If you've recently been diagnosed with breast cancer, taking action quickly is important. Knowing your options is just as important.

Find questions for your doctor, treatment resources, and more at BreatheKnowGo.com/TakeAction

When a breast cancer diagnosis overwhelms you,

Breathe. Know. Go.

The steps towards a breast cancer action plan.

When you learn you have breast cancer, you might feel overwhelmed or lost. But now is the time to breathe, collect yourself, and learn what's possible. This is the time to engage with your care team and be confident that an action plan can help you feel informed, empowered, and in control as you prepare to move forward.
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You may be feeling totally overwhelmed since being diagnosed with breast cancer. That is understandable and to be expected. It’s unlikely you had getting a diagnosis of breast cancer on your list of goals to accomplish now, or for that matter, ever. But it has been added to the list, and that can stop a woman in her tracks. You may be feeling alone and isolated. You may be feeling confused and at a loss as to where to get help. Rest assured that there is guidance and support available. Let me tell you about some available resources.

First of all, turn to the multidisciplinary team that is going to take care of you, beginning with your oncology navigator. She is a wealth of knowledge and support and can provide you with information about breast cancer, including details about interpreting the stage of your breast cancer. She can translate into simple terms what your treatment options are, provide psychological support for you and your family, and make sure you stay on track for each phase of your treatment. Consider her your “go to” person throughout your cancer treatment. She may be able to connect you with volunteers who have already completed treatment for breast cancer, so you can talk directly with a survivor who has “been there.” Your oncology navigator may also work with team members who can help remove barriers to your care by providing transportation if needed for your appointments or financial support for prescriptions and other medical expenses. In some cases, she may even help you work with team members to find assistance with paying your household bills while receiving treatment. Each member of your healthcare team specializes in some aspect of your care and treatment. Each professional helping you along your journey will provide educational support designed to empower you so you can participate more confidently in making decisions about your treatment options—to the degree that you wish.

There are national and regional advocacy organizations that you may never have heard of unless you have had personal experience (yourself, a family member, or a close friend) with breast cancer. Your breast cancer navigator will tell you about them. There are organizations that focus on young women and those dealing with stage IV breast cancer. Take advantage of these organizations. They are there for you.

Your family and friends may be as distressed as you that you have been diagnosed with breast cancer. You may have siblings who are worried. If you are in a...
relationship, your spouse/partner may be spending hours online trying to figure out how to “fix” this by finding the right treatment for you. Of course, no one can become an oncologist overnight. Still, this individual may have a personal need to try to read everything available. Men have a tendency to want to shield you from their emotions. You might be sitting in a puddle crying, and the men in your life—spouse/partner/brother/father—may appear quite stoic. Don’t be fooled. They are very upset but trying to hold it together. Mothers often become basket cases and commonly cry even more than the patient. They try to figure out why and how this happened. Your mother may retrace your entire life back to when she was pregnant with you, trying to determine what you were exposed to, experienced, or may have inherited genetically that caused your breast cancer. (By the way, there is an organization to support her too. Otherwise, trying to comfort her could drain you of your energy.)

If you have children, you may receive support from them or need to provide support to them, depending on their ages. You should keep a young child’s routine as normal as possible. If you have teenagers, you may be calling on them to help with more chores around the house, including preparation of meals, babysitting, food shopping, and other assignments. If that is the case, keep in mind that although you are treating them more like adults, they are still teenagers and need emotional support. Be sure to let them still be teens, going to the movies on Friday nights and having friends over after school.

When it comes to your friends, particularly close friends, many desperately want to be there for you. Although distressed, they are ready to roll up their sleeves and do whatever you need. A breast cancer patient may hear from many friends, “Please tell me what you need, and I’ll do it,” and often the response given is, “Oh, OK. I’ll get back to you on that.” But the patient doesn’t get back to the friend. Well, you need to make a list of the chores and needs that you do in fact have and start parceling them out to these friends. Believe me, it will be a godsend to you, and it will also make them feel better knowing they are contributing in some way. Taking your son to ball practice, picking up a prescription from the pharmacy, baking casseroles to put in your freezer are all things you need, so tell them so. You will be doing the same thing for them when they experience a crisis in the future, right?

As you continue on your journey, you will discover more helpful resources on your own. Write them down. Make your navigator aware of them as well so she can pass them along to other newly diagnosed patients.

Remember, you are not alone. There is a wealth of support just waiting to help you and guide you along this journey.

Co-Founder

AONN Academy of Oncology Nurse & Patient Navigators
Karen Eubanks Jackson founded Sisters Network in 1994 to connect with other African American breast cancer survivors. At least that was the initial reason for its founding. As she learned more about the impact of the disease in the African American community, she found a staggering breast cancer mortality rate, limited culturally sensitive materials, and a general lack of support and sisterhood for those diagnosed. In founding Sisters Network, she endeavored to make a difference on a national level. She wanted to break through the silence and shame of breast cancer that immobilize many African American women and ultimately impede early detection and affect survival rates.

Under her leadership, Sisters Network has developed numerous national breast health outreach initiatives, including the first national African American Breast Cancer Conference, the annual Stop the Silence African American Breast Cancer 5K Walk/Run, and the Breast Cancer Assistance Program.

To this day, Sisters Network is the only national African American breast cancer survivorship organization with more than 40 chapters throughout the country.

I had the great pleasure of speaking with Ms Jackson about her experience as an African American breast cancer survivor, the impact of Sisters Network, and her advice to young women in her community about breast health. In speaking with her, it became clear that Ms Jackson believes strongly in the creed of Sisters Network: In unity there is strength, in strength there is power, in power there is change. What follows is our thoughtful exchange.

**How was Sisters Network established?**

I was diagnosed with stage II breast cancer in 1993. I was aware that I had a family history, but I didn’t know very much about the disease or what to expect as a survivor. I felt the need to speak with other survivors who looked like me. I wanted to join a national organization for African American women, but, to my surprise, there was nothing to join!
The lack of a national organization for African American survivors was a concern for me, and I believed there was a universal need for sisterhood among African American women.

I jumped right in, not knowing what to expect; I just knew that it was the missing link for women across the country. We needed to share our experiences to help each other and our community. So, in 1994, I founded Sisters Network.

How would you describe your experience as an African American breast cancer survivor in 1993?

In 1993, African American women felt that they were being blamed for not seeking medical care early enough. Because African American women are more likely to have triple-negative breast cancer, which is aggressive, we were being diagnosed with stage III/IV. There was backlash from the medical community about what the African American community was not doing—namely screening. But at that time, the African American community didn’t want to speak the word “cancer,” let alone talk about the disease.

For many women diagnosed with triple negative, there was a feeling of “What’s the point? If I have this type of cancer, there is no cure.” There was a general feeling of hopelessness with this diagnosis.

When I started Sisters Network, the first thing I want-ed to do was to change the narrative around breast cancer as a death sentence. And to let people know that there are different types of breast cancer—not everyone is triple negative. And even if you have triple-negative disease, there is hope. We really had to educate women about the different types of breast cancer.

Can you share a Sisters Network success story?

Yes, one immediately comes to mind. I’ll preface by saying, this was an unusual circumstance. A woman approached me who had heard of Sisters Network. She was scared, so I went with her to the doctor, who confirmed that she did have cancer. Although she had her own accounting business, she didn’t have health insurance. The reason this case is
unusual, is that I just happened to have an opportunity to go on a radio program to talk about Sisters Network, and I shared this woman’s story. We were attempting to raise money to help her cover the cost of treatment. Shockingly, someone contacted us to pay for her treatment—an anonymous donor.

This was a wonderful but unusual story. Really, every day we have success stories. We are out there talking to women in our community about breast health, helping the newly diagnosed, and providing support to long-term survivors. We’re providing the education that they need and connecting them to resources.

It’s important for women in our community to learn about available and appropriate resources and how to access them within their communities. Some people may think that if they get sick, they can go to the local hospital and they can fix you. But not all hospitals are equipped to handle cancer. Not all cities have a cancer center. We believe that there are people within the African American community who have breast cancer and insurance, yet don’t know how to go about finding the best care available. You should be seen by a doctor who specializes in your type of cancer. Anytime we can ensure one more woman is aware of the best resources and care available to her, well, that is a success.

Prioritize your health by knowing your health history. Open that discussion with your family. I understand that sometimes there is a stigma around talking about cancer, but I want to tell you that information is power. Learn your family history and understand what it means for you. If there is a history of breast cancer in your family, it doesn’t necessarily mean you will have breast cancer, but understanding your risks, taking the right precautions, and talking about it with others will help empower you.

What advice would you give to young African American women regarding breast health?

Prioritize your health by knowing your health history. Open that discussion with your family. I understand that sometimes there is a stigma around talking about cancer, but I want to tell you that information is power. Learn your family history and understand what it means for you. If there is a history of breast cancer in your family, it doesn’t necessarily mean you will have breast cancer, but understanding your risks, taking the right precautions, and talking about it with others will help empower you.

There is hope. Get over the initial shock and fear of the words “breast cancer” and get on with living.

What would you say to a newly diagnosed woman?

There is hope. Get over the initial shock and fear of the words “breast cancer” and get on with living. I personally know many long-term survivors. I am a 26-year survivor; one of our members is a 15-year triple-negative survivor. There is hope.

I understand you are in the process of publishing a book?

Yes! I am very excited about it! The title is In the Company of My Sisters: My Story, My Truth, and it will be released this year at the Sisters Network Stop the Silence Walk on April 25 in Houston, Texas. The book recounts my experience as a breast cancer survivor and as an advocate for others.
A breast cancer diagnosis is challenging for many reasons, and for patients there is the special challenge of learning the medical language that pertains to their diagnosis. The information can be overwhelming, and there are many moving pieces in the care journey. Researching new terms on the Internet can lead to misinformation and increased fear, but a trustworthy guide of terms pertaining to their disease can help breast cancer patients feel more fluent in understanding their condition and more confident in their treatment.

**TYPES OF BREAST CANCER**

Different types of breast cancer are defined by where the cancer cells started growing and whether they have grown into the surrounding breast tissue.

*Invasive Lobular Carcinoma*
- Breast lobules are glands where milk is produced. Cancer that begins in the lobule and grows out into surrounding breast tissue is called invasive lobular carcinoma.

*Ductal Carcinoma In Situ*
- Ducts within the breast are thin tubes that carry milk from the lobules to the nipple. The growth of abnormal cells that start in the lining of the duct but have not grown into surrounding breast tissue is called ductal carcinoma in situ (DCIS) and is considered stage 0. There is no way of knowing whether DCIS will become invasive. Because we know that some DCIS lesions will become invasive, it’s important that it’s treated.

*Invasive Ductal Carcinoma*
- Cancer that starts in the lining of the duct and grows into surrounding breast tissue is called invasive ductal carcinoma.

*Metastatic Breast Cancer*
- When breast cancer cells move to other parts of the body, such as bones, liver, lungs, or brain, it is called metastatic breast cancer. This is considered stage IV breast cancer.

**STAGING OF BREAST CANCER**

Staging is a system that is used to determine and describe the extent of cancer in the body. Stage ranges from 0 (DCIS) to IV (cancer cells have spread to other parts of the body). Knowing the stage is important because doctors will use this information to determine the best treatment plan. Staging is primarily based on tumor size and whether the cancer has spread to the lymph nodes or other parts of the body. Doctors may use a pathology report in combi-
nation with imaging such as x-ray, CT scan, MRI, or PET/CT to determine staging.

**GRADING OF BREAST CANCER**

Grades are reported by using a combination of characteristics that are seen by a pathologist when tumor cells are viewed through a microscope. The more cancer cells that look like normal cells, the lower the grade (these cells are also called well differentiated). Cancer cells that look very different from normal cells are considered high grade (also called poorly differentiated). Grades range from 1 to 3 and help to predict how aggressive a tumor is and how likely it is to recur. Typically, the higher the grade, the more likely it is to recur.

- Grade 1: Low grade
- Grade 2: Intermediate grade
- Grade 3: High grade.

**MARKERS AND TESTS**

Breast cancer cells may contain certain proteins that are estrogen (ER), progesterone (PR), or human epidermal growth factor receptor 2 (HER2) receptors. Determining receptor status is important for selecting the most appropriate treatment options. Testing for receptor status is performed either on a biopsy sample or when the tissue is removed surgically. Receptor status is either positive or negative.

- ER positive: Breast cancers that have estrogen receptors are called ER positive
- PR positive: Breast cancers that have progesterone receptors are called PR positive
- HER2 positive: Breast cancers that have human epidermal growth factor receptor 2 are called HER2 positive
- Triple negative: Breast cancers that are not ER, PR, and HER2 positive are called triple negative.

Another marker tested for is the Ki-67 protein, which shows how rapidly the breast cancer cells are dividing and forming new cells. The Ki-67 score can range from 1% to 100%. A score of 0% to 2% is called grade 1 or low grade; between 2% and 20% is known as grade 2 or intermediate grade; a score over 20% is known as grade 3 or high grade. A high score indicates rapid tumor growth.

**Genomic tests** are used to evaluate a sample of the cancer tumor to see how active certain genes are and how likely it is that the cancer will grow and spread. Genomic tests are used to help determine if additional treatments after surgery will be beneficial. Two such tests are discussed below.

The **Oncotype DX** test analyzes the activity of 21 genes to determine the likelihood that the patient will benefit from chemotherapy if he or she has an early-stage invasive breast cancer, and whether the breast cancer is likely to return. Oncotype DX eligibility is based on stage, receptor status, and whether the cancer has spread into the lymph nodes.

**MammaPrint** is another genomic test that analyzes the activity of 70 genes and calculates a recurrence score that indicates either low or high risk. MammaPrint eligibility is based on age, size of cancer, grade, and whether the cancer has spread into the lymph nodes.

**SURGICAL TREATMENTS**

**Lumpectomy** is a surgical procedure to remove cancer from the breast in which only a portion of the breast is removed. A small amount of normal tissue around the lump, called a margin, is also taken to ensure that all cancer and abnormal tissue is removed. This procedure can also be referred to as breast-conserving surgery.

**Mastectomy** is a surgical procedure to remove all breast tissue from a breast. There are several types of mastectomies, including simple, modified radical, radical, nipple sparing, and skin sparing.

**Partial mastectomy** is a surgical procedure that
is a lumpectomy surgery in which more tissue is removed than in a standard lumpectomy.

**Breast reconstruction** is surgery, typically performed by plastic surgeons, that restores the breast to near normal shape, appearance, symmetry, and size after a mastectomy. Breast reconstruction includes multiple procedures performed in stages and can start during the time of the mastectomy or be delayed. Implant-based reconstruction uses breast implants to help form a new breast. Flap-based reconstruction uses a patient’s own tissue from another part of the body to form a new breast.

**THERAPEUTIC TREATMENTS**

There are several types of therapies used to fight cancer, including medical and radiation treatments, hormonal therapies, and immunotherapies. Some common definitions include:

- **Neoadjuvant therapy**: Treatment that is given as the first step of cancer therapy to help shrink a tumor before the definitive treatment, which is surgery. It can also be called induction therapy
- **Adjuvant therapy**: Additional treatments given after surgery to lower the risk of recurrence
- **Targeted therapy**: A treatment that uses chemotherapy that identifies and attacks specific cancer cells with less harm to normal cells. Targeted therapies can:
  - Block the growth and spread of cancer cells by blocking the action of certain types of enzymes and proteins
  - Help the immune system kill cancer cells
  - Deliver toxic substances to the cancer cells to kill them.

**Chemotherapy** is treatment with anticancer medications that travel through the blood to cells in the body to help decrease and prevent the growth of cancer. Chemotherapy is typically given directly into the bloodstream via a tube placed into the veins or a port; however, there are some types of chemotherapy that are taken by mouth.

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

**Hormonal therapy** is treatment that adds, blocks, or removes hormones that are responsible for cancer growth. Aromatase inhibitors are a common hormonal therapy that helps prevent the formation of estradiol in postmenopausal women who have ER-/PR-positive tumors. Tamoxifen is a common hormonal therapy in premenopausal women that blocks the effect of estrogen in the breast tissue and may help keep breast cancer from growing.

**Immunotherapy** is a treatment that uses substances, made either naturally in the body or in a lab, that can stimulate or suppress the immune system to help the body fight off cancer cells. Some common types of breast immunotherapies include targeted antibodies (trastuzumab, pertuzumab) and immunomodulators (atezolizumab).

**CONCLUSION**

Receiving a breast cancer diagnosis can be overwhelming. Taking in and digesting so many details, while often still reeling from the words “You have breast cancer,” may seem impossible. However, understanding the diagnosis and treatment options is an important step toward empowering patients to be an active participant in their cancer journey.

**Sources**


A fellow labor and delivery nurse called one Saturday to talk about her new breast cancer diagnosis. As I listened, and offered support, I tried to remember the last time I had done a breast self-exam. When the call ended, I walked to my bathroom, put my hand on my right breast, and immediately knew that I, too, had found breast cancer. Over the next few weeks, my suspicions were confirmed. With no family history or high-risk factors, I was diagnosed with stage III breast cancer. The next year was consumed by a double mastectomy, chemotherapy, radiation, reconstructive surgery, and lots of pink ribbons. Shortly after my 1-year cancer-versary, my hospital joined the Sarah Cannon network and started a navigation program. At the suggestion of my medical oncologist, I applied for the breast navigator position and have been there ever since. I would like to share a few of the valuable insights I have learned from the more than 1,000 patients I have had the privilege to navigate.

LESSON #1: LIVE TODAY

Many of us cope with unpleasant tasks by focusing our attention on the end result. Have you said things like, “I will sleep better when the surgery is done,” “I can’t wait to finish chemo,” or “As soon as I finish treatment, I’m going to…”? Cancer is awful. We want to be on the other side of treatments. I’ve learned that even in the midst of all the awful, there is good to be found. There is strength and power when you can stand in the moment.

You don’t have to wait for treatment to be over, for tumor markers to reach a certain level, or for some arbitrary amount of time to pass before you can find joy, do something extravagant, or fully claim your “survivor” status. Survivorship starts at diagnosis. You are living today.
LESSON #2: REACH OUT WITH AN OPEN HEART

Sharing your diagnosis can trigger a flood of well-wishes and offers for help, but it’s hard for others to know how to be supportive. As a navigator, I have had many calls from patients’ friends and family members looking for gift basket ideas. While the demonstrations of support are meaningful, a gift basket may not hold the support items you need. How can your family help? Is there something that a friend could buy or do for you that will make you feel better? If so, tell them! Ask for what you need with compassion. Allowing someone to help will benefit you both.

LESSON #3: IT’S OKAY TO BE AFRAID

You have already encountered one of the biggest fears—hearing the words, “You have cancer.” You were hoping, praying, begging for a different result, but you have survived hearing the news. Now you likely have new fears. How will I tell my family? What will treatment feel like? What if the treatment doesn’t work?

Fear is a normal response to cancer. The sooner you admit to yourself and to others that you are afraid, the sooner you will work through it. Somehow, verbalizing our fear weakens it.

The fear of recurrence or worsening disease affects every cancer survivor I know. Any unexpected pain, new lump, or friend’s diagnosis can bring a flood of emotions. The only advice I can offer is “BREATHE!” Inhale, exhale. Then reach out and share your fear with someone who can support you through it.

LESSON #4: KEEP MOVING

Before my diagnosis, I had settled into the best health routine of my life. I was going to the gym 2 or 3 times a week for Zumba and yoga classes. Throughout treatment, I continued to attend whatever activities or events I could. I was amazed by the number of people who saw my bald head as an invitation to share their own cancer stories. Without fail, they would say, “I wish I had exercised throughout my treatment! It was really hard to get back into shape after it was over.”

LESSON #5: YOU HAVE YOUR OWN STORY

You may find yourself feeling surrounded by cancer stories since your diagnosis. It may feel like everyone (including me!) has words of encouragement or advice for you. It is important to remember your cancer, treatment, survivorship, and life are unique. Your story is the one that matters. Live it well.
Oftentimes, the patient is merely a listener and not the one initiating a discussion with the medical oncologist. Listening, of course, is important. As a listener, you sit and try to absorb the information being told to you. The oncologist may ask questions, such as how are you feeling, or give recommendations about what treatment to have next. There are, however, specific things that YOU as a breast cancer patient need to inform your medical oncologist about so that he or she has an understanding of where you are coming from related to your diagnosis and treatment decisions. Ideally, your doctor would be asking you about these things, but often that isn’t what happens. So take the initiative to share these ideas with your doctor, without waiting to be prompted. Tell your doctor that you want to share some information about yourself before you begin getting into discussions about treatment planning. The following notes should help you talk with your oncologist.

1. TELL THE DOCTOR HOW MUCH YOU CURRENTLY KNOW ABOUT YOUR BREAST CANCER

Do you know what kind of breast cancer you have? (Is it invasive lobular carcinoma, invasive ductal carcinoma, metastatic breast cancer, or some other type?) Do you know what the stage is? (Stages range from 0 to IV. Stage IV is metastatic breast cancer, meaning the cancer has spread beyond the breast and traveled to other organ sites such as the bones, liver, lungs, or brain.) Do you know what the grade of your cancer is? (The grade is measured on a scale from 1 to 3 and helps describe how fast the cancer cells are growing.) Do you know any of the pathology features of the breast cancer cells themselves, and do you understand what these prognostic factors mean? (These features include the size of the tumor in the breast, whether there are lymph nodes that contain cancer cells, whether the tumor is stimulated to grow by female hormones in your body, and whether there is an overproduction of HER2 proteins making the tumor more aggressive.) Describe what you know.

If you believe you know how you ended up getting breast cancer, discuss your ideas with your doctor. Commonly, patients do try to figure this out, sometimes blaming themselves for having gotten this disease. Reasons patients give include having been a smoker, being overweight, being under a lot of stress, not following a healthy diet, or taking female hormones in the past. The fact of the matter is that you likely won’t know the cause, so it might be best to stop trying to figure it out. You have already been diagnosed. Rather than looking backward, focus on moving forward to learn what you need to do next to get healthy again.

When trying to explain what they know, patients sometimes get confused about the meaning of the stage and the grade of the cancer. Stage describes the extent of cancer in the body and is based on the size of the tumor originally in the breast, whether lymph nodes contain any cancer, and whether the cancer has spread to other organs. As previously mentioned, the cancer stage ranges from 0 to IV. Ductal carcinoma in situ is stage 0, meaning the cancer is contained in the breast ducts only, and the noninvasive cells have not spread to the lymph nodes or elsewhere. However, these cells can
become invasive, and early treatment can be important. In stage I, the original tumor measures up to 2 cm and cancer cells have spread within the breast but not into the lymph nodes. At stage II, the tumor is between 2 cm and 5 cm, cancer cells have spread within the breast, and lymph nodes may be involved. Cancer designated as stage III means the tumor may be larger than 5 cm and cancer cells have spread to lymph nodes. Stage IV is the most advanced form of breast cancer in which cancer cells have traveled from the breast through the lymph nodes or bloodstream to other organs in the body. Those with stage IV metastatic breast cancer may be confused and say that they have breast cancer and lung cancer and liver cancer, when they don’t. They have breast cancer that has spread to these organ sites, but they do not have 3 different primary cancers. At this stage, the cancer is not curable, but it is treatable.

The grade tells us how rapidly the breast cancer cells are growing and multiplying. The grade is either 1, 2, or 3. Grade 1 is slow growing, grade 2 is average growing, and grade 3 is rapidly growing. The speed of the growth of the cells can seem scary. Grade 3, however, doesn’t necessarily mean that the cancer is growing super fast. If a breast tumor is 1 cm in size (approximately 1/3 of an inch), it likely has been growing 5 to 7 years even if the cells are a grade 3.

A common mistake patients make is confusing the stage and grade values. A patient may have very early stage I breast cancer while the cells are an aggressive grade 3, actually a very common scenario. However, this patient may tell her doctor that she has stage III breast cancer that is grade 1. This reversal of terms describes an advanced breast cancer with a large tumor that is locally advanced and at high risk of spreading to other organs, although it is growing very slowly. When we compare these 2 scenarios, the treatments would be very different. This is why it is so helpful to explain in your own words what you believe you know about your breast cancer.

In addition, you may have a family history of breast cancer. This is important to tell your medical oncologist and your entire multidisciplinary team. In 10% to 12% of cases, the cause of the breast cancer can be linked to a breast cancer gene mutation. Having a great aunt diagnosed in her 70s, however, is very different from having a mother or sister diagnosed in the recent past. Having several first-degree relatives (mother, sister, daughter, brother, father) who have had breast cancer, ovarian cancer, pancreatic cancer, melanoma, or even prostate cancer diagnosed at a young age would indicate a much higher probability of your breast cancer being caused by a gene mutation than having a distant relative like a great aunt having been diagnosed in her 70s. About 70% of women diagnosed with breast cancer have no known risk factors, and there are almost certainly additional breast cancer gene mutations that have not yet been discovered.

Telling your doctor what you believe you know about your breast cancer will determine how accurately you understand your medical situation.

THOSE WITH STAGE IV METASTATIC BREAST CANCER MAY BE CONFUSED AND SAY THAT THEY HAVE BREAST CANCER AND LUNG CANCER AND LIVER CANCER, WHEN THEY DON’T.

ABOUT 70% OF WOMEN DIAGNOSED WITH BREAST CANCER HAVE NO KNOWN RISK FACTORS.
3. WHAT ARE YOU HOPING FOR?

This topic requires thoughtful reflection on your part. You may tell the doctor that you are hoping to survive this breast cancer and that is your one and only goal: to survive. However, you are likely hoping for something more than that. Are you hoping to survive and live out a normal life expectancy that includes having a good quality of life? If you live through this experience but have so many side effects from treatment that you don’t have a good quality of life, are you still going to be happy?

Commonly, patients get what I call foxhole religion. They will say that their only goal is survival. When all is said and done and they have survived the breast cancer, but they are dealing with chronic debilitating side effects, they are then angry about what their life has become.

So take the long view—look way down the road. What are you hoping for? You hope to be able to enjoy significant milestones that will be coming up during your treatment, such as going to your sister’s wedding in 3 months and feeling well that day, and still being able to work during treatment to the degree possible. You hope to have a family of your own one day. You hope that your children won’t be diagnosed with cancer in the future and want to know how to help reduce their risk. You hope to save your breasts if possible and not sacrifice them to this disease. You want to feel good about your self-image after treatment is done, with your hair having grown back, your weight in control, your body image restored, etc.

Those with stage IV breast cancer will commonly say that they want to experience a miracle cure. They want to be there to raise their young children. Many women are living longer with stage IV breast cancer. But as time progresses and treatments stop working, your doctor will recommend future treatments that are appropriate and rational to try. Your navigator will help you move through the various phases related to your treatment.

Some of your answers will directly influence the treatment recommendations. If you plan to have a family one day and need chemotherapy as part of your treatment, you may very well need to have a referral to a doctor who specializes in fertility preservation. You don’t want to be finished with treatment and then ask your doctor when you can start trying to have a family only to hear him or her say that they didn’t know this and that it may not be possible since the chemotherapy may prevent your ovaries from functioning properly. If having a family is an important life goal for you, state it up front.
4. WHAT ARE YOU MOST WORRIED ABOUT?

Initially you have so many concerns, it is hard to even think through them, much less prioritize them for yourself and for your doctor. The team wants to help alleviate your worries whenever possible. Someone with stage I breast cancer who has a 90% probability of becoming a long-term survivor may be worrying that she is going to die, when that possibility is quite low. She may have read some misinformation on the Internet, not knowing that going into a chat room where breast cancer patients post information about themselves or what they are hearing out there somewhere is not evidence-based research to hang your hat on. If someone believes it, however, she can be worrying for nothing. How terrible to lose sleep and not be able to function well due to reacting to misinformation.

You, however, might be worried about your finances. Perhaps you have a large deductible and large copayments and pay your living expenses paycheck to paycheck. Your breast cancer navigator will be able to help you with these financial concerns to dramatically reduce this worry. She may have resources from pharmaceutical companies to get discounted drugs for you or access to advocacy organizations to help you with food, utility bills, and other routine expenses while you are getting your active treatment.

There can be other worries such as concern about what you will look like if you need a mastectomy. Your experience might be what your grandmother’s mastectomy looked like 40 years ago. This worry may be reduced by showing you photographs of before and after images of women having had mastectomies without and with reconstruction, including each form of reconstruction. We have come a long way in the surgical management and cosmetic results of mastectomy surgery. If you are a candidate, for example, for nipple- and areola-sparing as well as skin-sparing mastectomy, you may be surprised with how “normal” you will still look. If, however, your concern is that your partner may reject you sexually no matter what type of surgery you have, then this is something for a deeper discussion with a counselor that can be arranged for you by your navigator as a referral.

A woman with stage IV breast cancer worries about who will keep her memory alive in the minds of her young children, instill her values in them, provide the motherly love that only she can, and give her children the good advice that she knows they will need to guide them through life. Believe it or not, even if the children’s mother does pass away when her children are young, there are proven ways to achieve all of this. She can maintain a journal for each child; prepare cards for every milestone each child will reach in the future; record her advice, love, and guidance in her own handwriting in each of the cards. What does she want to say when her son graduates from high school? When her daughter gets her driver’s license? What does she want to tell her daughter who today is only 10 years old but who may marry in her late 20s—what does she want to say on her wedding day? Strangely enough, the words written in these cards can make an even bigger impact and have a stronger influence on young people than having had their mother physically present for these events.

5. TELL YOUR DOCTOR 3 THINGS THAT BRING YOU JOY

Joy? Maybe right now your response would be, “Nothing is bringing me joy.” Again, such a conversation requires you to think about this question. Here are some examples.

You love watching your middle-school son playing basketball because he is good at it, he is passionate about it, and you can see how much he enjoys playing and hearing you root him on, especially when he scores a basket.

You love babysitting your newborn granddaugh-
ter because you get to have her all to yourself on Thursday afternoons. She is 7 months old and is laughing more and her personality is beginning to develop. There is no greater joy than seeing that she recognizes you, smiles at you with her own joy, and you get to spoil her by giving her all of your undivided attention for 4 hours.

You love listening to country music, the old stuff. You are studying to be a concert pianist and want to continue your studies while undergoing treatment. If you don’t tell your doctor that your greatest joy is playing the piano and he/she recommends drugs that cause numbness and tingling of the fingers and feet (peripheral neuropathy), then you may not be able to play the piano again, or certainly not concert pianist quality. So speak up.

Hopefully, you have a long list of joys when you take the time to sit down and think about them. Prioritize them and tell the doctor your top 3. Over time, the joys and the way you rank them may change. The joys you experience are a key part of how you define your own quality of life. You simply may never have needed to sit down and think about this before. Why should your doctor care about this? Well, you will want your joys, your quality of life as you define it, to be preserved during and after your treatment. Those dealing with stage IV breast cancer may need their quality of life restored at some point. And, in your case, the things that are important to you—your joys—will change over time. You love your job and enjoy feeling productive and making a difference as a school teacher. You may not be able to work any longer, but you can still be present with the children and their parents by attending the Holiday Musical the school plans for this year.

These are 5 topics you need to share with your medical oncologist. Write them down. Don’t rely on your memory. If your doctor seems rushed, let them know that these are important things you need to relay because they will impact your ability to participate in the decision-making about your treatment options, that they provide information about your understanding of the type of breast cancer you have, and how easy or difficult it may be to effectively treat. You want the doctor to know you as a person and not just as another woman with breast cancer. And if he or she lacks interest even then in listening to you, consider getting a second opinion. You are in a unique relationship with your medical oncologist. The higher the number is for the stage of breast cancer you have, the more challenging it is to treat it successfully. You need to be heard. You need your doctor to know you are more than just your pathology results.

Keep in mind, however, that if you ramble on and on, no one really has time to hear the additional information you are trying to express. So make a list of answers for each of these questions. Write or type them out. Make them concise. Be direct. If you feel you will ramble or get upset while talking because you are such a basket of nerves, take someone you trust with you to read the information for you exactly as you have recorded it.

But don’t just give your papers to the doctor. This requires a conversation. Remember, this is likely going to be a long-term relationship. And as time goes by and things change for you, especially regarding what you are hoping for, what you are worrying about, and what brings you joy, let your doctor and the other members of your treatment team know your new responses. Always have your navigator informed about where you are mentally and emotionally with all that is happening to you. The navigator is your patient advocate and speaks for you when you are not there. The navigator, of all people, needs to know you well, as a person.
Evaluating a Selective FGFR Inhibitor Treatment for Advanced Cholangiocarcinoma (CCA)

An investigational, targeted, oral, chemo-free agent

The Phase 3 PROOF Trial is evaluating the efficacy and safety of infigratinib (BGJ398), a targeted, oral, chemo-free agent, vs chemotherapy in patients with unresectable locally advanced or metastatic CCA with FGFR2 fusions.

**Inclusion criteria***:

- Have histologically or cytologically confirmed unresectable locally advanced or metastatic CCA†
- Have written documentation of local laboratory or central laboratory determination of FGFR2 gene fusions/translocations from tumor tissue collected before treatment

**Note**: Molecular testing offered by the trial, if needed.

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QED is focused on developing infigratinib, a potent, selective tyrosine kinase inhibitor to treat FGFR-driven diseases.

Efficacy and safety of infigratinib in CCA have not been established. Infigratinib is not currently approved by the FDA or other health authorities.

**To learn more, please contact us at**:  
- PROOF301@QEDTx.com  
- QEDPROOFTrial.com

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If you've recently been diagnosed with breast cancer, taking action quickly is important. Knowing your options is just as important.

Find questions for your doctor, treatment resources, and more at BreatheKnowGo.com/TakeAction