BREAST CANCER
RESOURCE CENTER

PRESENTS

BREAST CANCER COMPANION

YOUR GUIDE THROUGH DIAGNOSIS AND CARE

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512-524-2560

BREAST CANCER COMPANION

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ABOUT BCRC

For 30 years, the Breast Cancer Resource Center (BCRC) has been a pioneer in providing comprehensive and compassionate support to breast cancer survivors and their families. As a nationally recognized leader in breast cancer education and advocacy, BCRC transforms lives by equipping patients, caregivers, and healthcare professionals with the knowledge they need to manage treatment options, navigate side effects, and address the unique needs of survivors and those living with metastatic breast cancer.

Breast Cancer Resource Center (BCRC) is a community-based non-profit serving Central Texans since 1995. Strengthened by our mission to empower those affected by breast cancer with personalized support and compassion and in collaboration with our community partners, BCRC envisions a future where no one faces breast cancer alone.

BCRC offers individualized, client-centered care from the time of diagnosis, through treatment, and into survivorship. Through our pillars of support - Guidance, Education, and Peer Support Groups, BCRC's Certified Patient Navigators, who are all breast cancer survivors themselves, empower those affected by breast cancer to become active and knowledgeable participants in their healthcare. All BCRC programs and services are offered at no cost to our clients and their loved ones.

BREAST CANCER UNIVERSITY

Breast Cancer University™ (BCU), created by the Breast Cancer Resource Center, is a comprehensive educational platform designed to support everyone touched by breast cancer. Our mission is to provide a wide range of accessible information and resources that educate and empower not only those diagnosed but also caregivers, family members, health professionals, patient navigators, and community health workers.

On this site you will find:

- Expert-led courses covering topics from breast cancer treatment options, survivorship, and living with metastatic disease by subject matter experts
- Healthcare provider tools including information and training materials for doctors, nurses, patient navigators, allied health professionals, and community health workers. Content is designed to enhance patient care and improve outcomes.
- Community education resources for advocates and educators to understand the complexities of breast cancer to support anyone who has been diagnosed

www.breastcanceruniversity.org

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DISCLAIMER

This material is provided for informational purposes only and should not be considered medical advice or instruction. Consult your licensed medical practitioner for advice relating to a medical problem or condition. Readers are advised that research on breast cancer topics is ongoing, and treatments may change over time.

Dear Reader,

If you are reading this guide because you were told you have breast cancer, you may be feeling many things—worried, scared, upset, confused, or even angry. You might also feel like you have lost control of your life. The plans you had may now be pushed aside or squeezed between tests, treatments, doctor visits, surgery, phone calls, and tough choices.

We understand those feelings. We have been through them too.

We also know that dealing with breast cancer takes both information and organization. This booklet is here to help with both. Inside, you will find an overview of what it's like to have and treat breast cancer. You will also find tools to help you sort your thoughts, write down your questions, and set your priorities. Sprinkled throughout the booklet you'll see "Pro Tips" – advice that BCRC navigators and clients found helpful as they coped with their breast cancer diagnosis.

We've organized this information into 5 categories:

1. Your medical team
2. Your breast cancer diagnosis and treatment
3. How finances and work might be impacted
4. How to turn to family and friends for support
5. Things you can do to feel as mentally and physically strong as possible

As you read this, remember that you are not alone—many people have walked this road and found strength they did not know they had. With care, support, and information, you can face each step with courage and determination.

WHAT WE WISH WE HAD KNOWN AT THE BEGINNING

1. Cancer is a complex disease. There are hundreds of types of cancer, and even **breast cancer has many different forms.**

> *Each time you have a test, or get a lab report, or experience a side effect, your doctors learn more about your cancer. As each new detail emerges, your doctors will evaluate your treatment plan and make any changes that will help you progress to the best possible outcome. It is normal for a person's treatment plan to change as their treatment goes on.*

2. It's understandable to feel worried if you learn that your treatment plan is different from someone else's.

> *Your cancer and your body are different from anyone else's, and your doctor is creating a personal treatment plan that will lead to the best possible results for you*

3. **It is okay to ask your medical care team questions** about your diagnosis, your test results, your treatment plan, and anything else about breast cancer that is on your mind.

> *When you understand your diagnosis and options, you can work with your doctor to make a plan that matches what matters most to you.*

4. At first, a lot of us thought we could "handle" our cancer on our own. Many of us found **things became smoother when we let others support us.** We learned that things were better when we allowed people to help.

> *People won't necessarily know what you need. You may have to ask for the kind of help that is useful. Ultimately, though, it's easier to get through the emotional and physical changes of cancer treatment with support from friends or family or support groups.*

5. **Bring a friend or family member who can help listen, take notes, and ask questions** to your medical appointments.

★ **PRO TIP**

Bring someone who is very matter of fact and doesn't easily get emotional. They will be the best at making sure all your questions are answered, and all the information is clear. ***Trusting and communicating well*** *with your medical team (doctors and nurses and office staff) is just about the most important thing! And establishing a good working relationship with your medical team can take some time.*

> *If you don't feel entirely comfortable with your doctors, small communication adjustments can make a big difference. We offer some suggestions in the section called 'Communicating with Your Medical Team.' But if, after trying those steps, you still don't feel supported or understood, it's completely okay to seek care from another doctor.*

6. **Palliative care is an extra layer of support that is helpful at any stage** of a serious illness. Many people hear the term and think of hospice and end of life, but they are not the same.

> *Palliative care is special medical care that helps people feel better by focusing on relieving pain, stress, and other symptoms, not just treating the disease. The goal is to improve quality of life for both you and your family.*

YOUR MEDICAL TEAM

Cancer is a complex and serious disease. Because of this, many kinds of doctors and health workers are needed to help treat it. Each person on your medical team has a special role, and it's important to know who they are and how they help.

In addition to knowing the roles of each member of your medical team, it's important to have a medical team you trust. When you trust your doctors and nurses, it's easier to talk openly and share important information. This helps your doctors create a treatment plan that fits your needs. Studies also show that trust can help lower anxiety about treatment, making the whole experience more positive and less stressful.

ONCOLOGISTS

Doctors who treat cancer are called oncologists. They are trained to find out what kind of cancer you have and how to treat it. Different types of oncologists focus on different parts of cancer care, like medicine, radiation, or surgery. The type of breast cancer you have will determine which doctors you need to see.

- **Medical Oncologists** manage your overall cancer care. They treat cancer with medications like chemotherapy, hormonal therapy, biological therapy, and/or targeted therapy.
- **Radiation Oncologists** treat cancer by transmitting high energy radiation to shrink and kill cancer cells.
- **Surgical Oncologists (also called Breast Surgeons)** plan a lumpectomy or mastectomy and then perform the surgery to remove the tumor.

★ PRO TIP

Make sure you feel comfortable with your medical oncologist. Of all your doctors, this is the one you'll work with the most and for the longest time. Other specialists usually give a specific treatment and then step back from your care. Your medical oncologist will keep seeing you and checking on your health even after your main cancer treatment is over.

OTHER STAFF AT THE DOCTORS' OFFICES

Doctors aren't the only ones caring for you. People being treated for cancer also receive help from other medical professionals, including nurses, nurse navigators, and social workers. Each of these professionals can give you information that helps you get ready for treatment.

- **Oncology nurses** coordinate with your medical oncologist to provide direct clinical care, such as administering chemotherapy or other cancer treatments.
- **Oncology nurse navigators** are specialized nurses who understand the difficulties a person with breast cancer might face and help to minimize or remove those difficulties by connecting you with resources that make it easier to navigate the complex healthcare system.
- **Social workers** can provide counseling about family or financial concerns during treatment.

OTHER DOCTORS

- **Plastic surgeons** perform breast reconstruction after breast surgery.
- **Primary care physicians** (PCPs) treat common illnesses and attend to your general healthcare needs. Often, your medical oncologist becomes the primary doctor for your healthcare while you are in active treatment. Once treatment ends, you might want your PCP more involved in your medical care. It is a good idea to ask both your PCP and your oncologist what role they will have in your survivorship care.

PATIENT NAVIGATORS

Patient Navigators (like those at the Breast Cancer Resource Center) help people with breast cancer understand and cope with what it means to have breast cancer. They are not doctors or nurses, but they are trained to give support and guidance.

Patient Navigators offer one-on-one guidance based on your questions and your needs. They can help you with:

- Emotional support and encouragement during a stressful time.
- Referrals to resources that can help with such things and finances and support for children.
- Advice on getting ready for surgeries or treatments.
- Support groups and connections with other people going through a similar experience.

At the Breast Cancer Resource Center, all the Patient Navigators are also breast cancer survivors. They have gone through many of the same treatments and tests that you will go through.

Their main job is to make sure people with breast cancer don't feel alone and know where to go for the help they need.

If you live in Central Texas and want to receive our free patient navigation services,

call the BCRC Helpline at 512-524-2560.

COMMUNICATING WITH YOUR MEDICAL TEAM

Many people with breast cancer say that trusting their medical team and feeling heard, understood, and comfortable is one of the most important parts of their care.

If you ever feel unsure or uneasy about your team, here are some steps that might help:

1. **Notice what feels off**
    - Think about what's making you uneasy — maybe you don't feel heard, rushed, or confident in your doctor's explanations.
    - Write down specific examples. This helps you understand what's really bothering you and makes it easier to talk about.
2. **Get ready before appointments**
    - Make a short list of your top questions or worries (for example: "What are my treatment options?" or "What side effects should I expect?").
    - Bring a friend, family member, or patient navigator to take notes and help you remember details.
    - If something isn't clear, speak up. You might say, "Can you explain that in simpler terms?" or "Can you show me what that means for me?"

3. **Use your whole care team**
    - Nurses, social workers, and patient navigators can often explain information, help you prepare questions, or talk through your concerns.
    - If communication with your doctor is hard, a navigator or nurse can sometimes help bridge that gap.

4. **Ask for a second opinion**
    - Many people with breast cancer get a second opinion — it's completely normal.
    - A fresh perspective can help you feel more confident in your treatment plan.
    - Ask your clinic how to request copies of your test results, scans, and notes to share with another specialist.

5. **Talk it out**
    - Share your concerns with someone you trust — a friend, support group, or counselor who understands the cancer journey.
    - They can help you practice how to ask questions or express what you need from your care team.

6. **Consider changing doctors**
    - If you've tried to improve communication and still don't feel comfortable, it's okay to find another provider.
    - It is important that you feel that you have a doctor who listens to you, explains things clearly, and treats you with respect.
    - Ask your insurance company or patient navigator for help finding someone who's a better fit.

SECOND OPINIONS

Breast cancer disrupts daily routines and future plans. People going through a breast cancer diagnosis often feel that they have lost control of their schedule – they feel swept up in a wave of appointments, tests, procedures, and treatments.

Remember, though, that you do have choices!

For some people, getting a second opinion – asking another doctor for their recommendations based on their interpretation of your medical records – is a way to regain some control of your life. Second opinions can also give peace of mind when people want to confirm their diagnosis and treatment plan or want a better understanding of their options.

You can seek a second opinion at any point, but some of the more natural times to consult with a different medical team are:

- When you are first diagnosed
- When your treatment plan changes
- When you feel uncertain about or uncomfortable with your medical providers
- If you answer "no" to any of the following questions:
    - Do I trust and feel confident about this person?
    - Does this doctor seem approachable?
    - Do we communicate well?
    - Did I feel rushed? Was there enough time to ask questions?
    - Did the doctor listen carefully to what I said and seem to understand my point of view?

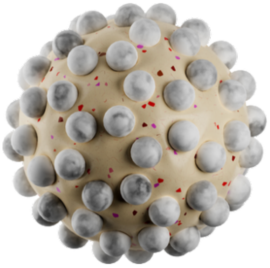
YOUR BREAST CANCER AND TREATMENTS

WHAT IS CANCER?

Cancer happens when abnormal ("cancerous") cells in a person's body grow in an uncontrolled way. These cancerous cells can crowd out healthy cells and use up a lot of the body's energy as they grow.

It's also important to know that cancer starts in a person's own cells. Because everyone is unique, each person's cancer can act differently. Even when two people have the same type of cancer, it may behave in its own way for each person.[1]

Because doctors now know that cancer may be slightly different from person to person, Cancer treatment has also evolved from one-size-fits-all strategies to much more tailored approaches. This approach, called precision medicine or personalized medicine, is the reason that your cancer treatment might be different from other people who also have breast cancer. Your care will be personalized to fit your specific situation.



TYPES OF BREAST CANCER

Breast cancer is the type of cancer where abnormal cells start growing in a person's breast. Women and men can develop breast cancer, although it is much less common in men.

Breast cancer is not just one disease. There are several ways doctors classify breast cancer[2]:

- Where it begins
  - Cancerous cells can start growing in either the milk ducts or the lobules of the breast
- Whether it's invasive
  - Non-invasive ("in situ") breast cancer means the cancer cells haven't spread to other areas of the breast or body.
  - Invasive breast cancer means the cancer cells have spread beyond the ducts or lobules where they first started. This means they can spread to other areas of the breast, to lymph nodes, or even to other parts of the body.
- How it looks
  - Breast cancer grades describe how different the cancer cells look from healthy cells when viewed under a microscope.
- What kind of receptors it has
  - Some breast cancer cells have proteins that are "hormone receptors". If your cancer has these receptors (that is, if your cancer is "HR+"), it means that the hormones estrogen and/or progesterone can stick to the proteins and help the cancer cells grow. It also means that your cancer can be treated with hormone therapy.
  - Breast cancer can:
    - Have receptors for estrogen and progesterone ("ER+/PR+", sometimes shortened to "HR+")
    - Have receptors for estrogen but not progesterone (ER+/PR-")
    - Have receptors for progesterone but not estrogen (ER-/PR+)
    - Have no hormone receptors ("ER-/PR-", sometimes shortened to "HR-")
- If the cells make extra HER2 ("human epithelial growth factor-receptor 2").
  - Knowing the HER2 status tells doctors if targeted therapy against HER2 will be effective.

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[1] https://www.cancercenter.com/community/blog/2023/10/cancer-is-not-one-disease

[2] https://www.mayoclinic.org/diseases-conditions/breast-cancer/in-depth/breast-cancer/art-20045654

  - All of these details help your oncologist know what kinds of anti-cancer treatment to use. Your doctor gets these details from your pathology reports.

PATHOLOGY REPORTS

When you have a biopsy or breast cancer surgery, the surgeon sends a small piece of the tissue removed to a special doctor called a pathologist. The pathologist looks at the tissue under a microscope to figure out what's going on. The report they write is called a pathology report, and it gives your oncologist important details about your breast cancer.

Pathology reports created after a lumpectomy or mastectomy ("excision pathology report with synoptic summary") will describe all the characteristics of the whole cancer. This is the report that tells you the stage of your cancer.

- A cancer's stage (from Stage 0 to Stage IV) describes the extent of a cancer. The stage number tells you how big the tumor is and whether it has spread. Because you can't see exactly how big a tumor is until it is removed in surgery, you won't receive this piece of information until after a lumpectomy or mastectomy.
- Stage 0 cancer is also called "Ductal Carcinoma In Situ" or "DCIS". It is the most common non-invasive breast cancer.

Another classification you could see on your pathology report is "Lobular Carcinoma In Situ" or "LCIS." Technically, this isn't cancer, but it is a marker of increased risk. If you have LCIS, you and your doctor will discuss treatment decisions to minimize your future risk of developing breast cancer.

Make sure to get copies of all your pathology reports. Even though they're included in your medical record, having your own personal copy is an important part of staying informed.

★ PRO TIP

Bring your pathology report with you to oncology appointments so you can ask questions and talk about your care using the exact information in the report.

FOR MORE INFORMATION:

- "Understanding your Pathology Report" from BreastCancer.org - https://www.breastcancer.org/pathology-report

TREATMENT BASICS

Just as there are several types of breast cancer, there are several ways of treating breast cancer.

- "Local" treatments focus on specific areas of the body where cancer is located.
- "Systemic" treatments reach all parts of your body, usually by travelling through the bloodstream

The treatment or treatments you will receive depends on several factors, including information from your pathology report. You and your doctor will discuss your treatment options and determine what treatment or combination of treatments fits your situation the best.

In general, a person's treatment is a combination of:

- Surgery
- Radiation
- Hormone therapy

- Chemotherapy
- Targeted therapies

CHEMOTHERAPY ("CHEMO")

WHAT IT IS

- Cancer treatment that uses powerful chemicals to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.
- There are many types of chemotherapy drugs.
- Chemotherapy is sometimes given before surgery ("neoadjuvant chemotherapy") to shrink the tumor before it is removed.
- Systemic treatment

HOW IT'S GIVEN

- Taken by mouth or injected into a vein or muscle

HORMONAL THERAPY

WHAT IT IS

- Cancer treatment that uses drugs or surgery to reduce the production of hormones or block them from working.
    - If hormones aren't present or don't work, then cancer cells that are sensitive to them won't have fuel to grow.
- This is often used on breast cancers that are ER (Estrogen Receptor) and/or PR (Progesterone Receptor) positive.
- If hormones are disrupted with medicines, it is systemic treatment; if they are disrupted with an oophorectomy (surgery to remove the ovaries), it is local treatment.

HOW IT'S GIVEN

- Medicines are taken by mouth or injected into a vein or muscle

IMMUNOTHERAPY

WHAT IT IS

- A cancer treatment that helps the body's immune system kill cancer cells.
- A type of "Biological therapy" because it uses substances made from living organisms to treat disease.

HOW IT'S GIVEN

- It is typically administered via intravenous (IV) infusion

TARGETED THERAPY

WHAT IT IS

- In targeted therapy, drugs or other substances are used to identify and destroy specific cancer cells without harming normal cells.
- A type of treatment that targets specific molecules that cancer cells need to survive and spread.

- Cancer treatment that uses medicines that are directed at (target) proteins on breast cancer cells
- A type of “Biological therapy”

HOW IT’S GIVEN

- Targeted therapy medicines are administered either infusions, pills, or injections

SURGERY

WHAT IT IS

- Local treatment
- An operation to remove the cancer from the breast.
- Lymph nodes under the arm are usually removed and examined under a microscope to see if they contain cancer cells.
- 2 main types:
    - Breast-conserving Surgery (also called “lumpectomy”) – removes the cancer, but not the breast itself. How much of the breast is removed depends upon factors such as size and location of the tumor.
    - Mastectomy – removes the entire breast, including all breast tissue and additional nearby tissue. There are different types of mastectomies, including simple (or total) mastectomy, skin-sparing mastectomy, and nipple-sparing mastectomy. The type that is best for you depends on where the tumor is, your breast size, the condition of your skin, and your surgeon’s advice.

RADIATION

WHAT IT IS

- Local treatment
- Uses high-energy rays (like X-rays) to kill cancer cells or stop them from growing.
- Often used after surgery to make sure any cancer cells left behind are destroyed.

HOW IT’S GIVEN

- Radiation therapy is usually given in a hospital or clinic using a special machine that aims high-energy beams at the part of the body with cancer.
- Treatments are quick, painless, and often happen every day for several weeks.

CLINICAL TRIALS

Clinical trials are research studies that test new treatments, medicines, or ways to care for people with breast cancer. They help doctors learn if these new approaches are safe, effective, and better than current treatments. Taking part in a clinical trial does not guarantee a cure, but it can give people with cancer access to the latest treatments and help doctors improve care for future patients.

Deciding to join a clinical trial is a personal choice. It is voluntary to join, and you can leave it at any time. Doctors and research teams explain all the details, including possible benefits and risks, so people with cancer can make an informed decision. Many people find it empowering to take part because they are helping to advance breast cancer treatment. People who take part in clinical trials usually get more check-ups and extra support during the study than they would with regular treatment. All current treatments for breast cancer – including Herceptin (generic name: trastuzumab), aromatase inhibitors, tamoxifen, radiation, and more – were initially studied in clinical trials.

FOR MORE INFORMATION:

To learn more about clinical trials, talk with your oncologist, who can explain which trials might be a good match and answer questions about safety and benefits.

To look up clinical trials related to breast cancer:

- The American Cancer Society has a clinical trial matching service called Access to Clinical Trials and Support (ACTS) at www.cancer.org/acts
- www.breastcancertrials.org, in collaboration with the Susan G. Komen organization offers a custom matching service to help find clinical trials that fit your needs.

QUESTIONS TO ASK

As you begin meeting with your medical team and learning about your diagnosis and upcoming treatments, these are questions that you can ask to help you understand your diagnosis and treatment options:

ABOUT YOUR BREAST CANCER:

1. What type of breast cancer do I have?
2. What stage is my cancer and what are the different types of stages?
3. What is my prognosis?
4. What are the treatment options for my type of breast cancer?
5. What is the recommended treatment?
6. How quickly do I need to decide about treatment?

ABOUT YOUR BREAST CANCER TREATMENT OPTIONS:

1. What does the treatment do?
2. Is the goal of the treatment to cure my cancer, control my cancer, or give me symptom relief?
3. What are the risks and side effects? Will I lose my hair?
4. What can I do to prepare for the treatment or to manage side effects if they happen?
5. Will the treatment affect my fertility?

6. Should I avoid certain foods, vitamins, or supplements while in treatment?

   ____

7. What is the expected timeline for each treatment option?

   ____

   a. How many treatments will I need? ____________________________
   b. How often? ____
   c. How long will each treatment session last? ______________________

ABOUT LIFE DURING AND AFTER CANCER TREATMENTS:

- Can I keep doing my normal activities, like work or exercise?

  ____

- How will we know if the treatment is working?

  ____

- What happens if the cancer doesn't respond to the treatment?

  ____

- Will I need more tests to find out if there are cancer cells left in my body?

  ____

ABOUT ADDITIONAL SUPPORT AND RESOURCES:

- Who do I call if I have questions after hours?

  ____

- What support services (support groups, counseling, nutrition help) are available for me and my family?

  ____

- Can someone in your office help me with insurance or financial resources?

  ____

FOR MORE INFORMATION:

- https://www.oncolink.org/cancers/breast
- The American Cancer Society has a detailed list of questions to ask at: https://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/questions-to-ask-your-doctor.html

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★ PRO TIP

Write your questions down and bring this sheet to your appointments. There are no "wrong" questions—your care team is there to help.

INSURANCE, FINANCES, AND WORK

Because cancer treatment is expensive, a lot of people worry about paying for their medical expenses. This section defines what you need to know about your insurance coverage and gives you tips for lessening the financial pressure you might feel.

INSURANCE

IF YOU DO NOT HAVE INSURANCE:

You may qualify for a public insurance program. To get help, check with:

- Your oncology office. They may have dedicated staff (such as a Patient Navigator, Nurse Navigator, Financial Navigator, Financial Counselor, or Social Worker) who can help with insurance questions.
- Your hospital's billing department or patient services department.
    - Nonprofit hospitals are legally required to offer charity care programs, which are often called "Financial Assistance Programs."
- Your state's Medicaid office.
    - Every state has a Medicaid program for breast cancer.
    - In Texas, call the "Medicaid for Breast and Cervical Cancer program" at 512-776-7796.
    - In other states, google your state's name, "breast cancer", and Medicaid to look up the name and number of the office to call.

IF YOU DO HAVE INSURANCE:

Review the details of your coverage:

- What is your annual deductible? *(How much do you have to pay out-of-pocket each year before your health insurance policy begins to pay its portion of your medical expenses?)*
- What is your maximum out of pocket? *(How much do you have to pay each year before your health insurance policy starts paying 100% of your covered essential health benefits?)*
- A comprehensive conversation with your insurance provider can help you understand your coverage and prevent unexpected costs. You can request to be assigned a case manager who can help with complex claims.
- Confirm coverage and network status.
- Ask what specific medical procedures, treatments, tests, and medications are covered.
- Confirm which specialists and facilities are "in-network" to avoid higher out-of-pocket costs.
- Understand out-of-pocket expenses: Clarify your total deductible, co-payment for each service, and co-insurance percentage.
- Ask how and when to make payments for bills and how to track your progress toward your out-of-pocket maximum.
- Navigate the prior authorization process: Determine if any part of your treatment plan requires "prior authorization" from the insurance company before you can begin.
- Appeal denied claims: Understand the appeals process for denials of coverage. Your hospital's billing department can help with this process by providing documentation from your doctor.

DEFINITIONS:

- Co-insurance (also known as cost-share) is a percentage difference in what the insurance company pays for your medical expenses and what you pay for your medical expenses. For example, if you have an 80/20 plan, the insurance company pays 80% of your medical expenses and you are responsible for 20% of your medical expenses, after paying your deductible.
- Co-pay (also known as co-payment) is the fixed dollar amount you pay when you get medical care. You usually pay your co-payment at the time you get care.
- In-network provider is a doctor, hospital, or facility that has a contractual agreement with your health insurance plan to provide services at a specific, pre-negotiated rate (an "allowed amount").
- Out-of-Network provider does not have a contractual agreement with your health insurance plan, which means that services from that provider could either cost you more or not be covered by your health insurance plan.

Insurance definitions courtesy of Triage Cancer "Quick Guide to Health Insurance" found at https://triagecancer.org/quick-guides/health-insurance-basics

WHERE TO GET HELP WITH INSURANCE QUESTIONS:

- Triage Cancer's Legal & Financial Navigation Program – Fill out the online form on this page (https://triagecancer.org/legal-and-financial-navigation-program) to schedule a phone call with a Triage Cancer Attorney

FOR MORE INFORMATION:

- Texas Department of Insurance Health Insurance Glossary: https://www.tdi.texas.gov/consumer/health-insurance-glossary.html

FINANCES

If you are worried about paying for your appointments and treatments, talk to your healthcare team or the hospitals or treatment centers where you receive care.

Bring up concerns early by saying to your medical team: "I am concerned about the cost of treatment" or "I'm worried about missing work and paying my bills". You may be able to get help with:

- Hospital bills
    - Ask if the hospital has internal financial assistance programs or if you can set up a payment plan for costs not covered by insurance.
    - Dollar For is a nonprofit organization that helps individuals "navigate and access hospital financial assistance program – programs that forgive or reduce bills based on income." You can find them online at https://dollarfor.org/.
- Prescriptions
    - Ask about patient assistance programs from pharmaceutical companies or referrals to other programs that provide financial assistance for specific medications.

Other tips include:

- Requesting cost estimates: Ask for an estimate of the total cost of your treatment plan, including fees for office visits, labs, scans, and therapies.
- Seeking help from non-profit organizations that offer financial counseling and resource information.
    - Cancer Support Community (www.cancersupportcommunity.org)

    - Cancer*Care* (www.cancercare.org)
    - Patient Advocate Foundation (www.patientadvocate.org)
- Utilizing online resources and databases from organizations like the Cancer Financial Assistance Coalition (CFAC) to find national and regional programs offering aid for various cancer-related costs.

> ★ **PRO TIP**
>
> *Check every bill and explanation of benefits for accuracy! Inadvertent mistakes can happen. If you notice anything that seems wrong or doesn't make sense, call the medical provider or insurance company to have them double check the information.*

WORK

- Find out your employer's policies for sick time and short- and long-term disability.
- The Federal Medical Leave Act (FMLA) protects an employee's job if they must take leave for a serious medical condition that makes you unable to work.
    - Some important points about FMLA:
        - FMLA protects a job, which means that at the end of the leave period, you will be able to return to your job or a similar job.
        - It also requires continuation of your group health benefits while you are on leave.
        - The leave period is 12 weeks in a 12-month period, and you can take it intermittently (in short chunks of time) or continuously (all at once).
        - It protects your job, but not your pay. It does not guarantee that you will receive your paycheck while you are on medical leave.
        - Only certain types of employers are required to offer FMLA. These "covered employers" include:
            - Private sector employers with 50 or more employees.
            - Any public agency (such as Federal, State, or local government).
            - Local educational agencies.
- Try to streamline appointments as much as possible by scheduling multiple visits on the same day to reduce travel costs and the number of days off work.

FOR MORE INFORMATION:

- Cancer and Careers (www.cancerandcareers.org)
- Triage Cancer (www.triagecancer.org)
- FMLA Fact Sheet – "The Employee Guide to the Family and Medical Leave Act" can be found at https://www.dol.gov/agencies/whd/fact-sheets/28-fmla

YOUR PERSONAL SUPPORT SYSTEM

Aside from choosing your medical team, deciding to share your diagnosis with friends and family is an important personal decision. There is no one right answer to the question of who to tell and how. An advantage to telling friends and family about your cancer, however, is that it gives them the opportunity to support you at a time when it feels hard to take care of everything on your own.

Some tips for telling others:

- Tell them in a way that feels best to you.
    - If talking about your cancer face to face is difficult, you can share your news over the phone, in a letter, or by text or email.
- Ease into the conversation by saying, "This is going to be difficult, but I need to tell you something."
- Tell them how you feel.
    - You do not have to be positive and cheerful to make them feel better. If you are worried and let them know, they can better support you.
- Expect that they may be very quiet upon hearing your news.
    - The news you are sharing is big, and the other person might not know what to say immediately.
- Sharing updates over and over is tiring. Choose a trusted person to communicate on your behalf.
    - You could also use a website such as CaringBridge (www.caringbridge.org), Lotsa Helping Hands (www.lotsahelpinghands.com), or SupportNow (www.supportnow.org) to post updates once for all your family and friends.
- Let people know how they can help you and the best way to reach out to you.
    - As one former client said, "People wanted to call me, and I didn't feel like talking on the phone. Communicating by text was easier and less tiring."

★ PRO TIP

Family and friends often want to help by bringing meals to you. Meal Train (www.mealtrain.com) is one way to organize friends and family who want to support you with meals.

Telling children about a cancer diagnosis is a particularly sensitive area. Children in your household will notice that things have changed and that you are doing things differently. What a child can understand about your cancer depends on how old they are.

- Wonders and Worries (www.wondersandworries.org) offers these tips for talking with children about cancer:
    - Say the name "breast cancer."
    - Share the treatment plan so children know what you are doing to help treat the cancer.
    - Encourage children to ask questions. And for questions where you don't know the answer, get more information to share with them.
    - Let children and teens know they can still have fun and do normal activities even though your family is dealing with a serious illness.

Everyone going through cancer benefits from emotional support, even if it doesn't come from friends and family. Support groups for people with a breast cancer diagnosis can give you a space to talk openly about how things are going to people who can relate to your feelings and experiences. The "Support Group" section on page 22 gives some information on finding a support group that fits your needs.

Pro Tip: Even though your first impulse might be to do everything on your own, getting through cancer can be more bearable if you accept support and help. As one BCRC client said, "I missed out on so many great events by not wanting to reach out for help."

FOR MORE INFORMATION:

- General Guidance When Discussing Illness with Children: https://wondersandworries.org/general-advice/

TIPS FOR CAREGIVERS

Listen without judging and without "cheerleading."

- It might be tempting to say "You will be fine" if your loved one expresses fearful or sad thoughts. Your ability to simply sit with the person as he or she shares those feelings is probably one of the most significant contributions you can make to his or her well-being.

Support your loved one's treatment decisions.

- While you may be able to share decision-making, ultimately it is your loved one's body and spirit that bears that impact of the cancer.

Be specific about the help you can offer.

- Saying "Call me if you need something" may put your loved one in an uncomfortable position. It is better to offer help with specific tasks.
- These are some everyday tasks that might make a big difference to a person going through breast cancer:
  - Cooking and meal prep: Preparing nutritious meals, freezing ready-to-eat meals, or arranging meal delivery.
  - Grocery shopping and errands: Picking up groceries, prescriptions, or household essentials.
  - Cleaning and laundry: Light cleaning, vacuuming, washing clothes, and changing bedding.
  - Pet care: Walking dogs, feeding pets, or cleaning litter boxes.
  - Transportation: Driving to doctor appointments, chemotherapy, radiation, or lab tests.
  - Yard work: Mowing or raking the yard.
  - Pick up or drop off children from school or activities.

Stay connected. Cancer treatment can be lengthy.

- People with cancer often note that friends and family "don't call anymore" after the initial crisis of diagnosis. Checking in regularly over the long haul is tremendously helpful.

Keep things normal.

- Often, we try to make life easier for the person going through cancer by "doing things" for him or her. It is a way of feeling useful at a time when we would otherwise feel helpless. However, it's just as important to respect your loved one's wishes to do normal "pre-cancer" tasks. For some people, being able to cook dinner or continue working can lessen the sense that cancer is taking over their lives.

Be receptive to your loved one's needs when treatment is over.

- Often this is the time when people realize the enormity of what they have been through. Prior to this, they were deeply involved in, and distracted by, all the medical concerns such as getting to treatment and coping with side effects. While your loved one may no longer need help getting through treatment, he or she may still need your emotional support.

Your own feelings matter, too.

- Caregivers for someone with breast cancer can feel exhausted, stressed, and emotionally drained from managing medical appointments, daily needs, and providing constant support. It's common for them to feel overwhelmed, and they may need breaks, help from others, or professional support to take care of their own well-being.

FOR MORE INFORMATION:

These organizations offer free, ongoing support groups just for cancer caregivers:

- Texas Oncology Foundation
    - Caregiver Connections (https://texasoncologyfoundation.org/caregiverconnections/)
- SHARE Cancer Support
    - Caregiver Support Group (https://www.sharecancersupport.org/webinar-supportgroup/caregiver-support-group-2/)

Books about caregiving:

- *The Caregiver's Guide to Cancer: Compassionate Advice for Caring for You and Your Loved One*
    - by Victoria Landes, LCSW
- *Things I Wish I'd Known: Cancer Caregivers Speak Out*
    - by Deborah J. Cornwall

HOW TO SUPPORT YOUR MENTAL AND PHYSICAL HEALTH

Having cancer brings up a lot of emotions including worry, sadness, fear, and/or anger. Techniques that have been shown to help people cope with all the feelings that come with a cancer diagnosis include:

- Talking to your oncologist, nurse, navigator, or social worker.
    - They may be able to help or refer you to specialists who can help.
- Reaching out to people in your personal network.
    - Family members, friends, or those who share your faith may be good to talk to.
- Staying as active as you can.
    - Physical activity has been linked to lower risk of depression among people who have cancer.
    - Light walking can help with distressing feelings.
- Going outside.
- Taking time for activities that help you unwind or relax.
    - Meditation, guided imagery, or gentle yoga are a few techniques that can be effective.

SUPPORT GROUPS

Friends and family, even when they are well-meaning, can't always offer as much support as you need because they don't understand exactly what things are like for you. Support groups – which are made up of people sharing a common experience or diagnosis – can be very therapeutic.

Benefits of support groups include:

- Reassurance and camaraderie from being around people who are experiencing the same things you are.
- The realization that you are not alone in your cancer experience.

Support groups meet either online or in-person and give members the opportunity to share their experiences and ask questions of people who have gone through the same kinds of things.

To find a support group:

- Contact the Breast Cancer Resource Center
    - We offer online and in-person (Austin, Texas area) options, including groups for people who have finished active treatment.
    - We can be reached at:
        - 512-524-2560;
        - Support@bcrc.org; or
        - https://bcrc.org/support-groups-online-forum/#support-groups
    - BCRC groups are open to people with breast cancer who live in Central Texas.
- Ask your medical team
    - They often know about local peer-led and professionally facilitated support groups.
- Contact a national resource that offers online support groups
    - BreastCancer.org - www.breastcancer.org/community/virtual-meetups
    - National Breast Cancer Foundation - https://www.nationalbreastcancer.org/nbcf-programs/breast-cancer-support-group/
- Cancer*Care* offers telephone support groups which allow people from across the country who share similar concerns to visit over the phone in weekly, regularly scheduled sessions.
    - Call 800-813-HOPE (4673) for details.
- SHARE Cancer Support – Breast Cancer Support

    - National Support Line: Call 844-ASK-SHARE (844-275-7427)
    - Website: https://www.sharecancersupport.org/breast-cancer/
- Cancer Support Community
    - Phone and Live Chat Support: 888-793-9355
    - Website: https://www.cancersupportcommunity.org/get-support

WHEN TO SEEK PROFESSIONAL SUPPORT:

Sometimes, support groups, staying active, going outside, and taking time for yourself don't adequately help with the uncomfortable feelings that come from a breast cancer diagnosis. If you find it difficult to get through your days, talking with a counselor, therapist, or psychiatrist can make a real difference. Reaching out is a strong and healthy way to take care of your whole self.

You might benefit from professional mental health support if you:

- Feel sad, anxious, or overwhelmed most of the time
- Have trouble sleeping or are sleeping much more than usual
- Notice big changes in appetite or weight
- Lose interest in activities that used to be enjoyable
- Have difficulty concentrating or making decisions
- Feel hopeless, helpless, or unusually irritable
- Are withdrawing from friends, family, or social activities
- Struggle to cope with daily tasks or responsibilities
- Use alcohol, drugs, or other unhealthy habits to manage emotions
- Have thoughts of self-harm or feeling like life has no purpose

If you or someone close to you notices one or more of these signs lasting for more than a couple of weeks—or if symptoms are severe at any time—it's a good idea to reach out for professional help.

If you need mental health support immediately, call 911.

For more routine needs, ask your oncologist, nurse navigator, patient navigator, or social worker for a referral to a mental health specialist.

PALLIATIVE CARE: AN EXTRA LAYER OF SUPPORT

Palliative care is specialized medical care for people with serious illnesses — not just end-of-life care. It can be provided at any stage of an illness, even while you're getting treatment to cure your cancer.

The goal of palliative care is to help you feel better by easing symptoms, side effects, and stress. A team of doctors, nurses, social workers, and other helpers work together to support you physically, emotionally, and spiritually.

Some examples of breast cancer issues that palliative care can address include:

- Managing the physical discomfort of pain, fatigue, shortness of breath, nausea, or constipation
- Coping with difficult emotions such as anxiety, fear, or depression
- Helping with taste changes or loss of appetite

They can also help you make an advance care plan — a guide for your future medical wishes if your health declines.

Ask your oncologist if you'd like a referral to a palliative care doctor. You might receive push back but keep asking if you believe this could help you while living with cancer.

FOR MORE INFORMATION:

www.getpalliativecare.org

RESOURCES

IF YOU LIVE IN CENTRAL TEXAS

The Breast Cancer Resource Center offers free Patient Navigation services for anyone with a breast cancer diagnosis who lives in Bastrop, Caldwell, Hays, Travis, or Williamson Counties.

- Contact us by phone at 512-524-2560 or via email at support@bcrc.org

IF YOU LIVE OUTSIDE OF CENTRAL TEXAS

Here’s a practical list of strategies to find support and information about breast cancer:

1. Talk to your healthcare team

- Your doctor, nurse, or patient navigator can provide trusted information about local resources.
- Social workers or oncology nurses can help connect you with support groups, financial assistance, or counseling.

2. Reach out to national organizations such as:

- Susan G. Komen – helplines, education, and local programs - Helpline: 1-877-465-6636
- Breastcancer.org – easy-to-understand medical information and community forums
- National Cancer Institute (NCI) – clinical trial information and treatment resources
- American Cancer Society offers support to people with breast cancer via an app called ACS CARES. Access the app at www.cancer.org/support-programs-and-services/acs-cares.html
- CanCare has trained cancer survivors who are available for one-on-one support. Learn more and sign up at www.cancare.org/services/one-on-one-cancer-support

3. Use reliable online resources

- Look for .gov, .org, or well-known cancer center websites.

Avoid unverified blogs or social media posts that may give inaccurate information.

★ PRO TIP

BCRC lists some national resources on our website at www.bcrc.org/local-and-national-resources/

ORGANIZATIONS MENTIONED IN THIS GUIDE:

These are all the support organizations mentioned:

American Cancer Society	www.cancer.org
Access to Clinical Trials and Support	www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials/acs-acts.html
CARES (Community Access to Resources, Education, and Support)	www.cancer.org/support-programs-and-services/acs-cares.html
Questions to Ask When You've Been Diagnosed with Cancer	www.cancer.org/cancer/managing-cancer/making-treatment-decisions/questions-to-ask-your-doctor.html
BreastCancer.org	www.breastcancer.org/
BreastCancerTrials.org	www.greastcancertrials.org
CanCare: A Survivor by Your Side	www.cancare.org/
Cancer and Careers	www.cancerandcareers.org/en
Cancer Financial Assistance Coalition	www.cancerfac.org/
Cancer Support Community	www.cancersupportcommunity.org/
Cancer*Care*	www.cancercare.org/
CaringBridge	www.caringbridge.org
Dollar For	www.dollarfor.org
Get Palliative Care	www.getpalliativecare.org
Lotsa Helping Hands	www.lotsahelpinghands.com
Meal Train	www.mealtrain.com
National Breast Cancer Foundation	www.nationalbreastcancer.org
National Cancer Institute: Breast Cancer	www.cancer.gov/types/breast
OncoLink Breast Cancer	www.oncolink.org/cancers/breast
Patient Advocate Foundation	www.patientadvocate.org
SHARE Cancer Support	www.sharecancersupport.org
SupportNow	www.supportnow.org
Susan G. Komen Breast Cancer Foundation	www.komen.org
Texas Department of Insurance: Health Insurance Glossary	www.tdi.texas.gov/consumer/health-insurance-glossary.html
Texas Oncology Foundation	www.texasoncologyfoundation.org
Triage Cancer	www.triagecancer.org
US Department of Labor: Employee Guide to the Family and Medical Leave Act	www.dol.gov/agencies/whd/fmla
Wonders and Worries	www.wondersandworries.org

GLOSSARIES

Coping with breast cancer means learning a whole new language filled with unfamiliar medical terms. We have found that these glossaries give concise, easily understandable explanations:

- English
    - National Cancer Institute Dictionary of Cancer Terms - https://www.cancer.gov/publications/dictionaries/cancer-terms
    - Breast Cancer Glossary from the National Breast Cancer Foundation - https://www.nationalbreastcancer.org/resources/breast-cancer-glossary/
- Spanish
    - Diccionario de cáncer del NCI - https://www.cancer.gov/espanol/publicaciones/diccionarios/diccionario-cancer

CANCER AND SURVIVORSHIP

As you step into your journey of cancer diagnosis and treatment, you may hear the words "survivor" and "survivorship" to describe you and your path through cancer treatments.

Many people are surprised to learn that survivorship begins the day you are diagnosed and continues through treatment and beyond.   It's about more than finishing treatment—it's about taking care of your body, mind, and life while living with and beyond cancer. Survivorship includes managing side effects, coping with emotions, and finding ways to stay healthy and strong.

Right now, you are already a survivor – no matter what stage you're in or where you are in treatment.

Getting a diagnosis of breast cancer can bring many emotions and questions. By spending time reading this companion, you've already taken a proactive step toward becoming an active partner with your medical team. Learning more about your options and what to expect can help you feel a little more in control during an uncertain time.

We hope the information in this guide helps you feel like an informed, confident, and supported survivor as you move forward. Every person's journey is unique, but you are not alone. Your care team, loved ones, and community resources are here to help you every step of the way. As you begin your treatment path, we hope this guide serves as a steady source of knowledge and encouragement.

NOTES

BREAST CANCER
RESOURCE CENTER

WWW.BCRC.ORG
WWW.BREASTCANCERUNIVERSITY.ORG

HELPLINE:
512-524-2560