# Taking the Lead When it Comes to Your Breast Cancer

### **Engaging With Your Medical Team**

hen faced with a breast cancer diagnosis or a recurrence of breast cancer, there is a lot of information to take in, such as available treatment options or strategies to reduce insurance barriers. As a patient, you will hear medical and clinical terms, which can certainly be overwhelming. To help make sense of your situation, consider these tips when discussing your treatment:

- Bring someone with you to your appointment. They can ask questions you may not think of and help you take notes. Or with your provider's permission, record the conversation to review later.
- Write down your questions before your doctor's visit. List the most important ones first to ensure they are answered, and leave space to write down the answers for future reference.
- Ask your provider to show you diagrams or drawings that may help increase your understanding. It's important for you to fully comprehend your treatment plan. If you don't, ask to spend time with an oncology nurse to discuss your concerns with you.

- Learn more about your treatment team. Your treatment team may consist of medical oncologists, radiation oncologists, breast surgeons/surgical oncologists, nutritionists, genetic counselors, social workers, and others.
- It's okay to take your time deciding on the best course of treatment for you. Allow yourself time to ask questions, conduct your own research, speak with family and friends, or seek a second opinion, without feeling rushed by your doctor. Remember that it's also okay to ask your doctors questions about the cost of your care and treatment.





### Men Get Breast Cancer Too

One in a thousand men are diagnosed with breast cancer, which means about 2,550 new cases are diagnosed each year. While it is rare that men develop breast cancer, male breast cancer has the same symptoms as breast cancer in women, including a lump or changes to the breast tissue and surrounding lymph nodes. Breast cancer treatment for men can include the same treatments women are prescribed, including surgery, chemotherapy, and radiation. Because men are less likely to believe that a lump is breast cancer, often they are diagnosed at a later stage. Therefore for men, it is especially important to discuss all available treatment options, including clinical trials.

Patient Advocate Foundation

patientadvocate.org (800) 532-5274



### **Informed Choices Let You Take the Lead**

Just as we have many options when we purchase an item from a retail store, every breast cancer patient has a variety of treatment options available. Treatment plans may include standard therapies which are successful for most patients, or cutting-edge and promising therapies new to the market. Your doctor may want to utilize a personalized treatment based on your cell types, complimentary or holistic approaches, or a combination approach.

The decision is ultimately yours to make based on the information you have available. There are a number of factors to consider – genetics, characteristics of *your* cancer, fertility, age, side effects, other medical conditions you may have, your doctor's past successful outcomes and more. It is your right, <u>and</u> your responsibility, to ask questions before and during about your treatment.

Resist the idea that you are a passive participant of the process. Instead, be the leader in your treatment plan!

Ask why your medical team has designed the specific treatment plan for you and why other options are not recommended in your case. Do not be afraid to seek a second opinion, even if you have no reason to disagree with your doctor. Sometimes another medical professional can give a fresh perspective or can confirm what your original medical team has suggested. In any case, more information will only help you feel confident in your choices.



### **Second Opinions Are Always an Option**

A second opinion is when another doctor reviews your medical records to give you advice based on their training and expertise, most frequently to provide diagnosis or treatment recommendations. In fact, doctors will encourage you to seek a second opinion, and should not take it personally. Most insurance providers will cover the visit and it is so common that many doctors assume you will get one. Often, you can ask your doctor for suggestions on whom to visit for a second opinion. Otherwise, you can contact your health insurance for a list of providers within your network.

> Second opinions are a normal part of receiving the best possible care. A second opinion is NOT second-guessing your doctor.



Here are two examples of why second opinions are important:

Jennifer	Brittany
• Late 40s	• Early 30s
• No family history of	• Family history of
breast cancer	breast cancer
•Has estrogen-receptor	Concerned about her
(ER) positive results	future fertility

In this scenario, let's assume both women were initially recommended the same treatment. After a second opinion, Jennifer was prescribed a different therapy that had seen promising outcomes for patients with ER positive results. Brittany's second opinion confirmed that her previously recommended treatment plan was the best approach, plus the second doctor proposed some fertility protection options that could be done before treatment started. In both cases, second opinions were helpful when choosing a care and treatment plan.



### **Emotional Support is Crucial**

Emotional support is a component of treatment and recovery that is often overlooked. Caring for your emotional well-being is an integral part of your care. A breast cancer diagnosis is life-altering and can cause a lot of emotional unrest for you and your family or caregivers. Also, research and patient experience shows that focusing on your emotional health can be beneficial to your other treatments.

Consider seeking these types of resources to help you find the support that works best for you:

- Peer connections of others with your diagnosis
- Support groups (both in-person and online)
- Professional-led therapy (in-person, via phone, and online)
- Faith-based emotional support sessions are regularly hosted by local churches and are often open to the community
- Provider-sponsored or endorsed support groups. Ask your doctor for a list
- And over one hundred more support organizations which can be found in Patient Advocate Foundation's Resource Directory online at www.patientadvocate.org/breastcancerresources



## Understanding the specifics of your diagnosis

What type of cancer do I have?

Ask for the specific types and descriptors that are part of a formal diagnosis.

#### What stage is my cancer?

Look not just for the number, but also for the letter designation that goes along with it.

How common or rare is my cancer, and does this change the treatment options I have?



What is my hormone receptor status?

What is my HER2/neu status? Are there any other genomic markers that can help target my treatment plan?

Can I be tested for known inherited gene mutations?

Some types of breast cancers are stimulated by the hormone estrogen. These types may be treated with hormonal therapy.

HER2 status and specific genomic characteristics in tumors may respond better to certain drugs or treatments.

### **Questions to Ask**

Aking informed choices about the care that is best for you involves having the right information available to you. It can be difficult to know where to start or what questions to ask when faced with such a big decision. Take it one step at a time, beginning with asking questions about your diagnosis, your treatment plan, and other impacts on your life. Below is a list of topics that are easily missed in conversations with doctors, that can help guide your decision-making process.

## Understanding your treatment plan and choosing your plan

What is my recommended treatment plan? Why was this plan chosen for me?

Why are other treatment options not available or recommended for me?

Am I able to participate in clinical trials?

What is the goal of my treatment? What does success mean?

Clinical trials are often thought of as a last option after other treatments have failed. Actually, some clinical trials are more effective in the early stages of treatment.

Ask yourself whether your doctor's goals align with <u>your</u> goals for treatment. If not, this is important to discuss.

Where will I receive treatment (in the hospital, in the doctor's office, or at home)?

Will you or another specialist oversee my care and treatment?

Will I need someone to drive me to and from treatment?

What are the possible side effects of my treatment? How can these be managed?

Understanding the specifics

What are my options and the timeline for breast reconstruction?

If you have other pre-existing medical conditions like diabetes or heart disease, it is crucial to keep your other doctors briefed on your diagnosis and treatment.

Understanding your treatment plan

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You can call your insurance company using the member services number on your insurance card and discuss coverage for your treatment plan. Always double check that the medical team is within your coverage network.

# Understanding how cancer affects your life

How will this care impact my work? Can I work at the same level? Will I need to take time off of work for my treatments and recovery?



Who else should I inform to help and coordinate my care?

What does my caregiver or family need to know about my care?



Who can I talk to about financial resources? Is there someone in your office available to discuss this?

How much of my treatment and care is covered by my insurance? What are the costs I will be required to pay?

## **Seeking Financial Assistance**

Planning for the cost of care begins with asking about the cost of care. Breast cancer influences all parts of your life, and can certainly impact your finances, even if you're insured with comprehensive coverage. For the majority of patients, the cost of treatment and care will strain your monthly budgets and decrease savings. While you are in treatment, breast cancer may also impact your ability to work and bring income to your household.

Within many medical offices today, there are patient advocates or financial counselors that can assist you with filing for government financial assistance programs and ensure you're receiving employment protections. Your doctor and other providers may also be able to offer you payment options if you alert them to any financial challenges you may be experiencing. Additionally, there are non-profit organizations and programs that can offer patients help paying for medical bills, insurance co-pays, and/or prescription costs.

Be honest with your medical team about how you are dealing with care costs. It will not reduce the options available to you, but your doctors want to lessen the impact and stress of worrying about the finances and will offer help when they can. A breast cancer diagnosis doesn't have to ruin your financial health.

The good news is there are resources available to you to assist in planning and managing the financial aspect of your care, both within your doctor's office and from outside programs.

### **National Financial Resource Directory**

**B** rought to you by the professional case management team at Patient Advocate Foundation, this self-help tool helps insured and uninsured patients quickly locate programs and resources for a broad range of needs including housing, utilities, food, reconstruction, medical devices, pharmaceutical agents, and transportation to medical treatment. Learn more at www.patientadvocate.org/financial



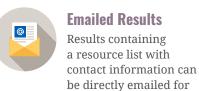
#### **Certified Resources**

Each resource has been thoroughly researched to ensure that it is immediately useful to patients.



### **Custom Description**

A custom description tells you exactly what you need to know in order to quickly assess a resource's usefulness to your unique situation.

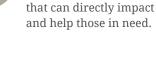


### Mobile App In addition to

In addition to web use, an easy-to-use app available for iPhone and Android tablets and phones is available. Simply search "My Resource Search" in your app store.

future reference.







### **Powerful Search**

Fully customize your search and filter results based on age, location, insurance status, and illness or disease. Search for resources based on over 35 unique assistance categories.

Direct Help The directory focuses only on the resources



### **Helpful Resources**

*Black Women's Health Imperative - Breast Cancer* www.bwhi.org/health-matters/breast-cancer/

**Breast Cancer Trials** www.breastcancertrials.org

**BreastCancer.org** www.breastcancer.org

Cancer and Careers www.cancerandcareers.org

Cancer Care www.cancercare.org

Cancer Support Community www.cancersupportcommunity.org

FORCE: Facing Our Risk of Cancer Empowered www.facingourrisk.org

HIS Breast Cancer Awareness www.hisbreastcancer.org

*Lazarex Cancer Foundation* www.lazarex.org

Living Beyond Breast Cancer www.lbbc.org

Male Breast Cancer Coalition

Men Against Breast Cancer

My BC Team www.mbcnetwork.org

National Cancer Institute www.cancer.gov www.cancer.gov/clinicaltrials

*Nueva Vida* www.nueva-vida.org

**Patient Advocate Foundation** www.patientadvocate.org

Pink Link Breast Cancer Social Network www.pink-link.org

**SHARE** www.sharecancersupport.org

*Sharsheret* www.sharsheret.org

*Sisters' Network* www.sistersnetworkinc.org

Susan G. Komen ww5.komen.org

*The Pink Fund* www.thepinkfund.org

Triple Negative Breast Cancer Foundation www.tnbcfoundation.org

*Triple Step Toward The Cure* www.triplesteptowardthecure.org

Young Survival Coalition www.youngsurvival.org

Male-focused Charity

