THE COMPREHENSIVE PATIENT NAVIGATION GUIDE

11TH EDITION

Breast Cancer

Treatment Handbook

UNDERSTANDING THE DISEASE, TREATMENTS, EMOTIONS AND RECOVERY FROM BREAST CANCER

JUDY C. KNEECE, RN, OCN

Breast Cancer

Treatment Handbook

Understanding the Disease, Treatments, Emotions and Recovery from Breast Cancer

Judy C. Kneece, RN, OCN

Your Breast Cancer Recovery Guide

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About the Author

Judy C. Kneece, RN, OCN, is a certified oncology nurse specializing in breast cancer. In 1991, she began her career as a nurse at Baptist Medical Center in Columbia, SC, where she pioneered the first nurse-led clinical navigation program for breast cancer patients. Her innovative care-delivery model involved registered nurses intervening at the time of diagnosis to provide education and support for patients and their families, while serving as consistent caregivers throughout treatment. The program quickly demonstrated success by increasing patient satisfaction, reducing patients' psychological distress, and improving treatment compliance.

In 1993, her program gained national recognition for innovations in delivering patient-centered care and was featured in *COPE* magazine. Building on this success, she founded EduCare Inc. in 1994 to train other nurses in the principles and practice of patient navigation.

Over the past three decades, EduCare has led the development of patient education materials and nurse training curricula to support individuals diagnosed with breast cancer. Judy has personally trained more than 2,300 registered nurses through a 40-hour course to become Breast Health Navigators, serving patients in hospitals, breast centers, and physicians' offices. In 1998, she introduced Comprehensive Strategic Planning for breast center and hospital administrators, guiding them in implementing patient-centered breast health programs. Today, over 500 hospitals have adopted her model, which emphasizes pre-treatment interdisciplinary care conferences and the pivotal role of the Nurse Navigator in educating and supporting patients from diagnosis through the completion of treatment.

Her experience as a Breast Health Navigator revealed the critical educational and emotional support needs of women and families facing breast cancer. This insight led her to author the *Breast Cancer Treatment Handbook* (1995), now in its eleventh edition, and its companion guide, the *Breast Cancer Support Partner Handbook* (1995), now in its tenth edition. She also wrote the *Breast Cancer Survivorship Handbook*, *Male Breast Cancer Treatment Handbook*, *Sexuality After Cancer Treatment*, and the *Breast Health Navigator Manual*.

In a 1994 interview with *COPE* magazine, editor Tricia Brown asked Judy about her motivation for initiating breast health navigation. Judy responded, "Empowering patients with an understanding of their disease, treatment options, and providing tools for recovery management are essential for complete recovery. Breast cancer is more than scars on the breast; it can also scar the heart. We must address the psychological and social issues breast cancer brings if a woman is to manage her disease successfully. Getting well is more than surgery and treatments; it is a woman understanding the vital role she can play in managing her own recovery."

In 2015, the National Consortium of Breast Centers (NCBC) honored Judy with the Inspiration Award for her pioneering work in breast navigation. The award read: "For unrelenting devotion to the journey of women with breast cancer, for developing the field of patient navigation from diagnosis to survivorship, and for providing education to breast care professionals and for all those in need, the NCBC expresses its deepest gratitude for your service to our patients."

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As Survivors, we learn that survivorship is an attitude we adopt.
It is the one component of recovery that no one else can do for us.
We have to decide for ourselves how we intend to respond
to our illness and how we will approach our recovery.
We, alone, decide to become Survivors.

– Judy Kneece

Using This Handbook

The *Breast Cancer Treatment Handbook* is a comprehensive guide designed to help you understand breast cancer treatment and work as an informed patient with your healthcare team. This partnership helps you make decisions that are best suited for you.

Because breast cancer and its treatments vary between patients, not all chapters will be relevant to your specific care. To help you focus on relevant information without feeling overwhelmed, we've grouped major treatment categories with their related chapters and tear-out worksheets. Instead of reading everything at once, focus on the sections that applies to your current treatment decisions. Use the worksheets at the back to help guide and manage your personalized care.

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Chapter 6

What Is Breast Cancer?

When I was told I had to have breast surgery, I didn't focus on what I was losing but what I was gaining. Yes, my breasts are a big part of being a woman, but they DON'T define me. They DON'T make me feel passion. They DON'T fuel my self-esteem. My breasts are only body tissue. I am MORE than breast tissue. I decided to approach my need for breast surgery very logically—if my appendix was diseased, I would have it removed; if my gallbladder was diseased, I would have it removed. I felt the same way about my breasts; they were diseased, and they had to be removed to save ME. When I thought about it that way, I had no choice!

—Lisa DelGuidice

After a breast cancer diagnosis, it's important to understand the basic facts about the disease. This knowledge can help explain why cancer treatment is necessary and why women with the same diagnosis may receive different treatment plans.

Breast cancer is not a single disease—it's an umbrella term for about 15 distinct types of cancerous breast tumors. Factors such as tumor type, size, grade, hormone receptor status, biomarkers, and genetic mutations make each breast cancer case as unique as a fingerprint. After surgery, your final pathology report will provide a detailed analysis of your specific cancer characteristics. This information is essential for determining the next steps in your treatment plan.

What Causes Breast Cancer?

Inside each cell in your body is DNA that contains instructions for the cell's characteristics and functions. When the DNA in a healthy cell is damaged (mutated), the cell may lose its ability to repair itself. This damage can lead to uncontrolled growth, resulting in cancer.

All cancers arise when mutated cells lose the ability to control their growth. Most breast cancer mutations occur after birth, while some are inherited at conception and are known as hereditary breast cancer. Before genetic testing was available, doctors relied on family history patterns to identify patients with inherited mutations. Hereditary mutations vary in terms of when cancer develops and how it behaves in the body, which required a different approach to treatment. Today, genetic testing can identify mutations linked to hereditary breast cancer and guide oncologists in choosing the most effective treatment.

This chapter helped me understand the latest science behind this disease. The explanations and clearly illustrated graphics eased my fear that my cancer was an unsolvable mystery.
—Robin Hurley

'Know thy enemy'—what an understatement. I learned so much about cancer in the first few weeks after my diagnosis. And I continue to learn as much as possible, as this is an unending battle!
—Anna Cluxton

Chapter 6

One of the first steps in creating a personalized treatment plan is reviewing your medical and family history of breast cancer. If your history suggests a genetic link, your doctor may recommend genetic testing. If mutations are found, the results can influence which treatment options are recommended.

Three Categories of Gene Mutation Involvement:

- **Sporadic Breast Cancer:**
  - Most common type, accounting for 70–80% of diagnosed breast cancers
  - Caused by an accumulation of mutations that occur **after** birth
  - Usually occurs **after** age 50, with an average diagnosis age of 62
  - Typically occurs as a **single tumor** in **one** breast
  - No significant family history of breast, ovarian, or pancreatic cancer
  - Genetic testing is not required; no inherited mutation is involved
- **Familial Breast Cancer:**
  - Accounts for approximately 15–20% of all diagnosed breast cancers
  - Clustering of breast cancer in families without a known gene mutation
  - Family history may include multiple relatives with breast cancer or ovarian cancer occurring across two or more generations
  - Patients are often diagnosed at a younger age (typically between 30–50)
  - Higher risk of cancer in both breasts (bilateral) and the possibility of multifocal disease (more than one tumor in the same breast)
  - No identified genetic mutation in the family, or genetic testing has not been done
  - Caused by shared genetics and environmental exposures
- **Hereditary Breast Cancer:**
  - Accounts for approximately 5–10% of all diagnosed breast cancers
  - Often diagnosed at a younger age (20s, 30s, or before 50)
  - Caused by inherited mutations, such as BRCA1, BRCA2 (5–10 % of cancers)
  - Tumors may develop in one or both breasts, and may be multifocal
  - Mutation is identified through genetic testing using a blood or saliva sample
  - Carries an increased lifetime risk of developing ovarian, pancreatic, and melanoma cancers

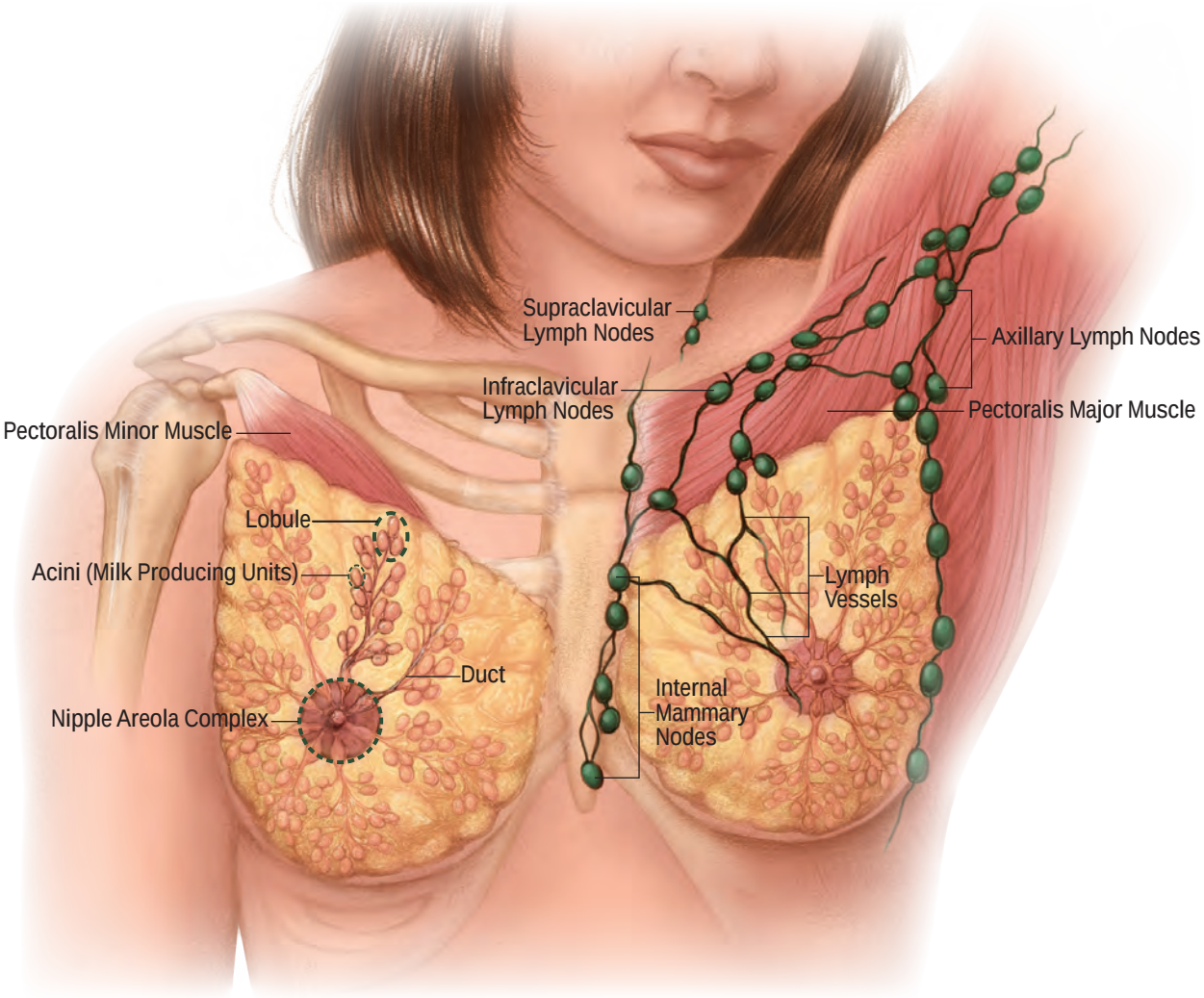
Genetic testing for hereditary breast cancer is advised **before** treatment begins. Treatment for inherited mutations often requires different surgical and medical approaches than treatment for sporadic or familial cancer. If you are adopted or lack access to your biological family history, your personal cancer characteristics may still indicate a need for genetic testing. You may qualify for testing even without family history information.

Criteria for Hereditary Genetic Testing

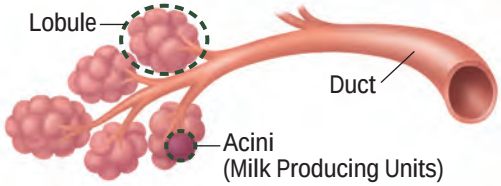
- **Personal History:**
  - Breast cancer diagnosed before age 50
  - Triple-negative breast cancer (negative for estrogen, progesterone, and HER2 receptors)
  - Two primary breast cancers or bilateral breast cancers
  - Lobular breast cancer combined with Ashkenazi Jewish ancestry
  - A personal history of ovarian cancer

- **Family History:**
  - Breast or ovarian cancer diagnosed before age 50, or male breast cancer at any age
  - Two primary breast cancers at any age, or ovarian or fallopian tube cancer at any age
  - Pancreatic cancer at any age
  - Metastatic prostate cancer at any age
  - An Ashkenazi Jewish ancestry, with or without a family history of breast cancer

Internal Structure of the Female Breast



Enlargement of Duct and Lobules



Chapter 6

Why Cancer Treatment Is Necessary

Most women feel physically fine when diagnosed with breast cancer, which can make the need for aggressive treatment seem confusing. However, understanding how cancer cells behave—growing uncontrollably, invading healthy tissue, and spreading to other parts of the body—helps explain why prompt and thorough treatment is essential

Cancer Cells Exhibit Uncontrolled Growth:

- Cancer cells multiply rapidly. They grow and divide much faster than normal, healthy cells.
- Cancer cells do not respond to signals that regulate cell division; instead, they exhibit uncontrolled growth. They rarely stop growing.
- Unlike normal cells, most cancer cells do **not** die naturally (a process called apoptosis). Instead, they will continue to grow and spread to distant parts of the body, where they may become life-threatening unless they are surgically removed from the body or killed with chemotherapy drugs or radiation therapy.

Cancer Cells Are Aggressive and Invasive:

- Unlike normal cells that stay in place and do not grow into surrounding tissues, cancer cells are aggressive and will **invade** nearby tissues. Cancer cells will grow into and through surrounding cells, ignoring boundaries that non-damaged cells respect.

Cancer Has the Ability to Spread (Metastasize):

- Cancer cells have the ability to invade the bloodstream or lymphatic system.
- Once in the blood and lymph systems, cancerous cells can travel to distant parts of the body and form new tumors, known as **metastasis**. Normal cells do **not** spread in this way.

All cancer cells have the potential to become life-threatening if not treated. This threat requires interventions to stop the cancer. For this reason, your treatment team will recommend surgery to remove the cancerous tumor. Then, according to your tumor's characteristics, additional treatments of chemotherapy, targeted therapy, radiation therapy, immunotherapy, or hormonal therapy are recommended. Each of these additional treatments will be thoroughly explained in later chapters.

Types of Breast Cancer

Each of the 15 distinct types of breast cancer has a unique pattern of cellular structure (histology) that a pathologist identifies when the specimen is viewed under a microscope. Not only do they look different, but they also have distinct characteristics of how they behave in the body.

Cancers are first classified according to where they begin in the breast, either in a duct or lobule. **Breast carcinoma** refers to cancer that develops in the cells that line either a duct or a lobule.

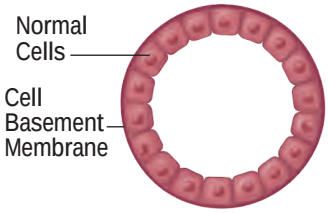
Cancers Are Classified as Either In Situ (Non-Invasive) or Invasive (Infiltrating):

- **In situ (non-invasive)** means the cancer cells are still confined to the place where they started. For example, in breast cancer, "ductal carcinoma in situ" (DCIS) means the abnormal cells are contained within the milk ducts or lobules and have not spread beyond the basement membrane—a thin, supportive layer that separates and supports different tissue layers (illustration 2).
- **Invasive (infiltrating)** means the cancer cells have broken through the basement membrane and spread into the surrounding healthy tissue. This allows them to potentially invade nearby structures and, in some cases, spread to other parts of the body (illustration 3).

What Is Breast Cancer?

Normal Cells

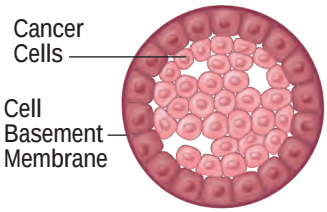
1



Normal ducts and lobules are lined with one or more layers of orderly cells.

In Situ Cancer Cells

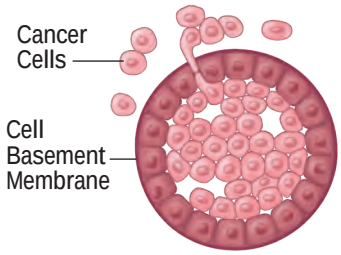
2



In situ carcinomas are contained within the wall of the duct or lobule. Cancer has not grown through or invaded surrounding tissues.

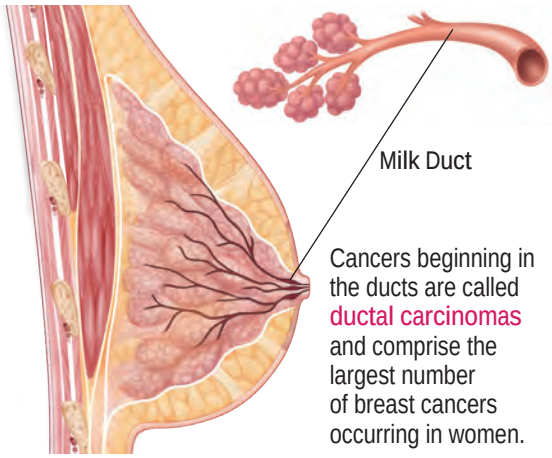
Invasive Cancer Cells

3



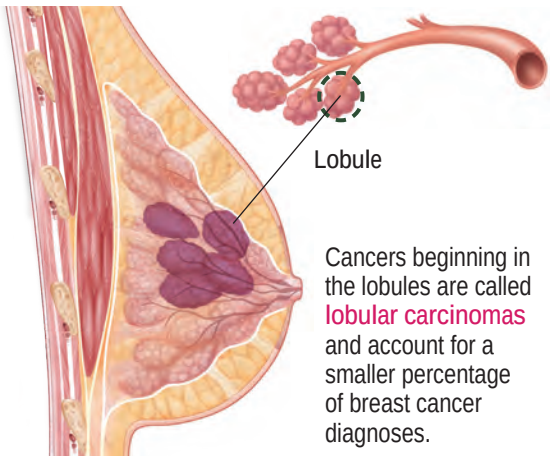
Invasive or infiltrating carcinomas are cancers that have grown through the duct or lobular walls and into surrounding connective tissues.

Ductal Carcinoma



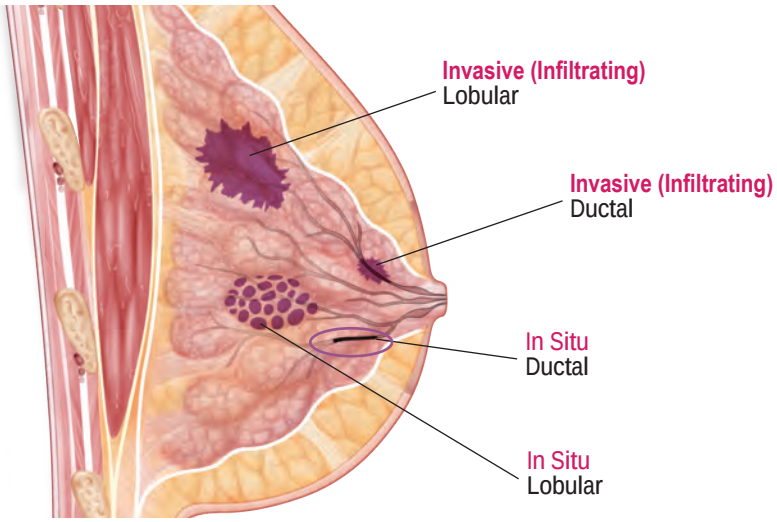
Cancers beginning in the ducts are called ductal carcinomas and comprise the largest number of breast cancers occurring in women.

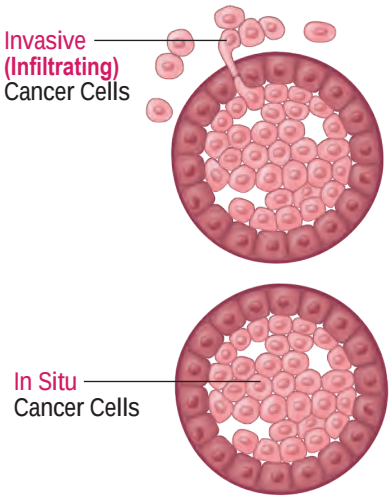
Lobular Carcinoma



Cancers beginning in the lobules are called lobular carcinomas and account for a smaller percentage of breast cancer diagnoses.

In Situ and Invasive Cancers

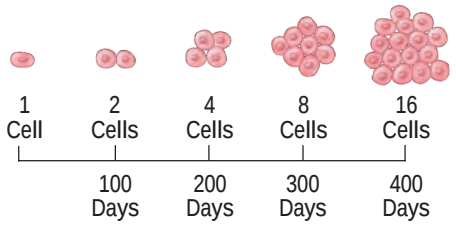




Cancer Growth Rate

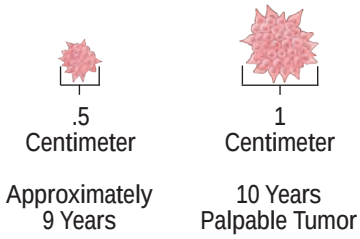
Cancer begins with just one damaged cell that begins to divide and multiply. Over time, it continues to grow, doubling in size again and again until it is discovered. Breast cancers vary widely in their growth rates; some grow rapidly, while others grow slowly. The estimated time for a cancer cell to double in size ranges between 25 and 209 days. If we take an estimated doubling time of 100 days, a tumor would have been in your body for approximately eight to ten years when it reaches one centimeter in size (about ⅜ inch)—the size of the tip of your smallest finger. Cancers may grow in spurts, and the doubling time may vary at different times. However, by the time a one-centimeter tumor is found, the cancer has been present in the body for years and has grown from one cell to approximately 100 billion cells.

Doubling Rate of Cancer Cells



Breast cancer cells may vary in doubling time anywhere from 25 to 209 days. Illustration shows the doubling process based on 100 days.

Tumor Growth Rate



Based on a 100-day doubling time, it would take a tumor 8 to 9 years to grow to .5 centimeter or approximately 10 years to grow to 1 centimeter (tip of smallest finger). However, tumors grow at different rates, some much faster and others much slower.

Summary

Breast cancer is not a sudden occurrence, but rather a process that has been silently developing over an extended period of time. Therefore, when a biopsy confirms the presence of a cancerous tumor, you most often are not facing an immediate medical emergency. The majority of patients have time to learn about their particular disease and treatment options.

For most patients, physicians recommend surgery within several weeks after a positive biopsy. There are exceptions; for example, inflammatory carcinoma (a rare cancer type that grows rapidly) requires immediate treatment with chemotherapy for maximum control. Additionally, metastatic breast cancer (Stage 4), which has spread to distant organs and has become life-threatening, may require urgent systemic treatment depending on the symptoms.

Additional Information

Appendix

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Special Breast Cancer Diagnoses

Bilateral Breast Cancer

Bilateral breast cancer means that cancer was found in both breasts. Evaluation may include:

- After a biopsy of each tumor, your pathology report will reveal if the cancers are of the same cell type or two different cell types.
- MRI may be ordered to evaluate your breasts further.
- Genetic testing may be recommended if you are premenopausal or perimenopausal and have characteristics of hereditary breast cancer to determine if you have a mutated gene.
  - If you test **positive** for a hereditary gene mutation:
    - » Bilateral mastectomy is often recommended, with or without reconstruction, to reduce future cancer risk. (Physician's decision)
  - If you test **negative** for a hereditary gene mutation:
    - » Bilateral mastectomies, with or without reconstruction
    - » Bilateral lumpectomies, if both tumors meet the criteria for size
    - » Lumpectomy on one side and mastectomy on the other, with or without reconstruction
- Staging is determined by the largest tumor found in either breast

Occult Breast Cancer

Occult breast cancer means that a cancerous lymph node was identified by biopsy, but mammography did **not** find a cancerous tumor in your breast. An MRI may be ordered to study the breast further for an abnormality. If an abnormality is not identified, a mastectomy may be recommended. Additional treatment recommendations are based on the pathology of the removed cancerous lymph node.

Inflammatory Breast Cancer (IBC)

Inflammatory breast cancer is a rare but very aggressive cancer. It involves cancerous cells that block the lymph vessels in the breast, causing redness, swelling, and eventually pain. Inflammatory breast cancer requires immediate chemotherapy **before** surgery to shrink the cancer and control the disease. After chemotherapy, a mastectomy is typically recommended.

Paget Disease

Paget disease is a rare cancer that begins on the surface of the nipple and in the underlying milk ducts. Cancer may be contained within the ducts (DCIS), or it may have spread beyond the ducts into surrounding tissues (invasive ductal carcinoma). MRI is typically used to evaluate the extent of cancer. After biopsy, the pathology report describes the histological characteristics of the tumor. There are two surgical approaches to treating Paget disease. The first is a central lumpectomy that removes the nipple, areola, and underlying ducts. This often leaves a concave area (similar to a doughnut) in the center of the breast. The second is a total mastectomy, which offers better cosmetic outcomes.

Pregnant With Breast Cancer

Being diagnosed with breast cancer while pregnant can feel emotionally overwhelming. At a time when you were preparing to bring a new life into the world, you now find yourself forced to fight to protect your own life. The reassuring news is that it is possible to safely receive treatment for breast cancer **after** the first trimester (three months) of the pregnancy. Cancer treatment can be adapted so that your baby will not suffer ill effects from your treatment. Studies show that breast cancer does not appear to harm a baby after the first trimester. When comparing patients diagnosed in the same stage of cancer, treatment during pregnancy produces survival outcomes similar to the treatment of women who are not pregnant.

In the past, women were often advised to end their pregnancies when they were diagnosed. Today, that advice is rare. Pregnancy termination is only considered if your cancer requires chemotherapy during the first three months of your pregnancy. The National Cancer Institute states, "Ending the pregnancy does not seem to improve the mother's chance of survival and is not usually a treatment option." Most treatment options can be adapted to allow you to safely continue with your pregnancy.

Surgery and Radiation Therapy During Pregnancy

You can safely have surgery during pregnancy. Mastectomy can be performed at any time during pregnancy. A lumpectomy may be an option if surgery can be scheduled within six weeks of your due date. This allows radiation to be delayed until after delivery since it is not safe during pregnancy. A lumpectomy usually requires postoperative radiation therapy as a part of treatment.

Chemotherapy and Pregnancy

Chemotherapy is not safe during the first trimester when the embryo is developing vital organs due to the risk of birth defects. If you are diagnosed in the first few weeks of pregnancy and your stage of disease requires immediate chemotherapy (for example, you are diagnosed with inflammatory breast cancer) in the first trimester, your doctor may recommend that you consider ending the pregnancy. However, if your cancer is less aggressive and you are further along in your first trimester, your doctors will likely delay any recommended chemotherapy until the start of the second trimester (starting the fourth month of pregnancy). Each woman must be individually evaluated to determine the safest and most effective treatment option for her specific diagnosis.

Male Breast Cancer

Male breast cancer may occur at any age, but it is most often diagnosed between the ages of 60 and 70. Male breast cancer accounts for about one percent of all breast cancers diagnosed each year.

Since there is no routine breast cancer screening for men, male breast cancer is usually discovered when the patient notices a change in his breast. Male breast cancer presents with symptoms similar to those in women and may include a hard lump in the breast or bloody nipple discharge. Diagnostic and biopsy procedures are the same. Surgery and treatment are also very similar to female breast cancer.

Common Types of Male Breast Cancer

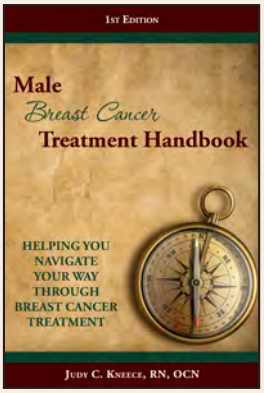
- Infiltrating or invasive ductal carcinoma (also the most common female breast cancer)
- Inflammatory breast cancer
- Paget disease of the nipple

Male survival rates, when compared to women diagnosed at the same stage, are very similar.

Genetic Testing

After diagnosis, breast cancer genetic testing is recommended to determine if an inherited gene mutation caused your cancer. If your genetic test is positive for hereditary gene mutation, your children have a fifty percent risk of inheriting the same gene mutation from you, placing them at the highest known risk for future cancer. If your genetic test is positive, your first-degree relatives can also have genetic testing to determine if they, too, are hereditary breast cancer gene carriers. If they test positive, they have options that may include increased surveillance by having regular breast clinical exams.

Comprehensive information on male breast cancer is available online:
www.cancer.gov/cancertopics/pdq/treatment/malebreast.



Male Breast Cancer Treatment Handbook

www.EduCareInc.com

Remember...

- *Breast cancer is not a sudden occurrence; it has been developing for years. The average breast cancer has been growing silently in the body for 8 to 10 years when it is discovered.*
- *When a patient is diagnosed with breast cancer, characteristics of their tumor and their age, along with their personal and family history, serve as indicators of which type of cancer, either sporadic, familial, or hereditary, they may have. If the characteristics appear to be hereditary, genetic testing can determine if a hereditary mutation is present. Determining the type of cancer is essential because treatment options differ for hereditary breast cancers.*
- *Most breast cancers (about 75–80%) are considered sporadic. This means that the genetic damage that caused cancer happened **after** birth and was not inherited from a parent.*
- *About 5–10% of breast cancers are caused by hereditary genetic mutations. These patients inherited a damaged breast cancer gene from either their mother or father at conception.*
- *If you have a strong family history over multiple generations, you have familial cancer.*
- *Cancer cells divide rapidly and uncontrollably. They rarely die naturally; they have to be removed from the body with surgery, chemotherapy, or radiation therapy. A cancerous tumor can invade surrounding tissues and move to distant parts of the body, where it can become life-threatening. Cancer, when confined within the **breast only**, is NOT life-threatening.*
- *Breast cancer is rarely a medical emergency. In most cases, you have time to ask questions, gather information, and consider your treatment options before surgery or treatment begins.*
- *Avoid comparing your breast cancer diagnosis with the diagnoses of others. There are approximately 15 different types of breast cancer, each with distinct behaviors and treatment options. Your breast cancer is as unique as your fingerprint.*
- *Because many variables influence your cancer, it is essential to rely on your healthcare team for accurate information. They are familiar with your final pathology report and are the most reliable source of information about your diagnosis. Let their knowledge guide your decisions.*

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Breast Cancer Treatment Handbook

The book that has helped over 840,000 women regain control after a breast cancer diagnosis.

Judy C. Kneece, RN, OCN, has trained over 2,300 nurses internationally to serve as Breast Health Navigators to coordinate the clinical, educational and support needs of patients. She has authored six books on breast cancer and benign breast disease, including a companion book for support partners, the *Breast Cancer Support Partner Handbook*.

Topics Include:

- Emotional Impact of Breast Cancer
- Patient Treatment Barriers Assessment
- Support Partner Relationship
- Telling Your Children
- Understanding Breast Cancer
- Surgical Treatment Decisions
- Reconstructive Surgery Options
- Understanding Your Pathology Report
- Chemotherapy and Hormonal Therapy
- Radiation Therapy
- Side Effects of Treatment
- Complementary / Alternative Therapies
- Sexuality after Breast Cancer
- Monitoring Your Emotional Recovery
- Future Fertility Issues
- Surgical Arm Care and Exercises
- Health Insurance and Employment
- Diet and Exercise
- Monitoring for Recurrence
- Survivorship Surveillance Guidelines
- Embracing Life as a Survivor

Book Reviews:

The 11th edition of the *Breast Cancer Treatment Handbook* by Judy Kneece is another in a series of excellent patient resources for women with breast cancer. From a surgeon's perspective, this book provides everything that women need to know about diagnosis, treatment options and recovery. The patient testimonials are impactful, relevant and compelling. This edition is unique in that there is a real emphasis on the patient, the patient's family and other support systems to make the journey from becoming a breast cancer victim to a breast cancer survivor less stressful.

—Maurice Nahabedian, MD, FACS
Professor of Plastic Surgery, Georgetown University

An informed patient makes better decisions and feels better about the decisions she makes. This book is a great resource for any patient trying to make sense and understand what is happening at any point in her breast cancer journey. This book will help you be a more informed patient.

—Kevin S. Hughes, MD, FACS
Director of Cancer Genetics, MUSC
Professor Emeritus, Harvard Medical School

As a physician trained in psychiatry and teaching in a medical school, I thought, *"Cancer won't happen to me. I'm healthy."* But to my utter surprise, I received a breast cancer diagnosis. My outdated knowledge of breast cancer was from medical school over 34 years ago. Suddenly, my role as a physician had changed to a patient. My navigator gave me a copy of the *Breast Cancer Treatment Handbook*. I immediately started reading and have read so many chapters over and over again. I needed information from a patient's point of view. Not only did it help me understand surgery and treatment options with great illustrations and charts, but it also addressed the emotional struggles and feelings of uncertainty that each new step brought. With each new phase of treatment, I would return to the book for facts, comfort, and help in addressing my scary feelings. This book made many unknowns a bit more bearable by explaining procedures in detail. I felt a sense of safety and comfort from understanding what to expect and what to ask my healthcare team. This book made a world of difference for me.

—Robin Hurley, MD, FANPA
Professor and Neuropsychiatrist

Find Hope, Inspiration, Encouragement and Much More!

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