



FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



BREAST CANCER

You are not alone if you or someone you care for has breast cancer. Breast cancer is the second-most common cancer among women in the United States. Men and non-binary people can get breast cancer too. This booklet offers an introduction to breast cancer and its treatment in simple terms. It provides useful information to help you learn more, plan for treatment, and find the tools you may need to cope with this disease.

What is Breast Cancer

Breast cancer occurs when cells in the breast grow out of control. The breast is an organ. It sits on top of the chest muscles and upper ribs. A person can develop breast cancer in one or both breasts.

Breast cancer can start in different areas of the breast. This may include the:

- **Lobules**—These are glands in the body that help make breast milk.
- **Nipple**—This is an opening in the skin of the breast. The nipple is surrounded by the **areola**. This is the area of the breast where the skin is slightly darker in color and thicker.
- **Ducts**—Ducts are small tubes that help carry breast milk from the lobules to the nipple.
- **Stroma**—Stroma are fat and connective tissues that help keep the ducts and lobules in place.
- **Lymph Vessels**—The lymph vessels help carry blood and fluid away from the breast.

KEY TERMS

Biomarker: A biomarker is a sign of disease or abnormal function that can be measured in your blood, tissue, or bodily fluid. In cancer, biomarkers are often used to help choose the best treatment for you. These biomarkers can be proteins, genes, or gene mutations.

BRCA: BRCA genes (BRCA1/ BRCA2) make proteins that help repair damaged DNA in cells. Changes in these genes, or mutations, can increase a person's risk of developing breast cancer.

Genes: Genes carry the information that pass on traits that can be inherited from parents to children. Chemically, a gene is made of DNA. Genes affect the way our cells and bodies work.

Genetic mutation: A genetic mutation is a change in a gene. Mutations in your genes can be inherited from your parents and passed on to children. Your genes can also develop a mutation during your lifetime. This is called an acquired mutation. These mutations are not inherited and cannot be passed on to children. Your genes may be tested for mutations that increase your risk of getting cancer.

Hormone receptors: Receptors are special proteins found inside or on the surface of certain cells throughout the body. This can include breast cancer cells. When activated, these proteins can cause cancer cells to grow and divide.



TYPES OF BREAST CANCER

The most common areas for breast cancer to develop are the lobules or ducts of the breast. Still, there are several different types of breast cancer. These types are based on where the cancer started, the type of cells that are changed by the cancer, and the types of genes or proteins the cancer might make.

Some of the most common types of breast cancer include:

- **Ductal Carcinoma in Situ (DCIS):** DCIS is an early form of breast cancer. DCIS occurs when cancer cells are found in the breast ducts. It is considered *non-invasive* because the cancer has not spread beyond the wall of the duct. It is also known as Stage 0 breast cancer.
- **Invasive Ductal Carcinoma:** This is the most common type of breast cancer. It forms in the tubes that help carry milk from the breast. The cancer cells have spread beyond the wall of the duct to nearby fatty and connective tissue. If left untreated, this cancer can spread to other organs.
- **Invasive Lobular Carcinoma:** This form of cancer starts in the lobules of the breast. The cancer cells have spread passed the lobules to nearby fatty and connective tissue. If left untreated, the cancer can spread to other organs in the body.
- **Inflammatory Breast Cancer:** This type of breast cancer typically looks like a rash or infection and can lead to swelling. This occurs when the cancer cells spread to lymphatic channels in the skin. This is what causes the cancer to look more like a rash, instead of lumps. This also causes the swelling.

- **Metastatic Breast Cancer:** Metastatic breast cancer means that the cancer has spread to other organs in the body. This can include the bone, lungs, liver, or brain. It is also known as advanced (or Stage IV) breast cancer.

- Metastatic breast cancer can begin as a new cancer. If you have breast cancer for the first time and it has already spread, it is called *de novo* metastatic breast cancer. Metastatic breast cancer can also be the return of a prior breast cancer. This type of cancer can be harder to treat compared to other breast cancers.

TRIPLE-NEGATIVE BREAST CANCER

A subtype of breast cancer that will be discussed throughout this resource is Triple-Negative Breast Cancer or **TNBC**. Doctors diagnose TNBC through lab tests. They test tumor tissue for the hormone receptors, estrogen (ER) and progesterone (PR). They also test for the biomarker HER2. Breast cancers that test negative for both hormone receptors and HER2 are considered “triple-negative”.

TNBC is considered invasive and an aggressive form of breast cancer. This means that it can start in the ducts or lobules and spread quickly to nearby tissue. TNBC can also be inflammatory. This means it looks like a rash and can lead to swelling.

This cancer is more common in people who carry the BRCA gene mutation and people who develop breast cancer before age 40. Black and African American persons are at higher risk for developing TNBC. Since it is an aggressive form of cancer, it can be more difficult to treat.





Breast Cancer Risk

Risk factors are things that can increase a person's chance of developing a disease. Research is improving our knowledge of the causes of breast cancer. While most breast cancer cases develop without warning, there are some known factors that can increase a person's risk. These include:

- Having a family history of cancer or genetic mutations
- Having a personal history of a previous breast cancer
- Having a personal history of non-cancer related diseases within the breasts
- Being older in age
- Having breasts that have a higher tissue density
- Never experiencing childbirth or giving birth at an older age
- Your race and ethnicity

BREAST CANCER RISK IN BLACK & AFRICAN AMERICAN COMMUNITIES

It is important to talk about the risk and impact of breast cancer in Black and African

American communities. White people have a greater risk of developing breast cancer. However, Black and African American persons are more likely to have poorer treatment outcomes and rates of survival. This includes having an increased risk of:

- Developing breast cancer at younger ages
- Developing TNBC, an aggressive form of breast cancer (3 times as likely as white people)
- Seeing breast cancer return after treatment
- Dying of breast cancer (42% more likely than white people)

It is unclear exactly why these differences exist. So, it is important to talk to loved ones about the ways they can reduce their risk of developing this cancer. Let your family know who has had cancer, what kind, and how old they were when they had it. If you have genetic testing, share the results even if they are negative. This information can help family members take the needed steps for their health.



WAYS TO REDUCE THE RISK OF DEVELOPING BREAST CANCER:

- Know the factors that may increase the risk of developing breast cancer. Once you are aware of these factors, make any lifestyle changes that will improve your overall health. This could mean getting more exercise, changing your diet, or avoiding smoking. Talk about these factors with your family and loved ones.
- Attend any routine medical appointments. **Early diagnosis helps.** The earlier a person is diagnosed, the more options will be available for treatment and overall cancer care.
- Stay on top of any recommended screenings. This includes your annual mammogram. Ask your doctor if there are any additional screenings that may be best for you as well. Be sure to ask them at what age you should start and how often you should get them done. You can learn more about the most common types of screenings for breast cancer later in this piece.

Breast Cancer & Genetic Testing

If you or a loved one has been diagnosed with cancer, be sure to ask your doctor about testing if you haven't done so already. Even if you do not have a family history of breast cancer, you still have the potential to carry a gene mutation. Be sure to share any results with your family. Having this information not only impacts your own cancer risk, but that of your family members too.

Genetic testing looks for mutations or changes in your genes. Testing to see if you inherited a mutation that increases your risk of getting cancer when you have no diagnosis of cancer can be called “genetic testing for inherited cancer risk”. If you have been diagnosed with cancer, doctors may recommend you see a genetic counselor to test your genes for an inherited mutation. The genetic counselor will ask detailed questions about who in your family has had cancer and at what age.



The most well-known genetic mutation that can lead to cancer occurs in the BRCA (Breast Cancer) genes. If you test positive in a BRCA genetic test (are BRCA+), that means there is a mutation in your gene. BRCA gene mutations can greatly increase your risk of developing certain cancers, like breast or ovarian cancer. Still, not every person who has a BRCA gene mutation will develop cancer. Be sure to discuss your test results with a genetic counselor or medical oncologist.

To learn more about genetic testing and the BRCA genes, read the ***Frankly Speaking About Cancer: BRCA Mutations*** overview fact sheet at www.CancerSupportCommunity.org.



Knowing the Signs & Symptoms

The most common symptom for breast cancer is finding a lump in the breast or armpit area. Other signs of breast cancer to look out for, include:

- Pain in the nipple
- Inverted nipple
- Skin changes (scaly or pitted skin) on the nipple
- Unusual breast pain or discomfort

- Swelling along with a lump in the breast
- Swelling in the armpit area (lymph nodes)
- Nipple discharge (occurs at random and from one side only)

SCREENING FOR BREAST CANCER

There are many ways to detect or screen for breast cancer. Regular screening is the best way to catch breast cancer early. When cancer is caught early, it is the easiest to treat. Here are some common ways to screen for breast cancer:

Breast Self-Exam: A monthly breast self-exam will help you notice changes to your breasts' texture, size, and skin condition. People who do breast self-exams know how their breasts normally look and feel and can see changes sooner. Do not hesitate to talk to a doctor or nurse if you have concerns about your breasts. Talk with them about how to perform a self-exam if you are unsure.

Clinical Breast Exam: During this process, a doctor will check your breasts, underarms, and collarbone area. A clinical breast exam should be a part of a regular visit to a gynecologist or a primary care doctor.

Screening Mammogram: A mammogram is a breast x-ray that shows if there are any lumps or anything unusual in the area. A mammogram can notice a lump before it can even be felt. Talk to your doctor to find out when is the best time to have a mammogram.

Breast Ultrasound: A breast ultrasound uses sound waves to create images of the inside of your breasts. With this, a doctor can look for any problem areas and check to see how well blood is flowing. If you have dense breast tissue, your doctor may also perform an ultrasound in addition to other tests. This is because a mammogram may not be able to see through the tissue.

Breast MRI: An MRI uses radio waves and a powerful magnet linked to a computer to create detailed pictures of the breast. MRIs are often used to screen high-risk women. They also help gather more information about anything unusual seen during a mammogram.



Diagnosing Breast Cancer

Breast cancer is found through routine screening or after symptoms appear. If your doctor suspects breast cancer, they will want to perform additional tests. This will help them learn as much as possible about the type of cancer, where it started, and where, if anywhere, it has spread. A complete cancer diagnosis often takes more than one appointment and may include:

- **Diagnostic Mammogram** - Like screening mammograms, diagnostic mammograms are x-rays of the breast. A diagnostic mammogram is often done after a screening mammogram. The physician may use different methods to get more detailed images of the breast. This will help them learn more about anything unusual or any lumps that appear.
- **Ultrasound** – This scan uses sound waves to create a picture of the breast. The picture can show whether a lump is solid or filled with fluid. Lumps that are filled with fluid are called cysts. Cysts usually do not lead to cancer. Any solid lumps or masses may lead to cancer.
- **MRI** – An MRI creates detailed pictures of the breast. These pictures can show the difference between healthy and unhealthy tissue. Because MRIs do not expose a person to radiation, it may be used to examine a breast lump found during pregnancy.
- **Biopsy** - A physician will look at a sample of breast tissue under a microscope. At this time, they will check the sample for cancer cells. If cancer cells are found, they will study them to learn as much as possible about the type of cancer. This may include testing the cancer cells for biomarkers.



BIOMARKER TESTING

If cancer cells are found during the biopsy, the doctor may run more tests. This is called **biomarker testing**. Biomarker testing looks for biomarkers in your cancer sample. A biomarker is a sign of disease or abnormal function that can be measured in your blood, tissue, or bodily fluid. Biomarkers are often referred to by a 3 or 4 letter abbreviation.

In cancer, biomarkers are often used to help choose the best treatment for you. These biomarkers can be proteins, genes, or gene mutations. Biomarkers can tell your doctor about the subtype of the cancer and if there is a chance that the cancer may return (cancer recurrence).

Your doctors may test your breast cancer cells for the following to help choose the best treatment option for you. This is not a complete list. Your doctors may recommend testing for other biomarkers as well:

- **BRCA Gene Mutations:** Even if your genetic tests show you did not inherit a BRCA1 or BRCA2 mutation, your cancer cells may contain or develop one over time. This is called a somatic mutation.



UNDERSTANDING BREAST CANCER STAGING

Staging is a key part of diagnosis. If cancer is found, the doctor will need to know the stage, or extent, of the disease to determine the best treatment. Staging is used to find out whether the cancer has spread, and if so, to which parts of the body. Doctors use the information they gather from blood tests, biopsies, and scans to get a full picture of the cancer.

Breast cancer is diagnosed in stages from 0 through 4:

- Stage 0 - 1 are the earliest stages. During these stages the cancer cells have not spread outside the breast area.
- Stage 2 - 3 means the cancer may have started to spread to nearby lymph nodes, but not to other organs.
- Stage 4 is also called advanced or metastatic cancer. In Stage 4, the cancer has spread to other parts of the body. Breast cancer usually spreads to the bones, lungs, liver, or brain.

- **HR+ and HR-:** Breast cancer cells are tested for hormone receptors (HR). A physician may say that the cancer cells are HR+ (positive) or HR- (negative). Knowing this will be helpful when deciding which treatment option may work best.
- **ER+ and PR+:** When breast cancer cells are tested for hormone receptors, the physician will look for estrogen receptors (ER) and progesterone receptors (PR). If the cancer cells have more of these receptors than a healthy cell, then the breast cancer will be listed as ER+ (positive) or PR+ (positive). Your doctor may recommend treatments to stop the specific hormone from working.
- **HER2+:** HER2 is a type of biomarker. HER2 receptors control cell growth. Some breast cancer cells can have too many HER2 receptors. These are called “*HER2+ (positive) cancers*”. HER2+ cancers can be more aggressive. This means they are more likely to grow and spread quickly.
- **HER2-Low:** Some breast cancer tumors may have low levels of HER2 receptors.

These are called “*HER2-low breast cancers*”. Some people with advanced stage HER2-low breast cancers, may be able to receive HER2+ treatments. This is possible even if the person originally tested negative for the HER2 biomarker.

- **Triple Negative:** Triple negative breast cancers test negative for extra estrogen, progesterone, and HER2 receptors.

Choosing Your Team

Cancer treatment can be complex. Recommended treatment options can change with new medical improvements. You need a treatment team you can trust to work with you and give you the best care. When choosing your team, it is important that you can have honest and open conversations. During appointments, make sure you share your concerns, ask questions, and feel like you are being heard.

The professionals who will work together on your team may include:





- **Primary care physician:** This person understands your medical history, preferences, and how you would like to manage your general health throughout your treatment and beyond. Your primary care physician can coordinate the team that will help you manage treatment decisions along the way.
- **Medical oncologist:** This physician specializes in the treatment of cancer. They will offer cancer treatment options and referrals. This includes chemotherapy, hormone therapy, radiation treatments or any other therapy after cancer surgery.
- **Radiation oncologist:** If you need radiation therapy you will need to see this specialist. They will advise the best timing to have radiation therapy along with any surgeries you may have.
- **Breast or general surgeon:** This person makes any surgical recommendations to remove the cancer in your breast. They determine which type of operation will be best for your treatment. They can also refer you to a medical oncologist, radiation oncologist, and/or plastic surgeon.
- **Plastic surgeon:** If you decide to undergo breast reconstruction surgery, this physician will oversee and perform the procedure. These specialists are certified by the American Board of Plastic Surgery. Your surgeon can tell you about the different reconstruction methods available. They can also provide advice on what might be best for you and your situation.
- **Physical therapist:** This specialist can help treat or reduce the physical side effects of treatment. Seeing a physical therapist can help you regain your strength and range of motion. Physical therapy can also reduce any tightness you may feel as your body heals. Specialized physical therapists are trained to help prevent or treat some longer-term side effects caused by surgery. This includes lymphedema and axillary web syndrome (AWS).



- **Palliative Care Specialist:** This person focuses on improving patients' quality of life. They can be helpful if you are having difficult symptoms, pain, or side effects. Palliative care is different from end-of-life care or hospice. You can see a palliative care physician at any point during your treatment.
- **Social worker:** These individuals are trained to assist with social and emotional needs. Social workers can help you and your family members find support groups and other psychosocial resources throughout diagnosis, treatment, and recovery.
- **Patient or nurse navigator:** Navigators help you manage your care. They help schedule appointments, get answers to your questions, and support you during your treatment and recovery.
- Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format (for example, a picture).
- Ask about the best way to get your questions answered. Is it better to call, email, or bring your list to appointments? Do you need to schedule an extra appointment if your list is very long?
- Bring a friend or family member to appointments to help listen and take notes if possible.
- Find out who to contact with questions and concerns between visits or after hours. Write down their contact information.
- Tell your team about:
 - Any side effects or symptoms you notice
 - Any natural treatments you are taking - including herbs, vitamins, supplements, or other complementary treatments
 - Any medicines prescribed by any other doctor for other health conditions

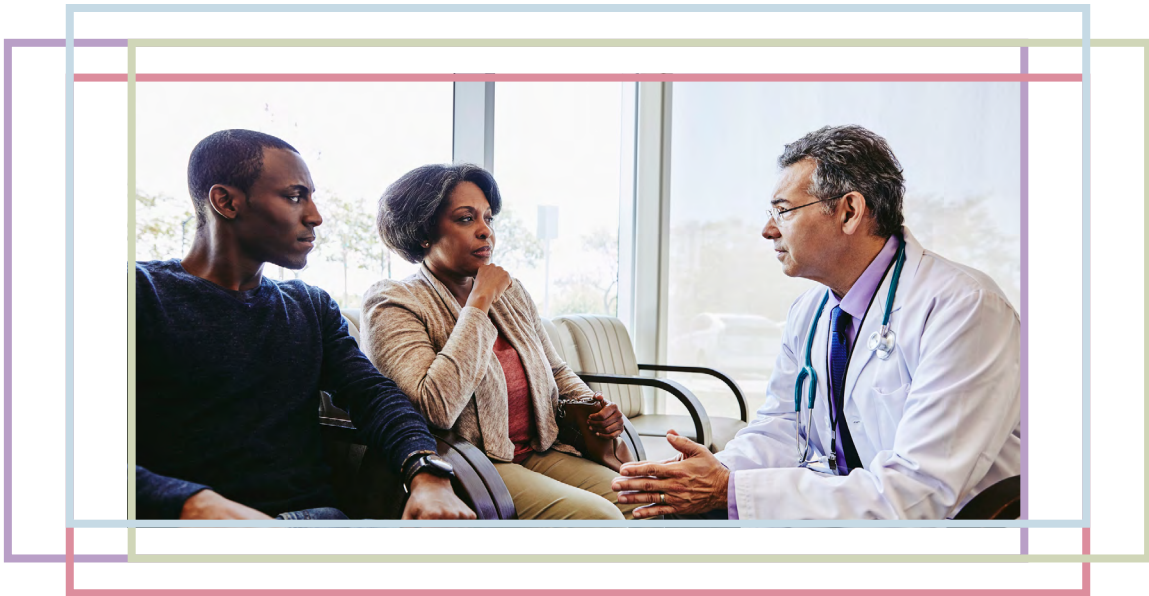
Communicating with Your Team

It is important to stay in communication with your doctor before a diagnosis even occurs. If you notice anything unusual on your breast, like a lump or rough patch of skin, talk with your doctor. If you are diagnosed with breast cancer, communicating with your team throughout treatment is key.

Here are some tips for communicating with your treatment team:

- Make sure your treatment goals and preferences are known and honored.
- Keep a running list of questions you would like to discuss.





Treatment Planning

As you talk about treatment options, you may work with your health care team to make several decisions. You might help choose the type of treatment, the timing of treatment, or the order of treatments. You may have the option to try a clinical trial. Making these choices is called treatment planning.

Good communication with your doctors will make treatment planning easier. Talk with them about your needs and preferences. Make sure you understand what they are saying about the stage and location of the cancer, and why one treatment might work better than another. Ask questions and bring up any concerns you may have.

GETTING A SECOND OPINION

At any point in your care, you can ask for a second opinion. Many people with cancer get a second or even third opinion to confirm their diagnosis and review treatment options. Another hospital or doctor may offer a different treatment, including clinical trials, or more useful support services. They may be a better fit for you in other ways. Do not worry about hurt feelings. You can always return to the first doctor if you want. But remember that timely cancer treatment is key when deciding to seek multiple opinions.

OPEN TO OPTIONS®

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



Treatment Options

Overview

Treatment for breast cancer will depend on the stage, location, and characteristics of the cancer. It also depends on your general health and your preferences and personal goals. The type of breast cancer you have will also impact your treatment options.

Treatments that work for one subtype often do not work for others. TNBC and metastatic breast cancer are harder to treat. They have fewer treatment options that will work compared to other types of breast cancer. Because of this, metastatic breast cancer and TNBC are often best treated by an experienced health care team. Be sure to share your preferences and work with your health care team to find the best treatment for you. You know your body and needs the best.

Here are some of the most common methods to treat breast cancer in general.

SURGERY

Most people with breast cancer will have some type of surgery as part of their treatment. It can be an important part of treatment for early-stage breast cancers. There are different types of surgery treatments. The goal of the surgery may differ depending on the location of the cancer and stage. For example, surgery may be used as a treatment option to:

- Remove as much of the cancer as possible during earlier stages
- Find out if the cancer has spread to other areas, like the lymph nodes
- Relieve symptoms related to advanced stage cancer



There are two main types of surgery:

Breast-conserving surgery removes the cancer and some of the surrounding tissue. It is also known as a lumpectomy, quadrantectomy, partial mastectomy, or segmental mastectomy. During this procedure, only part of the breast and tissue is removed. How much breast tissue is removed will depend on the location and size of the tumor.

A **mastectomy** is a type of surgery that removes the entire breast. All of the breast tissue and sometimes the lymph nodes are removed. Typically, most of the skin of the breast can be saved. Sometimes the nipple can be saved as well. This is called a nipple-sparing mastectomy. Some people may have both breasts removed as a form of treatment. This is called a double mastectomy. The specific type of mastectomy needed will depend on several different factors. Be sure to talk with your doctor about these factors and what surgery may be right for you.

BREAST RECONSTRUCTION SURGERY

Breast reconstruction is a type of surgery that helps to rebuild the shape & look of



the breast after treatment for breast cancer. When one or both breasts are completely removed during a mastectomy, you may be given the option to undergo reconstruction. Your doctor may suggest either immediate reconstruction or delayed reconstruction. They will base this suggestion on your health, your treatment needs, and the type of tumor you have.

Immediate reconstruction occurs at the same time as the mastectomy or breast-conserving surgery. Most of the time this is completed in stages. You may need at least two operations.

Delayed reconstruction can give you more time to adapt emotionally and research your reconstruction options. Some people prefer to have more time to recover from their mastectomy before beginning reconstruction. You may still have the option to undergo reconstruction surgery later on. In some cases, your doctor may even ask you to wait to have reconstruction surgery. People who have diabetes, have a higher weight, or need radiation after the mastectomy are often asked to wait to avoid surgical risks. This is often the case for people who smoke as well.

To learn more about breast reconstruction surgery, read the *Frankly Speaking About Cancer: Breast Reconstruction* overview booklet at www.CancerSupportCommunity.org/Breast-Reconstruction.

CHEMOTHERAPY

Chemotherapy (also called chemo) uses drugs to destroy or damage fast-growing cells like cancer cells. It is used to shrink tumors, slow cancer's growth, relieve symptoms, or help people live longer.

Chemotherapy drugs are given in different ways. It can be given orally by a pill, by injection, or through an IV in a vein (intravenously). Chemotherapy given after surgery is called “adjuvant” treatment. Chemotherapy given before surgery is called “neoadjuvant” treatment.

HORMONE THERAPY

Some cancer cells use hormones made by the body to grow. Hormone therapy can help stop or slow the spread of these cells. Some therapies stop the body from making these specific hormones. Other therapies may change how the body's hormones act.

Some hormones, like estrogen, can fuel breast cancer growth. Because of this, doctors use drugs that block estrogen from being created. They also use drugs that stop the hormone from functioning.

RADIATION THERAPY

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. The goal is to damage as many cancer cells as possible without harming healthy tissue. To lessen damage, doses are very precise, and treatment is often spaced out.

For breast cancer, most people receive some form of radiation therapy after surgery. This is especially true for people who undergo breast conservation surgery. Radiation therapy given after the surgical procedure is called “adjuvant” radiation therapy.

TARGETED THERAPY

Targeted therapy uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body.



QUESTIONS TO ASK YOUR TREATMENT TEAM

What is the type, subtype, and stage of cancer I have?

Where did the cancer start and has it spread? ?

Have you performed biomarker or genetic testing?

How will the test results affect my treatment options and long-term outlook (prognosis)?

What treatment options do you recommend and why?

What is the goal of each treatment?

What are the possible side effects and how will they be managed? Is there anything I can do in advance to help?

Can you tell me more about breast reconstruction surgery?

Am I eligible for any clinical trials?

What resources do you have for practical, financial, and emotional support?

CLINICAL TRIALS

Clinical trials are research studies to test new treatments or learn how to use existing treatments better. They find new and better ways to prevent or treat cancer.

Sadly, not all people have experienced the highest standards of cancer care in past studies. Historically marginalized communities have been mistreated or

excluded from high quality health care in past research studies. The ethical abuses that took place are unsettling and must be acknowledged and addressed.

Today the U.S. Food and Drug Administration (FDA) oversees clinical trials to keep all patients safe. Researchers must have their study approved by a review board before enrolling participants.





These review boards must have at least 5 members from diverse backgrounds. This includes diversity in their professional backgrounds, race and cultural heritage, as well as diversity in gender. Anyone who takes part in a clinical trial must go through a process called informed consent. This formal process explains the goals of the trial, potential benefits, any risks or side effects, and alternatives to participating. Talk to your doctor to learn more about which clinical trials may be available to you.

Here are some key things to know about clinical trials:

- No one receives a placebo or “sugar pill” in place of appropriate treatments during the trial.
- You can stop participating at any time.
- You can ask questions at any point of the trial.
- The sponsor of the clinical trial will usually pay for the costs of the drug being studied. Then, your health insurance and your copay will need to cover “standard” treatment costs. Be sure to ask about the costs to participate.

- After participating, you may become ineligible to join a future trial or treatment. Be sure to ask the research team questions about this.

To learn more about Clinical Trials visit, www.CancerSupportCommunity.org/Clinical-Trials.

Managing Treatment Side Effects

How you feel can affect your mood and outlook. It is hard to stay positive when you are tired, in pain, or uncomfortable. Managing symptoms and side effects can not only make you feel better physically but emotionally as well. It helps to learn about the side effects of treatment before you begin so you will know what to expect. When you know more, you can work with your health care team to manage your quality of life during and after treatment. Be sure to talk with your doctor about any possible side effects that may arise with each treatment option you consider.

Seeing a palliative care specialist can help address many side effects that may arise during treatment. Palliative care or supportive care can help you maintain your best possible quality of life. It can help you with physical, social, emotional, or spiritual concerns. Palliative care is different from hospice care and end-of-life care. It is available to you at any point of your treatment experience.



SURVIVORSHIP & RECURRENCE

Many people who complete their treatment for cancer often fear that it will return (cancer recurrence). After treatment, ask your doctor or oncology nurse for a 'survivorship care plan' specific to you. This plan will list out what follow-up care you'll need over time. It will also include any next steps for you and your care team to monitor your cancer. For example, you may be advised to have regular mammograms on your breasts every year. In most cases, people who had a mastectomy and breast reconstruction may not need a mammogram on the reconstructed breast.

PHYSICAL EFFECTS OF TREATMENT

If you undergo surgery as a treatment option, your ability to be physically active will change at first. Right away, you will not be able to lift heavy items, like a gallon of milk or large bags of pet food. This discomfort should disappear over time. Some exercises can help with recovery. Exercising can also help improve physical functioning over time. Ask your doctor about what exercises may be safe to do as you recover. They may be able to refer you to a physical therapist to help during your recovery.

Breast cancer surgery can lead to some longer-term physical changes. You may experience chronic pain, decreased strength or mobility, or lymphedema. **Lymphedema** is swelling in parts of the body caused by fluid buildup.

Axillary web syndrome (AWS) is another potential side effect if you have surgery that involves your lymph nodes. AWS is also known as 'cording'. If you develop AWS, you may see and/or feel a web of thick, ropelike structures under the skin of your inner arm on the side of the operated breast.

Some people may also experience **phantom breast syndrome (PBS)**. PBS occurs when people feel sensations in the area where a

breast was removed. This is usually caused by remaining pieces of breast tissue after surgery. These sensations can include pain and discomfort, itching, tingling, and even pressure in the area.

Talk to your doctor if you experience any of these or other new physical changes. They will be able to provide specific medications, therapies, and recommend lifestyle changes to help. Seeing a specialized physical therapist can also be helpful to prevent or treat symptoms like lymphedema and AWS.

Cost of Care & Financial Toxicity

The cost of cancer care is an issue for many people. It can add more stress to an already stressful time. Costs can be direct—bills that result from treatment such as copays—or indirect. This includes losing work, paying for childcare, gas money, parking for treatment. **Financial toxicity**, or financial distress, describes the problems that arise due to the high costs of cancer care. Many people facing cancer say that financial worries are a big source of stress, and they don't know where to turn.



Whatever your situation, there are resources and organizations that can help. Ask to sit down with the financial or insurance counselor at your health care facility. They can work with you to understand what the costs may be and help develop a plan to pay for it. An oncology social worker can also connect you and your family to helpful financial resources.

To learn more about managing health care costs, visit www.CancerSupportCommunity.org/Cost.

Coping with Breast Cancer

STRESS & EMOTIONAL WELLBEING

Life after cancer treatment may require more physical and emotional energy. It can also require more time and money. You may not be able to do all the things you used to do right away. How you feel about your body may change. In addition, some people in your life may respond in ways you dislike when they learn about your cancer and treatment decisions. Concerns about how others may respond can lead to another layer of stress.

It is important to take care of yourself, as you navigate life after a breast cancer diagnosis. This may mean putting your needs above other people's. It may also mean advocating for yourself – when you are uncomfortable or in pain – to get the support you need.

Managing both the emotional and physical impact of cancer can lead to a lot of stress. Here are some ways to take care of your mental health:

- **Do the things you enjoy:** Finding things to look forward to, no matter how small, can be helpful and bring a sense of joy. This can include watching your favorite show or trying something new.
- **Stay connected to others:** It is important to share your feelings with people you are comfortable with. Consider who already knows about your situation and who, if anyone, you would like to tell. You are the expert in making the best choice in this scenario. Talking with a counselor or therapist can help you cope with distress, anxiety, and depression as well.
- **Take care of your overall health:** Try to eat regularly and get enough sleep. Try to stay physically active once your doctor says it is safe to do so. Limit any use of substances, like smoking and alcohol. Try not to judge yourself harshly if these changes don't happen right away.

BODY IMAGE & FEELING OF LOSS

You are not alone if you have concerns about your body image. Surgery and other cancer treatments can change how a person views their own body. The option of having breast reconstruction surgery gives some people a new sense of control over their treatment. Still, many people may need an adjustment period. You may need more time to get used to your new appearance. You may also mourn the loss of your breast and its function. This may be the loss of feeling in the breast or losing the ability to breastfeed after surgery.



When coping with body changes, take time to mourn your losses. Know that it is OK to feel sad, angry, and frustrated. Your feelings are real, and you have a right to grieve. It may take some time to come to terms with your new body. The meaning of loss varies greatly from person to person. Take the time to ask yourself what the meaning behind any loss is to you and for others you care about.

Try to focus on the ways that coping with cancer has made you stronger and wiser. Look for new ways to love your appearance. Build connections and community with other survivors. Doing so can provide comfort, advice, and new ways to cope with this change. Over time, you may find that you develop a positive perspective and a new view of yourself.

INTIMACY & SEXUAL HEALTH

How you feel about and perceive your body can impact your feelings around sex and intimacy as well. Changes to perceived body image can make intimacy tricky for all involved. The first step to intimacy during and after any treatment is patience and understanding.

Talk openly and honestly with your partner about intimacy and how you are feeling. Sometimes seeking a specialist can help support this aspect of your life. If you undergo surgery, talk to your care team about being intimate after the procedure. Ask them about recovery time and when you may be able to engage in certain activities. Bring up any aspects affecting your sexual health. Let your doctor know if you experience any pain or discomfort.



They may be able to discover what is the cause and give advice to help reduce the symptoms. It can also be helpful to talk with other breast cancer survivors. Having support and guidance from people going through similar experiences can help as you navigate these new challenges.

Partners should allow time for those undergoing treatment to mourn any loss of physical confidence and changes to their body image. Those with cancer should be given the time to prepare themselves, find confidence in their bodies, and to communicate when ready. Openness and trust can ensure a healthy, comfortable, and intimate connection. Partners should be supportive of their loved one's changing body image. Offer acceptance and encouragement as your loved one makes changes to transition from a pre-cancer to a post-cancer body.





FINDING SUPPORT

It helps to have support, both during and after cancer treatment. Often, after treatment a flood of emotions may occur. Talking with people who understand your experience can help you cope and feel in control. A good support system can also help you with practical things. This could be staying physically active, eating well, and maintaining your overall health. There are many places to turn to for practical and emotional support.

Reach out to your health care facility to see if you can get connected to a patient or nurse navigator. These specialists can be a key resource during your treatment journey and recovery. They can help you cope with any physical changes and side effects long after surgery. They can be a resource as you adjust to your new normal.

There are several places to turn to for emotional support in your community. This may involve connecting with a therapist and/or spiritual/faith leaders. Support groups or peer mentors are resources available to assist you through your cancer experience. Talking with others who have experienced similar stressors can help you better understand and express what you are feeling. Ask your care team if they can recommend online or in-person support groups. It might take a couple of tries to find the right one.

Seek out local or national patient advocacy groups as well. Look for groups that work with people diagnosed with breast cancer. They can provide a variety of support and resources throughout your experience.

CANCER SUPPORT HELPLINE®:

If you need help finding resources or want help getting information about cancer, call CSC's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.



BREAST CANCER RESOURCES

Cancer Support Community · 888-793-9355 · www.CancerSupportCommunity.org/Breast-Cancer

Living Beyond Breast Cancer · 855- 807- 6386 · www.LBBC.org

Facing Our Risk of Cancer Empowered (FORCE) · 866-288-RISK (7475) · www.FacingOurRisk.org

Metastatic Breast Cancer Alliance · www.MBCAlliance.org

National Breast Cancer Foundation · 972-248-9200 · www.NationalBreastCancer.org

SHARE Cancer Support · 844-275-7427 · www.ShareCancerSupport.org

National Cancer Institute (NCI) · 800-422-6237 · www.Cancer.gov

NCI's Clinical Trials Registry · 800-422-6237 · www.Cancer.gov/ClinicalTrials

CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club network partners provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

Photos are stock images posed by models.

The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at www.CancerSupportCommunity.org/Breast-Cancer. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org.

Frankly Speaking About Cancer:
Breast Cancer Program Partner


LIVING BEYOND
BREAST CANCER®

This publication was made possible
through generous support from:

Lilly