."

**Placebo-controlled Studies** Clinical trials in which one group of participants does not receive the treatment being tested so that researchers can compare with and without the new treatment that is being tested.

**Pooled Analysis**

A method for collecting the individual data from a group of studies, combining them into one large set of data and then analyzing the data

as if they came from one big study.

**Positron Emission Tomography** (see PET)

**Post-menopausal**

See also menopause, above listing.

**Postmenopausal Hormone Use** (see Menopausal Hormone Therapy)

**Precision Medicine**

Using information about a person's genes, the tumor's genes, molecular characteristics of the tumor and the environment to prevent, diagnose and treat disease (such as the use of targeted therapies ). This may also be known as personalized medicine.

**Predictive Factors**

Factors (such as hormone receptor status) that help guide treatment for a specific cancer case.

**Predispose**

To make more at risk for a disease.

**Pre-menopausal**

The time before menopause.

**Premenopausal Women**

Women who have regular menstrual periods.

**Premium** (Insurance Premium)

The cost of insurance coverage for a certain period of time.

### **Preoperative**

**Chemotherapy** (see Neoadjuvant Chemotherapy)

### **Prevalence Rate**

The proportion (percentage) of people in a population who have a certain disease, behavior or characteristic at a defined point in time.

### **Prevention**

Steps taken to lower the risk of a disease.

**Primary Chemotherapy** (see Neoadjuvant Chemotherapy)

### **Primary Diagnosis**

The first diagnosis of breast cancer.

### **Primary Tumor**

The original cancer.

### **Progesterone Receptor**

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

### **Progestin**

Any substance (laboratory-made or natural) that has some or all of the effects of progesterone in the body.

### **Progesterone**

A hormone made in females by the ovaries that has effects on reproduction. Some breast cancer cells may grow in response to this hormone.

### **Prognosis**

The expected or probable outcome or course of a disease (the chance of recovery).

### **Prognostic Factors**

Factors (such as tumor type, size and grade) that help determine prognosis.

### **Progression**

The course of a disease. In cancer, the growth of tumors or spread of the disease.

### **Progression Free Survival**

The length of time during and after treatment in which a patient is living with a disease that does not get worse. Progression-free survival may be used in a clinical study or trial to help find out how well a new

treatment works. Also called PFS.

### **Proliferative**

Rapidly growing and increasing in number.

### **Proliferation Index**

A number that shows what percentage of the cancer cells are actively dividing at a given time.

### **Prophylactic Mastectomy**

Preventive surgery where one or both breasts are removed in order to prevent breast cancer. When both breasts are removed, the procedure is called bilateral prophylactic mastectomy.

### **Prospective Study**

An observational study that follows people forward in time. See Cohort Study.

### **Prosthetic** (Breast Prosthetic, Prosthesis)

An artificial breast form that can be worn under clothing after a mastectomy.

### **Protocol**

An outline or plan for the use of an experimental drug, treatment or procedure in cancer therapy or diagnosis.

## **Punch Biopsy**

Removal of a small circle of skin (with a special instrument called a punch or trephine) to be tested for cancer cells.

## **Q**

### **Quadrantectomy**

Surgery where one quadrant or 25 percent of the breast is removed. See Lumpectomy.

### **Quality of Care**

Measures of how well breast cancer is treated and how well a person is cared for during and after treatment.

### **Quality Life**

The quality of an individual's daily well-being.

### **Quartiles**

Categories of an exposure (like body weight or exercise) based on four equal parts of the total number of people in the study.

### **Quantiles**

Categories of an exposure (like body weight or exercise) based on equal parts of the total number of people in the study. When the total number of people is divided into thirds, the categories are called tertiles. When the

total number of people is divided into quarters, the categories are called quartiles.

## **R**

### **RAD (Dose of Radiation)**

Short for "radiation absorbed dose." This term describes the amount of radiation absorbed by the tissues. One RAD is equal to one centigray. See Centigray.

**Radial Scars (Complex Sclerosing Lesions)**  
A benign (not cancer) breast condition with a core of connective tissue fibers. Ducts and lobules grow out from this core.

### **Radiation Oncologist**

A doctor who specializes in treating cancer with radiation.

### **Radiation Therapy**

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer

cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radio-labeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiotherapy.

### **Radiofrequency Ablation**

A procedure using radio waves to heat and destroy abnormal cells. The radio waves travel through electrodes. Radiofrequency ablation may be used to treat cancer and other conditions.

### **Radical Mastectomy**

(Halsted Radical)  
Surgical removal of the breast, chest muscles and underarm lymph nodes. Used only when the breast tumor has spread to the chest muscles.

### **Radio-opaque**

Does not allow radiation to pass through. A radio-opaque object will show up on an X-ray.

### **Radiologist or Breast Imaging Radiologist**

The physician imaging specialist who interprets all of the breast

imaging studies. These doctors also perform the needle procedures used to biopsy (ultrasound, stereotactic, or MRI guided) and preoperatively localize the problem areas. They are breast imaging specialists who work with the breast surgeons, breast oncologists, and breast radiation therapists in the team approach.

**Radiotherapy** (see Radiation Therapy)

### **Raloxifene**

A drug first used to treat osteoporosis and now also used to lower the risk of breast cancer in postmenopausal women at high risk.

### **Randomized Controlled Trials**

Studies where researchers change some participants' behavior or provide a certain therapy to see how it affects health. Participants are randomly assigned (as if by coin toss) to either an intervention group (such as one getting a new drug) or a control group (such as one getting standard treatment).

### **Recurrent Disease**

Cancer that has come back.

**Reconstruction** (see Breast Reconstruction)

### **Recurrence** (Relapse)

Return of cancer. Local recurrence is the return of cancer to the same breast or the same side chest wall. Distant recurrence is the return of cancer that has spread to other parts of the body, such as the lungs, liver, bones or brain. See Metastases.

### **Regimen**

A treatment plan.

### **Regional Lymph Nodes**

In breast cancer, the axillary (in the underarm area) lymph nodes, infraclavicular (under the collarbone) lymph nodes, supraclavicular (above the collarbone) lymph nodes and internal mammary nodes. See Lymph Nodes.

### **Regression**

Decreases in the tumor size or spread of cancer.

### **Relative Risk**

A measure used to describe the increase (or decrease) in risk related to a specific risk factor. A relative risk is the ratio of two absolute risks: the numerator is the absolute risk among those with the risk factor

and the denominator is the absolute risk among those without the risk factor. A relative risk that is greater than one shows a factor increases risk. A relative risk that is less than one shows a factor decreases risk. And, a relative risk of one shows the factor neither increases nor decreases risk (this means the factor is not likely related to risk of the disease).

### **Relative Survival**

(Relative Survival Rate)

A measure used to compare the survival of people who have a certain disease with those who do not at a given time after diagnosis or treatment. The relative survival rate shows whether the disease shortens life. If relative survival is 100 percent at five years after treatment, there is no difference in survival between those who have the disease and those who do not five years after treatment.

### **Retrospective Study**

A study where both the exposure (such as alcohol use) and the outcome (such as breast cancer) occur before the start of the study.

**Risk** (of disease)

Probability (chance) of disease developing in a person during a specified time period.

**Risk-Benefit Ratio**

The relationship between the possible (or expected) side effects and benefits of a treatment or procedure.

**Risk Factor**

Any factor—from a lifestyle choice (such as diet) to genetics to an environmental exposure (such as radiation)—that increases or decreases a person's risk of developing a certain disease.

**RNA** (Ribonucleic Acid)

A molecule made by cells containing genetic information that has been copied from DNA. RNA performs functions related to making proteins.

**S****Saline**

A saltwater solution similar to that found in IV fluids. Saline can be used to fill a breast implant.

**Scalp Cooling**

The use of a cap filled with a chilled substance

during chemotherapy. Scalp cooling is under study as a technique for reducing hair loss due to chemotherapy.

**Schedules**

The different combinations and timing for chemotherapy and other drugs.

**Sclecting Adenosis**

Small, benign (not cancer) breast lumps caused by enlarged lobules. The lumps may be felt and may be painful.

**Scintimammography**

(see Nuclear Medicine Imaging of the Breast)

**Screening**

A test or procedure used to find cancer or a benign (not cancer) condition in a person who does not have any known problems or symptoms.

**Screening Mammogram**

A test used to find early signs of breast cancer in a woman who does not have any known breast problems or symptoms.

**Second Primary Tumor**

A second breast cancer that develops in a different location from the first. This is different

from a local recurrence, which is the return of the first breast cancer.

**Selection Criteria**

In a summary research table, the specific standards (such as study design and number of participants) a study has to meet to be included.

**Selective Estrogen Receptor Modulator (SERM)**

A drug that can either block the effects of estrogen or behave like estrogen, depending on the part of the body being treated. Tamoxifen and raloxifene are SERMs.

**Sensitivity**

The proportion (or percentage) of people who truly have the condition of interest who test positive for that condition.

**Sentinel Node Biopsy**

The surgical removal and testing of the sentinel node(s) (first axillary node(s) in the underarm area filtering lymph fluid from the tumor site) to see if the node(s) contains cancer cells.

**Side Effect**

Unwanted effect caused by medicines or treatments, including emo-

tional and physical

### **Silicone Gel**

Medical-grade, solid form of silicone used for breast implants. Silicone implants can mimic the feel of a natural breast better than saline implants.

### **Simple Mastectomy**

(see Total Mastectomy)

### **Skin-Sparing Mastectomy**

A procedure that surgically removes the breast, but keeps intact as much of the skin that surrounds the breast as possible. This skin can then be used in breast reconstruction to cover a tissue flap or an implant instead of having to use skin from other parts of the body.

### **Sonogram**

(see Ultrasound)

### **Specificity**

The proportion (or percentage) of people who truly do not have the condition of interest who test negative for the condition.

### **Stages of Breast Cancer**

These describe the extent of the cancer in the body and are based

on whether the cancer is invasive or non-invasive, tumor size, lymph node involvement, and whether or not it has spread to other body parts. Cancer staging is one of the key factors that allow healthcare providers to determine prognosis and treatment.

### **Staging**

Performing tests to determine extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body. It is important to know the stage of the disease in order to plan the best treatment.

### **Standard Treatment**

(Standard of Care)

The usual treatment of a disease or condition currently in widespread use and considered to be of proven effectiveness on the basis of scientific evidence and past experience.

### **Statistical Significance**

Describes whether or not the result of a study is likely due to chance. A statistically significant result likely shows a true link between a risk factor and breast cancer.

### **Stereotactic Needle Biopsy**

Core needle biopsy done with the use of stereotactic (three-dimensional) mammography guidance.

### **Stereotactic Mammography**

Three-dimensional mammography used to guide a needle biopsy.

### **Supraclavicular Lymph Nodes**

The lymph nodes above the clavicle (collarbone). See Lymph Nodes.

### **Surgeon**

Physician who performs any surgery, including surgical biopsies and other procedures related to breast cancer.

### **Surgical Oncologist**

A physician specializing in the treatment of cancer using surgical procedures.

**Survival** (see Overall Survival and Relative Survival)

**Survivor** (Breast Cancer Survivor)

A person living with breast cancer (from the time of diagnosis).

### **Survivorship**

The emotional and

physical health, life and care of a breast cancer survivor from the time of diagnosis until the end of life.

### **Systemic Therapy**

Medicines/treatments that treat the whole body by traveling through the blood-stream.

## **T**

### **Tamoxifen** (Nolvadex)

A hormone therapy drug (taken in pill form) used to treat early and advanced stage breast cancers that are hormone receptor-positive. These breast cancers need estrogen to grow. Tamoxifen stops or slows the growth of these tumors by blocking estrogen from attaching to hormone receptor in the cancer cells.

### **Targeted Therapy**

Treatment that uses drugs or other substances, such as monoclonal antibodies, to identify and attack specific cancer cells. Targeted therapy may have fewer side effects than other types of cancer treatments.

### **Tertiles**

Categories of an expo-

sure (like body weight or exercise) based on three equal parts of the total number of people in the study.

### **Therapeutic Touch**

An integrative or complementary therapy where trained practitioners enter a semi-meditative state and hold their hands just above a person's body to sense energy imbalances due to illness. Healing energy is then said to transfer to the person.

### **Thermography**

An imaging technique that uses infrared light to measure temperature differences on the surface of the breast. The U.S. Food and Drug Administration (FDA) and the American College of Radiology do not view thermography as a valuable breast cancer screening method.

### **Tissue**

A group or layer of cells.

**Tomosynthesis** (see Breast Tomosynthesis)

### **Total Mastectomy**

(Simple Mastectomy) Surgical removal of the breast but no other tissue or nodes. Used for

the treatment of ductal carcinoma in situ and, in some cases, breast cancer recurrence. Also used in prophylactic mastectomy.

### **Trastuzumab**

(Herceptin)

A drug that is a specially made antibody that targets cancer cells with a lot of the protein called HER2/neu on their surfaces. When attached to the HER2/neu protein, trastuzumab slows or stops the growth of the cancer cells. Trastuzumab is used to treat HER2/neu-positive breast cancer. Herceptin is the brand name for trastuzumab.

### **Treatment Breaks**

Short breaks in treatment that allow for rest or for special events.

### **Triple Negative**

(ER-negative, PR-negative, HER2/neu-negative) Breast cancer cells that do not have estrogen receptors, progesterone receptors, or large amounts of HER2/neu protein. Also called ER-PR-HER2/neu- and TNBC.

### **Tumor**

An abnormal growth or mass of tissue that



may be benign (not cancerous) or malignant (cancerous).

### **Tumor Grade**

Describes how closely cancer cells look like normal cells. Grade 1 tumors have cells that are slow-growing and look the most like normal cells. Grade 3 tumors have cells that are fast-growing and look very abnormal. Grade 2 tumors fall in between grade 1 and grade 3.

### **Tumor Marker**

A substance that may be found in tumor tissue or released from a tumor into the blood or other body fluids. A high level of a tumor marker may mean that a certain type of cancer is in the body. Examples of tumor markers include CA 125 (in ovarian cancer), CA 15-3 (in breast cancer), CEA (in ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (in prostate cancer).

### **Tumor Profiling** (Gene Expression Profiling)

Tests that give information about thousands of genes in cancer cells. Specific genes (or combinations of genes) may give information useful

in prognosis and in making treatment decisions.

### **Two-Step Procedure**

Biopsy and further surgical treatment done at two separate times.

### **Tyrosine-Kinase Inhibitors**

A class of drugs that target enzymes important for cell functions (called tyrosine-kinase enzymes). These drugs can block tyrosine-kinase enzymes at many points along the cancer growth pathway.

## **U**

### **Ultrasound** (Sonogram)

Diagnostic test that uses sound waves to make images of tissues and organs. Tissues of different densities reflect sound waves differently.

### **Usual Hyperplasia**

A benign (not cancer) breast condition where breast cells are growing rapidly (proliferating). The proliferating cells look normal under a microscope. Although usual hyperplasia is not breast cancer, it increases the risk of breast cancer.

## **V**

### **Vaginal Atrophy**

(Atrophic Vaginitis)  
Vaginal dryness.

### **VEGF**

A substance made by cells that stimulates new blood vessel formation. Also called vascular endothelial growth factor.

## **W**

### **Wire Localization**

(Needle Localization)  
Insertion of a very thin wire into the breast to highlight the location of an abnormal area so that it can be removed during biopsy or lumpectomy.

## **X**

### **X-ray**

Radiation that, at low levels, can be used to make images of the inside of the body. For example, a mammogram is an X-ray image of the breast. At high levels of radiation, X-rays can be used in cancer treatment.

# NOTES

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# NOTES

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