Toolkit to Navigate
BREAST CANCER

Tools and Tips for a New Breast Cancer Diagnosis
# Tools and Tips for a New Breast Cancer Diagnosis

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If you’re reading this guide it probably means you or someone you care about has recently been diagnosed with breast cancer. Breast cancer is both all too common and incredibly individual. Each year, nearly a quarter of a million women are diagnosed with breast cancer. Yet no two people have the same experience. And there isn’t a roadmap that works for everyone.

This resource is intended to help you make deeply personal treatment decisions based on current information about breast cancer. It should be paired with Breast Cancer Action’s *What You Need to Know About Breast Cancer* overview, which provides information about the various types of breast cancer and range of possible treatments.

Most people diagnosed with breast cancer face several treatment options, each with its own benefits and potential harms. These isn’t a ”right” choice that’s best for everyone and it’s up to each of us to figure out what is right for us. Sometimes, doing nothing is a reasonable option and should be considered and weighed against possible interventions. We may not be able to control if we get breast cancer, but we each get to make our own decisions about tests, treatments, and care within the range of options for our specific diagnosis.

That said, it can feel overwhelming to be presented with all these choices! You may feel that you don’t know where to begin or even what questions to ask. There are so many impenetrable medical terms to learn, so many options to consider, so many feelings to juggle. Few of us are experts on breast cancer when we are diagnosed, and for many of us this is the first serious diagnosis we have ever faced.

We want you to know you are not alone and those who have been down this road before you have a good deal of wisdom to share to help you navigate the information, advocate for yourself, and get the care that works best for you. This document was written with input from others who have gone through this experience. Breast Cancer Action brings a patient perspective to the data, and you can rest assured that since we never take funding from pharmaceutical or biotechnology companies, we are not beholden to any one treatment, drug, or company.

Our hope is that the information, ideas, and tips gathered here will make living with your breast cancer diagnosis easier for you and your loved ones. And most importantly, we hope we can support you so you can make the right decisions for you.
Being diagnosed with breast cancer can stir up a lot of powerful feelings. Many of us are scared when we are first diagnosed: we don’t know what it all means and we are afraid of the unknown, possible pain, physical changes, unwanted side effects, and even death. Practical questions about treatment, financial costs, personal relationships, and quality of life can make us feel anxious. It is easy to feel lost and overwhelmed by unfamiliar medical terms, procedures, and advice. Some of us feel angry, whether at the unfairness of getting cancer or the insensitivity of people who just don’t “get it.” We may feel frustrated at the bureaucratic hassles on top of everything else. Whatever you are feeling is perfectly normal. There is no single right way to feel or best way to handle a breast cancer diagnosis. And your feelings will probably change over time.

Very few, if any, of the decisions we face as part of a diagnosis are cut and dry, and all of the data has to be weighed according to our individual preferences, circumstances, and values. Even though it can feel like there’s a mythical “average” patient who is the subject of a lot of the resources out there, many of you reading this may be younger or older than average, you may not identify as a woman, or you may have complex health issues unrelated to breast cancer. There isn’t one way to experience breast cancer; and the most important thing you can do is to find the information and support you need to figure out the way that is best for you.

The truth is that, when we’re first diagnosed, there is no way to know exactly what is going to happen in our individual case. We each make the best decisions we can, based on the information that is available to us at the time. For this reason, we encourage you to take the time you need to talk to healthcare workers and others who have personal experience with breast cancer so you can ask questions, and consider multiple viewpoints and options. It’s important you feel comfortable with whatever decisions you make.

Over the years we have gathered some basic and not-so-basic suggestions that have been helpful to those who have just received a breast cancer diagnosis. We’ve grouped these suggestions under headings to give them some context. No matter where you are in the process, you may find some of these tips helpful.

Each year, nearly a quarter of a million women are diagnosed with breast cancer. Yet no two people have the same experience.
GETTING THE MOST OUT OF YOUR MEDICAL APPOINTMENTS

SUGGESTIONS/TIPS

Don’t be rushed into decision-making. It may be helpful to let the initial shock of a cancer diagnosis pass before making life-changing decisions. Take time to talk to people with different perspectives, whether multiple specialists or other patients, before making big decisions, when possible. The more information you have the better.

Keep track of everything in one place. The amount of information you gather can quickly become overwhelming. Try to keep all your records in one place, whether in a notebook, folder, 3-ring binder, or in on your computer. This will help if you want to refer back to information in the future.

Keep an ongoing list of questions. Questions may come up when you are not in a medical appointment. It can be helpful to write these questions down in one place so you don’t forget them and can follow up the next time you meet with your healthcare provider. It can also be helpful to prepare in advance and bring your list of questions to all appointments. (See a list of suggested questions for your healthcare provider in the section below.)

Plan for appointments to run late. Long before a cancer diagnosis, most of us already know that appointments with healthcare providers often run late. Waiting can add to the anxiety, frustration, and discomfort of a diagnosis. In addition to bringing a friend or light distractions like a good book, crossword, or podcast, choosing one of the first appointments in the day, before your provider’s schedule really backs up, helps reduce the chance your provider will be running late.

Take care of your body. Waiting can often include discomforts like hunger, thirst, and cold. We recommend bringing food and water to your appointments, as well as layered clothing to keep you from shivering in your paper gown. Often your physician’s medical assistants will provide warm blankets or tea and coffee if you ask.

Bring an ally. Having someone you trust in the room whenever possible can be both emotionally and practically helpful. Although it can be helpful to have the same person go to all appointments, it’s not always possible, and you may have a support network of people who divide appointments based on their schedules. The main thing is to think about what you want from your support person and to communicate that to them in advance. For example, do you want help asking questions of the provider, or do you want your ally to write down and record the information you are getting? A second set of ears is helpful, but you may not want your ally to start “running the show.” Discuss these issues with your ally in advance of your appointment.

If possible, leave children and other dependents at home. Many of us are caregivers ourselves, but this is an important time to focus on your own learning, understanding, and feelings. If possible, reduce distractions at your healthcare provider visits so you can give them your full attention and focus on your own needs.

Record information from each appointment. Some people retain information better by writing it down and others find the act of writing interferes with listening. There is no right way for everyone, but you may want to consider using a voice recorder with adequate capacity to record your entire visit, and asking your healthcare team if you can use it.

Repeat what you hear. One useful strategy to confirm your understanding is to repeat, in your own words, what you heard your provider explain. This way providers can confirm your understanding and add or clarify important information.

Get copies of your images and results. If possible, get a copy of all test results and images at the time you get them done. Make sure all of your healthcare providers get reports of all provider laboratory visits, x-rays, and tests. Ask your primary care provider to facilitate this, and follow up to be sure that they do. Don’t forget to ask for your own copies, and keep them in your binder.

Advocate for yourself. Often, healthcare providers are overwhelmed themselves and it can feel hard to navigate a busy facility that is stretched thin. Don’t be afraid to follow up; push for appointments, tests, and other things you need to keep things moving forward. Don’t be afraid to ask for help from your healthcare providers at any time. It is okay to email or call on a Sunday afternoon or Friday evening if you are experiencing pain or have an urgent question.

Get educated, but be careful of too much online research. With so much information available online, it can be tempting to spend hours reading about your diagnosis online. One of the best things about the web is its ability to connect people across distance, and many breast cancer patients have found valuable community that way. But the downside is that there is a lot of confusing and inaccurate information circulating online. Make sure the websites you are looking at are reliable, and be sure to talk with your healthcare provider before following advice you find online. Sometimes it can be helpful to turn the computer off and take a walk, spend time with loved ones, or just get a good night’s sleep.
Your healthcare provider should be a resource and partner for you.

They have expert medical knowledge but only you are the expert on YOU. Like any relationship, good communication with your provider is based on mutual respect and trust. It is most powerful if you and your healthcare provider engage in what’s called “shared decision-making.” Your healthcare provider has a wealth of information and expertise to share, and you are a critical partner in helping to formulate the best plan for you.

For some health conditions, there is a single treatment that is the clear standard of care, and patient preference has a limited role (for example whether a broken bone requires a cast or surgery.) With breast cancer, however, there is often more than one reasonable path forward, each with possible benefits, limitations, and harms.

Make sure your healthcare provider explains your treatment options so they are understandable to you. Clearly and patiently answering all of your questions is an essential part of their job—so don’t be shy and don’t hold back. The provider’s medical expertise is important for understanding your treatment options, including risks and benefits, but only you know all the relevant factors about what this will mean for you, including how it fits with your own preferences and values. Most healthcare providers appreciate this time with patients and feel that their job is not only to treat you but to support your informed decision-making, based on your individual circumstances, values, and preferences.

Be sure you are comfortable with your provider.

Choosing your healthcare provider is like any other relationship, and you need to feel that it’s a good fit. You always have the right to change providers, and you don’t have to explain if something doesn’t feel right to you. Excellent communication is the foundation of good medicine: if you feel your provider isn’t really listening and considering your input, it may be time to find a new provider. After all, you are entrusting this person with your body and your life.

Consider a second opinion for any major medical treatment, even if you have total confidence in your provider.

Most insurance will cover a second opinion for a cancer diagnosis, and your provider should not be surprised—let alone offended—by you seeking a second opinion. You can even talk to your provider about what you learned from the second opinion and ask them to explain any discrepancies. A small delay in starting treatment in order to get a second opinion almost certainly won’t affect the outcome of your treatment, but it may be very helpful to you in choosing which treatment, or even which provider, is best for you.

Everyone deserves healthcare that is respectful and responsive to your own individual preferences, needs, and values.

At Breast Cancer Action we are working to help realize a healthcare system in which everyone has access to healthcare that is compassionate, culturally competent, evidence-based, supportive of patient decision-making, and devotes adequate resources to prevention.
Ask for and accept help.
We know it can sometimes be hard to ask for and accept help. And not all of us have a big, local support network that can step up. We’ve found that support can come from many places besides family and close friends who live nearby. Many of us have been surprised and deeply touched by support we’ve gotten from acquaintances who are not yet good friends, individual healthcare providers (often nurses), support groups, online communities, and other places. Consider reaching out if you need help or support that you aren’t currently getting.

Consider a routine dental cleaning before treatment begins.
Breast cancer patients are sometimes advised not to get dental work while in treatment because of the risk of infection. We recommend talking with your provider about taking care of dental work before treatment, particularly if you will be getting chemotherapy.

Keep a journal of medications and symptoms.
Keeping track of medications and symptoms of treatment can be very helpful for you and your healthcare provider. In addition to tracking when and how much of each medication you take, knowing how your body responds is important and can help you answer your healthcare provider’s questions. Some things to include are:
- What does the symptom feel like?
- When does it occur?
- How long does it last?
- What makes it worse?
- What makes it better?

Keep a list of things friends can do to support you.
After a breast cancer diagnosis, many friends and relatives want to help. As wonderful as such offers are, they can take some organizing. It can be useful to make a list of tasks you could use help with. Sometimes it’s helpful to ask one friend to organize and assign people jobs. Tasks friends and family members can help with include:
- Providing rides to healthcare appointments
- Helping with household tasks including cooking, house cleaning, shopping
- Babysitting/childcare
- Taking care of pets
- Providing updates to other people, since it can feel overwhelming to answer questions and give updates to everyone who cares about you
- Giving you a break by taking you out to lunch, a movie, or an activity that isn’t cancer-related
- Helping you do research about support agencies and services
- Helping with work issues, like filing for a leave or disability

Be gentle and patient with yourself.
It’s not uncommon for some people to feel pressure to be the perfect cancer patient—to stay cheerful, to “count our blessings,” and to exercise through treatment. And although healthy meals and regular exercise can help you feel better while you are in treatment, it may be difficult to keep up with your own and others’ expectations. Having cancer is hard: it’s hard on your body and on your mind. Part of taking care of yourself is letting go of judgments and knowing that your best is good enough, even if it means taking time off from work and commitments.

For free, one-on-one breast cancer information and resources, reach out:
- phone: 800/877.2.STOPBC
- email: info@bcaction.org
Being diagnosed with breast cancer may feel like taking a crash course in biology and medicine.

Few of us come to this with existing knowledge about breast cancer. There is a lot of new information and a lot to learn. Most importantly, you want to know what your diagnosis means for you.

Medicine involves uncertainty and there is no way to know exactly what will happen in your specific case. Your providers will talk about likelihood, probabilities, percentages, and overall statistics. When discussing treatment options, it is important to understand the difference between the relative benefit (or risk) and the absolute benefit (or risk).

- **Relative benefit** tells you how much a particular treatment or something you do can change your risk compared to an alternative. If a treatment cuts the risk of recurrence in half, it does not mean you have a 50/50 chance of recurrence with treatment and 100% without. It may mean it reduces your risk of recurrence from 4% to 2% or from 20% to 10%. Relative benefit is like a coupon: how much you save depends on the starting price.

- **Absolute benefit** is the likelihood you will personally benefit. Put another way, it’s the true size of the benefit. So if your risk of recurrence is 2% over 5 years, and treatment cuts the risk by 50%, the absolute benefit is a 1% reduction in the risk of recurrence.

See *What You Need to Know About Breast Cancer* for essential, fact-based information for anyone who wants to learn about the disease.
Sample Questions
Here are some sample questions that may be helpful to get you started as you discuss your diagnosis and your treatment options with your healthcare provider. Not all of these questions may feel important to you. It may be helpful to rewrite the questions in your own words and add your own questions.

Often the answers to one question will spark new questions. This is a conversation with your healthcare provider, and you deserve the time and attention you need to have all of your questions answered to your satisfaction.

GENERAL QUESTIONS

- What is my diagnosis? What type of breast cancer is it? Is it estrogen positive (ER+) or estrogen negative (ER-), HER2 positive or HER2 negative?
- What is the stage of the cancer, and is there any evidence of lymph node involvement?
- How aggressive is the cancer?
- What does that mean for me? What is my prognosis?
- What are my treatment options?
- What is the goal of these treatments? For example, possible goals may be:
  - Remove all the cancer
  - Control the growth of the tumor
  - Reduce the risk of a recurrence
  - Increase comfort level (reduce pain, stimulate appetite, increase energy)
- Are there individual or other personal factors that affect my treatment options?
- What do you recommend for me personally and why?
- What if I decline to do a test or to undergo treatment?
- What is the recovery like and how long will it take?
- What are the most common side effects of the test/treatment? (short-term and long-term)
  - How many patients experience that side effect?
  - What are the options to control or address that side effect?
- What are the most serious risks/harms of the test/treatment? (short-term and long-term)
  - How many patients experience that risk/harm?
  - What are the options to control or address that health harm?
- How many patients like me have you treated? [You may want to highlight the specific demographic group you are part of or the specific type of cancer you are dealing with.] What specialized training or expertise do you have in my specific situation?
- What studies or sources of data are most relevant to my situation?
- How long can I take to make a decision?
- How can I contact you if I have any additional questions?
- Are you referring me to any other health providers or specialists?
- Who are the national experts on my specific condition?
- Should I go for genetic testing? How would the results of my tests change my decision-making?
  - If you decide to get genetic testing, work with an independent genetic counselor (i.e. from a hospital or university), not a counselor from the private company doing the testing.
- Are there any research studies I may want to consider being part of?
- Can you refer me to someone I can talk to who has faced similar treatment choices?
- What support services are available to me?

QUESTIONS ABOUT MEDICAL TESTS

- What information will this test provide and how might it change my treatment choices? (If it does not change the planned treatment, why are you recommending it?)
- How long is my recovery and when can I get back to my usual activities?
- Will I need someone to drive me home or care for me after I am released?
- What should I watch for and what problems should I report to you?
- When will I get my test results, and will you explain/discuss them with me?
- How can I get a copy of my test results or images?

additional questions continue on next page
QUESTIONS ABOUT SURGERY

- What surgery are you recommending and why?
- If there are positive lymph nodes during my sentinel node biopsy, will you remove additional lymph nodes and why? [Note that because you will be under general anesthesia when the surgeon makes this decision, it is important to be clear in advance about what will happen if there are positive lymph nodes.]
- Will I be at risk for lymphedema and how can we reduce that risk?
- What are my options for reconstructive surgery and what are the risks associated with each option?
- How long is my recovery and when can I get back to my usual activities?
- Will I need someone to drive me home or care for me after I am released?
- What should I watch for and what problems should I report to you?
- Will my tumor be saved and if so, how will it be used or stored?

QUESTIONS ABOUT COMPLEMENTARY AND INTEGRATIVE CARE

- Is there anything I can do besides the treatment you are recommending to improve my prognosis?
- What can I do to reduce or manage side effects?
- Are there any medications, supplements, or complementary therapies I should avoid while I am being treated?
- Do you have experience with integrative and complementary therapies?

ADDITIONAL QUESTIONS FOR PATIENTS WHOSE CANCER IS LOCALIZED AND HAS NOT SPREAD TO LYMPH NODES

- If I do this treatment, what is the likelihood of recurrence in the same or the other breast? (absolute vs. relative benefit of treatment)
- If I do this treatment, what is the likelihood the cancer will spread to other organs? (absolute vs. relative benefit of treatment)
- If I choose not to do this treatment, what are the chances the cancer will return or spread? (absolute vs. relative risk)
- What is my ongoing care plan after treatment? How often will you see me, and what should I expect?

ADDITIONAL QUESTIONS FOR PATIENTS WHOSE CANCER IS AGGRESSIVE, ADVANCED OR METASTATIC

Some people are diagnosed with advanced or metastatic cancer when they are first diagnosed. We want you to know that, while this is less common than an early-stage diagnosis, you are not alone. If it’s possible for you, we recommend you seek treatment (or at least a second opinion) from a major cancer/teaching hospital. Major cancer centers see more people who have advanced cancers and are likely to have access to and involvement with the latest treatments, as well as access to new or emerging treatments and trials. And because you may be in treatment for some time, it’s even more important to see your medical provider as a trusted ally, someone you can speak honestly with and who can be your partner in decision-making. Questions to add to your list:

- How many people with my same diagnosis have you treated?
- What treatments do you recommend?
- What is the goal of treatment?
- What are the likely side effects?
- How will we know if the treatment is working?
- Is there a clinical trial I qualify for that you think could be beneficial for me?

There isn’t a “right” choice that’s best for everyone and it’s up to each of us to figure out what is right for us.
Some people find it useful to make a table to compare treatment options side-by-side, like the example below. As you learn about your specific options, you may want to customize the chart to add other factors that are important to you.

<table>
<thead>
<tr>
<th>FACTORS TO CONSIDER</th>
<th>TREATMENT OPTION A</th>
<th>TREATMENT OPTION B</th>
<th>NO TREATMENT</th>
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</thead>
<tbody>
<tr>
<td>Efficacy of treatment</td>
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<tr>
<td>Length of treatment</td>
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<tr>
<td>Length of recovery</td>
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<tr>
<td>Most common side effects</td>
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<td>Most serious side effects</td>
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<td>Long term health effects</td>
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<tr>
<td>Best-case scenario</td>
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<td>Worst-case scenario</td>
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<tr>
<td>Financial impact of treatment</td>
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<tr>
<td>Other factors to weigh</td>
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</tbody>
</table>
Complementary and Integrative Treatments

Many people are concerned about the side effects of conventional cancer treatments and decide to look into non-Western healthcare. It is estimated that nearly a third of Americans use nonconventional medicine. These treatments may include supplements (such as vitamins, herbs, and probiotics), mind-body techniques, or non-Western healthcare (such as acupuncture, Ayurvedic medicine, or naturopathy).

The terms “alternative,” “complementary,” and “integrative” are sometimes used interchangeably, but they have distinct meanings. Alternative therapy is rare and is used in place of any conventional medical treatment. Complementary therapies are used alongside conventional Western medicine and are sometimes seen as a tool to support the body during treatment. Integrative healthcare brings together conventional and complementary approaches in a coordinated way. More and more cancer centers are adding integrative approaches to their programs.

Conventional cancer treatments, such as chemotherapy, are approved by the U.S. Food and Drug Administration (FDA) after rigorous testing through clinical trials to prove they work and to evaluate the side effects and risks of treatment. These trials take time and are expensive; the result is that medical research usually focuses on treatments that can be patented and make a lot of money.

Most nonconventional treatments cannot be patented and have not been through such rigorous testing, although there have been some limited clinical trials of acupuncture and some supplements. This leaves patients in a difficult situation because the lack of data does not mean that these treatments are necessarily ineffective, but there isn’t proof that the treatment works, or how it may interact with conventional treatments. There also isn’t data about the harms, side effects, or most effective dosing. Remember that the fact that alternative treatments are considered “natural” does not mean they are not harmful or don’t have their own side effects. There are specialists who study the available evidence about integrative oncology, and it’s important to let your providers know if you’re using complementary and integrative therapies while you’re in treatment.

There is often more than one reasonable path forward when diagnosed with breast cancer, each with possible benefits, limitations, and harms.
After Treatment and Ongoing Treatments

For most people, treatment will eventually end. It is estimated that more than 3.5 million people are alive right now who have been through breast cancer treatment, and most of these people experience ongoing impacts on their body, their finances, and their psyche.

People with metastatic breast cancer may be in treatment for the rest of their lives. Many live for years and may change treatment multiple times. Even for people with advanced cancers, there may be periods of remission when there’s no evidence of active disease.

The period immediately after treatment can be especially difficult. Many of the physical and psychological impacts of treatment do not end on the last day of treatment. It is not uncommon for someone to experience a surge in anxiety that the cancer might return after active treatment has ended. Some people who didn’t previously have a support group find it helpful after treatment. There are many resources for people after, as well as during, cancer treatment.

In acknowledgment of the ongoing impact of breast cancer on our lives and bodies, as well as the risk that our cancer may recur, many of us choose the phrase “living with breast cancer” instead of “survivor” to describe our relationship with breast cancer.

Let’s Not Forget the Caregivers

Disease and disability have a profound impact on our lives and our relationships. In addition to the person who is diagnosed—and has to go through treatment—cancer challenges our families, loved ones, and friends. And caregiving is both physically and emotionally demanding.

It can be helpful to build a broad base of support that does not put too great a burden on any one person. No caregiver can do everything and caregivers will need to say “no” at times. It is important that caregivers are able to ask for and get help because caregivers also need support, whether they are stepping up for a short-term crisis or providing longer-term care. Caregivers will have their own feelings and physical needs that are just as valid as those of the person they are caring for. Depression is not uncommon for long-term caregivers, and there are resources to help.

You can contact the Family Caregiver Alliance www.caregiver.org for more information or online support.

For free, one-on-one breast cancer information and resources, reach out:
• phone: 800/877.2.STOPBC
• email: info@bcaction.org
At Breast Cancer Action, we recognize that the personal is political. Breast cancer is a social justice issue and a public health crisis that impacts some communities disproportionately. It is a widespread women’s health crisis in a male-dominated and profit-driven society, and addressing and ending the breast cancer epidemic requires profound changes at every level of our society. Individual action alone, whether in terms of lifestyle or behavioral choices, is not sufficient to tackle the root causes of this breast cancer epidemic. We focus on systemic interventions that will address the root causes of the disease and produce broad public health benefits.

Breast Cancer Action was founded by women who met at a support retreat for women living with, and dying from, breast cancer. They discovered they shared a deep anger and outrage that more wasn’t being done to address the disease. And they decided to form a group and reach out to more women who shared their urgency to do something, both for themselves and for their daughters and granddaughters.

The outreach flyer they developed from their first meeting in 1990 read: “We are meeting to organize Breast Cancer Action. Our goals are education and political action to prevent a further rise in the incidence of breast cancer; indeed, we hope that our efforts will serve in the future to lower the breast cancer rate in the United States.”

Three decades after that first meeting, we carry on our founders’ fearless vision and commitment to education and political action. In order to address and end the breast cancer epidemic, we must tackle the root causes of these health inequalities, which are the result of a complex interplay of culture, power, economics, racism, and sexism. We believe that no single injustice can be effectively addressed in isolation, and we recognize that injustices in our society reinforce each other in many ways and at many levels.

Over the years we’ve accomplished a lot together, but we still have a long way to go. Both things are deeply true and drive our work every day here at BCAction. We hope you will join us in connecting your personal experience to larger systems and advocating for system change. Visit BCAction.org to find out how to:

- Sign up for emails
- Join us on Facebook and Twitter
- Listen to our podcasts and webinars
- Speak to our Information and Resource specialist
- Come to an event
- Volunteer and get more involved

We are working for a world where lives and communities are not threatened by breast cancer. For as long as it takes, we will continue our work to achieve health justice for all women at risk of and living with breast cancer.

Most importantly, know we’re here for you right now—or whenever you need our help. Through our free Information and Resource service, we provide unbiased information about breast cancer to anyone who needs it. You can speak one-on-one with a knowledgeable staff member so you can make informed decisions. You can also access our vast resource of breast cancer information online at BCAction.org. Please contact us.

Breast cancer is a social justice issue and a public health crisis.

See What You Need to Know About Breast Cancer for essential, fact-based information for anyone who wants to learn about the disease.